

# EXPLORING THE SEX DISPARITY IN AUTISM SPECTRUM CONDITIONS (ASCs)

Report presented by

Naomi Tanya Carolyn Phillips

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## **Abstract**

A study was designed to examine differences and similarities among males and females with Autism Spectrum Conditions (ASCs). A sample of 69 individuals with Asperger Syndrome (AS) and High Functioning Autism (HFA) aged 18+ completed a newly designed quantitative Likert style questionnaire and a further 10 females aged 18+ with AS undertook a 30 minute qualitative audio-recorded semi-structured interview. Informed by previous literature the questionnaire and interviews focused on eight specific areas; Appearance, Personality, Social Relationships, Childhood, Interests, Physical Behaviour, Co-morbid Disorders, Cognitive Abilities. Mann Whitney U tests and Factor Analysis were used to analyse questionnaire data, Thematic Analysis was used to analyse the transcribed interview data and the main findings were presented and discussed. Results indicate that whilst many areas of similarity exist between males and females with ASCs, there are also several areas of significant difference involving appearance, sensory issues, interests and co-morbidity.

## Introduction

### **Clinical Description of Autism Spectrum Conditions**

Autism and Asperger syndrome, initially documented by Leo Kanner (1943) and Hans Asperger (1944), are neurodevelopmental disorders. Together, and with the inclusion of high functioning Autism and pervasive developmental disorders – not otherwise specified (PDD-NOS), form what is referred to as Autism Spectrum Conditions (ASCs) (NHS, 2012). They are classified by the American Psychiatric Association (APA) as pervasive developmental disorders (PDDs) (APA, 1994). ASCs are recognised as one of the most acute lifelong developmental disabilities often presenting within the first three years of life (The National Autistic Society, 2011; APA, 1994; Frith, 1989). The three main types of ASCs are known as “classic” Autism, Asperger syndrome (AS) and Pervasive Developmental Disorder – Not otherwise specified (PDD-NOS) (also known as Atypical Autism) (NHS, 2012). Originally, Autism was a diagnosis referring to a specific manifestation of introverted and isolating behaviour but over the last twenty years the definition has broadened and Autism is now understood to be a ‘spectrum’ condition. The concept of a spectrum is used to describe the way that these conditions present themselves through a diverse range of features varying from one person to another and in their severity (NHS, 2012; APA, 1994). As it is not possible to diagnose ASCs by blood tests or other medical procedures, identification is based on the clinicians’ discretion as to whether they deem the behaviour of individuals to fit the current diagnostic criteria; the triad of impairments in communication, imagination and social interaction (NHS, 2012; APA, 1994; Tantum, 1991; Wing and Gould, 1979). The only difference between Autism and

AS is that impairments in cognitive development and language are not associated with AS (Lawson et al., 2004; Schopler, 1985).

### **Prevalence**

Over the last twenty years incidence rates of ASCs have increased significantly (NHS, 2012; The National Autistic Society, 2011). The expanding and changing definitions of ASCs over the past few years, along with better diagnostic tools have been seen as the main cause for increasing incidence rates and variations both globally and within countries (The National Autistic Society, 2011; Powell et al., 2000). Statistics illustrate ASCs to be relatively common within the United Kingdom with prevalence rates for children with ASCs estimated to be 1 in 100 (NHS, 2012; The National Autistic Society, 2011). Based on the 2001 census, stating the UK population to be 58,789,194, children under 18 forming 13,354,297, the number of children under 18 with ASCs is approximately 133,500 (The National Autistic Society, 2011).

### **Co-morbidity**

ASCs are often co-morbid to other disorders, both directly and indirectly, resulting in diagnosis and treatment being complicated (Gillberg and Billstedt, 2001). Co-morbid disorders include medical conditions, psychiatric disorders and behavioural and motor dyscontrol symptoms (Gillberg and Billstedt, 2001). The most common cognitive issue associated with “classic” Autism is mental retardation (occurring in approximately 80% of cases) with other disorders overlapping with classic Autism such as epilepsy (5-40% of cases), speech and language disorders, hearing deficits and visual impairments whilst

being relatively uncommon in individuals with AS (Levisohn, 2004; Tuchman and Rapin, 2002; Gillberg and Billstedt, Mouridsen, et al., 1999; 2001; Wing, 1996; Rutter, 1983). Motor disorders usually overlap with AS (Gillberg and Billstedt, 2001). More explicit medical diagnoses such as tuberous sclerosis (1-4% amongst autistic population and 8-14% in those with Autism with other seizure disorders), Angelman syndrome and Moebius syndrome are co-morbid to both Autism and AS (Wiznitzer, 2004; Gillberg and Billstedt, 2001; Smalley, 1998). As other disorders are co-morbid to ASCs, diagnosis and treatment of ASCs may be increasingly complicated resulting in some cases of ASCs being under diagnosed or misdiagnosed for other conditions.

### **Aetiology**

The cause of ASCs remains unclear but the aetiology appears likely to be multifactorial (Matson and Minshawi, 2006). However, research suggests there to be four main factors associated with causing ASCs; genetic susceptibility, environmental factors, psychological factors and neurological factors (NHS, 2012; Behaviour Neurotherapy Clinic, 2009). It may be the case that the causal root of ASCs is genetic. However, this in turn manifests across all levels of broader consideration e.g. cognitive, hormonal, neurophysiological etc.

Some of the current research investigating the aetiology of ASCs on the biological level has focused on whether the behavioural features of ASCs are the result of poor connections between the brain hemispheres and/or specific brain regions, the result of specific hormones (testosterone being the main focus of research) or the result of an imprinted X-Chromosome (e.g. Carper, 2002; Skuse, 2000; Tordjmann, 1997; Breedlove,

1994). These aspects will be discussed later in further detail in relation to the sex disparity in ASCs.

Deficiencies in key nutrients in diets interacting with genetic polymorphisms have been found to contribute to ASCs. The particular nutrients affecting neural development resulting in weaknesses in cell membranes and the internal processes of cells include Zinc, Selenium, Vitamin B12, Vitamin D and Folate (Richardson, 2004; Kidd, 2002). Deficiencies in these nutrients can result in the characteristics of Autism to appear magnified and individuals are more likely to be affected by environmental antigens and toxins (Richardson, 2004; Kidd, 2002). Recent research found antigens such as toxic chemicals, metals, viruses and bacteria attack the weakened cells causing mutations in the expression of the genetic code resulting in the processes of the cells being impaired and unable to carry out their functions (e.g. Singh et al., 2002; Hornig and Lipkin, 2001).

Although ASCs are difficult to conceptualise on a cognitive level, three main theories have been influential in explaining the behavioural patterns associated with ASCs. The Theory of Mind and Empathising-Systemising model were created to explain social features and the Executive Dysfunction model and the Weak Central Coherence model were developed to explain non-social features (Hill, 2004; Lawson et al., 2004; Baron-Cohen, 2002; Baron-Cohen et al., 1985). However, it could be argued that these theories do not seem to explain all behavioural characteristics of ASCs.

### **Sex Disparity**

Hans Asperger, in 1944, believed that the condition he described (now known as AS) could only affect males (Attwood, 2007). Although this has been falsified, clinical and

epidemiological studies have provided evidence suggesting that ASCs predominate in males with males being 3-4 times more likely to have Autism than females and 10 times more likely to have AS than females (Honda et al., 2005; Thompson et al., 2003; Fombonne, 1999). Additionally, males are 10 times more likely to be referred for diagnosis than females with females often being diagnosed later in life (Attwood, 2006; Wagner, 2006; Goin-Kochel et al., 2006; Ehlers and Gillberg, 1993). Although findings from twin studies suggest that ASCs have a genetic constituent and are approximately 80% heritable, the cause for the sex disparity of ASCs is unknown and requires greater investigation (Ronald and Hoekstra, 2011).

It has been argued that ASCs are heritable. Skuse (2000) proposed a biological theory for the sex disparity, the imprinted X-liability theory, arguing ASCs to be the result of a sex-linked genetic cause (Skuse, 2000). Skuse (2000) suggested that a protective factor controlled by a gene on the paternally transmitted X-chromosome to daughters inflates the threshold for phenotypic expression of ASCs. Skuse further argued that the threshold for phenotypic expression of ASC characteristics is considerably lower in males due to their inherently vulnerable maternally transmitted single X-chromosome where this protective gene on the X-chromosome is apparently suppressed (Jones et al., 2008; Skuse, 2000). This suggests that males are less able to conceal ASC traits compared to females with ASCs making the condition more prominent. However, the validity of this theory is questionable as other studies have failed to locate this protective gene on the X-chromosome suggesting that other possible causes must account for the prevalence of ASCs in males (e.g. Kilpinen et al., 2009; Schutz et al., 2002; Shao et al., 2002).

The sex disparity in ASCs has also been suggested to be a natural reflection of common biological sex differences with males often being better at visual spatial tasks and

language abilities being superior in females (Wing, 1981). The Extreme Male Brain theory (EMB), a cognitive theory for the sex disparity, proposed that males have a greater propensity to systemize (to explore and create rule-based systems) and females have a greater tendency to empathise (to understand other peoples thoughts and feelings and be able to respond appropriately) (Baron-Cohen et al., 2011; Baron-Cohen, 2003; Baron-Cohen, 2002). According to the EMB theory, individuals with ASCs are impaired in being able to empathise but are often much better at systemising which lends ASCs to be biased toward males. This may be due to exposure to above average levels of testosterone in the womb resulting in more male-like characteristics (Baron-Cohen and Wheelwright, 2004). However, studies investigating the ability to empathise or systemise using pattern recognition tasks such as the embedded figures task or the intuitive physics test, provide evidence that on average males with ASCs are better at systemizing than females (Lawson et al., 2004; Baron-Cohen, 1999; Jolliffe and Baron-Cohen, 1997). According to this theory, both males and females diagnosed with ASCs will possess a ‘hypermale’ brain and are likely to be better at systemising than empathising with males remaining superior to females in systemising tasks. As a result, it could be argued that it appears logical for the number of females likely to have ASCs to be lesser than the number of males as on average females are empathisers rather than systemisers.

