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AN EXPLORATION INTO GENDERED EXPERIENCES IN
AUTISM.

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My intrigue regarding the autism spectrum began in 2006 when I spent a year working with Professor Robyn Young and Dr Carrie Partington at the Early Intervention Research Program (EIRP) at Flinders University, Adelaide. Robyn, Carrie and their team offered me important and highly formative opportunities to work with families who had been through the autism diagnostic process. The experience, skill and sensitivity held within this team was instrumental in me pursuing my interests in psychology and, more specifically, autism. Thank you to the inspirational families and professionals at the EIRP.

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In loving memory of my dad.

Overview of the Major Research Project

Section A introduces theoretical and empirical literature related to current diagnostic concepts, procedures and practices in autism. The review explores their development in the context of the gender ratio in autism spectrum conditions (ASC). Two widely-used diagnostic instruments are presented and the methodologies used in their initial reliability and validation analyses are critiqued in relation to gender differences. Findings from six papers are then reviewed and critiqued. These findings form hypotheses around why the gender ratio in the diagnosed population of people with ASC is heavily-male. The clinical and research implications of the review conclude Section A.

Section B presents an empirical study which explores whether females on the spectrum use masquerading strategies to cover up their difficulties with socio-communication. Semi-structured interviews with ten adolescent females were analysed using Interpretative Phenomenological Analysis. Participants' attempts to adapt to changes in developmentally driven social expectations in the context of having social communication differences are explored and common themes within the sample are presented. Limitations to the study are noted and the clinical and research implications are discussed.

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Section A: A Review of Diagnostic Concepts, Procedures and Practices in Autism in
Relation to Gender

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Abstract

An overview of the historical construction of the concept of autism is presented in this review. The process of developing the current classification criteria and some of the dominant theoretical perspectives are both outlined. The emphasis is upon the androcentric foundations of current diagnostic practices. The review explores and critiques the methodological foundations of 'gold-standard' autism diagnostic tools. Further to this, research around gender differences in populations of people diagnosed with autism spectrum conditions (ASC) is reviewed. Methodologies are critiqued and findings are presented, organised by four hypotheses on the predominantly-male prevalence in diagnosis of ASC: (i) current methodology is insensitive to the female presentation (ii) different symptom expression exists between genders (iii) there are different developmental trajectories between genders and (iv) females are more able than males to blend in with typically developing peers. Clinical and research implications from the review conclude the paper.

Keywords: autism, diagnosis, female, gender.

1. Introduction to the Autism Spectrum

1.1. Definition and Classification

Autism is one of the most commonly diagnosed neurodevelopmental conditions¹ in the UK (Baron-Cohen, Scot, Allison, Williams, & Bolton, 2009). Kanner (1943) coined the term ‘early infantile autism’ following identification of characteristics shared by eleven children, including the children’s “inability to relate to themselves” (p. 242) and “extreme autistic aloneness” (p. 242). Kanner commented on the possibility that these children had been labelled schizophrenic by other professionals. There are shared traits within the autistic population, yet these traits are not specific only to autism. Consequently, lack of specificity creates confusion with regard to diagnosis. Classification of the condition has always been contentious due to debates around what the core, autism-specific symptoms are and where the spectrum of symptoms begins and ends.

The Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association [APA]) is one of two widely used classification systems in the UK in the diagnosis of mental disorders. The diagnostic term ‘autism’ first appeared in the third edition of the DSM (APA, 1980). Autism was conceptualised as a triad of impairments; social interaction, social communication and restricted & repetitive behaviours & interests (RRBIs). Although some of the language used to define the DSM-III criteria for a diagnosis of Autistic Disorder (AD) has changed from Kanner’s (1943) descriptions (e.g. from ‘extreme autistic aloneness’ to ‘qualitative impairment in social interaction’), many of the core features Kanner described have been retained. The aetiology of autism has always been disputed, with a vast array of theories emerging, some of which are outlined in this paper.

¹ The use of the term “condition” refers to a collection of symptoms whilst not suggesting that those with the symptoms are disordered. Where the term “disorder” appears within the text, it is compatible with language used in classification criteria.

The unidentified aetiology combined with dissidence around the core features makes diagnosis of autism very complex.

The DSM-IV retained the triad of impairments for a diagnosis of AD and included sister diagnoses such as Asperger's Syndrome (AsS) and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), in keeping with the theory that symptoms exist across a spectrum of severity. At the time of writing, the DSM-IV-Text Revision (DSM-IV-TR; APA, 2000) was extensively used by clinicians and academics; therefore, references throughout this paper to the range of spectrum conditions are relevant.

The DSM-5 (APA, 2013) has recently been published and includes significant changes to autism diagnostic criteria. The triad of impairments is collapsed into a dyad; social communication and interaction comprise one category whilst restricted, repetitive patterns of behaviour, interests or activities (RRBIs) form the other. The sole diagnosis Autism Spectrum Disorder (ASD) supersedes the previously available breadth of categories such as AsS and PDD-NOS. Many individuals with a diagnosis of AsS object to the loss of their label, over concerns about their self-identity and eligibility for support (Wing, Gould, & Gillbert, 2011). Although revisions to the DSM-5 are significant, it is beyond the scope of this paper to explore them in detail (see McPartland, Reichow and Volkmar, 2012 for an evaluation of the potential impact). The revisions are illustrative of the continuous changes in the understanding of autism.

1.2 Prevalence and gender ratio

In the UK, the prevalence rate for autism in school-age children is around 1/1,000 (Thrower, 2000). Prevalence rates have increased significantly over time but it is unclear whether this is due to incidence factors such as improved identification or changes in the clinical application of diagnostic classification criteria (Baird et al., 2006). The significant

difference in diagnostic rates between genders has, however, remained stable, with a male to female ratio of 4:1 in autism and 10:1 in AsS (Fombonne, 2003).

Kanner's (1943) description of the disorder was based on a sample of 8 boys and 3 girls. His later report on the nosology of autism made no reference to girls (Kanner, 1949). Although researchers (e.g. Honda, Shimizu, Imai, & Nitto, 2005) explain that the gender ratio in their studies reflects that of the clinical population, the reasons behind the difference are rarely the focus of such work. Since the findings are then applied to the clinical population, which then becomes the source of future samples in research, the cycle between theory, research and clinical practice is maintained. This may explain why the gender ratio has remained consistent over six decades. There are signs, however, that the gender ratio in prevalence rates is narrowing; clinicians working in specialist ASD teams have reported this trend (e.g. Gould & Ashton-Smith, 2011). A clinician based at a UK national and specialist centre estimated that referrals for diagnostic assessments for females made up 40% of the total referrals received in 2012 (R. Parham, personal communication, 17th May, 2013). Rigorous research into the female profile is in its infancy but is emerging (e.g. Dworzynski, Ronald, Bolton, & Happé, 2012).

1.3 Impact of ASD

ASD symptoms bring many challenges for those on the spectrum. Typically, social communication and interaction skills are relied upon to build interpersonal relationships; therefore, relationships can be very difficult for people with a diagnosis (Haq & Le Couteur, 2004). It is common for those on the spectrum to have difficulties with emotion identification and regulation which further complicates interpersonal relationships (Kuroda, Kawakubo, Kuwabara, Yokoyama, Kano, & Kamio, 2013). RRBIs occupy and/or soothe people on the spectrum but create a barrier to new learning and social experiences (Leekam, Prior, & Uljarevic, 2011). Sensory issues are extremely common. The seeking or avoidance

of sensory stimulation impacts on the individual's ability to tolerate variations in noise, foods, temperature, textures and visual stimuli which makes an array of environments extremely challenging (Reynolds, Bendixen, Lawrence, & Lane, 2011). Deficits in executive functioning make initiation and generalisation difficult. This often leads to decreased autonomy and increased need for external support which impacts on an adult's ability to sustain relationships and employment (Hume, Loftin, & Lantz, 2009).

The prevalence of mental health problems in the ASD population is substantially elevated compared to the general population (Simonoff, Pickles, Charman, Chandler, Loucas, & Baird, 2008). It is not always clear whether symptoms are primary (e.g. fixation with routine due to RRBI) or secondary (e.g. ritualistic behaviour stemming from anxiety). Difficulties in identifying the aetiology together with discord around symptom classification makes diagnosis and treatment complex and this may lead to individual needs remaining unmet. Co-morbidity with intellectual disability is estimated to be around 75% of the autistic population (Fombonne, 2003); many people on the spectrum will face significant challenges arising from co-morbid difficulties.

The impact of ASD on daily life is profound and is not limited to the individual with the diagnosis. Cadman et al. (2012) suggest that those who care for adolescents on the spectrum experience greater strain than those who care for people with other developmental disorders (DDs). The societal cost of ASD in the UK is estimated to exceed £1 billion (Järbrink, Fombonne, & Knapp, 2003). The impact of ASD is costly to the individual, their system and society.

1.4 Brief Overview of Theories

There are numerous theories around the aetiology of ASDs and it is beyond the scope of this paper to outline each of them; therefore, three predominant theoretical perspectives are offered. Following this overview, a thorough review of the extant literature on ASD and

gender is presented and critiqued, covering assessment/identification in females, methodological issues and gender-profiles. This precedes implications for research and clinical practice which conclude the paper.

1.4.1 Biological theories. The Extreme Male Brain (EMB) theory (Baron-Cohen, 2002) suggests that there are biological differences between genders. The theory states that males have naturally superior systemising skills (i.e. understanding and organising systems) and use their understanding of the underlying rules of systems to predict outcomes and/or behaviours. In contrast, it is explained that females are better at empathising (i.e. understanding emotions and identifying thoughts) and use empathy to predict others' behaviour.

Baron-Cohen (2002) recognises that behaviours may be shaped by environmental and societal factors. However, the EMB theory notes that behavioural gender differences are observed in infancy and maintained across the lifespan. This is interpreted as indicative of biological underpinnings to gender differences. The EMB theory suggests that people with autism tend to make sense of the world and behave in exceptionally systematic (i.e. male) ways; hence the term 'EMB'.

It is hypothesised by some that biological differences may give rise to autism and an ASD phenotype may exist (Zhao et al., 2007). This theory suggests that boys are innately less protected than girls in terms of the loss of cognitive skills related to language, social skills and repetitive behaviour; therefore prevalence is higher in males. Family history of diagnosis may be characteristic of other neurological differences, including, for example, dyscalculia, (Shalev, Manor, Kerem, Ayali, Badichi, Friedlander, & Gross-Tsur, 2001). This suggests that biological factors may be correlated with a broad range of developmental differences.

Biological theories have been critiqued, for example, Fine (2008) warns of neurosexism, whereby females are disadvantaged through misleading interpretation of neuroscience research which reinforces patriarchal social constructs. Whilst Fine agrees that sex differences exist, she argues that neuroscience, when presented in books such as *The Essential Difference* (Baron-Cohen, 2004), can discourage consideration of other factors contributing to gender differences, such as social expectations. It has also been suggested that the EMB theory may mean ASD is not expected and therefore not assessed in females (Gould & Ashton-Smith, 2011).

The interaction between biological and environmental factors in the manifestation of individual differences is largely unknown (Blakemore, Winston, & Frith, 2004). Whilst biological and neuropsychological research is extremely useful in understanding autism, to limit theories to biological underpinnings without regard to the interplay with other factors could be misleading and reductionist.

1.4.2 Environmental theories. “Environment” may be conceptualised in many ways. Firstly, a bioecological (Bronfenbrenner & Evans, 2000) perspective is considered (i.e. biopsychosocial development as a reciprocal interaction between the human and its immediate physical environment). Secondly, factors in the familial environmental (microsystem) are discussed.

It is understood that DNA produces proteins through interactions with the physical environment; the environment is instrumental in neuronal development. However, longitudinal research into DDs from an environmental perspective is sparse (London, 2000). It has been suggested that specific environments (e.g. gestational infection of Rubella) play a causal role in the development of ASD (London, 2000). For instance, research into the prevalence of ASDs in a Township close to hazardous waste sites in New Jersey found a two-fold increase in neural tube defects (Bove, Shim, & Zeitz, 2002), which have been

closely linked to autism (Rodier, Ingram, Tisdale, & Croog, 1997). However, London (2000) warns that “evidence for an environmental origin for autism is circumstantial” (p. 404).

In terms of familial environment, one historically well-known theory on the aetiology of autism was that of the ‘refrigerator mother’ (i.e. a cold and unresponsive mother; Bettelheim, 1967). This theory suggests that a lack of warmth and responsiveness from the mother creates attachment issues between mother and child, leading to autism. Conversely, it has been contended that any perceived lack of maternal warmth may be the result of psychological stress arising from continual rejection of the mother by the child (Koegel, Scheibman, O’Neill, & Burke, 1983).

The ‘refrigerator mother’ theory has not withstood empirical testing, but theories around the correlation between the family environment and ASD remain. Hughes and Ensor (2006) investigated the impact of harsh parenting on child behaviour and specific cognitive skills thought to be deficient in ASD. Predictive effects were found for harsh parenting, on Theory of Mind (ToM; see section 1.4.3.1 for more information), verbal ability and gender. ToM appeared to have a mediating effect on behaviour; the children with the lowest ToM were particularly affected (operationalised as the frequency and intensity of behavioural problems) by harsh parenting. The greater the child’s ToM, the less an effect harsh parenting had on its behaviour. Whilst this study suggests that parenting style does have an impact on the behaviour of young children, the interplay between family and child is important to consider.

Links between environments and ASDs may be circumstantial and the relationship between familial factors and the child is complicated. Whilst the environment is an important variable in the manifestation of ASD, identification of specific environmental causes is very challenging.

1.4.3 Cognitive theories. Cognitive theories offer descriptions of different types of brain differences whereas environmental and biological frameworks attempt to explain why brain differences occur. Three highly-regarded cognitive theories of ASD-related differences are now presented.

1.4.3.1 Theory of mind. ToM is the ability to attribute mental states to oneself and others and the ability to understand that one's mental state may differ to that of other peoples' (Frith & Frith, 2005). It is theorised that neurotypical people use knowledge of their own mental state to predict and explain the mental state of others. Those without ToM are said to be unable to make such predictions as they lack the ability to understand their own mental state and do not recognise that others' mental state may be different. It is suggested (e.g. Premack & Woodruff, 1978) that people with ASD are unable to attribute mental states to themselves and others and thereby lack ToM. Concepts related to ToM are (i) joint attention (Baron-Cohen, 1991), where a person identifies an object of interest and attempts to direct the attention of others towards the object in order to share their interest, and (ii) empathy, which is often described as the ability to fully understand the perspective of another. A ToM deficit has serious implications on the individual's abilities to understand the world around them. Deficits in related concepts affect the individual's ability to engage with others in a typical manner and may lead them to appear disinterested and insensitive.

1.4.3.2 Theory of executive dysfunction. Executive function describes a collection of cognitive processes (e.g. attention and response inhibition) which manage cognitive and behavioural control. It is hypothesised that executive dysfunction underlies the cognitive inflexibility observed in ASD. Executive dysfunction affects tasks which require attention and/or response inhibition and is not exclusive to people with ASD (Schmitz, Rubia, Daly, Smith, Williams, & Murphy, 2006). People with ASD commonly display difficulties with

tasks which require executive function, such as mental flexibility; therefore, it has been hypothesised that executive dysfunction underlies such difficulties.

1.4.3.3 Weak central coherence theory. It is suggested that people with ASD have a weak or absent drive for global coherence; rather than processing information globally before coordinating it into a general meaning, they may process in a piecemeal way (Frith, 1989). This theory was developed based upon evidence that people with autism have a tendency to notice detail at a much greater level than neurotypical people, but may struggle to form a wider view.

Numerous cognitive theories exist but there is contention around the operationalisation of many concepts. For example, there are debates regarding ToM; one ‘narrow’ conceptualisation is based predominantly upon research on 3-5 year olds’ performance on the false-belief task (Baron-Cohen, Leslie, & Frith, 1985). A ‘broad’ definition also exists, encompassing a wider range of mental states (Hughes & Leekam, 2004). Furthermore, there are flaws in the objective measurement of cognitive processes; ToM is thought to be dependent on an innate cognitive mechanism, although neuropsychological data have been unable to pinpoint functions to specific structures (Gallagher & Frith, 2003). Geurts, Corbett and Solomon’s (2009) review described links between observed behaviour and underlying cognitive deficits as tenuous; researchers cannot confidently ascertain that outcomes can be attributed to specific cognitive processes.

1.5 Summary of Theories

ASD may be considered from multiple perspectives. Baron-Cohen and his colleagues have described gender differences and hypothesised about biological aetiology. However, the EMB theory is regarded by some to be too narrow an explanation for gender differences in ASD. It is also important to be mindful of the impact of socially-constructed gender-stereotypes on gendered-expectations.

Cognitive theories substantiate some biological arguments; e.g. if female brains are typically better at empathising, it could logically be suggested that females have better ToM than males. Nonetheless, there are significant difficulties with conceptualising and measuring cognitive processes so conclusions must be evaluated carefully. Environmental factors, in terms of physical habitat and parenting style, have been linked to ASD. There are disputations regarding the circumstantial nature of some evidence and an inability to differentiate between causal factors and outcomes; it is suggested that the interplay between environmental and other factors is considered when investigating ASDs.

So far, this paper has introduced and critiqued some concepts and theories surrounding the aetiology of autism. Such complexities lead to complications in diagnosis which subsequently obstructs access to treatment. Without diagnosis, needs remain unmet. Furthermore, a significant number of females may remain undiagnosed because the understanding of ASDs has been built upon a male presentation; there may be “a diagnostic bias towards identification of males” (p. 1148, Kothari, Skuse, Wakefield, & Micali, 2013).

2. Literature Review

A thorough literature search was conducted to synthesise findings on gender differences in the ASD population and to understand their contribution to the extant evidence base. Firstly, assessment methods are reviewed in relation to gender. Secondly, information regarding the female ASD-profile is presented. The review concludes with identification of areas in which our understanding remains underdeveloped.

