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# **Exploring gender identity within the context of Asperger's Syndrome**

By

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

> University of Warwick, Department of Psychology and Coventry University, Faculty of Health & Life Sciences

> > May 2012

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# **Acknowledgements**

Firstly, I wish to thank my research supervisors Dr David Sanders and Dr Gavin

Farrell for their help and support. Thanks also to Dr Helen Rostill, Dr Tom Patterson

and Dr Carolyn Gordon for invaluable guidance and encouragement.

I have been humbled and overwhelmed by the support given to me by the Asperger's community. In particular, my thanks go to Joanne Gumbrell and her team at Aspire West Midlands for their help with participant recruitment. Thanks also to the Coventry Asperger's Support Group who took such an interest in my project; it was a pleasure to meet you all. And finally, to Rod Morris at WASP (With Asperger) Ltd., I am hugely grateful for your professional advice and consultation and I continue to be in awe of the fantastic work you do for and on behalf of people with Asperger's Syndrome and their families.

Sincere thanks to my family and friends who gave me the strength I needed to get through this and the welcome distractions when it all got too much, particularly Kathryn Lloyd-Williams and Victoria Magrath for helping code transcripts and keeping me sane. Eternal thanks to my parents, Alan and Sheila Elliott for their practical support along the way, and for always believing I would achieve this.

And finally, I dedicate this thesis to Antony and Daniel; thank you for your neverending love, patience and kindness, and for sharing the journey. This is for us.

# **Declaration**

This thesis was carried out under the supervision of Dr David Sanders and Dr Gavin Farrell. Other than this, I conducted all stages of the research process myself.

Ethical approval was given by Coventry University (see Appendix three). This thesis has not been submitted towards a degree at any other university. Authorship of any papers published from this work will be shared with Dr David Sanders and Dr Gavin Farrell.

The literature review has been prepared for submission to *Child Development* (see Appendix ten; Author Guidelines). The empirical paper has been prepared for submission to *Self & Identity* (see Appendix eleven; Instructions to Authors).

# **List of abbreviations**

**ANCOVA** Analysis of Covariance

**APA** American Psychiatric Association

**AS** Asperger's Syndrome

ASD Autism Spectrum Disorder

**BFQ** Big Five Questionnaire (Caprara, Barbaranelli, Borgogni & Perugini, 1993)

BSRI Bem Sex Role Inventory (Bem, 1974)

**CBCL** Child Behaviour Checklist (Achenbach, 1991)

**CBT** Cognitive Behaviour Therapy

**CDI** Children's Depression Inventory (Kovacs, 1981)

**CSRI** Children's Sex Role Inventory (Boldizar, 1991)

**DSM** Diagnostic and Statistical Manual of Mental Disorders

**GID** Gender Identity Disorder

**GP** General Practitioner

**HFA** High Functioning Autism

**IPA** Interpretative Phenomenological Analysis

PAS Personal Attributes Scale (Spence, Helmreich & Stapp, 1974)

**PDD** Pervasive Developmental Disorder

**SDQ-1** Self-Description Questionnaire 1 (Marsh, 1988)

**SDQP** Self-Description Questionnaire for Preschoolers (Marsh, 2009)

SIS Sexual Identity Scale (Stern, Barak & Gould, 1987)

**SPPA** Self-Perception Profile for Adolescents (Harter, 1988)

**SPPC** Self-Perception Profile for Children (Harter, 1985)

**UK** United Kingdom

WRAT Wide Range Achievement Test (Wilkinson, 1993)

## Summary

Gender identity is an integral part of who we are and can have a huge impact on our functioning, behaviour, and psychological well-being. For years, researchers and theorists have studied the developmental course of gender identity including why, how, and when it is formed, and how it shapes our neurobiology and psychology.

The first chapter of this thesis reviews existing literature on the relationships between gender identity and psychological well-being across the course of childhood. The review indicates that psychosocial adjustment and self-worth are highest when children feel secure in their gender identity, yet able to explore gender atypical options. Feelings of gender atypicality or dysphoria are associated with poorer psychological outcomes and vulnerability to mental ill health, particularly depression. The review highlights various methodological limitations within the literature and suggests improvements such as using more socially diverse samples.

Chapter two presents an empirical study exploring gender and identity in adult men with Asperger's Syndrome capturing their perceptions of masculinity, gender-typed behaviours, relationships, and societal influences. Interpretative Phenomenological Analysis of the data suggests that for participants, identifying with male gender provides a platform for fitting in by allowing them to learn from societal stereotypes and rehearse playing 'male' roles. Participants displayed ambivalence in their feelings of being drawn to the perceived safety of females but resenting the 'feminine' side of themselves. Recommendations are made for psychoeducation for

professionals and parents of children with Asperger's syndrome around potential gender identity confusion.

The third chapter presents a reflective review of the author's experience of conducting the research. The paper provides a personal insight into issues pertaining to methodological processes, relationships with participants and associated emotions.

# **CHAPTER ONE**

The relationship between gender identity and psychological well-being in children and adolescents: A review of the literature.

Word count: 6350 (excluding table, references, and footnotes)

## 1.1. Abstract

Gender identity is complex and multi-dimensional, yet integral to one's sense of self. Previous research suggests that having a strong sense of gender identity aligned to one's biological sex promotes well-being. Various studies have linked gender dysphoria to poor social and psychological outcomes. For individuals diagnosed with Gender Identity Disorder (GID), some degree of psychological distress is often implied. However few studies have explored the relationship between gender identity and psychological well-being within a non-clinical population.

The present paper systematically reviews the literature on gender identity and psychological well-being in children and adolescents. Psychosocial adjustment and self-worth are highest when children feel secure in their gender identity, yet able to explore gender atypical options. Feelings of gender atypicality or dysphoria are associated with poorer psychological outcomes and vulnerability to mental ill health, particularly depression. Evidence from the present review suggests cultural variation in the extent to which gender identity issues affect young people's psychological well-being, possibly due to differences in societal pressure to comply with particular gender-roles. Despite a growing body of literature linking gender identity to psychological functioning in children and young people, measures used in the studies reviewed here were of variable quality and appropriateness. Findings from the present review indicate that further research using longitudinal designs is needed to better understand the aetiology and prognosis of psychological difficulties in young people who report gender identity issues.

## 1.2. Introduction

#### 1.2.1. Terminology

The term 'gender identity' was coined in the 1960's by Hooker and Stoller, who defined it as "a young child's developing a fundamental sense of belonging to one sex, and not the other" (Hooker & Stoller as quoted in Zucker, 2002). Some debate continues as to the age of acquisition of gender identity in infants although prominent authors in the field suggest that the process may begin at approximately age 2½ years (Stoller, 1968) and is consolidated by age 3 or 4 (Bradley & Zucker, 1997).

Other frequently associated terms include 'gender role', which is used to "...signify all those things that a person says or does to disclose himself or herself as having the status of boy or man, girl or woman, respectively" (Money, 1955, pp. 254). The term 'gender role behaviour' refers to the behaviour of an individual which is consistent with local cultural definitions of masculinity and femininity. Gender role behaviours are felt to emerge in children following the development of correct self-labelling as either male or female (Fagot, Leinbach & Hagan, 1986), with an increase in gender-typical activities seen at age 4 or 5 and continuing throughout the remainder of childhood (Serbin, Powlishta & Gulko, 1993).

The term 'self-concept' typically refers to the perceptions individuals hold regarding themselves (Harter, 1990) as a broad psychological construct which includes self-esteem and the evaluation of one's positive or negative attributions to onself.

According to multidimensional models that are favoured amongst contemporary researchers<sup>1</sup>, self-concept is viewed as a construct along various domains that may only be partially related, thus allowing one to hold a self-concept in several areas. Several studies have shown gender-based differences in self-concept dimensions, such as boys evidencing higher levels of self-concept in mathematics and athletics, and girls evidencing higher levels in verbal academic subjects (such as English) and friendships (Wilgenbusch & Merrell, 1999). To hold high self-concept in a particular domain indicates a feeling within oneself of being relatively high functioning or superior in that area, whether or not this is reflected in reality, e.g. a child who expresses high levels of self-concept in athletics may hold the belief 'I am a fast runner'.

# 1.2.2. Overview of theory

Theories of gender identity development tend to fit broadly within three themes; biological and hormonal theories of gender, environmental theories, and social constructionist theories. These are categorised by Liben & Bigler (2002) as gender essentialism, gender environmentalism, and gender constructivism, respectively.

Biological or gender essentialist theories focus on the role of sex-linked genes, prenatal hormones (e.g. Swaab, 2007), evolutionary psychology (e.g. Geary, 2002), and neuropsychology (e.g. Swaab & Garcia-Falgueras, 2008) in the development of gender. The most prominent medical model of western society is the dichotomous biological differentiation between male and female in infants. Infants born with

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<sup>&</sup>lt;sup>1</sup> See Wilgenbusch & Merrell (1999) for a comprehensive meta-analysis of studies of self-concept in children and adolescents.

intersex conditions such as congenital adrenal hyperplasia undergo immediate surgery to correct this 'defect' (Zucker, 2002). In cases where an individual's gender identity deviates from their biologically determined sex, these individuals are labelled 'disordered'<sup>2</sup>. However, despite a strong leaning towards medical science, many of the more recent essentialist theories acknowledge the role of environment in influencing gender identity (Liben & Bigler, 2002).

A large number of theories fall under the umbrella of what Liben & Bigler (2002) term gender environmentalism, emphasising the role of society in a child's gender identity development. In particular, social learning theorists argue that children learn gender role behaviours primarily through observational learning (Bandura, 1977) and that this is influenced by the different ways in which parents and teachers treat individuals of either gender (Fagot & Hagan, 1991; Leaper, 2000). Environmentalist theories also give consideration to the role of language in society and the way in which gender is emphasised linguistically in relation to children's gender identity development (e.g., see Bigler, 1995; Liben, Bigler & Krogh, 2002). To some extent, cultural stereotypes relating to gender roles also come under the category of gender environmentalism. Hill and Lynch's Gender Intensification Hypothesis (1983) posits that adolescents face increased pressure to conform to culturally sanctioned gender roles causing more gender differences to be apparent at this age, which ultimately affects perceived gender identity.

<sup>&</sup>lt;sup>2</sup> DSM-IV classifies Gender Identity Disorder (GID; APA, 2000) as 'evidence of a strong and persistent cross-gender identification which is the desire to be, or the insistence that one is, of the other sex'.

The constructivist family of theories views children as active agents who develop the schemata that underlie their gender beliefs and behaviours, and then apply these schemata for further processing (Liben & Bigler, 2002). One of the earliest constructivist theories of sex-role development is that of Kohlberg (1966), who proposes a cognitive maturational stage model of gender development in children reminiscent of the work of Piaget<sup>3</sup>. The first stage of Kohlberg's model is the *gender* identity stage at age 2, where a child is able to correctly label their own biological sex. By age 4 the child is said to reach the gender stability stage where she realises that her gender remains the same over time. The gender constancy stage, reached by age 7, allows the child to understand gender as being independent from external features, for example that a boy wearing a dress is still a boy. Later theories, whilst based largely on Kohlberg's work, tended to focus more on the role of the environment in shaping a child's gender cognitions and schemata, and can therefore be described as leaning towards social constructivism (e.g., see Bem, 1981; Bussey & Bandura, 1999; Martin & Halverson, 1981). More recent 'social cognitive' theories proposed by Bussey (2011) and Khajehpour, Ghazvini, Memari & Rahmani (2011) posit that self-conceptions of gender and gender role are constructed through a combination of personal and sociostructural factors within a variety of societal subsystems.

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<sup>&</sup>lt;sup>3</sup> Swiss developmental psychologist and philosopher Jean Piaget (1896-1980) proposed four developmental stages in a child's cognitive development. For a detailed account of Piaget's stage model see Santrock (2008).

# 1.2.3 Gender Identity and Psychological Well-Being

Prominent theorists have largely debated the notion that if gender identity is central to our understanding of ourselves, then it is likely that we might spend time reflecting on what our gender means to us and how we fit in with other people of the same or different gender. For example, Egan & Perry (2001) argue that these reflections on our gender identity begin during childhood and ultimately affect psychosocial adjustment. In line with environmentalist theories of gender identity, gender roles have been linked to emotions within the context of societal expectations in that distress and sadness are stereotypically associated with femininity (e.g. Wupperman & Nuemann, 2006) and the expression of anger is stereotypically associated with masculinity (e.g. Kopper, 1993).

A relationship between gender identity and psychological well-being has been widely speculated about for years, with some theorists explaining gender dysphoria or non-conformity biologically, as resulting from anomalous levels of prenatal hormones (e.g. Green & Young, 2001), anatomic brain differences in the central subdivision of the nucleus of the stria terminalis (Zhou, Hofman, Gooren & Swaab, 1995), or genetic heritability (see Meyer-Bahlburg, 2010 for a review). Alternatively, gender identity issues can be understood from a socialization perspective in terms of environmental instabilities in childhood leading to anxiety and difficulties in the attachment relationship (Zucker and Bradley, 2004).

Several empirical studies note the co-occurrence of gender identity issues such as gender dysphoria and diagnosed mental illness (Mizock & Fleming, 2011; LaTorre,

1976), although research tends to suggests that the relationship is not always causal and gender identity issues can exist distinct from mental ill health in many cases. The diagnosis of Gender Identity Disorder (GID) remains controversial and has been criticised by many as contributing to gender stereotypes and undermining the complexity of gender identity and emotional suffering (Lev, 2005). According to Zucker (2010), although "it remains unclear how distress is to be inferred independently of the clinical indicators" (p.489) in DSM-IV diagnostic criteria for GID, "the constructs of distress and impairment require a great deal of further investigation." (p.490).

Several lines of evidence suggest that there are empirical reasons to posit a link between sex-typed behaviour in early childhood and later gender identity and sexual orientation (Drummond, Bradley, Peterson-Badali & Zucker, 2008). Since most of the academic literature emphasises the salience of childhood in the development of core gender identity, and given current rates of diagnosis of GID in children and young people as young as 3 years of age (Cohen-Kettenis, Owen, Kaijser, Bradley & Zucker, 2003), it seems important to investigate the complex relationship between gender identity and psychological well-being in this population further.

#### 1.2.4. Rationale for the current review

There are no existing literature review papers in publication which critically appraise empirical studies of the relationship between gender identity development and psychological well-being in children and adolescents specifically.

This is a topic which carries significant implications for our understanding of how children perceive themselves in relation to their gender and how this affects other areas of their functioning and mental health. The present review will critically evaluate research in this field and draw conclusions, taking account of existing theories of gender identity as well as considering implications for clinical practice. The review focuses on normally developing populations and excludes literature relating to children who have received a psychiatric diagnosis of Gender Identity Disorder. There is a wealth of existing literature examining functioning in children who present clinically with psychological distress relating to gender (e.g. see Drummond et al., 2008; Shechner, 2010; Zucker & Bradley, 2012) and comparing psychiatric and psychological treatment outcomes for this population (e.g. see Leibowitz & Spack, 2011; Zucker & Cohen-Kettenis, 2008) and so these papers are not included in the current review. Rather, the aim of the present paper is to critically appraise the empirical evidence on the complex relationships between gender identity and psychological well-being during the course of childhood and adolescence.

## 1.2.5. Search strategy and inclusion criteria

Literature searching was carried out between September 2011 and August 2012. The databases PsycINFO, PsychArticles, Sociological Abstracts, and ASSIA on the ProQuest platform were used to search for relevant articles from peer-reviewed journals. Search terms included 'gender identity' AND 'mental health' OR 'wellbeing' AND 'child' OR 'young or youth'. Further citation searches were carried out using Web of Science.