These ideas are further supported by the Androgen theory of Autism purporting ASCs to be the result of a biological cause; higher levels of foetal testosterone. High levels of foetal testosterone affect the anatomy of the brain including the hypothalamus, limbic system and neocortex and causes aggression and activity levels to increase (Tordjmann et al., 1997; Breedlove, 1994; Arnold and Gorski, 1984; MacLusky and Naftolin, 1981). Although fewer females appear to have ASCs, studies have demonstrated that individuals

with ASCs often have high levels of foetal testosterone; consistent with this theory (Tordjmann et al., 1997). Although generally females are more passive than males, this theory suggests that females with ASCs will tend to display more masculine characteristics such as aggressive behaviour (Tordjmann et al., 1997). According to this theory, it could be argued that the sex disparity appears logical as males are more likely to display this hypermasculinised behaviour than females suggesting a plausible explanation for why females are likely to not fit the diagnostic criteria or display the characteristics of ASCs.

Although these theories present the disparity at both a biological and cognitive level and are separate to a degree, they appear inter-related as they all seem to categorise individuals with ASCs as having hypermasculinised characteristics. Females with ASCs appear marginalised to a small majority with hypermasculinised traits as diagnosis is based on the discretion of the clinician's assessment of the triad of impairments and appears focused on the stereotypical male characteristics of "classic Autism". It has been argued that the theories and clinicians fail to recognise the possibility that females may incur different symptoms. Subsequently, the diagnostic criterion, which is the same for both genders, may result in females with ASCs not being picked up or not being referred for diagnosis if they do not fit the current 'male focused' diagnostic criteria (Attwood, 2000; Ehlers and Gillberg, 1993; Wing 1981).

### **Possible sex differences in the characteristics of ASCs within the Autism Spectrum**

Little empirical research has been conducted to directly explore the presentation of ASCs in females. However, some recent empirical and autobiographical research has alluded to possible distinctions in the manifestation of ASCs between the sexes (e.g.

Simone, 2010; Nichols et al., 2009; Attwood, 2006, McLennan et al., 1993; Holliday-Willey, 1999; Le Couteur et al., 1989). Literature indicates ASCs in females appears to be more subtle, better concealed and less definitive supporting the notion that currently females with possible ASCs may be being overlooked. Females with ASCs, whilst often very shy, have been found to be cared for and included by their peers compared to boys who appear more excluded and bullied due to males' antagonistic and competitive natures (Nichols et al., 2009; Sansone and Sansone, 2008; Wing, 1981). Additionally, females with ASCs tend to be more social, more competent at following social actions and tend to respond appropriately to other people's emotions and behaviour through delayed imitation practices (Attwood, 2007; Le Couteur et al., 1989). Consequently, females with ASCs may present as being more sociable than in reality through being better able to mask their symptoms. As being unsocial and isolated are behaviours that can signify ASC mannerisms, females who are being looked after by others may be being missed. Therefore, the mothering behaviour by other peers may require careful monitoring and further exploration to consider whether it is an indicator for potential ASCs in females.

Furthermore, females with ASCs seem to participate more in solitary play, pretend play and play with dolls in addition to creating and interacting with imaginary friends compared to males with ASCs (Wilkinson, 2008; Attwood, 2006; Holliday-Willey, 1999; Wing, 1981). As these behaviours are generally deemed gender appropriate up until a certain age in females, the indicators for an ASC in females could be being masked. Unlike typically developing females, females with ASCs may be more domineering in play than the more common reciprocity type of behaviour associated with typically developing females play (Wilkinson, 2008; Attwood, 2006; Holliday-Willey, 1999; Wing, 1981). The interests of females also tend to differ to males interests. Whilst males are often interested

in transport, maths, science and electronics, females are often more interested in and obsess over animals, music and classic literature in addition to the typical male oriented interests (Nichols et al., 2009; Attwood, 2007). This suggests that these types of obsessions and interests need to be considered more closely and assessments need to recognise and incorporate these interests into the diagnostic criteria.

A recent study by Bremser and Gallup Jr (2012) extending the empathising-systemising theory explored mental state attribution and body configuration in women. They stated that women with higher levels of oestrogen have a low waist to hip ratio (WHR) (narrow waist and broad hips) and usually excel at recognising emotional states of other individuals and demonstrate a more empathising rather than systemising cognitive style (Bremser and Gallup Jr, 2012). On the other hand, males with higher levels of testosterone have a high shoulder to hip ratio and narrower hips (Bremser and Gallup Jr, 2012). In view of this, as previous research has shown high levels of foetal testosterone to be contributing factor for causing ASCs and females with ASCs as having higher levels of testosterone and a more systemising cognitive style, it would be interesting to explore whether females with ASCs have a predominantly smaller waist to hip ratio than females with higher levels of oestrogen.

Some research has highlighted particular co-morbid disorders that appear to occur more in females with ASCs than males with ASCs. It has been found that cases of epilepsy occur more commonly in females with ASCs than in males (Nichols et al., 2009; Ingudomnukul et al., 2007). Atypical physical movements such as dystonic posturing of hands and fingers and hand flapping have also been evident more commonly in females than males with ASCs (Tsai et al., 1981). Additionally, other disorders more common in females with ASCs than males have been found to be anorexia, schizophrenia, obsessive

compulsive disorder (OCD), attention-deficit hyperactivity disorder (ADHD), bipolar disorder, sleep disorders, Tourette's Syndrome and the most prevalent disorders being depression and anxiety (Wilhelm et al., 2002; Ghaziuddin, 2002; Ghaziuddin et al., 1998; Fisman et al., 1996). This appears to indicate that the more female dominated co-morbid disorders are more social disorders (not genetically rooted) rather than the typical genetic disorders dominated by males. As a result, during diagnosis for these co-morbid conditions, the possibility that females may have an ASC may be being overlooked resulting in females being either misdiagnosed for other conditions or underdiagnosed when they may have a co-morbid ASC. When considering females with a diagnosis for these conditions and behaviours, it may be useful to assess them for possible ASCs to prevent under-diagnosis. Additionally, as females are often misdiagnosed for these conditions when in fact they have ASCs or a possible co-morbid ASC, it should be investigated as to whether assessment for ASCs should be automatic if these conditions are diagnosed and include these conditions in the diagnostic criteria for ASCs.

Through exploring the available research on ASCs in females, it is clear that empirical knowledge about 'female manifestation' is limited, unreliable and not empirically evidenced; thus further investigation is necessary. A sex disparity in ASCs has been highlighted but the cause of this is controversial and unclear. Whilst the main triad of impairments of ASCs appear to manifest in both genders, females appear to display other symptoms and may present differently. As the current diagnostic criterion seems to neglect these differences, there exists a possibility that females on the spectrum may be being under diagnosed or misdiagnosed.

## **Aims**

As a first step in addressing this situation, this research project aimed to explore in detail how ASCs manifest among females, how this might vary from the standard clinical description and subsequently how the manifestation of ASCs in females may differ to males. Through answering this first question it may provide some insight as to whether females are being under diagnosed, if indeed they are. From reviewing previous literature (including autobiographies, parent accounts etc.) eight categories of interest emerged for further investigation: appearance, personality, social relationships, childhood, interests, physical behaviour, co-morbid disorders and cognitive abilities. A questionnaire was developed to examine whether and in what way these eight factors might vary between males and females with ASC. Given the lack of previous literature it is difficult to make specific predictions about outcomes. However, it is expected that the females with ASC will show greater tendencies towards sociability and agent interest. A proportion of females with AS undertook a semi-structured audio-recorded interview based on the same 8 categories in the questionnaire to gain a more in-depth understanding of their personal presentation.

## **Research Design and Methods**

### **Participants**

Sixty-nine adults over the age of 18 (n= 20 males and n= 49 females) with a clinical diagnosis of AS and/or High Functioning Autism (HFA) were recruited by writing to organisations (Appendix 2) both within the community and online such as specific ASC charities, societies, support groups, online blogs and forums across the UK to complete a questionnaire study. The age range of participants recruited ranged from 18-60+ (21 females and 4 males age 18-29, 16 females and 5 males age 30-39, 5 females and 7 males age 40-49, 4 females and 2 males age 50-59 and 3 females and 2 males age 60+). Ten females with AS (4 age 18-29, 3 age 30-39, 1 age 40-49, 1 age 50-59 and 1 age 60+) were selected for interview by 'purposive sampling' (Bryman, 2008: 458) from those that consented to undertake a 30-40 minute audio-recorded semi-structured qualitative interview. This sampling method involves the researcher choosing participants that would be suitable and relevant to the research question (Brymans, 2008). As a result it allowed a wider selection of participants to be interviewed in terms of their age range and location and was thus advantageous as it would reduce the chances of the results being specific to a particular area of the UK and not generalisable to the wider population. Only adults with ASCs were recruited for the study as it was hoped that they would have a greater understanding of their condition and greater comprehension to be able to understand the purpose of the research, understand the questions and be able to respond appropriately and with insight. The questionnaire was completed with participants either face to face, by post or via the research website [www.ntcphillips.co.uk](http://www.ntcphillips.co.uk) and the interviews in person.

## **Design**

An independent measures (between group) design was used with each participant being required to complete the questionnaire so that sex differences between the items (statements) could be examined. Participants were invited to complete the questionnaire and from the females that consented to be interviewed ten females were invited to undertake the semi-structured interview. The dependent variables (DV) were the Likert derived scores for each item, each of which was focussed on an aspect of one of the eight subcategories in the questionnaire (Appearance, Personality, Social Relationships, Childhood, Interests, Physical Behaviour, Co-morbid disorders, Cognitive Abilities). The independent variable was group with one level being males over 18 with AS or HFA and the other level being females over 18 with AS and HFA.

## **Materials**

This research consisted of two methods of data collection. Firstly, a new standardised questionnaire (Appendix 3) was developed that used five point Likert scales to measure agreement / disagreement to a set of statements. The questionnaire comprised of two sections A (personal information), and B (statements pertaining to the 8 categories indicated by the literature where possible sex disparities may occur including appearance, personality, social relationships, childhood, interests, physical behaviour, co-morbid disorders and cognitive abilities. The 8 categories were developed from examining previous literature, autobiographies and parent reports about where particular sex differences in the manifestation of ASCs may be observable. It was vital when designing the questionnaire that the language was basic and unambiguous to ensure there was little

discrepancy in the underlying meaning of each statement to maintain the validity of the responses. The questionnaire was piloted on two teenagers aged 14 and 16 with AS to ensure that the questions were clear which resulted in a couple of the questions being rephrased.