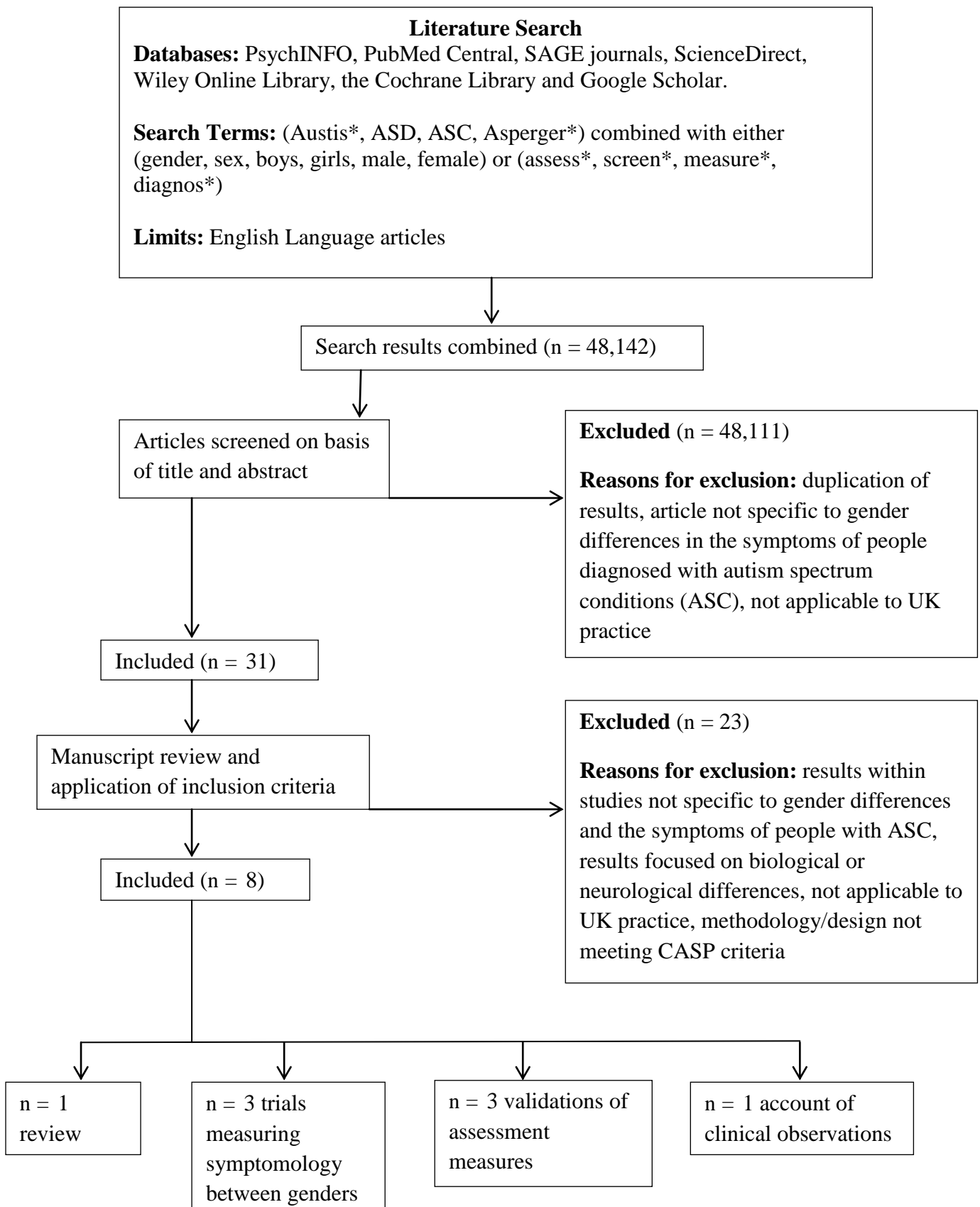
2.1 Review Methodology and Structure

The following electronic search engines were used: PsychINFO, PubMed Central, SAGE journals, ScienceDirect, Wiley Online Library, the Cochrane Library and Google Scholar. References were hand-searched for additional relevant material. Full criteria of

search strategies used can be found in Figure 1. There were no parameters around publication dates since research into the area is in its infancy.

The search identified two ‘gold-standard’ assessment measures. The process of validation is described and critiqued, following a traditional review structure (i.e. critical examination of the methods employed during their development). The focus then turns to literature regarding females on the spectrum. Using a scoping review structure (i.e. an analysis of the papers with identification of gaps), six papers are presented and critically evaluated.

Figure 1: Process of Selection of Reviewed Papers



2.2 Assessment of ASD Characteristics

As illustrated above, the construct of ASD is largely built upon Kanner's (1943) illustration of male presentation of ASD. To assess the depth of this androcentric understanding and to establish whether diagnostic processes may be disadvantageous for females, it is crucial to understand how commonly used assessment tools were developed.

2.3 Introduction to Measures

Since the National Institute of Clinical Excellence (NICE, 2011) does not identify specific ASD-diagnostic tools, measures were selected based upon the high regard for them in the research literature and their routine use within UK clinical and research contexts. These were identified as the Autism Diagnostic Interview – Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) and the Autism Diagnostic Observation Schedule - Generic (ADOS-G; Lord et al., 1989). A search using Google Scholar returned 8260 results for the ADI-R and 2490 for the ADOS-G. The ADI-R was not originally developed for use in diagnostic assessments, however, despite this, it is commonly referred to as the 'gold standard' tool for diagnostic assessment (e.g. Constantino et al., 2003). The ADOS-G is described as "the most widely used and best validated diagnostic assessment" (Pasco, 2011, p.2).

2.4 The ADI-R

2.4.1 Description. The ADI-R is a semi-structured interview used to assess behaviour in three functional domains: language and communication, reciprocal social interactions and RRBIIs (Lord et al., 1994). The interview was designed to differentiate between autism and other DDs in very young children. Parents are questioned regarding the child's previous and current social skills, communication, play and interests. The outcome relies on the assessor's clinical judgment of the parents' descriptions (Lord et al., 1994).

It is suggested by the authors that the ADI-R cannot reliably be used alone in diagnostic assessment as it only collects parental reports of the child's history. It is

recommended that this information is supplemented by direct behavioural observations before diagnosis can be reached. The ADI-R has undergone scrutiny; comparisons to other measures have been made (e.g. Constantino et al., 2003) and factor analysis has been completed (e.g. Frazier, Youngstream, Kubu, Sinclair, & Rezai, 2008). The focus of this review is the original study of reliability and validity (Lord et al., 1994) as these results form the foundations for subsequent use.

2.4.2 Reliability and validation. Initial reliability analyses assessed 10 autistic (8 male, 2 female) and 10 “mentally handicapped” ([MH] p. 666) or language impaired ([LI] 8 male, 2 female) children (Lord et al., 1994). Mental ages ranged between 21-74 months. Inter-rater reliability on all algorithm items was strong and overall internal consistency was high. Reliability over time was tested by interviewing 6 caregivers 2-3 months later, producing exact agreement of over 83%; the authors acknowledge that this needs to be studied further with a larger sample.

The authors also measured the validity of the instrument and recruited 15 extra autistic and 15 MH/LI children, bringing the total in each group to 25. The gender ratio is not reported. Parents of five of the additional autistic children and seven of the additional MH/LI children were not interviewed and it is not stated how these children were assessed; since the ADI-R is a parent/caregiver interview, this is important information to omit. Only items appropriate to children under the age of 4 were included in the validity analyses due to the age range of the sample. All items within the social domain were significantly different between the two groups, indicating that the instrument had discriminant validity when differentiating between ASD and MH/LI children of this age. The overall algorithm found that only one boy in the autistic group did not meet the ADI-R criteria for an International Classification of Disease-10 (ICD-10)/DSM-IV diagnosis of autism. Two males within the MH/LI group met the criteria for diagnosis of autism using the ADI-R but were not given the

diagnosis. The authors considered the ADI-R to be a valid measure of ASD behaviours, as defined by the DSM-IV and ICD-10.

2.4.3 ADI-R and gender. Park et al. (2012) compared cognitive and behavioural sex differences between 51 typically developing (TD) children (51% male, 49% female), 111 children with ASD (82% male, 18% female) and 98 unaffected siblings of children with ASD (48% male, 52% female). They found that ASD-males scored higher on the non-verbal communication and repetitive stereotyped behaviour (RSB) domains of the ADI-R compared to ASD-females. Male siblings scored significantly higher on more ADI-R domains than female siblings. Park et al. (2012) suggest that these findings might be used to predict that males are at higher risk of ASD than females. Alternatively, since the reliability sample for the ADI-R was predominantly male, it is possible the ADI-R is not sensitive to the lower intensity of RRBI that females may present (Hattier, Matson, Tureck, & Horovits, 2011).

2.4.4 Critique. The generally homogenous standardisation samples are small. This has implications for the predictive power of the instrument when used with different populations. The absence of report on the gender ratio in the validation sample suggests that the possibility of detecting gender differences was disregarded within the analysis. The gender ratio for the reliability sample was predominantly male; females are measured against a male presentation. The algorithm was constructed using a small, heavily male sample with an average age of under four years old. Girls are often referred for assessment much later than boys (Gould & Ashton-Smith, 2011); when an older girl is assessed using the ADI-R, it is likely that her presentation, when compared to that of a small sample of young boys, will not match the ADI-R interpretation of the ASD profile.

The ADI-R is linked closely with ICD-10 and DSM-IV criteria. These criteria appear to have been taken as valid and reliable constructs in themselves. Classification criteria have been disputed, as they are symptom-based and are easily influenced by ideological and

political forces (Jablensky, 1999). As outlined earlier, DSM classification criteria for autism was established upon findings from a small, mainly-male sample. It is therefore suggested that the ADI-R has used small, largely male samples to substantiate criteria founded upon a small and largely male sample; when girls are referred for diagnostic assessment, they are measured against this. Discussion around the implications of this are covered later in this paper.

2.5 The ADOS

2.5.1 Description. The ADOS-G (Lord et al., 2000) is a semi-structured, standardised, observational assessment of social interaction, communication, play and demonstration of imagination for individuals who may have autism or other pervasive developmental disorders (PDDs). Four modules are available to enable reliable assessment of individuals with various levels of expressive language. The authors suggest it cannot be used alone in making a diagnosis of ASD as it does not elicit developmental history or information on behaviour in different contexts (Lord et al., 2000). The ADOS-G does not measure RRBI and only provides a measure of functioning demonstrated during the assessment.

The ADOS-G is closely linked to DSM-IV and ICD-10 criteria for diagnoses under the PDD umbrella. It is claimed that the ADOS-G algorithms can discriminate between diagnoses of autism and PDD-NOS as both the number and severity of symptoms are measured (Lord et al., 2000). Evaluation of data in this review is limited to the original report of the study of reliability and validity (Lord et al., 2000) for the same rationale as the ADI-R.

2.5.2 Reliability and validation. Analyses of all four modules included 381 participants. Samples in validation analyses by each module are as follows: Module 1: n =

74² (15 months to 10 years; 77% male, 23% female), Module 2: n = 55 (2 – 7 years; 71% male, 29% female), Module 3: n = 59 (3 – 20 years; 80% male, 20% female) Module 4: n = 45 (10 – 40 years; 82% male, 18% female). Within each sample, around half had a diagnosis of autism (i.e. met ADI-R criteria for the disorder), a third had PDD-NOS and a sixth had non-spectrum disorders. A few TD participants were included within each module to ensure that the ADOS-G did not misclassify individuals without a diagnosis.

Items with mean weighted kappas below .40 were excluded unless it was felt by the authors to be extremely important to retain. Retained items were checked, re-written and further evaluated before being included. Inter-rater reliability for each module was strong. Test re-test reliability was measured by re-assessing 27 participants around 9 months later. The authors established clear differentiation in cut-off scores between a non-spectrum diagnosis and autism/PDD-NOS; specificity was prioritised between spectrum and non-spectrum diagnoses to ensure that those who warranted a diagnosis received one and those who did not were not mislabelled.

It is concluded that the ADOS-G has “excellent inter-rater reliability, internal consistency and test re-test reliability on the item, domain and classification levels for autism and non-spectrum disorders” (p.220) when measuring social-communicative behaviour. Diagnostic validity for autism versus non-spectrum disorders is also described as excellent.

2.5.3 ADOS-G and gender. Results from reliability analyses included a main effect of gender on all domain scores in Module 3 (designed for verbally fluent children). Gender effects were not found elsewhere and this is likely due to the inclusion of a disproportionate number of males making it impossible to accurately identify gender differences.

² The Module 1 sample size is reported as 54 in Lord et al.’s (2000) text but the figures in their table amount to 74. Discrepancies were not identified elsewhere.

The ADOS-G only codes social behaviours and communication; RRBI's are coded if they occur but are not included in the overall algorithm. Some studies (e.g. Hattier et al., 2011) have found that females had significantly fewer RRBI's than males; it is possible that the absence of RRBI's in the overall algorithm disadvantages males who present with DSM-IV ASD impairments which are not coded for in this measure.

2.5.4 Critique. ADI-R diagnostic criteria were used as inclusion criteria; validation of the ADOS-G included participants who fit this androcentric understanding, thus conserving it. Furthermore, two of the three authors of the ADI-R also authored the ADOS-G so it is likely that the two measures will reinforce each other. Whilst using complementary diagnostic tools makes sense, it may be argued that this bolsters the androcentric foundations of the construct of ASD. The authors explain that use of the ADOS-G is clearly related to the skill of the examiner as it requires practice in the administration, observation and scoring. The acquisition of such skill may be established through experience in adopting an androcentric perspective of ASD.

The ADOS-G is a measure of observed functioning during a 40 minute assessment. These observations are substantiated with parental accounts of functioning and ultimately lead to a decision regarding diagnosis. Although parental report may alert clinicians to concerns not observed during assessment, ADOS-G scoring is based upon what the child actually demonstrates. Since it is possible that girls' expression of ASD symptoms may be more subtle than boys, if the clinician does not observe what they consider to be ASD-typical behaviours, the child may go undiagnosed (Kopp & Gillberg, 2011). Indeed, it has been found that females who have achieved a diagnosis have more severe expressions of the symptoms than boys (Nydén, Hjelmquist, & Gillberg, 2000), suggesting that their presentation has to be more pronounced in order for a diagnosis to be made. Such evidence suggests that females may be disadvantaged by use of the ADOS-G.

2.6 Scoping Review

A review of literature regarding gender differences in the ASD population is now presented. Using the search criteria outlined above and guided by the Critical Appraisal Skills Programme (CASP, 2014), six papers were identified. A brief overview of the aims and design of each paper is provided in Table 1. Methodological flaws are discussed before findings are presented, structured by four hypotheses around the gender prevalence in ASD. Gaps in the evidence base conclude the paper.

Table 1

Reviewed Papers

<u>Paper</u>	<u>Aims</u>	<u>Theory</u>	<u>Sample</u>	<u>Entry criteria</u>	<u>Assessment Tools^a</u>
Rivet and Matson (2011)	Reviews the background of ASD (including classifications, assessment methods, gender differences in core symptomatology in ASC & TD populations). Presents an in-depth review of evidence around the aetiology of gender differences		Does not clearly state which papers are reviewed	Lacks a clear description of search methods	Methodologies are broad, drawing on psychometric, genetic and epidemiological data; all are quantitative designs
Kopp and Gillberg (2011)	To develop and validate the ASSQ-Revised Extended Version (ASSQ-REV), an extension of the Autism Spectrum Screening Questionnaire (ASSQ). The authors question whether there	Current screening instruments have been modelled on the ASD phenotype described by Kanner	Sampled 191 6-16 year olds split into three groups; community-girls (n = 58), clinic-girls (n = 71) and clinic-boys (n = 62)	Clinic groups: FSIQ \geq 70, with diagnosis of ASD, ADHD or referral for neuropsychiatric diagnoses. Community-girls: FSIQ \geq 80, without serious	DSM-IV, ASSQ + 18 items from ASSQ-GIRL (i.e. ASSQ-REV)

is a female ASD phenotype

medical illness, LD, neuropsychiatric disorder or family members with likelihood of any of these

Hsiao, Tseng, Huang, and Gau (2013)

To examine the association between children and adolescents' social deficits and school- & social-adjustment in Chinese culture. To examine the moderating effects of age and gender and the interaction of both on this putative association

There may be a link between early social inadequacy/peer difficulties and a range of maladaptive outcomes (e.g. affective/behavioral disorders)

Four groups (n = 1321, 48.7% boys, aged 6.7 – 15.6 years): Chinese boys, girls, younger (Grades 1-4, 50% male,) and older (Grades 5-8, 44% male)

Those with maternal reports of diagnosis of ADHD, ASD, DD were excluded

Lai et al. (2011)

To investigate behavioural sex differences and similarities in the ASD population

EMB theory

Sampled 83 18-45 year olds with formal diagnosis of ASD (54% male and 46% female)

Without LD, current or historic psychotic disorders, substance-misuse or medical conditions

ADI-R, ADOS-G, Eyes Test, Autism Spectrum Quotient (AQ), Systemising Quotient (SQ) &

Empathy
Quotient (EQ)

Gould and Ashton-Smith (2011)	To present observations on the behavioural profiles of ASD-females	Hypothesises that females are likely to experience misdiagnosis and missed-diagnosis due to an androcentric understanding of ASD	Referrals to The Lorna Wing Centre (UK clinic accepting complex cases where definitive ASD diagnosis has not been reached)		Empathy Quotient (EQ)
Park et al. (2012)	Hypothesised that (1) ASD-females are less severely affected than ASD-males in terms of language/social competence (2) there is an absence or reduction of sexual dimorphism (i.e. obvious differences between genders) in neurobehavioural profiles and cognitive style only in the ASD	EMB theory	Korean 4-15 year olds divided into 6 groups: 91 ASD-boys, 20 ASD-girls, 47 male ASD-siblings, 51 female ASD-siblings, 26 TD-boys and 25 TD-girls, IQ and age-matched between genders and	IQ > 50, without clinically significant neurological diseases, medical conditions or chromosomal anomalies. Siblings highly suspected to have ASD were excluded. No psychiatric	Korean Social Communication Questionnaires (SCQ) Child versions of the AQ, EQ and SQ

group (3) male ASD-
siblings present with a
stronger ASD-profile
than female
counterparts

equivalent groups diagnosis in the
TD group

^aFor brevity, only tools referred to within this review are included in this table. Please refer to the original papers for further details, if required.

2.6.1 Methodological issues. Rivet and Matson (2011) critique the current diagnostic process. Nevertheless, in the absence of alternatives, the studies included in the review have abided by current classification systems and measures (e.g. DSM, ADI-R). The review is comprehensive, yet it lacks a clear description of search criteria or methods, so it is difficult to gauge its robustness. It does not make clear that the findings presented are ‘best-guesses’ regarding gender differences given the absence of established alternatives to current androcentric methods and based upon the inclusion of only quantitative designs.

Kopp and Gillberg (2011) suggest that separate criteria, different cut-offs or gender-norms might be appropriate to use with females, who may have more subtle socio-communicative difficulties than males. Thus, they attempt to characterise the female phenotype. Whilst the sample may be large enough to detect differences between groups, the developmental course across the age span (6-16 year-olds) has not been accounted for. It is therefore suggested that statistical analysis may have flattened out any developmental differences in phenotypes and consequently the results may not be indicative of real-life presentations.

Hsiao et al. (2013) examined correlations between social-deficits characteristic of ASD (i.e. not diagnosed ASD) and social- and school-adjustment. Whilst the difficulties associated with ‘narrow’ diagnostic criteria are hereby circumnavigated, the results are not specific to any clinical population, so cannot easily be generalised. The method of participant-exclusion is crude; findings may have been confounded by inclusion of participants with formal diagnoses.

Lai et al. (2011) used the ADOS-G and ADI-R, which are potentially male-biased. This is a justifiable choice, given the preponderance of the use of these measures, yet the authors do not mention that any differences picked up by these measures may actually be greater than the results suggest due to potential insensitivity. The Eyes Test (Baron-Cohen,

Wheelwright, Hill, Raste, & Plumb, 2001), AQ (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) and EQ (Baron-Cohen & Wheelwright, 2004) were co-developed by Baron-Cohen (who developed the EMB theory) so it is unsurprising that results include an absence of typical sex differences in systemising and empathising, in line with the EMB theory.

Gould and Ashton-Smith's (2011) observations are not empirically tested in this paper. Concepts such as 'social imagination' are not operationalised and it is unclear how such skills have been assessed. The observations may inform future investigation but have not arisen from empirical research and therefore need to undergo testing.