Studies were considered for inclusion if they provided qualitative or quantitative data on the relationship between gender identity and psychological well-being and had been published as full papers in peer-reviewed journals. In line with previous recommendations on conducting systematic reviews, studies were excluded if they had only been published as abstracts or conference proceedings (e.g., Knipschild, 1995; Lloyd Jones, 2004). Articles were considered for inclusion if they were post 2000 and involving primary research with children under the age of 18, or with their parents or teachers.

Abstracts were read to determine relevance to the topic. Use of this criteria resulted in 15 empirical studies being included in this review (see appendix one; *Outline of literature search strategy*). Following examination of these papers, three main themes within the empirical literature on gender identity and psychological wellbeing were identified: gender identity and adjustment; gender identity and psychopathology; and gender identity and socio-environmental contexts.

Therefore, the papers reviewed will therefore be discussed in line with these themes.

# 1.3. Table of Studies

Study	Participants	Method	Findings
Priess, Lindberg & Hyde, 2009	410 adolescents in USA	The Children's Sex Role Inventory (CSRI), Children's Depression Inventory (CDI), Adolescent Perceived Events Scale.	Positive trajectories in masculinity for both girls and boys predicted fewer depressive symptoms.
Yunger, Carver & Perry, 2004	106 children aged 8-14 in USA	Self-Concept Questionnaire, Peer Nomination Inventory (PNI), Sociometric assessment	Gender identity is multidimensional. Low gender typicality and high felt pressure can lead to internalizing problems.
Smith & Leaper, 2005	229 adolescents in California	Self Perception Profile, Multidimensional Gender Identity Inventory	Found positive relation between feelings of gender typicality and self-worth, mediated by perceived peer group acceptance.
Egan & Perry, 2001	182 children aged 9-14	92-item self-report questionnaire; sociometric assessment.	Gender identity is multi-dimensional and relates to psychosocial adjustment. Felt pressure for gender conformity is especially harmful.
Menon, 2011	357 secondary school children in UK	Self-report questionnaires	Children who perceive themselves as using gender-atypical friendship styles feel less gender compatible, accounting for negative evaluations of self and feelings of sadness.
Rieger & Savin-Williams, 2012	245 high school students in USA	Surveys	Both childhood and adolescent gender nonconformity were negatively related to well-being. Gender-atypical traits may be more relevant for psychological health than same-sex sexual orientation.
Bos, Sandfort, de Bruyn & Hakvoort, 2008	866 Dutch high school students aged 13-15	Computer based questionnaires about same sex attraction	Participants who experienced feelings of same sex attraction had higher levels of depression, lower self-esteem and poorer academic performance.

Study	Participants	Method	Findings
Cooper, Guthrie, Brown & Metzger, 2011	103 African American Adolescents in USA, mean age 15	Daily Hassles Questionnaire; Children's Sex Role Inventory; depression and anxiety measures	Masculine gender roles associated with reduced psychological functioning in response to daily hassles. Female gender roles associated with fewer depressive/anxious symptoms
Corby, Hodges & Perry, 2007	863 5 <sup>th</sup> Grade pupils in USA, mean age 11	Self-Concept Questionnaire and Peer Nomination Inventory	Implications of gender identity for adjustment depend on ethnicity and racial group.
Cox, Mezulis & Hyde, 2010	316 youths aged 11-15 and their mothers	Mother-child observation; Children's Sex Role Inventory, Ruminative Response Scale, Children's Depression Inventory, Attitudes Towards Sex Roles Scale	Feminine gender role identity and encouragement of emotion expression by mothers significantly mediated the association between child sex and the development of depressive rumination
Grossman & D'Augelli, 2006	24 transgender adolescents, mean age 16	Focus groups	Themes related to low self-esteem, feelings of shame and unworthiness. High risk of self-harm and social isolation/rejection.
Renaud, Berlim, Begolli, McGirr & Turecki, 2010	55 child suicide victims	Semi-structured proxy-based interviews and questionnaires	Victims with same-sex orientation were more likely to meet criteria for anxiety disorders. No effect of gender identity was found.
Simonson, Mezulis & Davis, 2011	136 adolescents	Personal Attributes Questionnaire, Perseverative Attention to Negative Events Scale	Female gender role is a predictor of rumination

Study	Participants	Method	Findings
Yu & Xie, 2010	201 boys and 160 girls aged 9 to 12 in China	Self-report Gender Identity measure, Children's Loneliness Scale, Self-Perception Profile for Children	Higher gender typicality was related to greater global self-worth, greater social competence, and lower sense of loneliness. Neither felt pressure nor gender contentment predicted psychological adjustment.
Simonelli, Rossi, Tripodi, DeStasio & Petruccelli, 2007	246 Children from schools in Italy, their teachers and parents. Range: 9-13	Gender Identity Interview for Children, Big Five Questionnaire (BFQ), Child Behaviour Checklist/4-18 (CBCL)	40% of children did not recognize any positive elements to their gender. Girls showed personality traits associated with gender non-conformity.

Table 1. Table of papers included in literature review

#### 1.4. Literature Review

## 1.4.1. Gender Identity and Adjustment

Several studies use questionnaire-based methods to investigate the relationship between gender identity and psychological adjustment. Egan and Perry (2001) assessed 182 North American children aged between 9 and 14 using their own 92-item self-report gender identity scale which measured global self-worth, self-perceived peer social competence, gender compatibility, felt pressure, intergroup bias, male-typed activities, female-typed activities, agentic<sup>4</sup> traits (e.g. "taking charge"), communal traits (e.g. "showing concern for others"), and heterosexual identity. Participants also completed a sociometric assessment measuring how much they liked each of their participating classmates. Correlations of the data support Egan and Perry's hypothesis that gender identity is multidimensional and that by middle childhood children have developed fairly stable conceptions of the degree to which they typify their gender category, their contentedness with their gender assignment, the option to explore cross-gender options, and whether their own sex is superior to the other.

Further, all of these dimensions of gender identity were found to relate to psychosocial adjustment. Egan and Perry posit that children's adjustment is optimized when they are secure in their conceptions of themselves as typical members of their sex, yet feel free to explore cross-sex options should they desire

<sup>&</sup>lt;sup>4</sup> See Bandura (2001); Social Cognitive Theory describes agency as intentionally making things happen by one's actions. Agentic action in exploring, manipulating and influencing the social environment plays a part in shaping the structure and function of the child's developing brain. Agency involves not only the deliberative ability to make choices and action plans, but the ability to shape appropriate courses of action and to motivate and regulate their execution.

(rather than to solely gender-stereotyped activities). Gender contentedness was unrelated to self-esteem for children who scored/reported low felt pressure to conform, but was strongly predictive of self-esteem for children with high felt pressure.

Another finding of this study was that negative effects of felt pressure on adjustment were more evident for girls than for boys. The authors suggest this may be due to girls' tendency to take to heart the social evaluative feedback of others and/or the greater prestige attributed by society to male-typed traits and occupations. However, these hypotheses are not discussed in the context of the data collected by the authors and undoubtedly require further enquiry.

In a similar study, Yunger et al. (2004) studied 106 North American children aged 8 to 14 years over a period of two years using the Peer Nomination Inventory<sup>5</sup> to measure adjustment and Egan and Perry's (2001) Self-Concept Questionnaire to assess gender identity and self-esteem. The findings support Egan and Perry's suggestion that gender identity is a multidimensional concept and that feeling gender typical and content with one's gender are generally positive influences on children's well-being, whereas feeling pressure to conform to gender stereotypes generally is a negative influence. However, Yunger et al. do not take into account social and cultural contexts which may mediate the impact of gender identity on adjustment, for example comparisons could have been made between different ethnic groups.

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<sup>&</sup>lt;sup>5</sup> Modified from Wiggins and Winder (1961); Cronbach's alphas 0.92-0.97.

In another adolescent study, Smith & Leaper (2005) conducted a questionnaire-based study, in which 229 girls and boys aged between 12 and 17 completed Harter's (1988) Self-Perception Profile and Egan and Perry's (2001)

Multidimensional Gender Identity Inventory whilst attending summer sports camps in California, USA. In line with previous studies, a positive relationship was found between feelings of gender typicality and feelings of self-worth in both boys and girls. However, this effect was found to be partially mediated by perceived peergroup acceptance, suggesting that gender typicality alone does not account for positive self-worth. Indeed, they suggest that peer acceptance is likely to be more fundamental to adolescent's self-worth than gender conformity, although they do not explore this concept in more detail.

Menon (2011) also studied the effect of self-perceived gender non-conformity on psychosocial adjustment, testing the hypothesis that gender-atypical friendships styles are distressing because they undermine felt gender compatibility. Four indices of adjustment—self-esteem, peer social competence, depression, and narcissism—were assessed in 357 English children aged 11 to 13 from the same secondary school. Questionnaires were completed assessing friendship styles<sup>6</sup>, gender compatibility<sup>7</sup>, and adjustment. Adjustment measures consisted of four self-report measures of self-esteem and peer social competence<sup>8</sup>, depression<sup>9</sup> and

<sup>&</sup>lt;sup>6</sup> Derived from Hodges, Finnegan & Perry (1999); Cronbach's alphas ranging from 0.79-0.86.

<sup>&</sup>lt;sup>7</sup> Using Corby, Hodges & Perry's (2007) adaptation of Egan and Perry's (2001) original scale; Cronbach's alpha = 0.81.

<sup>&</sup>lt;sup>8</sup> Harter's (1985) six-item global self-worth scale; Cronbach's alpha = 0.86.

<sup>&</sup>lt;sup>9</sup> Kovacs' (1981) 10-item short depression inventory; Cronbach's alpha = 0.79

narcissism<sup>10</sup>. Correlational analyses and linear regressions provided strong evidence to indicate that children who perceive themselves as using gender-atypical friendship styles feel less gender compatible which, the findings suggest, accounts for negative evaluations of the self and feelings of sadness. No gender-atypical friendship styles were related to narcissism, suggesting that self-perceived gender non-conformity is associated with negative self-evaluations rather than a grandiose or over-inflated sense of self. However, this study was designed to test a specific hypothesis relating to four domains of psychosocial adjustment and a limitation is that it therefore does not consider other correlates of adjustment that might account for the results.

Priess et al. (2009) studied the effect of cultural pressure for gender conformity on adolescents' psychosocial adjustment, particularly in relation to depression. Using a sample of participants already undertaking the Wisconsin Maternity Leave and Health Project, 410 adolescents aged 11 to 15 years completed questionnaires on gender-role identity<sup>11</sup>, depressive symptoms<sup>12</sup>, and negative life events. The 59-item Adolescent Perceived Events Scale (Compas, Davis, Forsythe & Wagner, 1987) was used to assess significant life events experienced in the previous year. The authors examined whether gender-role identities become more stereotypical across adolescence depending on family and cultural factors such as sibling composition, socioeconomic status etc., and in turn how this gender-role intensification relates to mood.

<sup>&</sup>lt;sup>10</sup> Using a 17-item scale adapted from Barry, Frick & Killian (2003); Cronbach's alpha = 0.72.

<sup>&</sup>lt;sup>11</sup> A 15-item version of the Children's Sex Role Inventory (CSRI; Boldizar, 1991); Cronbach's alphas 0.75-0.84.

<sup>&</sup>lt;sup>12</sup> Short 10-item form of the Children's Depression Inventory (CDI), abbreviated from Kovacs (1981).

Priess et al. found a reduction in gender differences in masculinity over the course of adolescence which mirrors the findings of previous studies in this area (e.g., see Wichstrøm, 1999). They explain this finding in terms of it being more socially acceptable for girls to take on more masculine traits such as competitiveness, self-confidence and participation in sports. Alternatively, they suggest that boys may lag behind in more feminine domains such as interpersonal relationships and that they 'catch up' some of these feminine traits post adolescence. Perhaps most strikingly, this study could not provide evidence to support Hill and Lynch's (1983) Gender Intensification Hypothesis and instead concludes that adolescents do not necessarily perceive themselves as more gendered as they get older.

However, it is important to note the twenty-five year time difference between Hill and Lynch's original paper and Priess et al study. Social and cultural stereotypes relating to gender have undoubtedly shifted during this time and it is therefore possible that the adolescents studied by Priess et al. may not feel the same pressure to conform to gender roles. Further, although their study found more masculinity reported in both girls and boys who had an older brother, they found no effect of other external factors such as parental educational level and family income, suggesting that further exploration of environmental factors is necessary.

Their findings link masculinity to lower rates of depressive symptoms, particularly among adolescents who had experienced moderate stress in the previous year.

However, this finding is not explained by gender-role identity given that masculinity

was present in both boys and girls. The study therefore fails to offer an explanation for the commonly held view that femininity is associated with depression<sup>13</sup>. Given that the presence of masculine traits in females has become more socially acceptable in the years since the Hill and Lynch conducted their research, the Priess et al. study highlights potential flaws in using older and possibly outdated psychometric measures of these concepts.

Simonelli et al. (2006) examined cognitive and affective aspects of gender identity in 246 Italian preadolescents aged 9-13 years. As well as gender identity measures, the Big Five Questionnaire (BFQ; Caprara, Barbaranelli, Borgogni & Perugini, 1993) was administered alongside the Child Behaviour Checklist/4-18 (CBCL; Achenbach, 1991). The majority of children were satisfied with the sex to which they belonged, although 40% did not recognise any positive elements to their gender. Subjects with a sex-atypical profile exhibited high emotional instability and low conscientiousness, although implications for psychological well-being are not discussed in relation to particular personality traits and therefore warrant further investigation.

Rieger and Savin-Williams (2012) included sexual orientation as a variable in their study of gender nonconformity and well-being. 475 American high school 'seniors' aged 16-18 from a rural town in the state of New York completed questionnaires on sexual orientation as well as well as an abbreviated version of the Childhood Gender Identity/Gender Role Questionnaire (Zucker, Mitchell, Bradley, Tkachuk,

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<sup>&</sup>lt;sup>13</sup> See Essau, Lewinsohn, Seeley & Sasagawa (2010), Harris (2007) and Hyde, Mezulis & Abramson (2008) for further review of the association between femininity and depression.

Cantor & Allin, 2006) and the Gender Diagnosticity Measure (Lippa, 2005a,b) in addition to two psychological well-being measures<sup>14</sup>. Results suggested that both childhood and adolescent gender nonconformity were more directly linked to well-being than was sexual orientation, for both boys and girls. Rieger & Savin-Williams conclude that although not all homosexual and bisexual individuals are gender nonconforming, those who are may experience poorer psychological well-being. However, similar results were found for heterosexuals who were gender nonconforming. The authors suggest that it is the social reactions to gender nonconformity that compromise psychological well-being, particularly for homosexual boys who are treated negatively by their peers. This indicates that, within a minority-stress model, it is important to pay particular attention to the long-term effects of discrimination and social rejection in childhood.

#### Summary

The literature on gender and psychosocial adjustment suggests that children who hold conceptions of themselves as typical members of their biological sex are more secure, have more self-worth, and better emotional stability. Children who feel pressure to conform to gender stereotypes exhibit more negative evaluations of themselves and tend to have lower self-esteem. These emotional effects are more prominent in girls than they are in boys. However, other factors may also influence self-worth and emotional stability, such as peer-group acceptance. Gender differences in perceived masculinity reduce during adolescence and teenage children appear to feel less pressure to conform to gender stereotypes as they get

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<sup>&</sup>lt;sup>14</sup> Satisfaction with Life Scale (Pavot & Diener, 1993), Cronbach's Alpha = 0.83; Psychological Well-Being Scale (Ryff & Keyes, 1995).

older. These findings are likely to be influenced by social factors such as acceptability of cross-gender behaviours and the more relaxed gender stereotype boundaries of our modern society. Although the reviewed studies measured multiple dimensions of gender identity and adjustment, self-report questionnaires are always susceptible to response biases and other non-gender-related extenuating factors such as mood effects. Further, the correlational design of studies does not allow cause-and effect predictions and thus it remains unclear whether poor psychosocial adjustment may have preceded perceived gender non-conformity rather than vice versa in some cases.

