Life Satisfaction of Neurotypical Women in Intimate Relationship
With a Partner Who Has Asperger’s Syndrome: An Exploratory Study

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A thesis submitted in fulfilment of the requirements for the degree of

Master of Applied Science

Faculty of Health Sciences

The University of Sydney

December, 2017
Abstract

Asperger’s syndrome (AS) is a neurodevelopmental disorder also defined as an autistic spectrum disorder (ASD). AS is characterised by an average or above average IQ, impairments in social interactions, communication and empathy, restricted and repetitive patterns of behaviour and sensory sensitivities. There is an abundance of published empirical studies that have focused on individuals with AS within a number of contexts (e.g., education, health, workplace, career, and family), and a number of studies investigating the impact that the core characteristics of AS have upon the individual with AS within these contexts. Although there is general consensus among researchers, clinicians and other persons with interest in this field of study that adults with AS do enter into successful careers, marry and have children, there is a paucity of empirical data focused on the impact that the behavioural expression of AS characteristics may have upon a non-Asperger’s or neurotypical (NT) spouse or intimate partner. Stage 1 of this study conducted a systematic review of the available published peer-reviewed literature and found that there were no published empirical data focused on the impact of AS characteristics upon an NT partner within the context of an intimate partner relationship. Stage 2 of this project was an exploratory study focusing on the subjective wellbeing (SWB/life satisfaction) of NT women within this context, with a secondary focus on the empathy characteristics of this group of women. An online data collection survey format was chosen to collect quantitative data on SWB and empathy using the Personal Wellbeing Index – Adult (PWI-A) and the Cambridge Behaviour Scale (EQ). An open-ended question format was used to collect qualitative data. Relevant demographic data was also sourced. Survey data from 500 NT women and 53 controls comprised the final data set for analysis. The study found that NT women experienced a statistically significant lower SWB than controls and the PWI-A normative sample for Australian women; and NT women had a statistically significantly higher EQ than the controls and the normative sample. Implications of these findings, limitations of the study and recommendations for further research are discussed.

Keywords

life satisfaction, neurotypical women, NT, Asperger’s syndrome, autism, ASD, autistic disorder, partner, spouse, male, female, intimate relationship, empathy, subjective wellbeing, SWB
Declaration by Author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly authored works that I have included in my thesis.

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Acknowledgments

I extend my most sincere gratitude and appreciation to my primary supervisor, Associate Professor Steven Cumming. I say without equivocation that if it were not for Steven Cumming’s consistent, unwavering and enthusiastic support for me and for this project throughout the entire term of my candidature, this thesis would never have reached completion. Associate Professor Cumming’s academic giftedness, professional and personal generosity, and integrity of mind and spirit have contributed to improving the quality of life of the population of women whose life challenges were explored for this study, and to the enhancement of knowledge of the wider community of clinicians who dedicate their working life to this particular area of human need, as well as to my own personal and professional quality of life. I will remain in awe of Associate Professor Cumming’s ability to ‘turn a phrase’, and in so doing, give ‘distinctive, artistic, and graceful form’ to my often almost unintelligible utterances.

To my Associate Supervisor, Professor Anita Bundy, I thank her for being there just in case I needed her. I was aware that her workload was already extensive when I approached her, desperately seeking her assistance with my candidature, and she did not turn me away.

To University of Sydney staff members Professor Craig Veitch and Dr Rob Heard, who provided me support at a crucial time in my candidature, I extend my sincere appreciation.

To the University of Sydney IT staff and the Faculty of Health Sciences Library and Research and Innovation staff, I extend my sincere appreciation for their invaluable support during my candidature.

Special mentions: Carol Grigg OAM, Adjunct Professor Tony Attwood, and the very special population of women without whose courage and determination this study would never even have been conceived.

Last but never least: my family and friends – I could never do anything without your support and love.

This journey is at an end and yet just beginning.

The larger the island of knowledge,
the longer the shoreline of wonder.

Ralph W. Sockman
DEDICATION

To my dearly beloved brother Hayden, whose opportunities were less than my own, I dedicate this work to you and to your beautiful children, Sam Michael and Caitlin Rae Bostock-Young.

Hayden Gregory Bostock 13/02/1961 – 26/01/2014

Out beyond ideas of wrongdoing
and rightdoing there is a field.
I'll meet you there.
When the soul lies down in that grass
the world is too full to talk about.

Rumi
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Chapter 1: Introduction

The objective of this study was to obtain empirical evidence for the life satisfaction of neurotypical (NT) women in an intimate relationship with a partner who has Asperger’s Syndrome (AS). The study had three broad aims: (1) to investigate the quantity and quality of available peer-reviewed published evidence regarding the life satisfaction of NT women and the recommended treatment interventions; (2) to explore the life satisfaction and empathy of NT women in intimate relationship with a partner who has AS; and (3) to add to the existing body of evidence-based knowledge regarding the life satisfaction of NT women in relationship with a partner who has AS.