Park et al. (2012) do not refer to their heavily-male ASD sample. The use of child versions of the AQ, EQ and SQ is appropriate to the hypotheses as these measures are sensitive to neurobehavioural profiles and cognitive styles; however, they are Baron-Cohen's measures so it is likely that any data that falls outside of the EMB theory will not be collected.

To summarise, there is an absence of qualitative experiences of females on the spectrum within the papers under review. Gould and Ashton-Smith's paper is the closest to this, but is a presentation of observations, rather than empirical research. Frequent use is made of classification criteria and assessment measures which are androcentric; it is likely that gender differences are not being accurately uncovered in these papers. Hsiao et al. (2013) position their study away from this issue by not using a sample diagnosed with ASD. They also factor in developmental trajectories of their participants. However, further investigation is necessary before the findings can be generalised to non-Chinese populations.

The remaining three research designs do not account for developmental confounds in the development of ASD despite it being defined as a neurodevelopmental disorder. Two of

the studies appear to have EMB at the underpinnings; as explained earlier, this theory may encourage neurosexism.

Four hypotheses regarding the gender prevalence in ASD are now presented and provide structure to the review of the results of the studies.

2.6.2 Current methodology is insensitive to the female presentation. There is consensus between the reviewed papers that the current process of ASD diagnosis disadvantages females. Rivet and Matson (2011) suggest that ASD-females may appear less impaired when comparing them to ASD-males but more impaired than TD females. This may be interpreted as indicative of the necessity for female-to-female comparisons. Kopp and Gillberg's (2011) trial found that community-girls differed from clinic-girls on all versions of the ASSQ, suggesting that ASD-girls can be identified as different to non-ASD female peers when using these instruments. The study found that ASD-girls did not differ significantly from ASD-boys on the mean scores on any version of the ASSQ; in terms of overall detection of symptoms, there was very little difference between genders. This may indicate that the measures are sensitive towards identifying ASD-females from their non-ASD female peers whilst retaining sensitivity towards ASD-males.

Overall, the papers concur that current methods are androcentric. Suggestions include introduction of gender-specific norms to better identify females hypothesised as being on the spectrum. Preliminary trials of the ASSQ-REV (Kopp & Gillberg, 2011) suggest that there may be an alternative to current tools which both retains ability to detect ASD-males and is sensitive to ASD-females.

2.6.3 Different symptom expression between genders. Lai et al. (2011) explain that since ASD is defined in behavioural terms and diagnosis is based upon expression of certain behaviours, sex-specific criteria may be needed because behavioural differences between the genders exists in the TD population. Rivet and Matson's (2011) review found that girls tend

to be clingy rather than exhibiting 'extreme autistic aloneness'. Gould and Ashton-Smith (2011) note that the intensity and quality of ASD-girls' interests differs to that of non-ASD girls, rather than the topic.

Over- and under-reaction to sensory input has been observed in females but whether this differs significantly to males is yet to be established through empirical research (Gould & Ashton-Smith, 2011). Lai et al. (2011) created an 'unusual sensory response' composite score from three ADI-R items which addressed sensory behaviours. They found that females had more unusual sensory responses than males, substantiating Gould and Ashton-Smith's observations. The creation of a composite score out of three items is a rudimentary method and will need further investigation.

Lai et al. (2011) state that ASD-females displayed less ASD behaviour than equivalent males on the RSB and social communication domains on the ADOS but scored higher than males on the self-report AQ. The authors suggest that the discrepancy between self-report symptoms and those measured objectively may be indicative of ASD-females having less severe ASD-symptoms but being more aware of them. Alternative interpretations not posed by the authors include the possibility that the ADOS may be male-attuned and therefore more sensitive to identifying males' symptoms.

Hsiao et al. (2013) found that between their 'younger groups', boys had more ASD traits, were less socially aware, less socially emotional and had more school problems than girls. These findings suggest that in terms of both overall ASD symptomology and also on specific domains, males displayed more severe ASD-type difficulties than girls during their early years.

Park et al. (2012) found that ASD-males had higher SCQ (Rutter, Bailey, & Lord, 2003) scores, greater non-verbal communication impairments and more RSBs than ASD-females (i.e. females have a more subtle presentation in these domains than males). Kopp

and Gillberg (2011) suggest that parents and professionals may overlook lack of social reciprocity in females and perceive them as more social than they really are; it is possible that males and females express similar degrees of severity in social reciprocity deficits but when each is viewed within the context of gendered-expectations, ASD-females' difficulties are overlooked.

In summary, the papers present data suggesting presence of both qualitative and quantitative differences in symptom expression between males and females on the spectrum. There are, however, methodological issues with many of the findings, including the use of clinical observations, androcentric samples and crude statistical analyses.

2.6.4 Different developmental trajectories. The developmental trajectory is different between genders in the TD population. However, few studies take this into consideration when ASD is explored. Females are measured against norms which are gender- and developmentally- inappropriate; a double-hit of unsuitable comparisons. Girls are recognised and diagnosed later than boys (Lai et. al, 2011) and there is a greater delay between referral and diagnosis for girls (Rivet & Matson, 2011); the diagnostic process for females is far more protracted than it is for boys.

Rivet and Matson (2011) explain that younger ASD-girls showed less impairment in early socio-communicative behaviour than ASD-boys. In adolescence, this pattern was reversed; adolescent & adult ASD-females had greater impairment in friendships than equivalent ASD-males. Kopp and Gillberg (2011) suggest that adolescence highlights ASD-females' social deficits because female peer relationships are more demanding due to their communicative and social nature; it is possible that girls do not develop difficulties with socio-communicative behaviour until slightly later than males and/or impairment only becomes apparent when demands requiring the use of these skills increase. Hsiao et al. (2013) suggest that the "impact of ASD traits on social functioning may not present until

pressure from demands for new social adaptation arises across major developmental transition” (p. 256).

In summary, it is understood that females experience a delay in both recognition of their difficulties and between diagnosis and assessment. Combining some of the findings from the papers under review offers a developmental framework for understanding why this may be so. As yet, very few research designs take development into consideration.

2.6.5 Blending in. Rivet and Matson (2011) suggest that parents expect more socio-communicative behaviour from daughters than sons so more frequently prompt daughters to act in a social manner. According to adult ASD-female accounts, parental engineering of friendships occurs which young girls often go along with and it is also possible that ASD-females are likely to be mothered by TD-girls (Gould & Ashton-Smith, 2011). These observations suggest that females may have their deficits compensated for by others who expect and encourage them to develop social skills.

Rivet and Matson (2011) explain that girls speak earlier and more frequently than boys and also have greater social imitation skills yet the possibility that core ASD-deficits may be masked by these differences is overlooked in their review. Hsiao et al. (2013) suggest that girls are more socially-oriented and are more aware of/have greater need for social interaction than boys and this may lead them to develop ways to appear socially-typical. Lai et al. (2011) suggest that females may camouflage their difficulties as they are better able than males to compensate for their socio-communication difficulties; teenage girls with ASD may develop social skills such as reciprocal interaction and eye contact which allow them to go unrecognised.

Gould and Ashton-Smith (2011) suggest that ASD-females may take on a social role which is informed by intellect rather than intuition and/or position themselves on the periphery of groups to reduce demands to interact. They suggest that ASD-females examine

and imitate others in order to initiate social contact, leading observers to believe that they have innate social skills. Lai et al. (2011) found that ASD-females had higher AQ scores (a self-report measure of ASD symptoms) than ASD-males, leading them to suggest that females may be more aware of their difficulties and this awareness enables them to mask symptoms. Lai et al. (2011) suggest that most of the females in their ASD adult clinics can only reveal their social functioning difficulties through self-report; they are not immediately apparent from observation. This is interpreted by the authors as indicative of the necessity to explore an individual's coping mechanisms in social situations.

In summary, naturally occurring gender differences may make females aware of their difficulties in the context of having a greater drive than males to develop peer relationships. This, in combination with gendered social expectations, may enable the ASD-female and those around her to develop skills and strategies that camouflage her core ASD-deficits.

2.7 Areas for Future Research

Guided by the above findings and following critique of their methods, possible areas for further investigation into the area of gender differences in ASD are now suggested.

Development of female cut-offs/norms/items on assessment tools have been suggested by the authors of a number of reviewed papers. The current assessment process is described as androcentric as Kanner's phenotype forms its foundations. It is possible that construction of new tools or revisions to existing ones may allow for greater equity between genders in the assessment of ASD. Revisions of existing tools would require thorough exploration of their ability to identify girls; a broadening of the current construct of ASD, which many of the reviewed papers suggest are too narrow, may be needed. A better understanding of the female ASD phenotype would be required if new female-sensitive items were to be developed.

A more accurate picture of gender differences may be revealed if further investigation into the female phenotype did not rely on the use of androcentric tools. Since few gender-neutral tools are widely available³, research into the impact of socio-communication deficits rather than ‘pure’ ASD may circumnavigate the use of androcentric tools. This may then require investigation into other aspects of core symptomology (i.e. measures of RRBIs) in order to measure the remaining strand of the DSM-5 criteria, if this is the classification the researcher wishes to adhere to. It may also be useful to develop a robust measure of sensory disturbance, since authors of the reviewed papers suggest that this may be an aspect of the female presentation which differs significantly to males.

A thorough review of the extant literature from a developmental perspective may create better understanding of the course of ASD, by gender. This could include results from comparative studies across the age span, although it may be confounded by factors including recruitment methods and inconsistent use of measures. However, such a review might inform a longitudinal research design which explores the trajectory of symptoms over time in relation to gendered developmental tasks and social- and cultural-norms/expectations.

Two of the studies were completed in East Asia. Cultural context is important to consider when investigating a condition which is influenced by social and environmental factors, yet cultural beliefs have not been discussed within any of the papers. Researchers might be wise to not continue to neglect this important variable.

Qualitative investigations into the experiences of ASD-girls are absent within this review. This data may help (a) substantiate observations made by clinicians (b) offer an alternative to the androcentric understanding of ASD (c) inform development of gender-specific measures (d) reveal female-specific differences that current research methods do not

³ The ASSQ-REV and the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing, Leekam, Libby, Gould, & Larcombe, 2002) are likely to be less androcentric but are not commonly used in diagnostic assessment.

uncover, due to the possibility that females are motivated and able to camouflage their difficulties.

2.8 Conclusions

In conclusion, there appears to be concordance between authors that current diagnostic processes may be insensitive to detecting females on the spectrum. This may be due to factors including gender differences in ASD symptomology, trajectory and the coping strategies of ASD-females. Future research may enable better understanding of the female profile which may bring greater equity to the diagnostic process.

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Section B: Are Girls on the Autism Spectrum able to Mask their Socio-communication Difficulties?

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Abstract

The aim of this study was to explore the experiences of adolescent females on the autism spectrum. During adolescence, the quality of friendships and social expectations implicitly change, challenging those on the spectrum. The study aimed to understand how girls cope in social situations in the context of having socio-communication difficulties and at a developmental stage where demand to use these skills increases.

Semi-structured interviews were designed and piloted before ten participants with a diagnosis of any autism spectrum condition (ASC) were recruited. Interpretative Phenomenological Analysis was used to explore emerging themes within each interview. Themes were cross-referenced between interviews to identify phenomena within the sample. It was found that participants experienced peer rejection as a result of their ASC-related difficulties. Most participants were motivated to build friendships and had developed sophisticated strategies of masking and imitation in order to fit in with peers. The impact of using such strategies was often highly detrimental to the mental health of participants. Findings also included the catalysing effect of transitioning between primary and secondary schools on the participants' mental health and subsequent seeking of professional support.

The limitations and clinical implications are explored and suggestions for future research are presented.

Keywords: Adolescence, female, Autism Spectrum, social relationships, imitation

1. Introduction

1.1 Gender Ratio in the Prevalence of Autism Spectrum Conditions (ASC)

Autism is one of the most commonly diagnosed neurodevelopmental conditions in the UK (Baron-Cohen, Scott, Allison, Williams, & Bolton, 2009), estimated at 1/1,000 in school-age children (Thrower, 2000). The male: female ratio is approximately 4:1 in autism and 10:1 in Asperger's Syndrome ([AsS] Fombonne, 2005). The gender ratio has remained consistent for decades. However, it is likely that circularity between research (samples are androcentric) and diagnostic practices (e.g. referrals for ASC diagnostic assessments are predominantly male) has contributed to this stasis.

1.2 Characterisation of ASC

The term 'autism' emerged when Kanner (1943) described shared characteristics within a sample of 8 boys and 3 girls. Since 1943, research has mainly focused on male presentations of ASC and recruitment of androcentric samples is frequent in the validation of commonly-used ASC diagnostic/screening instruments; the sample used in the original reliability analyses for the Autism Diagnostic Interview – Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) comprised 20 children, 16 of which were male (Lord et al., 1994). Subsequent analyses of the ADI-R have used predominantly male samples (e.g. Cox et al., 1999).

The ADI-R focuses on developmental history which is combined with an observational measure of social behaviour and communication to confirm ASC diagnosis (NICE, 2011). The ADOS-G (Lord et al., 2000) is often used to collect the observational data. The original validity analysis of the ADOS-G used a 78% male sample (Lord et al., 2000). Whilst the gender ratios reflect those in the clinical population, these widely-used instruments have been founded on a mainly male characterisation of ASC.

1.3 Theory on Gender Prevalence

It is beyond the scope of this paper to present the breadth of theories around gender and ASC (see Rivet & Matson, 2011 for a comprehensive review); therefore, only one of the most frequently-cited and influential theories is introduced. The Extreme Male Brain (EMB; Baron-Cohen, 2002) theory describes how typically developing (TD)-girls spend time together sharing emotions and contrasts this to interactions between TD-boys, who attempt to climb the ‘social hierarchy’ in a strategic way. In brief, the EMB theory proposes that people with ASC have exceptional systemising skills and difficulties with empathy, thus displaying extreme versions of male traits. The theory suggests that the male-prevalence arises from females being biologically protected from exhibiting ASC.

1.4 Gender and Diagnosis

Whilst biological differences exist, it has been suggested that girls may not be referred for ASC diagnosis due to gender stereotyping by professionals (Gould & Ashton-Smith, 2011). If females are assessed, Kopp and Gillberg (2011) state that they are likely to be measured using instruments modelled on Kanner’s phenotype. Lai et al. (2011) propose that since gendered behavioural differences exist in the TD population and diagnosis is based upon behavioural expression, sex-specific criteria may be needed. Dworzynski, Ronald, Bolton, and Happé (2012) explain that bias may exist towards the male presentation of ASC-behaviours in current diagnostic criteria, concepts or practices.

1.5 Female-specific Difficulties

If girls are measured against an androcentric construct of ASC, their ASC-related difficulties may not be revealed. Girls with high levels of ASC traits but without a diagnosis were found to be “significantly more pro-social” (p. 792) than equivalent boys (Dworzynski et al., 2012). Furthermore, inherent gender differences may lead ASC-females to be more

motivated and able than ASC-males to develop and use strategies which hide their socio-communicative difficulties (Gould & Ashton-Smith, 2011).

There may be differences between genders in the trajectory of ASC, partly due different gendered social expectations across the lifespan. Hsiao, Tseng, Huang, and Gau (2013) suggest that the “impact of ASD traits on social functioning may not present until pressure from demands for new social adaptation arises across major developmental transition” (p. 256).

Adolescence is turbulent for males and females (Wainscot, Naylor, Sutcliffe, Tantam, & Williams, 2008) but there are qualitative differences in peer relationships between genders. Kopp and Gillberg (2011) explain that TD-female friendships are more demanding than TD-males’ friendships due to their communicative and social nature. Stewart (2012) explored the experiences of four adolescent AsS-girls, finding that socio-communication impairments often led to peer-rejection. Peer-rejection is also problematic for ASC-males but there may be different coping strategies by gender; ASC-boys may withdraw from peers (Wainscot et al., 2008) whereas ASC-females may use patterns of socio-communication that are largely rote-learned in order to fit in (Gould & Ashton-Smith, 2011).

It has been suggested that boys become aware of their differences to TD peers in adolescence and ‘masquerade’ their stress at school (Carrington & Graham, 2001). The process of masquerading may be something that both genders use. Again, however, there appear to be qualitative gender differences. Attwood (2006) suggests that ASC-females are able to engage in reciprocal social conversation by adopting a social persona based on the characteristics of a TD peer; perhaps ASC-females go to far greater lengths than ASC-males to hide their differences.

There is little empirical evidence to consult when trying to understand the masquerading strategy and there are methodological flaws with findings. Daniel and

Billingsley (2010) present two parental accounts of their son's use of such strategies which do not detail the aims or process of masquerading. Attwood's (2006) suggestions arise from clinical experience, rather than empirical research. Both genders may use masquerading to hide some ASC difficulties, but females may use more sophisticated methods. However, due to a dearth of robust research, understanding this area is difficult.

1.6 Secondary Difficulties

Solomon, Miller, Taylor, Hinshaw and Carter (2012) found very similar symptom profiles in ASC-males and ASC-females but very different psychopathology. ASC-females had significantly higher internalising scores (combined levels of anxiety, depression and behaviours typically associated with turning difficult feelings towards the self) than equivalent males, who tended to display aggression towards others. Internalising could lead to depression and suicidal ideation (Colman, Wadsworth, Croudace, & Jones, 2007). It is possible that secondary problems related to female-specific inhibition of ASC core-deficits may increase ASC-females' likelihood of developing serious co-morbid psychiatric difficulties.

1.7 Female-specific Strategies

If girls hypothesised as having ASC use masquerading and internalising strategies, they may not be referred for diagnosis. Dworzynski et al. (2012) suggest that ASC-females' coping strategies could be explored to clarify whether females are more likely to receive mis-diagnosis or missed-diagnosis. Without "think[ing] beyond the lists of criteria in the various classification systems" (p 40), Gould and Ashton-Smith (2011) suggest that females may not receive an appropriate ASC diagnosis (i.e. missed-diagnosis) or may be diagnosed with a label which only captures secondary-symptoms (i.e. mis-diagnosis).

1.8 Critical Issues

Since the ASC-female profile is unknown, females with hypothesised-ASC may be measured against a male characterisation. ASC-females who fall below cut-off scores on diagnostic measures which have been validated on androcentric samples will struggle without support. This may lead to secondary problems and increased complexity in later life. In order to gain a better understanding of where ASC-females fit on the spectrum, it is imperative to know more about their profile.

1.9 Summary and Research Aims

It is understood that males are more likely to be diagnosed with ASC than females. Biological differences may lead to greater prevalence in males. It is also possible that since the construct of ASC has been developed mainly on a male characterisation, the female profile is not understood; females are less likely to be referred for diagnostic assessment and when they are, they are compared to ASC- and TD-males, a disadvantageous method in the context of gender differences in the TD population. It has been suggested that females may have the ability to masquerade their socio-communicative difficulties in a way that males do not. ASC-deficits may be hidden, leading to additional complications with diagnosis and potentially secondary mental health difficulties in ASC-females. Observations from specialist-ASC clinicians have not always lead to investigation into gender differences; whilst clinically, it may be understood that the current diagnostic process may be disadvantageous to females, research to substantiate this is lacking.