## 1.4.2 Gender Identity and psychopathology

Several studies directly measured presence of psychological symptoms in relation to gender identity in young people. Bos et al. (2008) investigated psychosocial functioning and mental health in 866 Dutch children aged 13-15 in relation to same sex or opposite sex attraction. Participants completed computer-based questionnaires relating to sexual attraction, relationships with peers and parents, and mental health 15. Adolescents with same sex attraction were found to experience more mental health problems than those without, including higher incidences of depression and lower self-esteem, as well as more difficulties at school. The authors suggest that higher levels of gender atypicality among adolescents with same sex attraction might lead to loss of protection by both peer and family groups, leading to poorer adjustment. However, Bos et al. did not

<sup>&</sup>lt;sup>15</sup> Measures included General Health Questionnaire (GHQ; Goldberg, 1972), Cronbach's alpha = 0.86; Rosenberg Self-Esteem Scale (Rosenberg, 1979), Cronbach's alpha = 0.76

directly measure gender atypicality or nonconformity as a separate construct to sexual attraction, thus making findings difficult to generalise.

Cox et al. (2010) explored whether depressive rumination could be predicted by gender role identification. Over 300 American youths aged 11 to 15 years and their mothers were studied in a longitudinal large-scale project combining observations of parent-child interactions, measures of depressive rumination <sup>16</sup>, symptoms of depression<sup>17</sup> and gender role identity<sup>18</sup>. An emergent gender difference in depressive rumination was found, with adolescent girls reporting significantly more rumination than boys by age 15. Further, girls with a more feminine gender role identity were more likely than girls with a less feminine gender role identity to become more ruminative in the transition to mid-adolescence. The findings also suggested that parents play a role in the sex difference in depressive rumination, with mothers of girls being more likely to encourage emotional expression and to make emotion-focused attributions. These findings suggest that gender is central to the socialization of emotion, however the authors do not explore the relationship between depressive rumination and diagnosable depression. Rather, the study suggests that greater vulnerability to depression is associated with female gender identity and female family relationships.

<sup>&</sup>lt;sup>16</sup> A short form of the Ruminative Response Scale of the Response Style Questionnaire (Nolen-Hoeksema & Morrow, 1991)

<sup>&</sup>lt;sup>17</sup> Children's Depression Inventory (CDI; Kovacs, 1985)

<sup>&</sup>lt;sup>18</sup> Child Sex Role Inventory (Boldizar, 1991)

In a similar study, Simonson et al. (2011) used questionnaires<sup>19</sup> to investigate the relationship between gender identity and depressive rumination in older adolescents (aged 16-19) who were followed over an eight-week period. They found that femininity partially accounted for sex differences in interpersonal and event-related rumination but not rumination about achievements. Simonson et al. attribute these findings to the emphasis on emotion-focus and interpersonal orientation in the feminine gender role. They conclude that adolescent girls are more likely to ruminate than boys and that the link between femininity and depression could account for higher rates of diagnosis of depression in females. As with other studies of this nature, Simonson et al also note the prevalence of masculine traits in females within the context of changing societal norms, which may explain some of the variation in their results. Unlike other papers reviewed here, Simonson et al. refer frequently in their discussion to some of the presumed positive psychological attributes related to feminine gender role identity as protective factors for mental health (e.g. emotion expression, positive relationships, social functioning). Further research would benefit from measuring both positive and negative mental health traits in relation to gender identity within the same population to allow for conclusions to be drawn regarding overall functioning.

Grossman and D'Augelli (2006) conducted three focus groups to explore mental health in adolescents aged over 16 from the New York State metropolitan area who identified themselves as transgender. Each focus group contained 8 participants

<sup>&</sup>lt;sup>19</sup> Personal Attributes Questionnaire (PAQ; Spence, Helmreich & Stapp, 1973), Cronbach alphas ranging from 0.71-0.77; Perseverative Attention to Negative Events Scale (PANE; Mezulis, Abramson & Hyde, 2002), Cronbach alphas ranging from 0.89-0.92.

with a mean age of 16.5 years. On average, participants in this sample felt that they were aware that their gender identity did not correspond to their biological sex as early as age six and reported experiencing negative reactions and even physical abuse from family, peers and communities in response to their gender atypical behaviour. Further, participants felt that the threat of discrimination and abuse provoked anxiety and caused them to be fearful for their lives. Disclosure of their gender identity had had a significant impact on participants' self-esteem and led to increased risk of self-harm or suicide, particularly for those coming from religious backgrounds. Feelings of shame and unworthiness were prominent, and some participants reported experiencing trauma symptoms relating to circumstances around their disclosure, for example being thrown out of their family home. Indeed, many of the mental health issues raised by participants related to social isolation and rejection.

The authors argue that health and social care providers have a significant role to play in reducing discrimination and stigma around atypical gender identity, as well as in developing resources and services to support these young people socially and emotionally. Finally, and perhaps more controversially, the authors argue that young people with atypical gender identity should be educated about society's gender constructs and how these "contribute to their vulnerability and devalue their health status" (Grossman & D'Augelli, 2006, pp. 126). Grossman & D'Augelli do not, however, suggest any mechanisms to facilitate this proposed development, or indicate how positive outcomes for mental health might be achieved. Although qualitative data of the type collected by Grossman & D'Augelli is undoubtedly

invaluable in terms of understanding the lived experience of atypical gender identity, a more thorough analysis may have allowed inferences to be made regarding the meaning of these experiences for participants and their well-being.

Renaud et al. (2010) explored sexuality and gender identity in 55 youth suicide victims aged 11-18 through the use of proxy-based interviews and questionnaires<sup>20</sup>. Compared with controls, there was greater prevalence of anxiety disorders among youth suicide victims of same-sex sexual orientation. Adolescents with same-sex sexual orientation were significantly more likely to have consulted mental health services than their heterosexual counterparts, although the exact reasons they sought help remain unknown. Although Renaud et al.'s data shows a link between sexual orientation and anxiety in suicide victims, this relationship cannot be proved to be causal and has not been tested directly. Collecting data by proxy is open to questionable reliability and validity and requires interpretation with caution.

Notably, although the study found increased levels of anxiety among those with same sex sexual orientation, gender identity issues were no more prevalent in the suicide population as they were in controls. The level and type of anxiety experienced in relation to gender identity therefore requires further investigation.

# <u>Summary</u>

The literature on gender identity and psychopathology makes various links between a young person's gender role identification and presence of negative psychological symptoms. Findings suggest that there may be higher rates of depression, anxiety

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<sup>&</sup>lt;sup>20</sup> Based on Shaffer, Fisher & Hicks (1995)

and low self-esteem in young people who are gender nonconforming, i.e. those who identify with a gender that is not their biological sex. More than one study found a link between feminine gender role identity and depressive rumination, which authors suggest may lead to a vulnerability to depression in young girls who identify more strongly with feminine traits. Focus group participants described moderate to severe psychological symptoms relating to their gender identity, particularly as a consequence of maltreatment within their families and society. Despite a growing number of papers identifying an association between certain gender identity variables and psychopathology, determining a definitive link between gender identity issues and susceptibility to symptoms of mental ill health, would require that data be collected on a much larger scale and compared to a normal population in order to account for extraneous variables and other social, biological and environmental factors.

#### 1.4.3 Socio-environmental contexts

Various studies are beginning to emerge which focus on the relationship between gender identity and well-being within the context of wider social, cultural and environmental factors. In particular, there is a growing body of literature on the role of ethnicity and culture within gender identity. Cooper et al. (2011) studied depressive symptoms in 103 U.S. African American females (mean age=15) in relation to their gender role orientation<sup>21</sup>. Greater androgyny and higher femininity

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<sup>&</sup>lt;sup>21</sup> Measured using Children's Sex Role Inventory-Short Version (CSRI-S; Boldizar, 1991), Cronbach alphas ranging from 0.72-0.85.

were both found to be associated with fewer anxiety symptoms <sup>22</sup>, which suggest that feminine-typed personality traits such as emotional expressivity may encourage optimal mental health. In contrast, findings showed that girls with a more masculine gender role orientation experienced more anxiety and more depressive symptoms when faced with daily stressors. The authors suggest that masculine-typed traits such as emotional restriction may lead to reduced psychological functioning when present in females. Cooper et al. go on to suggest that African-American girls display more masculine-typed traits than their European counterparts, though as their study did not include European participants, future research to investigate the suggested difference between these two populations is indicated.

Following on from Egan & Perry's (2001) paper, Yu and Xie (2010) explored the relationship between gender identity and adjustment in 361 Chinese children aged 9-12. Measures included Egan & Perry's (2001) self-report measure of gender identity, the Self-Perception Profile for Children (Harter, 1985), and the Children's Loneliness Scale (Asher, Hymel & Renshaw, 1984)<sup>23</sup>. In comparison with similar studies within American culture, Yu & Xie's findings suggest both cross-cultural similarities and differences with respect to gender identity and its relationship to psychological well-being. Findings suggest that multidimensional models of gender identity can be generalized to Chinese populations. Males felt more pressure to conform to gender roles, which they felt was reflected in Chinese culture's "strict"

<sup>&</sup>lt;sup>22</sup> As measured using the State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983)

<sup>&</sup>lt;sup>23</sup> 24-item loneliness and social inadequacy scale using 5-point Likert measure. Cronbach's alpha = 0.90.

socialization" (pp.110) of boys to gender stereotypes. Girls' pressure to conform decreased with age, which is consistent with Western findings and relates to cultural norms shifting more for females to allow more masculine-typed traits. Masculinity was more positively related to acceptance of others, which is the converse of Western findings.

Gender typicality was positively and significantly related to psychological adjustment, which suggests that this finding is consistent across cultures.

Interestingly, Yu & Xie found the relationship between these variables for Chinese girls to be stronger than for girls of other cultures, suggesting that seeing oneself as gender typical holds significant importance for a child's well-being within Chinese culture. No significant relationship was found between gender contentedness and self-esteem, which Yu & Xie suggest is due to cultural variation in the value of self-worth. Neither was gender conformity found to be directly related to adjustment, which Yu & Xie explain in terms of conformity and obedience of social rules being central to a child's upbringing in China and therefore almost accepted without question. However, future research would benefit from exploring possible psychological distress resulting from gender nonconformity in cultures where societal expectations and obligations are more strictly embedded from birth.

Corby, Hodges & Perry (2007) also explored the applicability of Egan and Perry's (2001) multidimensional model within different cultural contexts. They

administered questionnaires<sup>24</sup> to 863 White, Black and Hispanic children in the same school grade in Southeast Florida (5<sup>th</sup> grade, mean age=11). Previous findings relating gender identity to psychosocial adjustment were replicated for White children but results were not significant for Black children. For Hispanic girls, gender contentedness was associated with *more* internalizing problems. In this study, Black and Hispanic children reported more felt pressure to conform to gender stereotypes than their White counterparts. However, Corby et al. warn against naïve interpretation of these findings within broader cultural contexts as no cultural variables were empirically measured, and children are likely to differ in the messages they receive about gender even within specific subcultures. The authors argue that the lack of association between gender identity and adjustment in Black children may not be a reflection of the value of gender within that population, but rather that there may be other influential dimensions of their identity (e.g. racial minority issues) that are currently more prominent.

Corby et al. suggest that Egan and Perry's (2001) multidimensional model of gender identity requires reformulation in terms of its applicability to Black and Hispanic cultures. They argue that the implications of gender identity for adjustment depend on the messages children receive about gender from their families, religion, neighbourhoods and the media, and the extent to which these messages are internalized. Children's socialized conceptions of gender roles therefore become integral to the model and to our understanding of implications for psychosocial adjustment.

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<sup>&</sup>lt;sup>24</sup> Egan and Perry's (2001) gender identity self-report measure; Harter's (1985) Global Self-Worth Scale; Wiggins & Winder's (1961) Peer Nomination Inventory.

#### <u>Summary</u>

There are few papers in publication with include ethnicity and cultural difference as variables when measuring gender identity and well-being. Results are varied but seem to suggest that although western models of gender identity development appear to be generalizable to children of different cultures, more research is needed to understand subtle differences in the implications for psychological adjustment. Expected gender roles, pressure to conform, religion, exposure to media influences, and family dynamics are all have relevance to gender identity and further investigation of the role of such factors is indicated. Finally, more research is required to explore the relationship of gender identity to psychological well-being across different ethnic groups.

#### 1.5. Discussion

#### 1.5.1. Summary and clinical implications

Most of the literature reviewed here supports the hypothesis that gender identity is multidimensional and that by middle childhood children have developed fairly stable conceptions of the degree to which they typify their gender category.

Psychosocial adjustment and positive self-worth are considered to be highest when children feel secure in their own gender identity yet able to explore gender atypical options. Felt pressure to conform to gender stereotypes is potentially psychologically distressing and seems more likely to affect girls than boys, perhaps due to girls' increased social awareness and emotional sensitivity. Gender nonconformity appears to be a predictor of psychological symptomatology and

susceptibility to mental illness across various populations of young people, although this relationship appears not to be directly causal and a number of other factors require further investigation. Cultural variations in psychological functioning as a consequence of gender atypicality are noted in the literature but require further investigation in terms of the significance of wider social and systemic factors within the gender environmentalism model (Liben & Bigler, 2002).

Research into childhood gender identity continues to both challenge and enrich existing theories on the topic, albeit at a relatively slow pace. Clinically, the implications of this research are arguably rooted in our understanding of child development and childhood mental health. The link which continues to be identified between feelings of gender typicality and self-worth has relevance for the treatment of young people who present with low mood and self-esteem difficulties. Perhaps a factor to consider when treating these children is how they feel about their own gender and how much they perceive themselves to conform to gender stereotypes imposed by the systems around them. Of wider impact, educationally, this research could inform school curriculums to reduce the emphasis on gender stereotyping and promote a more inclusive environment. This is particularly important given that school environments play a pivotal role in the development and well-being of our children and young people (Huebner, 1991a,b).

The findings linking gender identity issues with mental ill health, identified in the present review, are particularly concerning as the evidence appears to indicate a greater vulnerability to psychological distress in young people who feel gender

atypical. Given these findings, and the already alarmingly high rates of mental illness among children and adolescents (Costello, Mustillo, Erkanli, Keeler & Angold, 2003; Tolan & Dodge, 2005), professionals working with young people have a responsibility to promote environments where gender roles and stereotypes are discussed openly and non-judgmentally in order to reduce the fear and shame described by young people (Grossman & D'Augelli, 2006).

#### 1.5.2 Limitations of the research

Many of the papers reviewed here cannot be described as completely independent or unbiased. Due to the relative paucity of psychological research into gender identity and gender differences in self-concept, there are a small number of academics specialising within a community of renowned and respected researchers. Thus, several of the papers are co-authored by or acknowledge other researchers on whose work their own research is based. The influence of prominent theorists such as Egan and Perry is clear when reading the work of other aspiring researchers. Although gender identity research is indebted to Egan and Perry and others for providing the foundations upon which further research can build, it is hoped that interest in this area will grow and inspire a new generation of independent researchers in this field.