Secondly, a standardised twenty to thirty minute audio-recorded semi-structured qualitative interview (Appendix 4) was conducted with ten females with AS who consented to be interviewed. This method of data generation is rooted in a phenomenological paradigm suggesting individuals socially construct their opinions and beliefs and the researcher aims to gather first hand information directly from the participant at a micro level (Gilbert, 2001; Taylor and Bogdan, 1989). Although this can be seen to be an advantage of this method of data generation, interviews are time-consuming to ‘arrange, conduct, transcribe and analyse’ (Priebe and Slade, 2002: 89). The interview comprised of open questions based on the same eight categories in the questionnaire about their personal ASC characteristics to gain a more in depth understanding to support the questionnaire responses. In order to test the interview schedule construct and to ensure that the questions were not leading and clear, pilot interviews were conducted with two teenagers aged 14 and 16 with AS. The pilot interviews revealed that the interview schedule produced was suitable for the purpose of this research as it had a logical flow and the questions allowed the pilot participants the freedom to voice their experiences of their ASC without needing to clarify the underlying meaning or terminology of the questions.

## **Procedure**

Individuals with AS and HFA were invited to participate by letter (Appendix 5). If willing to take part in the study an information sheet (Appendix 6) (to inform them about

the research, the importance of the research and how they fit the participant criteria), a questionnaire and consent form (Appendix 7) were posted or given to them. Participants were also recruited via distributing the link to the research website ([www.ntcphillips.co.uk](http://www.ntcphillips.co.uk)) where participants were greeted with the information sheet highlighting that if individuals wished to participate they needed to indicate they had read and understood the information sheet by ticking a tick box (the first question at the top of the questionnaire). The information sheet stated that if females wished to participate in the interview, they were required to complete the consent form on the thank you page which popped up after submitting the questionnaire. The personal details in section A of the questionnaire were not mandatory apart from the questions to indicate their age range and their gender. The thank you page stated that if they would like a debriefing letter (Appendix 8) they could enter their email address here. It was not a mandatory field and it was made clear that their email address would be deleted as soon as a debriefing letter had been sent to them in order to maintain confidentiality and anonymity of the participants. Written debriefing was offered to each participant who completed the questionnaire and a verbal debriefing was given to female participants after completing the interview. The debriefing provided an explanation of the purpose of the research and the exploratory nature of the study. The participants were informed that individual results would not be available to them but that they were welcome to receive a summary of the results if they wished by providing their email address which would be deleted as soon as the information had been sent to them.

Participants completed the questionnaire on their own. Once the questionnaires had been submitted, section A was removed, kept separate from the questionnaires and the questionnaires were given a reference number from 1 to 69 corresponding with their

personal details on section A to maintain the confidentiality and anonymity of the responses.

The semi-structured interviews were conducted one to one and face to face in a private, quiet, and relaxed room either at Oxford Brookes University or a location of the participants choosing. A standardised interview schedule based around the 8 categories was used to outline the structure of the interviews. However, participants were prompted based on their responses to gain a more in depth understanding of the manifestation of their ASC and differed due to them being asked as a reaction to participant's responses. All questions were open ended in order to allow participants the freedom to explain the manifestation of their ASC and voice their experiences. As a result, the interviews appeared conversational and free flowing allowing a better rapport to be built with the participants and greater in depth responses to be gathered. It also allowed participants to guide the order of the questions allowing them to present their attitudes and opinions with little researcher influence resulting in their responses being more valid. The interviews were audio-recorded, transcribed verbatim and then the narratives were analysed using Thematic Analysis. Pseudonym initials replaced the names of the participants during the write up.

### **Ethical Considerations**

This research required special consideration due to the vulnerability of the participants. As a result the study adhered strongly to the code of ethics and conducts presented by the British Psychological Society (Ethics Committee, 2009). A Criminal Records Bureau check was conducted on the researcher and sampling only commenced

once a “favourable opinion” had been presented by the ethics committee (Appendix 1). In order to gain informed consent from the participants, an information sheet was presented to the AS and HFA participants before completing the questionnaire. The first question on the questionnaire required participants to tick that they had read and understood the information sheet, had a chance to ask questions and consented to complete the questionnaire. A consent form was presented and completed by females with AS if they were willing to undertake the interview. Parents/guardians of the participants were not required to give consent for the participants to take part as the participants were aged 18+ and are considered capable of understanding the information sheet and the notion of informed consent. The purpose of the research and the tasks participants were required to complete were briefly outlined and explained to participants via the participant letter inviting them to participate and the information sheet. It highlighted that participant’s questionnaire responses would be recorded and female participants who consented to undertake the interview would be audio recorded but their personal information would be kept confidential and anonymous.

To protect participants from harm, participants were made aware that they were free to ask any questions or clarify anything at any time, were free to pause and/or free to withdraw from the research at any time. The potential for adverse effects to the participants was also minimal as the development of questions for the questionnaire and interview schedule were carefully considered to ensure that they were not particularly sensitive. The researcher also endeavoured to remain respectful, supportive, sympathetic and neutral during the interviews to address the potential for adverse effects to the participants. The research was conducted in a safe, relaxed, familiar and quiet room if completing the study face to face with participants or it was completed online via the

website ([www.ntcphillips.co.uk](http://www.ntcphillips.co.uk)). A debriefing letter was offered to the participants as soon as the participants had completed the research to inform them in greater detail about the research project. All responses were kept anonymous during the write up and confidentiality was maintained throughout.

## **Data Analysis**

To analyse the data from the Likert style questionnaire responses were coded in order to quantify the data (strongly agree = 5, agree = 4, neither agree nor disagree = 3, disagree = 2 and strongly disagree = 1). The statements requiring yes or no responses under the co-morbid disorders category were also coded (yes = 1, no = 0). Statistical analysis was performed on this data using IBM SPSS statistics 19 for Windows version 11.0.1. Man Whitney U (non-parametric test) tests were run to examine whether there were any significant differences between males and females responses to the statements. Through using a non-parametric test the analysis was not reliant on restrictive assumptions and offered the opportunity to look at differences without a few extreme scores possibly affecting the results as it relies on ranked data and can subsequently be seen to be advantageous. The main disadvantage of using a non-parametric test is that it has less power compared to an equivalent parametric test but it is more appropriate when dealing with data derived from Likert scores. Factor analysis was used to examine the pattern of correlations between the statements (variables) in order to identify the factors which may explain the majority of the variance in the variables (Brace, 2008).

Thematic analysis was conducted to analyse the data from the semi-structured qualitative interviews. This method of analysis is a dynamic and fluid process to identify

and analyse themes and patterns of similarity within qualitative data (Braun and Clark, 2006). It was conducted in an inductive manner involving becoming familiar with the data, allocating small codes (open codes) to segments, parts or words of data to be categorised under minor themes to later be categorised under major themes and phrases from the responses of participants to be selected to support the themes (selective codes) (Boyatzis, 1998). The major themes were common to all interviews and were produced by comparing the minor themes from each interview to discover commonalities. Through analysing the data in an inductive way, it increases the validity of the findings as it reduces the amount of researcher bias influencing the results by exploring the experiences of the participants without any preconceptions or theories about the themes that may emerge from the data.

## Results

### **Part A: Questionnaire Analysis:**

#### 1. Inferential Statistics:

Mann-Whitney U tests were run on all items (statements). Of these, seventeen items demonstrated significant sex differences.

#### *Appearance Items:*

Mann-Whitney U tests revealed that agreement scores for:

- ‘I like to wear clothes that are currently in fashion’ (AP5) were significantly higher for females (Mean=1.53) than males (mean= 1.00),  $U= 341.00$ ,  $p=0.039$ ,  $r= -0.26$ .
- ‘My clothes are feminine’ (AP7) were significantly higher for females (Mean=2.33) than males (Mean= 1.25),  $U= 206.00$ ,  $p= 0.000$ ,  $r= -0.42$ .
- ‘My clothes are masculine’ (AP8) were significantly higher for males (Mean= 2.50) than females (Mean= 1.90),  $U= 318.50$ ,  $p= 0.016$ ,  $r= -0.29$ .
- ‘I have a masculine figure’ (AP12) were significantly higher for males (Mean= 2.60) than females (Mean= 1.06),  $U= 95.00$ ,  $p= 0.000$ ,  $r= -0.66$ .
- ‘I am curvy’ (AP13) were significantly higher for females (Mean= 2.76) than males (Mean= 1.30),  $U= 156.50$ ,  $p= 0.000$ ,  $r= -0.55$ .

#### *Social Relationships:*

Mann-Whitney U tests revealed that agreement scores for:

- ‘I can recognise when someone is upset’ (SO4) were significantly higher for females (Mean= 2.41) than males (Mean= 1.70),  $U= 296.50$ ,  $p= 0.006$ ,  $r= -0.33$ .

- ‘I am in a relationship’ (SO11) were significantly higher for females (Mean= 2.22) than for males (Mean= 1.30),  $U= 345.50$ ,  $p= 0.048$ ,  $r= -0.24$ .

*Childhood:*

Mann-Whitney U tests revealed that agreement scores for:

- ‘I liked to pretend play’ (Ch3) were significantly higher for females (Mean= 2.64) than males (Mean= 1.85),  $U= 333.50$ ,  $p= 0.033$ ,  $r= -0.26$ .

*Interests:*

Mann-Whitney U tests revealed that agreement scores for:

- ‘I like maths’ (In5) were significantly higher for males (Mean= 2.85) than for females (Mean= 1.86),  $U= 295.50$ ,  $p= 0.008$ ,  $r= -0.32$ .
- ‘I like music’ (In10) were significantly higher for females (Mean= 3.41) than for males (Mean= 2.80),  $U= 319.00$ ,  $p= 0.013$ ,  $r= -0.30$ .

*Physical Behaviour:*

Mann-Whitney U tests revealed that agreement scores for:

- ‘I do repetitive actions’ (Ph5) were significantly higher for females (Mean= 2.73) than for males (Mean= 2.30),  $U= 334.00$ ,  $p= 0.024$ ,  $r= -0.27$ .
- ‘I like to dance around when I am happy’ (Ph6) were significantly higher for females (Mean= 2.39) than for males (Mean= 1.35),  $U= 274.00$ ,  $p= 0.003$ ,  $r= -0.35$ .

*Co-morbid disorders:*

Mann-Whitney U tests revealed that agreement scores for:

- ‘I get anxious about food’ (Co5) were significantly higher for females (Mean= 0.53) than for males (0.15),  $U= 303.50$ ,  $p= 0.006$ ,  $r= -0.35$ .

### *Cognitive Abilities:*

Mann-Whitney U tests revealed that agreement scores for:

- ‘I am good with numbers’ (Cg4) were significantly higher for males (Mean= 2.75) than for females (Mean= 1.98),  $U= 316.00$ ,  $p= 0.018$ ,  $r= -0.28$ .
- ‘I am clumsy’ (Cg10) were significantly higher for females (Mean= 2.92) than for males (Mean= 2.30),  $U= 322.00$ ,  $p= 0.017$ ,  $r= -0.29$ .
- ‘I taught myself to read’ (Cg11) were significantly higher for females (Mean= 2.88) than for males (Mean= 2.10),  $U= 318.00$ ,  $p= 0.018$ ,  $r= -0.28$ .
- ‘I have good spatial awareness’ (Cg15) were significantly higher for males (2.40) than for females (Mean= 1.47),  $U= 288.00$ ,  $p= 0.006$ ,  $r= -0.33$ .