The purpose of this study is to explore whether females with ASC use masquerading strategies to hide socio-communication difficulties to enable them to fit in with peers. Such research has clinical relevance in understanding the profile of females on the spectrum. It may contribute towards understanding why there is disparity between genders in the

diagnosis of ASC and may identify areas in which current diagnostic processes might be improved in order to make a more accurate assessment.

2. Method

2.1 Design

Interviews with adolescent ASC-females were planned. Interpretative Phenomenological Analysis (IPA) fitted well with the exploratory design as it has hermeneutics (interpretation) and phenomenology (detailed examination of the participant's experiences) at its origins; IPA aims to understand how a person makes sense of/interprets their experiences within a given context. IPA principles state that participants' accounts are understood within the context of the researcher's own world-view. It utilises an iterative process of analysis which enables the researcher to see the perspective of the participant whilst maintaining awareness that their own view will affect the way they understand the participants' accounts. It is therefore imperative that the researcher remains aware of their own biases as much as possible by constantly referring to the raw data and being influenced as little as possible by their own assumptions.

The study featured semi-structured interviews which enable the researcher to explore the participant's narrative. Parents⁴ or carers could attend the interview. This was debated since the participants' responses may have been influenced/inhibited by the parent/carer's presence. However, it has been suggested that people on the spectrum are not always aware that their communication style is atypical (Didehbani et al., 2012), so the inclusion of a parent/carer may have facilitated dialogue. Parents/carers were only present when the participant indicated this as their preference. To guard against dominance of parents/carers, it

⁴ It is recognised that parents may or may not be biologically related to their child. In the interests of brevity and inclusivity, the term 'parent' is used to describe parents of all origins.

was confirmed during pre-interview discussions that the perspective of the participant would be prioritised.

The age-range was guided by literature on psychological development in the TD (e.g. Marcia, 1980) and ASD populations (e.g. Pfeifer & Peake, 2012). The adolescent phase of development (approximately 13-19 years old) requires the navigation of changing and nebulous rules. The type of peer-relationship that females typically develop (i.e. ones which make heavy use of empathy; Baron-Cohen, 2003) makes puberty exceptionally difficult for females on the autism spectrum due to their difficulties with socio-communication and adapting to change. Since ASC-females are required to negotiate a constellation of challenges during this developmental stage, strategies to overcome them might be explored as they are developed and utilised in situ.

2.2 Participants

Using purposive sampling, ten adolescent females with a diagnosis of any ASC were sought. The sample size was guided by Willig (2008) who suggests that an IPA study includes six to eight participants if experiences are to be considered a phenomenon, rather than idiographic. Since participants were unlikely to provide elaborate answers due to their communication styles and age, ten participants were sought.

2.2.1 Inclusion criteria. Participants were 13-19 year old females, with a formal diagnosis of ASC. Fluency in English was essential as participants were required to verbalise their experiences. Girls with co-morbid diagnoses of organic, neurological or affective disorders were included as exclusion would have further narrowed the participant pool and reduced the generalisability of findings; co-morbidity is common within the ASC population.

2.2.2 Exclusion criteria. No formal exclusion criteria were used. However, potential participants with issues impinging on their ability to provide informed consent or narratives were not interviewed.

2.3 Interview Schedule

A semi-structured interview schedule (Figure 1) was developed and piloted with two adolescents with ASC. It was imperative that the schedule accommodated for any idiosyncrasies in participants' communication whilst addressing the research aims. Clinical techniques such as summarising and reflection allowed the interviewer to complete in-depth exploration of emerging themes.

Figure 1: Interview Schedule

Check Terminology regarding differences and diagnosis.

1. Open with something **general**:

Prompts: school, upcoming holidays (appropriate to time of year of interview e.g. Christmas, summer),

2. Draw out diagram of **social networks**:

Prompts: How many people are you friends with? How long have you known them for? How did you meet? (school, social, clubs, internet) Do you have a best friend?

3. **Making friends:** Describe how you/other people make friends?

Prompts: Concrete examples based on diagram (how did you become friends with X?) How would you make friends if you moved class or school? How does your brother/sister make friends? (compare & contrast)

Prompts: Try to get rich descriptions (a really easy friend, a really hard friend)

4. **Social situations:** How would you cope with a school party?

Prompts: How would X friend cope with the same party? Would you do anything to prepare for it? Would your friends do anything different to you whilst you're there? Would your friends do anything different to you before the party? Would anyone give you advice about how to cope?

5. How would a friend describe you?

Remember: Distraction and refocusing techniques. Use special interests as a way in (e.g. how do cats and friends get on?).

2.3 Procedure

Approval was granted by a NHS Research Ethics Committee (Appendix 3) and two NHS Trusts' Research and Development Directorates (Appendices 4-5). Potential recruits were identified by staff based at Child and Adolescent Mental Health Services (CAMHS) within two NHS Foundation Trusts.

Participants recruited through CAMHS were identified by practitioners as having met the inclusion criteria. Verbal consent was provided before contact details were passed onto the researcher. After the researcher made contact with the potential recruit, an information pack (Appendices 6-8) and consent form (Appendices 9-10) was sent. Once written consent had been provided by the participants or their carers (see Ethical Considerations), interviews were arranged.

Potential recruits also identified themselves by responding to advertisements placed on two charitable organisations' websites (Appendices 11-12). The information pack was sent before formal written consent was provided by the participant/their parent/carer. A formal diagnostic report was seen by the researcher before interviews commenced.

Recruitment and interviews took place between February 2013 and December 2013. Interviews were completed on a one-to-one basis, unless a parent/carer was present, at a mutually agreeable, private location.

The procedures of IPA (Smith & Osborn, 2007) were followed. The first transcript was read several times in order to become familiar with the data. Keywords were noted in the left-hand margin. Parents/carers' contributions which clarified or enriched the participants' account were analysed. The transcript and notes were re-read so that higher level interpretations could be made in the right-hand margin (Appendix 13). These interpretations were organised into clusters of related concepts to develop initial themes (Appendix 14). This process was repeated for each transcript. A coding sheet (Appendix 15) was then used to aid

cross-referencing between transcripts. Unique and new information was integrated into the analysis to strike a balance between the idiographic nature of IPA and the identification of shared experiences. Once all transcripts were analysed, initial emergent themes were collated (Appendix 16) before final emergent themes were identified.

2.4 Quality Assurance

An important part of IPA is 'meaning-making' of a given phenomenon within a given context (Smith & Osborn, 2007). In order to perceive the phenomena with consideration towards the participants' own 'meaning makings', it is important that the researcher is transparent about their position. IPA requires the researcher to remain aware of difference and how it may influence the subjectivity of the dialogue (Smith & Osborn, 2007. See Appendix 17 for a sample of the reflective diary). IPA does not aim to establish 'truth' but is used to explore the experiences and collective phenomena of individuals within a given population. IPA is an iterative process so after analysis, each participant received a brief interpretation of their interview (Appendix 18). Participants reviewed the summary and some provided feedback on the interpretation. Feedback was used to check the quality and validity of the analysis. When participants provided comments which contradicted interpretation, they were taken as additional data and included where appropriate.

The analysis was reviewed by an external researcher (Appendix 19) who traced the course of initial notes through to emergent themes for three transcripts to ensure that the researcher could demonstrate transparency in the analytic process.

2.5 Ethical Considerations

Service users reviewed the information sheets to ensure they were age- and diagnosis-appropriate. Informed consent for the thirteen to fifteen year old participants was provided by parents/carers. Females aged sixteen to nineteen provided their own consent.

Participants may have been invited to think about times when they had felt alienated. The information sheet made this risk clear. Attention was paid to any expressed distress throughout the interview. The participant was informed that should risk issues arise during the interview, the researcher may share information with health professionals to ensure the safety of the participant.

3. Results

Twenty-five females were contacted regarding participation. Ten were recruited. See Appendix 20 for participant flow diagram. Participant demographics are shown in Table 1.

Table 1

Participant Demographics

<u>Participant^a</u>	<u>Age</u>	<u>Recruitment Channel</u>	<u>School Placement</u>	<u>Multiple School Placements (number of moves)</u>	<u>Diagnosis (age of diagnosis)</u>	<u>Family Contact with ASC^b</u>
Gemma	13	NHS	All-girls Grammar	No	AsS (12)	Professional
Janita*	15	NHS	Mainstream Secondary	No	High Functioning Autism (4)	
Laura	14	NHS	Mainstream Secondary	No	AsS (4) & ADHD (13)	
Kate*	15	Charity	Pupil Referral Unit	Yes (2)	AsS (12)	Professional & Personal
Stephanie	16	Charity	Open University	Yes (8)	AsS (15)	
Rosie*	15	Charity	Out of School (4 years)	Yes (2)	AsS (7)	Personal
Nadia*	15	Charity	Mainstream Secondary	Yes (1)	AsS (14)	
Siân*	13	Charity	Mainstream All-girls Secondary	No (moved classes due to difficulties)	ASC & anxiety (10)	Professional
Emily*	13	Charity	Mainstream Secondary	No	AsS (8)	
Joëlle	15	Charity	Home Educated since 13 years old	Yes (1)	AsS (12)	Personal

* Mother attended interview

^a Pseudonyms are used to protect the identity of participants

^b Professional refers to Mother working with people with ASC. Personal refers to family history of ASC

Four superordinate themes and 13 subthemes emerged. These are presented in Table 2. Extracts from transcripts are used to illustrate the findings⁵. Results are presented within their corresponding themes.

Table 2

Emergent Themes

<u>Superordinate Theme</u>	<u>Subtheme</u>
1. Experiences of Social Environment	1.1 Incommodious
	1.2 Impenetrable
	1.3 Misunderstandings and Mis-labellings
2. Desire for Friendships	2.1 Context for Making Friends
	2.2 Challenges to Developing Friendships
	2.3 Motivations for Befriending
3. Overcoming Challenges	3.1 External Support
	3.2 Using Innate Skills
	3.3 Using Imitation
	3.4 Using Masking
	3.5 Repercussions of Strategies
4. Developmental Tasks	4.1 Triggers for Difficulties
	4.2 Sexual Identity

3.1 Experiences of the Social Environment

This superordinate theme captures participants' perspectives of their social environment (i.e. when in the company of others, outside of their home). This was predominantly school,

⁵ Quotes are denoted with #:# (i.e. transcript number: line number). Text within [] denotes text added for clarity. ... denotes words removed for clarity/brevity

partly due to the age range of participants. Participants' perceptions of themselves in relation to peers within social contexts are also described.

3.1.1 Incommodious. The social environment felt unsafe to participants. For some, this led to retraction from it; three had permanently withdrawn from school. Others sought safety within different peer groups, classes or schools. Lack of safety arose from feeling ostracised and at the mercy of more powerful others, broadly conceptualised as those who understood social rules. Three participants described how they experienced the school environment as predatory.

Emily: It feels like in my classroom that I'm surrounded by lions ... I feel like a mouse and everyone else is like a giant cat or something. 8:375

The social environment triggered sensory distress for most participants. Joëlle described experiencing synaesthesia when her stress peaked at school. Kate explained that when she experienced the environment as stressful, she could smell odours that others could not. Many participants described school corridors as highly distressing due to activation of sensory sensitivity when moving between classes amongst large numbers of peers; this was often experienced as physically assaultive.

A number of participants experienced sensory overload as traumatic. Some described how they felt that their brains were absorbing so much information that it triggered a trauma response.

Joëlle: I ... just try to focus on one thing and instead of just sort of noticing everything at once which is a bit sort of traumatic sometimes. 10:971

3.1.2 Impenetrable. Many participants experienced their social environments as rejecting. Participants had often made great efforts to be accepted by peers and faced constant

rebuffal. This informed their expectations of future interactions; many assumed that they would be always be rejected.

Rosie: I don't get on with girls who are not on the spectrum because they don't get on with me. I would be happy to hang around with them if they would accept me but they don't. 6:34

Gender expectations contributed to the sense of feeling unable to fit in. Many participants described feeling ‘ungirly⁶’ in relation to female peers. Family members and peers had also identified the participant as ‘ungirly’. Differences were in terms of appearance, interests and communicative styles. Participants caricatured female peers as wearing revealing clothes, preoccupied with their appearance and with irrational ways of relating to each other. This contrasted to participants’ own ‘boyish’ appearance, interests (different topics such as computer games and/or intensity such as being immersed in a TV show) and straight-forward communicative style. Participants often aligned with male peers; their interests were often similar, participants felt accepted rather than judged and they spent time together without engaging in emotion-based conversations.

Stephanie: I think ... it's probably harder for girls with Asperger's in a way than boys cos generally people socialise more with their own gender ... being a boy with Asperger's you're probably more similar to neurotypical boys whereas an Asperger's girl is different to neurotypical girls. 5:903

3.1.3 Misunderstandings and mis-labellings. Differences in socio-communication style in relation to TD-females resulted in participants frequently feeling misunderstood and confused by others. Misunderstandings compounded their sense of alienation; participants faced constant misunderstanding and rejection and this contributed towards their sense of perceiving the social environment as impenetrable.

⁶ A word used by a number of participants to describe their experiences

Emily: AsS is talking to another person through an intercom machine or something and somehow the wires get crossed and they get the wrong message. 9:913

Being labelled 'naughty' arose frequently. Participants described how they broke covert social conventions and this was interpreted by teachers as intentionally disruptive. This labelling, combined with frequent peer-rejection, led many participants to feel that they could not fit into their social environment, however hard they tried. Many participants expressed their inability to feel safe in social environments; rules were nebulous and they felt alienated and mis-labelled.

Joëlle: *The teacher was like "it's a technique that we use for really naughty children" ... I might have come across as naughty, but I never intended to be.* 10:261

3.2 Desire for Friendships

This superordinate theme describes how participants conveyed desire for friendships. Subthemes encapsulate their positioning within the social environment, their motivations for making friends and some of the challenges to making and/or maintaining friends.

3.2.1 Contexts for making friends. Most participants made friends at school. Some found that making friends over the internet was preferential, due to struggles with befriending in face-to-face situations. For others, use of the internet was partly due to lack of alternatives.

Nadia: *I don't know how to act when I'm face-to-face with someone but I know how to act when I'm talking over the internet.* 7:587

Rosie: *I'm not in a lot of social situations apart from on the internet and to make friends you literally add someone and say "do you wanna be friends" and that's it.* 6:1017

3.2.2 Challenges to developing relationships. Misunderstandings obstructed the development of relationships. Participants were aware of their tendency to misinterpret others' communication and participants were misunderstood by others. In addition to

heightening the sense that the social environment was impenetrable, this mutual misunderstanding led participants to feel very confused about and anxious in social interactions. Participants could not read the intentions or meanings in others' communication and their own style of communication was difficult for their peers to understand; the pair found it hard to relate to each other.

Kate: I think it's just like the whole misinterpreting things cos just like I give off different sort of images to other people and sometimes they give off different things to what I think and it's just a bit- sort of gets confusing after a while. 4:810

Nearly all participants described finding group communication challenging. This impacted on their ability to maintain friendships because the people they befriended often had a group of friends which the participant struggled to integrate into. If they could not access this group, the participant would often be left behind by the friend. Difficulties with groups also impacted on participants' educational experience; they were often set group tasks at school which they felt ill-resourced to cope with. This created distress for the participant leading to disengagement from group tasks and negative repercussions from peers and teachers.

Emily: With a group, there's loads of different people all at different times and it turns into a murder mystery game of Cluedo where somebody made this go wrong, we've got to find out who it is, people blaming each other, splitting each other up and just wrecking everything. I don't like it at all. 9:482

A minority of participants described being members of very large social groups, stating that they had around 100 friends. Mothers sometimes attributed this to their daughter having an atypical understanding of what a 'friend' is. Participants sometimes explained that whilst they had large numbers of friends, they positioned themselves on the periphery:

Laura: *You know they have them interview rooms where you can see in but they can't see out? I'd rather be on the outside of one of them than the other way round.* 3:752

Possibly arising from encountering frequent misunderstandings in the context of a stressful social environment, many participants described how social contact was exhausting. Most participants explained that they spend much less time with their friends than their peers did as they felt exhausted by the effort it took. Not being in frequent contact introduced the risk of deterioration in the friendship.

Kate: *I don't really talk to people as much as most other people cos quite often, you know, it's too much effort. So it's a bit stressful cos you have to sort of think about the other person's feelings, it's just a bit too much for me sometimes ... but I do worry quite a bit like if the friendship starts to deteriorate and they don't see me as friends any more.* 4:848

One participant wanted to spend more time with her non-ASC female peers but felt excluded:

Nadia: *Clare snapchat me and sends pictures ... she'd say like "out with the gang!" and I'd take a picture of me and it's just a frown and "all alone, me and my Xbox" (laughs). Yeah, I would like to go out a little bit more but they don't invite me.* 7:1379

3.2.3 Motivations for befriending. All participants had an innate desire to have friends. This intrinsic motivation combined with experience of frequent peer rejection, sometimes stirred up ambivalent feelings about friendships; participants wanted friends, but had to go to great lengths to make and maintain friendships.

Joëlle: *I suddenly realised "oh God! I really miss them, I wanna keep in touch with them".* 10:429

Stephanie: *I definitely couldn't be some kind of hermit. As much as I would like to be able to I don't think it would be good for me at all.* 5:734

Participants valued their friendships. They appreciated the support their friends offered and enjoyed providing support to their friends. Support from friends appeared to have a protective element for many participants, in the context of their sense of social vulnerability.

Rosie: *When I'm not with friends ... I always just... think of all the bad things in life and just carry on thinking about them over and over and over and over until I get really depressed.* 7:716

3.3 Overcoming Challenges

This superordinate theme presents accounts of how participants attempted to overcome the challenges they faced in developing and maintaining friendships. Within this theme, the support provided by those around them as well as the strategies participants themselves used are described.

3.3.1 External support. All participants had struggled to form friendships. They tended to become friends with people who had nurtured them. Some participants' friends would ensure that she was not alone during stressful situations (e.g. transitions between classes). Friends noticed her socio-communicative difficulties and would scaffold conversations for her. Friends understood her need to remove herself from interactions when she felt overwhelmed or exhausted and did not judge her choice or intensity of interests. Participants generally described female peers when discussing how they had been supported; whilst males were inclined to not judge her interests or communicative style, female peers tended to actively support participants in her acquisition of social skills. Accepting this support allowed participants to develop safe, accommodating friendships.

Kate: *I think they probably noticed that I was ... not very good at it so they probably pitched in a bit more but I did try to do my best at trying to talk to them.* 4:464

Joëlle: *There was something about them that was more mothering rather than “oh, get out of here, you’re strange, we don’t want anything to do with you”.* 10:764

Oftentimes friendships were assisted by parents. Many participants had friendships which were formed in infancy. These long-term friendships had generally been engineered by parents. Some mothers described how they could see that their daughter was struggling to socialise and encouraged her to do so by setting up contact with female peers.

Rosie’s mum: To form that whole circle took a lot of input from parents. 6:699

3.3.2 Participants’ use of innate skills. Nine participants described how they had used their natural abilities to develop strategies in order to establish friendships. Some of the strategies were built upon what they described as very strong innate empathising skills.