A further limitation is that many of the studies reviewed used versions or adaptations of psychometric measures originally created by researchers in the field who hold particular theoretical perspectives which may open up their test materials to bias. It is also important to note the frequency with which researchers in this

field have created different versions of particular measures when existing ones have not quite fitted the age group or personality construct they have wished to investigate. From a methodological perspective, the use of multiple versions and adaptations of questionnaires potentially jeopardises the validity and robustness of any empirical data collected (Shriesheim & Denisi, 1980). Also, as many of the studies use different measures, there is little scope for comparison of findings across studies.

Given the heavy leaning within the literature towards social and environmental theories of gender identity, the appropriateness of some of the older measures used needs to be reviewed by researchers in this field. Societal gender roles and stereotypes are changing at an incredible rate, particularly with regard to women (Diekman & Eagly, 2000) and younger generations of children are thus growing up with different views of gender roles and exposure to less rigid societal expectations than their older counterparts (e.g. see Sinno & Killen, 2009). Newer measures of self-concept and gender therefore need to adapt to changing stereotypes in accordance with the dynamic shifts we are observing in gender roles and societal values.

#### 1.5.3 Areas for future research

Many of the studies considered in the present review relied primarily or solely on survey methodologies. Future research would benefit from employing mixed methods of data collection to include self-report measures, parental report and behavioural analysis, as well as the inclusion of more qualitative data from young

people. Given the complexity of the developing mind and the importance of wider social and environmental factors, studies employing mixed methodologies to facilitate the collection of both quantitative and qualitative data would perhaps provide a more in-depth and possibly more rounded account of gender identity than has been provided by previous research.

Future research may also benefit from exploring socioeconomic diversity as a variable given the widely reported links between parental income, occupation and educational attainment and children's cognitive and emotional development (Bradley & Corwyn, 2002). Finally, when studying the psychological development of young people it is also advantageous to have longitudinal data across the lifespan (0-18 years) on a much larger-scale. Any longitudinal data of this kind could continue to be collected into adulthood in order to study longer-term effects and findings could be used to help to better understand questions regarding prognoses.

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# **Chapter Two**

# Exploring Gender Identity in Adults with Asperger's Syndrome

Word count: 9252 (excluding tables, references and footnotes)

#### 2.1. Abstract

Several case studies describe individuals with Asperger's Syndrome (AS) who experience difficulties or confusion relating to their gender identity, although no prevalence data currently exists. Little explanation has been offered as to why this phenomenon may occur. Semi-structured interviews were carried out with seven adult men with AS to explore gender identity, sexuality and perceptions of masculinity. Interpretative Phenomenological Analysis of the data revealed three main themes each containing three sub-ordinate themes: 'Is gender the key to belonging?', 'Not in control of own sense of maleness', and 'Continuing to seek validation from women'. For participants, the complexity and multi-faceted nature of gender identity appears to remain an enigma within an already confusing concept of 'self'. Identifying with male gender provides a platform for fitting in by allowing these individuals to learn from societal stereotypes and rehearse playing 'male' roles. At times, expectations of masculinity and heterosexual identity have highlighted feelings of powerless and lack of control. Participants also displayed ambivalence in terms of feeling drawn to a perceived safety in females while also feeling some resentment towards perceived 'feminine' aspects of themselves. The study identifies distress, self-doubt and high levels of self-reflection in participant discourse about gender identity. Further research is needed to explore the evolution of gender identity in AS across the lifespan and to compare AS and non-AS populations in this regard.

#### **2.2 Introduction**

#### 2.2.1 Asperger's Syndrome

Asperger's syndrome (AS) is a developmental disorder characterised primarily by marked and sustained difficulties in social interaction and emotional relatedness, and by unusual patterns of circumscribed interests and behavioural peculiarities (Klin & Volkmar, 1997). Asperger's syndrome is considered to form part of the Autism Spectrum of conditions which also includes High Functioning Autism (HFA) and Pervasive Developmental Disorder (PDD). Autism was first identified by the American Psychiatrist Leo Kanner in 1943, which was followed a year later by Hans Asperger's paper on Autistic psychopathy in children (Boucher, 2009).

The recognition of AS has been one of the biggest changes in diagnostic practice in recent years (Frith, 2003). Current diagnostic criteria in DSM-IV (American Psychiatric Association, 2000) include; qualitative impairment in social interaction, restricted repetitive and stereotyped patterns of behaviour, interests and activities; clinically significant impairment in social, occupational, or other important areas of functioning; no clinically significant general delay in language; no clinically significant delay in cognitive development or in the development of ageappropriate self-help skills, adaptive behaviour, and curiosity about the environment in childhood. AS is often diagnosed later in childhood than classic Autism, and is often not even diagnosed until adulthood (Baron-Cohen, 2008). Therefore, many individuals with AS remain unsupported and poorly understood throughout their childhoods, adolescence and early adulthood. Although late

diagnosis can be reassuring, containing, and can provide a window to accessing services and financial benefits, many individuals have found the journey to get there incredibly confusing and distressing (Punshon, Skirrow & Murphy, 2009).

In addition to difficulties relating to other people, individuals with AS often experience either hyper- or hypo-sensitivity to sensory experiences. Indeed, some adults with AS consider their sensory sensitivity to be more problematic than their emotional or social difficulties (Attwood, 2007). Although the most common sensitivity is to sound, tactile experiences are also very common and have a profound effect on levels of intimacy within relationships.

# 2.2.2 Gender identity

Gender identity is defined as the fundamental sense of belonging to one sex, and not the other (Hooker & Stoller as quoted in Zucker, 2002) which develops in childhood and is thought to be consolidated by age 4 (Bradley & Zucker, 1997). The terms gender role and gender role behaviour are also used to describe an individual's labeling of themselves as male or female and the behaviours they display which are consistent with cultural definitions of maleness or femaleness. Many studies have found marked differences in how males and females see themselves within various concepts (e.g. see Wilgenbusch & Merrell, 1999).

Frequently used measures of gender identity include the Bem Sex Role Inventory (BSRI; 1974), Personal Attributes Scale (PAS; Spence, Helmreich & Stapp, 1974), and the Sexual Identity Scale (SIS; Stern, Barak & Gould, 1987). Most measures take the

form of self-report rating scales assessing adherence to gender roles, gender constancy, and attitudes towards gender (Beere, 1990).

#### 2.2.3. Gender identity and AS

Academic literature has often alluded to a higher incidence of bisexuality, homosexuality, and transgenderism in the Asperger's population (Hénault, 2006) yet very little research exists that has explored this phenomenon in more detail or considered the experiences of the individuals themselves.

Gender dysphoria in two male children with Autism was reported in a case study as long ago as 1996 (Williams, Allard & Sears), although it was posited that the boys' preoccupations with feminine activities and objects was merely a feature of their Autism Spectrum conditions and did not meet criteria for Gender Identity Disorder (GID). Williams et al. do acknowledge, however that cross-gender preoccupations in children on the Autistic Spectrum are highly prevalent and widely underreported.

More recently, a few case studies of people with AS and GID have been reported in the literature (Gallucci, Hackerman & Schmidt, 2005; Kraemer, Delsignore, Gundelfinger, Schnyder & Hepp, 2005; Tateno, Tateno & Saito, 2007), although these reports are brief and undetailed. Robinow (2009) reported a strong over-representation of individuals with suspected AS at a Gender Identity Clinic in Canada. Drawing on object relations theories, Robinow suggests that transgenderism in people with AS may result from disturbances in the early mother-child bond. He suggests that if the individual with AS has impairment in

their ability to integrate their parents' responses to their behaviours, then it is possible that their working models of femaleness and maleness may be impaired also.

#### 2.2.4 Gaps in the literature and implications

Although there has been a recent increase in publications linking gender identity issues with AS, most of these studies focus on gender pathology and consist of anecdotal case studies. There are currently no published studies which explore the concept of gender identity in individuals within the AS population.

# 2.2.5 Aims of the current study

The aims of the present study were to capture and explore the experiences of adults with AS in relation to their gender identity, gender-role constancy, the extent to which they relate to others of the same or different gender, and the development of their gender and sexual identity. These experiences are considered in relation to current theory and existing literature, and implications for the clinical care of this population will be discussed.

# 2.3 Methodology

# 2.3.1 Design

A qualitative design was adopted for the present study, given the lack of previous research in this area and for the quality and richness of experiential, exploratory data as opposed to numerical, measurable concepts. The qualitative approach

chosen was Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). This method was considered preferable for the purpose of exploring individuals' personal experiences and how they make sense of them.

#### Theory of Mind and IPA

Deficits in Theory of Mind (ToM) are universally recognised<sup>25</sup> as a symptom of Asperger's Syndrome and are often termed 'mind-blindness' (Baron-Cohen, 1995). Theory of Mind refers to a persons' ability to recognize and understand the thoughts and feelings of others in order to make sense of their behaviour and predict their responses (Attwood, 2007). Research has shown impairments in ToM to be more prevalent in children with Asperger's than adults, with several studies suggesting adults with Asperger's syndrome to show no impairments in ToM on standardized tests (see Spek, Scholte & Van Berckelaer-Omnes, 2010). ToM impairments are thought to affect recognition of more subtle emotional states and perhaps require intelligence and experience to 'read' others as opposed to intuition (Attwood, 2007). Despite a paucity of research into the experiences of people with AS, examples do exist of qualitative methods such as thematic analysis and IPA being used successfully with this client group (Foley, Blackmore, Girdler, O'Donnell, Glauret, Llewellyn & Leonard, 2012; Williams, 2004) and it is therefore considered to be a viable research methodology for the current study.

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<sup>&</sup>lt;sup>25</sup> See Baron-Cohen, 2000; Frith, 1989; Happé, 1994.

#### 2.3.2 Materials

An interview schedule (see Appendix two) was created in consultation with an adult professional with AS in order to provide a structural framework on which to guide each interview. The interview schedule was developed and revised in accordance with suggested IPA methods as outlined by Smith et al. (2009). Open questions were used in order to elicit open, un-biased responses and to encourage participants to share information. Additional sub-questions were included in the schedule in the event that participants struggled to respond and required further gentle prompting. The interview schedule was used flexibly to guide and structure the interview format and further questions arose in response to subject matter raised by participants.

Existing measures of gender identity and sexuality were used to guide the main themes of the interview schedule. Questions focused on participant perception of own gender and gender role behaviours, feelings and emotions associated with gender (Personal Attributes Scale; Spence, Helmreich & Stapp, 1974), understanding of and responses to gender stereotpyes, significant gender role models (Bem Sex Role Inventory, 1974), and experiences of puberty and sexuality (Sexual Identity Scale; Stern, Barak & Gould, 1987). However, interview questions for the current study were broader, open-ended and attempted to cover as many of these themes as possible within the allotted time, whilst producing as rich a qualitative data set as possible.

Due to the nature of AS, questions were as clear, transparent and concise as possible. All questions were ratified by a consulting professional with AS in order that any ambiguity relating to theory of mind be corrected. For example, questions requiring participants to comment on how they may be perceived by others were worded appropriately to ensure that it was clear that responses could be subjective or based on concrete experiences as opposed to 'mind-reading'.

#### 2.3.3. Participants

Participants for the present study were recruited via support groups within the West Midlands region. Some participants were recruited via a regional Autism charity and others were members of local privately-run support groups at which the researcher was invited to speak. Inclusion criteria for the study were that participants were aged 18 or over, spoke English as a first language, and reported having received a diagnosis of AS. Diagnoses were not confirmed via any other source due to the ethical implications associated with access to medical records.

The participants were 7 adults aged between 26 and 69, mean age 48. All participants were male. Average age at which diagnosis was given was 40. Table 2 below provides further demographic information relating to each participant.

Participant	Gender	Age	Age at diagnosis	Ethnicity	Marital status	Living situation
Charlie*	М	40	37	White European	Single	Homeowner, Living alone
Gary*	М	26	21	White British	Single	Living with parents
Martin*	М	51	25	White British	Single	Living alone
Clive*	М	69	65	White British	Married	Living with spouse
Simon*	М	48	46	White British	Single	Living with parents
Derek*	М	67	62	White British	In a relationship	Living with partner
Jon*	M	34	24	White British	Single	Living in shared accommodation

 Table 2. The seven participants.

<sup>\*</sup>Pseudonyms have been used to preserve anonymity.

## 2.3.4 Procedure

## 2.3.4.1. Ethical Approval

Ethical approval for the study was granted by Coventry University Ethics Committee (see Appendix three)

# 2.3.4.2. Recruitment of Participants

Participants recruited via the regional charity were approached by a member of support staff at the end of one of their weekly meetings. Research information leaflets (see Appendix four) were distributed by staff and interested parties were able to contact the researcher directly in order to arrange an interview time. Other participants were recruited following the researcher's attendance at a local privately-run AS support group where the premise of the study was explained and research leaflets were distributed. On this occasion, potential participants had the option of signing up immediately or contacting the researcher at a later date.

Participants were informed that they would be entered into a prize draw to win a £20 gift voucher, and that this would not affect their right to withdraw at any time.

## 2.3.4.3. Data collection

Participants recruited via the regional charity were interviewed at the organisation's head office in a private room. Participants recruited via the private support group were interviewed in a private room on University premises. All interviews lasted between 50 minutes and 1 hour, with drinks and a break offered if necessary.

Prior to interview, participants were asked to read and sign the information sheet (see Appendix five) outlining full details of the study. Time was allocated for questions and all participants were reminded of their right to withdraw. Those who agreed to participate in the study were requested to sign a form (see Appendix six) to provide their consent for their interview to be digitally audio-recorded and analysed as part of the study. Basic demographic information was collected by the researcher at this point and entered onto a form (see Appendix seven)

After each interview, time was allocated for a verbal de-brief with the researcher and an opportunity to ask questions or raise concerns about the process.

Participants were given a debrief sheet (see Appendix eight) to take home in the event that they should experience distress and wish to discuss this with a professional, or wish to make a complaint about any part of the process.

The researcher transcribed all audio data by hand, giving each interview a code and changing any names or other identifying information in order to maintain confidentiality and anonymity.

## 2.3.5. Data analysis

Data was transcribed, analysed, and coded using IPA methodology as outlined by Smith et al. (2009) to identify emergent and super-ordinate themes. A summary of the analytic process and an example of a coded transcript can be found in Appendices nine and ten, respectively. Following initial noting by the first author, patterns of commonality and difference were drawn together to identify common

themes across transcripts. Transcripts were revisited and subjected to a further stage of more interpretative coding with the aim of identifying emergent themes on a case by case basis drawing upon knowledge, theory and concepts beyond the frame of reference of participants. At all times, connections were maintained between transcript excerpts, interpretative codes and themes.

The developing structure of codes and themes was then reviewed by supervising members of the research team as recommended to ensure the validity of emerging concepts and themes using triangulation in accordance with the general guidelines for qualitative research as provided by Elliot, Fischer, & Rennie (1999).

## 2.3.6. Subjectivity

The primary researcher is a Trainee Clinical Psychologist with professional experience of Autism Spectrum Disorders. In her clinical role, the researcher has observed adults with Asperger's Syndrome who struggle with some aspect of their gender identity and/or sexuality and become interested in possible reasons for this phenomenon. However, the current study is aimed at AS populations who do not currently access secondary care mental health services. IPA guidelines have been followed closely in order to reduce bias and ensure a valid analysis (see section 2.3.5. above).