## 2. Factor Analysis:

Factor analysis was run using a varimax rotation to determine the factorability of the 106 questionnaire items within the 8 categories. To check the factorability of the data, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was conducted. The Bartlett’s test of sphericity was run to check the inter-correlation between the variables (items). These were conducted for all 8 categories. The KMO scores were all  $>0.5$  and the Bartlett’s test of sphericity revealed significance values of  $p<0.001$  therefore factor analysis could be conducted.

In order to determine which factors should be extracted, eigenvalues for each of the items and scree plots were considered. Examination of the eigenvalues and the scree plots revealed that a four factor solution was appropriate for the following categories; ‘appearance’ (explaining 64% of the variance), ‘interests’ (explaining 62.8% of the variance) and ‘physical behaviour’ (explaining 63.0% of the variance). A five factor solution was appropriate for the following categories; ‘personality’ (explaining 64.8% of the variance) and ‘social relationships’ (explaining 65.3% of the variance). A three factor solution was appropriate for the following categories; ‘childhood’ (explaining 68.4% of the variance) and ‘co-morbid disorders’ (explaining 63.8% of the variance) and a six factor solution was appropriate for the ‘cognitive abilities’ category (explaining 72.8% of the variance). The full factor analysis results are displayed in the Table 1 below:

Table 1: Factor analysis details and emergent factor names

Category	KMO value	Bartlett’s test for Sphericity Value	Factor	Items loaded onto factor	Factor Name
<b>Appearance</b>	0.695	F(78) = 306.305 p<0.001.	Factor 1	1, 2, 3, 5, 6	Pride in Appearance
			Factor 2	9, 10	Eccentric Clothing
			Factor 3	8, 7, 11	Femininity
			Factor 4	12, 13	Masculinity
<b>Personality</b>	0.647	F(120) = 326.480 p<0.001.	Factor 1	2, 3, 5, 6, 15, 16	Outgoing and Flexible
			Factor 2	1, 9, 11, 14	Individualistic
			Factor 3	4, 7, 8, 12	Emotional and Anxious
			Factor 4	10	Meltdowns
			Factor 5	13	Acting
<b>Social Relationships</b>	0.763	F(171) = 595.454 p<0.001.	Factor 1	1, 7, 8, 9, 10, 13, 14, 16, 18	Socially Comfortable and Aware
			Factor 2	2, 3	Social Communication
			Factor 3	4, 11, 12, 19	Emotionally

					Aware
			Factor 4	6	Comfortable Environment
			Factor 5	15, 17	Solitary
<b>Childhood</b>	0.609	F(28) = 138.493 p<0.001.	Factor 1	2, 3, 5	Fantasy
			Factor 2	7, 8	Isolated and Bullied
			Factor 3	1, 6	Introverted
<b>Interests</b>	0.574	F(66) = 216.725 p<0.001.	Factor 1	1, 2, 3	Obsessive
			Factor 2	4, 5, 9	Logical and Numerical
			Factor 3	6, 7, 10	Creative and Literate
			Factor 4	8, 11, 12	Animals and Organised
<b>Physical Behaviour</b>	0.695	F(66) = 231.759 p<0.001.	Factor 1	2, 3, 5, 6	Coping Mechanisms
			Factor 2	4, 11 12	Uncontrollable Behaviour
			Factor 3	8, 9	Centre of Attention
			Factor 4	1	Aggressive
<b>Co-morbid Disorders</b>	0.695	F(36) = 61.953 p = 0.005.	Factor 1	4, 5, 8	Issues around food and Depression
			Factor 2	1, 3, 7	Other Disorders and Seizures (Co-morbid)
			Factor 3	2, 9	Easily Fazed and Hearing
<b>Cognitive Abilities</b>	0.695	F(136) = 484.470 p<0.001.	Factor 1	1, 2, 3, 5, 6	Logic and Intelligence
			Factor 2	8, 9, 16	Distracted
			Factor 3	2, 3, 11	Literately Intelligent
			Factor 4	12, 17	Change
			Factor 5	10, 13, 15	Forgetful and Clumsy
			Factor 6	14	Technology

## **Part B: Semi-Structured Interview Analysis**

Through conducting thematic analysis on the ten semi-structured interviews, seven broad themes were identified; appearance, sensory issues, coping mechanisms, traits/feelings, interests, triggers/social situations and male and female differences. The themes have been discussed below in relation to the small initial open codes and selective codes (quotes) to support the findings (P= Participant: Initial of participant, L=Line, Line number). The full table of smaller open codes, minor themes, major themes and selective codes developed from thematic analysis can be seen in Appendix 9.

### Appearance

This major theme was developed due to four minor themes; clothes, hair, colour, material and body type. Most participants indicated that they would not describe their appearance as ultra girly but would still describe their appearance as “feminine” (P:C, L9) and “individual whilst trying to blend in” (P:TT, L55). Participant L explained “the cut of my clothes is quite tomboyish but in terms of colour they’re quite feminine” (P:L, L7/8). All ten participants suggested the main factor influencing their choice in clothing and their hairstyle is predominantly for ‘comfort’ and ‘practicality’ (e.g. P:AB, L6; P:KR, L28). Participant MS for example said “I wear practical clothing and...I am more of a comfy dresser” (P:MS, L7/20) and participant C stated “I wear anything that is comfortable” (P:C22, L22). All participants mentioned that they have a practical hairstyle that doesn’t take much grooming with two of the participants describing their hairstyle in particular as “wash it and go” (e.g. P:TT, L22; P:SS, L24/26). Whilst this suggests that they are not necessarily interested in fashion or the appearance of their hair as such, participants stated

certain factors to do with preference e.g., they only like to wear “certain colours” (P:C, L4) but often wear “bright colours” (P:SS, L10). A couple of the participants mentioned that they often “coordinate the colours of their clothes” (P:KL, L5) and their belongings. Participant KL for example explained “I always have everything coordinated in colours and stuff and I tend to have my bears coordinated with me” (P:KL, L6). The other feature that seemed to determine the appearance of participants being predominantly practical was due to sensory factors in terms of the feel of their clothes or drafts against their skin. Participant L for example stated that “anything that I wear against my skin needs to be cotton” (P:L, L15) and participant RP stated that they “can’t stand wool or velvet” (P:RP, L21).

### Sensory

This major theme was developed due to five minor themes; noise, touch, heat, material and colour. Five of the participants mentioned they suffered from sensory issues which can determine the types and colours of clothes that they wear, the hairstyle they choose to the different locations that they can socialise (e.g. P:KR, P:MS, P:KL, P:AB and P:C). For example Participant KR explained “I am very sensitive on touch which affects what I wear...I don’t like drafts on my arms....my hair itches my face so that stays up as well” (P:KR, L17,20,72). Participant C stated “red will make my eyes hurt” (P:C, L5/6). Additionally, participants stated they suffered from sensitivity to noise and heat which makes them choose not to go to certain location. Participant C stated “I hate going into shops, they’re too loud and too noisy...too hot” (P:C, L13/14).

## Coping Mechanisms

This major theme was developed due to three key minor themes; physical mannerisms, avoidance and order and listing. All ten participants claimed that they do have coping mechanisms to cope with situations where they feel stressed, anxious, tentative or elated. Coping mechanisms included singing, creating lists, planning dialogues before they talk, mirroring behaviour or removing themselves from the situation. Five of the participants stated that they kept “lists” (P:KR, L217 and 220; P: C, L250; P:L, L238), “segment the day” (P:TT, L109-111) and or “write everything down” (P:SS, L222) to help them keep calm, maintain a routine and remember everything.

When participants were in an uncomfortable situation where they felt anxious and or upset, some of them mentioned that they would “rock” (P:SSE, L118; PLMS, L33) themselves, “sway from one foot to the other” (P:SSE, L109), “fiddle” (P:AB, L46; P:L, L40, P:KL, L75-777) with either their hands or belongings or “play with their hands like a cat’s cradle” (P:SSE, L:119) or “hum” (P:KR, L142) and “sing” (P:SS, L169) to themselves. Some participants mentioned they would either avoid or remove themselves from the situation (P:C, L218; P:RP, L46; P:SS, L410). Participant KR for example stated “I put my fingers in my ears” (P:KR, L142) when they couldn’t cope with noise or conversation. A few of the participants stated when they were happy or elated, they would “clap” (P:MS, L33; P: C, L184) or “flap” (P:KL, L120; P:RP, L54) their hands and or “jump up and down” (P:KL, L120).

In order to cope with social interaction a few of the participants mentioned that they may “mirror” (P:TT, L128) or “mimic” (P:SS, L99) the behaviour of the other person, “plan a list of questions” (P:L, L238; P:RP, L96) or “prepare a dialogue” (P:TT, L233) they would want to ask or say to the other person, “repeat what they said” (P:MS, L52) in

their head and/or “analyse other people” (P:TT, L135) to learn what is appropriate behaviour, language or dress code for a particular situation.

### Traits/Feelings

This major theme was developed due to three minor themes; personality traits, physical traits and emotions as all participants mentioned particular traits and feelings that they believed to be a result of their ASC in addition to their difficulties with social communication, interaction and imagination. Some of the participants mentioned that they are obsessive in their day to day lives and also with their particular interests and are perfectionists (P:KR, L405; P:TT, L199; P:L, L:144; P:MS, L90; P:SS, L222). Participant KR for example stated “I exhaust myself being a perfectionist” (P:KR, L205).

Other traits that participants stated they suffer from included seizures, panic attacks and anxiety (P:SS, L42; P:AB, L29; P:RB, L138; P:MS, 30; P:L, L161; P:KL, L158; P:SSE, L108; P:KR, L421). One participant stated that she had issues with food and suffered from “very bad teenage anorexia” (P:SSE, L336).

### Interests

This major theme was developed due to six minor themes; literature and history, arts and creative activities, animals, fantasy, science and technology and toys. The majority of participants mentioned that they had particular interests and obsessed over them (e.g. P:SS, L222; P:MS, L90; P:L, L144; P:TT, L199). Participant MS for example stated that she “obsesses over drama” (P:MS, L96).