Joëlle: *People say that people with AsS aren’t empathetic ... I think that’s so wrong ... I’m really actually quite good at putting myself into other peoples’ situations.*

10:1290

Many participants described consciously developing empathy due to awareness that being able to take another’s perspective would enhance their befriending skills. Often, empathy was informed by a naturally good memory. It is possible that participants built empathy skills like a jigsaw puzzle (e.g. matching corresponding memories to another person’s situation in order to create a concrete reference point which they could identify with).

Gemma: *I have a very good memory so I can ... relate that to a situation the other person’s in.* 1:480

Difficulties in understanding implicit social conventions were sometimes overcome by using innate observation skills. Participants described how they naturally absorbed a lot of information about their environment and had turned their observations

towards peer interactions. Observations informed development of a social code they could adhere to.

Gemma: I [would] be quiet and listen and record that for next time. 1:561

Siân: *I can see that they're all doing that and this is the way it goes.* 8:901

Participants generally felt that they had natural strengths in empathy, memory and observation. Many had utilised these skills to inform the development of their own social code with the aim of appearing akin to peers in social situations.

3.3.3 Using imitation. Acting featured in most interviews. Many participants were involved with drama classes and described how this had improved their confidence and skills in social situations. Participants also described sophisticated levels of peer-imitation. Some pretended to be occupied with an activity (e.g. reading) when they actually were observing peers in order to imitate them. The attempts to imitate peers were driven by a strong desire to not stand out as different to them. Copying included facial expressions, postures, tone of voice, topic of conversation, choice of interests; the breadth of imitation was vast. Participants sometimes explained that they thought TD-peers pretended to be interested in things in order to fit in. However, participants were aware that the frequency and intensity of their own pretence was far greater than that of their peers. Furthermore, participants went to great lengths to disguise their imitation as they were fearful of being 'caught out'.

Laura: *I see how other people act first then copy them in my own way... I change it a little bit so it's not like I'm really copying them.* 3:543

Gemma: I would try and copy them but not look like I was exactly copying them so if they were playing a game and they moved and they did something then I would try and copy it but not exactly like them. 1:960

Many participants who attended the interviews alone were able to describe their conscious use of complex imitation in order to blend in with peers. When mothers attended, they often provided additional detail around the process of imitation. Mothers explained that the imitation was so automatic for their daughters that she was unaware that she was employing it.

One participant explained that whilst she could easily imitate others in order to blend in, she chose not to; she wanted friends who liked her for who she really is. Another participant's mother said that she had not observed her daughter blending in and believed that she had no desire to. Motivation to blend in was necessary before such sophisticated methods could be developed.

3.3.4 Masking strategies. As well as attempting to overcome difficulties by developing their socio-communication skills and using imitation, participants described how they masked difficulties. All participants described feeling unhappy and anxious in social situations. In order to survive, they all said they masked their true feelings by wearing either an excessively happy facial expression or a very blank one. Many participants wore their mask in most social environments; even when they had developed friendships, they often maintained their mask, through fear of losing the friendship should their true feelings be unveiled.

Laura: If I happen to be upset ... I'll tell myself I'm not and think that everyone else wouldn't know, and then act like excessively happy so then they'll think "there's no chance that she's upset". 3:760

Nadia: I do hide many of my emotions and I'm used to like having a smile on my face. 7:1204

3.3.5 Repercussions of strategies. The consequences of using sophisticated and intense imitation and the frequent use of masking and pretence were discussed. Using these strategies sometimes resulted in emotional explosions if participants surpassed their threshold

to maintain their efforts. Some participants described a stark contrast between their social-persona and how they interacted with family, where they felt they could be their 'true selves'. For many, constantly wearing the mask and imitating at school left them feeling exhausted at the end of the day.

Gemma: *It's very hard and when I come home from ... school I was ... often very exhausted and tired cos I'd acted so much.* 1:1344

The repercussions of trying to cope were severe for many participants. Five participants had used self-harm as a way to cope with feelings associated with frequent rejections & miscommunications. The strain of frequently and intensely masking their feelings and/or imitating others often led to anxiety and depression. Mental health difficulties, self-harm and/or suicidal ideation often brought the participants to the attention of CAMHS.

Kate: I was stressed big time. It got quite bad I think throughout the whole time that I was at mainstream school. I got quite a few throat infections and I think that was from all the stress and all the pressure from school.

Mum: ... *she started self-harming* and got really depressed. 4:1552

Joëlle: *I was getting to the point where I actually couldn't control some urges that I had ... I was a little bit suicidal.* 10:129

For Stephanie, the impact of constantly pretending to be like her peers led to her identity crisis:

Stephanie: I think I had a *sort of identity crisis really because I wasn't quite sure who I was anymore because I was so used to ... pretending to be the same as everyone else when really I knew that I wasn't.* 5:342

Stephanie started speaking to herself as she had no friends to interact with and she started to experience voices in response. The combination of hearing voices, self-harm and depression led to her spending three months in hospital:

I would sort of talk to myself and reply to myself and that was when I started to hear voices and things like that as well and I think that just stemmed from being really lonely. 5:719

Participants had generally been using the masking and imitation strategies since the onset of adolescence; over time, they had finely honed their sophisticated methods. Since participants had used their strategies so effectively, those around them were surprised when they learnt that the participant was masking her true feelings. This led to a vast discrepancy between others' perception of the participant's mental state and abilities and that of her family members. Participants provided accounts of teachers expressing disbelief that she was struggling so severely. The absence of observable struggles created extra stress for mothers who endeavoured to get their daughters' needs met through health, education or social care services.

Rosie's mum: *[I'd] go "oh she was really stressed today" and [teachers at school would] go "no she was happy all day, it's not true"*. 6: 491

Nadia: *They didn't believe me that I was upset because I was always happy cos I was trying to mask that I was upset.* 7:142

3.4 Developmental Tasks

This superordinate theme consists of tasks specific to adolescence. The impact of developmental tasks such as gaining independence are included. This theme presents changes in expectations which prompted differences to either emerge or become problematic. Also included is how some participants made sense of their sexual identity.

3.4.1 Triggers for difficulties. This sub-theme encapsulates factors that perhaps catalysed some difficulties. All participants identified the transition from primary to secondary school as the point where they felt that difficulties emerged. Some described being aware of differences at a young age but such differences became problematic only when they reached adolescence. Others perceived no differences until adolescence and cited the changes in social expectations as the trigger for emerging struggles. Adolescence brought about multiple major unspoken changes in social etiquette which confused participants. These covert changes seriously challenged participants' ability to both understand and abide by new social norms.

Emily: If they just decided "I'm gonna list a giant book of teenage girl etiquette so that ... every single teenage girl has to live to these standards" ... if only that happened ... I'd be able to interact with them in the right way. 9:365

Changes included peers developing interests and objectives which participants did not share. These changes, alongside increased social expectations in adolescence, sometimes led to friendship groups disintegrating around the participant, one-by-one, as members of the group gradually became aware that the participant was taking a different direction to the rest of the members.

Stephanie: When you get to secondary school, people really split into different groups and there's more of a sort of social ladder and people always aiming to be the most popular people and I wasn't aiming for that. 5:610

Siân's mum: Social standing is different and expectations are different ... that sort of time of adolescence of when the girls were [making] more of their appearance and more is expected of you. 8:1168

The transition between schools led to the diagnosis of ASC for around a third of participants. Some cited the size of the school as problematic; it increased opportunities for

triggering sensory distress and for tripping up over new covert rules. Extra demands were placed on the participants' socio-communication skills as they were expected to make new friends. When participants began to struggle to cope with these tasks, serious problems surfaced in terms of the expression of ASC core-deficits in socio-communication. Secondary mental health difficulties (e.g. affective disorders) often then emerged. The emergence of these core and secondary difficulties often prompted referral for professional support, which for many resulted in diagnosis of ASC. For others, referral led to support with affective difficulties, self-harm and social-skills training.

Interviewer: *Can I ask ... why you got to age 12 before you were diagnosed?*

Kate: Well that was because when I went to high school I got quite depressed because of all the stress and chaos that happened at high school. 4:1476

Janita's mum: *I always said ... if it proved to be a problem when she grew up then we would seek a diagnosis and it was only when she was in year 7 [when] she was going to secondary school. It was that much bigger and that much faster. She seemed to be getting in trouble all the time. 2:1321*

3.4.2 Sexual identity. During adolescence, development of sexual identity begins. Four participants made reference to having sexual relationships. Two described themselves as bisexual and discussed their sexuality in the context of individual differences in relation to peers; her sexuality was another defining marker in terms of differences to peers. One participant made a link between gender, AsS and sexuality:

Joëlle: *I wanna know... if... other teenage girls with Asperger's think the same way as me because I think like or identify with another gender ... sometimes, like I don't feel like particularly female occasionally or I feel like I'm not particularly attracted to one gender or anything like that and ... I've always wondered whether that's*

something to do *with me personally or it's something to do with* like every other girl *with Asperger's*. 10:1359

4. Discussion

The aim of the study was to explore the experiences of adolescent ASC-females in social situations. The results are now discussed in relation to the research aim and existing theory. Clinical implications, limitations and directions for future research are noted.

Participants recognised the emotionally-intimate quality of peers' female-to-female friendships and often found that they did not understand, and therefore could not abide by, the covert rules within these relationships. When participants broke these rules, they were identified as "different" and consequently experienced rejection. This, in combination with not adhering to gendered social expectations, led to participants feeling unable to fit into social situations. Participants' socio-communicative difficulties were a barrier to developing friendships as mutual misunderstandings made bonding difficult. Participants were motivated to have friendships; therefore, obstacles to making friends caused discomfort and distress.

Most participants developed sophisticated strategies which utilised innate strengths and enabled them to appear socially-competent to observers. Participants often used masking/imitation strategies to hide/overcome obstacles to developing and maintaining friendships. In relation to the research aim, the sample within this study provided accounts of using masquerading strategies to mask socio-communication difficulties.

4.1 Secondary Impact of Coping

For many participants, use of these strategies had negative repercussions on their mental health and also possibly hampered access to support since their difficulties were hidden. There are subjective accounts from ASC-females (e.g. Craft, 2012) and from ASC-specialist clinicians (e.g. Attwood, 2006) which suggest that ASC-females are motivated and

able to develop and use strategies which create access to social relationships. This study may be one of the first to present detailed accounts of ASC-females' motivation and methods in building these friendships and also of their subjective experience of the consequences of using masking/imitation strategies.

4.2 ASC-Associated Difficulties

Core ASC-difficulties (e.g. with socio-communication) resulted in frequent peer-rejection and loneliness. This led many participants to develop secondary mental health difficulties which triggered referrals to CAMHS. This is consistent with studies which suggest that ASC-females may be referred to services due to either more severe social deficits or greater concomitant psychopathology than ASC-males (Hofvander et al., 2009). Aloneness has often been conceptualised as a characteristic preference of the ASC profile; however, recent findings suggest that loneliness arises from lack of social skill and understanding (Jobe & Williams White, 2007). The findings from this study are consistent with this notion.

Social environments were hard for participants to tolerate. Difficulties with sensory distress and peer-rejection led many participants to endure multiple school-placements in an attempt to find an accommodating environment. Accounts of sensory distress in this study are consistent with Stewart's (2012) research which found that adolescent-ASC-females experienced frequent and intense sensory disturbances. Since a reliable and valid measure of sensory sensitivity is yet to be developed (Mandy, Chilvers, Chowdhury, Salter, Seigal, & Skuse, 2012) it is difficult to gauge how problematic sensory distress may be for this population.

4.3 Gender-specific Challenges

Some participants described an ability to easily integrate with their peers during infancy. Factors around early adolescence (e.g. the transition to a secondary-school environment, changes in social expectations, female peers' development of complicated

social relationships and new ‘girly’ interests) seemed to catalyse difficulties in the social abilities of participants. This led to alienation from peers, mislabelling of behaviours and often to a decline in mental health. This supports the observations of clinicians (e.g. Gould & Ashton-Smith, 2011) who have suggested that adolescence presents ASC-females with demands which they struggle to meet, due to core ASC-deficits. This is a gender-specific difficulty; ASC-females face a different set of social expectations to ASC-males (e.g. Wood, 2011). This, in combination with differences in symptom profiles between females and males (e.g. Rivet & Matson, 2011), presents unique challenges for ASC-females.

4.4 Familial Relationships with ASC

Three participants’ mothers worked with people with ASC and two had family members with ASC diagnoses. It is possible those with a family history were at greater risk of inheriting ASC traits (Piven, Palmer, Jacobi, Childress, & Arndt, 1997). Also, participants may have been identified by family members who already had knowledge of the ASC phenotype. This is pertinent to the ASC diagnostic process which relies heavily on parental identification and report of developmental concerns (De Giacomo & Fombonne, 1998). As advised by Eriksson, Westerlund, Anderlid, Gillberg and Fernell (2012), these findings suggest that familial background should be broadly reviewed in ASC-assessment.

4.5 Limitations

One limitation is the lack of comparison groups; this was an exploratory study and the findings cannot easily be compared to TD-/ASC-males or TD-females. Comparisons are necessary to help identify ASC-female-specific difficulties and coping strategies.

Whilst the use of IPA may have facilitated exploration of this under-researched population, generalisation from this idiographic methodology is limited (Willig & Billig, 2011). However, it is possible to transfer findings from this study and combine them with other sources of understanding such as quantitative research and clinical experience

(Hefferon & Gil-Rodriguez, 2011). Limitations to transferability are increased if participant self-selection occurred; it is likely that only girls who had developed strategies to survive social situations would volunteer to discuss the topic. The cultural and social context within this sample was narrow. This further limits the transferability of the findings.

Although mothers generally enriched participants' narratives and largely allowed their daughters to present their own accounts, their presence will have affected their daughter's interaction with the interviewer. It is possible that enlightening data was not collected due to participants feeling unable to present it in the presence of their parent.

4.6 Clinical Implications

To aid identification of females on the spectrum, it might be helpful for clinicians to enquire around their coping methods; it is possible that current practice is not uncovering vital information. Mothers in this sample were generally very able to describe (a) their daughters' use of imitation to mask difficulties (b) their observations of discrepancies in their daughters' presentations across different social contexts and (c) incongruence between their daughter's facial expression and how she was really feeling (i.e. socio-communication deficits behind the mask). This information may illuminate ASC core-difficulties which cannot be observed by a clinician due to the female's use of masking and/or imitation strategies. If asked, parents may also describe the social support provided to their daughter by family members and female peers which might enable clinicians to see that she is protected by gendered-expectations in a way that males may not be. Exploration of coping strategies of ASC-females has been identified as crucial in uncovering what may be hidden aspects of the ASC-female profile (Dworzynski et al., 2012).

None of the strategies (e.g. masking, imitation) or characteristics (e.g. motivation to have friends) described by participants in this study are assessed for in ASC-diagnostic procedures. Current methods measure against a male characterisation of ASC yet much of the

data here came from comparisons between the participant and TD-female peers. It is therefore suggested that there is a poor fit between current diagnostic procedures and the ASC-related difficulties described within this sample. As suggested by Lai et al. (2011), revisions to existing diagnostic procedures may give more focus to females and thus increase diagnostic equity between genders.

Participants explained that the transition to secondary school catalysed their struggles. It may be useful to adopt a developmental framework when assessing for hypothesised ASC; since female development differs to that of males, difficulties may only emerge when gendered and developmentally-driven demands exceed the abilities of the ASC-female, as suggested by Hsaio et al. (2013).

Interventions which develop empathy through utilisation of cognitive processes may enable access to peer relationships. Similarly, design of interventions which use drama classes may develop socio-communication. However, consideration would need to be given to the individual's need to be able to drop her act, so that she had both space to be herself and skills to enable her to integrate with others.

4.7 Areas for Future Research

The majority of this sample were diagnosed with AsS; future research might explore whether girls with more severe deficits and/or co-morbid difficulties employ similar strategies. The development of the strategies described by this sample utilised cognitive processes and some awareness of social expectations and norms. Further research may help understand how ability and/or awareness interplay with masquerading strategies.

A longitudinal design which explores the symptomology of ASC between genders may allow for better understanding of both the trajectory of the ASC-female profile and differences in the ways the genders cope with their ASC-difficulties. This would be further

enhanced by including a comparison group from an equivalent TD-population, in order to identify ASC-specific items.

4.8 Conclusions

In conclusion, the majority ASC-females in this sample were motivated to have friendships. After facing frequent peer-rejection and experiencing their social environment as incommodious, they developed sophisticated methods of masquerading (i.e. peer-imitation/masking) in order to blend in with TD-peers. These findings imply that, as predicted by the EMB theory, females on the spectrum may have an innate social drive and social abilities which motivates them to devise strategies to overcome socio-communication difficulties. The use of such strategies was often highly detrimental to their mental health. Developmental tasks catalysed participants' socio-communicative struggles and often led to referral for professional support/ASC-diagnosis.

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1. Appendices

Appendix 1: National Research Ethics Service Confirmation to Proceed

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Appendix 2: NHS Foundation Trust Research and Development Directorate Permission to Proceed

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Appendix 3: NHS Foundation Trust Research and Development Directorate Permission to Proceed

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Appendix 4: Information for Participants aged 13-15**Participant information sheet (13-15 year olds)****Version 2:5th February 2013****Information for participants about the research****How do girls with Autism see the world?**

My name is Siobhan Tierney. I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you want to.

What is the purpose of the study?

I am interested in understanding how girls with a diagnosis of autism or Asperger's see themselves. I am interviewing girls with a diagnosis to find out what life is like for them. I am very interested in how girls with the diagnosis make friends. I would like to understand how difficulties with social situations or communication might affect the ways girls form friendships.

Why have I been invited?

I am asking ten girls between the ages of thirteen and nineteen to tell me about their social experiences. I have invited you because I understand that you have been given a diagnosis of autism or Asperger's.

Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, I will ask your parent/carer to sign a form which says that you've agreed to join in. You are free to drop out at any point before I write up your interview, without giving a reason.

What will happen to me if I take part?

- I will arrange a time that suits you. I will ask you some questions and try to make sure that I get a really good idea about who you are and what life is like for you.
- The interview will take up to an hour. You will be able to take breaks during this time if you need to.
- If you like, a parent or carer can be at the interview with you. This decision is yours.
- Our interview will be recorded using a digital audio recorder. This is so that I don't forget anything. The only people who would ever listen to this are me, and possibly my tutors. There is more information about this in Part 2 of this information sheet.
- Once I have interviewed you, I will write up what we have spoken about, word for word (this is known as a 'transcript'). I will then write up a report which makes it easier for people to understand what life is like for you and other girls with the diagnosis. I will ask you to read

what I have written and tell me whether you think I have done a good enough job. After I've made adjustments based on your feedback, it is likely that you will not need to have any more contact with me. You will still be able to contact me though, if you need to.

Expenses and payments

I will pay your travel expenses if it costs you to travel to meet me.

What will I have to do?

I will ask you some questions about yourself and you can answer however you want. If there are things that you do not feel comfortable talking about, just tell me that you do not wish to answer my question. If you are unsure about any part of the interview process, please tell me and I will do what I can to make things clearer for you.

What are the negatives of taking part?

Some of the questions I ask may invite you to think about things other people have said about you and things that you think about yourself. Some of these things may be positive, others may be negative. If you feel upset in the interview, please let me know. If I can see that you are upset, I will ask you if you wish to continue and the decision will be yours.

What are the possible benefits of taking part?