# 2.4. Results

Three super-ordinate themes were identified, each with its own structure of further sub-ordinate themes (see Table 3, below). Each of the super-ordinate themes was supported by evidence from all transcripts, as highlighted in the analysis and discussion section.

Super-ordinate Themes	Sub-ordinate Themes
Is gender the key to belonging?	Felt social and environmental pressure to behave certain ways.
	Learning to play the role of a man.
	Responding to rejection; I don't fit anyway.
Not in control of own sense of maleness.	Sexuality as an overwhelming and confusing force.
	Striving to achieve a feeling of status.
	Feeling dissatisfied and hopeless.
Continuing to seek validation from women	Drawn to the perceived security of female company.
	Recognising value of feminine qualities in self.
	Ashamed of emotional needs; I shouldn't cry because I'm not a woman.

Table 3: Super- and sub-ordinate themes emerging from analysis of the data

## 2.5. Analysis and Discussion

This section describes in more detail the main themes that emerged from the analysis, using supportive examples from the data. The discussion focuses on both commonalities and differences between participants' accounts in line with the IPA approach. Quotations are presented in italics, followed by the participant's pseudonym.

## 2.5.1. Theme 1: Is gender the key to belonging?

The first theme reflects participants' experiences of living with Asperger's

Syndrome and a general sense that they have faced a continuous struggle to

establish their identity and feel part of the world around them. For all of the

participants, the concept of 'gender' seemed to be perceived as a further aspect of
their identity that they neither understood nor owned.

## Felt social and environmental pressure to behave certain ways

Five of the participants discussed an acute awareness that certain social expectations of men exist and that gender stereotypes have been socially constructed, influencing the way people behave according to their biological sex in various situations. Several participants described these stereotypes in mechanical or even rehearsed ways, as if they knew of such constructs but did not have lived experience of them. For example, Gary's use of hesitant language (such as "suppose" and "maybe") to describe male gender stereotypes suggests that is he is not entirely sure how he is expected to behave;

"I suppose for me as a, for being a man, I suppose a stereotypical view is that I'm supposed to be sort of like this big sort of maybe loud-mouthed who likes drinking, likes the football." (Gary)

Although this use of descriptive language in a passive, detached way is common in people with Asperger's Syndrome who may have more concrete thinking styles, it may also be an indicator that gender stereotypes are one of potentially many social constructs that are learned but perhaps not <u>lived</u> by people with AS.

Participants shared feelings of discomfort on occasions when they had felt pressure to conform to gender stereotypes, particularly relating to social pressure from peers in school and work settings. Most participants described having, at times, succumbed to this felt pressure, but on nearly all occasions ultimately feeling that attempting to overtly display their masculinity didn't feel quite right. Jon very clearly explained why he tried to behave like his male peers during his early adulthood despite not feeling 'like him';

'Cause I thought I wanted to be like a normal person at the time...you know, fit in to society....I wouldn't do it now 'cause I've learned my lesson but at the time, I was only 18 or 19 at the time, that's what I wanted to do really....drank alcoholic stuff, watched Chris Evans on a Friday night type of thing. (Jon)

Of the 5 participants who talked about felt pressure to conform to male gender stereotypes, most referred mainly to social groups, particularly at school or university. Clive, however, described being introduced to gender stereotypes earlier in life, particularly under the influence of his immediate family and parental roles.

As Clive was one of the older participants, he may have grown up around more

traditional gender roles, which may have influenced his understanding of stereotypes and his interpretation of expectations of him.

## Learning to play the part of a man.

Four participants described in detail how they had spent a lifetime playing different 'roles' in an attempt to fit in to the world around them. Specifically, Charlie and Gary both described the roles they had learned to play through years of supporting professional football. Here, Charlie talks about the persona he puts on in order to feel part of the masculine energy of the football crowd;

I think I just let myself adopt the persona. It's er...you know, so....I start off being quite reserved and intelligent and by the end I'm shouting at people....you get into the sort of aggression and allow yourself to sort of enjoy that.....you feel like you're in a group and you're not on your own, you're certainly not an individual any more, you're part of a sort of more male, male group. (Charlie)

The football environment is clearly one where both Charlie and Gary have learned to feel safe and accepted at some level by following very specific social rules (team chants, insults to the referee) and stereotypically masculine behaviours (shouting, swearing, displaying aggression, making threats). However, for both of them, this feeling of belonging seemed fleeting and lasted only as long as they remained inside the stadium on a Saturday afternoon. Interestingly however, Charlie's use of the words "let" and "allow" suggest that 'adopting' the persona may come more naturally than they realise.

More generally, participants described learning different ways to behave in different contexts which varied depending on the gender of the people around them, for example in secondary school talking about girls, or at work talking about sports. In the majority of cases, participants were describing how these strategies they had learned seemed to be appropriate to very specific situations, but rarely changed how people perceived them or how they saw themselves. For example, Gary describes trying to emulate his male peers during adolescence but ultimately still feeling rejected by them;

I went through a period when erm....I tried to be more outgoing, you know I was a bit louder, this is probably when I was around 16 to er, 18, I was basically being a bit loud and I was just trying to make a good impression on people.....and the thing was it wasn't working and people were still saying "Oh yeah, Gary's alright" but then they would go over to their other little clique and er....stay with them, really. (Gary)

Two of the participants (Derek and Clive) had been married and had children. Both Derek and Clive talked about their decision to get married and have children as being almost unconscious and assumed according to societal expectations of men. For them, the expectation that as a man you will inevitably become a husband and then a father felt like it detracted from their experience of and satisfaction with these roles. For both Derek and Clive, being a husband felt like a role they had wanted to fulfill but that there was something missing in their expectations of how it would feel, as illustrated in the following example;

I mean I have bought flowers for [partner's name] often and er, in the past, but....
just erm....well a willingness to try and help and to do things for them
and....unfortunately I was desperate to want to help my ex-wife but she felt that the

kitchen was her domain.....but I really wanted us to be together doing things.....and er.....I found that a bit upsetting. (Derek)

Derek's use of the word 'want' in "I was desperate to want to help her" suggests that his perception of a stereotypical doting husband did not come naturally to him and was not something he was motivated to achieve.

### Responding to rejection; I don't fit anyway

Participants shared lifetime experiences of invalidation and rejection by society, which several of them had learned to cope with by becoming rejecting of others. In particular, participants had been bullied and teased at school for being 'different' or 'strange', had frequently been romantically rejected by women, often had negative experiences of being patronised and dismissed by health professionals, and in several cases had experienced early abandonment by parental figures, particularly fathers. Jon, in particular expressed considerable anger towards the world and a desire to keep people 'at a distance', which could be interpreted as a defence against a fear of further rejection. Jon demonstrates this in the following extract, when he spoke loudly and aggressively;

I know I'm hard work at times but I am trying my damned best....it's just frustrating that the old brain doesn't work, function properly....socialising and things...'cause I think people are laughing at me and taking the mickey....They just think I'm strange and that....you know, they call me a 'retard' and them horrible names....but they don't understand, you know? (Jon)

Here, Jon's repetition of "you know" suggests a desire for the interviewer to understand his experience, which may indicate a history of feeling misunderstood. Listening to participants' accounts of their experiences of rejection, it seemed that these experiences were associated with feelings of hurt and sadness that they had defended against by pushing people away. Conforming to gender stereotypes that are constructed by a society that has historically rejected them may expose individuals with AS to further hurt and abuse.

Early experiences of invalidation also affected how participants' saw themselves as men. Five out of seven participants told the interviewer (unprompted) that they thought their fathers might have met criteria for Asperger's Syndrome, although none were diagnosed. These participants described cold, unaffectionate fathers who did not invest time in bonding with their sons. Simon described being very overtly rejected by his father;

My Dad wasn't really interested in me as a person, in us as kids....he just wanted to watch his sport and even he'd like lock us in the back garden, you know lock us outside if his football was on.....so, and that was the sort of, erm....nurturing element....[laughs]. (Simon)

Simon used laughter frequently when describing painful experiences of rejection. His use of laughter here suggests that the "nurturing" that was missing was something that he craved and that its absence was strongly felt. Participants' lack of closeness to their fathers (either due to their own AS or his) may have prevented them from learning about maleness and masculinity early in their development, at a time when most boys begin to admire and emulate their fathers. Indeed, having AS

does not negate a child's innate desire for closeness to a father figure, as demonstrated in the following extract where Derek describes his father polishing his football but never actually playing with him;

My father used to dubbin this case ball for me regular and erm, so I took it up to the fields and in a manner of speaking I bought myself into the game of football....and looking back I, I see all this and....yeah, it's a shame really. (Derek)

The sadness in Derek's story of a small boy continually approaching his father with a football, only to have the ball polished and returned to him to play with alone was echoed in many of the other participants' stories of wanting more closeness with their fathers and never truly feeling validated by them. It seems possible that these Autistic boys and their fathers were trapped in a perpetual cycle of craving male closeness and paternal validation but having never learned what this looks or feels like.

# 2.5.2. Theme 2: Not in control of own sense of maleness

The second theme reflects a sense, emerging from all participants, of not feeling satisfied or fulfilled as men and how this affects their self-esteem and identity more generally. Participants described their masculinity as being under scrutiny of society and other people, as well as experiencing hormonal drivers of maleness such as sexual urges.

## Sexuality as an overwhelming and confusing force

All participants identified as being heterosexual and experiencing sexual attraction towards women. Participants described their sexuality as something biologically driven that had a 'hold' over them which can lead to feelings of frustration associated with both lack of control and fulfillment. Given that the participants also identified themselves as being reflective thinkers, they were often overwhelmed by the internal conflict between feeling the urge to have sex and needing to analyse these feelings, as highlighted by Charlie;

You end up sort of not being able to perform because you can't, because it's too much effort and it's difficult intense and everything else and everything feels overwhelming and so you're dissatisfied, they're dissatisfied, you know it's not good....Yeah, because I mean physically, I'm a pretty sexual being and mentally it's a bit more of a heck...don't like that. The brain's such a strange thing. (Charlie)

Participants described spending a significant amount of time trying to understand and control the world around them in order to feel safe. Being a man with hormonal urges may challenge their self-identity and throw them into turmoil by introducing spontaneous and unpredictable feelings.

This confusion had been compounded for some by the interjection of others who had challenged their sexuality and hence made them question their own identity as a heterosexual man. Three of the seven participants described having questioned their own gender identity and two of these had experimented with homosexuality,

only to decide that homosexual intercourse felt uncomfortable too. Gary describes his experiences in the following extract;

I was basically accused of being gay, by the kinds on my estate....the reason that I was considered gay was because I wasn't sleeping around as well and I wasn't, you know....sort of chasing those girls really..... I did question it, briefly when I was about 17 'cause I noticed I was....noticing more male features and....sort of admiring them really and I thought.....maybe I am. (Gary)

If gender role and sexuality are components of identity which are confusing and intangible for men with AS, it seems understandable that they are vulnerable to influence from others as their sense of self may be less robust and more open to doubt.

#### Striving to achieve a feeling of status

All participants described aspects of their personality that they felt proud of and through which they could feel some sense of superiority. The most commonly cited example was that of intelligence, with participants feeling that their intellectual ability was what set them apart from their peers and gave them a sense of value. Other examples included physical and athletic strength (Derek), creativity and artistic flair (Simon, Gary, Jon), and musical talent (Martin). In all of the interviews, participants mentioned things that they saw as strengths, despite not being directly asked about this. Participants appeared to have coped with experiences of abuse and rejection by attempting to elicit some sense of status wherever possible. For

example, Martin proudly described having an important role in his class as a child in helping other children with their spellings when the teacher was unattainable;

There's another strange talent I have is, is, although I don't like boasting....I seem to be, er....good erm at word spelling remembrance....and this has definitely been right through my life, I remember...helping some....at one of my earliest schools, others who didn't know the spelling they sometimes had to come to me, for me to write it.

(Martin)

For Gary, his experiences of attending a special needs school and being mocked for being 'stupid' had left him feeling inadequate as a man. Consequently, he had channeled his desire to feel significant into his work, where he was very proud to be at supervisor grade;

I mean, at work I'm a supervisor, I mean yeah I will talk to people fairly normally, I haven't really told many people that I've got Asperger's and I went to a special needs school. (Gary)

The above extract is one of many times Gary mentioned his supervisor status to the interviewer, highlighting the significance of this position of power within his identity. What is interesting here is that he also suggests that the AS part of his identity directly challenges his identity as a man in a position of power and therefore he has refrained from disclosing it within this context.

### Feeling dissatisfied and hopeless

When discussing how they saw themselves within the context of gender, participants shared a general sense of dissatisfaction and feeling that somehow

they had failed as a man. Mostly, participants described feeling like a failure within the context of social and sexual relationships, and particularly in their lack of success with women. Some participants appeared to externalize their feelings of worthlessness and blame others for their perceived lack of social standing. For example, Jon blamed his parents, the education system and wider society for him being bullied and victimized by his male peers;

'Half my life I was just trapped upstairs in my bedroom while my mum and dad was arguing, my mum and dad don't understand my condition.....I went to another school which was a special school, that's where they sent me....my auntie....even she said I was in the wrong school.....But the system, the government [should] be there to help educate these kids that we're all human beings at the end of the day. (Jon)

In relation to perceived lack of sexual prowess, four participants cited this as something which directly challenged their gender identity and sense of masculinity. Not only did participants describe feeling like a failure due to their lack of sexual experience, some also implied that they would never feel fulfilled as a man because the fantasy of a perfect relationship with they perceived all 'neurotypical' or non-AS men to have felt completely unattainable. Consequently, many participants implied that they had given up trying to develop meaningful sexual relationships because they felt their Asperger's Syndrome would always stand in the way of achieving this;

So you look at that rubbish [pornography]....so you know I've seen it all done it all, backwards, forwards, everything....erm, but I've never done it, so....I'd probably be a complete waste of space...in reality....That was the time when I thought oh people have these sort of women, people have these relationships...there are women out there who....can make your life a lot better.(Simon)

As well as feeling frustrated and ashamed at their lack of success with women as demonstrated by Simon's use of terms such as "rubbish", "complete waste of space", participants also shared a deeper sense of sadness and almost grief for their missed opportunities;

Well, as I said it was a bit, it was slow in understanding the sexy parts....I didn't like it at first, I didn't understand how it was nice....I was quite late in life to understand that so that missed the chance of it....I have a feeling sometimes that I've been wasting my life on....poetry and composing and had nobody to love so....just been wasting my heart in a way....nobody to love so I'm wasting a heart. (Martin)

Martin's description of 'wasting' his heart is a beautiful example of the feeling shared by all participants that they have never really felt completely comfortable with their identity and that for 5 of them, their sexuality has been fundamental to this.

## 2.5.3. Theme 3: Continuing to seek validation from women

The third theme reflects the significance and influence of women in shaping the identity of all participants. Every participant described feeling closer to their mother than their father, and most referred to their fathers as absent or emotionally unavailable. Subsequently, participants had developed significant relationships with other females over the course of their lives, which they talked about in depth.

These relationships tended to be with female teachers (Charlie, Gary), aunts (Gary, Jon, Derek), grandmothers (Gary, Jon), work colleagues (Martin), and wives (Clive,

Derek). All participants gave the impression that they were more naturally drawn to the company of women, and 6 out of 7 felt that they preferred female company to male. However, participants also seemed ambivalent in feeling drawn to women but at times wishing they weren't. Clive was the only participant who felt more comfortable around men, citing his reasons for this as having had years of experience at school and in his career of practicing being around males and learning how to act around them more so than females.