There were three research questions formulated to lead this enquiry. First, is the life satisfaction of NT women significantly different from that of women who are not in relationship with a partner who has AS? Second, is the empathy of NT women significantly different from that of women not in relationship with a partner who has AS? And third, what are the predictors of life satisfaction for NT women?

1. Asperger’s Syndrome

During the course of the present project, the diagnostic classification of Asperger’s disorder within the Diagnostic and Statistical Manual of Mental Disorders (DSM) has changed, presenting some difficulties in terminology and expression. The following section briefly reviews these changes and explains the features of Asperger’s syndrome (AS) as understood for the purposes of this project.

Asperger’s disorder was first identified as a separate diagnostic category in the 10th edition of the

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1 Asperger’s syndrome (AS), Asperger’s disorder (AD), autism, autistic disorder, autism spectrum disorder (ASD), Asperger’s, Aspergers’ and Asperger are all terms commonly used throughout the literature to refer to the one disorder, which was formally categorised within the DSM as Asperger’s disorder. For the purposes of this project, the term ‘Asperger’s syndrome’ was adopted due to its popular use through the published literature. Where reference to the DSM is made, the diagnostic term Asperger’s disorder is used.

2 The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the handbook used by doctors, health care professionals and insurers in the United States and much of the world as the authoritative guide to the diagnosis of mental disorders. It is often referred to as ‘the Bible of diagnosis in psychiatry’ (Baron-Cohen, 2009). The DSM contains descriptions, symptoms, and other criteria for diagnosing mental disorders. It provides a common language for clinicians to communicate about their patients and establishes consistent and reliable diagnoses that can be used in the research of mental disorders. It also provides a common language for researchers to study the criteria for potential future revisions and to aid in the development of medications and other interventions (American Psychiatric Association, 2014).

The classification of AD as a separate diagnostic category within the DSM-IV was controversial. During the intervening period between publication of the DSM-IV and DSM-5 there was much debate among academics, nosologists, researchers, clinicians and members of the affected populations regarding the extent to which this disorder is sufficiently different to autistic disorder to warrant a separate diagnostic classification within the DSM. The debate over the diagnostic classification of AD lead to a recommendation by the DSM-5 Neurodevelopmental Working Group that AD be merged into the diagnostic category of autism spectrum disorder (ASD), losing its distinction as a previously held separate diagnostic category within the pervasive developmental disorders (PDD; American Psychiatric Association, 2012). The decision was informed by research evidence that concluded that AD symptomatology is insufficiently different from ASD symptomatology to warrant a separate diagnostic classification (American Psychiatric Association, 2012; Attwood, 2007, pp. 29–39; Frith, 2004; Frombonne, 2008; Ghaziuddin, 1992; Hartley & Sikora, 2009; Kim, Leventhal, Koh, Frombonne, Laska, Lim, & Grinker, 2011; Lawson, 2008; Lord, Petkova, Hus, Gan, Martin, & Risi, 2011; Macintosh & Dissanayake, 2004; Wazana, Bresnahan, & Kline, 2007; Witwer & Lecavalier, 2008; Wolff, 1996).

The Working Group also believed that a single umbrella disorder with the recommended diagnostic criteria changes would increase the potential for earlier diagnosis of ASD. One key element of the diagnostic criteria change under the DSM-5 is that individuals diagnosed with an ASD must demonstrate symptoms of the disorder from early childhood even if the symptoms are not recognised until later on in the individual’s life. It is considered that this change (from a focus on diagnosis at ‘school age’ under the DSM-IV) would encourage earlier diagnosis as well as providing opportunities for diagnosis to those individuals whose symptoms are not recognized until later in life, when social demands exceed capacity (American Psychiatric Association, 2012). As the current project was designed and commenced under DSM-IV criteria, the terminology and conceptualisation from that edition has been used.
throughout this thesis.

The diagnostic criteria for AD as documented in the *DSM-IV* are:

(A) Qualitative impairment in social interaction as manifested by at least two of the following:

1. marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. Lack of social or emotional reciprocity

(B) Restricted, repetitive and stereotyped patterns of behaviour, interests and activities as manifested by at least one of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, non-functional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

(C) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning

(D) There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction)

(E) Curiosity about the environment in childhood.

(American Psychiatric Association, 2000, p. 84)

People with AS generally fall within at least the average range for intelligence quotient (IQ) and some may experience *impairment in sensory sensitivities* (Attwood, 1998, 2006; Attwood & Garnett, 2010; Bentley, 2007; Bliss & Edmonds, 2008; Hènault, 2006; Lawson, 2005, 2008; Slater-Walker & Slater-Walker, 2002).