It may be helpful for you to have someone to talk to about how you feel and what you think. I hope that what we discuss will help other people who have a diagnosis of autism or Asperger's and the people who care for them.

What if there is a problem?

If you have any complaints about the way you have been treated by me, there will be ways for you to bring this to the attention of others. The details about this are included later on in this information.

Will my taking part in the study be kept confidential?

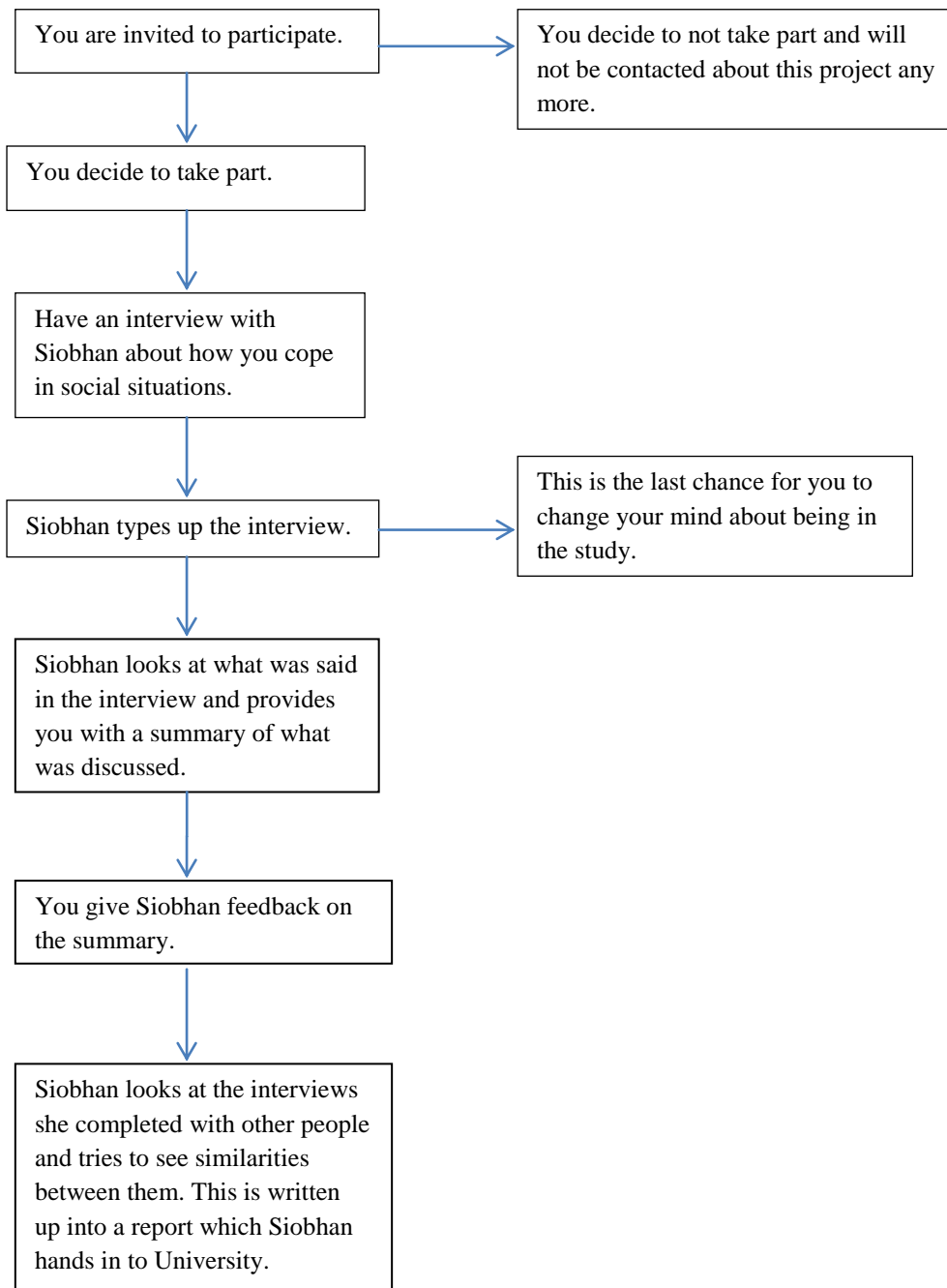
Yes. The details about this are included later on in this information.

What will happen if I do not want to carry on with the study?

If you change your mind about being involved with the study after I have interviewed you, please contact me and let me know. Unfortunately, if you tell me you wish to withdraw after I have written up your interview, it will not be possible for me to take you out of the study. Therefore, if you do change your mind, it would be best if you could tell me as soon as possible.

If you tell me before I have written up your interview, I will delete our recording and confirm to you in writing that you are no longer involved in the study.

If you do decide to withdraw, your treatment will in no way be affected. I may ask you for feedback so that I can try to be as good as possible at what I am doing, but you do not have to give a reason for wanting to change your mind. The diagram should help explain things.



What if there is a problem?

You and/or your parent/carer can contact Professor Paul Camic, Research Director at Canterbury Christ Church University, on 01892 507 773 or paul.camic@canterbury.ac.uk. If speaking to Paul does not help, you can go through the NHS Complaints Procedure. I will give this information to your parents.

Will my taking part in this study be kept confidential?

- The recording and transcript of your interview will be stored electronically on a memory stick that I will securely store.

- The recording and transcript will not be accessible to anybody not involved in this research.
- I will protect your identity. If I include anything that you say word-for-word in the interview (in other words, if I quote you) I will not reveal your name or anything else that would make it possible for people to know it was you who said it.
- The interview recording will be used only for the purposes of this research.
- Once I have completely finished with writing up the recording, I will permanently delete it.

Involvement of other people

It is not necessary for your GP or any other health professional to be informed that you are taking part in this study. It is your choice whether you tell other people that you are involved. Information will be passed onto me from the Phoenix Centre in Bromley [this will be adapted to include the source of contact for the participants] about your age, diagnosis and how I can contact you. I do not need to gather any other information from the Centre as I will be asking you directly to tell me about yourself.

The only time I would pass on information about what we talk about in the interview is if I need to do so to protect you. This is very unlikely, but if you told me that you are at risk of harm, I may need to tell your GP or another health professional so that we can make sure you are as safe as possible.

What will happen to the results of the research study?

The results of the study will be reviewed by Canterbury Christ Church University. The study will be marked by two examiners.

I hope to submit my results to an academic journal (professional magazines written for people with specific interests). This means that many people would be able to read the results from the study. These people may use them to help make decisions about treatment, diagnosis and future research.

I will not provide any information about you are in my write up. If you wish to be told about the results of the study, I can make plans to send you an outline of the findings and, if the research is published in a journal, explain how you can access a copy.

Who is organising and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to make sure you are not harmed or taken advantage of. This study has been reviewed and given favourable opinion by London Hampstead Research Ethics Committee.

Further information and contact details

If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me at 01892 507673. Please say that the message is for me [Siobhan Tierney] and leave a contact number so that I can get back to you.

If you feel unhappy about this study, you can speak to me, if you feel comfortable to do so. If you would rather speak to someone else about your concerns, please contact Paul Camic on 01892 507 773.

¹ It is recognised by the researcher that parents may be biological or adoptive. Every time the word “parent” is used in this information sheet, it covers all parents.

Appendix 5: Information for Participants aged 16-19**Participant information sheet (16-19 year olds)****Version 2: 5th February 2013****Information for participants about the research****How do girls with Autism see the world?**

My name is Siobhan Tierney and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you want to.

What is the purpose of the study?

I am interested in understanding how girls with a diagnosis of autism or Asperger's see themselves. I am interviewing girls with a diagnosis to find out what life is like for them. I am very interested in how girls with the diagnosis make friends. I would like to understand how difficulties with social situations or communication might affect the ways girls form friendships.

Why have I been invited?

I am asking ten girls between the ages of thirteen and nineteen to tell me about their social experiences. I have invited you because I understand that you have been given a diagnosis of autism or Asperger's.

Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, I will ask you to sign a consent form which says that you've agreed to participate. You are free to drop out at any point before I write up your interview, without giving a reason.

What will happen to me if I take part?

- I will arrange a time that suits you. I will ask you some questions and try to make sure that I get a really good idea about who you are and what life is like for you.
- The interview will take up to an hour. You will be able to take breaks during this time if you need to.
- If you prefer, a parent or carer can be at the interview with you. This decision is yours.
- Our interview will be recorded using a digital audio recorder so that I can make an accurate interpretation of what we discuss. The only people who would ever listen to this are me, and possibly my tutors. There is more information about this in Part 2 of this information sheet.
- Once I have interviewed you, I will write up what we have spoken about, word for word (a 'transcript'). I will then write up a report which makes it easier for people to understand what life is like for you and other girls with the diagnosis. I will ask you to read what the report and

provide feedback on the accuracy of it. After I've made adjustments based on your feedback, it is likely that you will not need to have any more contact with me. You will still be able to contact me though, if you need to.

Expenses and payments

I will pay your travel expenses if it costs you to travel to meet me.

What will I have to do?

I will ask you some questions about yourself and you can answer however you want. If there are things that you do not feel comfortable talking about, just tell me that you do not wish to answer my question. If you are unsure about any part of the interview process, please tell me and I will do what I can to make things clearer for you.

What are the negatives of taking part?

Some of the questions I ask may invite you to think about things other people have said about you and things that you think about yourself. Some of these things may be positive, others may be negative. If you feel upset in the interview, please let me know. If I can see that you are upset, I will ask you if you wish to continue and the decision will be yours.

What are the possible benefits of taking part?

It may be helpful for you to have someone to talk to about how you feel and what you think. I hope that what we discuss will help other people who have a diagnosis of autism or Asperger's and the people who care for them.

What if there is a problem?

If you have any complaints about the way you have been treated by me, there will be ways for you to bring this to the attention of others. The details about this are included later on in this information.

Will my taking part in the study be kept confidential?

Yes. The details about this are included later on in this information.

What will happen if I do not want to carry on with the study?

If you change your mind about being involved with the study after I have interviewed you, please contact me and let me know. Unfortunately, if you tell me you wish to withdraw after I have written up your interview, it will not be possible for me to take you out of the study. Therefore, if you do change your mind, it would be best if you could tell me as soon as possible.

If you tell me before I have written up your interview, I will delete the recording and confirm to you in writing that you are no longer involved in the study.

If you do decide to withdraw, your treatment will in no way be affected. I may ask you for feedback so that I can try to be as good as possible at what I am doing, but you do not have to give a reason for wanting to change your mind. The diagram should help explain things.

[FLOW CHART AS FOR APPENDIX 6]

What if there is a problem?

You and/or your parent/carer can contact Professor Paul Camic, Research Director at Canterbury Christ Church University, on 01892 507 773 or paul.camic@canterbury.ac.uk. If speaking to Paul does not help, you can go through the NHS Complaints Procedure. Details about this can be obtained from

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx>

Will my taking part in this study be kept confidential?

- The recording and transcript of your interview will be stored electronically on an encrypted memory stick that I will securely store.
- The recording and transcript will not be accessible to anybody not involved in this research.
- I will protect your identity. If I include any direct quotes from the interview, I will not reveal your name or anything else that would make it possible for people to know it was you who said it.
- The interview recording will be used only for the purposes of this research.
- Once I have completely finished with writing up the recording, I will permanently delete it.

Involvement of other people

It is not necessary for your GP or any other health professional to be informed that you are taking part in this study. It is your choice whether you tell other people that you are involved. Information will be passed onto me from the Phoenix Centre in Bromley [this will be adapted to include the source of contact for the participants] about your age, diagnosis and how I can contact you. I do not need to gather any other information from the Centre as I will be asking you directly to tell me about yourself.

The only time I would pass on information about what we talk about in the interview is if I need to do so to protect you. This is very unlikely, but if you told me that you are at risk of harm, I may need to tell your GP or another health professional so that we can make sure you are as safe as possible.

What will happen to the results of the research study?

The results of the study will be reviewed by Canterbury Christ Church University. The study will be marked by two examiners.

I hope to submit my results to an academic journal. If my report is published, many people would be able to read the results from the study. These people may use the results to help make decisions about treatment, diagnosis and future research.

I will not provide any information about you are in my write up. If you wish to be told about the results of the study, I can make plans to send you an outline of the findings and, if the research is published in a journal, explain how you can access a copy.

Who is organising and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to make sure you are not harmed or taken advantage of. This study has been reviewed and given favourable opinion by London Hampstead Research Ethics Committee.

Further information and contact details

If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me at 01892 507673. Please say that the message is for me [Siobhan Tierney] and leave a contact number so that I can get back to you.

If you feel unhappy about this study, you can speak to me, if you feel comfortable to do so. If you would rather speak to someone else about your concerns, please contact Paul Camic on 01892 507 773.

¹ It is recognised by the researcher that parents may be biological or adoptive. In the interests of inclusivity and also to ensure information sheets are easy to read, in this document the term “parents” refers to parents of all origins.

Appendix 6: Information for Parents

Parent Information Sheet

Version 2: 5th February 2013

Information about the research for parents and/or carers¹

How do girls with autism or Asperger's cope with social communication?

My name is Siobhan Tierney and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite your daughter to take part in a research study. If your daughter decides she would like to be involved and before you decide whether you are happy for her to participate, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen if you give permission for your daughter to take part.

Part 2 gives you more detailed information about the conduct of the study.

Part 1:

What is the purpose of the study?

I am interested in understanding how girls with a diagnosis of autism or Asperger's see themselves. I would like to find out more about how girls make sense of their personal world, particularly the social aspects of their world. I would like to know more about how girls with difficulties with social interaction and communication overcome these obstacles to form friendships. Therefore, I am interviewing girls with a diagnosis to find out what life is like for them. I hope that these interviews will help other researchers and health professionals know more about the experiences of girls and that these experiences may be taken into consideration when thinking about diagnosis and plans to support girls on the autism spectrum.

Why has my daughter been invited?

I am asking ten girls between the ages of thirteen and nineteen to tell me about their social experiences. I have invited your daughter because I understand that she has been given a diagnosis of autism or Asperger's.

Does she have to take part?

If your daughter chooses to participate, she will be required to provide written consent confirming her decision. She is free to withdraw at any point before I transcribe your daughter's interview, without giving a reason. This would not affect the standard of care she receives.

What will happen to her if she takes part?

- I will arrange a time and location that is convenient for her to talk with me. I will ask her some questions about what she thinks of her social skills and questions about how she

communicates with people. I will ask her about other areas too, to make sure that I get a really good idea about who she is.

- It is unlikely that the interview will last longer than an hour. She will be able to take breaks during this time.
- You can attend the interview with her if your daughter wants you to do so. It is really important that I hear your daughter's perspective about herself. However, there may be things that you wish to contribute which will be really useful for me to know. The decision about whether you want to sit in on the interview is your daughter's.
- I will give you and your daughter the opportunity to discuss how the interview was for you/her and ask any questions you/she may have.
- Our interview will be recorded using a digital audio recorder. This is so that I have an account of exactly what we discuss. The only people who would ever listen to this are me, and possibly my supervisors. I will ensure that the interview will not be listened to by anybody else by saving it on an encrypted, password protected memory stick. Once I have completely finished with the recording, I will permanently delete it. The NHS and the University both have policies for this and I will follow them. There is more information about this in Part 2 of this information sheet.
- Once I have interviewed your daughter, I will prepare a transcript of the recording. I will then analyse, interpret and write up report on all of the interviews I complete in this research. Once I have done this, I will ask her to read what I have written and tell me whether she thinks I have accurately and fairly represented her. If you have attended the interview, I will ask you for your feedback as well. This feedback will be used to make any necessary adjustments to my report. After these adjustments have been made, it is likely that you and your daughter will not need to have any more contact with me. If you had any questions or worries at this stage, you will be able to email me and I will do what I can to help you.

Expenses and payments

If I ask you to visit a location that means you incur travel costs (e.g. the X Centre in [name of town] where you and your daughter completed some diagnostic assessments [this will be adapted according to how the participants were sourced]), I will reimburse you.

What will she have to do?

I will ask her some questions about herself and her social life. If there are things that she does not feel comfortable talking about, that is fine. If you and/or your daughter are unsure about any part of the interview process, please tell me and I will do what I can to make things clearer for you.

What are the possible disadvantages and risks of taking part?

Some of the questions I ask may invite her to think about things other people have said about her. Some of these things may be positive, others may be negative. If this does become upsetting at any stage, I will give her the option of ending the interview or stopping to take a break. I will not ask any questions which will be intentionally upsetting to your daughter. If you discover that your daughter has any concerns about the interview or any other part of the process, I will be available for you to contact.

What are the possible benefits of taking part?

It may be helpful for her to have someone to talk to about how she feels and thinks. I hope that what we discuss will improve the understanding of what life is like for girls with autism or Asperger's.

What if there is a problem?

If you have any complaints about the way you and/or your daughter have been treated during the study or any possible harm she might suffer, there will be ways for you to bring this to the attention of others. The detailed information on this is given in Part 2.

Will taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2:**What will happen if I do not want to carry on with the study?**

If your daughter changes her mind about being involved with the study before or after the interview, please contact me and let me know. Unfortunately, if I am told that she wishes to withdraw after I have transcribed the interview, it will not be possible for me to take your daughter out of the study. Therefore, if she changes her mind, it would be best if I was informed as soon as possible.

If I am notified before I have transcribed the interview, I will delete the recording and confirm to you in writing that you are no longer involved in the study.

If she does decide to withdraw, her treatment will in no way be affected. I may ask her for feedback about the process of being involved in my study for the purposes of my development, but she does not have to give a reason for wanting to change her mind.

Complaints

You and/or your daughter can contact Professor Paul Camic, Research Director at Canterbury Christ Church University, on 01892 507 773 or paul.camic@canterbury.ac.uk. If speaking to Paul does not help, you can go through the NHS Complaints Procedure. Details about this can be obtained from <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx>

Will taking part in this study be kept confidential?

- The recording and transcript of the interview will be stored electronically on a password protected, encrypted memory stick.

- The recording and transcript will not be accessible to anybody not involved in this research. If it is necessary for those involved in this work (i.e. my supervisors) to review any part of the interview, the information I pass on to them will be anonymised, so no identifying information will be given to them. It is unlikely that anybody else apart from me will listen to the recording, so you and your daughter will not be identified by your voices.
- The interview recording will be used only for the purposes of this research. It will be destroyed as soon as the transcription process is complete.

Involvement of the General Practitioner/Family doctor (GP)

It is not necessary for your GP or any other health professional to be informed that your daughter is taking part in this study. It is your choice whether you tell other people that you are involved in this research. Information will be passed onto me from the [Phoenix Centre in Bromley: to be adjusted, as appropriate] about your daughter's age, diagnosis and how I can contact you. I do not need to gather any other information from the Clinic as I will be asking you and her directly.

If, in the unlikely event that your daughter raises something in the interview that causes concern for her safety, I may need to inform either her GP or another health professional about my concerns. This would be to ensure that she can be made as safe as possible.

What will happen to the results of the research study?

The results of the study will be reviewed by Canterbury Christ Church University. The study will be examined and marked by an internal and an external examiner (a staff member from another educational institution).

