

THE SCHOOL EXPERIENCES OF  
FEMALES WITH ASPERGER'S  
SYNDROME: THE  
RECOLLECTIONS OF ADULTS  
AND PERSPECTIVES OF  
PARENTS

*Belinda Claire Jarman*

BA (University of Tasmania, 2008)

GradDipCouns (University of Tasmania, 2009)

MTeach (University of Tasmania, 2011)

M.Ed (University of Tasmania, 2012)

Submitted in partial fulfilment of the requirements for the degree of Master of  
Education with Honours

Faculty of Education

University of Tasmania,

Hobart, Tasmania.

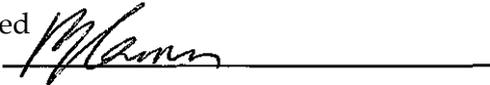
October 2013

## Statement of Authenticity and Access

To the best of my knowledge and belief, the work presented in this thesis is original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution. Apart from direct consent from the author, this thesis may be made available for loan and limited copying with conformity to the Copyright Act 1968.

Name: Belinda Jarman

Signed



Date: 22.10.2013

## Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines of the Human Research Ethics Committee (Tasmania), the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University. (See also Appendix B and Appendix D for approval of the project.)

Name: Belinda Jarman

Signed  \_\_\_\_\_

Date: 22.10.2013

## Acknowledgments

I have been both privileged and honoured to work with two wonderful supervisors while undertaking this research and completing this thesis. I would like to thank both Doctor Christopher Rayner and Associate Professor Kim Beswick for their support, advice and enthusiasm.

This research would not have been possible without those who responded to my surveys-I am very grateful to all my participants who were willing to share so much detail about their own, or their daughters' school experiences.

Thanks must go to my parents for their love and support, especially my Mum who always told me I could achieve anything I wanted to, as long as I worked hard. I am also grateful to my good friend "A" who continually indulged me by listening to me talk about this project from the first day to the last, and my oldest friend Lesley for her ongoing support. And finally, I thank God for His limitless grace and wisdom for leading me to this point, and allowing me to achieve something I once did not think possible – 'I can do all things through Christ who strengthens me' (Philippians 4:13).

## **Abstract**

In this qualitative study, the school experiences of females with Asperger's Syndrome (AS) were examined. A total of 32 participants (24 adults with AS, 8 parents of daughters with AS) completed an anonymous online survey with 8 open-ended questions in regards to their, or their daughter's, school experiences. Participants described their, or their daughter's experiences with issues such as a lack of teacher understanding of AS, particularly in regards to females, and the social difficulties experienced by females with AS at school, such as a high incidence of bullying, feeling different from their peers, difficulties developing and maintaining friendships, and a vulnerability to mental health concerns. In addition, participants also discussed helpful and unhelpful teaching strategies, and academic experiences. Results from this study indicate there is a need for further teacher education in regards to AS and its associated characteristics and challenges, particularly in regards to females. In addition, the results have suggested that the social aspects of school are particularly challenging for many female students with AS, and that females with AS are vulnerable to developing mental health problems. Implications of these findings, as well as recommendations and suggestions for further research are discussed.

# Table of Contents

<b>Statement of Authenticity and Access.....</b>	<b>i</b>
<b>Statement of Ethical Conduct.....</b>	<b>ii</b>
<b>Acknowledgments.....</b>	<b>iii</b>
<b>Abstract.....</b>	<b>iv.</b>
<b>Table of Contents.....</b>	<b>v.</b>
<b>List of Tables.....</b>	<b>x.</b>
<b>Glossary.....</b>	<b>xiv</b>
<b>Chapter 1 - Introduction.....</b>	<b>1</b>
1.1    Asperger’s Syndrome.....	1
1.1.1 <i>Asperger’s Syndrome as a diagnostic category</i> .....	2
1.1.2 <i>Asperger’s Syndrome and High Functioning Autism</i> .....	3
1.1.3 <i>Asperger’s Syndrome and DSM-V</i> .....	3
1.2    Characteristics of Asperger’s Syndrome .....	4
1.2.1 <i>Social skills</i> .....	5
1.2.2 <i>Communication and language</i> .....	6
1.2.3 <i>Intense and narrow interests</i> .....	6
1.2.4 <i>Impaired executive functioning</i> .....	7
1.2.5 <i>Impairments in motor skills</i> .....	8
1.3    The non-obvious nature of Asperger’s Syndrome.....	9

1.4	Asperger’s Syndrome and gender.....	10
1.4.1	<i>Diagnostic rates and issues</i> .....	10
1.4.2	<i>Females with Asperger’s Syndrome</i> .....	11
1.5	Outline of the study.....	13
1.5.1	<i>Problem statement</i> .....	13
1.5.2	<i>Purpose</i> .....	14
1.5.3	<i>Conceptual framework</i> .....	14
1.5.4	<i>Structure of the thesis</i> .....	15
<b>Chapter 2 - Literature Review .....</b>		<b>16</b>
2.1	Introduction.....	16
2.2	Research strategy .....	16
2.3	Characteristics of articles reviewed .....	17
2.4	Findings from the literature review .....	19
2.5	Social experiences .....	19
2.5.1	<i>Developing and maintaining friendships</i> .....	19
2.5.2	<i>Masquerading</i> .....	22
2.5.3	<i>Bullying</i> .....	23
2.6	Asperger’s Syndrome and mental health.....	26
2.6.1	<i>Anxiety</i> .....	26
2.6.2	<i>Depression</i> .....	27
2.6.3	<i>Suicidal Ideation</i> .....	28
2.6.4	<i>Eating Disorders</i> .....	29
2.7	Teacher characteristics and teaching practices.....	30
2.8	Gender and Asperger’s Syndrome.....	31

2.8.1	<i>Play</i> .....	32
2.8.2	<i>Social skills and communicative behaviours</i> .....	34
2.8.3	<i>Interests</i> .....	38
2.8.4	<i>Motor skills</i> .....	39
2.9	Identification of Asperger’s Syndrome .....	39
2.10	Summary.....	41
<b>Chapter 3 - Methodology</b> .....		<b>43</b>
3.1	Introduction.....	43
3.2	Ethical Considerations .....	43
3.2.1	<i>Gaining permission to conduct research</i> .....	43
3.2.2	<i>Consent</i> .....	43
3.2.3	<i>Assessment of risk</i> .....	44
3.2.4	<i>Privacy</i> .....	45
3.3	Research Design.....	45
3.3.1	<i>Participants</i> .....	46
3.3.2	<i>Recruitment of participants</i> .....	46
3.3.3	<i>Survey instruments</i> .....	48
3.3.4	<i>Approach to data analysis</i> .....	51
3.4	Summary.....	52
<b>Chapter 4 - Results</b> .....		<b>53</b>
4.1	Introduction.....	53
4.2	Study.....	53
4.3	Analysis of Survey Responses .....	55

4.4	Category 1: Issues requiring more understanding .....	58
4.4.1	<i>Theme 1: There is a lack of understanding regarding exactly what AS is, and its associated characteristics and challenges.....</i>	58
4.4.2	<i>Theme 2: AS is a “non-obvious” condition, perhaps even more so in females</i>	60
4.5	Category 2: Teaching strategies which had a positive impact .....	63
4.5.1	<i>Theme 1: Teachers who understood and accommodated sensory sensitivities</i>	63
4.5.2	<i>Teachers who had a positive perception of the student, worked from a strengths based approach, and were supportive .....</i>	65
4.5.3	<i>Theme 3: Providing the opportunity for female students with AS to participate in structured activities.....</i>	68
4.5.4	<i>Theme 4: Providing classroom environments which are predictable, while still allowing for flexibility .....</i>	70
4.6	Category 3: Areas of Academic Need.....	72
4.6.1	<i>Theme 1: Females with AS are capable of performing well academically.....</i>	72
4.6.2	<i>Theme 2: Each female student with AS is an individual in terms of her academic strengths and weaknesses, and subject preferences.....</i>	74
4.6.3	<i>Theme 3: Some teachers may have reduced expectations of female students with AS.....</i>	76
4.6.4	<i>Theme 4: Some female students with AS may experience executive function impairments.....</i>	78
4.7	Category 4: Areas of Social and Emotional Challenge and Need.....	80
4.7.1	<i>Theme 1: The social aspects of school are the most challenging for many female students with AS .....</i>	81
4.7.2	<i>Theme 2: The experiences of “feeling different” and “not fitting in” are common among female students with AS .....</i>	82
4.7.3	<i>Theme 3: Female students with AS often have difficulty developing and maintaining friendships.....</i>	84

4.7.4	<i>Theme 4: Female students with AS are vulnerable to being bullied.....</i>	87
4.7.5	<i>Theme 5: Female students with AS are vulnerable to experiencing mental health concerns .....</i>	89
4.8	Summary.....	92
<b>Chapter 5 - Discussion .....</b>		<b>94</b>
5.1	Introduction.....	94
5.2	Issues requiring more understanding .....	94
5.3	Teaching strategies and practices which had a positive impact .....	98
5.4	Areas of academic need .....	100
5.5	Areas of social and emotional challenge and need.....	102
5.5.1	<i>The experiences of “feeling different” and “not fitting in” are common among female students with AS.....</i>	102
5.5.2	<i>Female students with AS often have difficulty developing and maintaining friendships .....</i>	103
5.5.3	<i>Female students with AS are vulnerable to being bullied .....</i>	105
5.5.4	<i>Female students with AS are vulnerable to developing mental health Concerns.....</i>	108
	5.5.4.1 <i>Anxiety.....</i>	108
	5.5.4.2 <i>Depression.....</i>	110
	5.5.4.3 <i>Eating Disorders.....</i>	112
5.6	Implications and recommendations.....	113
5.6.1	<i>Education for teachers .....</i>	113
5.6.2	<i>Peer mentors.....</i>	115
5.6.3	<i>Social skills training and support.....</i>	116
5.6.4	<i>Mental health.....</i>	119

5.7	Limitations and future directions.....	122
5.8	Conclusion.....	123
	References.....	127
	Appendices.....	143
	<b>Appendix A:</b> Summary of Articles Reviewed .....	144
	<b>Appendix B:</b> Human Research Ethics Committee (Tasmania) Approval .....	168
	<b>Appendix C:</b> Participant Information Sheet.....	170
	<b>Appendix D:</b> Human Research Ethics Committee (Tasmania)Amendment Approval.....	174
	<b>Appendix E:</b> Adult Survey Questions .....	175
	<b>Appendix F:</b> Parent Survey Questions.....	176

## List of Tables

<i>Table 4.1</i>	Geographic Location of Participants.....	54
<i>Table 4.2</i>	Age Ranges of Female Adults with AS.....	55
<i>Table 4.3</i>	Age Ranges of Female Children with AS.....	55
<i>Table 4.4</i>	Themes Identified by Participants .....	57
<i>Table 4.5</i>	Responses Relating to Category 1, Theme 1: There is a Lack of Understanding Regarding Exactly what AS is, and its Associated Characteristics and Challenges (Parent Participants) .....	59
<i>Table 4.6</i>	Responses Relating to Category 1, Theme 1: There is a Lack of Understanding Regarding Exactly what AS is, and its associated Characteristics and Challenges (Adult Participants).....	59

<i>Table 4.7 Responses Relating to Category 1, Theme 2: AS is a Non-obvious Condition, Perhaps Even More So in Females (Parent Participants).....</i>	<i>61</i>
<i>Table 4.8 Responses Relating to Category 1, Theme 2: AS is a Non-Obvious Condition Perhaps Even More So in Females (Adult Participants).....</i>	<i>62</i>
<i>Table 4.9 Responses Relating to Category 2, Theme 1: Teachers who Understood and Accommodated Sensory Sensitivities (Parent Participants).....</i>	<i>64</i>
<i>Table 4.10 Responses Relating to Category 2, Theme 1: Teachers who Understood and Accommodated Sensory Sensitivities (Adult Participants).....</i>	<i>64</i>
<i>Table 4.11 Responses Relating to Category 2, Theme 2: Teachers who Had a Positive Perception of the Student, Worked From a Strengths Based Approach, and were Supportive (Parent Participants) .....</i>	<i>66</i>
<i>Table 4.12 Responses Relating to Category 2, Theme 2: Teachers who Had a Positive Perception of the Student, Worked From a Strengths Based Approach, and were Supportive (Adult Participants) .....</i>	<i>66</i>
<i>Table 4.13 Responses Relating to Category 2, Theme 3: Providing the Opportunity for Female Students with AS to Participate in Structured Activities (Parent Participants) .....</i>	<i>69</i>
<i>Table 4.14 Responses Relating to Category 2, Theme 3: Providing the Opportunity for Female Students with AS to Participate in Structured Activities (Adult Participants).....</i>	<i>69</i>
<i>Table 4.15 Responses Relating to Category 2, Theme 4: Providing Classroom Environments which are Predictable, while Still Allowing for Flexibility (Parent Participants).....</i>	<i>70</i>
<i>Table 4.16 Responses Relating to Category 2, Theme 4: Providing Classroom Environments which are Predictable, while Still Allowing for Flexibility (Adult Participants).....</i>	<i>71</i>
<i>Table 4.17 Responses Relating to Category 3, Theme 1: Female Students with AS are Capable of Achieving Well Academically (Parent Participants) .....</i>	<i>73</i>

<i>Table 4.18</i> Responses Relating to Category 3, Theme 1: Female Students with AS are capable of Achieving Well Academically (Adult Participants) .....	73
<i>Table 4.19</i> Responses Relating to Category 3, Theme 2: Each Female Student with AS is an Individual in Terms of Her Academic Strengths and Weaknesses, and Subject Preferences (Parent Participants).....	75
<i>Table 4.20</i> Responses Relating to Category 3, Theme 2: Each Female Student with AS is an Individual in Terms of Her Academic Strengths and Weaknesses, and Subject Preferences (Adult Participants).....	75
<i>Table 4.21</i> Responses Relating to Category 3, Theme 3: Some Teachers May Have Reduced Expectations of Female Students with AS (Parent Participants).....	77
<i>Table 4.22</i> Responses Relating to Category 3, Theme 3: Some Teachers May Have Reduced Expectations of Female Students with AS (Adult Participants).....	77
<i>Table 4.23</i> Responses Relating to Category 3, Theme 4: Some Female Students with AS May Have Executive Function Impairments (Parent Participants).....	79
<i>Table 4.24</i> Responses Relating to Category 3, Theme 4: Some Female Students with AS May Have Executive Function Impairments (Adult Participants).....	79
<i>Table 4.25</i> Responses Relating to Category 4, Theme 1: The Social Aspects of School are the Most Challenging for Many Female Students with AS (Parent Participants).....	81
<i>Table 4.26</i> Responses Relating to Category 4, Theme 1: The Social Aspects of School are the Most Challenging for Many Female Students with AS (Adult Participants).....	82
<i>Table 4.27</i> Responses Relating to Category 4, Theme 2: The Experiences of Feeling Different and Not Fitting In are Common Among Female Students with AS (Parent Participants).....	83
<i>Table 4.28</i> Responses Relating to Category 4, Theme 2: The Experiences of Feeling Different and Not fitting In are Common Among Female Students with AS (Adult Participants).....	83

<i>Table 4.29</i> Responses Relating to Category 4, Theme 3: Female Students with AS Often Have Difficulty Developing and Maintaining Friendships (Parent Participants ).....	85
<i>Table 4.30</i> Responses in Relation to Category 4, Theme 3: Female Students with AS Often Have Difficulty Developing and Maintaining Friendships (Adult Participants).....	85
<i>Table 4.31</i> Responses in Relation to Category 4, Theme 4: Female Students with AS are Vulnerable to Being Bullied (Parent Participants).....	88
<i>Table 4.32</i> Responses in Relation to Category 4, Theme 4: Female Students with AS are Vulnerable to Being Bullied (Adult Participants).....	88
<i>Table 4.33</i> Responses in Relation to Category 4, Theme 5: Female Students with AS are Vulnerable to Experiencing Mental Health Concerns (Parent Participants) .	90
<i>Table 4.34</i> Responses in Relation to Category 4, Theme 5: Female Students with AS are Vulnerable to Experiencing Mental Health Concerns (Adult Participants)...	90

## Glossary

- Anorexia:** An eating disorder which is diagnosed based on the following criteria outlined in DSM-IV and DSM-IV-TR: (a) body weight below what is considered to be normal for height and age, and refusal to maintain weight at or above a minimally normal weight for age and height, (b) intense fear of gaining weight despite being objectively underweight, (c) disturbance in how body weight or shape is perceived, denial of low body weight or self-evaluation unduly based on body weight or shape (d) amenorrhea in postmenarcheal females. DSM-IV and DSM-IV-TR specifies there are two subtypes of Anorexia: (1) restricting: weight loss is achieved and maintained through restrictive eating, and the individual does not binge eat or engage in inappropriate compensatory behaviours, (2) Binge-eating/purging: the individual regularly binge eats and/or engages in inappropriate compensatory behaviours while experiencing an episode of Anorexia (American Psychiatric Association, 1994, 2000).
- Anxiety** An unpleasant emotional state in which the individual experiences feelings of fear and apprehension, which are accompanied by physiological symptoms (Davison, Neale & Kring, 2004).
- Asperger's Syndrome** A mild Autism Spectrum Disorder. Individuals with AS

- (AS):** share the same DSM-IV and DSM-IV-TR characteristics as those with Autistic Disorder; however, individuals with AS have average or above average intelligence, and do not experience any delays in language development (American Psychiatric Association, 1994, 2000).
- Aspergirl:** An informal term for a female with Asperger's Syndrome (Simone, 2010).
- Aspie:** An informal term for an individual with Asperger's Syndrome (Willey, 1999).
- Autism Spectrum Disorder:** An umbrella term referring to a range of Pervasive Developmental Disorders. The three main conditions in this category are Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified (American Psychiatric Association, 2000; Bernier & Gerdt, 2010).
- Autistic Disorder:** An Autism Spectrum Disorder categorised by the following: (a) impairments in social interaction, (b) impairments in communication, (c) restrictive repetitive and stereotyped behaviour patterns and activities, and (d) delayed or abnormal functioning in one or more of the following areas: social interaction, language, and symbolic and imaginative

play (American Psychiatric Association, 2000).

**Bulimia:**

An eating disorder which is diagnosed based on the following criteria in DSM-IV-TR: (a) recurrent episodes of binge eating, in which individuals eat an amount of food objectively larger than what most people would eat in the same time frame and situation, and feel they have lost control over what and how much they are eating, (b) recurrent inappropriate compensatory behaviours (c) binge eating and compensatory behaviours occur at least twice a week on average, for 3 months or more, (d) the individual evaluates themselves unduly based on their weight or body shape (American Psychiatric Association, 2000).

**Depressive Episode:**

Described in DSM-IV-TR as a persistent depressed mood, or loss of pleasure or interest in usual activities for two weeks or more. In addition, for the depressive episode to be clinically significant, individuals must experience at least four symptoms from the following list: change in weight or appetite (in the absence of dieting), feeling worthless or guilty, loss of energy or fatigue, change in sleep patterns, indecisiveness, difficulty thinking or concentrating, or recurrent thoughts of death, or suicide (American Psychiatric Association, 2000).

**Diagnostic and**

The official system used to classify, describe and diagnose

<b>Statistical Manual of Mental Disorders (DSM):</b>	psychological and psychiatric conditions. It is published by the American Psychiatric Association. It is currently in its fifth edition, published in May 2013. In this project, DSM-IV (American Psychiatric Association, 1994) and DSM-IV-TR (American Psychiatric Association, 2000) are referred to. AS is not included in DSM-V.
<b>Eating Disorders:</b>	A term used in the DSM-IV and DSM-IV-TR to describe serious disturbances in regards to eating behaviours. The eating disorders outlined in DSM-IV and DSM-IV-TR are Anorexia, Bulimia and Eating Disorders Not Otherwise Specified (American Psychiatric Association, 1994, 2000).
<b>Eating Disorders Not Otherwise Specified (EDNOS):</b>	A category used in DSM-IV and DSM-IV-TR to refer to individuals who have serious disturbances in regards to their eating behaviours, but do not meet the full diagnostic criteria for either Anorexia or Bulimia (American Psychiatric Association, 1994, 2000).
<b>Executive Function:</b>	A term used to describe the cognitive functions used to carry out the following tasks: prioritising, organising, planning, time management, self-reflection and self-monitoring. Executive functioning also involves the ability to understand complex and abstract ideas, and short-term/working memory (Attwood, 2007; Davison et al., 2003).

<b>Generalised Anxiety Disorder:</b>	An anxiety disorder outlined in DSM-IV and DSM-IV-TR. Individuals with Generalised Anxiety Disorder experience chronic and persistent anxiety and worry which is difficult for them to control. The anxiety is accompanied by physiological symptoms and causes significant distress and impairments in daily functioning (American Psychiatric Association, 1994, 2000).
<b>Hidden Curriculum:</b>	This term refers to skills and knowledge in relation to social interactions which are not explicitly taught, and for which there is an assumption that everyone acquires these skills and this knowledge incidentally (Myles & Simpson, 2001).
<b>High Functioning Autism:</b>	Often used interchangeably with Asperger's Syndrome, this term generally refers to individuals with an Autism Spectrum Disorder who experienced early speech delays which were rectified by adolescence, thus meaning the individual now meets the DSM-IV-TR criteria for Asperger's Syndrome (Attwood, 2007).
<b>Major Depressive Disorder:</b>	A mood disorder outlined in DSM-IV and DSM-IV-TR. An individual with Major Depressive Disorder experiences one or more clinically significant depressive episodes (American Psychiatric Association, 1994, 2000).

<b>Masquerading:</b>	A term used to refer to the ability of some individuals with AS to watch and imitate what others say and do, particularly in social situations, to conceal their social impairments (Carrington, Papinczak & Templeton, 2003a).
<b>Pervasive Developmental Disorder (PDD);</b>	A term used in DSM-IV and DSM-IV-TR in reference to atypical developmental in terms of social skills, communication, language and interests (American Psychiatric Association, 1994, 2000; Davison et al., 2004).
<b>Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)</b>	A diagnostic category used in DSM-IV and DSM-IV-TR for individuals with atypical development in the areas of communication, social skills and interests, but they do not meet the criteria for either Autistic Disorder or Asperger's Syndrome (American Psychiatric Association, 2000; Lawson, 2001).
<b>Prosody:</b>	The aspects of speech which enhance meaning, i.e. intonation, speed, rhythm and expression (Shriberg et al., 2001; Willey, 1999).
<b>Suicidal Ideation:</b>	Recurrent thoughts of suicide, a common symptom of depression, Post-Traumatic Stress Disorder and Bipolar Disorder. These can range from brief passing thoughts to making detailed plans regarding how a suicide attempt might be carried out (Reber & Reber, 2001).

**Typically Developing:** In this project, this term is used to refer to individuals who do not have an Autism Spectrum Disorder. The term “neurotypical” is also sometimes used in this instance (Lawson, 2001).

## Chapter 1 - Introduction

### 1.1 Asperger's Syndrome

Asperger's Syndrome (AS) is an Autism Spectrum Disorder (ASD). ASD refers to a spectrum of conditions which the *Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition-Text Revision (DSM-IV-TR))* (American Psychiatric Association, 2000) refers to as Pervasive Developmental Disorders (PDD). PDD is a term used in the DSM-IV-TR to denote atypical development in terms of social skills, communication, language, and interests (American Psychiatric Association, 2000; Lawson, 2001). AS is on the milder end of the Autism Spectrum (Attwood, 1998, 2007; Sciotto, Richwine, Mentrikoski & Niedzwiecki, 2012; Wilkinson, 2008). For an individual to receive a diagnosis of AS, Autistic Disorder (AD) must first be ruled out as a possible diagnosis (American Psychiatric Association, 2000). While both AS and AD are characterised by impairments in social interaction, individuals with AS do not experience any significant delays in language or cognitive development (American Psychiatric Association, 2000). Individuals with AS are of average or above average intelligence (Attwood, 1998, 2007; Sciotto et al., 2012; Wilkinson, 2008) and are generally educated in mainstream settings (Hill & Bird, 2006; Humphrey & Lewis, 2008; Saggars, Hwang & Mercer, 2011; Wagner, 2006). However, in comparison to their typically developing peers, students with AS experience more difficulties at school, the majority of which can be categorised into the triad of impairments identified by Wing (2001): social interaction, communication, and thinking/processing. Other characteristics associated with AS include a compulsive

need for routines, impaired executive functioning, intense and narrow interests, poor motor skills and sensory issues (Attwood, 2007; Church, Alisanki & Amanullah, 2000).

### ***1.1.1 Asperger's Syndrome as a diagnostic category***

AS was first recognised by paediatrician Hans Asperger in 1944, from whose name the term was eventually derived. Asperger (1944) noticed that some of the children he was treating were similar in terms of personality, and exhibited similar behaviours (as cited in Attwood, 2007). In addition, Asperger (1944) observed these children were often teased by their peers, had extensive vocabularies, but used language in strange ways, had restricted interests based around a particular subject, were highly sensitive to any criticism or perceived criticism, and were physically clumsy (as cited in Attwood, 2007; Lawson, 2001).

The term AS was initially used by psychiatrist and physician Lorna Wing (Attwood, 2007). Wing (1981) reported on children who had exhibited signs of severe Autism throughout infancy and early childhood who had improved as a result of early diagnosis and intervention to the point where their symptoms became milder (as cited in Attwood, 2007). Wing (1981) felt a new diagnostic category was warranted (as cited in Attwood, 2007). In 1994, with the publication of DSM-IV, AS was included for the first time as a diagnostic category.

### **1.1.2 *Asperger's Syndrome and High Functioning Autism***

The term High Functioning Autism (HFA) was first used by Demyer, Hingten and Jackson (1981) to describe children who met the diagnostic criteria for more severe Autism in infancy and early childhood, but improved as they developed, achieving better than expected academic and social outcomes (as cited in Attwood, 2007). There are conflicting opinions and evidence regarding whether AS and HFA are essentially the same condition, and these terms are often used interchangeably. Koyama, Tachimori, Osada, Takeda, and Kurita (2007) have suggested that individuals with AS may have a higher verbal intelligence than individuals with HFA. Language development is another area which may differ between individuals with AS and HFA. According to Ozonoff, South and Miller (2000), there are sometimes delays in language development among individuals with HFA; however, it is specified in DSM-IV-TR that there are no such delays for individuals with AS (American Psychiatric Association, 2000). Ozonoff et al. (2000) have suggested the difference between AS and HFA may be the developmental course. It has been reported that any differences regarding language development between individuals with AS and HFA are no longer apparent by adolescence. In addition, Attwood (1998, 2007) has asserted that there have been no results reported to date which would suggest AS and HFA are separate conditions.

### **1.1.3 *Asperger's Syndrome and DSM-V***

In DSM-V, which was released by the American Psychiatric Association in May, 2013, the subtypes of ASD, including AS, which were included in DSM-IV and

DSM-IV-TR as Pervasive Developmental Disorders, have been removed. The revised diagnosis is Autism Spectrum Disorder (ASD) which is to be used for individuals exhibiting severe symptoms of Autism to those with mild symptoms who would have been formally diagnosed with AS (American Psychiatric Association, 2013). It is not anticipated that these changes should impact the results of the present study in any way; all participants or participant's daughters would have received their diagnosis of AS under the criteria outlined in DSM-IV or DSM-IV-TR. In addition, it is stated by the American Psychiatric Association (2013) that individuals who received a diagnosis of AS under DSM-IV or DSM-IV-TR should still meet the DSM-V criteria for ASD.