Participants talked about their childhood interests. A few of the participants stated that they were “interested in kind of boys stuff” (P:TT, L212) like “lego, toy cars, toy trains and dinosaurs” (P:TT, L212/213; P:KR, L214). Participant TT stated that they “didn’t really want to play with dolls and do girly stuff” (P:TT, L213). Some of the other participants on the other hand stated that whilst they were interested in typical boys interests like “computer games” (P:KR, 381; P:SS, L334; P:MS, L89; P:AB, L105) they also “liked dolls” (P:AB, L74; P:SS, L349) and “teddy bears” (P:AB, L75; P:KL, L38).

Seven of the participants stated that they liked “literature” (P:SS, L273) whether that was to “read” (e.g. P:C, L102; P:AB, L112, P:RP, L125; P:L, L195; P:KL, L136; P:KR, L157) and/or “write” (P:SS, L137; P:TT, L226/262, P:SSE, L74; P:KR, L254) literature. Participant SS for example stated “I like to make up and write lyrics” (P:SS, L173). Participant TT and SSE mentioned that they like social history, family history and heritage (P:TT, L264; P:SSE, L247). Six of the participants stated that they didn’t like maths. Participant AB for example stated “I am rubbish at maths” (P:AB, L109). However, a couple of the participants said that they liked algebra (P:258). Participant C for example claimed that they “love maths and sciences but hated things like history or geography” (P:C, L156/157) and that “algebra is my first language” (P:C, L167).

Seven participants stated that they were particularly interested in “animals” (P:SS, L91; P:C, L112; P:AB, L99; P:RP, L117; P:L, L73; P:KL, L38; P:KR, L214) and a few stated in particular “animal behaviour” (P:RP, L126; P:L, L84). One participant stated “I don’t get animals at all” (P:TT, L306). All participants but one mentioned that they weren’t particularly interested in sports. Participant SS for example explained “I have never been sporty really” (P:SS, L284) whereas participant AB stated “I am a football fan” (P:AB, L101).

### Triggers/Social Situations

This major theme was developed due to three minor themes; uncomfortable situations, feelings and comfortable situations. All participants claimed that particular triggers cause them to feel anxious, stressed, confused and their behaviour to become less controlled; in particular social situations. Participants mentioned that large crowds of people, situations where there is a high level of exposure, loud shops, parties, and generally unfamiliar environments tend to trigger these emotions and uncontrollable behaviour (e.g. P:KR, L93; P:SSE, L41; P:KL, L64; P:RP, L43; P:C, L13; P:MS, L26). Participant C found shop environments too difficult and claimed that they felt “anxiety, depression the more time that goes on I just want to lie down on the floor and cry and have what I refer to as tard fits and have a tantrum basically” (P:C, L49-51).

Some of the participants described how they felt in uncomfortable situations. Participant SSE stated that “in awkward social situations, I tend to go a bit blank...in the way computers freeze for a while” (P:SSE, L216). Participant TT stated that “it is like having Vaseline over my eyes” (P:TT, L149). All participants mentioned that they liked periods of quiet and solitude as well as doing solo activities without others but felt comfortable with people and situations familiar to them. Participant KR for example stated that in “familiar situations I can be quite chatty” (P:KR, L83). Participants claimed that they feel comfortable in situations where there are a small number of people with the maximum number being about 4, 5 or 6 people (e.g. P:KR, L88; P:KL, L60, P:AB, L36). This was partly due to being concerned about other people judging them, being bullied or due to sensory overload (e.g. P:KR, L124; P:SSE, L52; P:L, L:55; P:C, L13; P:SS, L74).

Participant RP for example stated that “the larger the number of people the more confusing it is” (P:RP, L87) and participant L said that she “keeps thinking people will judge me” (P:L, L55).

### Male and Female differences

This major theme was developed due to three minor themes; male differences, female differences and similarities. Participant’s mentioned a few differences they had noticed between themselves and their male acquaintances with ASCs regarding interests, their level of social awareness and their general personality. However, participants stated that there do appear to be more similarities between themselves and males than differences (e.g. P:SS, L334; P:L, L257). Participants mentioned that both themselves and males have difficulties with social communication, interaction and imagination but “males appear to be more unaware of how they come across” (P:L, L260).

Participant SS stated that “males tend to be more inappropriate” (P:SS, L340) in their language and behaviour, generally “more noisy” (P:KR, L357), “more outgoing” (P:L, L252; P:MS, L143) and “more disruptive” (P:KR, L402). The participants mentioned that “females with AS tend to be more emotionally aware” (P:C, L231), “more quiet” (P:L, L254), “more anxious” (P:L, L262) and generally “ASC traits tend to be more low level” (P:KL, L190).

The majority of participants stated their interests appear to differ compared to males (e.g. P:KL, L191-195; P:SS, L338). The participants mentioned that most females they know including themselves were interested in literature, art, animals, music and science (particularly biology) whereas the males were more interested in comics, science

(physics), maths and computer games (e.g. P:KL, L194; P:SS, L338). Participant KL for example stated males are more interested in “scifi, DS games and stuff like that” (P:KL, 195).

## **Discussion**

The main aim of this research project was to examine differences and similarities between and among males and females with an ASC diagnosis. The results, overall, indicate that despite many similarities there are some key areas of distinction between males and females with ASCs.

### **Appearance and Personality**

Differences were indicated in the personality traits of males and females with ASCs and their appearance in terms of their choice of clothes and hair. The focus of both males and females was on being comfortable, practical, hassle free and to blend in with other people. This is very much in-line with 'autistic thinking' in the literature. However, the females with ASCs were greater influenced by social influence and social norms which manifested in their appearance and personality. Females were more interested in wearing clothes that appeared feminine (in terms of colour and pattern) and clothes that were more fashionable whereas males to a lesser extent were interested in wearing masculine clothes. Simultaneously, whilst females were more into fashion, they were found to agree more strongly with describing their clothes as masculine compared to when males described their clothes as feminine. Females with ASCs also described themselves as curvier, more quiet and anxious than males and males were found to be more disruptive and outgoing. These results support the Androgen Theory of Autism which suggests individuals with ASCs are likely to have higher levels of foetal testosterone which can result in both males and females with ASCs to display hypermasculinised appearance, personality and behaviour (Tordjmann et al., 1997; Breedlove, 1994; Arnold and Gorski, 1984; MaLusky and Natoflin, 1981). However, the theory neglects the idea that females may still be

interested in portraying their femininity. It can be argued that both males and females appear aware of gender stereotypical clothes and behaviour and strove to fit in with society through adopting the appropriate stereotype. It would be reductionist to stereotype individuals with ASCs as simply all being hypermasculinised and females with ASCs being more likely to present themselves as more male and may result in females that do not meet this stereotype being missed from the spectrum.

### **Social Situations and Social Relationships**

Both male and female participants highlighted difficulties in understanding social communication and social interaction as well as difficulties in particular social situations. Females have been found to be logical and systematic but also able to understand other people's emotions whilst males appear to be greater systemisers than females and unable to recognise other people's emotions as easily. This appears to support the Extreme Male Brain Theory proposed by Baron-Cohen which suggests that individuals with ASCs are impaired in their ability to be able to empathise and are greater systemisers leading ASCs to be biased towards males (Baron-Cohen et al 2011; Baron-Cohen, 2003; Baron-Cohen, 2002). However, this theory neglects the idea that whilst individuals with ASCs maybe greater systemisers, they may also be able to empathise to an extent. It could be argued that when diagnosing individuals with ASCs it would be reductionist to only consider individuals as potentially having ASCs if they are solely systemisers. Instead, empathising might manifest in a different way.

The results also suggest female superiority on a host of differences that could be construed as aspects of social competence. Females were more likely to be in a

relationship than males, they were better able to follow social situations through imitating other people's behaviour and language, repeating what other people say in their head, preparing dialogues before taking part in conversation or replying to another person and participating in pretend play with their peers during childhood in addition to participating in pretend play on their own. This supports research conducted by Attwood (2007) and Le Couteur and colleagues (1989) which found females to be more social, better able to follow social action and have a greater affinity with emotions to be able to respond appropriately to others in relation to their emotions and behaviour. Whilst both males and females with ASCs are stereotyped as having difficulties with communication and social interaction, it seems that females are able to *appear* more socially competent through using particular coping mechanisms to overcome their difficulties such as mimicking, imitating, repeating and preparing dialogues. However, results indicate that this is only a surface appearance 'act'; during the interviews, female participants explained that whilst they can follow social interaction and communication to an extent, it becomes increasingly difficult when they are in uncomfortable and unfamiliar situations where there are large crowds of people, unfamiliar people or if the location is very noisy or hot. The participants mentioned they would prefer to be in smaller groups that socialise in activity centred situations which allows conversation to be available but optional.

## **Interests**

The results again support previous findings with ASCs that individuals have obsessive interests. However, the findings also indicated that male and female interests tend to differ in a number of ways. Males were found to be particularly interested in maths, science, technology and history and females were found to be more interested in music,

literature, animals, fantasy, arts and creative activities as well as the typical male oriented interests. Female participants mentioned that although they were interested in the male oriented interests, their focus was different to males being more interested in biology rather than physics and algebra rather than particularly number oriented mathematical processes. This supports research by Nichols and colleagues (2009) and Attwood (2007) which found females to be interested in animals, music and classical literature in addition to the typical male oriented interests. This suggests that when diagnosing both males and females with ASCs, particular male oriented interests should be looked out for. However, females with ASCs are also interested in more literate and creative subjects. It may be that when considering if an individual has an ASC, the focus should be on the relationship with those subjects such as how they interact with toys (lining cars or dolls up for example) and how obsessive they are with them.

### **Coping Mechanisms/ Physical Behaviour**

Male and female participants have stated they use coping mechanisms and display physical mannerisms in particular situations. It has been found that the coping mechanisms of females appear more subtle than those of males with ASCs. Females have been found to display more repetitive actions, create lists and fiddle more with their belongings and hands in public in comparison to males who are more likely to be more obvious with their coping mechanisms by rocking for example. During the interviews, female participants did mention that they may rock, clap, jump, dance and sing but that this would be more likely if they were at home as they were aware of the abnormality of this behaviour. This supports research by Tsai and colleagues (1981) who found females to display more

dystonic posturing of hands and fingers. This suggests females are more aware of what is considered socially acceptable behaviour than males resulting in a greater ability to be able to control and hide the stereotypical ASC traits. When diagnosing individuals with ASCs it appears that the coping mechanisms and physical traits to be considered differ depending on their gender and on the situation.