### <u>Drawn to the perceived security of female company</u>

Despite all participants recognizing that they feel drawn to women, their interpretations of why that might be the case differed slightly. Some participants found it difficult to articulate a reason why they might seek out female company. For example, Martin described some elements that make women more appealing;

It's always the long hair....yes, I like their soft voices as well, and I think it's very valuable at the shop I'm at where so many nice young ones come. (Martin)

Martin was not alone in citing women's perceived kindness and soft voices as qualities that are both attractive and comforting. Having grown up as a victim of bullying and verbal abuse from male peers, it seems understandable that one might avoid aggression or confrontation wherever possible. Clive went as far as to explain that if he ever meets a woman who exhibits these stereotypically male attributes, he finds it confusing, intimidating and unnerving;

I've come across one woman..... who was ADHD and, er...I panicked, I just didn't know how to handle it, erm....because she was a woman and because she shouted, you know she was angry with me.....And I don't with a woman, I just don't know what to do....I'm half expecting her to hit or scratch or something....and, er....get violent and I know I couldn't do a thing about it. (Clive)

As well as being attracted to the perceived softer, caring side of women that participants had described experiencing early on in their lives either from their mother or other female relatives, there was also a sense that by being around women they may stand a better chance of being both accepted and understood. Again, this links in with previously mentioned accounts of males as being perceived as rejecting and abusive. Indeed, Simon went as far as to suggest that being around women helps men with Asperger's Syndrome to expose themselves to those things that they struggle to understand, such as emotions;

'Cause women are more intuitive and generally....er, more into relationships....feelings and stuff, that's what I want to understand more, so I suppose there's that side of it, erm....and they're quieter, generally, they're not....fighting and shouting. (Simon)

There was also a shared feeling that women are able to offer more containment than men, which seems particularly important for those on the Autistic Spectrum who often feel anxious as a consequence of the world around them seeming confusing and unsafe. For example, Charlie explains that when growing up he would turn to his mother at times when he lacked confidence or felt worried, and he has found that as an adult he still often looks to other women for the same validation;

Once I've experienced something I sort of relate it to other situations and I think because of that strong influence, influencing from my mum I think that's sort of, again it helps me relax when women are also like that because it feels a bit more sort of safer and sort of confident. (Charlie)

### Recognising value of feminine qualities

As well as identifying more with women, all participants also recognized stereotypically feminine qualities in themselves which both helped them to develop social relationships but also called into question their masculinity. Participants were torn as to the value of feminine qualities in themselves as men. For example, Jon and Gary describe being comfortable and proud of their femininity and owning it as a positive characteristic that draws people closer to you;

Well some might say I'm a very nice person, I'm very intelligent I know that...I'm a good listener, I do listen to people....I always give people good advice....That's what it is 'cause I am an emotional guy, you see 'cause I'm not feminine but I'm not Mr Macho-man, not like some of these on a Friday night that go [mimics rowdy cheering noise], I like to keep myself to myself, really. (Jon)

I mean, naturally I am kind of sensitive and.....I want people to like me. I think people see me as, like a fairly trusting person which I, I hope I am, really....and I'm not somebody who is gonna take advantage of somebody if...if you were drunk, or feeling really down and they just....need an arm round 'em or whatever. (Gary)

In both of these example, Jon and Gary specifically name stereotypically masculine traits that they are happy not to possess ("Mr Macho-man", "taking advantage [of

girls]") and interestingly describe being emotionally sensitive and offering oneself as a 'shoulder to cry on' as traits they seem proud of. Given that participants (and in particular, Jon and Gary) described a lifetime of failed attempts to join in with and be accepted by their male peers, it seems they have learned that an easier and more effective strategy may be to get closer to women in the role of 'confidante' and that being a good listener is a characteristic which others, particularly women may be drawn to.

### <u>Ashamed of emotional needs</u>

In spite of their acceptance of feminine traits as being generally construed by others as positive, participants were torn between feeling comforted that they were more emotional and sensitive than they perceived 'neurotypical' men to be, and resenting their 'emotional side' which was perceived as challenging their gender identity. For example, Clive had felt uncomfortable with social pressure to suppress his emotions;

I've always been an extraordinarily emotional person, I can cry like....[clicks fingers]....you know, easy, as you've seen but for understandable reasons......A lot of them say....you know, I shouldn't [cry] because, you know I'm not a woman....and some people like [friend's name] says erm....that's the female side of me. (Clive)

Clive's use of the word "shouldn't" implies a sense of shame at being emotional which he feels is directly related to gender stereotypes and judgment by others.

Similarly, several participants felt that their Asperger's Syndrome required them to need support (e.g. from parents, carers, or charitable organisations) and that this

vulnerability was in direct conflict with their sense of identity as a grown man who society dictates should be strong, independent and powerful. Martin described feeling ashamed and frustrated that he is dependent on others;

I'm reluctant to believe that I have, erm self-vulnerability....my supporter....he's telling me that I am vulnerable....but I don't want to believe that because it seems to be attacking my effort to, er feel mature. (Martin)

Martin's use of language is interesting here, in particular the word "attacking" which evokes images of feeling powerless and threatened. Use of such emotive language suggests that needing to have a supporter (who, incidentally, was a man less than half Martin's age) is particularly distressing for Martin and associated with a great deal of shame.

Another sub-theme that was relevant to all participants was a sense of frustration and anger at themselves for being so reflective and thoughtful. All seven participants explained that they spend considerable time thinking about themselves as a person and how they fit with other men and women, and society more generally. As well as perceiving this to be part of a feminine 'side' to their identity, most participants talked about their level of self-reflection as something they wish they could change. As Martin articulates;

It's a bit like, ooh, being kept in a prison in the autism inside my life. (Martin)

Generally, the participants presented as articulate and insightful men who were acutely aware of their difference and often felt confused and overwhelmed by all aspects of their gender. The fact that being reflective and emotional are both qualities stereotypically associated with women merely added to the identity confusion they already felt.

### 2.6. Conclusion

#### 2.6.1. **Summary**

The analysis identifies cognitive, affective, and narrative elements in the data whilst placing individual participants' perspectives at the centre, which is at the heart of the principles of IPA (Smith, 1996). In attempting to examine the phenomenon of gender identity from the perspective of adults with Asperger's syndrome, the analysis has found that for these participants, gender identity remains an enigma within the already confusing concept of 'self'. For many, gender identity has provided a platform for devising and practising strategies to belong to a group by rehearsing what maleness 'should' be. Gender stereotypes imposed by society, peers, and family have been learned, observed, and felt. At times playing a 'male' role has brought participants in the present study closer to a feeling of acceptance from others, but mostly it has resulted in further rejection and feelings of insecurity and identity confusion. Participants described learning to respond to rejection from male peers and relatives by rejecting them first with some ultimately seeming to give up trying to fit the gender mould.

Maleness represents yet another facet of their identity that participants experienced as beyond their control. In particular, sexual urges appear to be confusing, overwhelming, and at times distressing. In pursuit of some sense of control in attempting to combat feeling anxious and powerless in an unpredictable world, men with AS in the present study have tried to elicit their masculine prowess in other ways such as demonstrating their superiority over others. Lack of sexual desirability is blamed on social 'awkwardness' associated with AS and leads to feelings of despair and a sense of hopelessness as a man.

Findings suggest that men with AS may be drawn to the comfort and solace of women and with participants in the present study having positive memories of being nurtured by females in contrast to feeling rejected and humiliated by males.

Despite seeking out women from whom to learn about emotions and adopting some feminine characteristics to attract people, participants portrayed a sense of shame at being emotionally sensitive and resented this quality in themselves at times.

# 2.6.2. Findings in relation to existing literature

Participants in the current study expressed some uncertainty regarding their gender and sexuality related to how others see them. The limited existing literature addressing gender identity in people with AS has drawn links with obsessive-compulsive traits, suggesting that individuals on the autistic spectrum may have a tendency towards obsessive-compulsive presentations (Leyfer, Folstein, Bacalman, Davis, Dinh & Morgan, 2006) and that this may lead them to exhibit particular

pervasive preoccupations and distress with gender role (Gallucci et al., 2005). The current study has not found evidence to support this theory as, although a few participants did express some historical distress regarding their gender and sexual identities, obsessive or preoccupied thinking relating to gender identity specifically was not something that emerged from the data.

A more likely theory to explain participants' questioning of self is that posited by Gallucci et al. (2005) who suggest that given the difficulties people with AS face in social functioning and relating to others, self-questioning and identity crises may arise from an attempt to adapt to environmental stressors. Given the findings of the current study, it seems understandable that individuals who are confused by, isolated from, and rejected by society may reflect on their difference to the point that they begin to question whether their identity needs to change to try and fit those around them. Personality theory asserts that identity in adulthood takes the shape of a coherent narrative that integrates interpretations of the past with the present self (Singer, 2004). Difficult experiences, such as the bullying and victimization described by participants in the current study, may challenge this narrative and invite identity questioning and transformation, which ultimately has a negative effect on subjective well-being and life satisfaction (Pals, 2006). Indeed, the participants in the current study all expressed some level of dissatisfaction or desire for their lives to be better in various different ways.

Kraemer et al. (2005) explain gender identity difficulties in a female with AS as arising from over-developed logical thinking and low emotionality, both of which

they describe as male characteristics. Thus, if a female experiences a subjective consciousness of being male as a by-product of her Asperger's Syndrome, it seems understandable that she may have taken on a male gender identity in accordance with the extreme male-brain theory of Autism (Baron-Cohen, 2002). Despite the absence of female participants in the current study, the male participants interviewed generally expressed themselves as being high in emotionality, with some participants overtly expressing that being emotional felt in conflict with their gender. Thus, the opposite assumption could be made regarding men who are highly emotional and reflective and the extent to which their emotionality may call into question their perceived masculinity.

Tateno et al. (2008) suggest that gender identity difficulties in AS might be directly linked to relationship experiences such that a boy who is bullied by other boys withdraws from his own gender group and begins to relate more to girls. Indeed, all participants in the current study described a lifetime of maltreatment and abuse by men and comfort-seeking from women. It could therefore be argued that men with AS adopt female characteristics as a result of increased time spent with females and this may, but does not necessarily, make them question their identity or feel less masculine.

The study does not support Robinow's (2009) theory that gender identity disturbance occurs due to ruptures in the early mother-child bond in individuals with AS. Participants described being closer to their mothers than their fathers and receiving more emotional support from them. However, due to the strong genetic

basis of Autism Spectrum Disorders (Volker & Lopata, 2008), participants may also have had fathers who met diagnostic criteria, which could potentially affect the father-child bond. Relationships with parents are certainly worthy of further research in order to explore this possible link between attachment and gender identity.

The study also replicated other key, well-researched findings within the AS literature. Adults with AS have difficulty forming and maintaining friendships despite longing for closeness (Müller, 2008), face challenges to education and employment (Higgins, Koch, Boughfman & Vierstra, 2008), enjoy sex but are often frustrated by lack of opportunities to engage in sexual relationships (Gougeon, 2010), and have difficulty recognizing and tolerating emotions in themselves and others (Golan, Baron-Cohen & Hill, 2006; Laurent & Rubin, 2004).

#### 2.6.3. Limitations

Small sample sizes used in qualitative research make findings difficult to generalize to wider populations. Furthermore, participants were all male, White British, and diagnosed in adulthood, and are therefore not a particularly diverse sample. Participants were recruited via support groups and were approached indirectly by either the researcher or a staff member which may have led some individuals to feel pressure to volunteer. Similarly, it could be argued that those volunteering are doing so because they have experienced some difficulties relating to their gender identity that they wished to share. The wider population of adults with AS who do not engage with services is therefore not represented by this sample.

IPA methodology inevitably involves a degree of subjectivity on the part of the researcher (Smith et al., 2009). As previously stated, the primary researcher had a professional interest in gender identity pathology in the AS population and it is therefore possible that difficulties in this area were picked up on more readily. In order to minimise bias, sections of transcript were coded alongside fellow researchers and checked by other members of the research team.

In addition, it is important to consider that there may be limitations in terms of researcher neutrality. On re-reading of transcripts, occasions were apparent when the researcher expressed empathy for the participants' stories. Remaining a neutral enquirer is considered to be one of the most common challenges faced by mental health professionals undertaking qualitative research (Thompson & Russo, 2012).

Furthermore, despite allowances being made in the interview schedule to accommodate any potential deficits in Theory of Mind (ToM) associated with Asperger's Syndrome, it is possible that some of the interview questions may have been too emotionally abstract for participants to fully or accurately answer. In the absence of sustained mutual empathic engagement with other people, individuals with AS may intellectualise and devise cognitive strategies to help them negotiate the world around them (Williams, 2004). However, these strategies may be limited and inflexible, potentially restricting the richness of data open to interpretation. Although it is important to give people with AS a voice, future research may benefit from combining qualitative data with scores on more standardised measures of

gender identity in order to account for potential lack of depth in interview responses.

## 2.6.4. Clinical Implications

Although there have been some positive advances in the development of specialist services for people with AS in the UK in recent years, particularly thanks to voluntary sector organizations and the tenacity of individuals with AS themselves<sup>26</sup>, there remains significant gaps in services available to a population who clearly experience difficulties across various aspects of their functioning and well-being over a lifetime.

The current study highlights indicators of low mood, low self-esteem and anxiety in adults with AS as a consequence of a lifetime of maltreatment and bullying by others. Good outcomes have been reported in the use of Cognitive Behaviour Therapy (CBT; Weiss & Lunsky, 2010) and psychotherapy (Ramsay, Brodkin, Cohen, Listerud, Rostain & Ekman, 2005) with adults with AS who present to services with anxiety and depression. Given the prevalence of psychiatric disorders in this population (Ghaziuddin, 2005), challenges to therapy associated with AS including lack of self-awareness (Sofronoff & Beaumont, 2009) and a lack of therapist experience and perceived competence in working with this client group (Powell, 2002), more work should be dedicated to training mental health practitioners and other relevant professionals such as GPs in working effectively and sensitively with these individuals. Further, clinicians need to be made aware of possible issues

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<sup>&</sup>lt;sup>26</sup> See Lorna Wing's (2005) paper on her own reflections of progress and controversy in the world of AS since she first published her paper on Asperger's Syndrome in 1981.

relating to gender identity and sexuality within this population in order to accurately identify and address these difficulties as potential precursors or indicators of poor mental health. In addition, clinicians would be wise to reflect on their own assumptions about gender and stereotypes in order to aid their understanding of patients' experiences.

Further, early intervention for young people with AS diagnosed in childhood could be targeted at raising awareness of possible gender identity confusion and implications for mental health. Parents of newly diagnosed young people may benefit from psychoeducation around gender identity formation and possible signs of distress.

#### 2.6.5. Areas for future research

Although fewer women (Ehlers & Gillberg, 1993) and ethnic minorities (Mandell, Wiggins, Carpenter, Daniels, & DiGuiseppe, 2009) receive diagnoses of AS, future research would benefit from including these sub-groups where possible in order to further explore issues relating to gender and identity. Previous research has found more incidences of bisexuality, asexuality and tomboyism in women with AS, which has been suggested to be caused by elevated testosterone levels (Ingudomnukul, Baron-Cohen, Wheelwright & Knickmeyer, 2007). However, further research could explore alternative social and environmental factors that may account for this phenomenon.

Research suggests that early intervention and increasing availability of services for young people with AS will have positive outcomes for future generations of adults (e.g., see Gillespie-Lynch, Sepeta, Wang, Marshall, Gomez, Sigman & Hutman, 2012). Since rates of diagnosing in early childhood are increasing (Matson, 2007) and gender identity begins forming in infancy, longitudinal studies could be used to capture the experiences of individuals who are diagnosed earlier. Age at diagnosis has also been found to affect individual's perceived self-identity (Punshon, Skirrow & Murphy, 2009) which warrants further investigation in terms of intrapersonal factors such as mood and functioning.