I hope to submit my results to an academic journal. This will mean that professionals, academics and researchers would be able to read the results from the study. These results may go some way towards shaping future decisions about treatment, diagnosis and future research involving girls on the autism spectrum.

I will ensure that your daughter (and you, should you choose to attend the interview) will not be identifiable in the results. If I do quote her/you directly at any point in my write up, I will not provide any information about your identity(ies). If you wish to be told about the results of the study, I can arrange to send you an outline of the findings and, if the research is published, explain how you can access a copy.

Who is organising and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London Hampstead Research Ethics Committee.

Further information and contact details

If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me at 01892 507673. Please say that the message is for me [Siobhan Tierney] and leave a contact number so that I can get back to you.

If you feel unhappy about this study, you can speak to me, if you feel comfortable to do so. If you would rather speak to someone else about your concerns, please contact Professor Paul Camic, Research Director at Canterbury Christ Church University, on 01892 507 773 or paul.camic@canterbury.ac.uk.

¹ It is recognised by the researcher that parents may be biological or adoptive. In the interests of brevity and inclusivity, the term “parents” refers to parents of all origins.

Appendix 7: Consent form (Participants aged 16-19)

Consent form for participants

Version 2: 5th February 2013**Study Number:** 117713 or 13/LO/0050

Patient Identification Number for this trial:

CONSENT FORM FOR PARTICIPANTS

Title of Project: **Do girls on the autism spectrum use and report ways of masking their problems with social communication**Name of Researcher: **Siobhan Tierney**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated February 2013 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason before my interview has been transcribed, without my medical care or legal rights being affected.

3. I understand I wish, I am welcome to attend the interview with a parent/carer and that he/she might make contributions which may aid the understanding of the researcher. I understand that if my parent/carer participates, the same principles of confidentiality will apply to them.

4. I understand that the interview will be audio recorded for the purposes of transcription. I am aware that this recording and the transcript will be stored with encryption and that only those involved in the collection and analysis of the data will be able to access it. I understand that the disposal of this data will be completed in line with the Data Protection Act, National Health Service, Canterbury Christ Church University and British Psychological Society policies and procedures.

5. I understand that parts of the interview may be quoted verbatim in the published reports of the study. If this is the case, I am aware that these quotations will not allow my identity to be revealed.

6. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Date Signature
taking consent

Appendix 8: Consent Form (Parents of participants aged 13-15)Consent form for parents/carers¹Version 2: 5th February 2013**Study Number:** 117713 or 13/LO/0050

Patient Identification Number for this trial:

CONSENT FORM FOR PARENTS/CARERS

Title of Project: Do girls on the autism spectrum use and report ways of masking their problems with social communicationName of Researcher: **Siobhan Tierney**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated February 2013 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my daughter's participation is voluntary and that she is free to withdraw at any time without giving any reason before my interview has been transcribed, without her medical care or legal rights being affected.

3. I understand if my daughter wishes for me to be present, I am welcome to attend the interview with her and that I might make contributions which may aid the understanding of

the researcher. I understand that if I participate, the same principles of confidentiality will apply to me.

4. I understand that the interview will be audio recorded for the purposes of transcription. I am aware that this recording and the transcript will be stored with encryption and that only those involved in the collection and analysis of the data will be able to access it. I understand that the disposal of this data will be completed in line with the Data Protection Act, National Health Service, Canterbury Christ Church University and British Psychological Society policies and procedures.

5. I understand that parts of the interview may be quoted verbatim in the published reports of the study. If this is the case, I am aware that these quotations will not allow her identity to be revealed.

6. I agree to allow my daughter to take part in the above study.

Name of Participant Date Signature

Name of Person Date Signature

taking consent

¹It is recognised by the researcher that parents may be biological or adoptive. In the interests of brevity and inclusivity, the term “parents” refers to parents of all origins.

Appendix 9: Advertisement for Participants via Burgess Autistic Trust e-newsletter**How do girls on the autism spectrum manage social situations?**

I am completing some research on how girls on the spectrum manage social situations. I am interested in how girls make and maintain friendships. I believe it may be possible, due to naturally occurring gender differences, for girls on the spectrum to use strategies in a way that boys on the spectrum may not.

I also believe that it's possible that girls on the spectrum present differently to boys on the spectrum. This difference has implications for diagnosis, treatment and the general understanding of what autism spectrum disorders look like. Since research on girls is sparse, the current understanding of ASDs is centred around a male presentation. I would like to contribute towards a change in this understanding by interviewing girls aged 13-19 about their experiences of forming and maintaining friendships. If you would like to help with this contribution, please contact me on [email address] or [phone number] for an informal discussion and more information.

Appendix 10: Advertisement for Participants via National Autistic Society

The screenshot shows the National Autistic Society website. At the top, there are navigation links: Personalise, Set nation, Display preferences, and a search bar. The main header includes the NAS logo and a navigation menu with categories like 'About autism', 'Living with autism', 'Schools and services', 'Working with people with autism', 'Get involved', 'News and events', and 'Community'. A prominent pink 'Donate' button is visible in the top right.

The central content area features a large, handwritten-style purple text advertisement: "Research: How do girls on the autism spectrum manage social situations?". Below this, a breadcrumb trail reads: "You are here: Home > Get involved > Volunteer > Volunteering opportunities > Take part in surveys and research > Research: recruit people or participate > Research projects: children and young people > How do girls on the autism spectrum manage social situations?".

On the left side, there is a 'Get involved' sidebar menu with options such as 'Push for Action', 'Why support us?', 'Donate', 'Leave a gift in your will', 'Raise money', 'Campaign for change', and 'Volunteer'. Under 'Volunteer', there are sub-options like 'Volunteer fundraising', 'Volunteering opportunities', and various roles like 'Volunteer as a Supporter Care Assistant, Islington'.

The main content area below the breadcrumb trail includes a 'Print this page' link and a quote from Siobhan Tierney, a researcher at Canterbury Christ Church University. Her text reads: "I am completing some research on how girls on the spectrum manage social situations. I am interested in how girls make and maintain friendships. I believe it may be possible, due to naturally occurring gender differences, for girls on the spectrum to use strategies in a way that boys on the spectrum may not." She also states: "I also believe that it's possible that girls on the spectrum present differently to boys on the spectrum. This difference has implications for diagnosis, treatment and the general understanding of what autism spectrum disorders look like. Since research on girls is sparse, the current understanding of ASDs is centred around a male presentation." Her goal is to contribute to a change in understanding by interviewing girls aged 13-19 about their experiences of forming and maintaining friendships. Contact information is provided: "If you would like to help with this contribution, please contact me on slt31@canterbury.ac.uk or 07968 343 880 for an informal discussion and more information."

On the right side, there is a 'Find local services' section with a search form for services and locations, and a 'Support the NAS' section with links for 'Donate now', 'Join us', 'Volunteer', and 'Take action'. A 'Last updated: 15th March 2013' timestamp is also present.

Appendix 11: Sample Transcripts

This has been removed from the electronic copy.

Appendix 12: Sample of Themes for one Participant

Table 1

Sample Themes for One Participant

Theme	Subtheme and Quotation ^a
How to make new friends	<p>Systematic reciprocation during conversation - Me: yeah I see. So do you have sort of questions in your head that you might ask them about? <i>I: errrrrm I'd ask them what primary school they went to before</i> ME: mmmm <i>I: and I'd ask them yeah if they had any brothers and sisters</i> Me: mmmm <i>I: and yeah I could talk to them about my brothers and sisters</i> Me: right <i>I: and then I'd talk to them about if they had any pets and my pets</i> Me: hmhhh <i>I: and then I'd talk to them about lessons they liked and lessons I liked</i> 249</p> <p>Anticipate/predict possible responses - everybody can answer them they can say "oh I have no pets" or "I have a lot of pets" or "I have one pet" or "I have no brothers and sisters" or "I have a step-brother" or "I have a half-sister" – 275</p>
Skill acquisition	<p>Acting lessons - I looked at them and listened to them and I sort of watched them and that's how I learnt to act and to be so good at talking – 930</p> <p>Observe others - so I sort of gradually built up my information about what other people did by watching them and often in my old primary school I'd sit and read and people would think that I'd be reading but I'd be looking around at what everybody else was doing- 454</p>
Social world contains danger	<p>Must maintain the mask - think I would try hard, I would really try hard to act like them but maybe I'd let it slip and they'd notice Me: mmmm <i>I: and they'd think I was weird and different</i> – 1274</p> <p>Fear of being caught out - If I exactly copied them they would</p>

notice and would like wonder why I was doing that - 966

Focus on the past

Painful memories of loneliness : I sort of felt like a bit like an alien cos everybody else in class they had lllllloads of things in common – 1069

Hiding feelings - at my primary school I would never do that
I would never show anybody that I'm sad – 679

Awareness of own limitations or differences

Making friends is intuitive to others - *I don't think that my sister has any rules in her head if she talks to somebody it comes naturally to her* - 528

Rules for friendships

Please others I would talk about subjects more about what she liked rather than what I liked – 860

Pretend to like the same things - and I had to pretend to be normal pretend to like the same thing- 1075

Be reflexive - *I just see what they're doing and then I try to copy them and I f- f- f- I go through in my head and say "they're acting and talking about this so I need to act and talk about this"* if it was somebody else and they were a bit different and their normal was different to what my *normal was, I'd go through like "they're not doing this but they're doing this so I need to change that and do this instead"* - 1335

Communication style

Pairing of similarities and differences - T has a little brother and *I've got a little brother*

Me: right

I: and I've got a sister who's roughly the same age as her brother and sheeee had a hamster and my sister's got a hamster – 207

Lots of dichotomies - I was really quite good at my primary school, really, really good and the rest of the people were quite bad – 76

Awareness of own strengths

Can easily take someone else's perspective - *I'm also very good at putting somebody else in somebody else's place so I can imagine I'm in somebody else's place and think about what would I be thinking and what would I be feeling and what would I want to talk about* – 46

How to be normal

Synthesise different types of normal - sometimes I look around and think *“that person’s doing that but that person’s doing something different so maybe if I slightly use what they’re doing and slightly use what they’re doing, maybe I can be pretend to be normal and blend in”* – 548

Be like “the target” - *I’d be with her I could learn a bit about her and try and act like her as much as I possibly could* – 834

Copy frequently, intensely and deeply - I act in more depth I try and appear exactly like them and I don’t try and slightly like them I try to appear like fully like them - 1377

^aQuotes from the transcript illustrate the content captured within each subtheme.

Appendix 13: Sample of Cross-Referencing Themes between Participants

<u>Participant 1</u>	<u>Participant 2</u>	<u>Participant 3</u>	<u>Participant 4</u>	<u>Participant 5</u>
1. How to make new friends	13. Developing new friendships	6. Making new friends	9. Making new friends	12. Making friends
1.1.1 Initiate conversation	13.1 Growing closeness	6.1 Link people and locations	9.1 initiate contact	12.1 Context
1.1.2 Ask questions	13.2 Common interests	6.2 Boys off-limits	9.2 be nurtured	12.1.1 Level playing field
1.1.3 Systematic reciprocation during conversation	13.3 Camaraderie	6.3 Chance		12.1.2 Impenetrable Groups
1.1.4 Talk about things you know about	13.4 Emotional support	6.4 Camaraderie		12.2 Strategies
1.1.5 Anticipate/predict possible responses	13.5 Empathy	6.5 Aided by parents		12.2.1 be agreeable
3.2.1 Creation of catalogue of “safe topics”				
4. Focus on the past		10. The past	3. The Past	2. The past
4.1 Alienation		10.1 Informed by others	3.1 Difficulties with coping at school	2.1. School
4.1.1 Painful memories of loneliness		10.2 Forming friendships	3.2 Structure of school	2.1.1 Multiple moves
4.1.2 Heterogeneous peer group is problematic		10.3 Paranoia	3.3 Disruptive environment	2.1.2 High Expectations
4.2 Reactions from others		10.4 Coping with worry	3.4 Difficulties with friends	2.1.3 Isolation/loneliness
4.2.1 Being teased		10.5 Catalyst for worries	3.5 Trigger for “problems”	2.2 friendships
4.2.2 Lack of support			3.6 Quirky, not problematic	2.2.1 Straying away
4.2.3 Repels other people				2.2.2 Broken relationships
7. Rules for friendships	2. Maintaining friendships	9. Maintaining friendships	5. Maintaining friends	5. Maintaining Friends
7.4 Please others	2.3 Communication with friends	9.1 Spending time together	5.1 Keep in touch (hard to initiate contact)	5.1 Obstacles
7.5 Copy covertly	2.4 On own terms	9.2 Understanding idiosyncrasies		
7.6 Pretend to like the same things	2.5 Frequency of contact	9.3 Managing conflict		
8. Communication style	10. Communication style	2. Communication style	11. Communication Style	6. Communication Style

8.1 Absence of details about emotions	10.1 Figures of speech	2.1 Depersonalising	11.1 Hard to find words	6.1 Contradiction
8.2 Pairing of similarities and differences	10.2 Literal interpretations	2.2 Contradictions	11.2 Miscommunications (due to AsS)	
8.3 Lots of dichotomies	10.3 Opinions	2.3 Absence of process	11.3 Interpersonal communication is effortful	
11. Awareness of own strengths	14. Personal strengths	12. Personal insight	13. Insight	14. Reflection and realisation
11.1.1 Can sense what mood people are in	14.1 Perceptive	12.1 Blind spots	13.1 protecting others from her difference	14.1 learning from mistakes
11.1.2 Can easily take someone else's perspective	14.2 Observant	12.2 Mastery of anxiety (HIDING IT)	13. 2 AsS Symptoms	14.2 seeing Emerging gaps
11.1.3 Uses memory to inform empathy	14.3 Considerate	12.3 Empathy	13.3 Into own processes	X Retrospective awareness
13. How to be normal		14. Social skills	12. Social mask	
13.1 Synthesise different types of normal		14.1 Adaptation (CHAMELEON)	12.1 Keeping guard up	
13.6 Copy frequently, intensely and deeply			12. 2 Letting mask down	
13.3 Pretend to be happy when feeling sad			12.3 Empathy	
14. Social world contains danger	12. Unsafe world	13. Social fears	14. Social experiences are traumatic	
14.1 Fear of being caught out	12.2 Illogical social behaviour	13.1 Being misunderstood		
14.2 World is illogical	12.3 Lack of control	13.2 Being disliked		
14.3 Fear of judgment	12.4 Unpredictability	13.3 Of being different		
14.4 Must maintain the mask	12.5 Rejection from others	13.4 Isolation		
	9. Gender roles	11. Gender roles	10. Gender Roles	11. Gender
	9.1 Manliness		10.1 Non-girly friends	11.1 Social expectations
	9.2 Communication styles		10.2 Girls are confusing (includes hair & Make-up)	11.2 Gender differences
	9.3 Emotional awareness (includes			

	nurturing)			
	9.4 Femininity			
	9.5 coping style			
	11. Coping strategies (includes self-harm)	15. Coping skills	4. Coping strategies	
	11.1 Academic	15.1.1 Imitation	4.1 With anxiety (INCLUDES FAKING IT)	
	11.2 Social	15.2.1 Let others lead	4.2 With sensory disturbance (Includes COPYING)	
	11.3 General stress management	15.4.1 Hiding	4.3 With social situations (Includes COPYING)	

^aNumbers correspond to the subtheme and theme for each participant, as organised within each full Table of Themes (i.e. the full version of Appendix 14) and were used by the researcher as a reference back to the origin of the subthemes

Appendix 14: Table of Initial Emergent Themes

Table 3

Initial Emergent Themes ^a				
<u>Superordinate Theme</u>	<u>Master Theme</u>	<u>Subtheme</u>	<u>Transcript notes</u>	
Making Friends	Context	Internet	7. Internet, 10. Ease of internet	
		School	1. Eat lunch with friends , 12.Level playing field	
		Out of school	3. Link people and locations	
	How to make friends	Initiate		1. Initiate conversation, 1. Ask questions, 4. Initiate contact, 8. Identify target, 8. Passive stance, 9. Initiation, 10 Initiating
			Mask feelings/preferences	3. Strategizing, 1.Creation of catalogue of “safe topics”, 1. Acting lessons, 5. Be agreeable, 5. Pretend to fit in, 5. Be anything but yourself, 5. Masking, 8. Being in “role”, 8. No desire to conform
			Use empathy	1. Anticipate/predict possible responses, 2. Empathy, 7. Identify vulnerable others, 1. Identification of vulnerable others, 10. Identification of vulnerable others, 6. Identification of vulnerable others, 7. Friends with Differences, 10. Identification of vulnerable others
			Over Trying/perfectionism	6. Over-trying, 1. Talk about things you know about, 1. Systematic reciprocation during conversation, 1. Observe others
	External factors	Nurtured by peers		1. Look for people who look friendly, 4. Be nurtured, 5. External support, 8. Nurtured by peers, 10. Nurtured by friend
			Parental Engineering	6. Parental input, 3. Aided by parents, 8. Parental engineering, 10. Parental engineering, 9. Parental engineering
			Acceptance of difference	2. From others, 2. Of others, 3. Accepting of others, 4. Accepted by others, 10. Being accepted, 9. Tolerant of differences
Who with			Vulnerable others	9. Shared history of difficulties, 8. Difficulties, 6. Friends with Differences, 7. Shared history of stress
	Shared interests	2. Common interests, 10. Shared interests, 9. Shared interests, 10. Shared interests		

		Non-girly female friends	4. Non-girly friends, 7. Non-girly friends, 8. Non-girly friends, 10. Non-girly friends
	Motivations for friends	Support	1. Wanting company, 2. Emotional support, 7. Support, 2. Camaraderie, 3. Camaraderie, 3. Desire for new friends, 4. Ease the pressure, 4. For support, 4. To feel less alone, 4. To escape from stress, 5. Camaraderie through lack of choice
		Protect Mental Health	7. Protect Mental Health, 6. Protect Mental Health, 5. Needing to talk, 9. protects MH
Maintaining Friends		Conflict – engaging in and avoiding	2. Conflict in friendships, 2. Compromising, 1. Pretend to like the same things, 3. Managing conflict, 3. Understanding idiosyncrasies, 5. Obstacles, 6. Conflict, 5. Broken relationships
		Keeping in contact	2. Frequency of contact, 3. Spending time together, 2. Communication with friends, 2. Lack of initiation of contact, 3. Initiating contact, 4. Hard to initiate contact, 8. Hard to initiate contact, 7. Hard to initiate contact, 10. Interpersonal communication is effortful
		Stay on the outside & observe	2. Safety in numbers, 3. Emotional intimacy
		Copy intensely/keep mask on?	7 Copy covertly, 1. Be reflexive
The process of developing social relationships	Communication	Focus on words	1. Focus on quantity but not quality, 4. Hard to find words, 3. Borrowing words, 9. Focus on words - not innate, 10. Lack of reliance on verbals, 8. Lack of reliance on verbals
		Flexible and rigid	1. Pairing of similarities and differences, 2. Figures of speech, 2. Literal interpretations, 3. Turn of phrase, 3. Black and white, 8. Use of analogy, 10. Use of sarcasm, 7. Use of phrases
		Lack of detail	1. Absence of details about emotions, 3. Absence of process, 7. Lack of detail, 10. Elaboration
		Difficulties with communication creating problems in relationships	8. Expressive difficulties, 8. Use of prompts, 8. Reliance on others, 10. Needs prompts, 6. Coping with numbers, 5. Impenetrable Groups, 10. Coping with numbers, 8. Coping with numbers (See interpersonal: Dealing with groups)