## **1.2 Characteristics of Asperger's Syndrome**

AS is a lifelong and complex condition, far more multifaceted than it appears in DSM-IV (Attwood, 2007; Durbin, 2007). Although individuals with AS are of average or above average intelligence, they can experience many difficulties in their daily lives (American Psychiatric Association, 2000; Attwood, 2007; Lawson, 2001; Sciotto et al., 2012; Simone, 2010). Many of these difficulties can be categorised into the triad of impairments (Wing, 2001), while other characteristics associated with AS can also be problematic for individuals at times (Attwood, 2007; Lawson, 2001). Each of the triad of impairments is discussed in the following sections.

### 1.2.1 Social skills

It has been suggested by Church et al. (2000) that impairments in social skills are both the most distinctive, and problematic characteristic of AS. Impairments in social skills often become prominent during primary school (Barnhill, 2007; Church et al., 2000). It is stated in DSM-IV-TR that although younger individuals with AS may have limited interest in developing friendships with their peers, older individuals may have the interest, but lack the understanding of social conventions (American Psychiatric Association, 2000). This is supported by Church et al. (2000), who reported that although many characteristics of AS become milder over time, including impairments in social skills, this remains a problematic area for individuals with AS. Attwood (1998) has illustrated these difficulties in the following example:

The least intellectually able child can be socially skilled, a leader and a comedian; yet despite their intellectual ability, when a person with Asperger's Syndrome tries to have friends, be the centre of attention or tell jokes, they are excluded, teased or ridiculed (p.159).

A particular aspect of social functioning which causes anxiety and confusion for individuals with AS is "the hidden curriculum" (Myles & Simpson, 2001, p. 280). The hidden curriculum refers to social skills and knowledge which are not explicitly taught, and for which there is an assumption that everyone acquires these skills and this knowledge incidentally (Myles & Simpson, 2001). Individuals with AS also have difficulty reading facial expressions, body language, and other social cues (American Psychiatric Association, 2000; Barnhill, 2007; Church et al., 2000; Lawson, 2001). Developing and maintaining friendships also remains an area of difficulty for many adults with AS (Attwood, 2007; Barnhill, 2007; Portway & Johnson, 2005).

### **1.2.2 *Communication and language***

Despite experiencing no significant delays in language development, and possessing fluent speech and extensive vocabularies, individuals with AS often present as having unusual language abilities which affects their communication (American Psychiatric Association, 2000; Saalasti et al., 2008). It has been reported that some children with AS use quite formal language in comparison to their peers (Attwood, 2007; Montgomery & Grandin, 2012). For example, as a young child, Temple Grandin, a female with HFA, insisted on addressing her peers by both their first and surnames, and never used any nicknames (Montgomery & Grandin, 2012). Prosody is another area impacted by AS for both children and adults. Prosody refers to aspects of speech which enhance meaning, such as intonation, speed, rhythm, use of appropriate expression when speaking, and the ability to understand the meaning in others' speech from their intonation (Shriberg et al., 2001). Some individuals with AS speak in a monotone regardless of the grammatical structure of what they are saying, while others speak too loudly or too softly (Attwood, 2007; Lawson, 2001). Furthermore, some individuals with AS have difficulty understanding tone of voice (Attwood, 2007; Lawson, 2001). Both children and adults with AS also tend to interpret and use language literally, which impacts upon their communication abilities (Lawson, 2001; Saalasti et al., 2008).

### **1.2.3 *Intense and narrow interests***

Intense and narrow interests are another characteristic associated with AS (American Psychiatric Association, 2000, Simone, 2010). For an interest of an

individual with AS to be of clinical significance, either the interest itself, or the intensity of the interest must be abnormal (American Psychiatric Association, 2000). According to Attwood (2007), it is easier to identify whether an interest is abnormal in focus than intensity. This is illustrated in the following example provided by Attwood (2007): in the case of a child with AS whose special interest was lawnmowers, this could be objectively regarded as clinically significant due to the abnormal focus. The interests of individuals with AS; however, are just as likely to be similar to those of typically developing individuals (Attwood, 2007; Simone, 2010). Therefore, the interests of individuals with AS are not always of clinical significance in terms of the interest itself, but in terms of the intensity of the interest (Attwood, 2007; Simone, 2010). In his role as a clinical psychologist working with clients with AS, Attwood (2007) explained that a subjective judgement must be made in regards to whether an interest is a hobby, or an interest of clinical significance. The intensity of the interest, and the time and energy devoted to it are taken into account when judging if it is of clinical significance (American Psychiatric Association, 2000). Also, while a typically developing individual will generally outgrow childhood interests, this is not always the case for individuals with AS (Attwood, 2007; Simone, 2010).

#### ***1.2.4 Impaired executive functioning***

Impaired executive functioning is another characteristic associated with AS (Hill & Bird, 2006; Saalasti et al., 2008); this includes issues such as difficulties with prioritising, organising and planning, working memory/short term memory, time management, understanding complex and abstract ideas, and the ability to self-

reflect and self-monitor (Attwood, 2007; Hill & Bird, 2006). Lawson (2001) suggested that some of the difficulties experienced by individuals with AS in relation to executive functioning may be a result of “monotropism” (p. 33). According to Lawson (2001), this means individuals with AS have difficulty focussing on more than one task, or more than one aspect of communication at a time. Many of these are issues which will particularly impact upon individuals with AS in the context of school (Attwood, 2007).

### ***1.2.5 Impairments in motor skills***

It is stated in DSM-IV-TR that individuals with AS experience impairments in motor skills and coordination (American Psychiatric Association, 2000). This can include the use of the large muscles (e.g. movement of arms and legs), particularly bilateral movement, and fine motor skills, such as using scissors, tying shoelaces and learning to write (Attwood, 2007; Carrington & Graham, 1999). Some individuals with AS have difficulty determining where their body is in terms of the space around them, which means they can often trip over, bump into objects or people, and drop and spill things, which can give the impression they are clumsy (Attwood, 2007). Although in most cases the motor skills impairments in individuals with AS are mild, they are noticeable enough to contribute to the peer rejection and social isolation often experienced by this population (American Psychiatric Association, 2000).

### 1.3 The Non-obvious Nature of Asperger's Syndrome

Portway and Johnson (2005) have described AS as a “non-obvious” disability referring to individuals who appear to be “normal”; however, they do not “quite fit in” (p. 73). It has been emphasised by Portway and Johnson (2005) that while people generally understand physical and sensory impairments, the social and communication difficulties experienced by individuals with AS are frequently misunderstood. Liane Willey (1999), a female with AS, has described her own experiences in regards to appearing “normal” despite her AS related challenges: “Asperger’s Syndrome can mystify those who know nothing about it, particularly in my case where the manifestation is so subtle. My children cannot point to an obvious physical disability and silently ask others to give their mother a break” (p. 118).

Some of the risks for students with a non-obvious condition such as AS include being labelled as naughty or stupid, as well as an increased risk of peer rejection and peer bullying as a result of being misunderstood and misunderstanding others (Portway & Johnson, 2005). This is supported by Brewin, Renwick & Schormans (2008), who found that parents reported their children with AS were often perceived as naughty, undisciplined and obnoxious by people who were unaware of the condition. However, in the same study, it was also found that many people aware of the diagnosis frequently misunderstood what a diagnosis of AS meant in comparison to AD (Brewin et al., 2008). Individuals with AS often have what Attwood (2007) and Lawson (2001) have called an uneven ability profile. This refers to the experience of many individuals with AS who are highly skilled in some areas, and impaired in others. Similarly, Portway and Johnson (2003) reported that

parents of children with AS frequently described the difficulties their children encountered in looking “normal”, but never quite fitting in. Wendy Lawson (2001), who has HFA, articulated her own experiences of living with a non-obvious condition, and her uneven ability profile:

I seem to be a bundle of uneven skills. I have university qualifications, I have been married and I have four grown children. However, I have huge problems with being disorganised, getting lost, using public transport, understanding others and just the practical interactions of social situations. (p.46).

## **1.4 Asperger’s Syndrome and Gender**

### **1.4.1 Diagnostic rates and issues**

As a broad category, ASD is diagnosed more frequently in males than females; the generally accepted gender ratio is an average of 4:1 (Mandy et al., 2012; Thompson, Caruso & Ellerbeck, 2003). However, Whiteley, Todd, Carr and Shattock (2010) have claimed it is higher (6.84:1). The average gender ratio in terms of AD is 4:1 (Attwood, 2007; Fombonne, 2003; Newschaffer et al., 2007; Thompson et al., 2003), although a higher gender ratio of 6.54:1 has been reported (Whiteley et al., 2010). The gender ratio increases further among higher functioning individuals, including those with AS, ranging from 8-9:1 (Mandy et al., 2012) to 12.07:1 (Whiteley et al., 2010). This is consistent with the professional experience of Attwood (2007) and Wagner (2006), who both reported a gender ratio of 10:1 for AS in terms of student referral and diagnosis.

In addition to being diagnosed with AS less frequently, females also tend to be diagnosed later than males (Attwood, 2007; Begeer et al., 2013; Mandy et al., 2012; Thompson et al., 2003; Wilkinson, 2008). In their sample of children and adults with ASD, Begeer et al. (2013) reported that the average time between first recognition of a potential ASD and subsequent diagnosis in females was 2.3 years, compared to 1.9 years for males. However, for AS, there was found to be an average delay of 1.8 years in recognising the condition in females in comparison to males (Begeer et al., 2013). This is supported by Mandy et al. (2012), who asserted that females with an ASD, especially higher functioning females, are identified later than males. Despite the reported gender ratio for AS, Attwood (2007) has claimed it is likely to be closer to 4:1. It is also argued by Attwood (2007) that the gender ratio for adult diagnosis of AS decreases to 2:1. The clinical experience of Attwood (2007) is supported by anecdotal evidence presented by Simone (2010, 2012).

#### ***1.4.2 Females with Asperger's Syndrome***

The term "Aspie" was first used by Willey (1999) in her autobiography *Pretending to be normal: Living with Asperger's Syndrome*. Subsequently, many individuals with AS identify as, and refer to themselves as "Aspies" (Lawson, 2011). Willey (2003) later explained she created this term because "I do not want a syndrome, nor do I want to live my life under the umbrella of a man's name" (p.12). More recently, Rudy Simone (2010) created the term "Aspergirls" to refer to females with AS in her book *Aspergirls: Empowering females with Asperger Syndrome*. Simone (2010) argued that in terms of females with AS "men may share most of our traits,

but I think their way of experiencing them and manifesting them is different” (p.14). Simone (2010) explained that one reason she wrote this book was because following her own diagnosis with AS, she had difficulty finding information related specifically to females with AS. Both these authors highlight the need for an understanding of the female experience of AS and the acknowledgment that the identity and experience of AS in females may differ from males.

Wilkinson (2008) reported that throughout the last decade, despite the increase in the number of children diagnosed with ASD, there is still a significant gender gap in terms of the diagnosis rate of AS. According to Mandy et al. (2012), the male to female ratio for ASD overall is on average 4:1. For AS; however, the gender ratio is generally reported as being 10:1 (Attwood, 2007; Wagner, 2006), although some authors (Mandy et al., 2012; Whiteley et al., 2010) have reported it as being slightly higher or lower. Attwood (2007) has argued that the gender ratio for AS is likely to be closer to that of ASD, meaning that there are females spending their school years, and possibly their lives, undiagnosed. Wilkinson (2008) emphasised that students with AS are at risk of peer rejection, mental health concerns such as anxiety and depression, and academic underachievement. If, as Attwood (2006) asserted, females with AS often go undiagnosed, or receive a late diagnosis, they are potentially at an increased risk of the factors outlined by Wilkinson (2008). This is supported by Wagner (2006) who reported that females with AS, particularly those with a late or a missed diagnosis, often do not achieve academic results consistent with their intelligence levels, and experience social difficulties such as peer rejection, loneliness and isolation. Furthermore, for those female students with AS who do

have a diagnosis, the support they receive and programs in which they are engaged are largely based on what is known about AS in males (Wagner, 2006). With this in mind, authors such as Wagner (2006) and Wilkinson (2008) have emphasised there is a need to fully explore the school experiences of females with AS to ensure they are receiving the appropriate academic and social support.

## **1.5 Outline of the Study**

### **1.5.1 Problem statement**

Although there have been several studies carried out on the school experiences of individuals with AS (Brewin et al., 2008; Carrington & Graham, 2001; Carrington et al., 2003a; Church et al., 2000; Humphrey & Lewis, 2008; Saggars et al., 2011; Sciotto et al., 2012), females were either unrepresented or underrepresented in all of these except Sciotto et al. (2012). Females have also been underrepresented in the AS research overall. Only one study (Kalyva, 2009) was found in the literature search which specifically considered females with AS. It is vital that research is carried out in relation to the school experiences of females with AS, as there may be a different AS profile for females than there is for males (Wagner, 2006; Wilkinson, 2008). If this is the case, it may be inappropriate to implement programs for, and provide support to female students with AS based solely on what is known about the condition in males (Wilkinson, 2008). Although much of what can be applied academically and socially to males can also be applied to females, it is important the female experience of AS is better understood so teachers can better support these

students in achieving academically and having improved social and emotional outcomes (Wagner, 2006).

### **1.5.2 Purpose**

The aim of this study was to contribute to an understanding of the school experiences – both academic and social - of females with AS. The areas explored included: challenges encountered at school, teaching practices perceived as helpful or unhelpful, academic experiences, emotions elicited in relation to school, as well as peer relationships and social experiences. The purpose of this study was to examine the school experiences of females with AS, both from the perspective of adult females with AS, and parents of school aged daughters with AS. In specifically examining the school experiences of females with AS, it is anticipated it will provide information regarding any specific challenges and needs of female students with AS, and assist teachers in helping these students in reaching their full academic, social, and emotional potential.

### **1.5.3 Conceptual framework**

This study involved the use of a feminist phenomenological approach. By using a phenomenological approach, the researcher was able to gain an understanding of the “lived experiences” (O’Leary, 2004, p. 123) of participants. This was done through interpreting the way in which participants described their opinions and experiences; therefore language was a vital element of the approach, both in constructing and conveying meaning (Patton, 1990; Rossman & Rallis, 1998).

Two of the main principles of feminist research are a focus on the experiences and perceptions of females, and aiming to change the inequality between males and females (Kumnar, 1998; Sarantakos, 1998). Despite the assertions of Wagner (2006) and Wilkinson (2008) regarding the importance of understanding the female AS school experience, no scholarly research has been carried out to date. Therefore, adopting a feminist approach to this research provided adult females with AS, and parents of school aged females with AS with the opportunity to share their experiences and perceptions, acknowledging that the school experiences of females with AS may differ from those of males, and females may have different needs and challenges.

#### ***1.5.4 Structure of the thesis***

Following this introductory chapter, Chapter 2 presents a literature review of the relevant findings in regards to the school experiences of students with AS. The literature review begins by discussing studies specifically examining the school experiences of students with AS, and discusses other issues related to AS, such as mental health, and gender differences. In Chapter 3, the methodology of this study is described. The ethical considerations, research design, survey instruments and approach to data analysis are outlined. In Chapter 4, the study sample is described, and the themes identified by participants are presented. Chapter 5, the concluding chapter, presents a discussion of the results. The limitations of the study and suggestions for future research are also outlined. The implications of the results are discussed, and recommendations are made.

## Chapter 2 - Literature Review

### 2.1 Introduction

This chapter analyses the findings from several studies which focussed on the school experiences of students with AS. In addition, several studies in relation to issues which have consistently emerged from the research focussing on AS and school are discussed. The reported relationship between AS and mental health is also examined. The gender ratios for the diagnosis rates of ASD overall, and AS are reported on, and some possible reasons for these are explored. This chapter concludes with a brief summary of the articles reviewed, and a discussion of the significance and purpose of the present study.

### 2.2 Research Strategy

In order to locate research studies related to the school experiences of female students with AS, a search of electronic databases (PsychINFO, PsyCarticles, A+Education, Medline and CINAHL) was carried out. The following search terms were used in each of these databases: Asperger's Syndrome OR Asperger Syndrome OR Asperger's OR Asperger's OR High Functioning Autism AND females OR female OR girls OR girl OR woman OR women AND school OR primary school OR elementary school OR middle school OR high school OR secondary school. From this search, no articles were found which specifically examined the school experiences of females with AS. A second search was carried out, using all the same search terms in these databases, but omitting the school related search terms. Through this search,

one article which had a sample of female adolescents with AS were found, and another which included a sample of 6 female children with ASD. A report was also found which discussed the lack of research on females with AS.

Another search was carried out, using the same electronic databases. For this search, the following terms were used: Asperger's Syndrome OR Asperger Syndrome OR Asperger's OR Aspergers AND children OR adolescents AND school OR primary school OR elementary school OR middle school OR high school OR secondary school AND gender differences OR sex differences. Articles found from this search were included in the literature review based on the following criteria (1) were published in a peer reviewed journal after 1981, (2) were published in English, (3) included children or adolescents with AS/HFA or parents of children or adolescents with AS/HFA (4) focussed specifically on school, or on issues relevant to students.

### **2.3 Characteristics of Articles Reviewed**

No articles were found which specifically focussed on the school experiences of females with AS. One article was found which included a sample of female adolescents with AS (Kalyva, 2009). Another was found which included a sample of six female children with Autism (Kopp & Gillberg, 1992). A report which discussed the lack of research focussing on female students with AS (Wilkinson, 2008) was also located. Eight articles were found which specifically focussed on the school experiences of students with AS (Brewin et al., 2008; Carrington & Graham, 1999; Carrington & Graham, 2001; Carrington et al., 2003a; Church et al., 2000; Humphrey

& Lewis, 2008; Saggars et al., 2011; Sciutto et al., 2012). A further 19 articles were included in the literature review which explored issues and experiences relevant to students with AS (Barnhill, 2001; Bauminger & Shulman, 2003; Berkman, Lohr & Bulik, 2007; Carrington et al., 2003b; Carter, 2009; Hill & Bird, 2006; Little, 2002; Martins, Young & Robson, 2008; Myles & Simpson, 2001; Portway & Johnson, 2005; Rastam, Gillberg & Wentz, 2004; Richard & Schneider, 2005; Ruta, Mungo, D'Arrigo, Vitiello & Mazzone, 2010; Schreck, Williams & Smith, 2004; Shtayermman, 2007; Shtayermman, 2008; Sofronoff, Dark & Stone, 2011; Wainscot, Naylor, Sutcliffe, Tantam & Williams, 2008; Whitehouse, Durkin, Jaquet, & Ziatas, 2009). Five articles were included which examined gender in AS and ASD (Begeer et al., 2013; Mandy et al., 2012; McLennan, Lord & Schopler, 1993; Thompson et al., 2003; Whiteley et al., 2010). Two outcomes studies on adults with AS (Barnhill, 2007; Portway & Johnson, 2003) and two epidemiological studies (Fombonne, 2003; Newschaffer et al., 2007) have also been included. Due to the lack of scholarly research focussing specifically on females with AS, a number of books, including autobiographical accounts of females with AS/HFA have also been drawn upon. A summary of the articles reviewed can be found in Appendix A.

## **2.4 Findings from the Literature Review**

It was evident from the journal articles and other sources identified that the majority of students with AS are educated in mainstream settings (Hill & Bird, 2006; Humphrey & Lewis, 2008; Sagers et al., 2011, Wagner, 2006). As no journal articles were found which focussed specifically on the school experiences of females with AS, or which explored gender differences regarding the school experiences of students with AS, these articles will be discussed in terms of the school experiences of students with AS generally. Other issues which emerged from the literature related to children and adolescents with AS are also discussed. Although none of the articles which examined AS populations considered gender differences as a result of the samples consisting only or predominately of males, a few studies which explored ASD overall did. These have also been discussed. In addition to the journal articles, a number of books related to AS, including autobiographical accounts, have been included.

## **2.5 Social Experiences**

### ***2.5.1 Developing and maintaining friendships***

Peer relationships and social experiences have been found to be a significant part of the school experiences of students with AS, especially in relation to the complexities AS can sometimes contribute to these phenomena. Several authors

(Carrington & Graham, 2001; Carrington et al., 2003a, 2003b; Church et al., 2000; Humphrey & Lewis, 2008; Portway & Johnson, 2003; Saggars et al., 2011) have found that although many students with AS desire friends, their social impairments can impact upon their ability to develop and maintain friendships. It has also been reported by Bauminger and Shulman (2003) that students with AS have less friends, socialise with their friends less frequently, and have friendships of less longevity than their typically developing peers. Church et al. (2000) found the social deficits of children with AS become more prominent in the later stages of primary school. These social impairments, such as misunderstanding or misinterpreting body language, and failing to respond appropriately to social cues, can unintentionally alienate peers. This creates a negative pattern which can follow students with AS throughout school (Church et al., 2000). Portway and Johnson (2003) have also reported that the social elements of school are one of the main reasons why school becomes increasingly difficult for students with AS. Difficulties in regards to social interaction and relationships often continue into adulthood for individuals with AS (Barnhill, 2007; Portway & Johnson, 2003).

Carrington et al. (2003a) found that some students with AS have difficulty understanding the concept of friendship. An adolescent participant in their study described a friend as someone who “is nice to you, and they’re not acting mean” (p. 18). In another study which examined the perceptions of friendship in adolescents with AS (Carrington et al., 2003b), the participants found it difficult to describe what a friend is; however, they found it easier to describe what a friend is not, which perhaps suggests those participants had more experience with the latter. Carrington

et al. (2003b) reported that two of their five participants masqueraded during their interviews in regards to their social lives and the number of friends they had.

According to Carrington et al. (2003b), this demonstrated the unmet needs of those students to have quality friendships. Attwood (2007) explained that both children and adults with AS can mistakenly believe that someone being friendly towards them out of common courtesy (for example an employee in a shop) is their friend.

Humphrey and Lewis (2008) emphasised that the strong desire of students with AS to develop friendships, combined with their social and communication difficulties can result in them becoming a victim of teasing or bullying, or being exploited by “unscrupulous peers” (p. 33). Similarly, Gutstein (2003) reported that individuals with AS, particularly during adolescence, are also vulnerable to becoming involved in “pseudo friendships” (p. 121). Gutstein (2003) described pseudo friendships as a situation where an individual with AS is befriended by a typically developing peer who has no genuine interest in developing a meaningful friendship with them. While the individual with AS believes they have a friend, the typically developing peer has in reality initiated the pseudo friendship to gain some benefit from them, or to subject them to teasing or bullying (Gutstein, 2003). Similarly, Attwood (1998) and Sofronoff et al. (2011) suggested that some typically developing students may view the naivety of students with AS as a weakness they can easily take advantage of, not only through blatant bullying, but also in more subtle ways.

The difficulties experienced by individuals with AS in understanding the hidden curriculum (Myles & Simpson, 2001), combined with not fully understanding

body language and social cues (Church et al., 2000) means that an individual with AS may not always realise when they are being teased or taken advantage of when it occurs subtly. In her autobiography, Grandin (1995) explained how her inability to read social cues meant she had difficulty identifying when people were not sincere or trustworthy; this resulted in her being betrayed by people who she had believed to be her friends. Willey (1999) described a similar incident – one of many – which occurred during her early twenties. She was invited to go shopping with some classmates, only to discover the sole reason she had been invited was so she could drive them (Willey, 1999). It has been suggested that some individuals with AS may be able to form connections with others based on mutual interests (Carrington & Graham, 1999, 2001). However, this may become increasingly difficult, particularly during adolescence, when as a result of their difficulties fitting into their peer group, students with AS become more aware of their “differentness” (Carrington & Graham, 1999, p.18), thus increasing the likelihood of social withdrawal, anxiety and depression.

### **2.5.2 Masquerading**

Masquerading is a term used to describe the façade adopted by some individuals with AS in order to conceal their social differences (Carrington & Graham, 2001; Carrington et al., 2003a, 2003b). By adolescence, individuals with AS are often acutely aware of their differences and impairments in comparison to their typically developing peers (Attwood, 1998, 2007; Carrington & Graham, 1999; Carrington et al., 2003a, 2003b; Church et al., 2000; Humphrey & Lewis, 2008). In an

attempt to fit in with their typically developing peers, many students with AS masquerade (Carrington & Graham, 2001; Carrington et al., 2003a, 2003b). Willey (1999) described her own experiences with masquerading throughout adolescence and young adulthood in the following way: "I could take part in the world as an observer. I was an avid observer. I was enthralled with the nuances of other people's actions. In fact, I often found it desirable to become the other person" (p. 22).

Although Carrington et al. (2003a) emphasised that masquerading can be a useful adaptive behaviour, it has been claimed by several authors (Carrington & Graham, 2001; Carrington et al., 2003a; Sciotto et al., 2012) that masquerading can also be a source of anxiety and stress. In a case study which examined the perceptions of two adolescent males with AS and their mothers in relation to school (Carrington & Graham, 2001), both mothers described the anxiety and stress experienced by their sons as a result of their efforts to conceal their social impairments at school. In addition, Sciotto et al. (2012) reported that both parents of children with AS and adults with AS described the exhaustion involved in masquerading and attempting to appear "normal."

### **2.5.3 Bullying**

Wainscot et al. (2008) asserted that AS is a risk factor for experiencing bullying at school, with students who have AS being reported to experience bullying more frequently than their typically developing peers. Several authors (Attwood, 2007; Carrington et al., 2003a; Carter, 2009; Durbin, 2007; Humphrey & Lewis, 2008; Little, 2002; Portway & Johnson, 2005; Saggars et al., 2011; Sciotto et al., 2012; Simone,

2010; Wainscot et al., 2008) have reported bullying to be a common occurrence for individuals with AS. All the students with AS in the study carried out by Saggars et al. (2011) experienced bullying at school. Shtayermman (2007) also found there to be a high incidence of bullying among adolescents and young adults with AS. In another study, 90% of mothers whose children had either AS or Nonverbal Learning Disorder (NLD) (75.4% AS, 9.2% AS and NLD), said their child had been bullied during the past year, with emotional bullying cited most frequently (Little, 2002). Fifty per cent of participants in the study carried out by Sciutto et al. (2012) reported that they, or their child with AS, had experienced bullying at school. Four of the five participants in another study (Carrington et al., 2003a) also experienced bullying at school, including behaviours such as teasing, having property destroyed and physical violence - one participant reported being hospitalised following a physical bullying incident. These findings are consistent with those reported by Carter (2009), who found that 65% of parents surveyed in her study said their child with AS had been victimised over the past year, and 50% said their child was frightened of their peers. Although not reporting any statistics, Humphrey and Lewis (2008) stated that the majority of their adolescent sample with AS experienced bullying at school on a regular basis.

Attwood (2007) also argued that in addition to overt bullying, many children and adolescents with AS are intentionally excluded by their peers. This is supported by anecdotal evidence provided by Simone (2010). According to Simone (2010), she, and the majority of females she interviewed, experienced bullying throughout school: "again and again throughout the conversations with Aspergirls I heard

stories that echoed my own. For some the bullying started earlier or later, but it almost always starts” (p. 30). Both Grandin (1995) and Lawson (2001), recounted experiencing bullying at school. Grandin (1995) described secondary school as the worst period of her life as a result of relentless bullying, and Lawson (2001) described school as a “nightmare” due to being “bullied and teased mercilessly” (p. 181).