### 1.2 Asperger’s: Neurotypical Intimate Relationships

Prevalence data for AS within communities are not readily available; however, based on estimates that there may be approximately 0.16% of adults living with AS (as a subtype of autism
spectrum disorder; Baio, 2014) and that 12,625,030 (58.7%) of Australian adults were living with a partner in 2011 (Australian Bureau of Statistics, 2011), as at 2011 there may have been approximately 11,800 Australian couples living in a relationship, or have lived in a relationship, where one partner had AS. This prevalence figure of AS of 0.16% is not well supported by empirical evidence; however, prevalence data for autism and its subtypes, including AS, is difficult to collect due to lack of awareness about the disorder/s; the lack of standardised measures, methods, and procedures for use in the assessment and diagnosis of these neurodevelopmental disorders, a lack of suitably trained clinicians to perform these assessments and a lack of consensus towards ‘best approach/best practice’ guidelines.

Consequently, the prevalence of AS can only be estimated from the literature available (Attwood, 2006, 2007; Attwood & Garnett, 2010; Autism Victoria Professional Advisory Panel, undated; Centers for Disease Control and Prevention & Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014; Elsabbagh et al., 2012; Hinkka-Yli-Salomaki et al., 2014; McPartland & Volkmar, 2009; Ritvo et al., 1989; Williams, MacDermott, Ridley, Glasson, & Wray, 2008). The prevalence of Autism (including subtype AS) is thought to be higher in males than in females and a 4:1 or 5:1 male to female ratio for autism is suggested (Autism Victoria Professional Advisory Panel, undated) while the Centre for Disease Control and prevention put this figure at 4.5:1 (Centers for Disease Control and Prevention & Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014). This same male:female ratio is adopted when referring to AS. Some researchers have suggested that females are more capable of hiding their AS symptoms and signs and of developing adaptive coping strategies (such as copying/modelling) and are therefore less likely than males to come to the attention of professionals working in the field. Females with AS are often thought of as ‘flying under the diagnostic radar’ such are their capabilities to mask their AS symptoms (Willey, 2012; Attwood & Grandin, 2006).

Despite the hallmark social and communicative difficulties, many people with AS form intimate relationships and have children (Aston, 2001, 2012; Attwood, 2007; Bentley, 2007; Eisenberg, 1957; Hendrickx, 2008; Larsen, 1997; Lawson, 2005; Lucas, 2001; Myhill & Jekel, 2008; Ritvo, Brothers, Freeman, & Pingree, 1988; Slater-Walker & Slater-Walker, 2002; Stanford, 2003; Weston, 2010; Willey, 1999). The hallmark characteristics of AS (and autism) appear to remain stable and consistent over the lifespan, although some individuals with AS are known to experience symptom improvement and ability to adapt to their psychosocial
Numerous accounts of neurotypical (NT) partners’ experiences within the NT-AS intimate relationship dyad have been published and represent a range of views, perspectives and coping recommendations for the NT female partner. These have largely been anecdotal, first-person accounts of the AS-NT relationship and represent a range of views, perspectives and coping recommendations for the NT female partner (Bentley, 2007; Bliss & Edmonds, 2008; Griffiths, 2008; Hadcroft, 2005; Hendrickx, 2008; Jacobs, 2006; Jessica Kingsley Publishers [http://www.jkp.com]; Myhill & Jekel, 2008; Slater-Walker & Slater-Walker, 2002; Stanford, 2003; Weston, 2010). A few clinicians of note drawing on their extensive practice and academic experience have also contributed to the published literature (Attwood, 2007; Aston, 2001, 2012; Lawson, 2005).

A second source of anecdotal narrative accounts of living in an AS-NT partnership is the self-help and support resources available online and via various social media (e.g., www.aspia.org.au; www.aspartners.org; www.asperger-marriage.info; www.meetup.com/neurotypicals; www.kmarshack.com). Most of these sites encourage users to share their stories, providing a rich, albeit highly selected and subjective, source of experiential material.

These available books, articles and internet/electronic resources suggest that NT partners of people with AS typically believe that their experience is unique and can only be understood by those who share the experience. The English idiom ‘Only the wearer knows where the shoe pinches’ seems to capture this belief. In some cases the literature reveals that there is expressed distrust and strong disappointment held towards members of the helping professions for their lack of recognition, knowledge, skills, and expertise in understanding the issues facing NT women.

The opinions and experiences expressed within this literature cited above indicate that some female NT partners experience a decline in mental and physical health, wellbeing and quality of life that they attribute to the symptom expression of their partner’s AS. Feelings of loneliness, confusion, frustration, isolation, and at times of ‘going insane’ are described, as are psychological disorders such as depression and anxiety. Problems with sexual intimacy and sexual activity are commonly reported, as are medical complaints such as high blood pressure. Comments that the NT-AS intimate relationship is marked by the unwillingness or inability of their partner to engage in shared activities, to provide appropriate emotional support, to effectively communicate, to reciprocate, or to be spontaneous or flexible in their beliefs and behaviours and to learn from
their mistakes, are frequently expressed. These accounts also suggest that misunderstandings in communication occur frequently, and empathic behavioural and communicative responses are often perceived by the NT partner to be significantly impaired in the AS partner.