The categorization and diagnosis of Asperger's Syndrome as a disorder distinct from Autism remains widely debated and variations in clinical practice are widespread (Matson & Wilkins, 2008). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) is scheduled for publication in 2013 (Frances, 2010) and has sparked controversy by proposing a single diagnostic category of Autism Spectrum Disorder meaning that Asperger's Syndrome will 'disappear' as a category in its own right (Ghaziuddin, 2011). Future research would be wise to explore the effects of this decision on outcomes and quality of life for the ever-growing population of individuals already labeled with AS, specifically with regard to their sense of identity, self-concept, and perceived well-being.

As previously mentioned, future research may benefit from combining qualitative experiential data with quantitative measures of identity in order to allow for inferences to be made from a richer data set (Tashakkori & Teddlie, 2003).

However, the efficacy and validity of gender identity measures has been questioned by researchers in this area (e.g. see Palan, Areni & Kiecker, 1999). Masculinity factors are no longer as strongly associated with biological sex given that present day females are more likely to exhibit traits which twenty years ago were more likely to have been perceived to be primarily masculine. More research is needed in order to ensure that empirical measures of gender identity keep up with cultural shifts in gender roles and evolving societal values so that valuable scientific research in this area can continue.

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# **Chapter 3:**

"What difference can I make?" – Reflections on a postgraduate research journey.

# 3.1. Overview

The following paper will review my personal experience of conducting research as part of my Doctorate in Clinical Psychology. Throughout the process of designing and conducting my research I have kept a reflective journal of my experiences, thoughts, hopes, fears, and doubts. This paper will present the contents of my journal following the chronology in which it was written, using quotes from my diary to introduce each section.

# 3.2. Initial fears - "Scared to do a good enough job"

When I embarked on my research journey, I surprised myself with how little confidence I had in my ability to complete a piece of work at this level. Given my relative inexperience in conducting clinical research, I found myself using words like 'daunted' in my diary to describe the anxiety I was feeling. I am very aware from my reflective practice throughout training that I often appear much more confident than I feel and doubt my academic ability more than is necessary or healthy. Postgraduate level research was another challenge that I wanted to face but was anxious about doing. As a result, I found myself procrastinating as much as I could get away with during the early stages, both in avoidance and fear of failure.

Another challenge that I found particularly hard was transforming a vague idea based on a general clinical interest into a robust piece of scientific research that would be worthy of reading. Having got the idea to look at gender identity in adults with Asperger's syndrome (AS) from my clinical observations of individuals within that population experiencing gender dysphoria, I had no idea how difficult it would

be to translate an idea into a valid research question that could be investigated in our allotted time. I found myself getting more anxious and feeling even less capable after emailing and meeting various researchers in the field who were used to larger scale and bigger budget projects. They bombarded me with terminology I did not understand and made my original ideas sound far more complicated than they had in my head. I remember feeling like I was starting to drown in theories and ideas, to the point where I wished someone could just tell me what to do and how to do it. At a point where I was struggling to keep my head above water, I wrote in my diary;

"Need to sit back, get some perspective and have confidence in my own ability."

Those words, alongside advise from my research team and others who had been through it and out the other side, helped me to find a balance between writing a piece of research that is worthy of publication and just being able to pass and receive the qualification that I have spent several years trying to attain. All I knew was that I wanted to stick to my guns and follow my original idea because I do not feel like a skilled enough researcher to undertake a project that does not fascinate me. That is a decision that, in hindsight, I am very glad I made.

# 3.3. Thoughts on participant recruitment - "I feel so grateful for their time"

As soon as I started to develop my research methodology, I began working with people with Asperger's syndrome; from the professional with AS who consulted with me from the beginning, to the people I met at Autism West Midlands and the head of the local support group who invited me to one of their meetings. I was genuinely overwhelmed by both their interest in my research and their willingness to help me. I have spent a lot of time reflecting on the warmth I felt towards all those individuals who met me, talked to me, and agreed to be interviewed by me. At times I found myself getting dragged down by participant numbers and fears of not recruiting enough people but now that I have finished I can look back and feel so grateful that 7 people gave up an hour of their lives to tell me their stories.

I often struggled with the thought that even though people overtly expressed their gratitude at being listened to by a professional and having their disorder (which so many of them feel proud of) researched by psychologist, I always worried about them being adversely affected by it all. After one particular interview, I had written in my diary;

"Feel so guilty when people break down emotionally and feel very unethical."

I took this issue to my research meetings on several occasions and felt like I needed regular reassurance that what I was doing was OK. I needed to keep reminding myself that even though some participants found it distressing to talk about certain things, a) I am a skilled clinician who knows how to act appropriately and

supportively, and b) they have chosen to come forward and be interviewed because they want to be heard. This is a moral dilemma that clinical researchers will always face when working with people's distress, and one which I found particularly hard to accept.

# 3.4. Introduction to the research interview process - "Did I even give people enough space to tell their story?"

I found the process of conducting interviews and thus listening back to them in during transcribing more exposing than I had thought it would feel. I am not accustomed to recording my clinical practice and listening back to it, although I have since thought about the obvious benefits of this process. As exposing as it was, listening back to the tapes of my interviews allowed me to reflect on and critique my own style and practice and is something that psychologists ought to do more regularly.

At times I heard myself interjecting during a pause or returning to one of my scheduled questions when I felt I could have allowed the participant to follow a different avenue of conversation. I remember feeling challenged by the time constraints of my interviews and trying to find a balance between allowing the interviewee space and following a prescriptive methodology. As Smith et al. explain "....getting the relationship between the schedule and the interview right is one of the hardest things for students to acquire" (Smith et al., 2009, pp65.). I therefore

found myself feeling reassured when my last interviewee, Jon\* commented at the end of his interview;

"That's my pleasure, I've erm really enjoyed this afternoon....talking about Asperger's which might I add is a gift at the end of the day.....I've always said that when I've been interviewed because of my art and that, I've always said that it's a gift. But people need to listen and to understand us. Not to provoke us.....or push us or put pressure on us.....so, thank you very much for listening and understanding, Vicky."

(Jon\*; line 977)

# 3.5. Role transition - "Wanting to 'therap' - conflict between psychologist and researcher"

Another dilemma I found myself facing during the interview process was how to use my skills as a clinical practitioner in order to capture somebody's experience for the purposes of research without creeping into the territory of psychological therapy. Although the scientist-practitioner model is thought to be the motivating force behind the training and practice of clinical psychologists, some ambivalence remains regarding the value of scientific research within the profession and indeed how well-equipped newly qualified psychologists feel in conducting research given current NHS contexts and ever-changing role expectations (see Chang et al., 2008). This has been a strong theme underlying the whole experience of Clinical Psychology training for me and therefore formed a large part of my reflections whilst conducting my research. As with many other Trainee Psychologists I feel

.

<sup>\*</sup> Name has been changed

more competent as a clinician than as a researcher (Wright & Holttum, 2012), with the latter taking up considerably less of my time in comparison with the amount of client therapeutic hours accrued during training.

During my interviews there were several occasions when participants became mildly distressed and tearful when telling me about difficult life experiences. Whilst I was able to acknowledge that the emotive experiences they shared were hugely enriching to the data, I often felt caught in the professional dilemma of wanting to work psychologically with the issues they were bringing, rather than just listen.

When reflecting on my emotions during the interviewing process and, in particular the sense of warmth I felt towards my participants and the desire to 'help' them, I came across an article by Dr Louise Rowling (Rowling, 1999) in Australia based on several years experience of conducting highly emotive qualitative interviews about loss and grief. I agree with Dr. Rowling's argument that relatively little attention is paid within the research literature to the emotional experience of the researcher and the dilemma of how much distance to maintain between you and your participants. I think this is of particular relevance to individuals who have spent years training to alleviate psychological distress, and is a dilemma I experienced almost immediately.

When reflecting on her position in the interview dynamic, Dr. Rowling found it helpful to look at not only the role she saw herself as fulfilling, but also the role she felt her participants perceived her as fulfilling. I found this extract from her paper

particularly relevant to my situation when thinking about what motivated my participants to volunteer to talk to me about Asperger's Syndrome;

"It appeared that being involved in research facilitated disclosure, disclosure some may not feel comfortable with in a counselling session where they perceive themselves as 'needing help'. It is my belief that in the research interaction they were 'powerful', they were offering their experience so that it might help others.

It was not a situation where they were exposing themselves as being unable to cope and needing counselling."

(Rowling, 1999; pp.173)

Given the number of occasions participants told me about their desire to reach out to others within the AS community and increase awareness of their condition amongst professional groups, I found myself feeling differently about my role within the research interview dyad and was able to sit more comfortably with any psychological distress that arose.

# 3.6. Personal reflections of transference - "I feel uncomfortable with some of the things they are saying"

As I became engrossed in the interviewing process, one of the issues that I reflected on a lot was my position as a female researcher interviewing men about their sexuality and sexual development. I often found myself feeling uneasy in the room when participants were talking quite graphically about examples of their sexual behaviours and preferences. As psychologists, we work primarily with emotions and

psychological distress and thus have a tendency to avoid talking to our clients about sexual issues in detail, instead signposting them elsewhere. I am still not sure why I felt so uncomfortable in some of my interviews; perhaps it was some of my own prudishness and embarrassment at hearing men talk so graphically, perhaps it was my lack of experience in working with sexual issues, or perhaps it was a reaction to the bluntness and lack of embarrassment exhibited by my interviewees as a result of having Asperger's Syndrome. Of course, it may be a combination of all of these factors.

These feelings made me reflect more generally on gender issues arising during therapy. By the very nature of my study, participants talked a lot about their sense of masculinity and how they believe males to be perceived within society as being strong, powerful and dominant. However, in this setting and in many therapeutic settings, these perceived gender roles become imbalanced when a man is being given the space to be emotional and show vulnerability to a woman in a perceived position of power. Studies have found that the extent to which clients perceive both themselves and their therapist to conform to gender-role stereotypes has a profound effect on the therapeutic relationship (Gehart & Lyle, 2001). If this is the case for client experience then it is likely to also be the case for therapists who perceive their client as conforming highly to gender-role stereotypes. I was aware that my discomfort was more prominent when the men I was interviewing were discussing the objectification of women and their sexual desires towards women, which I found particularly hard to listen to without challenging or questioning.

Given the potential impact of gender-role stereotypes within the therapeutic relationship eluded to by Gehart & Lyle and indeed the subject area of my empirical paper, I believe that more research could be done to investigate this phenomenon further, especially now that there is a growing gender-imbalance within the clinical psychology profession (Snyder et al., 2000).

# 3.7. Hopes and agendas - "What difference can I make?"

Despite recent growth in the popularity of qualitative methods for conducting research within psychology, I often wondered whether I could have conducted research on a larger scale and with more clinical applicability had I chosen a different approach. Historically, qualitative research has tended to evoke stereotyped objections from the scientific world for failing to be scientific, objective, reliable, generalisable, formalised, or intersubjective (Kvale, 1994). Although I was approaching my research as a required component within a qualification instead of a stand alone project, I have remained adamant throughout that I want my work to be worthwhile. More so than accolades or respect from academic peers, the most important thing to me has been that the time and effort I have applied to this piece of work can be valuable in raising awareness of Asperger's Syndrome and giving my participants a voice.

I never expected to become so emotionally attached to my participants and the AS community in general, nor did I expect to care so much about disseminating my work more widely. I have found myself feeling really pleased when colleagues have asked me what my research topic is and been genuinely interested by it. So,

ultimately I have ended up answering my own question because even if one person reads my paper, I will feel that I *have* made a difference to the people I interviewed.

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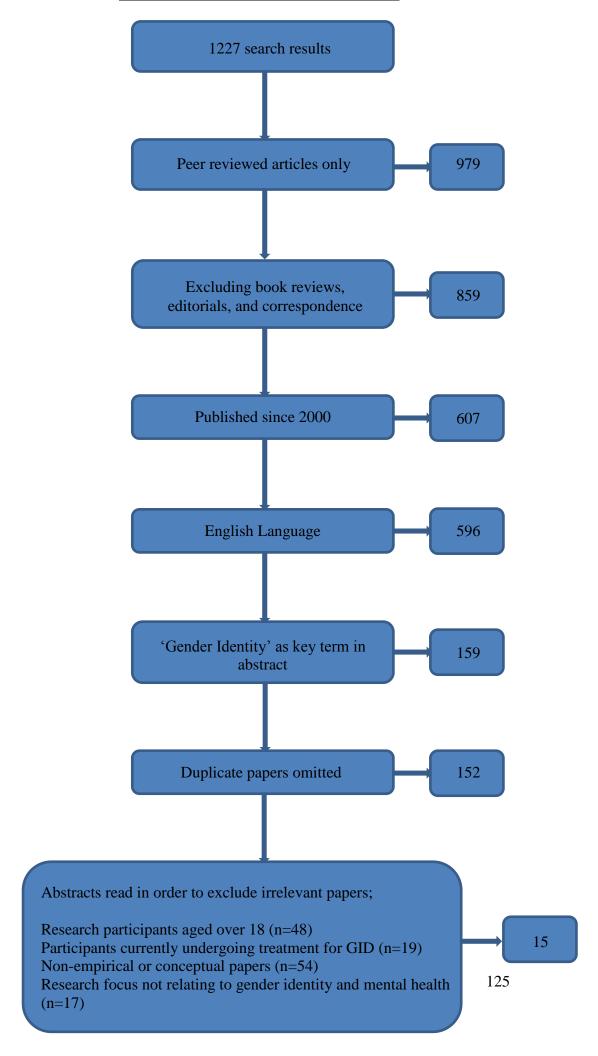
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# **Appendix One – Literature search strategy**



# **Appendix Two - Interview Schedule**

- 1. What do you understand by the term 'gender'?
  - What is your gender?
  - What does it mean to you to be a man/woman?
  - What do you think being a man/woman means in today's society and/or the media?
- 2. Tell me about your significant relationships, including friends, family, partners.
  - How do you get on with people?
  - Do you get on better with men or women?
  - Why do you think that is?
  - Who was your primary carer/parent?
  - What was your relationship like with your mother and father?
- 3. How do you think people see you?
  - Do you think people treat you differently because of your AS? In what ways?
  - How did people treat you when you were growing up?
  - Growing up, did you have anyone in your life who was a significant, positive role model?
- 4. Tell me about your experience of puberty.
  - What did the experience feel like? Was it distressing/difficult?
  - Did you talk to anyone about how you felt?
  - Do you think people could have helped you better?
- 5. What do you understand by the term 'sexuality'?
  - What is your sexuality?
  - What does your sexuality mean to you?
  - When were you first aware of your sexuality?
  - How do you express your sexuality? Current relationship?
- 6. Do you ever want to be different?
  - Do you feel you have things in common with other men/women?
  - Do you feel satisfied being a man/woman?

Version 2 – 08.08.11

# REGISTRY RESEARCH UNIT ETHICS REVIEW FEEDBACK FORM [Keynow locaback from a be completed within 10 working

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# Research Information Leaflet

# Exploring Gender Identity in Adults with Asperger's Syndrome.

This leaflet gives you information on the study I am undertaking as part of my research for my Doctorate in Clinical Psychology. The leaflet describes the purpose of the study and what taking part in the study will involve. If you have any additional questions please contact me using the details at the end of the leaflet.