A number of reasons have been identified by several authors (Attwood, 2007; Durbin, 2007; Humphrey & Lewis, 2008) as to why students with AS are more likely to be bullied than their typically developing peers. The social naivety of individuals with AS is one possible reason. Individuals with AS tend to take things at face-value and interpret what people say as the truth, which can lead to them getting laughed at, bullied, as well as unwittingly getting into trouble (Attwood, 2007; Durbin, 2007). Durbin (2007) also suggested that the difficulties which individuals with AS experience with interpreting non-verbal cues, and their odd use of language, contributes to the high bullying rates among this population. In addition, Attwood (2007) proposed that in comparison to their typically developing counterparts, children and adolescents with AS do not always know which of their peers they should avoid, and whether or not another person is trustworthy; both of these factors making them more vulnerable to potential bullies. Bullying remains an issue for adults with AS. According to Portway and Johnson (2005), ridicule, bullying and isolation are everyday risks associated with being an adult with AS, which in the long term leads to an increased risk of mental health issues.

## 2.6 Asperger's Syndrome and Mental Health

Mental health concerns, particularly anxiety and depression, have been reported to be associated with AS (Attwood, 2007; Barnhill, 2001; Carrington & Graham, 1999, 2001; Church et al., 2000; Humphrey & Lewis, 2008; Portway & Johnson, 2005; Ruta et al., 2010; Sciotto et al., 2012). There have also been some preliminary findings (Kalyva, 2009) and anecdotal evidence (Simone, 2012) which suggest there may be a relationship between AS and eating disorders, particularly during adolescence and young adulthood.

### 2.6.1 Anxiety

Anxiety and stress were consistently reported in studies which examined the school experiences of students with AS (Carrington & Graham, 2001; Church et al., 2000; Humphrey & Lewis, 2008; Portway & Johnson, 2005; Ruta et al., 2010; Sciotto et al., 2012). The most frequently reported sources of anxiety and stress were social situations, including the stress associated with masquerading (Carrington & Graham, 2001; Carrington et al., 2003a, 2003b; Sciotto et al., 2012). Other sources of anxiety and stress reported in relation to school included sensory sensitivities (Church et al., 2000; Humphrey & Lewis, 2008; Sciotto et al., 2012), and difficulties related to impaired executive functioning, such as difficulty concentrating and completing schoolwork and homework (Carrington & Graham, 2001; Sciotto et al., 2012). In samples of adolescents and young adults with AS, Shtayermman (2007, 2008) reported that 30% had comorbid Generalised Anxiety Disorder, while Ruta et al.

(2010) found that in comparison to their typically developing peers, children and adolescents with AS are more likely to display obsessive compulsive traits.

Portway and Johnson (2005) emphasised that anxiety and obsessive tendencies are long term risks associated with AS. In a sample of 25 young adults with AS aged between 18-35 years and their parents, all participants with AS reported experiencing some degree of anxiety, while 23 of the young adults experienced persistent and long-term problems in relation to anxiety and/or obsessive behaviours (Portway & Johnson, 2005). The parents who participated in this study (Portway & Johnson, 2005) attributed some of their adult children's mental health concerns to the lack of support they received at school, which suggests that unhappy school experiences and a lack of adequate support can potentially affect individuals with AS throughout their lives.

### **2.6.2 Depression**

According to Attwood (1998, 2007), both children and adults with AS are particularly vulnerable to developing depressive symptoms, and depression. Barnhill (2001) stated that depression is the most common comorbid condition of adolescents and adults with AS. In samples of adolescents and young adults with AS, Shtayermman (2007, 2008) reported that 20% of participants met the DSM-IV criteria for Major Depressive Disorder. Whitehouse et al. (2009) also asserted that in comparison to their typically developing peers, adolescents with AS have a higher level of depressive symptoms. In addition, Portway and Johnson (2005) observed that the majority of their adult participants with AS presented as unhappy and

depressed to varying degrees. Barnhill (2001) suggested that the high rate of comorbid depression and anxiety among adolescents and adults with AS may be related to their awareness of their differences in comparison to their peers. Furthermore, Attwood (2007) emphasised that this awareness of difference can contribute to children as young as seven developing clinically significant depression. Whitehouse et al. (2009) proposed that while difficulties developing and maintaining friendships, and loneliness, can contribute to the development of depressive symptoms, the depressive symptoms may also act as a barrier to the development of quality relationships, thus creating a vicious cycle for many individuals with AS.

### **2.6.3 Suicidal Ideation**

Suicidal ideation is another long term risk for adolescents and adults with AS. According to Portway and Johnson (2005), a few of the participants in their study had seriously considered suicide as a possible option. Furthermore, 50% of the adolescents and young adults with AS reported on by Shtayermman (2007, 2008) experienced clinically significant suicidal ideation. Portway and Johnson (2005) asserted that both depression and suicidal ideation are long-term risks for adolescents and adults with AS. Barnhill (2007) reported that suicide rates are higher amongst individuals with AS in comparison to the general population, while Shtayermman (2007, 2008) found that both adolescents and young adults with AS are at an increased risk of suicide.

#### 2.6.4 *Eating Disorders*

It has previously been reported that children with an ASD have a greater tendency to experience eating problems in comparison to typically developing children (Martins et al., 2008; Schrek et al., 2004). Reasons suggested for this have included sensory sensitivities, resistance to change and insistence on routine (Grandin, 2011; Schmidt & Heybyrne, 2004; Schrek et al., 2004). There are also suggestions there may be a relationship between AS and eating disorders (Attwood, 2007; Kalyva, 2009; Simone, 2012).

There is evidence to suggest there may be a relationship between ASD and Anorexia (Berkman et al., 2007; Rastam et al., 2003). In a review of the eating disorder literature, Berkman et al. (2007) reported that 10 years following initial diagnosis, individuals with Anorexia were significantly more likely to have AS or another ASD in comparison to control groups. Furthermore, in a sample of 51 adults with Anorexia who developed the condition during adolescence who were matched with a control group, 20% of the Anorexia group had an ASD (Rastam et al., 2003). When a group of adolescent females with AS were compared to a group of typically developing adolescent females, Kalyva (2009) found that the AS group were at a greater risk of developing an eating disorder. Kalyva (2009) proposed that anxiety and difficulty reading social cues and body language may be a contributing factor to this increased risk among individuals with AS. Simone (2012) provided further insight both from her own experiences, and those of her interviewees regarding why females with AS in particular may be at risk of developing an eating disorder, especially during adolescence and young adulthood:

This control over our own bodies might be the result of having no control over social situations and not fitting in. Since youth is much more about popularity and appearance than it should be, we might think that if we are skinny enough or pretty enough, we will be like other people, and other people will like us. (pp. 40-41)

Therefore, according to Simone (2012), this vulnerability among individuals with AS to developing eating disorders may be in relation to the awareness of differences in comparison to their typically developing peers (Attwood, 2007; Carrington et al., 2003b; Church et al., 2000) and the difficulties individuals with AS experience in regards to developing and maintaining friendships and fitting into their peer group (Carrington et al., 2003a, 2003b; Church et al., 2000).

## **2.7 Teacher Characteristics and Teaching Practices**

Teacher characteristics and practices were found to impact the school experiences of students with AS. Brewin et al. (2008) and Sciotto et al. (2012) found that their participants identified teachers who promoted acceptance and understanding among peers, and took the time to understand individual students and learn about AS had a positive impact. Students in the study carried out by Saggars et al. (2011) said they found it beneficial to have teachers who were understanding, but firm, and who did not yell. In addition, Brewin et al. (2008), Carrington and Graham (1999), Saggars et al. (2011), and Sciotto et al. (2012) all reported that teachers who made classrooms as predictable as possible, while still allowing room for flexibility, had a positive impact on students with AS. The use of written or visual schedules was found to help maintain the predictability which is important for individuals with AS (Brewin et al., 2008; Sciotto et al., 2012). Preparing

students beforehand in regards to any changes in routine was also identified as being helpful for students with AS (Brewin et al., 2008).

Both Carrington and Graham (1999) and Sciotto et al. (2012) suggested that teachers who incorporated the interests of students into the curriculum where possible and appropriate had a positive impact on students with AS. This is supported by Grandin (1995), who described how a teacher used her interests as a way to motivate her to complete her school work. Another beneficial teaching practice identified was flexibility in regards to presentation of school work (Carrington & Graham, 1999; Sciotto et al., 2012); for example, allowing students with handwriting difficulties, which is often associated with AS (Attwood, 2007; Carrington & Graham, 1999; Saggars et al., 2011; Willey, 1999), to present their work in an alternative format. Participants in the study carried out by Sciotto et al. (2012) identified that it was helpful when teachers broke tasks and assignments into smaller parts, and provided class notes ahead of time. Allowing students with AS to take a short break from class when over-anxious or over-stimulated was identified as a beneficial teaching strategy (Sciotto et al., 2012). In addition, it was found that making provisions for sensory sensitivities, such as allowing students to wear earplugs or listen to music through headphones was beneficial for students with AS (Saggars et al., 2011; Sciotto et al., 2012).

## **2.8 Gender and Asperger's Syndrome**

As noted in Chapter 1, AS is diagnosed more frequently in males than females. According to Simone (2010, 2012), some females – herself included – are

diagnosed with AS later in life. Simone (2012) emphasised that sometimes adult females are diagnosed with AS when “the stress, strain and exhaustion of intellectually analysing social situations and acting ‘normal’ but being rejected, bullied and teased, results in a secondary mood disorder such as depression, or an anxiety or eating disorder” (pp. 7-8). This is affirmed by Attwood (2007), who has stated that AS is sometimes identified in adult females who have sought professional counselling for mental health concerns, and employment and relationship problems. Attwood (2007) also asserted that sometimes AS is not initially identified in females because it is masked by the pervasiveness of a secondary issue, such as anxiety, depression or an eating disorder. This is supported by Kopp and Gillberg (1992), who stated that females with ASD, including those with AS, are sometimes given a variety of psychiatric labels, such as those mentioned by Attwood (2007) and Simone (2012), and others such as personality disorders and obsessive compulsive disorder, prior to a diagnosis of AS. It is suggested by several authors (Attwood, 2007; Simone, 2010; Wagner, 2006; Wilkinson, 2008) that the late and missed diagnosis of AS in females can be partially attributed to perceptions of gender, and a milder presentation of AS symptomology in females. Some of the reported gender differences in the presentation of AS and ASD are discussed below.

### **2.8.1 Play**

Attwood (2007) reported that in comparison to their typically developing peers, children with AS often play in an “unconventional or idiosyncratic way” (p.59). This is consistent with the description of AS in DSM-IV-TR, which specified

one of the diagnostic criteria is the presence of restrictive and repetitive behaviours which impact upon the interests and activities of the individual (American Psychiatric Association, 2000). Mandy et al. (2012) asserted there are gender differences in the play of males and females with ASD, including AS. It was found that males were more likely to engage in “oddly formal play” (p.1308); for example, lining up toys in a systematic manner rather than playing imaginatively with them. This is supported by Hubbard (2010), who stated that while males with AS are more likely to play in a restrictive and repetitive way, females with AS often engage in pretend play as typically developing children do. This reported tendency of females to engage in play which appears to be imaginative and creative has been identified by Faherty (2006) as a possible reason why a diagnosis of AS may be overlooked. This is illustrated by Willey (1999), who recounted how as a child she would collect school supplies and play “schools” with her imaginary friends. Although on the surface, it would appear that Willey (1999) was engaging in imaginary play in the same manner as a typically developing child, she explained that she placed more importance on, and found more enjoyment in arranging the materials as opposed to using them to teach her “students” (Willey, 1999). According to Faherty (2006), the presence of what initially appears to be creative and imaginative play may result in a diagnosis of AS being ruled out in females, as this behaviour does not appear to match the criteria for AS outlined in DSM-IV-TR regarding repetitive and stereotyped behaviours and activities (American Psychiatric Association, 2000).

### 2.8.2 *Social skills and communicative behaviours*

An area where males and females with ASD, including AS, have been reported to differ is social and communicative skills, although there have been some varying findings presented in this regard. A characteristic often associated with ASD and AS is difficulty with sustained eye contact (Attwood, 2007; Wagner, 2006; Wilkinson, 2008). Both Wagner (2006) and Wilkinson (2008) have argued that this characteristic is often perceived differently between males and females. If a young female is unable to, or has difficulty making eye contact, this may be interpreted as shyness, while in a young male, this characteristic is more likely to be associated with a potential ASD. In a study which examined sex differences in higher functioning individuals with Autism 6-36 years of age (McLennan et al., 1993), it was found that amongst younger children, males demonstrated more severe social deficits and communicative problems in comparison to females. However, among older children and adults, it was found to be females who were more socially impaired, particularly in regards to peer relationships (McLennan et al., 1993). This is in contrast to findings reported by Mandy et al. (2012), who found that among individuals with AD, AS and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), males were reported by teachers as having poorer peer relationships in comparison to females.

It has been observed that females with AS tend to have superior superficial social skills and social competence in comparison to their male counterparts (Attwood, 2006, 2007; Wagner, 2006; Wilkinson, 2008). Through observing and imitating others, some females with AS are able to appear to be socially competent. In reality; however, they are basing their behaviour on the characteristics they have

observed “of someone who would be reasonably socially skilled in the situation, and using intellectual abilities rather than intuition to determine what to say or do” (Attwood, 2007, p. 46). Therefore, possessing superficial social skills is another possible reason why AS is not recognised and diagnosed as frequently in females (Attwood, 2007; Wagner, 2006). It has also been suggested that females with AS may be more proficient at blending in amongst their peers, particularly if they have friends who can assist them in social situations, and protect them from potential bullies (Attwood, 2007; Wagner, 2006). Willey (1999) described how a friend she had in secondary school intuitively understood her difficulties in regards to social situations and the anxiety she experienced upon meeting new people, and frequently supported her.

According to Mandy et al. (2012), concerns regarding the social and communicative development of students are often initially raised by teachers. When the findings of McLennan et al. (1993) are considered, if males with ASD are displaying social and communicative impairments earlier than females, it means that males are more likely to be referred to the appropriate personnel for further assessment (Wagner, 2006). By the time any social deficits are beginning to have a significant impact on females, these might be overlooked, perhaps because they may be more subtle (Mandy et al., 2012). Kopp and Gillberg (1992) have emphasised that when females with AS present as having superior superficial social skills, an AS diagnosis is unlikely to be considered, meaning they may not receive the support they need. In addition, Attwood (2007) has suggested that females with AS may be more skilled at concealing their confusion in social situations. This has been

illustrated with the following example: if a female with AS is invited to play a game on the playground, she may initially stand back and watch before participating to ensure she does not make a mistake (Attwood, 2007). Similarly, a female with AS may seek advice and reassurance from others to ensure she does not make a social error (Attwood, 2007; Willey, 1999). Therefore, this may mean that females are more skilled at masquerading, as described by Carrington and Graham (2001) and Carrington et al. (2003a, 2003b) than their male counterparts. Carrington et al. (2003a) asserted that while masquerading is a useful adaptive behaviour, in the case of females with AS, strong masquerading skills may be another reason why females with AS are not always identified.

Despite their reported superior superficial social skills, and the possibility they may be more skilled at masquerading, Simone (2010) has suggested that females with AS may experience more difficulties in regards to establishing and maintaining friendships in comparison to males. It has been reported by Carrington and Graham (1999, 2001) and Carrington et al. (2003b) that some adolescents with AS develop friendships with peers based upon mutual interests, but Simone (2010) argued that this is less likely to occur for females than for males. According to Simone (2010), male friendships are more likely than those of females to be based on mutual interests; therefore female friendships are more dependent on social skills and an understanding of social nuances. This is supported by Richard and Schneider (2005), who reported that adolescent females tend to establish intimate friendships with one or two peers with whom they discuss their feelings and in whom they confide. Furthermore, McLennan et al. (1993) asserted that the interests of males tend to be

less verbal and socially interactive than the interests of females, meaning it is likely that females with AS may experience more difficulties in peer relationships than males. In addition, Wagner (2006) has observed that even during the primary school years, females with AS often struggle with the social aspects of school; while their typically developing female peers become “socially savvy” (p. 20), they do not. Therefore, superior superficial social skills, a more subtle presentation of social deficits and proficient masquerading skills might be masking the true social difficulties and needs of female students with AS, and decreasing the chance of identification, diagnosis, and appropriate support.

It has also been suggested that there are differences in the conversational skills of males and females with AS (Attwood, 2007; Mandy et al., 2012). A characteristic of young males with AS in regards to conversation is a tendency to use advanced vocabulary for their chronological age (Attwood, 2007). In addition, Attwood (2007) and Mandy et al. (2012) reported that the conversations of young males with AS are often filled with factual information, frequently in relation to their interests. Attwood (2007) has observed that young males with AS often sound like “little professors” (p. 47). In contrast, young females with AS, with their ability to think deeply about, and analyse social situations, can often sound like “little philosophers” (Attwood, 2007, p. 47). Simone (2010) has suggested that the ability of females with AS to think intellectually about social situations may conceal the fact they might be lacking in emotional maturity, another reason why a diagnosis of AS may not be considered.

### 2.8.3 *Interests*

It has been suggested there may be gender differences in regards to the interests of individuals with AS, and the presentation of these (Attwood, 2007; Simone, 2010). While it varies for each individual, the interests of male children with AS are more likely to be abnormal in focus, while the interests of females with AS are often similar to those of their typically developing female peers (Attwood, 2007). It is reported by Attwood (2007) that the interests of female children with AS often include dolls, reading and animals, while common interests of adolescent and adult females with AS often include classical and fantasy literature, and soap operas. All of these interests are also enjoyed by some typically developing females, thus these interests are not abnormal in focus (Attwood, 2007). Simone (2010) explains in the following example why the interests of females may be overlooked as a potential sign of AS:

If a girl reads voraciously, this is not as jarring or strange to a parent or physician as being fascinated with different types of plane engines built between 1940 and 1945. But what might not be realised is that behind our bedroom door, we may be reading the same book 124 times because we are obsessed by it. (pp. 24-25)

In the example described by Simone (2010), the interest itself is not abnormal in focus, but rather in its intensity (American Psychiatric Association, 2000). Therefore, as the interests of females with AS are generally not as unusual as those of their male counterparts, the decision as to whether an interest is clinically significant must be based on the intensity of the interest: the amount of time devoted to participating in and discussing the interest (Attwood, 2007). It has also been emphasised by Simone (2010) that while typically developing females tend to

outgrow their childhood interests, many females with AS retain childhood interests for longer, or else do not outgrow them. Simone (2010) has explained this argument through the following description of her own experiences as an adolescent: “I tried to get my teenage best friends to be as obsessed with Tolkien and music as I was but they bonded together in their hunt for more ‘normal’ pursuits (i.e. jobs and boys) and I was left behind” (p. 110).

#### **2.8.4 Motor skills**

Another difference which has been reported between males and females with AS is in relation to motor skills. Mandy et al. (2012) found that although males and females with AS were equally impaired in terms of gross motor skills, females with AS tended to have superior fine motor skills in comparison to males. These differences in regards to fine motor skills have also been observed by Attwood (2007), who found that motor skills impairments in females with AS may be less evident.

### **2.9 Identification of Asperger’s Syndrome**

It has been suggested by several authors (Attwood, 2007; Mandy et al., 2012; Wagner, 2006; Wilkinson, 2008) that the behaviours of male students with AS are more likely than the behaviours of female students to come to the attention of teachers. It has been observed that males, more frequently than females with AS, present with externalising behaviours such as hyperactivity and aggression (Attwood, 2007; Mandy et al., 2012). In addition, Mandy et al. (2012) found that

although teachers reported more problem behaviours among males with ASD, including AS, in comparison to females, parents observed more internalising problems in females than males. Similarly, Thompson et al. (2003) reported that like typically developing females, females with AS are more likely than males to develop conditions such as anxiety and depression, particularly during adolescence.

Furthermore, in contrast to the challenging behaviours sometimes displayed by males with AS (Attwood, 2007; Mandy et al., 2012), the opposite has been found for females. Several authors (Attwood, 2007; Wagner, 2006; Wilkinson, 2008) have asserted that females with AS are less likely to draw attention to themselves in the classroom, often presenting as quiet, polite, and well-behaved. Attwood (2007) even suggested that these behaviours may be a strategy utilised by some females with AS to avoid gaining attention from teachers and peers. Wagner (2006) also observed that females with AS tend to not indicate to teachers if they are experiencing difficulty with their school work, often out of concern their teacher will become angry or upset with them, sometimes intentionally concealing their difficulties for this reason.

It is males with potential AS, therefore, who are more likely to be noticed by their teachers in regards to their educational and behavioural needs, and subsequently referred to the appropriate personnel for further assessment (Attwood, 2007; Mandy et al., 2012; Wagner, 2006). Meanwhile, the presentation of AS in females leads them to be overlooked, and consequently underdiagnosed (Attwood, 2007; Wagner, 2006; Wilkinson, 2008).

## 2.10 Summary

With the exception of the study carried out by Kalyva (2009), and the adult sample reported on by Sciotto et al. (2012), females have been underrepresented and unrepresented throughout the AS literature. Wagner (2006) has emphasised that although much of what can be applied academically and socially to males with AS can also be applied to females, it is important to understand the female perspective of AS, and what their specific challenges and needs at school are. In addition, Mandy et al. (2012) asserted it is important to determine whether the differing behaviours of males and females with AS which have been reported are a result of females with AS adapting better to the school environment, or whether their difficulties and impairments present differently. Several authors (Attwood, 2007; Simone, 2010; Wagner, 2006; Wilkinson, 2008) suggest that the late and missed diagnosis of AS in females can be partially attributed to perceptions of gender, and a milder presentation of AS symptomology in females.

Wagner (2006) and Wilkinson (2008) have posed a very important question: where are the female students with AS? Despite the lack of research focussing on this population, it is clear from the professional experience of Attwood (2007) and Wagner (2006), and the anecdotal evidence provided by Simone (2010, 2012) that they do exist, and are not a rarity as some authors (Mandy et al., 2012; Whiteley et al., 2010) seemed to indicate. Perhaps even more important than asking where the female students with AS are is the following question: What are the school experiences of female students with AS? (Wagner, 2006). In the following chapter,

the research methodology will be described for the present study, which aimed to examine the school experiences of female students with AS.

## Chapter 3 - Methodology

### 3.1 Introduction

The purpose of this study was to examine the school experiences of females with AS. This study sought to provide insight into the specific challenges and needs of this population so that teachers and other school personnel can be better informed regarding how they can support females with AS in reaching their full potential: academically, socially and emotionally. This chapter describes the ethical considerations involved with this study, the research design, survey instruments and approach to data analysis.

### 3.2 Ethical Considerations

#### 3.2.1 *Gaining permission to conduct research*

Prior to the commencement of the data collection, a Minimal Risk Social Science Application was submitted. This study received approval from the University of Tasmania, Human Research Ethics Committee Network on 16<sup>th</sup> May, 2013 (Appendix B).

#### 3.2.2 *Consent*

In studies involving online surveys such as this one, participants are providing their informed consent by completing and submitting their surveys. Implied consent allowed participants in this study to remain anonymous.

Participants were provided with sufficient information on which to base their decision to participate. The survey was designed in such a way that participants were able to view the questions before deciding whether or not to participate. Participants were required to tick a box to indicate they had read and understood the provided information, and were consenting to participate; surveys without the consent box ticked were unable to be submitted. On the participant information sheet (Appendix C), the following information was provided: (a) a description of the study, (b) the educational institution the study was affiliated with, (c) an explanation of why the study was being conducted, (d) the inclusion criteria for participation, (e) a description of what participation involves, (f) benefits and risks of participation, (g) an explanation of what will happen to the data at the conclusion of the study, (h) an assurance that due to the anonymous nature of the study, participants would not be able to be identified by their responses and (i) a statement explaining that by completing and submitting their survey, and through ticking the consent box, participants are providing their informed consent.

### **3.2.3 Assessment of risk**

In assessing the risk for participants, it was determined the study could be classified as being of minimal risk. Participants were guaranteed anonymity, could only participate after providing their informed consent, and were free to answer the questions at their own comfort level. The nature of the questions on the survey instruments were such that there was not considered to be a significant risk of participants experiencing any psychological harm as a result of participation.

However, depending on the individual experiences of participants, there was a degree of risk some discomfort might be experienced through recalling adverse social and emotional experiences. This warranted the inclusion of contact information for confidential counselling services within the surveys. Despite this degree of risk, there were potential benefits for participants in sharing their experiences: the opportunity to “have their say”, and make a difference for others.

### **3.2.4 Privacy**

Through their participation in this study, participants were providing personal information in regards to their own, or their daughter’s experiences at school. In this study, it was possible to guarantee anonymity to all participants, as no identifying information was collected. The researcher was only aware of whether participants were the parent of a school aged female with AS, or an adult female with AS, based on which survey was completed and submitted.

### **3.3 Research Design**

This qualitative study sought to examine the following research question: What are the school experiences – both academic and social – of females with AS? In addition, answers to the following five sub-questions were sought: (a) what are the challenges faced by female students with AS at school? (b) what teaching practices are perceived by females with AS and their parents as helpful and unhelpful? (c) what are the academic experiences of female students with AS? (d) what are the emotional experiences of female students with AS in relation to school? and (e) what

are the experiences of female students with AS in relation to peer relationships and the social aspects of school?

### **3.3.1 Participants**

Two groups of participants were recruited for this study: (a) adult females 18 years of age and over with a diagnosis of AS, and (b) parents of females aged between 5 and 18 years, attending school at the time of the study, who had a diagnosis of AS. Prior to the commencement of this study, it was initially determined that 40 to 50 participants were needed to address the research question and fulfil the aims of the study. By Friday 2<sup>nd</sup> August, 32 participants had responded to the surveys. As the participant responses provided rich and detailed information, the decision was made to collect no further data for this thesis after this date.

### **3.3.2 Recruitment of participants**

Once approval from the University of Tasmania, Human Research Ethics Committee Network was granted, participants were recruited through AS and ASD related websites. The two websites used by Scitutto et al. (2012) – Wrong Planet (<http://www.wrongplanet.net>) and Asperger's Syndrome Education Network (<http://aspennj.org>) - were selected as they had been shown previously to be successful for recruiting participants. Because the present study focussed specifically on females with AS, taking the reported gender ratios into account, it was anticipated that participant recruitment may be difficult. For this reason, three additional

websites were selected on which to advertise the study: (a) the website of Dr Tony Attwood, prominent psychologist, AS researcher, and speaker (<http://www.tonyattwood.com.au>), (b) Asperger's Advice (<http://aspergersadvice.org>), and Amaze-the website of the main organisation for ASD in Victoria (<http://www.amaze.org.au>). These websites were selected because they are well known in the AS community, and they all regularly advertise research participation opportunities. It was anticipated that advertising the study on these websites would attract participants who are genuinely interested in, and concerned about the school experiences of females with AS. These websites were all contacted via email on 16<sup>th</sup> May 2013 in order to ask for assistance in advertising the study. An advertisement for the study was placed on the Amaze website (<http://www.amaze.org.au>) on 4<sup>th</sup> June 2013. On 12<sup>th</sup> June 2013, as advertisements had not been posted on any of the other websites initially contacted, an amendment form was submitted to the HREC so that other websites could be contacted. This amendment was approved on 14<sup>th</sup> June 2013 (Appendix D) and the following three websites were contacted: (a) Asperger's Victoria (<http://www.aspergersvic.org.au>), (b) Autism Queensland (<http://www.autismqld.com.au>) and (c) Autism New Zealand (<http://www.autismnz.org.nz>). The survey was posted on the Asperger's Victoria website (<http://www.aspergersvic.org.au>) on 15<sup>th</sup> June, on the professional website of Dr Tony Attwood (<http://www.tonyattwood.com.au>) on 20<sup>th</sup> June, 2013, the website of Autism New Zealand (<http://www.autismnz.org.nz>) on 21<sup>st</sup> June, 2013 and the Autism Queensland website (<http://www.autismqld.com.au>) on 2<sup>nd</sup> July, 2013. On all the websites which the study was posted, participants saw an advertisement of the study which contained a link to the Qualtrics online survey site.