### **Co-morbid Disorders**

This research has highlighted that there are differences in relation to co-morbid disorders that females and males with ASCs have been diagnosed with. It was found that females with ASCs are more likely to be anxious about food, suffer from seizures, panic attacks and anxiety. This supports findings from research by Ghaziuddin and colleagues (1998) and Ghaziuddin (2002) which found females with ASCs to be more likely to suffer from Anorexia, Schizophrenia, OCD, ADHD, Bipolar, sleep disorders, Tourettes, Depression and anxiety. This suggests that disorders likely to be co-morbid to females with ASCs tend to be more social disorders compared to the genetically rooted disorders (such as Downs syndrome) which males with ASCs are likely to be diagnosed with. Some of the female participants mentioned that they had been diagnosed with other disorders such as personality disorder prior to their ASC diagnosis. As a result, females who have been diagnosed with these disorders may be being missed from the spectrum by being misdiagnosed or under-diagnosed when they may have a co-morbid ASC.

## **Critical Reflection**

When conducting qualitative and quantitative research the researcher needs to consider factors such as reliability (how replicable the research is) and validity (how credible and truthful the findings of the research data is) (Franklin et al, 2010). Consequently, to be reliable a research study must follow a clear, precise and standardised methodological process. Due to remaining close to both the quantitative and qualitative data, transcribing the qualitative audio-recorded interview data verbatim and as accurately as possible and through utilising an interview schedule when conducting the interviews, the reliability and validity increased. Additionally, using thematic analysis as a method of analysis increased the validity of the research as it allows themes to emerge naturally through relying on the researcher remaining neutral and avoiding using preconceived ideas or theories to aid data analysis.

Although these can be seen as strengths of the research, due to time constraints there was little opportunity to be able to conduct a longitudinal study to gain a wider and larger sample comprising of an equal number of both genders with ASCs. The generalisability of the findings to the wider population is therefore questionable. Working with an ASC population presented challenges in itself. Due to being a minority population and ASC traits manifesting themselves over such an extensive spectrum, generalising the results can be even more problematic than with a typically developing population. However, when considering the generalisability of the data from the qualitative semi-structured interviews alone, it must be understood that the purpose of qualitative research is not to formulate a conclusion but to provide in-depth, inductive and holistic experiences at a micro level (Marshall, 1996).

## Conclusion

This study has demonstrated that in all sorts of ways there are similarities in the manifestation of ASCs in males and females but there are clearly identified differences. Previous research appeared to focus on the notion that both males and females with ASCs would have difficulties in relation to the triad of impairments and appear hypermasculinised. This research project sought to explore whether the sex disparity in ASCs was a result of this reductionist view neglecting to consider the idea that ASCs may manifest differently in females to males. A quantitative Likert style questionnaire and qualitative semi-structured audio recorded interviews were implemented to explore the manifestation of ASCs in eight areas including appearance, personality, social relationships, childhood, interests, physical behaviour, co-morbid disorders and cognitive abilities where potential sex differences may occur.

The analysis revealed that whilst both males and females with ASCs have difficulties regarding communication, social interaction and imagination, female ASC traits appear more subtle due to being more socially aware of their difficulties. Thus, females appear better able to cope with their difficulties through employing delayed imitation practices, prepared dialogues, repetition practices and through fiddling with their hands or belongings. Whilst both males and females seem interested in the typical male oriented interests such as maths, science and technology, females also demonstrated particular interests in animals, literature, music, arts and creative activities. Both males and females appeared aware of gender typical interests and behaviour which extended to and was evident in their personality and appearance. Although the aspect that seemed to shape both males and females clothing and hairstyle choices was comfort and practicality, females highlighted sensory issues that influenced their appearance and were more likely

to wear more feminine clothing in terms of pattern and colour in comparison to males. Another finding from this research was that females with ASCs were found to incur more social co-morbid disorders (such as OCD, anxiety, anorexia to name a few) than the more genetic disorders (such as Downs syndrome) associated with males with ASCs.

To develop the findings from this small-scale exploratory research project, future research could focus more closely on exploring the sensory issues that females with ASCs seem to incur and the impact this has on their behaviour, appearance and social competency. As previous research has neglected this area and females in this study explained the inconvenience that results from their sensory issues regarding being able to venture and cope in different locations such as hot, noisy and busy shops, clubs and pubs as well restricting the types of clothes and hairstyle they wear, it seems an important aspect to explore in greater detail. Furthermore, as females in this study have demonstrated that they appear more receptive and or sensitive to social influence and social norms (e.g. regarding appearance), further research could investigate what it is that makes females with ASCs more open to these influencing factors.

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## Appendix 1- Ethics Approval

E3/FH&LS

Oxford Brookes University

Faculty of Health and Life Sciences

Decision on application for ethics approval

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The Departmental Research Ethics Officer (DREO) / Faculty Research Ethics Committee (FREC) has considered the application for ethics approval for the following project:

**Reference number: 1112/122**

**Module number and course: MSc in Psychology P24118**

**Project Title: Exploring the Sex Disparity in Autism Spectrum Conditions (ASCs)**

**Name of Applicant/s:** Naomi Phillips

**Name of Supervisor/s:** John Lawson

Please tick one box

1. The Departmental Research Ethics Officer / Faculty Research Ethics Committee gives ethical approval for the research project.

**Please note that the research protocol as laid down in the application and hereby approved must not be changed without the approval of the DREO / FREC**

2. The Departmental Research Ethics Officer / Faculty Research Ethics Committee gives ethical approval for the research project, subject to the following::

3. The Departmental Research Officer / Faculty Research Ethics Committee cannot give ethical approval for the research project. The reasons for this and the action required are as follows:

Signed:  Approval Date: .....22.06.12.....

Designation: Departmental Research Ethics Officer

*(Signed on behalf of the Faculty Research Ethics Committee)*

Date when application reviewed (office use only):.....

H&LS/FRec/E3 August 2011

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Appendix 2 - Letter to Gatekeepers

<Type recipient's address here>

<address 1>

<address 2>

<address 3>

<address 4>

<address 5>

<post code>

3<sup>rd</sup> July 2012

Dear <type recipient's name here>

**RE: Research Project – Exploring the Sex Disparity in Autism Spectrum Conditions (ASCs)**

I am a Masters student at Oxford Brookes University conducting a research project concerned with exploring the sex disparity in Autism Spectrum Conditions. I was wondering whether it would be possible to approach your clients to invite them to participate in my research project. The research project is being conducted in order to gain a better understanding of the manifestation of ASCs. In particular, whether the sex disparity associated with ASCs is justified (males being more likely to have ASCs than females) or whether females are not being picked up through using the current diagnostic criteria due to females having different ASC characteristics. I am interested in gathering 40 males and 40 females with Asperger Syndrome. The participants would be invited to read an information sheet about the research project to inform them as to the importance of the research and how they fit the participant criteria. They would also be asked to complete a consent form if they do wish to participate.

The research project requires participants to complete a questionnaire which will ask them about the characteristics/ symptoms of their Asperger Syndrome or High Functioning Autism.

After completing the questionnaire, females with Asperger Syndrome or High Functioning Autism would also be invited to undertake a short interview. Not all females will be interviewed. If a signed and returned consent form is included with the completed questionnaire, it will indicate that the female participants also agree to be interviewed. This will help me to gain a more in depth understanding of the presentation of their symptoms.

If you would like any further information, please do not hesitate to contact me using the email address or phone number below. If it is ok with you, I will be in contact in the next few days to discuss the study. If you wouldn't mind, would it be possible for you to advertise the study on your website and distribute the information sheets, consent forms and questionnaires to your clients or allow me to come to the centre to do these things? It would be greatly appreciated.

Yours Sincerely

 Miss Naomi Phillips (Researcher)

DEPARTMENT OF PSYCHOLOGY  
FACULTY OF HEALTH AND LIFE  
SCIENCES

Headington Campus Gipsy Lane  
Oxford OX3 0BP UK  
T +44 (0) 1865 483787  
M +44 (0) 7950 138633

Email: (of supervisor):  
[jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk)  
Email: (of researcher):  
[11084093@brookes.ac.uk](mailto:11084093@brookes.ac.uk)

## Appendix 3 - Questionnaire

### Questionnaire

You are being invited to fill in this questionnaire about the characteristics of your Asperger Syndrome or High Functioning Autism. There are two sections to be completed. The return of the questionnaire will be taken as consent to you wanting to participate in the research study. If you are female and are happy to be interviewed in addition to completing this questionnaire, please include the attached consent form when posting this questionnaire back to me.

### SECTION A

This section will be detached from your questionnaire responses in order to keep your contribution to the research confidential and anonymous. Please fill in the following information:

**1. Are you male or female**

Male	Female

**2. How old are you?**

18 -28	30 - 39	40 - 49	50 - 59	60 +

**3. What is your email address?: .....**

**4. What is your home address?**

House number/ Name .....

.....

City .....

County .....

Post Code .....

**5. Telephone Number: .....**

**6. What date were you diagnosed with your ASC? .....**

**7. What is your specific ASC diagnosis? .....**

**8. Would you like a debriefing letter to be sent to you?**

YES	NO

### SECTION B

Please tick only one option per question that is most appropriate to you. Listed below are a number of statements. Please read each statement in turn and indicate your agreement or disagreement with a tick. Please only tick one box per statement.