NT partners describe how they find it difficult to motivate their AS partners to accept responsibility for activities associated with living within an intimate relationship. Examples cited are sharing of domestic duties, remembering special occasions such as birthdays and anniversaries, initiating contact with relatives and friends, being more equitable in the allocation of time spent on their interests and hobbies and time spent engaging in family and partner activities, and engaging in social activities (Evans, 2011; Myhill & Jekel, 2008).

Hardships experienced as a result of the AS partner’s financial mismanagement or inability or unwillingness to effectively engage in stable employment are also noted. A small number of these women reveal that they have ‘become physical’ towards their AS partner, and they further report a sense of personal shame associated with this and other ways they use to cope with their relationship problems (e.g., yelling, arguing, name-calling, threatening).

Although there is commonality among many of these experiences, intimate relationships between NT women with AS male partners are also very idiosyncratic and variable across dyads. For example, some women report difficulties with financial security resulting from the AS partner’s inability to manage finances appropriately, while others report that money is not a problem as the AS partner is meticulous when it comes to managing finances. Some report that their AS partner is verbally aggressive and sometimes violent, while another reports that their AS partner has a very gentle and quiet nature and has never been verbally or physically abusive towards them. Some report satisfaction with sexual activity and sexual intimacy within the relationship while others report experiences that range from infrequent and unsatisfying sexual encounters to not having been sexually intimate for years.

Similarly, some women report that their AS partner has always found difficulty finding and keeping a job, while others report that their AS partner has only ever held one job in his entire lifetime. Shore’s (2014) often-quoted statement ‘If you’ve met one person with autism – you’ve met one person with autism’ eloquently captures this theme found throughout this body of literature. Attwood (autismhangout, 2011) defines the NT partners’ observations of this variability within the AS profile of abilities as the ‘heterogeneity of AS symptom expression with many extremes’. This diversity of AS symptom expression contributes to the difficulties experienced by clinicians, family members and people with AS themselves in the identification
and/or diagnosis of AS.

Among the publications intended to provide advice and support to NT partners there are those that also reflect some common expectations regarding the NT partner’s role in the maintenance of their relationship. There is some suggestion that NT women should assume the bulk of the responsibility for the maintenance of their intimate relationship with their AS partner on the assumption that the NT partner has access to skills and abilities that are unavailable to AS men. For example, Martin and Hendrickx suggest that ‘it is incumbent upon NT’s to be empathic and to change their behaviour to facilitate and support social encounters for people with AS’ (Martin & Hendrickx, 2011, p. 26) and ‘NTs are invited to flex their presumably well-honed empathy muscles and look at the world through the eyes of people with AS. “I love you, you’re perfect, now change” does not really have a place in any relationship’ (Martin & Hendrickx, 2011, p. 31).

Similarly, Weston (2010) suggests that NT partners may find it useful to ‘let go of expectations’ of their AS partner to:

- try not to: expect empathy/caring, expect flowers (or whatever you hoped for), expect dinner to be cooked the way you requested … be grateful that the dinner was cooked for you at all and try not to rant and rave every time the Aspie forgets to do something. Often, they can’t help it. (Weston, 2010, pp. 29–30).

Weston goes on to recommend that the NT partner ‘detach emotionally from their partner’ and ‘avoid relying on the Aspie for anything’ (Weston, 2010, p. 34) as suggested coping strategies.

Gisela Slater-Walker had been partnered with her AS husband Chris for 12 years when in 2002 she and Chris co-authored An Asperger Marriage. An excerpt on intimacy written by Gisela from this book reveals one of her more personal struggles within her relationship with Chris:

The one thing that saddens me is that Chris’s inability to express himself has made me feel awkward about telling him how I feel about him, and has even discouraged me from using endearments. (Slater-Walker & Slater-Walker, 2002, p. 99).

Chris’s closing comments in this same book provide insight into one person with AS’s perspective on his intimate relationship: ‘I think the future will be very much like the present. The restricted social life, difficulties with interpersonal relationships, precarious employment prospects, arm’s length relationships with the family and so on are all unlikely to change in any significant way’ (Slater-Walker & Slater-Walker, 2002, p. 135).

In her book Alone Together – Making an Asperger Marriage Work, Katrina Bentley concludes
her work with the following reflection:

Gavin and I are different but we share many common interests and have similar goals in life. I’d like to finish our story with the famous quote from the French writer and aviator Antoine de Saint-Exupery: ‘Love does not consist in gazing at each other but in looking outward together in the same direction.’ (Bentley, 2007, p. 116).

Bentley (2007), Hendrickx (2008), Slater-Walker (Slater-Walker & Slater-Walker, 2002) and Weston (2010) are authors and NT female partners living within an NT-AS intimate partnership who acknowledge the difficulties inherent within their relationships, though they report having found coping strategies that work for them to maintain their partnerships. Through their publications and public speaking, they recommend their adaptive coping strategies to other NT women in similar relationships.