Upon clicking this link, participants were directed to information outlining the study, and a button to access the survey questions by which they gave consent.

### 3.3.3 *Survey instruments*

This study involved participants completing an anonymous, open-ended online survey. The open-ended format was selected because although there were specific questions being asked of participants, this format allowed participants to provide their opinions and insights, and describe their experiences in as much or as little detail as they wished and felt comfortable with (O'Leary, 2004; Sarantakos, 1998). Keeping the questions as open as possible also allowed participants to provide valuable and interesting information that the researcher was not anticipating (Burns, 2000; Sarantakos, 1998). In addition, as in the study carried out by Sciutto et al. (2012), it was hoped the online nature of the study would appeal to individuals with AS, knowing they could participate in the study and share their opinions, insights and experiences without having to deal with the social aspects of an interview or focus group or the associated anxiety this might have created.

In their study, Sciutto et al. (2012) used the same survey instrument for both participant groups: adults with AS and parents of children with AS. For the present study, the decision was made to use two survey instruments: one for adult females with AS (Appendix E) and one for parents of school aged females with AS (Appendix F). Despite the strong similarity in the questions on the two survey instruments, the decision to use two separate surveys was to ensure the questions were as clear as possible, particularly for the participants with AS; for example,

avoiding the use of language such as you/your daughter's in the questions. The adult survey also took into consideration that some of the adult female participants may not have received a diagnosis of AS while they were attending school.

Each survey consisted of eight open-ended questions. The survey questions were designed to obtain information pertinent to the research questions, while still providing participants with a flexible framework in which they could share their opinions, insights and experiences. Questions 1, 2, 3, and 7 were informed by questions from the survey instrument used by Sciutto et al. (2012). Question 1 asked participants about significant challenges faced at school, Questions 2 and 3 asked about helpful and unhelpful teaching practices, and Question 7 asked participants about what they wish teachers understood better about AS. Question 5 asked participants about academic experiences at school. This question was based on reports that individuals with AS, despite their intelligence, are at risk of academic underachievement (Carrington et al., 2003a; Wagner, 2006). Question 6 asked participants about the emotions individuals with AS experience in relation to school. This question was asked based on reports from several authors (Attwood, 2007; Barnhill, 2001; Whitehouse et al., 2009) that in comparison to their typically developing peers, students with AS experience more anxiety, stress, loneliness and feelings of sadness. In addition, Sciutto et al. (2012) reported on the emotional strain experienced by students with AS as they attempted to fit in with their peer group. It was therefore determined it was important to examine the emotions which school, and the various aspects of school elicit for females with AS.

Question 4 asked participants about the peer relationships and social experiences of females with AS at school. This question was included based on the insights and observations of Simone (2010) and Wagner (2006). Simone (2010) suggested that despite reports that females with AS have superior superficial social skills in comparison to their male counterparts, females with AS may experience more difficulties in regards to developing and maintaining friendships. Therefore, it was decided that this was an area worth specifically asking participants about in relation to the school experiences of female students with AS. Question 8 was an optional question in which participants could provide any information in relation to the school experiences of females with AS which was not covered in the previous questions.

In addition to the eight questions on the survey, demographic data was also collected from participants. Participants were asked to provide their age (Adult Participants), or their daughter's age (Parent Participants). Participants were also asked to provide their geographic location. The data in terms of location was collected to identify any similarities and differences in terms of the school experiences of females with AS. The location data was categorised in terms of country, with the exception of three European countries, which are collectively referred to as Europe. This was done because there was only one participant from each of these countries. Although the small sample means differences between groups are inconclusive, these data are provided in order to suggest possible areas where further research into the school experiences of female students with AS may

be warranted, and to demonstrate the school experiences of females with AS are generally consistent throughout western countries.

### **3.3.4 Approach to data analysis**

The survey data were analysed qualitatively, using an inductive reasoning approach (O'Leary, 2004) in order to identify the themes which emerged from the data. This approach to data analysis was used by Sciutto et al. (2012) to ensure the themes identified by the researchers were closely connected to the raw data, thus ensuring that the perspectives of participants were heard and accurately reported.

All individual survey responses were read, and all text provided by participants were entered into Microsoft Excel, and given an initial label which reflected what participants were communicating. Once this process was completed for all surveys, a list of themes was generated based on the initial labels. All themes were given a letter code, and a code was assigned to each response by individual participants to each survey question. In the case of data entries which initially did not fit into any existing categories, accommodations were made, such as adding new categories, or combining categories, until all data entries had an appropriate letter code. This process was carried out separately for the parent surveys and the adult surveys in order to identify any similarities and differences between the two participant groups. Once all the themes in relation to the school experiences of female students with AS had been identified from the data, they were analysed in terms of whether they were consistent with the AS literature related to the school experiences of students with AS, whether any themes appeared to be particularly

significant for participants, and whether any themes were generated which were not evident in the literature. Some of the issues discussed by participants were raised in response to multiple items; for example, whereas Question 4 on the surveys specifically asked participants about peer relationships and social experiences, Question 1, which asked participants to describe the most significant challenges which they or their daughters faced at school, and Question 7, which asked participants what they wished teachers understood better about AS, also elicited responses from participants into peer relationships and social experiences. The data from all eight questions have therefore been grouped into four broad categories, each containing several themes. The percentage of participants overall (Adult Participants and Parent Participants) whose responses reflected each theme have been calculated, and been rounded to the nearest whole number.

### **3.4 Summary**

The purpose of this study was to examine the school experiences of females with AS. This chapter outlined the research design, which included advertising the study through popular AS websites and inviting adult females with AS, and parents of school-aged females with AS to complete an anonymous eight question online survey. The procedures used to collect and analyse data were also outlined in this chapter. Based on the survey data, a list of themes was generated. A description of the participants, and their responses in relation to the school experiences of female students with AS is provided in the Results chapter which follows.

## Chapter 4 - Results

### 4.1 Introduction

As stated in Chapter 1, the purpose of this study was to examine the school experiences of females with AS. This chapter describes the study sample, and presents the results of the anonymous online surveys completed by participants.

### 4.2 Study Sample

There were a total of 32 responses to the surveys. Twenty four participants identified themselves as adult females with AS 18 years of age and over, and 8 participants identified themselves as parents of school aged females with AS aged between 5 and 18 years. Three of the adult participants reported they received their diagnosis of AS while attending school; the remaining 21 were diagnosed with AS as adults. There were not found to be any differences regarding the issues discussed by the three adult participants who were diagnosed with AS while at school in comparison to those participants who received their diagnosis later in life. All the female children with AS reported on by parents had a diagnosis of AS of which the schools were aware. The issues raised in response to the survey questions were consistent between both participants groups. Table 4.1 presents the number of participants in each group, and from each location.

Table 4.1

*Geographic Locations of Participants*

	Australia	USA	UK	Canada	Europe	Totals
Adult	7	8	3	3	3	24
Child	5	1	1	1	0	8
Totals	12	9	4	4	3	32

The 24 adult participants ranged in age from 18-61 years ( $M=36.25$ ,  $SD=11.82$ ).

The 8 female children reported on by parent participants were aged from 6-17 years ( $M=12.13$ ,  $SD=3.98$ ). Table 4.2 presents the age ranges of the adult participants, and Table 4.3 presents the age ranges of the female children with AS reported on by parent participants.

Table 4.2

*Age Ranges of Female Adults with AS*

Age	18-24	25-34	35-44	45-54	55-64	Totals
Number of participants	5	5	9	2	3	24

Table 4.3

*Age Ranges of Female Children with AS*

Age	6-9	10-13	14-17	Totals
Number of participants	2	3	3	8

### 4.3 Analysis of Survey Responses

Participant quotes have been used in the presentation of results in order to enhance the explanation of each theme. Following each quote, the question from which the quote was drawn from is indicated, and whether the participant was an adult female (Adult Participant) or the parent of a school aged female with AS (Parent Participant). Spelling errors made by participants in their responses have been corrected when the intention of the participant was clear. In addition, any American spelling used by participants has been changed to Australian English.

Table 4.4 presents the four broad categories the data were grouped into, and the themes contained in each of these. The percentages provided in the table indicate the percentage of participants overall (Adult Participants and Parent Participants) who contributed to each theme. In the following section, each theme from Table 4.4 is discussed in turn.

Table 4.4

*Themes Identified by Participants (n=32)*

Category	Specific Theme
Category 1: Issues requiring more understanding	<p>Theme 1: There is a lack of understanding regarding exactly what AS is, and its associated characteristics and challenges <b>(78%)</b></p> <p>Theme 2: AS is a “non-obvious” condition, perhaps even more so in females <b>(47%)</b></p>
Category 2: Teaching strategies and practices which had a positive impact	<p>Theme 1: Teachers who understood and accommodated sensory sensitivities <b>(13%)</b></p> <p>Theme 2: Teachers who had a positive perception of the student, worked from a strengths based approach and were supportive <b>(44%)</b></p> <p>Theme 3: Providing the opportunity for female students with AS to participate in structured activities <b>(16%)</b></p> <p>Theme 4: Providing classroom environments which are predictable, while still allowing for flexibility <b>(16%)</b></p>
Category 3: Areas of academic challenge and need	<p>Theme 1: Female students with AS are capable of achieving well academically <b>(72%)</b></p> <p>Theme 2: Each female student with AS is an individual in terms of their academic strengths and weaknesses, and subject preferences <b>(100%)</b></p> <p>Theme 3: Some teachers may have reduced expectations of female students with AS <b>(13%)</b></p> <p>Theme 4: Some female students with AS may have executive function impairments <b>(47%)</b></p>
Category 4: Areas of social and emotional	<p>Theme 1: The social aspects of school are the most challenging for many female students</p>

challenge and need	<p>with AS (78%)</p> <p>Theme 2: The experiences of “feeling different” and “not fitting in” are common among female students with AS (53%)</p> <p>Theme 3: Female students with AS often have difficulty developing and maintaining friendships (78%)</p> <p>Theme 4: Female students with AS are vulnerable to being bullied (47%)</p> <p>Theme 5: Female students with AS are vulnerable to experiencing mental health concerns (84%)</p>
--------------------	--

#### 4.4 Category 1: Issues Requiring More Understanding

The issues in regards to female students with AS which participants believed required more understanding have been grouped into two themes: (1) there is a lack of understanding regarding exactly what AS is, and its associated characteristics and challenges, and (2) AS is a “non-obvious” condition, perhaps even more so in females.

##### 4.4.1 *Theme 1: There is a lack of understanding regarding exactly what AS is, and its associated characteristics and challenges*

Participants’ responses reflected a belief that some teachers lack understanding of AS, including its associated characteristics and challenges. Six (75%) parent participants expressed this theme. Table 4.5 presents the locations, and the age groups of female children with AS reported on by parent participants.

Table 4.5

*Responses Relating to Category 1, Theme 1: There is a Lack of Understanding Regarding Exactly what AS is, and its Associated Characteristics and Challenges (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	2 (100%)	2 (67%)	2 (67%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	4 (80%)	0	1 (100%)	1(100%)

This theme was also consistently reported by adult participants, with it being evident in the responses of 19 (79%) participants. Adult participants from all locations described this theme, with participants from the United States of America (USA) and Canada discussing it most frequently. Table 4.6 presents the locations and age groups of adult participants who reported this theme.

Table 4.6

*Responses Relating to Category 1, Theme 1: There is a Lack of Understanding Regarding Exactly what AS is, and its Associated Characteristics and Challenges (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	3 (60%)	4 (80%)	7 (78%)	2 (100%)	3 (100%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	5 (71%)	7 (88%)	3 (100%)	3 (100%)	1 (33%)

Some specific examples provided by both participant groups included a lack of understanding among teachers about the sensory sensitivities and impairments in executive functioning often associated with AS. A number of participants also emphasised that some teachers did not understand that shouting at students with AS will not help them understand verbal instructions more effectively, and that it can also be frightening for them. Some adult participants reported that some teachers did not understand that individuals with AS generally do not like being the centre of attention, even for a positive reason; for example: "I was often used as an example of how to behave, or asked to answer questions that no one else could-that was very embarrassing and made the other kids laugh at me" (Adult Participant 7, Question 3). In addition, a parent participant reported that some teachers did not understand the severity of her/his daughter's social skills deficits, while another parent emphasised that some teachers did not recognise her/his daughter's anxiety and stress levels. As well as a lack of understanding about AS, some participants described instances where teachers had been unwilling to make accommodations for, and failed to be supportive of female students with AS. One parent noted that, "the most distressing aspect was the disregard of teachers for her difficulties and their unwillingness to help her" (Parent Participant 8, Question 1).

#### **4.4.2 Theme 2: AS is a "non-obvious" condition, perhaps even more so in females**

Several participants discussed the non-obvious nature of AS, especially in regards to females with the condition. This theme was discussed by 5 (63%) parent

participants, particularly by those with daughters in the older age groups. Parent participants from all locations reported this theme. Table 4.7 presents the locations, and the age groups of female children with AS reported on by parent participants.

Table 4.7

*Responses Relating to Category 1, Theme 2: AS is a Non-obvious Condition, Perhaps Even More So in Females (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	1 (50%)	2 (67%)	2 (67%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	2 (40%)	1 (100%)	1 (100%)	1 (100%)

This theme was also evident in a number of adult responses. It was described by 10 (47%) adult participants. It was mentioned the most frequently by participants in the two younger age groups, and by participants from Canada. Table 4.8 presents the age groups and locations of adult participants who reported this theme.

Table 4.8

*Responses Relating to Category 1, Theme 2: AS is a Non-obvious Condition, Perhaps Even More So in Females (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	3 (60%)	4 (80%)	2 (22%)	0	1 (33%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	4 (57%)	3 (38%)	0	3 (100%)	0

When they reflected upon their school experiences, a number of adult participants emphasised the need for teachers to be aware that AS may present more mildly in females, such as in this appeal to teachers: “do not dismiss the possibility because the child may have good eye contact, laugh, have empathy or want to interact with other children. We don’t all have the ‘full hand’ of Asperger’s characteristics” (Adult Participant 7, Question 7). Similarly, a parent participant asserted, “teachers need to be made aware that quiet, perfectly behaved little girls may have AS. They seem to believe that all kids with AS have to be badly behaved and cannot seem to comprehend that my daughter has AS” (Parent Participant 2, Question 8). Some parents explained that a challenging issue they encountered was having the validity of the AS diagnosis questioned by teachers because they did not personally witness any behavioural or emotional issues, as one parent participant noted: “my daughter holds her emotions in during the day and then melts down in the car and at home. The teachers see none of her behaviours, they find it hard to believe she has Asperger’s” (Parent Participant 4, Question 6). Several responses

from both participant groups indicated that female students with AS can sometimes be overlooked by teachers as a result of being quiet, passive, and well-behaved, such as in the following example: “she is almost invisible to them. Because she is so perfectly well-behaved, she does not gain much in the way of attention. She also gets overlooked when rewards are given” (Parent Participant 2, Question 3).

#### **4.5 Category 2: Teaching Strategies Which Had a Positive Impact**

The teaching strategies and practices identified by participants as having a positive impact on female students with AS have been grouped into four themes: (1) teachers who understood and accommodated sensory sensitivities, (2) teachers who had a positive perception of the student, worked from a strengths based approach and were supportive, (3) providing the opportunity for female students with AS to participate in structured activities, and (4) providing classroom environments which are predictable, while still allowing for flexibility.

##### ***4.5.1 Theme 1: Teachers who understood and accommodated sensory sensitivities***

When asked about beneficial teaching strategies and practices, 4 (13%) participants overall reported it to be beneficial when teachers understood and accommodated the sensory sensitivities of female students with AS. This theme was reflected in 2 (25%) parent responses. Both of these participants had daughters in the 10-13 age group, and were from Australia. Table 4.9 presents the locations, and the age groups of female children with AS reported on by parent participants.

Table 4.9

*Responses Relating to Category 2, Theme 1: Teachers who Understood and Accommodated Sensory Sensitivities (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	0	2 (67%)	0	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	2 (40%)	0	0	0

This theme was also reflected in 2 (8%) adult responses. Table 4.10 presents the age groups and locations of adult participants who reported this theme.

Table 4.10

*Responses Relating to Category 2, Theme 1: Teachers who Understood and Accommodated Sensory Sensitivities (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	0	0	1 (11%)	0	1 (33%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	1 (14%)	1 (13%)	0	0	0

A parent participant noted that it helped her/his daughter when teachers allowed her to listen to music through headphones while working to assist her concentration. Another parent explained that her/his daughter cannot tolerate the

beach due to her sensory sensitivities, and that this issue was accommodated on a school camp by ensuring she did not have to participate in any activities on the sand. An adult participant provided the following example of how her sensory sensitivities were accommodated:

One of the few teachers that was nice to me would let me sit in his room and be alone in the quiet to calm down...one teacher allowed me to draw in his classroom during lunch time, I didn't like the bustle and noise of the lunch room (Adult Participant 23, Question 2).

Although in the following example, no specific accommodations were made for the female student with AS, an adult participant expressed her gratitude to her former teachers for the classroom environments she experienced: "I would firstly thank them for providing me with a quiet, mostly distraction-free environment in which to learn" (Adult Participant 7, Question 7).

#### ***4.5.2 Teachers who had a positive perception of the student, worked from a strengths based approach, and were supportive***

This theme was reflected in 14 (44%) responses overall. It was reported by 2 (25%) parent participants. Both these participants were reporting on daughters in the two older age groups. Parent participants from Australia and the USA discussed this theme. Table 4.11 presents the locations, and the age groups of female children with AS reported on by parent participants.

Table 4.11

*Responses Relating to Category 2, Theme 2: Teachers who Had a Positive Perception of the Student, Worked From a Strengths Based Approach and Were Supportive (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	0	1 (33%)	1 (33%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	1 (20%)	1 (100%)	0	0

This theme was reflected in 12 (50%) adult responses. It was most frequently discussed by participants in the 25-34 age group, and by participants from all locations except Europe. Table 4.12 presents the age groups and locations of adult participants who discussed this theme.

Table 4.12

*Responses Relating to Category 2, Theme 2: Teachers who Had a Positive Perception of the Student, Worked From a Strengths Based Approach and Were Supportive (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	2 (40%)	4 (80%)	4 (44%)	1 (50%)	1 (33%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	4 (57%)	6 (75%)	1 (33%)	1 (33%)	0

A number of participants described in some detail how beneficial it was when teachers had a positive perception of the female student with AS, worked from a strengths based approach and were supportive. One parent described the efforts of one of her/his daughter's teachers as she worked to normalise ASD in the classroom, and the positive impact this had:

One of her teachers actually assigned readings about autism as part of the regular curriculum, without ever identifying my daughter or anyone else in the class as autistic. This helped immensely when my daughter "came out" later to some of her classmates. (Parent Participant 7, Question 2)

Another parent outlined how some teachers had used one of her/his daughter's strengths to assist her in managing social situations: "she is an enthusiastic writer, so if issues arise with friendships, a task may be for her to write a story about a similar situation (fictional) and how it was worked through. This helps her immensely"(Parent Participant 6, Question 2).

Although only three adult participants stated they had a diagnosis of AS when at school, a number of responses described how they benefited from a strengths based approach; for example:

I had wonderful teachers for third and fifth grades and I excelled in those years, They were both able to see my strengths and instead of making me repeat assignments where I made mistakes in spelling or arithmetic they gave me more challenging work which also allowed for more flexibility in how I communicated my answers." (Adult Participant 22, Question 2)

Some adult participants recalled that it benefited them both academically and socially when teachers held them in positive regard, such as the teacher referred to in the following example: "I went from being 'dim' to 'highly able' in the year I was in

her class. Freed from my former mystery I was able to engage with the school work and was good at it" (Adult Participant 3, Question 2). Other adult participants wrote about teachers who acted as mentors for them in secondary school who not only supported them academically, but also socially and emotionally. One participant attributed the fact she completed secondary school to the support she received from some teachers:

Some of my teachers also took a personal interest in my talents and well-being and encouraged me to pursue my passion, writing, and to take care of my mental and personal health. This support and encouragement could easily be designated as the only reason I survived high school. (Adult Participant 13, Question 2)

### ***4.5.3 Theme 3: Providing the opportunity for female students with AS to participate in structured activities***

The benefits female students with AS received through their participation in structured activities was described by 5 (16%) participants overall. This theme was described by 2 (25%) parent participants with daughters in the two younger age groups. These participants were from Australia, and the United Kingdom (UK). Table 4.13 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.13

*Responses Relating to Category 2, Theme 3: Providing the Opportunity for Female Students with AS to Participate in Structured Activities (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	1 (50%)	1 (33%)	0	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	1 (20%)	0	1 (100%)	0

This theme was mentioned by 3 (13%) adult participants. It was discussed most frequently by participants in the oldest age group, and participants from Australia and the USA. Table 4.14 presents the age ranges and locations of adult participants who discussed this theme.

Table 4.14

*Responses Relating to Category 2, Theme 3: Providing the Opportunity for Female Students with AS to Participate in Structured Activities (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	0	0	1 (11%)	0	2 (67%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	1 (14%)	2 (25%)	0	0	0

One parent participant said her/his daughter with AS enjoyed attending the structured after school activities the school provided, while another stated: "at my

daughter's current school, there are many specialist groups, such as friendship groups, story writing and poetry, which my daughter attends and loves" (Parent Participant 6, Question 2). Three adult participants described how their participation in structured activities, such as sporting teams, enabled them to develop friendships with their peers; for example: "in upper primary years I played a lot of sport and found it easier to relate to girls I played sport with" (Adult Participant 7, Question 4).

#### ***4.5.4 Theme 4: Providing classroom environments which are predictable, while still allowing for flexibility***

Overall, 5 (16%) participants indicated that classroom environments which were predictable, but still allowed for flexibility, were the most beneficial for female students with AS. One (13%) parent participant reported this theme; this participant was a parent of a daughter in the 14-17 age group, and was from Australia. Table 4.15 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.15

*Responses Relating to Category 2, Theme 4: Providing Classroom Environments which are Predictable, while Still Allowing for Flexibility (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	0	0	1 (33%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	1 (20%)	0	0	0

Among the adult participants, the benefits of a predictable but flexible classroom environment were described by 4 (17%) participants. It was discussed by participants in the oldest, and two younger age groups, and by participants from Australia, the USA and Canada. Table 4.16 presents the age groups and locations of adult participants who reported this theme.

Table 4.16

*Responses Relating to Category 2, Theme 4: Providing Classroom Environments which are Predictable, while Still allowing for Flexibility (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	2 (40%)	1 (20%)	0	0	1 (33%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	1 (14%)	2 (25%)	0	1 (33%)	0

In regards to how a predicable but flexible classroom environment had benefited her/his daughter, a parent participant explained: “in primary school it helped when teachers wrote the class schedule on the whiteboard, so she always knew what was going on” (Parent Participant 1, Question 2). Similarly, an adult participant emphasised it helped her when teachers informed her in advance of any changes to the classroom routine. Another adult participant described in detail the predictable and structured classroom environment which benefited her: “learning environment was very quiet, with minimal distractions. Most tasks were individual and not group based. Learning was very structured and explicit. Teachers expected

students to stay seated and not discuss issues or chat” (Adult Participant 7, Question 2).

#### **4.6 Category 3: Areas of Academic Need**

The areas of academic need for female students with AS reflected in participant responses have been grouped into the following four themes: (1) female students with AS are capable of performing well academically, (2) each female student with AS is an individual in terms of her academic strengths and weaknesses, and subject preferences, (3) some teachers may have reduced expectations of female students with AS, and (4) some female students with AS may experience executive function impairments.

##### ***4.6.1 Theme 1: Females with AS are capable of performing well academically***

A substantial number of participants stated that they, or their daughter with AS had achieved academic results ranging from good to excellent. This was reported by 23 (72%) participants overall. In addition, 9% of participants reported giftedness in some areas. Among parent participants, this theme was consistently reported, with 6 (75%) responses reflecting it. This theme was reported most frequently by parents with daughters in the older age groups. Parent participants from all locations discussed this theme. Table 4.17 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.17

*Responses Relating to Category 3, Theme 1: Females with AS are Capable of Performing Well Academically (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	1 (50%)	2 (67%)	3 (100%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	3 (60%)	1 (100%)	1 (100%)	1 (100%)

Seventeen (71%) adult participants stated they had performed well academically at school. This was reported in most age groups, and was particularly strong amongst younger participants. This theme was evident in responses from all locations. Table 4.18 presents the age ranges and locations of adult participants who discussed this theme.

Table 4.18

*Responses Relating to Category 3, Theme 1: Females With AS are Capable of Performing Well Academically (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	4 (80%)	5 (100%)	6 (67%)	0	2 (67%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	5 (71%)	6 (75%)	1 (33%)	2 (67%)	3 (100%)

Many participants said that they, or their daughter with AS, enjoyed learning; for example: “my longest running ‘special interest’ was academic performance, I had always pushed myself to do as well academically as I possibly could” (Adult Participant 13, Question 5). Some participants emphasised that although they or their daughter with AS performed well academically, this did not necessarily come easily, as one parent noted: “overall academic performance good, but comes at a personal cost (lack of free time, stress)” (Parent Participant 1, Question 5). This personal cost is also described by an adult participant who stated she was a straight A student: “calculus was my most difficult course in high school, followed closely by physics; after meltdowns and some self-injury, though, I managed to pull through” (Adult Participant 13, Question 5).

#### ***4.6.2 Theme 2: Each female student with AS is an individual in terms of her academic strengths and weaknesses, and subject preferences***

This theme was emphasised by 32 (100%) participants overall in the survey responses. Table 4.19 presents the locations and age ranges of female children with AS reported on by parent participants, and Table 4.20 presents the age ranges and locations of adult participants who reported this theme.

Table 4.19

*Responses Relating to Category 3, Theme 2: Each Female Student with AS is an Individual in Terms of Her Academic Strengths and Weaknesses, and Subject Preferences (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	2 (100%)	3 (100%)	3 (100%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	5 (100%)	1 (100%)	1 (100%)	1 (100%)

Table 4.20

*Responses Relating to Category 3, Theme 2: Each Female Student with AS is an Individual in Terms of Her Academic Strengths and Weaknesses, and Subject Preferences (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	5 (100%)	5 (100%)	9 (100%)	2 (100%)	3 (100%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	7 (100%)	8 (100%)	3 (100%)	3 (100%)	3 (100%)

All participants described a wide range of strengths, weaknesses and subject preferences. Regardless of their school experiences, all participants were able to identify some subject areas they, or their daughters with AS, enjoyed. Some participants reported strengths in and a preference for English and the Humanities areas, while others expressed a preference for Mathematics and Science. Others

preferred “hands on” subjects such as art, photography and woodwork. The only subject area which no participant reported that they, or their daughters liked, but several expressed a dislike for was Physical Education. Many participants attributed this to poor coordination and sensory sensitivities. However, despite no participants including Physical Education as one of their preferred subjects, an adult participant reported she played several sports throughout school, which enabled her to develop relationships with team mates, while another recalled “I didn’t like gym, because I was/am a klutz, but I loved to run” (Adult Participant 24, Question 5). A number of participants also noted that they, or their daughters with AS, had poor handwriting, as one participant explained: “I found handwriting very difficult, holding the pencil or pen took up so much energy it made me sick” (Adult Participant 4, Question 5)

#### ***4.6.3 Theme 3: Some teachers may have reduced expectations of female students with AS***

This theme was discussed by a few participants, with 4 (13%) participants indicating that teachers had reduced expectations of them, or their daughters with AS. Among parent participants, this was expressed by 1 (13%) parent. This parent’s daughter was in 6-9 age group (50%). Table 4.21 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.21

*Responses Relating to Category 3, Theme 3: Some Teachers May Have Reduced Expectations of Female Students with AS (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	1 (50%)	0	0	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	1 (20%)	0	0	0

Among adult participants, 3 (13%) recalled that teachers had reduced expectations of them at school. This theme was reflected in responses from adult participants in the three middle age groups, and from Australia and the UK. Table 4.22 presents the age ranges and locations of adult participants who discussed this theme.