### APPEARANCE

**1. I take pride in my appearance**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**2. I like to look nice**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**3. My appearance isn't important to me**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**4. I wear practical clothing**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**5. I like to wear clothes that are currently in fashion**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**6. What I wear isn't important to me**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**7. My clothes are feminine**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**8. My clothes are masculine**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**9. I like to look different from other people**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**10. My clothes are eccentric**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**11. I spend time doing my hair**

Strongly Agree	Agree	Neither agree	Disagree	Strongly Disagree
----------------	-------	---------------	----------	-------------------

		nor disagree		

**12. I have a masculine figure**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**13. I am curvy**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**PERSONALITY**

**1. I am eccentric**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**2. I am reserved**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**3. I am relaxed**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**4. I get anxious easily**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**5. I am confident**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**6. I am shy**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**7. I get emotional easily**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

		nor disagree		

**8. I like to stand out from the crowd**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**9. I am perceived as cold natured**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**10. I often have meltdowns**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**11. I have a short temper/ I get angry easily**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**12. I am sensitive**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**13. I present myself day to day as though it is a performance**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**14. I have strong opinions**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**15. If my routine is disrupted, it doesn't upset me**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**16. I am spontaneous**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

--	--	--	--	--

## SOCIAL RELATIONSHIPS

### 1. I can follow social situations easily

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 2. I am often misunderstood

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 3. I often misunderstand other people

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 4. I can recognise when someone is upset

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 5. I am happiest in a controlled environment

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 6. I am happiest around people I know

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 7. I like new situations

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 8. I like meeting new people

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 9. I rely on my friends

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

--	--	--	--	--

**10. I have lots of friends**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**11. I am in a relationship**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**12. I understand the meaning of love**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**13. I make friends easily**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**14. I am comfortable in a crowd of people**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**15. I irritate other people**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**16. I like to go out to parties**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**17. I like being on my own**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**18. I like to be around my friends**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**19. I have a vivid imagination**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**CHILDHOOD**

**1. I preferred to play on my own**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**2. I had an imaginary friend(s)**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**3. I liked to pretend play**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**4. I liked to play with my toys**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**5. I made up stories for fun (e.g. like fairytales)**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**6. I was looked after by my friends**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**7. I was isolated from my peers/friends**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**8. I was bullied**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

--	--	--	--	--

## INTERESTS

### 1. I have a particular interest

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 2. I am obsessive

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 3. I am obsessed with my particular interest

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 4. I like science

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 5. I like maths

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 6. I like art

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 7. I like reading

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 8. I like animals

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

### 9. I like trains (motor vehicles) (transport)

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

--	--	--	--	--

**10. I like music**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**11. My belongings need to be ordered**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**12. My belongings can be messy**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**PHYSICAL BEHAVIOUR**

**1. I am aggressive**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**2. I flap my hands**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**3. I rock myself often**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**4. I find my behaviour difficult to control**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**5. I do repetitive actions**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**6. I like to dance around when I am happy**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

--	--	--	--	--

**7. I am disruptive**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**8. I like being the centre of attention**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**9. I am attention seeking**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**10. I hear voices**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**11. I often have mood swings**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**12. I often notice small sounds whilst others do not**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**CO-MORBID DISORDERS**

**1. I have been diagnosed with other disorders**

Yes	No

**2. I have difficulty hearing**

Yes	No

**3. I have learning difficulties**

Yes	No

**4. I have gastro-intestinal problems**

Yes	No

**5. I get anxious about food**

Yes	No

**6. I get depressed**

Yes	No

**7. I have seizures**

Yes	No

**8. I sleep well**

Yes	No

**9. I am easily fazed**

Yes	No

**COGNITIVE ABILITIES**

**1. I am good at problem solving**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**2. I am very intelligent**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**3. I have a high IQ**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**4. I am good with numbers**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**5. I am good with patterns**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**6. I am good at science**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**7. I have a good memory**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**8. I lose concentration quickly**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**9. I am easily distracted**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**10. I am clumsy**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**11. I taught myself to read**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**12. I like change**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**13. I have to write instructions down**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**14. I like computers**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**15. I have good spatial awareness**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**16. I often change my mind**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**17. I can understand other people's emotions**

Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree

**THANK YOU FOR COMPLETING THIS QUESTIONNAIRE. IT IS GREATLY APPRECIATED!!**

## Appendix 4 – Interview Schedule

### Interview Schedule

Hello, how are you? .....glad to hear it. Well it is lovely to meet you and I would like to thank you for agreeing to be interviewed. I am going to ask you a few questions about yourself and your personal experience of having Asperger Syndrome. The interview shouldn't take too long but if you would like to stop for a break, not answer any questions, pause the tape or stop the interview completely at any point just let me know. Just to inform you that any information you give will be kept completely confidential and anonymous so if you could be as open and honest as possible that would be great.

Ok so to begin I am going to ask you a few questions about your appearance.

#### **APPEARANCE**

1. How would you describe your overall appearance?
2. How would you describe the types of clothes that you wear?
3. How important is your appearance to you?
4. How would you describe your body shape?
5. How long would you take to get yourself dressed to go out?

#### **PERSONALITY**

1. How would you describe your personality?
2. How would you describe your mood on a typical day?
3. How would you describe your emotions in difficult situations?
4. What coping mechanisms do you use to keep you calm emotionally?
5. How organised would you say you were?

#### **SOCIAL RELATIONSHIPS**

1. Do you find making friends easy?
2. Do you like meeting new people?
3. How comfortable are you in new situations?
4. How good are you at following a conversation?
5. Are you often misunderstood?

#### **CHILDHOOD**

1. How would you describe your behaviour when you were a child?
2. Who did you prefer to play with?
3. What games did you play?
4. Did you have any imaginary friends?
5. How many friends would you say you had/ have?

#### **INTERESTS**

1. What are your particular interests?
2. What are your hobbies?
3. What are you good at?
4. What are you not so good at?
5. Do you enjoy any form of sport?

**PHYSICAL BEHAVIOUR**

1. What physical mannerisms do you usually do on a typical day?
2. How would you behave in an upsetting/ unsettling situation?
3. What coping mechanisms do you use to control your behaviour?
4. What sort of things triggers your behaviour to become uncontrollable?

**CO-MORBID DISORDERS**

1. Have you been diagnosed with any other medical problems, learning difficulties or disorders?

**COGNITIVE ABILITIES**

1. Are you good at mathematics?
2. Are you good with patterns?
3. Are you artistic?
4. Do you enjoy playing rule based games such as chess?

Appendix 5 – Letter to Participants

**Hard Copy**

**PSYCHOLOGY DEPARTMENT**

Headington Campus, Gypsy Lane, Oxford OX3 0BP

Direct Line for Dr John Lawson (supervisor): +44 (0)1865 483787

Email: (of supervisor): [jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk)

Researcher's name: Naomi Phillips

Researcher's email: [11084093@brookes.ac.uk](mailto:11084093@brookes.ac.uk)      DATE 11th July 2012

Dear Sir or Madame,

**RE: Research Project – Exploring the Sex Disparity in Autism Spectrum Conditions (ASCs)**

I am a Masters student at Oxford Brookes University conducting a research project concerned with exploring the sex disparity in Autism Spectrum Conditions. I was wondering whether you would be interested in taking part in this study. You are being invited to take part as you are an adult with Asperger Syndrome or High Functioning Autism over the age of 18.

Please find enclosed an information sheet about the research project which describes the importance of the research, a consent form and a questionnaire which will ask you about the characteristics of your Asperger Syndrome or High Functioning Autism. All participants who agree to participate will be required to complete and return the questionnaire to Dr John Lawson at the above address.

If you are female and have Asperger Syndrome or High Functioning Autism you are also invited to undertake a short interview. Not all females will be interviewed. If you are female and are willing to take part in the interview, please sign and return the consent form that is also included along with the completed questionnaire. By interviewing individuals with Asperger Syndrome and High Functioning Autism, it will help me to gain a more in depth understanding of the presentation of ASC characteristics.

The research can also be completed online if you would prefer where you can complete the questionnaire and consent by going to the website address [www.ntcphillips.co.uk](http://www.ntcphillips.co.uk). On the website you will find the information sheet to tell you about the research, the questionnaire, a page asking whether you would like a debriefing letter sent to you and a consent form for the interview which is specific for females with Asperger Syndrome or High Functioning Autism.

If you would like any further information, please do not hesitate to contact me using the email address [11084093@brookes.ac.uk](mailto:11084093@brookes.ac.uk) or contact my supervisor Dr John Lawson via the email address [jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk) or the telephone number +44 (0) 1865 483787.

Yours Sincerely

Miss Naomi Phillips  
(Researcher)



**Online only**

**PSYCHOLOGY DEPARTMENT**

Headington Campus, Gipsy Lane, Oxford OX3 0BP

Direct Line for Dr John Lawson (supervisor): +44 (0)1865 483787

Email: (of supervisor): [jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk)

Researcher's name: Naomi Phillips

Researcher's email: [11084093@brookes.ac.uk](mailto:11084093@brookes.ac.uk)      DATE 11th July 2012

Dear Sir or Madame,

**RE: Research Project – Exploring the Sex Disparity in Autism Spectrum Conditions (ASCs)**

I am a Masters student at Oxford Brookes University conducting a research project concerned with exploring the sex disparity in Autism Spectrum Conditions. I was wondering whether you would be interested in taking part in this study. You are being invited to take part as you are an adult with Asperger Syndrome or High Functioning Autism over the age of 18.

If you would like to participate you would be required to complete a questionnaire which will ask you about the characteristics of your Asperger Syndrome or High Functioning Autism.

If you are female and have Asperger Syndrome or High Functioning Autism you are also invited to undertake a short interview. Not all females will be interviewed. If you are female and are willing to take part in the interview, you will need to complete the consent form as well as questionnaire. By interviewing individuals with Asperger Syndrome and High Functioning Autism, it will help me to gain a more in depth understanding of the presentation of ASC characteristics.

The research can be completed online by going to the website address [www.ntcphillips.co.uk](http://www.ntcphillips.co.uk). Here you will find the information sheet to tell you about the research, the questionnaire, a page asking whether you would like a debriefing letter sent to you and a consent form for the interview which is specific for females with Asperger Syndrome or High Functioning Autism.

If you would like any further information, please do not hesitate to contact me using the email address [11084093@brookes.ac.uk](mailto:11084093@brookes.ac.uk) or contact my supervisor Dr John Lawson via the email address [jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk) or the telephone number +44 (0) 1865 483787.

Yours Sincerely

Miss Naomi Phillips  
(Researcher)



**Appendix 6 – Information Sheet**  
**Information Sheet – Hard Copy**

**PSYCHOLOGY DEPARTMENT**

Headington Campus, Gipsy Lane, Oxford OX3 0BP  
Direct Line for Dr John Lawson (supervisor): +44 (0)1865 483787  
Email: (of supervisor): [jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk)  
Researcher's name: Naomi Phillips  
Researcher's email: 11084093@brookes.ac.uk      DATE 11th July 2012

Dear Sir or Madam,

**Exploring the Sex Disparity in Autism Spectrum Conditions**

You are being invited to take part in this research study. Before you decide whether you want to take part, it is important that you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

*What is the study about and what will it involve?*

The research will explore the difference in the occurrence of Autism Spectrum Conditions in males and females. One group of males with Asperger syndrome or High Functioning Autism (age 18+) will be compared to a group of females with Asperger syndrome or High Functioning Autism (18+). In order to match the individuals that will be participating, a diagnosis of Asperger syndrome or High Functioning Autism needs to have been given by a Clinician. This will be verified by you providing the date of your diagnosis in Section A of the Questionnaire and the name of the diagnosis you were given.

If you choose to participate in this research study, you will be required to complete and return the enclosed questionnaire which will ask you about the symptoms/ characteristics of your Asperger Syndrome or High Functioning Autism.