The personal accounts and professional contributions contained within the literature explored for the introduction to this study provides some evidence of converging knowledge within this field and provides interesting insights into the experiences of some NT women. What is not yet known, however, is the extent to which these experiences are generalisable to other NT women in NT-AS couple dyads.

1.3 Theoretical Constructs

Anecdotal self-reports and the opinions of those who provide support and advice to those NT women living with a partner who has AS suggest that these women are not happy and in many cases are experiencing significant stress related disorders as a result of their psychological reactions to the stressors within their relationship with their AS partner. These reports indicate that the stressors present within the NT-AS couple relationship are largely attributed to the AS partner and his/her behavioural expression of the core characteristics of AS (e.g., low/diminished empathy, verbal and nonverbal communication deficits, difficulties understanding and expressing emotions, restricted interests, egocentricity, and sexual functioning/activity difficulties). These stressors and resultant stress-related disorders are reported to manifest in mental and physical health decline, resulting in overall reduced life satisfaction for the NT partners.

The following section reviews the relevant literature on the theoretical constructs of life satisfaction and empathy and the rationale for the use of each construct in the current study is discussed.
1.3.1 Life Satisfaction

Life satisfaction has been positively associated with happy intimate relationships and the research also informs us that successful intimate relationships play a major role in psychological wellbeing, physical health, and longevity (Arrindell, van Nieuwenhuizen, & Luteijn, 2001; Cohen, Schulz, Weiss, & Waldinger, 2012), and are a key predictor of subjective wellbeing (SWB; Cummins, 2010, Cummins, October 30, 2012, personal communication; Cohen, Schulz, Weiss, & Waldinger, 2012; Ali & Chamarro-Premuzic, 2009). Sternberg argues that the love one feels towards one’s relationship partner is characterised by various combinations of the trio of constructs: intimacy, passion and commitment (Sternberg, 1998). The 2014 study, ‘Happy Marriage, Happy Life? Marital Quality and Subjective Well-Being in Later Life’, found that marital satisfaction was a significant correlate of life satisfaction and momentary happiness and that there was no effect by gender. The study also found that a husband’s marital quality and life satisfaction was positively correlated with his wife’s self-report of a happy marriage and negatively correlated when his wife reports low marital quality (Carr, Freedman, Cornman, & Schwarz, 2014).

In common language, life satisfaction may be synonymous with concepts such as ‘wellbeing’ and ‘happiness’; however, each of these terms has a distinctive theoretical and empirical legacy, as outlined here.

Life satisfaction is generally agreed to consist of two components: cognitive evaluations and affective reactions. Cognitive evaluation is the cognitive appraisal or evaluation of an individual’s life as a whole and includes domain satisfactions such as work, family, and leisure, as well as life satisfactions that include evaluating or appraising the dissonance between one’s perception of how life actually is and how one desires it to be (Diener, Suh, Lucas, & Smith, 1999; Helliwell, 2011; Helliwell, Layard, & Sachs, 2012). The other component, the affective reactions, is the emotional or affective appraisal of one’s life. This affective component has been referred to as the ‘moment-to-moment accounts of pleasure or pain’ experienced in one’s life (Bradburn, 1969; Helliwell et al., 2012; Lucas, Diener, & Suh, 1996) and consisting of positive affect (PA) and negative affect (NA) (Bradburn, 1969) or ‘the absence of negative affect’ (Diener, Oishi, & Lucas, 2003).

The 1960s saw the emergence of the empirical study of happiness, with Bradburn and Caplovitz’s 1965 pilot attempt ‘to develop operational measures for problems in living’ (Bradburn, 1969, p. 9). The outcome of this study was the identification and defining of the
construct psychological wellbeing, with this construct seen to consist of the two independent correlates, PA and NA (Diener et al., 2003). Bradburn describes PA and NA as feeling states and used items such as ‘Pleased about having accomplished something’, ‘That things were going your way’, ‘Proud that someone had complimented you on something that you had done’, and ‘On the top of the world’ to elicit responses to rate an individual’s PA; and items such as ‘So restless that you couldn’t sit long in a chair’, ‘Bored’, ‘Depressed or unhappy’, ‘Very lonely or remote from other people’ and ‘Upset because someone criticised you’ to elicit responses to rate an individual’s NA in his feeling states questionnaire (Bradburn, 1969, p. 56). Using this conceptual model, a person’s psychological wellbeing would be determined by the discrepancy between their level of PA and NA. Where PA is greater than NA for an individual, then that individual would be ‘high’ in psychological wellbeing; and where NA is greater than PA, an individual’s psychological wellbeing would be ‘low’. The two constructs – PA and NA – are considered to be independent, in that a rise or decline in one affective state does not necessarily or significantly effect a change in the other state (Bradburn, 1969; Diener, Lucas, & Scollon, 2006; Ryan, Huta, & Deci, 2008). Goldstein and Strube (1994) conducted a study to replicate Bradburn’s 1969 finding and found support for the independence of the two correlates both within and between situations and within and between subjects. They explain this in the example of success feedback where ‘success feedback increased positive affect but did not influence negative affect; failure feedback increased negative affect but did not influence positive affect’ (Goldstein & Strube, 1994, p. 57), lending support for the two-dimensional structure of affect. The significance of this finding lies in the notion that it is not possible to deduce from one state (PA) the condition of the other state (NA) within situations or between situations or subjects (Goldstein et al., 1994).