Table 4.22

*Responses Relating to Category 3, Theme 3: Some Teachers May Have Reduced Expectations of Female Students with AS (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	0	1 (20%)	1 (11%)	1 (50%)	0
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	1 (14%)	0	2 (67%)	0	0

According to one parent, one of the greatest challenges her/his daughter experienced at school was “reduced expectations from teachers resulting in lack of opportunity and poor academic outcomes” (Parent Participant 5, Question 1). Similarly, an adult participant recalled “I was put into ‘modified classes’ and some teachers would treat students in these like they were stupid” (Adult Participant 11, Question 2). Another adult participant believed her teachers had not supported her in achieving her full academic potential.

#### ***4.6.4 Theme 4: Some female students with AS may experience executive function impairments***

Executive function impairments were reported by 15 (47%) participants overall. Among parent responses, executive function impairments were discussed by 4 (50%) participants, all of these with daughters in the two older age groups. Parent participants from all locations except the UK discussed this theme. Table 4.23 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.23

*Responses Relating to Category 3, Theme 4: Some Female Students with AS May Experience Executive Function Impairments (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	0	2 (67%)	2 (67%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	2 (40%)	1 (100%)	0	1 (100%)

Impairments in executive function were described by 11 (46%) adult participants. This theme was discussed by participants from all age groups except the oldest group, and by participants from all locations with the exception of Europe.

Table 4.24 presents the age ranges and locations of adult participants who discussed this theme.

Table 4.24

*Responses Relating to Category 3, Theme 4: Some Female Students with AS May Experience Executive Function Impairments (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	3 (60%)	3 (60%)	4 (44%)	1 (50%)	0
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	3 (43%)	4 (50%)	1 (33%)	3 (100%)	0

While some participants simply stated they had executive function impairments, others provided more detail. One of the most common issues in this area mentioned by participants was difficulty following verbal instructions; for example: “following verbal instructions was challenging, and having to remember several steps, my short term memory is poor” (Adult Participant 2, Question 1). It was also mentioned by participants from both groups that teachers sometimes accused female students with AS who had difficulty following verbal instructions of failing to listen. Organisation and prioritising were other areas of difficulty mentioned by participants, as one participant explained:

Even though I did well at school academically, it was hard for me to organise myself and prioritise my time when I had lots of tasks and assignments. I have no doubt if I had been better at this, it would have spared me a lot of stress. (Adult Participant 24, Question 1)

Other areas of difficulty specifically mentioned by participants in this area were poor short term memory, generalising, synthesising information, and understanding abstract ideas.

#### **4.7 Category 4: Areas of Social and Emotional Challenge and Need**

Areas of social and emotional challenge and need were the aspects of school discussed most frequently, and in the greatest detail by participants. These have been grouped into the following five themes (1) the social aspects of school are the most challenging for many female students with AS, (2) the experiences of “feeling different” and “not fitting in” are common among female students with AS, (3) female students with AS often have difficulty developing and maintaining

friendships, (4) female students with AS are vulnerable to being bullied, and (5) female students with AS are vulnerable to developing mental health concerns.

#### ***4.7.1 Theme 1: The social aspects of school are the most challenging for many female students with AS***

Overall, the social aspects of school were identified by 25 (78%) participants as being a challenging area for female students with AS. This theme was discussed by 5 (63%) parent participants. It was evident in the responses of parent participants with daughters in all age groups, particularly the two older groups. This theme was discussed by parent participants from Australia and the UK. Table 4.25 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.25

*Responses Relating to Category 4, Theme 1: The Social Aspects of School are the Most Challenging for Many Female Students with AS (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	1 (50%)	2 (67%)	2 (67%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	4 (80%)	0	1 (100%)	0

This theme was reflected in the survey responses of 20 (83%) adult participants. It was consistently discussed by participants across all age groups, although there was a decrease in the oldest group. Adult participants from all

locations described this theme. Table 4.26 presents the age ranges and locations of adult participants who discussed this theme.

Table 4.26

*Responses Relating to Category 4, Theme 1: The Social Aspects of School are the Most Challenging for Many Female Students with AS (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	5 (100%)	5 (100%)	7 (78%)	2 (100%)	1 (33%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	5 (71%)	8 (100%)	2 (67%)	3 (100%)	2 (67%)

A number of participants simply stated that the social aspects of school were the most difficult for them. Others elaborated further, such as in the following example: “I was in the wilderness. I did not understand neurotypical social groups” (Adult Participant 3, Question 4). Other issues discussed by participants in relation to the social aspects of school are outlined in themes 2, 3, 4 and 5 of this category.

#### **4.7.2 Theme 2: The experiences of “feeling different” and “not fitting in” are common among female students with AS**

The experiences of “feeling different” and “not fitting in” were described by 17 (53%) participants overall. These experiences were described by 3 (38%) parent participants. These participants all had daughters in the 14-17 age group, and were

from Australia and the USA. Table 4.27 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.27

*Responses Relating to Category 4, Theme 2: The Experiences of Feeling Different and Not Fitting in are Common Among Female Students with AS (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	0	0	3 (100%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	2 (40%)	1 (100%)	0	0

Among the adult participants, this theme was discussed in 14 (58%) of the surveys. It was described by participants in all age groups, and from all locations. Table 4.28 presents the age groups and locations of adult participants who discussed this theme.

Table 4.28

*Responses Relating to Category 4, Theme 2: The Experiences of Feeling Different and Not Fitting in are Common Among Female Students with AS (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	3 (60%)	4 (80%)	4 (44%)	2 (100%)	1 (33%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	3 (47%)	7 (88%)	1 (33%)	2 (67%)	1 (33%)

Participants described in detail the experiences which they or their daughters with AS had regarding not fitting in at school, and feeling different; for example: “I always felt very different in school like I was somehow ‘other’ and didn’t belong” (Adult Participant 23, Question 6). Some participants provided comprehensive descriptions which detailed the realisation they were different from their peers, and the exhaustion involved in masquerading:

I was happy at school up until the third grade, then I began comparing myself to the other kids and I realised I was different. I tried to fit in, but it took so much energy. I would be exhausted when I got home and would cry and need to take a nap. (Adult Participant 24, Question 6)

#### ***4.7.3 Theme 3: Female students with AS often have difficulty developing and maintaining friendships***

Difficulty developing and maintaining friendships was a common experience reported by participants; 25 (78%) participants overall discussed this theme in their responses. This theme was evident in the responses of 5 (63%) parent participants. Although not described by parents with daughters in the 6-9 age group, it was consistently reported by those with older daughters. Parent participants from all locations except the UK discussed this theme. Table 4.29 presents the locations and age groups of female children reported on by parent participants.

Table 4.29

*Responses Relating to Category 4, Theme 3: Female Students with AS Often Have Difficulty Developing and Maintaining Friendships (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	0	2 (67%)	3 (100%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	3 (60%)	1 (100%)	0	1 (100%)

Among adult participants, this theme was reflected in 20 (83%) surveys. It was consistently reported by participants from all age groups and locations. Table 4.30 presents the age groups and locations of adult participants who discussed this theme.

Table 4.30

*Responses Relating to Category 4, Theme 3: Female Students with AS Often Have Difficulty Developing and Maintaining Friendships (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	5 (100%)	5 (100%)	7 (78%)	2 (100%)	1 (33%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	5 (71%)	8 (100%)	2 (67%)	3 (100%)	2 (67%)

When they discussed this theme, some participants stated that they, or their daughters with AS, had no, or few friends. Others explained that friendship difficulties often began in upper primary or early secondary school, as one parent commented: “good peer relationships before 5<sup>th</sup> grade, then increasing bullying and ostracism because she was ‘weird’ and ‘clueless’” (Parent Participant 7, Question 4). Many participants attributed this to levels of social maturity and changing interests; for example: “I had trouble relating to the other girls in high school, they were talking about boys, and I was still playing with Barbies until 14” (Adult Participant 2, Question 4). Another adult participant described a similar situation in which these difficulties began at an earlier stage:

I began puberty in the 4<sup>th</sup> grade and I looked different from the other girls which didn’t help. Although I developed physically earlier, they developed socially quicker than me. By the 5<sup>th</sup> grade a lot of the girls I’d been friends with in early elementary school were interested in boys, clothes and make-up, and I wasn’t. (Adult Participant 24, Question 4)

Another reason which participants attributed to difficulties with developing and maintaining friendships was difficulty in reading and understanding body language and social cues, such as in the following example:

If people were friendly, I would assume they were my friend, then I would latch onto them and as I have trouble with body language wouldn’t realise they didn’t want me there and would end up embarrassing myself. (Adult Participant 1, Question 4)

Similarly, a parent participant described her/his daughter’s confusion about the concept of friendship: “She seems to think she has lots of friends and is a good friend, but I could only name 2 people, and if they are absent she doesn’t engage with anyone else, so this is a false perception” (Parent Participant 6, Question 4).

These two descriptions from participants may be indicative of how parents perceive the friendships of their daughters with AS in comparison to the understanding, experiences and expectations of female students with AS themselves. Some participants described the experience having few friendships, but the friendships they did have were close. Generally; however, these friendships were not of great longevity; for example: “throughout elementary and early middle school, I had few, but close friends; most of these would change from year to year, though I did maintain a few longer friendships” (Adult Participant 13, Question 4). One parent stated that her/his daughter had good peer relationships, an achievement they attributed to the outside of school social skills training with which they provided her.

#### ***4.7.4 Theme 4: Female students with AS are vulnerable to being bullied***

Overall, 15 (47%) participants stated that they, or their daughters with AS, had experienced bullying at school. Bullying was reported by 4 (50%) parent participants, by parents who had daughters in the oldest and youngest age groups. Bullying was reported by parents from all locations except Canada. Table 4.31 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.31

*Responses Relating to Category 4, Theme 4: Female Students With AS are Vulnerable to Being Bullied (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	1 (50%)	0	3 (100%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	2 (40%)	1 (100%)	1 (100%)	0

Bullying was reported by 11 (46%) adult participants. It was discussed by participants from all age groups, and from all locations except Europe. Table 4.32 presents the age groups and locations of adult participants who recounted experiences of being bullied at school.

Table 4.32

*Responses Relating to Category 4, Theme 4: Female Students with AS are Vulnerable to Being Bullied (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	2 (40%)	2 (40%)	4 (44%)	2 (100%)	1 (33%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	3 (43%)	4 (50%)	2 (67%)	2 (67%)	0

Behaviours reported by participants included name calling, relational aggression, having property stolen, and physical violence. One adult participant referred to herself as “the school pariah” and described the impact on her of the relational aggression she experienced, emphasising she experienced “sadness and later humiliation to being shunned and bullied constantly” (Adult Participant 16, Question 6). Similarly, a parent participant asserted that teachers need to understand “how serious a problem relational aggression is for aspie girls” (Parent Participant 8, Question 7). Another parent participant described in detail how the bullying her/his daughter experienced was so horrific she changed schools three times, while an adult participant recounted her dual experience of being bullied and socially isolated, explaining she felt “worthless; no one to step in and risk their precious reputation to defend me; no true allies” (Adult Participant 21, Question 4). One participant was not only bullied by her peers; she recounted the humiliation she experienced when a teacher called her a derogatory name in front of her peers and encouraged them to laugh at her. In addition to the experience of being bullied, participants reported confusion as to why it was occurring and what they should do, as an adult participant recalled: “I was bullied and completely confused by it. I had no idea why it was happening to me or how to combat it” (Adult Participant 3, Question 4).

#### ***4.7.5 Theme 5: Female students with AS are vulnerable to experiencing mental health concerns***

Mental health concerns were common among both participant groups, with these being reported by 27 (84%) participants overall. This theme was discussed

consistently by parent participants, with 6 (75%) responses reflecting this theme. It was reported across all age groups and locations, with the exception of the USA.

Table 4.33 presents the locations and age groups of female children with AS reported on by parent participants.

Table 4.33

*Responses Related to Category 4, Theme 5: Female Students with AS are Vulnerable to Experiencing Mental Health Concerns (Parent Participants)*

<b>Age</b>	<b>6-9 (n=2)</b>	<b>10-13 (n=3)</b>	<b>14-17 (n=3)</b>	
	2 (100%)	2 (67%)	2 (67%)	
<b>Location</b>	<b>Australia (n=5)</b>	<b>United States of America (n=1)</b>	<b>United Kingdom (n=1)</b>	<b>Canada (n=1)</b>
	4 (80%)	0	1 (100%)	1 (100%)

Among adult participants, this theme was discussed by 21 (88%) participants.

It was evident in responses from all age groups, and locations. Table 4.34 presents the age groups and locations of adult participants who described this theme.

Table 4.34.

*Responses Related to Category 4, Theme 5: Female Students with AS are Vulnerable to Experiencing Mental Health Concerns (Adult Participants)*

<b>Age</b>	<b>18-24 (n=5)</b>	<b>25-34 (n=5)</b>	<b>35-44 (n=9)</b>	<b>45-54 (n=2)</b>	<b>55-64 (n=3)</b>
	4 (80%)	5 (100%)	8 (89%)	2 (100%)	2 (67%)
<b>Location</b>	<b>Australia (n=7)</b>	<b>United States of America (n=8)</b>	<b>United Kingdom (n=3)</b>	<b>Canada (n=3)</b>	<b>Europe (n=3)</b>
	7 (100%)	7 (88%)	2 (67%)	3 (100%)	2 (67%)

The responses from both participant groups attributed the anxiety and depression experienced by themselves or their daughters with AS to the following factors: social difficulties, loneliness, isolation, feeling different from peers, and bullying. Participants also specifically reported anxiety in relation to issues such as the pressures of school work, changes to routine and transitioning between classes or activities. Masquerading was also cited as a source of anxiety and stress; for example: “trying to ‘behave’ in a socially acceptable level takes an enormous amount of stamina” (Parent Participant 3, Question 6). In addition to anxiety and depression, 2 participants (6%) stated that they, or their daughter had engaged in self-harming behaviours. A parent participant described her/his daughter’s experiences which lead to this: “she does not have any close friends at school. She became depressed. She recently started cutting herself. I blame all the bullying for this” (Parent Participant 3, Question 4). An adult participant also recounted how she engaged in self-harming behaviours in secondary school when she felt anxious and stressed about the academic pressures she was facing.

Eating disorders were reported by 3 (9%) participants: 2 (8%) adult participants, and 1 (13%) parent participant. The parent participant explained that her/his daughter developed Bulimia, which they believed to be related to the relational aggression she experienced at school, and the damage this did to her self-esteem. One adult participant recounted how she developed Anorexia at the age of 16, which developed into Bulimia at 20. This participant also recalled she was both anxious and depressed when she developed Anorexia. Another adult participant

said she first developed Anorexia at 13, and Bulimia at 15. Both adult participants stated they were first diagnosed with AS when in treatment for their eating disorders, aged 23 and 26 respectively, as one explained:

I was diagnosed with AS when I was 23 (in the eating disorder clinic). People also need to know that other issues can be hiding the AS, for me it was only when receiving intensive eating disorder treatment that my AS was discovered by my treatment team.” (Adult Question 24, Question 7)

#### **4.8 Summary**

This chapter has presented the results obtained from the participants who consented to participate in this study which examined the school experiences of female students with AS. The study sample was described, and the results from the anonymous online surveys were presented by being categorised into the key categories and themes discussed by participants. Throughout the surveys, a number of key themes were consistently raised by participants.

The most frequently mentioned theme which emerged was that all female students with AS are individuals in terms of their academic strengths and weaknesses, and their preferred subjects. In addition, many participants emphasised that female students with AS are capable of achieving well academically, although a few participants described instances of teachers having lowered expectations of them, or their daughters.

Many participants from both groups indicated there is a general lack of understanding in relation to exactly what AS is, perhaps even more so in regards to females. This is reflected further by the smaller number of participants who reported

on teachers who made accommodations for issues such as sensory sensitivities, and had a positive perception of students with AS, particularly among parent participants. Areas of social and emotional need for female students with AS were strongly emphasised by many participants, such as a vulnerability to experiencing mental health concerns, high incidences of bullying, and difficulties developing and maintaining friendships.

In the following chapter, the results obtained in this study are contrasted with results from previous studies which examined the school experiences of students with AS, which included both male and female – although predominately male – participants. In addition, the results regarding issues such as mental health concerns and bullying are compared with those from studies which examined typical populations.

## Chapter 5 - Discussion

### 5.1 Introduction

This chapter presents a discussion of the results as they relate to the research question: 'what are the school experiences of females with AS?' Although there has been limited research specifically focussed on females with AS, the results from this study are discussed in relation to studies which included both male and female – although predominately male – participants. The results obtained in this study are also compared with findings from studies which examined typical populations. The four categories identified in the previous chapter (issues requiring more understanding, teaching strategies and practices which had a positive impact, areas of academic need, areas of social and emotional need) are discussed in turn. Implications for schools and teachers, and recommendations in regards to education for teachers and support for female students with AS are outlined. Possible future research directions in regards to further understanding the school experiences of females with AS, and teacher perception and understanding of AS in females are also discussed.

### 5.2 Issues Requiring More Understanding

The findings from the present study suggest that a common experience of female students with AS is having teachers who lack understanding of AS and its associated characteristics and challenges. These experiences reported by participants included a lack of understanding about the extent of the social challenges

experienced by female students with AS, as well as their sensory sensitivities and executive function impairments. Similar results were reported by Sciutto et al. (2012), although to a lesser extent than in the present study. That study (Sciutto et al., 2012) used a sample approximately 3 times larger than this study. In the present study, 78% of participants said that they, or their daughters with AS had experienced teachers who lacked understanding about AS. Sciutto et al. (2012) found that 17% of their participants emphasised that teachers need to understand that AS does in fact exist, and that “many people are not aware that it exists let alone the many subtle ways it can affect a child’s experience” (p. 179). Similarly, in the same study (Sciutto et al., 2012), 39% of participants indicated they felt the behaviours and challenges of students with AS were often misunderstood by teachers; for example, participants described instances of teachers not realising that behaviours or attitudes which can seem to be “defiant, rude or indifferent may actually reflect something else” (p. 181). In the present study, 38% of participants reported that behaviours and challenges of female students with AS were perceived by teachers as disobedience or rudeness, or the extent of their social difficulties, executive function impairments and sensory sensitivities were misunderstood and underestimated. In another study which examined the school experiences of adolescents with AS, while they did not report any statistics, Humphrey and Lewis (2008) emphasised that most of their participants believed their teachers did not understand their individual needs.

When comparing the results from the present study with the findings of Sciutto et al. (2012), the higher percentage of participants in the present study who believed that teachers lack understanding about AS generally may be a reflection of

the entirely female research sample. The similar issues raised by participants in this study, and the participants reported on by Sciutto et al. (2012) in regards to teachers misunderstanding behaviours and challenges associated with AS may indicate that this issue is pertinent for both male and female students with AS.

These results suggest there may be a need for more teacher training, either within education degrees, or as a component of ongoing professional development, regarding not only teaching students with AS, but also psycho-education. Psycho-education is an approach used by medical and mental health professionals in order to educate individuals about their medical or mental health conditions. The goal is for individuals to better understand and manage their condition (Lukens & McFarlane, 2004). Psycho-education can also be used to educate teachers about conditions affecting their students, such as AS, so they gain a better understanding of its associated characteristics and challenges (Hinton, Sofronoff & Sheffield, 2008).

In the present study, a lack of understanding from teachers in regards to AS was reported by participants from all geographic locations, which may tentatively suggest this is a common experience for female students with AS in Western countries. The lack of participants who reported teachers having positive perceptions of female students with AS, combined with participants who reported teachers who were not supportive and were unwilling to make accommodations may suggest that, combined with a lack of knowledge about AS, there are stereotypes and myths which need to be dispelled.

A number of participant responses in the present study supported the assertion of Portway and Johnson (2005) that AS is a non-obvious condition. Several participants wrote in detail about having their own, or their daughter's AS diagnosis questioned by teachers, because they did not personally witness any behavioural or emotional issues associated with AS. According to participant accounts, the AS diagnosis was sometimes questioned by teachers because the female students with AS were quiet and well-behaved. In one case, an adult participant recounted the reaction of the director of the disability support service at her secondary school upon being informed of her AS diagnosis: "she simply did not believe that I, a female, could possibly be diagnosed with Asperger's" (Adult Participant 20, Question 1). Other participants recalled experiences where they, or their daughters with AS, had been overlooked by teachers as a result of being quiet and compliant. These results are consistent with observations made by Portway and Johnson (2003) in relation to findings from their retrospective study which involved young adults with AS and their parents. Portway and Johnson (2003) reported that in some cases "the kind of disability children with AS experience is rarely obvious to the onlooker, but neither are their differences completely veiled" (p. 441). In relation to female students with AS specifically, the results from the present study are concurrent with the observations of Wagner (2006) and Wilkinson (2008), who asserted that female students with AS are often perceived by teachers as quiet and shy, rather than having a potential ASD.

### 5.3 Teaching Strategies Which Had a Positive Impact

The importance of having teachers who perceived the female student with AS positively, worked from a strengths-based approach, and were supportive, was identified by 44% of participants overall in the present study. This was consistent with findings reported by Sciutto et al. (2012), who stated that 26% of their participants said it was beneficial when teachers made the effort and took the time to understand individual students with AS. Some adult participants in the present study recalled the support they received from teachers in secondary school who acted as informal mentors for them, and the positive impact this had. Similarly, according to Sciutto et al. (2012), 23% of their participants emphasised it was beneficial for them, or their child with AS when teachers were empathetic and demonstrated a genuine positive regard and respect for the student with AS. In addition, it was reported that 14% of participants identified teachers who promoted an understanding and acceptance of students with AS had a positive impact (Sciutto et al., 2012).

When the results of the present study, and those reported by Sciutto et al. (2012) are considered alongside the findings of Hay and Winn (2005), Kite, Tyson and Gullifer (2011), and Macintosh and Dissanayake (2006), they indicate that there is a need for further education for teachers in regards to AS and teaching students with this condition. Hay and Winn (2005) focussed on students with AS in an inclusive secondary school environment, in which 15% of teachers reported they lacked understanding of AS, and believed that students with AS placed greater demands on their time in comparison to other students. In addition, 17% of teachers mentioned

students with AS who displayed “unusual or unpredictable social and communication behaviours” (Hay & Winn, 2005, p. 145). It was also observed by the researchers that “it was not uncommon for one teacher to maintain that a specific student with AS was a problem, while another teacher in the same focus group spoke more positively about this student” (Hay & Winn, 2005, p. 144). Similarly, in the study by Kite et al. (2011) which examined perceptions of AS, when asked about what they believed to be the key characteristics of AS, participants in the education professional focus group described challenging behaviours such as being disruptive and noncompliant, rather than issues consistent with the AS diagnostic criteria; for example, intense interests and impairments in social skills. Furthermore, according to Macintosh and Dissanayake (2006), when teachers compared students with AS/HFA with typically developing students, they described students with AS/HFA as less cooperative, having less self-control and as more hyperactive in comparison to typically developing students. These results indicate a need for more teacher education regarding AS, particularly since teachers themselves admitted they needed to know more (Hay & Winn, 2005). Many behaviours teachers reported in regards to AS, such as being disruptive, are more likely to be seen in males rather than females with AS (Wagner, 2006; Wilkinson, 2008). The results from the present study complement the findings from several other studies (Hay & Winn, 2005; Kite et al., 2011; Macintosh & Dissanayake, 2006; Scitutto et al., 2012) and suggest that there is a need for further education about AS generally, and particularly regarding its presentation in females.

An important and helpful teaching practice reported by 16% of participants in the present study was maintaining a predictable but flexible classroom environment. This is supported by several researchers (Brewin et al., 2008; Saggars et al., 2011; Sciutto et al., 2012) who all reported that students with AS prefer, and benefit most from flexible, but structured classrooms. Strategies mentioned by participants in the present study and other studies (Brewin et al., 2008; Saggars et al., 2011; Sciutto et al., 2012) that teachers used to ensure the environment was as predictable as possible was the use of visual schedules, consistent routines, and where possible, preparing students with AS in advance for any changes to the usual classroom routine. These results suggest that teachers who understand the strong need of students with AS for structure and predictability can have a positive impact on them. In addition, it further emphasises the need for further teacher education in regards to AS, so that more teachers understand this need, and are able consistently to implement strategies such as those described in the present study, as well as by Brewin et al. (2008), Saggars et al. (2011), and Sciutto et al. (2012).

#### **5.4 Areas of Academic Need**

Many participants (72%) in the present study emphasised that female students with AS are capable of achieving well academically. Some participants, however, also indicated that this can come at a personal cost, and that teachers may be unaware of this, and of the effort it takes for these students to achieve such results. In addition, 9% of participants reported that they, or their daughters with AS were gifted in some areas. Although this must be interpreted with caution given the small

sample size used in the present study, this is higher than what has been reported among general populations of students. According to Reid (2011), 3-5% of students are gifted, while Grant (2013) reported that gifted students make up 5% of all students. Some participants also described instances of teachers lowering expectations of their or their daughters' academic abilities. These results are consistent with the retrospective chart review conducted by Church et al. (2000). Many of the younger children in this study were described as "very bright" and were reported to enjoy achieving academically. In middle and secondary school, several students with AS were placed in gifted programs, while others continued to perform well academically (Church et al., 2000). It was emphasised, however, that some of these students were under a considerable amount of stress, particularly in relation to the social pressures of school. Other students had alternative arrangements made for their education, such as the use of private tutors, and attending alternative schools or community colleges (Church et al., 2000). This also occurred in the present study, with one parent reporting that her/his daughter was completing her education in an alternative setting after being severely bullied in a number of mainstream secondary schools. In addition, despite achieving academic results ranging from good to excellent, some participants in the present study explained that impairments in executive function, such as difficulties with organisation, and prioritising, caused them, or their daughters, considerable stress.

The results from the present study, as well as those reported by Church et al. (2000) illustrate that even if female students with AS are performing well academically, teachers should never assume they are not having difficulties. Even

female students with AS who are achieving academic results ranging from good to excellent may still require assistance with their school work, such as extra time, and multiple explanations. Wagner (2006) has recommended that regardless of academic results, teachers need to find out how long female students with AS are spending on their homework and assignments to ensure it is not taking over their home lives and causing undue anxiety and stress. In addition, these results indicate that teachers need to be observant in regards to the organisational skills of female students with AS, and if necessary, explicitly teach them how to organise themselves and to prioritise their time.

## **5.5 Areas of Social and Emotional Challenge and Need**

A number of areas of social and emotional need were identified by participants in the present study. The social aspects of school were identified by many participants as being the most significant challenge for them, or their daughters with AS. This included the experiences of “feeling different” and “not fitting in”, difficulties developing and maintaining friendships, and bullying as well as a vulnerability to experiencing mental health concerns.