# What is the purpose of the study?

The aim of the study is to find out about the experience of living with Asperger's Syndrome (AS) and what 'gender' means to you within the context of having AS.

# Why have you been approached?

I am planning to recruit a small number of adults who have a diagnosis of AS. The National Autistic Society and Autism West Midlands have kindly agreed to support the study.

# Do people have to take part?

No, participation is entirely voluntary. If you change your mind about taking part in the study you can withdraw at any point during the interview and at any time in the two weeks following that session. You can withdraw by contacting me by email or telephone (details at the end of this leaflet). If you decide to withdraw, all of your data will be destroyed and will not be used in the study. There are no consequences to deciding that you no longer wish to participate in the study.

# What will happen if you decide to take part in the study?

I will come to meet you at a venue we decide upon for a one-toone interview with me. This will last approximately one hour. During the conversation you will be asked questions about your experiences of growing up with AS and how you see yourself. We will talk about your sexuality and gender. This will be taperecorded, and you are free to take a break at any point.

# What are the possible disadvantages and risks of taking part in the study?

You may find it upsetting to talk about some of your past and present experiences living with AS. You can choose not to an-

swer any of the questions you might find difficult, or decide not to take part in the research even after the interview has finished.

# What are the possible advantages of taking part?

Everybody who takes part in this study will be entered into a prize draw for a £20 high street voucher. The winning name will be drawn after the last interview has taken place, and the winner will be informed by post. The study gives you the opportunity to talk about your experiences, including the things that have gone well for you in your life. This information will be helpful to both professionals and people with AS, particularly when looking at ways to provide you with the best support.

# What if something goes wrong or if you are not happy with some part of the process of taking part?

If you change your mind about taking part in the study you can withdraw at any point during the interview and at any time in the two weeks following that session by contacting me directly. If you decide to withdraw, all of your data will be destroyed and will not be used in the study. However your name will still be entered into the prize draw. If you feel distressed after taking part in the study, and wish to talk to someone other than family or friends, you can contact:

Dr Gavin Farrell - Chartered Clinical Psychologist. Tel. 0300 2000 395

If you wish to complain about any part of the study, please contact Dr Gavin Farrell or Dr David Sanders at Coventry University.

#### Will taking part in this study be kept confidential?

Yes. Only I will have access to the audio-tapes and the transcriptions of the interviews, which will be kept in a locked cabinet. The tapes and transcriptions will be given identification codes rather than being labelled by name. They will be destroyed after the research is completed. When the findings are written up, all quotes will be identified by the code rather than your name, and any other identifying details will be removed.

#### What will happen to the results of the research study?

The findings of the study will be written up and presented as part of my Clinical Psychology doctoral thesis. The paper may also be submitted to the journal 'Autism', and presented at a National Autistic Society conference. No names or identifying details will be included. If you wish to receive a written summary of the main findings from the study, please tick the box on the Consent Form.

Unfortunately feedback on your particular interview will not be available.

#### Who is organising and funding the research?

The research is organised by Victoria Elliott, who is a Trainee Clinical Psychologist at Coventry University. This project is funded by the University. The National Autistic Society and Autism West Midlands have kindly agreed to help with the recruitment of participants.

#### Who has reviewed the study?

This study has been through the University Peer Review process and been approved by the Chair of the University Applied Research Committee.

## Contact for further information:

Victoria Elliott (main researcher)
Clinical Psychology Doctorate Programme
Coventry University
James Starley Building
Priory Street
Coventry
CV1 5FB 02476888328
elliottv@uni.coventry.ac.uk

Victoria Elliott

# **Appendix Five - Participant Information Sheet**

**Title of the proposed study:** Exploring Gender Identity in adults with Asperger's Syndrome.

This sheet gives you information on the study I am planning to undertake as part of my research for my Doctorate in Clinical Psychology. The sheet describes the purpose of the study and what taking part in the study will involve. If you have any additional questions about the study please contact me on the details at the end of the information sheet.

# What is the purpose of the study?

The aim of the study is to explore what 'gender' means to people who have a diagnosis of Asperger's Syndrome (AS).

# Why have you been approached?

I am planning to recruit a small number of adults who have a diagnosis of AS. You have been chosen because you attend a support group for people with Autism Spectrum Disorders.

# Do people have to take part?

No, participation is entirely voluntary and has no effect on you attending the support group. If you change your mind about taking part in the study you can withdraw at any time during the interview or in the two weeks that follow. You can withdraw by contacting me by email or telephone using the details at the end of this sheet. If you decide to withdraw, all of your data will be destroyed and will not be used in the study.

# What will happen if you decide to take part in the study?

You will be asked to come to the venue of the support group for a one-to-one interview with me, which will last approximately one hour. During the interview you will be asked questions about your experiences of growing up with Asperger's syndrome and about how you see yourself as a person. I may also ask you about how you think other people see you. The interview will be tape-recorded, and you will be able to take a break at any point.

# What are the possible disadvantages and risks of taking part in the study?

You may find it upsetting to talk about some of the issues related to having AS and the experiences you have been through. If you feel that you need to talk to someone further after the interview has finished, this can be arranged. You can choose not to answer any of the questions you might find difficult, or decide not to take part in the research even after the interview has finished.

# What are the possible advantages of taking part?

Everybody who takes part in this study will be entered into a prize draw for a £20 high street voucher. The winning name will be drawn after the last interview has taken place, and the winner will be informed by post. The study gives you the

opportunity to talk about your experiences, including the things that have gone well for you in your life. This information will be helpful to both professionals and other people with AS, particularly when looking at ways to provide you with the best support.

# What if something goes wrong or if you are not happy with some part of the process of taking part?

If you change your mind about taking part in the study you can withdraw at any point during the interview and at any time in the two weeks following that session by contacting me using the email address or telephone number stated below. If you decide to withdraw, all of your data will be destroyed and will not be used in the study. However your name will still be entered into the prize draw. If you feel distressed after taking part in the study, and wish to talk to someone other than family or friends, you can contact:

Dr Gavin Farrell - Chartered Clinical Neuropsychologist. Tel. 0300 2000 395

If you wish to complain about any part of the study, please contact Dr Gavin Farrell.

# Will taking part in this study be kept confidential?

Yes. Only I will have access to the audio-tapes and the transcriptions of the interviews, which will be kept in a locked cabinet. The tapes and transcriptions will be given an identification code rather than being labelled by name. They will be destroyed when the project has finished. When the findings are written up, all quotes will be identified by the code rather than your name, and any other identifying details will be removed.

# What will happen to the results of the research study?

The findings of the study will be written up and presented as part of my Clinical Psychology doctoral thesis. The paper may also be submitted to the journal 'Autism', and presented at a National Autistic Society conference. No names or identifying details will be included. If you wish to receive a written summary of the main findings from the study, please tick the box on the Consent Form. Unfortunately, feedback on your particular interview will not be available.

## Who is organising and funding the research?

The research is organised by Victoria Elliott, who is a Trainee Clinical Psychologist at Coventry University. This project is funded by the University. The National Autistic Society has kindly agreed to allow the recruitment of participants from their local support groups.

## Who has reviewed the study?

This study has been through the University Peer Review process and been approved by the Chair of the University Applied Research Committee.

# **Contact for further information**

Victoria Elliott (main researcher)

Clinical Psychology Doctorate Programme
Coventry University
James Starley Building
Priory Street
Coventry
CV1 5FB
elliottv@coventry.ac.uk

Tel. 02476 887806

# <u>Appendix Six</u> <u>Exploring Gender and Identity in Adults with Asperger's Syndrome</u>

# **Informed Consent Form**

Please refer to the Participant Information Sheet (PIS.1/VE/DClinPsy/2011) for a summary of the research project.

1. I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions.	Please tick
2. I understand that my participation is voluntary and that I am free to withdraw at anytime without giving a reason.	
3. I understand that all the information I provide will be treated in confidence.	
4. I understand that I also have the right to change my mind about participating in the study during the interview process or up to two weeks following the date of my interview.	
5. I agree to be audio-tape recorded as part of the research project.	
6. I agree to take part in the research project.	
7. I wish to receive a written summary of the main findings of the study.	
Name of participant:	
Signature of participant:	

Date:	
Name of Researcher:	Victoria Elliott (Trainee Clinical Psychologist)
Signature of researcher	r:
0 111 11 111 11	
Data	

# Exploring Gender Identity in Adults with Asperger's Syndrome

Thank you for taking part in the study. I hope you have found the interview process useful. Please be assured that your participation is greatly appreciated; without your help this research would not be possible.

Please remember that if you wish to withdraw from the study at any point within the next two weeks, you can do so by contacting me using the details below.

In the unfortunate event that you feel distressed or upset about any of the things we have talked about today, please contact me so that I can arrange a follow-up appointment, if necessary, with Dr. Gavin Farrell.

If you wish to complain about any part of the interview process, please contact Dr. Gavin Farrell directly on the details below. Alternatively, please contact Dr. David Sanders at the Clinical Psychology Doctorate Programme.

## **Contact for further information**

Victoria Elliott (main researcher)
Clinical Psychology Doctorate Programme
Coventry University
James Starley Building
Priory Street
Coventry
CV1 5FB
elliottv@coventry.ac.uk

Tel. 02476 887806

Dr. Gavin Farrell
Clinical Neuropsychologist
Community Rehabilitation Team
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Coventry
CV1 4NZ
gavin.farrell@coventrypct.nhs.uk

Tel. 0300 2000395



# Appendix eight – Summary of the analytic process in IPA

# Stages of data analysis in IPA (Smith, Flowers and Larkin, 2009)

# Stage 1 - Reading and re-reading

Researcher immerses herself in original data by repeated listening to audio recordings of interviews and re-reading transcripts. Initial thoughts and observations are noted to be referred to later. Repeated reading allows active engagement with the data and ensures that the participant becomes the focus of the analysis.

# Stage 2 – Initial noting

Examines semantic content and language use. Descriptive notes are written on the transcript, remaining as close to participants explicit meaning as possible. Descriptive comments focus on content and subject of what participant says. Linguistic comments focus on specific use of language. Conceptual notes will then emerge which focus on more interrogative and interpretative reflections of the researcher.

# Stage 3 – Developing emergent themes

Reduces volume of detail whilst maintaining complexity by mapping connections and patterns between exploratory notes. Produces a concise statement of what was important in the various comments attached to each piece of transcript. Themes are expressed as phrases which speak to the psychological essence of the piece. Themes reflect not only participants' words but also researcher's interpretations.

# Stage 4 – Searching for connections across emergent themes Involves mapping how the researcher thinks the themes fit together. Draws together emergent themes into clusters of related themes. Can be achieved creatively, graphically, or visually.

# Stage 5 – Moving to the next case

Repeating the process above for the next participant's transcript, treating it on its own terms. Continue for each subsequent participant.

# Stage 6 – Looking for patterns across cases

Looking for potent themes and connections across cases. This process may lead to reconfiguring or re-labelling of themes. A creative process which can be displayed graphically or in a table of themes for the group.

# Appendix Nine - Example of coded interview transcript

VE Interview 2 - Gary\* Yeah, exactly, yeah. 'Cos there was a girls who was in my class at school, for the first seep she lived round the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and the comer from me and I know she had it quite bad as hard and I know she had it quite bad as hard and I know she had it quite bad as hard and I know she had it quite bad as hard and I know she had it quite bad as hard and I know she had it quite bad as hard and I know she had it quite bad as hard and I know she had it quite bad as hard and I know she had it quite bad as hard and I know she had a know she ha well.....erm, the thing was she used to scare quite easily so they would make all sorts of animal poisso to be make all sorts of animal noises to her and, in an attempt to set her offen what-not......so, I think in a way I kind of got a grasp quite early on of what people could be like and...... And some would say yeah I have got quite a dark view of things at times, but its only been from what I've experienced myself and what I've seen so that's where that's come from. 1: So you made that decision to say no, you get on with being how you are and I don't care what you think, I'm going to do what I want to do. Yeah. I mean, naturally I am kind of sensitive and .... I want people to like me but, you know its sort of, you sort of realise that actually....there are 1 Feels take gonna be people who try and drag you down, you know if you let them....and you've gotta stick to what you want to do and what you feel you've gotta do, really to get ahead. 1: P: (smiles) Thanks. So can you tell me a bit about your relationships generally, like how do 1: you get on with people? Fairly well, I think anyway. I mean, at work I mean, I'm a supervisor, I mean yeah I will talk to people fairly normally, I mean I haven't really told Important to him that he is in a power power others 5 \*name has been changed

VE Interview 2 - Gary\*

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many people that I've got Asperger's and I went to a special needs school because...... back then, er, it was a lot different especially when I left school because I felt that I lost friends, well supposed friends, and I lost missed opportunities because it was.....because I, I was being honost enough to say to people "yeah, I went to a special needs school, I have this" and they turned against me because of that really, and I missed opportunities because of that as well.......so I made that decision not to be as honest about it really......yeah, some would say it's a bit deceitful and its not being honest but being honest can cost you as well, really.....but I suppose in my relationships with people is that whilst I talk to people I am, I am an outsider.....really.....you know, when there's groups of people and I know, you know even if they're people I know fairly well....they'll be in their little groups and I'll be quite often on my own doing, if I'm working doing making sure there's stuff being done at work.....er, just generally making sure I'm doing my job properly and if they wanna involve me in the conversation then....they know where I am......basically......?

So why is that? Why do you think that is that you're an 'outsider'?

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(pause) Em.....I've always been an outsider, basically you know from Thopedessnees going to that special needs school...... because the kids knew I was different, I was the outsider, basically.....and then I went through a period when erm.....I tried to be more outgoing, you know I was a bit louder, this is probably when I was around 16 to er, 18, I was basically being a bit loud and I was just trying to make a good impression on people.....and the thing was is wasn't working and people were still saying, "Oh yeah, Dave's alright" but then they would go over to their other little clique and beauty indextlored er......stay with them, really......and......you know, it was only after you whom it was only after you wh

but stu pretending?

\*name has been changed

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# Appendix Ten - Child Development Guidelines

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Edited By: Jeffrey J. Lockman

Impact Factor: 3.77

ISI Journal Citation Reports © Ranking: 2010: 1/50 (Psychology Educational); 7/66 (Psychology Developmental)

Online ISSN: 1467-8624

Associated Title(s): <u>Child Development Perspectives</u>, <u>Monographs of the Society for</u> Research in Child Development

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## Chapter in edited book:

Craik, F. I. M., Naveh-Benjamin, M., & Anderson, N. D. (1998). Encoding processes: Similarities and differences. In M. A. Conway, S. E. Gathercole, & C. Cornoldi (Eds.), *Theories of memory* (Vol. 2, pp. 61-86). Hove, UK: Psychology Press.

# Journal article:

Adlington, R. L., Laws, K. R., & Gale, T. M. (2009). The Hatfield Image Test (HIT): A new picture test and norms for experimental and clinical use. *Journal of Clinical and Experimental Neuropsychology*, *31*, 731-753. doi:10.1080/13803390802488103

*Tables.* These should be kept to the minimum. Each table should be typed double spaced on a separate page, giving the heading, e.g., "Table 2", in Arabic numerals,

followed by the legend, followed by the table. Make sure that appropriate units are given. Instructions for placing the table should be given in parentheses in the text, e.g., "(Table 2 about here)".

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For more detailed guidelines see <u>Preparation of Figure Artwork</u>.

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"... results showed an effect of group, F(2, 21) = 13.74, MSE = 451.98, p < .001, but there was no effect of repeated trials, F(5, 105) = 1.44, MSE = 17.70, and no interaction, F(10, 105) = 1.34, MSE = 17.70."

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