Diener et al. (1999, p. 277) list the components of SWB as ‘Pleasant affect, unpleasant affect, global judgments of Life Satisfaction and Domain satisfactions (e.g., work, family, self, health etc.)’. The personality construct optimism as a correlate of SWB was later included by Diener et al. (2003). In their review of research on hedonic and eudemonic wellbeing, Ryan and Deci (2001) state that wellbeing is a complex construct and that the three components (life satisfaction, the presence of positive mood and the absence of negative mood) together are often summarised as happiness. Lucas, Diener, and Suh, (1996) found moderate to very good evidence for the discriminate validities of ‘(a) positive affect from negative affect, (b) life satisfaction from positive and negative affect, (c) life satisfaction from optimism and self-esteem, and (d) optimism from negative affect and positive affect’ (p. 627).
Regarding the question of how SWB should be reliably and validly measured, Diener et al. (1999) claim that the three constructs – life satisfaction, PA and the absence of NA – should be measured independently, as research demonstrates the independence of the three constructs. Hellwell (2008) asserts that it is important for researchers to know that both kinds of happiness (evaluative/cognitive and affective) have ‘predictable causes that reflect various facets of our human nature and our social life and that affective happiness and evaluative happiness measure very different dimensions of life’ (p. 7). Furthermore, each construct correlates as an indicator of psychological wellbeing (Segrin, Hanzal, Donnerstein, Taylor, & Domschke, 2007). Diener et al. (1999) conclude that SWB researchers should include measurements of both PA and NA in their research. They accept, however, that many researchers continue to measure a single aspect of wellbeing or ill-being, such as depression or life satisfaction.

While Diener’s model sees happiness clustered with joy and contentment as part of PA, Cummins departs from Diener’s model and suggests that the happiness most associated with SWB is a stable trait mood, ‘Homeostatically Protected Mood’ (HPMood), consisting of general contentment and positive arousal (Tunbridge & Weinberg, 2014, p. 14). Cummins’ model differs also from Diener’s model by asserting that HPMood (previously referred to by Cummins and others as core affect) is the dominant influence when evaluating questions used to measure SWB, and not cognitive appraisal, as suggested by Diener’s model; and further asserts that personality is not the driving force behind SWB (Davern, Cummins, & Stokes, 2007; Tunbridge et al., 2014).

The popularity of the approach by researchers to measure a single aspect of SWB (e.g., life satisfaction) is justified in a number of ways. Hellwell (2008) claims that his approach to measuring the construct life satisfaction, when looking at SWB from both an individual and a global perspective, is informed by practical, theoretical and empirical reasons. From a practical perspective, Hellwell claims that ‘self-assessments of life satisfaction are easy to collect as low cost add-on questions in surveys contrasted with difficult to collect and expensive “moment-by-moment/pleasure or pain” assessments’ (pp. 2–3).

Cummins (2010) comments that the semi-abstract nature of the questions in his scale, the Personal Wellbeing Index for Adults (PWI-A), is a deliberate attempt to minimise the impact of mood affect or, more precisely, ‘it allows the response that people give to be dominated by non-specific mood affect’ which he refers to as ‘the essence of SWB’ (p. 2).

Cummins refers to Tesser, Pilkington, and McIntosh’s (1989) study and their provision of
empirical support for self-evaluation maintenance (SEM) as having relevance to the influence of internal buffers on HP Mood (Cummins, 2010, p. 9). Tesser et al.’s (1989) model states (in part) that ‘According to the SEM model, although the self may recognize good performance on a variety of dimensions, the self aspires to be “good at” only a few such dimensions’ (p. 442). Cummins (2010), in line with Tesser et al.’s (1989) theoretical perspective, asserts that a person’s performance is only threatening to self-evaluation when ‘failures’ are identified as belonging to valued dimensions in life.

The literature is confounded by inconsistent use of terminology. For example, the acronyms ‘SWB’ and ‘SWL’ (satisfaction with life) are both used to refer to ‘subjective wellbeing’ and are also used interchangeably with the constructs ‘happiness’ and ‘life satisfaction’; ‘wellbeing’ is used interchangeably with the acronyms ‘SWB’, ‘SWL’ and life satisfaction and happiness; ‘psychological wellbeing’ is used interchangeably with ‘happiness’; and ‘SWL’ is not a uniformly adopted acronym for ‘life satisfaction’ or ‘subjective wellbeing’.