### ***5.5.1 The experiences of “feeling different” and “not fitting in” are common among female students with AS***

Results from the present study indicated that “feeling different” and “not fitting in” were a common component of the school experiences of female students with AS. These results are consistent with those reported by Carrington et al. (2003a)

and Humphrey and Lewis (2008). In the sample reported on by Carrington et al. (2003a), which consisted of five adolescents with AS (4 males, 1 female), the participants attributed the reason they were teased by their peers to being “different”. Similarly, in the sample of 20 adolescents with AS which Humphrey and Lewis (2008) reported on (the researchers did not specify how many males and females, although they described only male participants) “the notion of ‘being different’ or ‘not normal’” (p.31) was a recurring theme in participant comments. Similarly, Church et al. (2000) found that during middle school, children with AS become more aware of their differences, and as a result, experienced feelings such as sadness and anxiety. Furthermore, several authors (Attwood, 2007; Carrington & Graham, 2001; Carrington et al., 2003a, 2003b; Church et al., 2000; Humphrey & Lewis, 2008; Wagner, 2006) have reported that by adolescence, individuals with AS are often very aware of their differences in comparison to their typically developing peers.

### ***5.5.2 Female students with AS often have difficulty developing and maintaining friendships***

Difficulties in relation to developing and maintaining friendships was a frequently reported experience in the present study, particularly for females with AS in upper primary and secondary school. Reasons for this provided by participants included not maturing socially as quickly as their typically developing peers and difficulties understanding social cues and expectations. These findings are consistent with those from a number of studies which focussed predominately on male

participants (Brewin et al., 2008; Carrington & Graham, 2001; Carrington et al., 2003a, 2003b; Church et al., 2000; Humphrey & Lewis, 2008). The findings from these studies indicated that the social impairments of students with AS contribute to their difficulties developing and maintaining friendships. In addition, Church et al. (2000) reported that the social impairments of students with AS become more apparent as they get older. This is consistent with results from the present study, where several participants reported deterioration in their or their own daughter's friendships in late primary or early secondary school. Furthermore, it was reported by Carrington et al. (2003a) and Gutstein (2003) that some adolescents with AS have difficulty understanding the concept of friendship, which was also reported by some participants in the present study, indicating this is an issue for both males and females with AS.

The results from this study, as well as those from other studies examining the school experiences of students with AS (Brewin et al., 2008; Carrington & Graham, 2001; Carrington et al., 2003a, 2003b; Church et al., 2000; Humphrey & Lewis, 2008) indicated that difficulty developing and maintaining friendships may be as much an issue for males with AS as it is for females. However, based on the findings of gender differences in friendships among typical populations (Bauminger, Finzi-Dottan, Chason & Har-Even, 2008; De Goede, Branje & Meeus, 2009; Linden-Andersen, Markiewicz & Doyle, 2009), some female students with AS may find developing and maintaining friendships more difficult than their male counterparts. In adolescence, the friendships of females tend to be more intimate than those of males. Females generally place a greater emphasis on self-disclosure and empathy within their

friendships (Bauminger et al., 2008; De Goede et al., 2009; Linden-Andersen et al., 2009; Richard & Schneider, 2005), while male friendships are more likely to be focussed on competition and companionship (De Goede et al., 2008). The intimacy required in female friendships may be more difficult for females with AS, as such relationships are dependent on social skills and an understanding of social nuances (Simone, 2010).

### ***5.5.3 Female students with AS are vulnerable to being bullied***

Bullying was experienced by 47% of females with AS in the present study at school. These results are similar to those reported by Scitutto et al. (2012), who stated that 50% of their sample which consisted of both male and female participants, had experienced bullying at school. Other researchers have reported higher incidences of bullying among AS populations involving predominately male participants. Carter (2009) reported that 64.7% of students with AS are bullied at school, while in the sample examined by Little (2002), it was found that 90% of students with AS had been bullied. The higher incidences of bullying reported in samples which involved predominately male students with AS (Carter, 2009; Little, 2002) compared with the entirely female sample examined in the present study may be explained by the types of bullying behaviours experienced by students. It was found by Wang, Iannotti and Nansel (2009) that male students are more likely than females to be bullied physically and verbally, while female students are more likely to be the victims of relational or cyber bullying. In the present study, although some participants reported that they, or their daughters with AS had been physically or verbally

bullied at school, the most frequent type of bullying experienced was relational bullying. The difference in the results from this study when compared with those found by Carter (2009) and Little (2002) may be a result of the types of bullying experienced by male and female students. It may be easier for teachers, and other students to notice when a female student with AS is physically or verbally bullied, than it is to realise they are the victim of relational bullying, particularly if the student does not report this. This is consistent with the observations of Attwood (2007), who asserted that teachers are more likely to find out a student with AS is being bullied from witnessing it themselves, or from another student, rather than the student with AS reporting it. In addition, according to Wainscot et al. (2008), individuals with AS do not always have a complete understanding of all the behaviours which can be categorised as bullying.

When comparing the results of the present study, and other populations of students with AS (Carter, 2009; Little, 2002; Sciutto et al., 2012), to populations of typical students, there are generally higher incidences of bullying among AS populations. In one study (Glew, Fan, Katon, Rivara & Kernic, 2005), it was found that 6% of children said they were frequently bullied at school, while Wolke, Woods, Bloomfield and Karstadt (2001) reported that 39.8% of primary school aged children are victims of school bullying. According to Brunstein, Marocco, Kleinman, Schonfeld and Gould (2007), 20% of secondary students are bullied at school, while another study (Frisen, Jonsson & Persson, 2007) found that 39% of adolescents had experienced bullying at school. The differences in the results reported in the present study, and others that examined AS populations (Carter, 2009; Little, 2002; Sciutto et

al., 2012) in comparison to studies which reported on typically developing students (Brunstein et al., 2007; Glew et al., 2005; Frisen et al., 2007; Wolke et al., 2001) may be accounted for by some of the reported characteristics and challenges of students with AS. Specifically, students with AS tend to have fewer friends, and be more socially isolated than their typically developing peers (Attwood, 2007; Wainscot et al., 2008). In addition, the social naivety of many students with AS, combined with their tendency to be trusting (Attwood, 2007; Gutstein, 2003; Humphrey & Lewis, 2008; Wagner, 2006) places them at risk of being “easily exploited by unscrupulous peers” (Humphrey & Lewis, 2008, p. 33). Similarly, Sofronoff et al. (2011) reported there to be a strong positive correlation between social vulnerability, and bullying among students with AS. Another reason for the higher incidences of bullying among AS populations is the perceptions of their peers that they are “different” (Carrington et al., 2003a; Humphrey & Lewis, 2008). When comparing the results of the present study and others which involved AS populations to typical student populations, it supports the findings of Shtayermman (2007). In a predominately male sample of adolescents and young adults with AS, there was found to be a high incidence of bullying. Similarly, Wainscot et al. (2008) identified AS as a risk factor for experiencing bullying at school.

#### **5.5.4 Female students with AS are vulnerable to developing mental health concerns**

##### **5.5.4.1 Anxiety**

Anxiety was the mental health concern most frequently reported by participants in the present study. This is in contrast to the results of Barnhill (2007), who found depression to be the most frequently reported mental health concern of both adolescents and adults with AS. Anxiety in relation to school was reported in a number of previous studies which examined the school experiences of students with AS (Carrington et al., 2001; Church et al., 2000; Humphrey & Lewis, 2008; Scitutto et al., 2012), although none of these researchers provided any percentages. Shtayermman (2007, 2008) found that in samples of adolescents and young adults with AS which consisted predominately of males, 30% had a diagnosis of Generalised Anxiety Disorder. In the present study, 63% of parent participants reported anxiety in their daughters with AS, whereas 70% of adult participants recalled experiencing anxiety while attending school. Despite this high percentage; however, only 9% of participants overall specified that they, or their daughters with AS had been diagnosed with and treated for anxiety by a psychologist. When considering the number of participants overall who reported anxiety in themselves and their daughters, the results are higher than those reported among general populations of children. However, in regards to those participants who specified that they or their daughters with AS had been diagnosed with and treated for anxiety by a psychologist while attending school, those results are consistent with reported

incidences of anxiety disorders in typically developing children. According to Jones and Frydenberg (2003), 2.5-9% of typically developing children experience anxiety, while Spence (1998) found that 8-12% of children meet the diagnostic criteria for some form of anxiety disorder. In addition, in a sample of typically developing students, it was found that by the age of 6, females were twice as likely as males to have an anxiety disorder (Lewinsohn, Gotlib, Lewinsohn, Seeley & Allen, 1998).

These results must be interpreted with caution because although a large percentage of participants in the present study reported that they or their daughters with AS had experienced anxiety at school, a smaller percentage stated that the anxiety had been diagnosed by a psychologist. Due to the anonymous nature of the survey, it is not possible to know how many other participants, if any, had a formally diagnosed anxiety disorder. The percentage of participants who specified that they or their daughters with AS had a formally diagnosed anxiety disorder while at school is consistent with the findings of Jones and Frydenberg (2003) and Spence (1998) among typically developing students. However, the number of participants overall in the present study who reported anxiety is higher than that which has been reported among populations of typically developing students (Jones & Frydenberg, 2003; Spence, 1998), and among AS populations consisting predominately of males (Shtayermman, 2007, 2008). The results from this study suggest that female students with AS may be a population particularly vulnerable to experiencing anxiety, which can potentially impact upon their school experiences.

5.5.4.2 *Depression*

In the present study, 25% of parent participants reported on their daughters with AS experiencing depression, while 42% of adult participants described having experienced depression while at school. In terms of participants who specified that they or their daughter with AS had been diagnosed with and treated for depression by a psychologist, this was reported by 16% of participants. The overall incidence of depression reported by participants in the present study is higher than that reported by Shtayermman (2007, 2008), who found that 20% of predominately male samples of adolescents and young adults with AS met the DSM-IV diagnostic criteria for Major Depressive Disorder. For participants in the present study, it is likely the degree of depression being reported ranged from mild depression through to the levels reported on by Shtayermman (2007, 2008), where depression had been diagnosed by a psychologist. The percentage of participants from the entirely female sample in the present study who reported depression which had been diagnosed and treated by a psychologist is only slightly less than in the samples reported on by Shtayermman (2007, 2008). When comparing adolescents with AS to typically developing adolescents, Whitehouse et al. (2009) reported that 66% of their AS sample exhibited significant depressive symptoms, in comparison to 40% of the typically developing group.

The present study, as well as those of Shtayermman (2007, 2008) and Whitehouse et al. (2009) found higher rates of depression than those reported for general populations of children and adolescents. In a 7 year study carried out by Rohde, Beevers, Stice, and O'Neil (2009), it was found that 16.6% of adolescent

females experienced Major Depressive Disorder, while 20% experienced symptoms of depression, although not enough to meet the criteria for Major Depressive Disorder. Cicchetti and Toth (1998) reported lower results, stating that incidences of depression range from 0.4 to 2.5% in typically developing children and 0.4 to 8.3% among typically developing adolescents. It has also been found that from early adolescence, females are twice as likely as males to experience depression (Cyranowski, Frank, Young & Shear, 2000; Koenig, Isaacs & Schwartz, 1994;Thapar, Collishaw, Pine & Thapar, 2012).

The results from the present study support the assertions of Attwood (2007), Barnhill (2001) and Wainscot et al. (2008) that AS is a risk factor for developing depression. When comparing the results of the present study with those from the AS populations reported on by Shtayermman (2007, 2008), the higher incidence of depression in this study may be accounted for by the higher rates of depression among typically developing females in comparison to males (Cairney, 1998; Smith, Calam & Bolton, 2009; Thapar, et al., 2012). According to Smith et al. (2009) being female is a risk factor for developing depression. The results from this study must be interpreted with caution, as the incidence of depression reported by participants was based on self-reporting rather than diagnostic measures. However, the results tentatively suggest that being a female with AS represents a double risk factor for developing depression. In addition, these findings reinforce the importance of recognising depressive symptoms early.

5.5.4.3 *Eating Disorders*

Three participants (9%) in the present study reported that they, or their daughters with AS, had experienced at least one eating disorder while attending school. Two adult participants (8%) reported having experienced an eating disorder while at school, while one parent participant (13%) reported on her/his daughter with AS having an eating disorder. All participants who reported eating disorders stated that they, or their daughter with AS had been diagnosed and treated by a psychologist.

The overall results regarding eating disorders in this study are consistent with those reported by Stice, Marti & Rohde (2013) who found that during adolescence, 13.1 % of all females experienced at least one eating disorder. When examining the specific eating disorders experienced by participants in the present study, 2 (6%) participants overall experienced Anorexia at some stage, while 3 (9%) reported Bulimia. These results exceed those reported in relation to eating disorders among general populations of females. Stice et al. (2013) reported results which indicated that by the age of 20, 0.8% of females have experienced Anorexia, while 2.6% have experienced Bulimia. In addition, Hurst (2012) reported that 0.3% of females aged between 15 and 24 have a diagnosis of Anorexia, while le Grange, Loeb, Van Orman & Jeller (2004) found that 3% of all females have a diagnosis of Bulimia.

Despite having a small sample, the higher frequency of females with an eating disorder in the present study compared to samples of typical females (Hurst, 2012; le Grange et al., 2004; Stice et al., 2013) is consistent with the findings of Kalyva (2009). In that study Kalyva (2009) compared a group of female adolescents with AS

to a group of typically developing adolescent females in regards to eating attitudes and behaviours. It was found that 26.8% of the AS group were at risk of developing an eating disorder, in comparison to 7.1% of the typically developing group. These results, and those of the present study, suggest that AS is a risk factor for the development of eating disorders among adolescent females.

## **5.6 Implications and Recommendations**

In this section, a number of interventions and programs are discussed which could potentially benefit female students with AS, and their teachers. The possible interventions and programs have been grouped into the following four categories: (1) education for teachers, (2) peer mentors, (3) social skills training and support, and (4) mental health.

### **5.6.1 Education for teachers**

Many of the school experiences of female students with AS described by participants in the present study are related to a lack of knowledge and understanding about AS among teachers. In addition, some of the experiences described by participants indicated there may be some stereotypes about AS which need to be dispelled, such as “children with AS are disruptive and naughty,” “children who are quiet and well-behaved cannot have AS,” and even “females cannot have AS.” This lack of understanding can result in females with AS continuing to be undetected and under-diagnosed (Wagner, 2006; Wilkinson, 2008). In addition, for those female students who are diagnosed, having teachers who do

not understand their condition and its associated challenges, means they may not achieve their full academic potential, and struggle socially.

There is evidence that efforts to improve teachers' appreciation of the nature of AS and to equip them with strategies to recognise and assist students with AS can be effective. For example, Hinton et al.(2008) evaluated the effectiveness of a workshop for teachers who were currently teaching one or more students with AS. The purpose of the workshop designed by Hinton et al. (2008) was to assist teachers in feeling more capable and empowered in regards to teaching and managing students with AS. The researchers hoped that participation in the workshop would increase teacher understanding of AS, and would decrease the belief that all students with AS present in the same way (Hinton et al., 2008). The content covered in these workshops included the following (a) psycho-education; (b) classroom management, which included strategies to assist students with some of the difficulties associated with AS and academic modifications; and (c) social understanding, including strategies to assist students with AS to improve their social skills, and to manage social difficulties as they arise. Following their participation in these workshops, teachers reported their confidence had increased in regards to teaching and managing students with AS. In addition, teachers who had attended these workshops reported less problem behaviours from students with AS, and increased success in implementing behavioural and social strategies to assist these students.

Similar workshops could be carried out for teachers specifically in relation to females with AS. In addition to the topics covered by Hinton et al. (2008), in the psycho-educational component, teachers could receive information related to the

often milder presentation of AS in females. Furthermore, these workshops could present teachers with information about the mental health issues which females with AS may have an increased likelihood of experiencing. Participation in such workshops could assist teachers in challenging any preconceived perceptions they have about AS and females, while being provided with accurate information.

### **5.6.2 Peer mentors**

Some of the adult participants in the present study recalled having teachers in secondary school who acted as informal mentors for them and who supported them not only academically, but also socially and emotionally. A possible suggestion to assist females with AS socially, particularly with developing friendships and managing the social aspects of school is peer mentoring. Some researchers (Glennon, 2001; Hart, Grigal & Wier, 2010; Ogilvie, 2011) have found that having a peer mentor can be beneficial for university students with AS, particularly in relation to understanding and managing social situations. According to Hart et al. (2010) a peer mentor can introduce a university student with AS to other students with whom they could potentially develop friendships, while both Glennon (2001) and Ogilvie (2011) explained that a peer mentor can discuss any social concerns with their mentee, and practice and role play conversation skills and help them problem solve any issues they are having. Peer mentors could also be useful for female school students with AS. A female student with AS could be paired with a typically developing female peer who is socially mature, genuinely cares about others, and is respected by their

peers. The female peer could either be in the same grade, or an older grade. A peer mentor will have the understanding of the peer group dynamics, particularly in a secondary school setting, and of the hidden curriculum (Myles & Simpson, 2001) which the individual with AS will not intuitively have. Iland (2006) asserted that a peer mentor can assist female students with AS in developing skills such as beginning and maintaining conversations, and differentiating between levels of relationships and appropriate conversation topics for each level; for example, it would not be appropriate to discuss the same issues and topics with an acquaintance as you would with a close friend. A peer mentor can also assist female students with AS with issues such as learning how to identify whether others are interested in developing a friendship with them, detecting disinterest in others, and problem solving, such as building a repertoire of responses they can use to leave a situation where they are not wanted so they can avoid embarrassment (Iland, 2006).

### ***5.6.3 Social skills training and support***

Social skill programs, such as the circle of friends program (Kalyva & Avramidis, 2005; Whitaker, Barratt, Joy, Potter & Thomas, 1998) are a possible intervention to assist female students with AS socially. A circle of friends intervention involves the student with AS (the focus student), a small group of volunteer peers, and an adult facilitator. Prior to the commencement of the group, the adult facilitator discusses the needs of the focus student and their challenges and strengths with the focus student and the volunteers. The group meets on a regular basis to share experiences, discuss the challenges of the focus student, discuss any

problems and devise solutions. Kalyva and Avramidis (2005) observed that children with an ASD were able to generalise skills they learned from their participation in the intervention and apply them to new situations once the intervention was over. Similarly, Whitaker et al. (1998) reported on seven students with ASD, including AS, ranging from Grades 3 to 10 who were involved in a circle of friends program. According to Whitaker et al. (1998), involvement in the circle of friends program was a positive experience not only for the students with ASD and AS, but also their typically developing peers; only 4 out of 52 typically developing students said they would not want to participate in a circle of friends program again. The parents whose children with ASD and AS participated in the program reported that their children became more sociable, and demonstrated a greater preference for spending time with same age peers rather than children in younger grades as they had done previously (Whitaker et al., 1998). This type of intervention can potentially promote peer acceptance, and decrease the likelihood that the female student with AS will be rejected by their peers (Whitaker et al., 1998). In addition, it could provide the student with AS with the opportunity to practice social skills with peers in a safe and structured environment. It was found in this study, as well as by Church et al. (2000) that the social impairments of students with AS become more apparent during late primary school, and that difficulties with friendships become most prominent during this stage, and early secondary school. Ideally, female students with AS should be involved in a circle of friends program in mid-primary school, so it can act as a preventative strategy, rather than an intervention once problems have already occurred.

Another program which could assist both female students with AS and their teachers is the PEERS program (Laugeson, Frankel, Gantman, Dillon & Mogil, 2011). That program has been shown to be effective in assisting adolescents with HFA and AS in developing friendships. PEERS is a 14 week social skills intervention for secondary school students with HFA and AS. During each weekly session, participants learn various social skills and have the opportunity to practice these by role playing. While the adolescents attend the group, their parents attend their own session in which they learn ways they can support their child in developing the skills they are being taught (Laugeston et al., 2011). In addition to what is already involved in this program, teachers could potentially attend workshops similar to those for parents, in which they could learn about some of the specific social skills with which females with AS need support with, and how they can support them in developing these social skills. Furthermore, PEERS sessions could be designed to focus specifically on the social needs of female students with AS, because if a female with AS is placed in a social skills group with members who are only or predominately male there is a risk that “the girls will end up being overwhelmed by the male viewpoint, and have no female role model” (Wagner, 2006, p. 27).

The participation of female students with AS in social skills support groups, and being assigned a peer mentor may increase the likelihood of developing friendships with their peers, and decrease the likelihood of peer rejection and bullying (Kalyva & Avramidis, 2005; Laugeson et al., 2011).

#### 5.6.4 *Mental health*

The results of the present study support previous research which suggests individuals with AS are more vulnerable than the general population to developing anxiety and depression. Although teachers are not qualified to diagnose and treat anxiety and depression (nor is it their responsibility), they are in a position to identify possible signs of these conditions in their students (Auger, 2004; Trudgen & Lawn, 2011). In many cases, teachers are the adults who know students best, other than their parents, and have the advantage of being able to compare students' behaviours with those of many same-age peers (Trudgen & Lawn, 2011).

There is evidence that only a small number of parents and teachers seek psychological treatment for children with depressive symptoms (Puura et al., 1998). It has also been found that teachers are often guided by their intuition, rather than any formal training, when deciding whether to refer a student to a mental health professional (Trudgen & Lawn, 2011). Teachers' understanding of mental health can impact upon their ability to identify symptoms of anxiety and depression in their students (Trudgen & Lawn, 2011). Some teachers admitted they could not differentiate between students with anxiety or depressive symptoms, and typical adolescent development. Others believed anxiety is a normal part of adolescence, which suggests they would not view anxiety in students as a problem (Trudgen & Lawn, 2011). Puura et al. (1998) reported results which suggest when psychological treatment is sought for children with depressive symptoms, this is more likely to occur for males. It was emphasised that the most alarming finding from this study was that many children with depressive symptoms were never referred for

psychological treatment even when teachers and parents were aware of their symptoms (Puura et al., 1998). According to Trudgen and Lawn (2011), students with anxiety and depression, or with symptoms of these conditions are often not identified at school, as they do not tend to disrupt other students, or draw attention to themselves in other ways. If, as several authors (Attwood, 2007; Mandy et al., 2012; Wagner, 2006; Wilkinson, 2008) suggest, the behaviour of female students with AS is less likely to come to the attention of teachers than the behaviour of males, they may be at a greater risk of having symptoms of potential mental health concerns overlooked.

Students with AS are at a greater risk of developing mental health concerns in comparison to their typically developing peers (Barnhill, 2001; Sciutto et al., 2012; Shtayermman, 2007, 2008; Whitehouse et al., 2009). The results from the present study suggest that females with AS may be at an increased risk. Teachers need to be aware of the increased risk of anxiety and depression among students with AS, particularly females, who may be at an additional risk. In addition, it is important teachers realise that characteristics associated with AS, such as social withdrawal, may mask depressive symptoms; therefore, it is important that teachers check in with students with AS about how they are feeling. In regards to anxiety, particularly in children, mental health issues may manifest physically, such as through headaches and nausea (Jones & Frydenberg, 2003). Teachers therefore need to consider the possibility of anxiety in their students who present with these ailments frequently. According to Cicchetti and Toth (1998), depression in adulthood often originates in adolescence, and depression, anxiety and suicidal ideation have all been reported to

be long-term risks for individuals with AS (Barnhill, 2001; Portway & Johnson, 2005). When symptoms of mental health concerns are identified early, it allows protective factors, such as involving the student with AS in a social support group, to be put in place.

Although they were reported by participants to a lesser extent than anxiety and depression, there was a higher incidence of eating disorders reported in this study than has been found in samples of the general population. It is important teachers receive adequate knowledge, either within their university degrees or ongoing professional development in regards to eating disorders, as there are many unhelpful myths and assumptions surrounding these conditions (Wild, 2012; Yager & O'Dea, 2005). According to Yager and O'Dea (2005), however, teachers either receive little or no training about eating disorders. In addition, not all students with eating disorders fit the emaciated stereotype; for example, individuals with Bulimia generally maintain a normal weight, and can often hide their condition for months, and sometimes years (Orbanic, 2001). It is important, therefore, teachers receive training in regards to not only physical warning signs, but behavioural warning signs, as well as psychological and social risk factors (Wild, 2012). The results from this study, and those reported by Kalyva (2009) suggest that female students with AS may be particularly vulnerable to developing eating disorders, a factor teachers need to be aware of.

## 5.7 Limitations and Future Directions

A degree of caution should be taken when considering the results of the present study, as there were several factors that limit the conclusiveness and generality of the findings. First, the sample size was relatively small. In addition, the majority of participants identified themselves as adult females with AS, and so the majority of experiences described were retrospective, as opposed to the experiences of female students with AS who are currently attending school.

Due to the anonymous nature of this study, there was no way of knowing whether participants or participants' daughters had a formal diagnosis of AS, or if they were self-diagnosed. However, the similarity between the results obtained in the present study and those studies which included participants whose diagnosis was confirmed (e.g., Brewin et al., 2008; Carrington et al., 2003a, 2003b; Church et al., 2000; Humphrey & Lewis, 2008; Whitehouse et al., 2009) suggests that the participants did indeed have AS.

All participants reported living in Western countries, with the majority identifying as living in either Australia or the USA. The perspectives of females with AS from Asian, Middle Eastern and South American countries are therefore missing. Based on the current results, it can only be tentatively suggested that the experiences of school for females with AS is similar in Western countries.

A suggestion for future research would be to replicate this study. If similar results were obtained from another sample of adult females with AS, and parents of school aged females with AS, the results from this study would be more conclusive.

It would also be beneficial to compare the school experiences of female students with AS with their typically developing female peers. AS is often difficult to identify in females; therefore, such a study could potentially assist in identifying characteristics, behaviours and experiences which differentiate females with AS from typical females. Many responses in the present study identified that the social aspects of school are particularly challenging for females with AS. Further research could examine the experiences of females with AS in regards to developing and maintaining friendships, and investigate the effectiveness of social skills support groups, particularly as preventative strategies. Such studies could explore the effectiveness of implementing social support programs for females with AS in mid-primary school, before they reach the stage where they often have friendship difficulties.

This study focussed on the perspectives of parents, and adult females with AS. Future research in this area could involve the perspectives of teachers; specifically, examining their knowledge about AS, and about how the condition presents in females. In addition, future research could explore teachers' attitudes and beliefs about AS, and their experiences in teaching female students with AS.

## **5.8 Conclusion**

The purpose of this study was to examine the school experiences of females with AS in order to identify any specific needs and challenges of this population. A qualitative study was carried out so participants could describe their or their daughters' experiences in their own words, which provided the researcher with

detailed descriptions of how they, or their daughters with AS, experienced their school years. Much of the research carried out previously in relation to the school experiences of students with AS involved samples which consisted only, or predominately, of males. This study provided the opportunity for the female experience of AS to be heard.

The results from this study indicate there may be a lack of teacher understanding in regards to exactly what AS is, and its associated characteristics and challenges. The entirely female sample used in this study also suggests that female students with AS are sometimes overlooked by teachers, in part due to the way in which this condition presents in females. A range of social and emotional issues were frequently reported by participants. These included difficulties developing and maintaining friendships, the experiences of “feeling different” and “not fitting in”, a vulnerability to experiencing bullying, and an increased likelihood of developing mental health concerns, particularly when compared to populations of typically developing females.

Due to the small sample size, the results must be interpreted with caution. It cannot be assumed that the experiences described in the present study will be the same for all females with AS. However, considering the age range of participants and their geographic locations, these results do provide an example of the school experiences of females with AS in Western countries from the 1950s to the present day. Taking into account the majority of the adult participants were not diagnosed with AS while attending school, it is important to note that many of the same issues

and challenges were experienced regardless of whether or not AS had been diagnosed.