		Misunderstandings	4. Miscommunications (due to AsS), 6. Tangential, 7. Misunderstandings, 10. Misunderstandings
		Incongruence	3. Contradictions, 1. Lots of dichotomies, 6. Contradiction, 4. Difficulties with Face-to-face, 10. The Mask, 10. Blank face
		Logic	6. Logical, 8. Precise, 4. Listing, 7. Transparency
Overcoming difficulties	Using innate skills	Insight	7. Perceptive of others' mood, 1. Can sense what mood people are in, 2. Perceptive, 3. Into others
		Taking others' perspective	1. Uses memory to inform empathy, 2. Can easily take someone else's perspective, 10. Empathy, 3. Empathy, 7. Considerate
		Observant	2. Observant, 10. Very aware
Development of strategies	The Mask	Learning through drama Drama/acting	6. Masking difficulties, 9. Drama classes, 9. Scripted performance, 10. Drama, 1. Act like other people to blend in, 7. Blending in
		Fake happy	1. Pretend to be happy when feeling sad, 2. Smiling, 7. Hiding feelings, 5. Supersocial, 10. Making friends: acting happy
		Intense copying/mirroring	1. Copy frequently, intensely and deeply, 1. Be like "the target", 3. Normal by proxy, 7. Copying, 6. Chameleon, 1. Synthesise different types of normal, 3. Adaptation
		Behind the mask	4. Letting mask down, 7. Taking it off, 7. Impact of wearing, 6. Revealing "true self", 1. Impact of acting, 5. Behind the strategies, 5. Anticipating rejection, 10. Other's surprise, 6. Other's surprise, 7. Other's surprise, 8. Other's surprise
Social context: the world in which ASD girls exist	Positioning	Loner/weird	4. Interpretations, 8. Feeling Different, 1. "Normal" is easy to everyone else, 10. Loner, 10. Weird, 3. Isolation As a barrier to making friends
		Rejected by non-ASD girls	6. Rejection from non-ASD girls, 6. Differences to non-ASD girls, 7. Rivalry, 10. Rejection from others, 3. Being disliked, 4. Judgment
		Fears rejection	1. Please others, 6. Fear of negative reactions, 8. Fears of rejection/unavailability, 1. Fear of judgment, 10. Rejected by others, 7. Stereotypes of peers, 7. Being caught out, 1. Must maintain the mask, 3. Being caught out, 5. Fear of standing out

	Illogical	1. World is illogical, 2. Unfairness, 2. Illogical social behaviour, 10. Others are not clear, 8. Rules
	Trauma	9. Trauma, 4. Social experiences are traumatic, 10. trauma
	Triggers for sensory problems	3. Dislike of large events, 8. Sensory difficulties, 9. Sensory issues, 10. Sensory Sensitivity, 10. Physical pain
	Predatory	10. Predatory environment, 9. Predatory environment, 3. Being seen as vulnerable, 7. Others don't "get" ASD, 4. Being misunderstood, 8. Lost in translation
Gender specific nuances	Roles & expectations	5. Social expectations, 8. Expectations, 10. Expectations, 10. Parental Engineering, 5. Gender differences, 2. Emotional awareness (includes nurturing), 4. See Gender roles: girls are confusing
	Masculine/feminine	2. Manliness, 2. Femininity, 6. Others' confusion, 10. Preferences, 8. Girliness
	Differs to non-ASD girls	2. Coping style, 7. See Self-awareness (Differences to non-ASD girls), 6. See Gender: Differences to non-ASD girls), 4. see Insight: AsS Symptoms, 1. Difference in communication styles
	Need for space	8. Different quality of friendship, 2. Shorter-term friendships, 7. Need for space, 4. need for space (see Interpersonal Difficulties: Feeling overwhelmed)
	Not innate	4. Intensity of copying, 3. Intensity of chameleonism, 2. Is more sensitive, 1. Intensity of copying, 10. Making friends is intuitive to others
	Intensity of interests	8. Intensity of interests, 4. Absorbing/blocking out
	Girliness	7. Interests, 4. Girls are confusing (includes hair & Make-up), 2. Leisure time, 10. Sexuality, 8. Rules, 4. Gender differences, 6. Communication styles
	Similarities to non-ASD girls	1. Making friends, 2. Making friends, 2. Interests, 5. Similarities to TD population, 10. Similarities to TD population, 10. Empathy, 7. Desire for relationships, 5. Acting is normal, 1. Acting is normal
Developmental Trajectory		8. Emerging problems, 7. Retrospective realisations, 5. Seeing Emerging gaps, 9. Problems, 1. Emerging problems, 3. Triggers, 4. Triggers, 2. Emerging difficulties, 10. Triggers

^aNumbers correspond with participant numbers

Note: The same participant is listed more than once within a theme when the topic was discussed more than once within the interview.

Note: Final Emergent themes were developed through the collapsing of overlapping initial emergent themes and subsequent selection of the strongest themes, as guided by Smith & Osborn (2007).

Appendix 15: Sample of Reflective Diary

Post-interview Reflections: Participant 1

I know that her diagnosis is recent and I didn't want to press her buttons too much. She was intense in some ways. I got the impression that she listens very closely and was giving her full attention to the conversation. When she described her intelligence, her memory and her conscientiousness, I could see what she meant. She is focused.

She left me with some questions about how I developed my friendships. I have always been a bit of a loner and used to feel extremely isolated at high school. I didn't tell people about myself but didn't give anyone any indications that I was depressed.

She is aware of her differences, but, as her mum said, is possibly in an environment where she is surrounded by other girls with similar social awkwardness (cultural context is significant in terms of people feeling "alien" in comparison to others). She seems to be embracing her ability to be a bit of a chameleon. I really liked her.

Post-interview Reflections: Participant 5

- I felt intimidated by this participant's eloquence. Her directness added to my feelings of intimidation. It was interesting to observe my response to her style of communication; I did not experience much emotion in her accounts, despite them often being emotive subjects. In terms of transference, I get the sense that her emotions were quite separated from her verbal interactions with me, almost like they were tidied away somewhere and slightly inaccessible
- I noticed that her account was very intellectualised
 - However, she did describe feeling lonely and depressed
 - I remember feeling stunned at what she had been through but did not feel overwhelmed by it so the point of being unable to think. In terms of transference, might this suggest that she has processed her experiences in a way that allows her to integrate them into herself?
- The questions which invited her to make comparisons between herself and others seemed to elicit good information. However, when asking her to make comparisons to her peers, I gave her a difficult task as she has been out of contact with them for a long time. This could have been accounted for better by me. I need to think about how to do that.

Post-interview Reflections: Participant 7

- She took my questions very literally
- How much of what she described was typical "teen stuff" and how much is AsS stuff?

- Hard to separate the two
- An area for more research, perhaps using a comparative sample of TD girls?
- Would the use of Outcome Measures aid the teasing out of AsS from developmental tasks?
- Would it be possible to compare my findings to other studies using different populations to try and identify any differences and similarities between ASD groups and other groups?
- I noticed feeling disappointed in the lack of detail she provided. My expectations were possibly unrealistic.
 - Can this disappointment be data (i.e. might it suggest that others also have unrealistic expectations of the participant?)
 - I was pleased that Mum mentioned copying but disappointed that she did not go into a lot of depth about it
- What is this internet thing all about? It might be useful to find information on the typical uses of internet within her peer group including the amount of time used and what it's used for. I am out of touch with what the kids are doing these days
- I was surprised by her Theory of Mind; she really demonstrated a capacity to see the world from perspectives other than her own.
 - Is this a female-ASD specific thing? Could it also be an AsS (rather than an ASD) thing?
 - Her mother was also surprised; how often does [participant] get the opportunity to demonstrate her capacity? Might others' expectations of her sometimes be too low?
- What can I do as an interviewer to elicit more depth/detail?
- There seemed to be an overlap between her use of food and her social anxiety
 - Would this make it more likely that others would focus on this rather than her AsS?

Observations during Process of Analysis

- Am I getting lazy?
 - The words that come to mind during the first stage of analysis appear to be very similar to the ones I've used in earlier transcripts. I have primed myself, and am having to think at least twice about whether my notes are linked to what I'm reading in this interview or are simply very quick to come to mind as I've analysed a number of transcripts already
 - The process of constantly checking myself is tiring but essential, if I am to stay true to the data

- I am having to stay attuned to data which contradicts other themes – do not skip over stuff that doesn't fit, include it as it may come up in later transcripts. If it doesn't, it may not be a phenomenon
- It's really exciting to see emerging themes. However, it's important to not get carried away with them and to remain open to new themes, including ones that I did not spot earlier on in the analysis

Appendix 16: Sample of Summary Interpretation for one Participant

Hi [name of participant],

I hope you are well. I am aware that it has been a long time since we met. I think it was at the end of the summer in 2013! You and I spoke together one evening at your house. We spent about an hour in an interview where we spoke about your experiences in social situations. I promised that I would send you a summary of what we discussed. This is so that you have the chance to tell me if you think I've misunderstood anything, or if you think that I have a good idea of how things have been for you.

Please do feel free to make any kind of comments you want so that I can make sure that I have done the best job of knowing a bit about what life is like for you!

I am sorry that there has been such a big gap between me sending you this summary and when we had our interview. I hope that the gap doesn't make it too hard for you to remember our conversation.

Here's what I understood about how things have been for you:

1. When you want to make new friends, you think it's a good idea to talk about things that you know about because you don't want to get things wrong in front of another person
2. You've learnt how to act in social situations because you're very good at seeing how other people behave. You have used your understanding of how people behave to know how you should behave
3. You've sometimes felt a bit like an alien. This was more at your old school. You felt like that because it seemed that everybody else had a lot in common with each other but you didn't have much in common with everybody else
4. You think that making friends comes easier to a lot of other people than it does for you
5. You are very good at being like a chameleon (the animal that changes its colour to blend into its environment). When you are in social situations at school, you can act like other people to blend in. This acting can leave you feeling exhausted and tired by the time you get home
6. You are very skilled at copying people. People do not realise that you are copying them. The reason you copy them is to try to appear "normal"
7. You thought that acting like other people is not unusual for someone of your age. However, you think that you act in more depth and more often than people of your age
8. Another way for you to appear "normal" or like other people is for you to hide how you're feeling. You said that if you feel unhappy, you would act like you were really happy so that other people wouldn't know how you feel
9. You are also very good at putting yourself in other people's shoes. Being able to do this means that you can imagine what the other person needs
10. The idea of appearing "weird" to people of your age is really scary for you

It would be really great if you could let me know your thoughts on my summary. I can easily change or add anything if you think it would be helpful for me to do so.

Thank you so much for your help with my project.

Siobhan

Appendix 17: External Researcher's Comments on Analysis

• You replied on 21/03/2014 12:54.

Hi Siobhan

So sorry, I completely forgot to send you this...MRP Brain doesn't work too good!

Thank you for the extra table you sent...that definitely helped.


What I have done is gone through your analysis step by step, following your Process of Analysis document and making sure that I can see at every step how you have moved from one thing to another. I have also looked to see that your initial notes and emergent themes seem valid based on what is in the transcript, and that you have used these as a basis for developing super-ordinate themes and the later themes.

Your process is clear and transparent and this made it easy to follow, and at no stage did I feel that I could not see where a theme or idea had come from- it all looks to have come from the data and it seems as though you stayed close to the data initially which is good and made it easier to follow. In re-visiting earlier transcripts after looking at them all you made sure that you picked up on anything that might have been missed first time round.

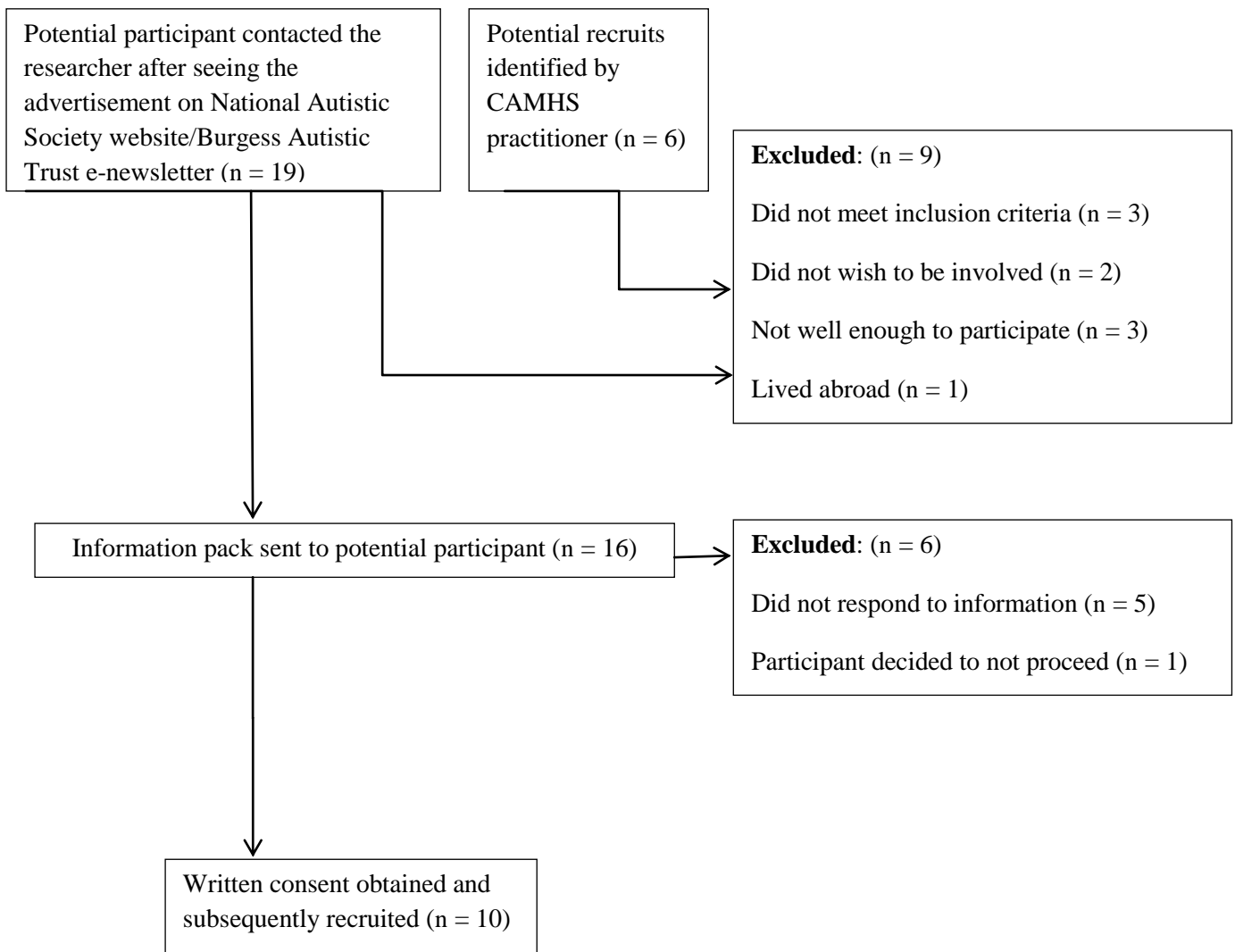
Also in looking at the final table draft and final table, although the structure has changed here, there isn't anything which isn't clearly in both tables, so it is clear where the elements of the final table have come from.

If you have any questions just email me, or if you want me to look at anything specific which I haven't mentioned let me know!

Hope all is going well!


Trainee Clinical Psychologist
Salomons, Canterbury Christchurch University

Appendix 18: Participant Flow Diagram



Appendix 19: Publication Guidelines for the Journal of Autism and Developmental Disorders

Double-Blind Peer Review

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The blinded manuscript containing no author information (no name, no affiliation, and so forth).
- The Author Note

Types of papers

Articles, Brief Reports, Letters to the Editor, Commentaries

- The preferred article length is 20-23 manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- A Brief Report or Case Report: About 8 double-spaced pages with shorter references and fewer tables/figures. May not meet the demands of scientific rigor required of a JADD article – can be preliminary findings.
- A Letter to the Editor is 6 or less double spaced pages with shorter references, tables and figures. Style sheet for Letter to Editor & Case Reports:
Style sheet for Letter to the Editor AND Case Report:
- A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information
- The blinded manuscript containing no author information (no name, no affiliation, and so forth):-
 - 6 or less double spaced pages with shorter references, tables and figures
 - Line 1: "Letter to the Editor"
 - Line 3: begin title (note: for "Case Reports start with "Case Report: Title")
 - Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

Review your manuscript for these elements

1. Order of manuscript pages

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Blinded Manuscript without contact information and blinded Abstract, and References

Appendix, Figure Caption Sheet, Figures, Tables, Author Note

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Appendix 20: Summary to Trust and National Research Ethics Committee

The aim of this study was to explore the experiences of adolescent females on the autism spectrum. During adolescence, social expectations implicitly change, challenging those on the spectrum who may find it both hard to adapt to change and adhere to covert social conventions. It has been suggested that neurotypical females develop friendships which make heavy use of empathy; therefore, females with an autism spectrum condition (ASC; who may have difficulties with empathy) are likely to struggle to develop these types of friendships with neurotypical female peers. It is likely that adolescence highlights ASD-females' social deficits because typical female peer relationships are demanding due to their highly communicative and social nature.

Some researchers have suggested that ASC-females are socially-motivated and consequently develop and use strategies which allow them to blend in with neurotypical peers in order to build social relationships. This study aimed to understand how girls cope in social situations in the context of having socio-communication difficulties and at a developmental stage where demands to use these skills increases.

Semi-structured interviews were designed and piloted before ten 13-19-year-old participants with a diagnosis of any ASC were recruited. Interpretative Phenomenological Analysis was used to explore emerging themes within each interview. Themes were cross-referenced between interviews to identify phenomena within the sample.

It was found that participants experienced frequent peer rejection as a result of their ASC-related differences. Participants experienced social environments as incommensurate due to factors including frequent peer-rejection and triggers to severe sensory sensitivity. Most participants were motivated to build friendships and had developed sophisticated strategies of masking and imitation in order to fit in with peers. Participants described wearing an extremely happy or blank facial expression in most social situations in order to mask her discomfort and distress. Astute observation of peers enabled many participants to develop

highly effective and complex peer-imitation which camouflaged their socio-communication difficulties. These strategies were used frequently and intensely and allowed participants to often go unidentified as having a diagnosis of ASC.

The impact of using such strategies was often highly detrimental to the mental health of participants. Many experienced clinical levels of anxiety and depression and had used self-harm to cope with their feelings. Some described having felt suicidal and one participant provided an account of hearing voices in response to talking to herself when she felt extremely lonely without any friends. Findings also included the catalysing effect of transitioning between primary and secondary schools on the participants' mental health. The move to a large, unfamiliar environment increased (a) the opportunity for sensory distress (b) expectations that the participant would make lots of new friends (c) the gap between the participant and her peers' socio-communication skills in the context of developing complicated dynamics. This transition and the subsequent triggering of ASC-related and secondary difficulties often led to the seeking of professional support.

The limitations and clinical implications are explored and suggestions for future research are presented.