Many authors provide a rationale for selecting their choice of terminology. Helliwell et al. (2012) acknowledge that they used the term ‘happiness’ in the title of the World Happiness Report simply because the word is likely to generate more interest than the words ‘subjective wellbeing’ or ‘life satisfaction’, and that sometimes SWL, the cognitive appraisal of an individual’s life, is referred to as ‘evaluative happiness’, while ‘affective appraisal’ is sometimes referred to as ‘affective happiness’.

Similarly, The Australian Unity Wellbeing Index, produced through a partnership between Australian Unity and Deakin University, titled their report on the wellbeing of Australians with the simple question What Makes Us Happy?, and stated that their rationale for using ‘wellbeing’ and ‘happiness’ interchangeably was because ‘happiness is a term that people can relate to and conceptualise easy’ (Australian Unity, Deakin University, & Australian Centre on Quality of Life, 2008, p. 9). They describe the relationship between happiness and wellbeing with the statement ‘… if our wellbeing fails our happiness suffers’ (Australian Unity et al., 2008, p. 6). Diener et al. (2003) report SWB as ‘what lay people call happiness, peace, fulfilment, and life satisfaction’ (p. 403). Bradburn, who with Caplovitz (Bradburn & Caplovitz, 1965) was credited with constructing the first wellbeing inventory, refers to the interchangeability of the terms in his work The Structure of Psychological Wellbeing (Bradburn, 1969, p. v).

However defined, the scholarly understanding of satisfaction with one’s life has interest for
societies from at least the 4th century BC; as reported by Helliwell, his theoretical approach to SWB is underpinned by Aristotelian philosophy:

that reflective answers to broad questions about life satisfaction provide a better measure of a life well-lived than momentary accounts of pleasure or pain and that, on empirical grounds, there is evidence that interpersonal and international differences are more likely to show up in answers to general questions about life satisfaction than in measures of recent pleasure and pain (Helliwell, 2008, p. 2).

This understanding is supported by others from this field of study (Bradburn, 1969; Diener et al., 2003; Diener et al., 1999; Helliwell, 2008, 2011; Ryan et al., 2001).

In his monograph *The Structure of Psychological Wellbeing*, a study into the exploration of ‘everyday life problems’ and ‘normal’ persons’ responses to those problems, Bradburn (1969) adopted a perspective illuminated by the ideas of Szasz (1961) by approaching the behavioural and emotional responses of ‘normal’ people to everyday life problems, not from a clinical diagnostic perspective but from a social-psychological perspective. In doing so, he further attempted to destigmatise and broaden understanding and perspectives on the concept of ‘mental health’. Bradburn’s research focused ‘on the relationship between an individual’s life situation and his psychological reactions to that situation’ (Bradburn, 1969, p. 2), selecting the construct of psychological wellbeing as his ‘dependent variable’.

The study of life satisfaction of populations also has broader implications for public policy. It has long been upheld that while economic strength is important and necessary for communities to flourish and be successful, it is not sufficient. The wellbeing of individuals has also been found to be a necessary element for the success of communities and the collection of data on the life satisfaction of individual and collective members of communities makes an important contribution towards policy development (Graham, 2010; Dolan & Metcalfe, 2012; Dolan, Peasgood, & White, 2008; Helliwell, 2008). Within the context of this study, data collection on the life satisfaction of NT women may assist policy makers when considering resource allocation to family members of person’s with disabilities (AS is a neurodevelopmental disability).

The rationale for the adoption of life satisfaction/SWB as the construct of choice to initiate investigation into the health and wellbeing of NT women in relationship with an intimate partner who has AS is that the theoretical underpinnings of the construct encompass a broad cross-section of physical, social and mental health domains (e.g., standard of living, health, achieving in life, relationships, safety, community-connectedness, future security, and
spirituality/religion); it has been a widely empirically studied and researched construct; it is measured using a brief self-report questionnaire making it easy and time efficient for study participants to complete and data easily collated; and is an individual’s own subjective assessment of how satisfied they are with their life overall. Adopting Cummins's theory of SWB which underpins the instrument the PWI-A, a measure of SWB will provide data from which conclusions about mental health vulnerability can be drawn when compared to normative data for Australian women. Data from this instrument also provides very useful indicators of participants’ vulnerability from across each of the eight domains of life and informative data on just how NT women’s lives compare with women not in relationship with an intimate partner who has AS.

In an attempt to obtain health and wellbeing data from a comparative sample, it was decided that as caregivers may experience relationship burden, restricted social lives, diminished relationship satisfaction, diminished sexual and/or emotional intimacy, increased overall responsibility for managing the household, and financial worries, which are similar experiences to those described by NT women, literature from this population may provide suitable comparison data. Additionally, some NT women describe themselves as being more like their partner’s carer or parent than a wife. A non-structured review of this literature suggests that members of this caregiver population experience depression symptoms, with wives who provide care to their spouses or children experiencing greater depressive symptoms than their non-caregiver counterparts (Dunkle, Feld, Lehning, Kim, Shen, & Kim, 2014), and with even greater stress and detriment for middle-aged and older caregivers than those caregivers who provide care to other relatives such as parents (Penning & Wu, 2015). A 2012 study on spousal caregiving found that caring for a spouse by managing their activities of daily living (ADL care) was a significant predictor of hypertension, with no variation between current (short) and long-term caregiving and the study finding no significant difference for gender (Capistrant, Moon, & Glymour, 2012).