Care must also be taken when making generalisations; however, this study has provided some preliminary insights into the school experiences of female students with AS, especially in regards to areas which are particularly challenging. The findings from this study have suggested that there is a lack of understanding of exactly what AS is, and the characteristics and challenges associated with the condition. This seems to be the case even more so in regards to females because the milder presentation of AS in females causes them to be overlooked, and as a result, not diagnosed until secondary school, or even as adults (Attwood, 2007; Wagner, 2006). The results from this study have emphasised the need for further education for teachers in this area; if this does not occur, females with AS are likely to be continued to overlooked, diagnosed at a later stage than males, or not diagnosed at all.

The survey questions asked participants about their experiences while attending school. However, many of the adult participants reported that the social challenges they experienced at school, particularly difficulties developing and maintaining friendships, have continued to be an issue for them. Furthermore, many adult participants who reported experiencing anxiety and depression, and both adult participants who developed an eating disorder while attending school emphasised that these issues have continued into their adult lives. This suggests there is a need for teachers to have a greater knowledge of these mental health issues, so students can be identified early, and be referred to the appropriate mental health professionals.

Despite the relatively small sample size and other identified limitations, the results of this study provide a sound basis for planning future investigations into the school experiences of females with AS. This study has allowed the voices of an often overlooked and underdiagnosed (Wagner, 2006; Wilkinson, 2008) population to be heard. Females with AS are often diagnosed later than males, but they need and deserve to be diagnosed earlier. It is vital that the often invisible challenges of females with AS are recognised and validated so they can receive support for their areas of difficulty as early as possible, and have the best possible chance of reaching their full potential not only academically, but also socially and emotionally.

## References

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed.). Washington, DC: APA.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed., text rev.). Washington, DC: APA.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.). Arlington, VA: APA
- Attwood, T. (1998). *Asperger's syndrome: A guide for parents and professionals*. London: Jessica Kingsley Publishers.
- Attwood, T. (2006). The pattern of abilities and development of girls with Asperger's syndrome. In T. Attwood (Ed.), *Aspergers and girls* (pp.1-8). Arlington, TX: Future Horizons.
- Attwood, T. (2007). *The complete guide to Asperger's syndrome*. London: Jessica Kingsley Publishers.
- Auger, R.W. (2004). The accuracy of teacher reports in the identification of middle school students with depressive symptomology. *Psychology in the Schools*, 41(3), 379-389.
- Barnhill, G. (2001). Social attributions and depression in adolescents with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*, 16(1), 46-53.

- Barnhill, G. (2007). Outcomes in adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 22*(2), 116-126.
- Bauminger, N., Finzi-Dottan, R., Chason, S., & Har-Even, D. (2008). Intimacy in adolescent friendship: The roles of attachment, coherence and self-disclosure. *Journal of Social and Personal Relationships, 25*(3), 409-428.
- Bauminger, N., & Shulman, C. (2003). The development and maintenance of friendship in high functioning children with autism: Maternal perceptions. *Autism, 7*(1), 81-97.
- Beeger, S., Mandell, D., Winjnker-Holmes, B., Vanderbosch, S., Rem, D., Stekeleenburg, F., & Koot, H.M. (2012). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(5), 1151-1156.
- Berkman, N.D., Lohr, K.N., & Bulik, C.M. (2007). Outcomes of eating disorders: A systematic review of the literature. *International Journal of Eating Disorders, 40*(4), 293-309.
- Bernier, R., & Gerdts, J. (2010). *Autism spectrum disorders: A reference handbook*. Santa Barbara, CA: Greenwood Publishing Group.
- Brewin, B.J., Renwick, R., & Schormans, A.F. (2008). Parental perspectives of the quality of life in school environments for children with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 23*(4), 242-252.

- Brunstein, K.A., Marrocco, F., Kleinman, M., Schonfeld, I.S., & Gould, M.S. (2007). Bullying, depression and suicidality in adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46(1), 40-49.
- Burns, R. (2000). *Introduction to research methods*. Frenchs Forest, NSW: Pearson Education.
- Cairney, J. (1998). Gender differences in the prevalence of depression among Canadian adolescents. *Canadian Journal of Public Health*, 89(3), 181-182.
- Carrington, S., & Graham, L. (1999). Asperger's syndrome: Learner characteristics and teaching strategies. *Special Education Perspectives*, 8(2), 15-23.
- Carrington, S., & Graham, L. (2001). Perceptions of school by two teenage boys with Asperger syndrome and their mothers: A qualitative study. *Autism*, 5(1), 37-48.
- Carrington, S.B., Papinczak, T., & Templeton, E. (2003a). A phenomenological study: The social world of five adolescents who have Asperger's syndrome. *Australian Journal of Learning Disabilities*, 8(3), 15-21.
- Carrington, S., Templeton, E., & Papinczak, T. (2003b). Adolescents with Asperger syndrome and perceptions of friendship. *Focus on Autism and Other Developmental Disabilities*, 18(4), 211-218.
- Carter, S. (2009). Bullying of students with Asperger's syndrome. *Issues in Comprehensive Pediatric Nursing*, 32(2), 145-154.

- Church, C., Alisanki, S., & Amanullah, S. (2000). The social, behavioural, and academic experiences of children with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 15*(1), 12-20.
- Cicchetti, D., & Toth, S.L. (1998). The development of depression in children and adolescents. *American Psychologist 53*(2), 221-241.
- Cyranowski, J.M., Frank, E., Young, E., & Shear, M.K. (2000). Adolescent onset of the gender differences in lifetime rates of major depression: A theoretical model. *Archives of General Psychiatry, 57*(1), 21-27.
- Davison, G.C., Neale, J.M., & Kring, A.M. (2004). *Abnormal psychology* (9<sup>th</sup> ed.). New York, NY: John Wiley.
- De Goede, I.H., Branje, S.J., & Meeus, W.H. (2009). Developmental changes and gender differences in adolescents' perceptions of friendships. *Journal of Adolescence, 32*(5), 1105-1123.
- Durbin, N. (2007). *Asperger syndrome and bullying: Strategies and solutions*. London: Jessica Kingsley Publishers.
- Faherty, C. (2006). Asperger's syndrome in women: A different set of challenges? In T. Attwood (Ed.), *Asperger's and girls* (pp. 9-14). Arlington, TX: Future Horizons.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders, 33*(4), 365-382.

- Frisen, A., Jonsson, A., & Persson, C. (2007). Adolescents' perceptions of bullying: Who is the victim? Who is the bully? What can be done to stop bullying? *Adolescence*, 42(168), 749-761.
- Glennon, T.J. (2001). The stress of the university experience for students with Asperger syndrome. *Work: A Journal of Prevention, Assessment and Rehabilitation*, 17(3), 183-190.
- Glew, G.M., Fan, M., Katon, W., Rivara, F.P., & Kernic, M.A. (2005). Bullying, psychosocial adjustment and academic performance in elementary school. *Archives of Pediatrics and Adolescent Medicine*, 159(11), 1026-1031.
- Grandin, T. (1995). *Thinking in pictures and other reports from my life with autism*. New York, NY: Doubleday.
- Grandin, T. (2011). *The way I see it: A personal look at Autism and Asperger's* (2<sup>nd</sup> ed.). Arlington, TX: Future Horizons.
- Grant, A. (2013). Professional conversations about young gifted children. *Every Child*, 19(1), 8-9.
- Gutstein, S.E. (2003). Can my baby learn to dance? Exploring the friendships of Asperger teens. In L.H. Willey (Ed.), *Asperger syndrome in adolescence: Living with the ups, the downs and things in between* (pp. 98-128). London: Jessica Kingsley Publishers.
- Hart, D., Grigal, M., & Wier, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorder and

- intellectual disabilities. *Focus on Autism and Other Developmental Disabilities*, 25(3), 134-150.
- Hay, I., & Winn, S. (2005). Students with Asperger's syndrome in an inclusive secondary school environment: Teachers', parents', and students', perspectives. *Australasian Journal of Special Education*, 29(2), 140-154.
- Hill, E.L., & Bird, C.M. (2006). Executive processes in Asperger syndrome: Patterns of performance in a multiple case series. *Neuropsychologia*, 44(14), 2822-2835.
- Hinton, S., Sofronoff, K., & Sheffield, J. (2008). Training teachers to manage students with Asperger's syndrome in an inclusive classroom setting. *The Australian Educational and Developmental Psychologist*, 25(2), 34-48.
- Hubbard, K. (2010). *Unwrapping the mysteries of Asperger's*. Bloomington, IN: AuthorHouse.
- Humphrey, N., & Lewis, S. (2008). Make me normal: The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12(1), 23-46.
- Hurst, K., Read, S., & Wallis, A. (2012). Anorexia nervosa in adolescence and Maudsley family-based treatment. *Journal of Counselling and Development* 90(3), 339-345.
- Iland, L. (2006). Girl to girl: Friendship, bullying and fitting in. In T. Attwood (Ed.), *Asperger's and girls* (pp. 33-64). Arlington, TX: Future Horizons.

- Jones, B., & Frydenberg, E. (2003). Anxiety in children-The importance of the anxiety sensitivity factor. *Australian Journal of Guidance and Counselling, 13*(2), 145-158.
- Kalyva, E. (2009). Comparison of eating attitudes between adolescent girls with and without Asperger syndrome: Daughters' and mothers' reports. *Journal of Autism and Developmental Disorders, 39*(3), 480-486.
- Kalyva, E., & Avramidis, E. (2005). Improving communication between children with autism and their peers through the 'circle of friends': A small scale intervention study. *Journal of Applied Research in Intellectual Disabilities, 18*(3), 253-261.
- Kite, D.M., Tyson, G.A., & Gullifer, J.M. (2011). Exploring the perception of Asperger's disorder. *Australasian Journal of Special Education, 35*(2), 204-219.
- Koenig, L.J., Isaacs, A.M., & Schwartz, J.A.J. (1994). Sex differences in adolescent depression and loneliness: Why are boys lonelier if girls are more depressed? *Journal of Research in Personality, 28*(1), 27-43.
- Kopp, S., & Gillberg, C. (1992). Girls with social deficits and learning problems: Autism, atypical Asperger syndrome or a variant of these conditions. *European Child and Adolescent Psychiatry, 1*(2), 89-99.
- Koyama, T., Tachimori, H., Osada, H., Takeda, T., & Kurita, H. (2007). Cognitive and symptom profiles in Asperger's syndrome and high functioning autism. *Psychiatry and Clinical Neuroscience, 61*(1), 99-104.

- Kumnar, R. (2011). *Research methodology: A step by step guide*. Thousand Oaks, CA: Sage.
- Laugeson, E.A., Frankel, F., Gantman, A., Dillon, A.R., & Mogil, C. (2012). Evidence-based social skills training for adolescents with autism spectrum disorders: The UCLA PEERS program. *Journal of Autism and Developmental Disorders*, 46(6), 1025-1036.
- Lawson, W. (2001). *Understanding and working with the spectrum of autism: An insiders view*. London: Jessica Kingsley Publishers.
- Lawson, W. (2011). *The passionate mind: How people with autism learn*. London: Jessica Kingsley Publishers.
- le Grange, D., Loeb, K.L., Van Orman, S., & Jeller, C.C. (2004). Bulimia nervosa in adolescence: A disorder in evolution? *Archives of Pediatrics and Adolescent Medicine*, 158(5), 478-482.
- Lewinsohn, P.M., Gotlib, I.H., Lewinsohn, M., Seeley, J.R., & Allen, N.B. (1998). Gender differences in anxiety disorders and anxiety symptoms in adolescents. *Journal of Abnormal Psychology*, 107(1), 109-117.
- Linden-Andersen, S., Markiewicz, D., & Doyle, A.B. (2009). Perceived similarity among adolescent friends: The role of reciprocity, friendship quality and gender. *Journal of Early Adolescence*, 29(5), 617-637

- Little, L. (2002). Middle class mothers' perceptions of peer and sibling victimization among children with Asperger's syndrome and non-verbal learning disorders. *Issues in Comprehensive Pediatric Nursing, 25*(1), 43-57.
- Lukens, E.P., & McFarlane, W.R. (2004). Psychoeducation as evidence-based practice: Considerations for practice, research and policy. *Brief Treatment and Crisis Intervention, 4*(3), 205-225.
- Macintosh, K., & Dissanayake, C. (2006). Social skills and problem behaviours in school aged children with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders, 36*(8), 1065-1076.
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders, 42*(7), 1304-1313.
- Martins, Y., Young, R.L., & Robson, D.C. (2008). Feeding and eating behaviours in children with Autism and typically developing children. *Journal of Autism and Developmental Disorders, 38*(8), 1878-1887.
- McLennan, J.D., Lord, C., & Schopler, E. (1993). Sex differences in higher functioning people with autism. *Journal of Autism and Developmental Disorders, 23*(2), 217-227.
- Montgomery, S., & Grandin, T. (2012). *Temple Grandin: How the girl who loved cows embraced autism and changed the world*. New York, NY: Houghton.

- Myles, B.S., & Simpson, R.L. (2001). Understanding the hidden curriculum: An essential social skill for children and youth with Asperger syndrome. *Interventions in School and Clinic, 36*(5), 279-286.
- Newschaffer, C.J., Croen, L.A., Daniels, J., Giarelli, E., Grether, J.K., Levy, S.E., Mandell, D.S., Miller, L.A., Pinto-Martin, J., Reaven, J., Reynolds, A.M., Rice, C.E., Schendel, D., & Windham, G.C. (2007). The epidemiology of autism spectrum disorders. *Annual Review of Public Health, 28*, 235-258
- Ogilvie, C.R. (2011). Step by step: Social skills instruction for students with autism spectrum disorder using video models and peer mentors. *Teaching Exceptional Children, 43*(6), 20-26.
- O'Leary, Z. (2004). *The essential guide to doing research*. London: Sage.
- Orbanic, S. (2001). Understanding bulimia: Signs, symptoms and the human experience. *The American Journal of Nursing, 101*(3), 35-42.
- Ozonoff, S., South, M., & Miller, J.N. (2000). DSM-IV defined Asperger syndrome: Cognitive, behavioural and early history of differentiation from high functioning autism. *Autism, 4*(1), 29-46.
- Patton, M.Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage.
- Portway, S., & Johnson, B. (2003). Asperger syndrome and the children who don't quite fit in. *Early Child Development and Care, 173*(4), 435-443.

- Portway, S.M., & Johnson, B. (2005). Do you know I have Asperger's syndrome? Risks of a non-obvious disability *Health, Risk and Society*, 7(1), 73-83.
- Puura, K., Almqvist, F., Piha, J., Moilanen, I., Tamminen, T., Kumpulainen, K., Rasanen, E., & Koiviso, A. (1998). Children with symptoms of depression- What do the adults see? *Journal of Child Psychology and Psychiatry*, 39(4), 577-585.
- Rastam, M., Gillberg, C., & Wentz, E. (2003). Outcomes of teenage-onset anorexia nervosa in a Swedish community-based sample. *European Child and Adolescent Psychiatry*, 12(1), 78-90.
- Reber, A.S., & Reber, E.S. (2001). *The penguin dictionary of psychology* (3<sup>rd</sup> ed.). London: Penguin.
- Reid, M. (2011). Teaching implications of gifted and talented learners within the mainstream classroom. *Journal of Student Engagement: Education Matters*, 1(1), 29-32.
- Richard, J.F., & Schneider, B.H. (2005). Assessing friendship motivation during preadolescence and early adolescence. *The Journal of Early Adolescence*, 25(3), 367-385.
- Rohde, P., Beevers, C.G., Stice, E., & O'Neil, K. (2009). Major and minor depression in female adolescents: Onset, course, symptom presentation and demographic associations. *Journal of Clinical Psychology*, 65(12), 1339-1349.

- Rossmann, R.B., & Rallis, S.F. (1998). *Learning in the field: An introduction to qualitative research*. Thousand Oaks, CA: Sage.
- Ruta, L., Mungo, D., D'Arrigo, V.G., Vitiello, B., & Mazzone, L. (2010). Obsessive-compulsive traits in children and adolescents with Asperger's syndrome. *European Child and Adolescent Psychiatry, 19*(1), 17-24.
- Saastamoinen, S., Lepistö, T., Toppila, E., Kujala, T., Laakso, M., Nieminen-von Wendt, T., von Wendt, L., & Jansson-Verkasalo, E. (2008). Language abilities of children with Asperger syndrome. *Journal of Autism and Developmental Disorders, 38*(8), 1574-1580.
- Saggers, B., Hwang, Y., & Mercer, K.L. (2011). Your voice counts: Listening to the voice of high school students with autism spectrum disorder. *Australasian Journal of Special Education, 35*(2), 173-190.
- Sarantakos, S. (1998). *Social research*. South Yarra, VIC: Macmillan Education Australia.
- Schmidt, C., & Heybyrne, B. (2004). *Autism in the school-aged child: Expanding behavioural strategies and promoting success*. Denver, CO: Autism Family Press.
- Schreck, K.A., Williams, K., & Smith, A.F. (2004). A comparison of eating behaviours between children with and without autism. *Journal of Autism and Developmental Disorders, 34*(4), 433-438.

- Sciutto, M., Richwine, S., Mentrikoski, J., & Niedzwiecki, K. (2012). A qualitative analysis of the school experiences of students with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 27*(3), 177-188.
- Shriberg, L.D., Paul, R., McSweeney, J.L., Klin, A., Cohen, D.J., & Volkmar, F.R. (2001). Speech and prosody characteristics of adolescents and adults with high-functioning autism and Asperger syndrome. *Journal of Speech, Language and Hearing Research, 44*(5), 1097-1115.
- Shtayermman, O. (2007). Peer victimization in adolescents and young adults diagnosed with Asperger's syndrome: A link to depressive symptomology, anxiety symptomology and suicidal ideation. *Issues in Comprehensive Pediatric Nursing, 30*(3), 87-107.
- Shtayermman, O. (2008). Suicidal ideation and comorbid disorders in adolescents and young adults with Asperger's syndrome. *Journal of Human Behaviour in the Social Environment, 18*(3), 301-328.
- Simone, R. (2010). *Aspergirls: Empowering females with Asperger Syndrome*. London: Jessica Kingsley Publishers.
- Simone, R. (2012). *22 things a woman with Asperger's syndrome wants her partner to know*. London: Jessica Kingsley Publishers.
- Smith, M., Calam, R., & Bolton, C. (2009). Psychological factors linked to self-reported depression symptoms in late adolescence. *Behavioural and Cognitive Psychotherapy, 37*(1), 73-85.

- Sofronoff, K., Dark, E., & Stone, V. (2011). Social vulnerability and bullying in children with Asperger syndrome. *Autism, 15*(3), 355-372.
- Spence, S.H. (1998). A measure of anxiety symptoms among children. *Behaviour Research and Therapy, 36*(5), 545-566.
- Stice, E., Marti, C.N., & Rohde, P. (2013). Prevalence, incidence, impairment and course of the proposed DSM-5 eating disorder diagnoses in an 8-year prospective community study of young women. *Journal of Abnormal Psychology, 122*(2), 445-457.
- Thapar, A., Collishaw, S., Pine, D.S., & Thapar, A.K. (2012). Depression in adolescence. *Lancet, 379*(9820), 1056-1067
- Thompson, T., Caruso, M., & Ellerbeck, K. (2003). Sex matters in autism and other developmental disabilities. *Journal of Learning Disabilities, 7*(4), 345-362.
- Trudgen, M., & Lawn, S. (2011). What is the threshold of teachers' recognition and report of concerns about anxiety and depression in students? An exploratory study with teachers of adolescents in regional Australia. *Australian Journal of Guidance and Counselling, 21*(2), 126-141.
- Wagner, S. (2006). Educating the female student with Asperger's. In T. Attwood (Ed.), *Asperger's and girls* (pp.15-32). Arlington, TX: Future Horizons.
- Wainscot, J.J., Naylor, P., Sutcliffe, P., Tantam, D., & Williams, J.V. (2008). Relationships with peers and use of the school environment of mainstream secondary school pupils with Asperger syndrome (high functioning autism):

- A case-control study. *International Journal of Psychology and Psychological Therapy*, 8(1), 25-38.
- Wang, J., Iannotti, R.J., & Nansel, T.R. (2009). School bullying among adolescents in the United States: Physical, verbal, relational and cyber. *Journal of Adolescent Health*, 45(4), 368-375.
- Whitaker, P., Barratt, O., Joy, H., Potter, M., & Thomas, G. (1998). Children with autism and peer group support: Using 'circle of friends'. *British Journal of Special Education*, 25(2), 60-64.
- Whitehouse, A.J.O., Durkin, K., Jaquet, E., & Ziatas, K. (2009). Friendship, loneliness and depression in adolescents with Asperger's syndrome. *Journal of Adolescence*, 32(2), 309-322.
- Whiteley, P., Todd, L., Carr, K., & Shattock, P. (2010). Gender ratios in autism, Asperger syndrome and autism spectrum disorder. *Autism Insights*, 2, 17-24.
- Wild, N. (2012). Eating Disorders: What teachers need to know. *Professional Educator*, 11(2), 12-15.
- Wilkinson, L.A. (2008). The gender gap in Asperger syndrome: Where are the girls? *Teaching Exceptional Children Plus*, 4(4), 2-10.
- Willey, L.H. (1999). *Pretending to be normal: Living with Asperger's syndrome*. London: Jessica Kingsley Publishers.

- Willey, L.H. (2003). [Introduction]. In L.H. Willey, *Asperger syndrome in adolescence: Living with the ups, the downs and things in between*. London: Jessica Kingsley Publishers.
- Wing, L. (2001). *The autism spectrum: A parents' guide to understanding and helping your child*. Berkeley, CA: Ulysses Press.
- Wolke, D., Woods, S., Bloomfield, L., & Karstadt, L. (2001). Bullying involvement in primary school and common health problems. *Archives of Disease in Childhood*, 85(3), 197-201.
- Yager, Z., & O'Dea, J.A. (2005). The role of teachers and other educators in the prevention of eating disorders and child obesity: What are the issues? *Eating Disorders*, 13(3), 261-278.

## **Appendices**

Appendix A: Summary of Articles Reviewed

Article reference	Aim/Research Questions	Participants	Summary of Procedure	Results/Conclusion
Barnhill (2001)	Examined the relationship between depressive symptoms and the social attributions of adolescents with AS	33 adolescents with AS (30 male, 3 female)	The following instruments were administered to participants: (1) Student Social Attribution Scale (SSAS, Bell & McCallum, 1995), (2) Children's Depression Inventory (CDI, Kovacs, 1992)	A positive correlation was found between attributing social failure to ability, and depressive symptoms
Barnhill (2007)	Addressed areas associated with adulthood AS	N/A	Explored current literature on adults with AS	Adults with AS experiences difficulties in the following areas: mental health, employment, social cognition, and neurological and sensory issues
Bauminger & Shulman (2003)	To compare the development and maintenance of friendships of children with HFA to	Mother of 28 children (14 HFA, 14 typically developing) -12 boys	Home visits from first author. Mothers completed demographic questionnaire and	The friendships of children with HFA rarely emerged spontaneously (without the influence of parents/teachers) and

	typically developing children	and 2 girls per group	Childhood Friendship Survey (Buysse, 1991)	were of less longevity than those of typically developing children. Children with HFA also socialised with their friends less than typically developing children
Begeer et al. (2013)	Examined sex differences in the timing of identification of ASD	2, 275 children (0-18) and adults (18-85) with ASD (1843 male, 432 female)	Participants completed questionnaire developed by Dutch National Autism Society. Surveys completed by parents, next of kin, or individuals with ASD	Child participants: AS identified in females later than males, but no delay for PDD-NOS or AD  Adult Participants: delay in AD diagnosis in females, but no delay for AS or PDD-NOS
Berkman et al. (2007)	Examined factors associated with outcomes among individuals diagnosed with Anorexia, Bulimia or Binge Eating Disorder	N/A	Search of electronic databases from September 1980-September 2005	When compared to control groups, individuals who had Anorexia were more likely than controls to have an ASD, including AS
Brewin et al. (2008)	To examine the quality of school life for students with AS from parental perspectives	9 parents (6 female, 3 male) of children with AS (7 male, 2 female)	Participants interviewed using a semi-structured format	Participants identified the following factors as affecting their children's quality of life at school: (1) the extent to which teachers and other staff understand what it means to have AS, (2) the involvement of schools in

				facilitating meaningful social interactions, and (3) the educational programs available and how these were implemented. Parents also identified a need for (4) improved teacher training, (5) social skills programs and (6) individualised programs for students with AS to address their specific needs and challenges
Carrington & Graham (1999)	Outlines challenges of students with AS, challenges for teachers and adaptive and compensatory strategies for teachers	N/A	N/A	Challenges associated with AS outlined were as follows: (1) communication, (2) motor skills, (3) social skills, (4) attention, and (5) obsessional interests. Challenges for teachers outlined were : (1) inclusive education, (2) behaviour management, (3) the need for a structured program, (4) communication, and (5) creativity in planning.
Carrington & Graham (2001)	To develop an understanding of the challenges related to school experienced by two	Two 13 year old males with AS and their mothers	In-depth interviews	3 key findings: (1) both adolescents had difficulty developing social relationships, (2) the obsessional interests of both adolescents can

	adolescent males with AS and their mothers			potentially impede their learning if not monitored and (3) both adolescents were aware of not fitting in with their peers
Carrington et al. (2003a)	To investigate the social experiences and the perceptions of friendship of adolescents with AS	Five adolescents with AS (4 male, 1 female)	Semi-structured interviews	The following key themes were described by participants: (1) Satisfactory and unsatisfactory social experiences, (2) hostility from peers, (3) importance of following rules, and (4) masquerading
Carrington et al. (2003b)	To investigate the perceptions of friendship among adolescents with AS	Five adolescents with AS (4 male, 1 female)	Semi-structured interviews	Key findings: (1) participants had difficulty describing what a friend is, (2) participants has less difficulty describing characteristics not associated with a friend, and (3) the researchers observed evidence of masquerading from participants to conceal social deficits.
Carter (2009)	To measure the frequency of bullying among children and adolescents with AS	34 parents of children with AS aged between 5 and 21. 88% of children reported on	Participants were mailed the following surveys: (1) Juvenile Victimization Questionnaire (JVQ,	65% of parents reported their child had been victimised by peers over the past year.