If you are female, you are also invited to undertake a short interview if you also consent to this by completing the consent form and returning the consent form along with the questionnaire. The interview will ask you to describe your personal characteristics related to your ASC.

If you would prefer, you can go online to [www.ntcphillips.co.uk](http://www.ntcphillips.co.uk) to complete the questionnaire and consent form.

*Why am I being asked to take part?*

You are being asked to participate as you are an adult with a diagnosis of an Autism Spectrum Condition. The questionnaires to be completed have been enclosed with this information sheet. The interviews that will be conducted with the females that consent to undertaking an interview (indicated by signing and returning the consent form enclosed) will be conducted at a location that is mutually convenient to both you and me. The interviews may be conducted at one of the centres or at Oxford Brookes University. From those who give consent, I will select 40 males with Asperger syndrome and 40 females with Asperger syndrome to complete the questionnaire. If you are female, you may be asked to undertake a short interview if you agree to. You will be seen individually for 15 minutes and asked to complete the questionnaire. If you are female and agree to undertake the short interview, a further 20-30 minutes of your time will be required.

*Do I have to give my consent?*

No. Giving your permission and taking part in the study is entirely voluntary. If you do decide that you want to take part, please be aware that you are free to withdraw at any time and do not need to provide an explanation. This information sheet is yours to keep. If you do participate, you will be required to fill in and return the consent form that is attached.

*Benefits and disadvantages of you taking part*

Through taking part, it will enable us to gain a better understanding of the presentation of ASCs in females. All that will be required is a maximum of 15 minutes out of your day if you are only completing the questionnaire and a total of 45 minutes if you agree to be interviewed.

*What will happen to the findings of this study?*

All data that is gathered will be kept confidential and anonymous. When the questionnaire has been returned to me, Section A (personal details) will be detached from the questionnaires, kept separate from the questionnaire responses and each questionnaire will be given a reference number to replace these details. The findings of this research will be used to better understand the manifestation of ASCs. In order to maintain confidentiality, it will not be possible for you to have access to the results of individual participants. However I will provide a summary of the research to you if you would be so kind as to leave me your email address. Your email address will be deleted once the summary is sent by the end of October 2012. The audio-recordings will be destroyed once results have been published.

*Ethics*

This study will adhere to the code of ethics and conduct presented by the British Psychological Society and has been approved by the Psychology Department Research Ethics Committee of the Faculty of Health and Life Sciences at Oxford Brookes University. If you have any concerns about this please contact [mmaclean@brookes.ac.uk](mailto:mmaclean@brookes.ac.uk)

Please do not hesitate to contact me with any other questions or queries about this research study. My contact details can be found at the top of this letter.

If you have any questions or queries about the study, please do not hesitate to contact me using the email address ([11084093@brookes.ac.uk](mailto:11084093@brookes.ac.uk)) or you can call my supervisor using the telephone number (+44 (0) 1865 483787).

**Thank you for taking the time to read this. If you agree to take part, please sign and return the attached consent form to the above address.**

## Information Sheet – On Website

### PSYCHOLOGY DEPARTMENT

Headington Campus, Gipsy Lane, Oxford OX3 0BP

Direct Line for Dr John Lawson (supervisor): +44 (0)1865 483787

Email: (of supervisor): [jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk)

Researcher's name: Naomi Phillips

Researcher's email: 11084093@brookes.ac.uk      DATE 2nd July 2012

Dear Sir or Madam,

### Exploring the Sex Disparity in Autism Spectrum Conditions

You are being invited to take part in this research study. Before you decide whether you want to take part, it is important that you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

#### *What is the study about and what will it involve?*

The research will explore the difference in the occurrence of Autism Spectrum Conditions in males and females. One group of males with Asperger syndrome or High Functioning Autism (age 18+) will be compared to a group of females with Asperger syndrome or High Functioning Autism (18+). In order to match the individuals that will be participating, a diagnosis of Asperger syndrome or High Functioning Autism needs to have been given by a Clinician. This will be verified by you providing the date of your diagnosis in Section A of the Questionnaire and the name of the diagnosis you were given.

If you choose to participate in this research study, you will be required to complete the questionnaire (which you can find by following the link at the bottom of this page which will ask you about the symptoms/ characteristics of your Asperger Syndrome or High Functioning Autism).

If you are female, you are also invited to undertake a short interview. If you would like to be considered for this, please complete the consent form found by following the link at the end of the questionnaire. Completing and submitting this consent form along with the questionnaire will indicate your willingness to be considered. The interview will ask you to describe your personal characteristics related to your ASC. You do not have to undertake the interview, it is your choice. You can just complete the questionnaire if you wish.

#### *Why am I being asked to take part?*

You are being asked to participate as you are an adult with a diagnosis of an Autism Spectrum Condition. The questionnaires to be completed can be found by following the link after this information sheet. Please tick the box at the top of the questionnaire to indicate you have read and understood this information sheet.

The interviews that will be conducted with the females that consent to undertaking an interview (indicated by signing and returning the consent form enclosed) will be conducted at a location that is mutually convenient to both you and me. The interviews may be conducted at one of the centres or at Oxford Brookes University. I am aiming for a minimum of 40 males with Asperger syndrome or High Functioning Autism and 40 females with Asperger syndrome or High Functioning Autism to complete the questionnaire. It should take no longer than 15 minutes. If you are female, you are invited to

undertake a short interview. If you are female and agree to undertake the short interview, a further 20-30 minutes of your time will be required at a mutually convenient location to both you and me.

*Do I have to give my consent?*

No. Giving your permission and taking part in the study is entirely voluntary. If you do decide that you want to take part, please be aware that you are free to withdraw at any time and do not need to provide an explanation. If you do participate, you will be required to tick the box on the questionnaire indicating you have read and understood this information sheet thus giving your consent to taking part. If you want to be considered for interview you are required to fill in and return the consent form that is found by following the link after the questionnaire.

*Benefits and disadvantages of you taking part*

Through taking part, it will enable us to gain a better understanding of the presentation of ASCs in females. All that will be required is a maximum of 15 minutes out of your day if you are only completing the questionnaire and a total of 45 minutes if you agree to be interviewed.

*What will happen to the findings of this study?*

All data that is gathered will be kept confidential and anonymous. When the questionnaire has been submitted, Section A (personal details) will be detached from the questionnaires, kept separate from the questionnaire responses and each questionnaire will be given a reference number to replace these details. The findings of this research will be used to better understand the manifestation of ASCs. In order to maintain confidentiality, it will not be possible for you to have access to the results of individual participants. However I will provide a summary of the research to you if you would be so kind as to leave me your email address. Your email address will be deleted once the summary is sent by the end of October 2012. The audio-recordings will be destroyed once results have been published.

*Ethics*

This study will adhere to the code of ethics and conduct presented by the British Psychological Society and has been approved by the Psychology Department Research Ethics Committee of the Faculty of Health and Life Sciences at Oxford Brookes University. If you have any concerns about this please contact [mmaclean@brookes.ac.uk](mailto:mmaclean@brookes.ac.uk)

Please do not hesitate to contact me with any other questions or queries about this research study. My contact details can be found at the top of this letter.

If you have any questions or queries about the study, please do not hesitate to contact me using the email address ([11084093@brookes.ac.uk](mailto:11084093@brookes.ac.uk)) or you can call my supervisor using the telephone number (+44 (0) 1865 483787).

**Thank you for taking the time to read this. If you agree to take part, please sign and return the attached consent form to the above address.**

Hard Copy

## CONSENT FORM

### Exploring the Sex Disparity in Autism Spectrum Conditions (ASCs)

Naomi Phillips (Researcher)  
Psychology Department  
Oxford Brookes University  
Headington Campus  
Gypsy Lane  
Oxford  
OX3 0BP

**Please initial box**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.
3. I agree to take part in the above study.

**Please tick box**

4. I agree to be interviewed
5. I agree to the interview being audio-recorded
6. I agree to the use of anonymised quotes in publications

**Yes**

**No**

Name of Participant

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of Researcher

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## On Website

### CONSENT FORM - Exploring the Sex Disparity in Autism Spectrum Conditions

Thank you to both males and females for your time, for completing and submitting the questionnaire. Your responses have been recorded.

\* Required

Please now close the browser if you are male, or a female not wanting to undertake the interview. If you are female and would like to be considered for interview, please fill in the following consent form.

#### CONSENT FORM - Interview (Females only)

\*

- I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

\*

- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason

\*

- I agree to take part and to be interviewed for the purpose of this study

\*

- I agree to the interview being audio-recorded

\*

- I agree for the use of anonymised quotes in publications

Name of Participant \*

Today's Date (DD/MM/YY) \*

Email Address \*

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**Appendix 8 – Debriefing Letter**

**PSYCHOLOGY DEPARTMENT**

Headington Campus, Gipsy Lane, Oxford OX3 0BP

Direct Line for Dr John Lawson (supervisor): +44 (0)1865 483787

Email: (of supervisor): [jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk)

Researcher's name: Naomi Phillips

Researcher's email: 11084093@brookes.ac.uk      DATE 17th July 2012

Dear Sir or Madame,

**RE: Research Project – Exploring the Sex Disparity in Autism Spectrum Conditions (ASCs)**

I am writing to thank you for participating in my research project. The research project was conducted to try and gain a better understanding of the characteristics of ASCs.

In particular, the aim was to try and find out whether the gender gap in Autism Spectrum Conditions (males being more likely to have ASCs) is justified or whether it is due to the reliance on diagnosing individuals with possible ASCs using a male focused criteria (i.e. a focus on clinicians using their understanding of how males present with ASCs to diagnose both males and females). This research aimed to identify whether Asperger Syndrome and High Functioning Autism in females causes different characteristics specific to females which may not be included in the current diagnostic criteria resulting in females with potential ASCs not being picked up.

If you have any further questions about the research project or the findings of the project, feel free to contact me via the email address 11084093@brookes.ac.uk. I will not be able to provide any individual results of participants but can provide overall findings of the project. Please be aware that this was an exploratory study and the results require further investigation.

Yours Sincerely

Miss Naomi Phillips  
(Researcher)

DEPARTMENT OF PSYCHOLOGY  
FACULTY OF HEALTH AND LIFE  
SCIENCES

Headington Campus Gipsy Lane  
Oxford OX3 0BP UK  
T +44 (0) 1865 483787  
M +44 (0) 7950 138633

Email: (of supervisor):  
[jlawson@brookes.ac.uk](mailto:jlawson@brookes.ac.uk)  
Email: (of researcher):  
11084093@brookes.ac.uk