		were male, 12% were female.	Hamby & Finkelhor, 2009)  (2) An instrument with three shunning items (Little, 2002)	
Church et al. (2000)	To explore the social, behavioural and academic experiences of children with AS	40 children with AS between 5 and 15 years (39 males, 1 female)	Retrospective chart review of children diagnosed with AS between 1986 and 1998	(1) Social skills remained the greatest challenge for children with AS  (2) Children with AS face the challenge of “looking normal” and having their challenges and behaviour misunderstood
Fombonne (2003)	Review of epidemiological studies of PDD’s, including AS	N/A	Review of 32 surveys published between 1966 and 2001	(1) Prediction of 42.7% increase in children under 5 diagnosed with a PDD by 2050 (USA)  (2) Improved awareness of PDD’s may explain increases in diagnosis over time  (3) Autism is overrepresented

				among males
Hill & Bird (2006)	To compare the executive function of individuals with AS to controls	44 participants (22 with AS, 22 controls. (AS: 16 males, 6 females) (Controls: 14 males, 8 females)	(1) Tests of executive functioning  (2) Measure of autistic symptoms  (3) Test of verbal and non-verbal communication	Significant executive dysfunction was found in participants with AS
Humphrey & Lewis (2008)	To explore the views and everyday experiences of students with AS in mainstream schools, and to identify teaching practices which facilitate or constrain learning and participation of students with AS	20 secondary school students with AS (gender not stated, although only male participants are mentioned)	Semi-structured interviews, student diaries and student drawings	(1) An awareness of being “different” or “not normal” was a recurring theme  (2) Teasing and bullying was experienced regularly  (3) Anxiety and stress were common
Kalyva (2009)	To compare the eating attitudes of adolescent females with AS to typically developing females	56 female adolescents with AS and 56 typically developing controls (and the mothers of the	Participants (adolescents and mothers) completed the EAT-26 (Garner et al., 1982)	26.8% of the AS group were at risk of developing an eating disorder, in comparison to 7.1% of the control group

		adolescents)		
Kopp & Gillberg (1992)	<p>(1) Could the social deficits associated with autism be more common in females than previously thought?</p> <p>(2) Is the overreliance of the male profile of autism one reason for the underreporting of females?</p>	6 female children with Autism, with IQ's ranging from 60-100 (described in case studies)	6 case histories reported	<p>(1) None of the female children with Autism received a diagnosis prior to the age of 6 despite assessments from psychiatrists, psychologists and paediatricians</p> <p>(2) Females with Autism may have more advanced language and imitation skills in comparison to males with Autism, which can delay diagnosis.</p> <p>(3) There may be a different profile for females with Autism</p>
Little (2002)	(1) Explore and describe mothers' perceptions of bullying experienced by their children with AS and Nonverbal	<p>Mothers of 411 children aged between 4 and 17 years (82% male, 18% female)</p> <p>Diagnosis of children reported on: 75.4% with</p>	A letter of invitation was posted on two national (USA) AS and NLD websites. Surveys were mailed to participants who responded.	<p>94% of mothers said their child had been bullied</p> <p>Frequency of bullying peaked at ages 6, 8 and 10</p> <p>Emotional bullying peaked at age</p>

	<p>Learning Disorder (NLD)</p> <p>(2) Examine the relationship of child characteristics (age, gender, diagnosis) with peer victimisation</p>	<p>AS, 15.3% with NLD, 9.2% with AS and NLD</p>	<p>Participants completed the Juvenile Victimization Questionnaire (JVQ, Hamby &amp; Finkelhor, 1999)</p>	<p>13</p> <p>AS and age were positively correlated with all peer shunning variables on the JVQ</p>
<p>Mandy et al. (2012)</p>	<p>To investigate the presence and stability of sex differences in individuals with ASD through childhood and adolescence</p>	<p>325 children aged between 3 and 18 (273 males, 52 females)</p> <p>AD: 97 males, 16 females</p> <p>AS: 81 males, 13 females</p> <p>PDD-NOS: 95 males, 23 females</p>	<p>The following measures were used:</p> <p>(1) Developmental Dimensional and Diagnostic Interview (3Di) : Semi-structured parent interview administered by child psychiatrist or psychologist</p> <p>(2) Autism Diagnostic Observational Schedule (ADOS, Lord et al., 2000):</p>	<p>A distinct female prototype for ASD was found:</p> <p>(1) Based on direct observation and parent reports, females demonstrated less repetitive and stereotyped behaviours compared to males</p> <p>(2) Females had superior fine motor skills</p> <p>(3) Females were reported by parents to have more emotional problems, compared with males, who were reported by teachers</p>

			<p>Semi-structured observational assessment</p> <p>(3) Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997): Completed by parents and teachers</p> <p>(4) Picture Vocabulary Scale (Dunn et al., 1892)</p> <p>(5) Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999)</p> <p>(6) Wechsler Intelligence Scale for Children-3<sup>rd</sup> ed (Wechsler et al., 1991)</p> <p>(7) Wechsler</p>	<p>to have more externalising and interpersonal problems.</p> <p>It was concluded that the milder presentation and less obvious and severe difficulties at school contributes to the under diagnosis in females.</p>
--	--	--	--	--

			Intelligence Scale for Children-4 <sup>th</sup> ed (Wechsler, 2003)	
Martins et al. (2008)	To compare the feeding and eating behaviours of children with ASD and typically developing children	41 children with ASD (83% male, 17% female) and 14 siblings  41 typically developing controls (56% male, 44% female)  Mothers completed questionnaires	Mothers completed the following measures:  (1) Eating Behaviours Questionnaire (Martins et al., 2008)  (2) Behavioural Pediatric Feeding Assessment Scale (BPFAS, Crist & Napier-Phillips, 2001; Crist et al., 1994)  (3) BPFAS Parent	Children with ASD were more likely to demonstrate problematic feeding and eating behaviours, although the rates of ritualistic feeding behaviours were consistent in all three groups.

			<p>Section</p> <p>(4) Food Neophobia Scale (FNS, Pliner &amp; Hobden, 1992)</p> <p>(5) Childhood Autism Rating Scale (CARS, Schopler et al., 1980)</p> <p>(6) Vineland Adaptive Behaviour Scales-Interview Edition (VABS, Sparrow et al., 1984)</p>	
McLennan et al. (1993)	To assess the differences between a group of males and females with ASD	21 males and 21 females with ASD (DSM-III) aged between 6 and 36 (Parents were interviewed)	Parents were administered the Autism Diagnostic Interview (ADI, Le Couteur et al., 1989)	<p>Females with Autism with mild or no mental handicap were less impaired in early social and communicative behaviours in comparison to males</p> <p>Older female children, adolescents and adults with Autism with mild to no mental handicap had more severe social deficits than males,</p>

				particularly in peer relationships.
Myles & Simpson (2001)	Discusses the hidden curriculum and the impact this has on social functioning	N/A	N/A	Children with AS need to be explicitly taught skills and knowledge which typically developing children learn incidentally. Not understanding the hidden curriculum can impede students with AS in regards to developing friendships, and can lead to bullying or teasing.
Newschaffer et al. (2007)	To provide an overview of the epidemiology of ASD	N/A	Literature Review	<ul style="list-style-type: none"> <li>(1) ASD's are complex neurodevelopmental conditions</li> <li>(2) More children are being diagnosed with ASD than in the past</li> <li>(3) ASD's are diagnosed more frequently in males</li> </ul>
Portway & Johnson (2003)	Explore the life experiences of young adults with AS (18-35)	18 young adults with AS, and 16 parents (gender not stated)	Participants were asked to tell their "life story"	<p>Key findings:</p> <ul style="list-style-type: none"> <li>(1) Participants (with AS) did not quite fit into normal</li> </ul>

				<p>patterns of life and relationships from childhood</p> <p>(2) Participants felt they “existed on the edge” of what society considers normal</p> <p>(3) Uneven ability profiles were common for individuals with AS-highly able in some areas, very impaired in others</p> <p>(4) Earlier detection and better understanding of AS is needed</p>
Portway & Johnson (2005)	To explore the risks of having a non-obvious disability	25 families with a young adult (aged 18-35) with AS (21 male, 4 female)	Participants were asked to tell their “life story”	<p>The following risks of having a non-obvious disability (AS) were identified:</p> <p>(1) Social risks (misunderstanding others, being misunderstood, loneliness, isolation,</p>

				<p>bullying)</p> <p>(2) Sensory sensitivities (which were often misunderstood by others)</p> <p>(3) Underachievement in school, and underachievement/under participation in employment</p> <p>(4) Mental health issues</p>
Rastam et al. (2003)	To compare individuals who had been diagnosed with Anorexia as adolescents to matched controls	51 individuals with adolescent onset Anorexia (mean age 24) (48 females, 3 males) and 51 matched controls	All participant had been interviewed at ages 16 and 21 regarding physical and mental health, then again at mean age of 24 (10 years after Anorexia onset)	20% of the Anorexia group had ASD 10 years following the onset of Anorexia compared to 0% of the control group.
Richard & Schneider (2005)	To assess and compare the friendship motivation of males and females during adolescence	490 5 <sup>th</sup> , 6 <sup>th</sup> and 7 <sup>th</sup> grade students (245 male, 245 female)	Participants were administered the Friendship Motivation Scale for Children (FMSC, Deci & Ryan, 1985) orally	<p>(1) Greater self-determined friendship motivation was reported by females than males</p> <p>(2) Females with greater self-</p>

			in class groups	determination were preferred by other students as play and work mates
Ruta et al. (2010)	To examine the occurrence and characteristics of Obsessive Compulsive Disorder (OCD) traits in children and adolescents	60 children and adolescents aged between 8-15 years  20 with OCD (16 males/4 females)  18 with AS (16 males/2 females)  22 controls (17 males/5 females)	Parents and children were interviewed, children were directly observed, and participants were administered the CY-BOCS (clinician rating inventory and a severity scale)	Children and adolescents with AS displayed less OCD behaviours than the OCD group, but more than the control group.
Saggers et al. (2011)	To explore the school experiences of students with ASD	9 adolescents aged between 13-16  2 females (1 AS, 1 ASD)  7 males (6 AS, 1 ASD)	2 semi-structured interviews and follow-up questions	Six categories emerged from interviews:  (1) Teacher characteristics are important for the inclusion of students with ASD  (2) Coping with heavy workloads can be difficult for students with ASD

				<ul style="list-style-type: none"> <li>(3) Students with ASD appreciate support, but like this to be done discreetly</li> <li>(4) Students with AS experience teasing and bullying</li> <li>(5) Friends are an important source of support</li> <li>(6) Sensory sensitivities can make learning difficult</li> </ul>
Sciutto et al. (2012)	To explore the school experiences of students with AS	<p>59 parents of a child with AS (80% of children reported on were male)</p> <p>27 adults with AS (4 male, 19 female, 4 unspecified)</p> <p>8 participants did not identify which participant group they belonged in</p>	Open ended online survey	<p>Key findings</p> <ul style="list-style-type: none"> <li>(1) Students with AS are often teased and bullied</li> <li>(2) Teachers who took the time to understand the individual child with AS, and demonstrated empathy and respect had a positive impact</li> <li>(3) Students with AS are often misunderstood</li> </ul>

				<p>(4) Predictable classroom environment is important</p> <p>(5) Teachers who accepted and encouraged differences and individuality had a positive impact</p>
Schreck et al. (2004)	To compare the eating behaviours of children with and without Autism	<p>Parents of children aged between 5-12 (n=472)</p> <p>Autism group 138 (88 male, 10 female)</p> <p>control group 228 (47 male, 53 female)</p>	<p>Participants completed a personal history form, and the following measures:</p> <p>(1)Children’s Eating Behaviour Inventory (CEBI, Archer, Rosenbaum &amp; Streiner, 1991)</p> <p>(2)Food Preference Inventory</p> <p>(3)Gilliam Autism Rating Scale (Gilliam, 1995)</p>	Children with Autism have more feeding problems than typically developing children, and eat a less varied diet.
Shtayermman	To examine the level of peer	10 adolescents and	Measures completed by	Participants experienced high

(2007)	victimisation, depressive symptoms, anxiety symptoms and suicidal ideation among adolescents and young adults with AS	young adults with AS (9 male, 1 female) and their parents	<p>adolescents and young adults with AS and a parent</p> <p>Measures used:</p> <ul style="list-style-type: none"> <li>(1) Social Experience Questionnaire (Crick &amp; Grotpeter, 1996)</li> <li>(2) Krug Asperger's Disorder Index (KADI, Krug &amp; Arick, 2003)</li> <li>(3) Patient Health Questionnaire for Adolescents (PHQ-A, Johnson, Harris, Spitzer &amp; Williams, 2002)</li> <li>(4) Suicidal Ideation Questionnaire (Reynolds, 1991)</li> </ul>	<p>levels of peer victimisation.</p> <p>50% experienced clinically significant suicidal ideation</p> <p>30% met criteria for Generalised Anxiety Disorder</p> <p>20% met criteria for Major Depressive Disorder</p>
Shtayermman	To examine the level of	10 adolescents and	Measures completed by	50% experienced clinically

<p>(2008)</p>	<p>suicidal ideation, Major Depressive Disorder and Generalised Anxiety Disorder among adolescents and young adults with AS</p>	<p>young adults with AS (9 males, 1 female) and their parents</p>	<p>adolescents/young adults with AS and their parents</p> <p>Measures used:</p> <ul style="list-style-type: none"> <li>(1) Suicidal Ideation Questionnaire (Reynolds, 1991)</li> <li>(2) Patient Health Questionnaire for Adolescents (PHQ-A, Johnson, Harris, Spitzer &amp; Williams, 2002)</li> <li>(3) Krug Asperger's Disorder Index (KADI, Krug &amp; Arick, 2003)</li> </ul>	<p>significant suicidal ideation</p> <p>20% met criteria for Major Depressive Disorder</p> <p>30% met criteria for Generalised Anxiety Disorder</p>
<p>Sofronoff et al. (2011)</p>	<p>(1) Evaluate factors which predict bullying among school aged children with</p>	<p>Parents of 133 children with AS aged between 6 and 16 (115 males, 18 females)</p>	<p>Parents Completed the following measures (parents of controls only completed SVS)</p>	<p>(1) Social vulnerability distinguishes children with AS from typically developing peers</p>

	<p>AS</p> <p>(2) Examine a new measure (Social Vulnerability Scale)</p>	<p>Parents of 23 typically developing children aged between 6 and 14 years (15 males, 8 females)</p>	<p>(1) Demographic questionnaire</p> <p>(2) Childhood Asperger Syndrome Test (CAST, Scott et al., 2002)</p> <p>(3) Spence Social Skills Questionnaire-Parents (SSSQ-P, Spence, 1995)</p> <p>(4) The Peer Relations Questionnaire for Parents (PRQ, Rigby &amp; Slee, 1993)</p> <p>(5) The Social Vulnerability Scale (SVS, Stone &amp; Sofronoff, 2006)</p>	<p>(2) Social vulnerability was found to be negatively correlated with social skills in children with AS</p> <p>(3) Social vulnerability was strongly negatively correlated with bullying in children with AS</p>
Thompson et al.	(1) Review of sex differences in	N/A	Literature Review	(1) There may be presentation differences regarding

<p>(2003)</p>	<p>typically developing children</p> <p>(2) Exploration of differences in presentation and prevalence of developmental and mental health disorders (with a focus on Autism)</p> <p>(3) Explore research needs related to gender and developmental disabilities</p>			<p>developmental disabilities in males and females</p> <p>(2) Cultural differences in the perception and treatment of males and females may influence identification and diagnosis of developmental disorders</p>
<p>Wainscot et al. (2008)</p>	<p>(1) How do students with AS/HFA spend the school day, in and out of class?</p> <p>(2) Where do students with AS/HFA spend recess and lunch?</p> <p>(3) How much do</p>	<p>57 students aged between 11-18 years (55 male, 2 female) (30 AS/HFA, 27 controls)</p>	<p>Semi-structured interview at the end of the school day</p> <p>Participants wore pedometers for the day to track physical activity</p>	<p>(1) Students with AS/HFA had fewer social interactions</p> <p>(2) Students with AS/HFA preferred to spend recess and lunch in quiet areas with adult supervision</p> <p>(3) Students with AS/HFA reported having fewer</p>

	<p>students with AS/HFA enjoy lessons and school, and is this reflected in attendance?</p> <p>(4) How do students with AS/HFA perceive their friendships, and do they feel they are bullied?</p> <p>(5) How physically active are students with AS/HFA?</p>			<p>friends, and were more likely to be bullied</p> <p>(4) Students with AS/HFA were less physically active</p> <p>(5) Students with AS/HFA had good attendance</p>
Whitehouse et al. (2009)	Investigated the relationship between friendship, loneliness and depression among adolescents with AS	<p>35 adolescents with AS (28 males, 7 females)</p> <p>35 typically developing adolescents (29 males, 6 females)</p>	<p>Participants completed four questionnaires:</p> <p>(1) Friendship Quality Questionnaire (FQQ, Parker &amp; Asher, 1993)</p> <p>(2) Friendship Motivation Questionnaire (FMQ,</p>	<p>(1) Students with AS had higher levels of depressive symptoms</p> <p>(2) For students with AS, loneliness was negatively correlated with friendship quality</p>

			<p>Richard &amp; Schneider, 2005)</p> <p>(3) Centre for Epidemiological Studies Depression Scale-Children's Version (CES-DC, Weissman, Orvaschel &amp; Padian, 1980)</p> <p>(4)De Jong-Gierveld Loneliness Scale (De Jong-Gierveld &amp; Kamphuis, 1985)</p>	<p>(3) In students with AS, loneliness was predicted by friendships with high levels of conflict and betrayal</p> <p>(4) Depression is related to poor friendship quality among adolescents with AS</p>
Whiteley et al. (2010)	To ascertain male: female ratio for PDD sub-groups (Autism, ASD and AS)	<p>1963 children</p> <p>Autism 460 (males 399, females, 61)</p> <p>ASD 1137 (males 992, females 148)</p> <p>AS 366 (males 338, females 28)</p>	Parent Report Questionnaire	<p>Higher male to female ratios were found than has been previously reported:</p> <p>PDD collectively: 7.38:1</p> <p>Autism: 6.54:1</p> <p>ASD: 6.84:1</p> <p>AS: 12.07:1</p>

Wilkinson (2008)	Discussed possible explanation for late and missed diagnosis of females with AS	N/A	Discussion of case vignette to demonstrate gender differences in AS, and how this impacts timely diagnosis and understanding of AS in females	Females with AS are diagnosed later, and less frequently than males due to a milder presentation
------------------	---	-----	---	--

Appendix B: Human Research Ethics Committee (Tasmania) Network approval

14 May 2013

Social Science Ethics Officer

Private Bag 01 Hobart

Tasmania 7001 Australia

Tel: (03) 6226 2763

Fax: (03) 6226 7148

Katherine.Shaw@utas.edu.au

<http://www.research.utas.edu.au//index.htm>



---

HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

---

Dr Christopher Rayner

Education

Private Bag 66

Dear Dr Rayner

Re: MINIMAL RISK ETHICS APPLICATION APPROVAL

Ethics Ref: H0013193 - The School Experiences of Females with Asperger's Syndrome:  
The Recollections of Adults with Asperger's Syndrome and the Perspectives of Parents

We are pleased to advise that acting on a mandate from the Tasmania Social Sciences HREC, the Chair of the committee considered and approved the above project on 14 May 2013.

---

This approval constitutes ethical clearance by the Tasmania Social Sciences Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approval of other bodies or authorities is required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.
  
2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au).
  
3. Incidents or adverse effects: Investigators should notify the Ethics Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
  

---

4. Amendments to Project: Modifications to the project must not proceed until approval is obtained from the Ethics Committee. Please submit an Amendment Form (available on our website) to notify the Ethics Committee of the proposed modifications.
  
5. Annual Report: Continued approval for this project is dependent on the submission of a Progress Report by the anniversary date of your approval. You will be sent a courtesy reminder closer to this date. **Failure to submit a Progress Report will mean that ethics approval for this project will lapse.**
  

---

6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely



**Lauren Black**

Ethics Administrator

Office of Research Services \_\_\_\_\_

Tel: +61 (03) 6226 2764

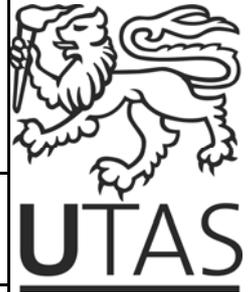
Email: [lauren.black@utas.edu.au](mailto:lauren.black@utas.edu.au)

University of Tasmania

Private Bag 01 Hobart Tas 7001

Appendix C: Participant Information Sheet

Locked Bag 1307 Launceston  
Tasmania 7275 Australia



FACULTY OF EDUCATION

The School Experiences of Females with Asperger's Syndrome: The  
Recollections of Adults with Asperger's Syndrome and Perspectives of  
Parents.

**Invitation**

This is an invitation to participate in a study about the school experiences of females with Asperger's Syndrome. This study is being carried out in partial fulfilment of an Honours degree in Education by Belinda Jarman, under the supervision of Dr Christopher Rayner and Associate Professor Kim Beswick.

**What is the purpose of this study?**

Although there have been several studies carried out exploring the school experiences of individuals with Asperger's Syndrome, females have been unrepresented or underrepresented in these. It is important that the experiences of females with Asperger's Syndrome at school are better understood so that teachers are better able to support these students. The results from this study can potentially provide information which will increase the understanding of the challenges faced by females with Asperger's Syndrome at school, and identify specific areas of need.

**Why have I been invited to participate?**

You are invited to participate in this study if:

- You are a parent of a female with a formal diagnosis of Asperger's Syndrome who is aged between 5 and 18 years, and is currently attending school

- You are an adult female (18 years and over) with a formal diagnosis of Asperger's Syndrome

### **What will I be asked to do?**

This study involves completing an online survey consisting of eight open-ended questions. There are two surveys available: which survey you complete depends on whether you are the parent of a school aged daughter with Asperger's Syndrome, or an adult female with Asperger's Syndrome. The survey includes questions about the following:

- Challenges experienced by you or your daughter at school that you believe are related to Asperger's Syndrome
- Helpful and unhelpful teaching practices
- Academic experiences at school
- The impact of Asperger's Syndrome on peer relationships and social experiences

Because this survey is asking you about personal experiences and opinions, the length of time to complete it will vary. It is estimated the survey may take up to half an hour to complete.

### **Are there any possible benefits from participation in this study?**

Although there are no direct benefits from participating in this study, any personal views and descriptions of experiences you provide can potentially be of great value in contributing to a greater understanding and awareness of the school experiences of females with Asperger's Syndrome.

### **Are there any possible risks from participation in this study?**

Participation in this study should not cause you to experience any physical or mental harm or discomfort.. What information you provide is your decision, and you are free to provide as much or as little detail in your answers as you wish.

If you do not feel comfortable sharing certain information, you are free not to answer. .If you experience any emotional distress during or following the completion of your survey, please consider contacting one of the following organisations (the details of which are also included within the survey), which provide free confidential telephone counselling 24 hours a day:

Lifeline (Australia) 13 11 14

Lifeline (New Zealand) 0800 543 354

The Samaritans (United Kingdom) 08 457 90 90 90

The Samaritans (Republic of Ireland) 1850 60 90 90  
National Hopeline Network (United States of America) 1800 442 4673  
National Suicide Crisis Hotline (Canada) 1800 448 1833

Alternatively, if you wish to discuss any concerns in person, your General Practitioner/Physician would be a good place to start.

**What if I change my mind during or after the study?**

Participation in this study is entirely voluntary. If you wish to withdraw at any time, simply stop completing the questions, and close your browser. None of your data will be collected if you do this. The completion of your survey, along with your ticking of the consent box at the beginning of the survey is interpreted as providing your informed consent.

**What will happen to the information when this study is over?**

The data collected from the surveys will be stored on a university password protected site, and in electronic files only accessible to the researchers via University password protected computer drives. The data will be stored for five (5) years. After this time, all files will be deleted from the computer and relevant computer drives, and the computer “recycle bin” will be emptied.

Due to the online nature of this survey, you can be guaranteed anonymity. No personal or identifying information about you will be collected.

**How will the results of the study be published?**

Following the completion of the study, a summary of results will be provided to each of the websites this study was advertised on. No participant will be identified in the publication of the results.

**What if I have questions about this study?**

If you have any questions about this study, please contact Chief Investigator, Dr Christopher Rayner via email at [Christopher.Rayner@utas.edu.au](mailto:Christopher.Rayner@utas.edu.au), Co-Investigator, Associate Professor Kim Beswick via email at [Kim.Beswick@utas.edu.au](mailto:Kim.Beswick@utas.edu.au), or Student Investigator Belinda Jarman via email at [bcjarman@postoffice.utas.edu.au](mailto:bcjarman@postoffice.utas.edu.au)

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person

nominated to receive complaints from research participants. Please quote ethics reference number: H13193.

Appendix D: Amendment Approval

Social Science Ethics Officer  
Private Bag 01 Hobart  
Tasmania 7001 Australia  
Tel: (03) 6226 2763  
Fax: (03) 6226 7148  
Human.ethics@utas.edu.au



---

RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

---

14 June 2013

*Sent via email*

Dear Dr Rayner

Re: APPROVAL FOR AMENDMENT TO CURRENT PROJECT  
Ethics Ref: **H0013193 - The School Experiences of Females with  
Asperger's Syndrome: The Recollections of Adults with  
Asperger's Syndrome and the Perspectives of Parents**

Amendment to recruit participants via three additional websites:  
Asperger's Victoria, Autism Queensland and Autism New Zealand.

---

We are pleased to advise that the Chair of the Tasmania Social Sciences  
Human Research Ethics Committee approved the Amendment to the above  
project on 13/6/2013.

Yours sincerely

A handwritten signature in blue ink, appearing to be the initials "R" and "S" followed by a flourish.

Appendix E: Adult Survey

Where do you live? \_\_\_\_\_ Country \_\_\_\_\_ State/Province (e.g. Tasmania, Australia)

How old are you? \_\_\_\_\_

1. Think about your experiences throughout school. In your opinion, what were the most significant challenges you faced which you believe were related to Asperger's syndrome? In other words, how did Asperger's syndrome affect your experiences in school?
2. Think about your experiences in the classroom. Please describe some things which your teachers did (or did not do) which you believe were beneficial to your school experiences.
3. Think about your experiences in the classroom. Please describe some things which your teachers did (or did not do) which you believe were not beneficial to your school experiences.
4. Thinking back to your time at school, how would you describe your peer relationships and social experiences?
5. Think about your academic experiences at school. In your opinion, what were your strengths and weaknesses? What were your favourite subjects and why? What were your least favourite subjects and why? How would you describe your overall academic performance?
6. Thinking back to your time at school, what are some of the emotions you can remember experiencing in relation to school? In what specific situations at school did you experience particular emotions?
7. Imagine you are discussing Asperger's syndrome and your school experiences with a group of teachers. Thinking back to your time at school, whether or not you had received a diagnosis of Asperger's syndrome at the time, what do you wish your teachers had understood better about Asperger's syndrome?
8. If there is anything else you would like to add about Asperger's syndrome and your school experiences, please do so here.

Appendix F: Parent Survey

Where do you live? \_\_\_\_\_ Country \_\_\_\_\_ State/Province (e.g. Tasmania, Australia)

How old is your daughter? \_\_\_\_\_

1. Think about your daughter's experiences at school up until this point. In your opinion, what have been the most significant challenges she has faced which you believe are related to Asperger's syndrome? In other words, in what ways has Asperger's syndrome affected your daughter's experiences at school?
2. Think about your daughter's experiences in the classroom up until this point. Please describe some things which her teachers did (and did not do) which you believe have been beneficial to her school experiences.
3. Think about your daughter's experiences in the classroom up until this point. Please describe some things which her teachers did (and did not do) which you believe have not been beneficial to her school experiences.
4. Think about your daughter's peer relationships and social experiences at school up until this point. Please describe her peer relationships and social experiences. How, in your opinion, does Asperger's syndrome impact upon this area of her school life?
5. Think about your daughter's academic experiences at school up until this point. What are her strengths and weaknesses? What subjects does she like/dislike? How would you describe her overall academic performance?
6. Think about your daughter's experiences at school up until this point. Based on your own observations, and what your daughter has shared with you, what are some of the emotions she experiences in regards to school? What specific aspects of school elicit particular emotional responses from your daughter?
7. Imagine you are discussing your daughter's school experiences and Asperger's syndrome with a group of teachers. Please describe what you wish teachers understood better about Asperger's syndrome.
8. If there is anything else you would like to add in regards to Asperger's syndrome and your daughter's school experiences please do so here.