Research that had a primary focus on the SWB of a population of a nationally representative sample of over 10,000 Australian caregivers found that with increasing informal care (intensive care >20 hours per week) there was a statistically significant negative association with life satisfaction, revealing that the greater the number of hours of caregiving the greater the negative impact on life satisfaction of the caregiver (van den Berg, Fiebig, & Hall, 2014). A study on depression and life satisfaction among spousal caregivers in a hospice found that female gender, caregiver health problems, and negative social interactions were risk factors for
diminished wellbeing. The study also revealed important caregiver differences, with caregivers who rated their caregiving tasks as less stressful and found meaning and subjective benefits in caregiving, together with having more social resources, showed higher life satisfaction and lower depression after controlling for variables such as patient and caregiver appraisal variables (e.g., caregiving burden, severity of patient illness; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Lee, Brennan, & Daly, 2001).

It is accepted that employment makes an important contribution to SWB. van Campen et al. (2012) found support for this contribution in their study, which explored the happiness of informal caregivers, non-caregivers and the contribution of paid and voluntary work. One might expect that work responsibilities outside the home (paid or voluntary) might place an additional burden on caregivers; however, the study found, consistent with SWB theory, that paid or voluntary work outside the responsibilities of caregiving is related to higher rates of happiness (van Campen, de Boer, & Iedema, 2013).

A further variable investigated within this body of published research is that of personality, which has been proposed to be a theoretically important factor in SWB where trait similarities between intimate partners is found to be positively correlated with SWB in males but not in females. Good marriage quality has been found to significantly predict SWB, and marriage stability and marriage quality are predicted by similarities between the couple (Arrindell & Luteijn, 2000). Care recipient personality facets of agreeableness (specifically trust and compliance) has been found to be associated with better physical health among caregivers, after controlling for the care recipient variables of pain and physical impairment (Riffin, Lockenhoff, Pillemer, Friedman, & Costa, 2013).

Given that this study is exploratory and, to the best of our knowledge, no other empirical studies have been conducted on this topic, it was decided following a review of the relevant literature, that a measure of SWB would provide informative and appropriate data across a broad range of life domains. This provides a useful starting point for further inquiry into the health and wellbeing implications reported by NT women in intimate relationship with a partner who has AS.

1.3.2 Empathy

Empathy as a construct has historically attracted disagreement in terms of how it should be defined and how it should be measured. However, there is a general consensus among scholars
in this field of study that empathy, similarly to SWB, is multifaceted and consists of two distinct components: a cognitive component or ‘perspective taking’ and an emotional or affective component (Baron-Cohen & Wheelwright, 2004; Davis, 1983; 1994, Hogan, 1969; Leiberg & Anders, 2006; Peloquin & Lafontaine, 2010; Rogers, Dziobek, Hassenstab, Wolf, & Convit, 2007). The cognitive component of empathy is said to refer to an individual’s ability to understand another person’s point of view or to put oneself in another’s place without experiencing their emotions (Hogan, 1969). Baron-Cohen (2012) explains empathy as an individual’s ability to imagine what someone else is thinking or feeling; to be capable of putting oneself in another’s shoes. He refers to this as the recognition part of empathy. The emotional or affective component is described by Baron-Cohen as the drive to respond to what someone else is thinking or feeling and to do so with an appropriate emotion (Baron-Cohen, 2012).

Baron-Cohen (2012) asserts that in any one person, empathy may be temporarily or permanently low, or average, or highly dependent upon social and biological factors and influences – it can be scientifically measured and it is not ‘all or none – it comes by degrees’ (Baron-Cohen, 2012). Rogers et al. (2007) comment: ‘A deficit in empathy has consistently been cited as a central characteristic of Asperger syndrome (AS)’ (p. 709). Describing people with ASD and empathy, Baron-Cohen (2012) explains that people with ASDs have low cognitive empathy but intact affective empathy, and that people with ASDs are confused by people’s intentions, thoughts, motives and feelings and struggle to understand them, and they withdraw, ‘preferring the more predictable world of objects’. He argues that people with ASD tend not to hurt other people and if they hear that someone is suffering it upsets them (Baron-Cohen, 2012). Other studies that looked at the relationship between ASD traits, trait affective empathy, emotional expressivity and interpersonal difficulties, suggest that a higher degree of ASD traits may have a negative association with trait affective empathy. They found that where an individual had relatively low trait affective empathy and more ASD traits, their emotional expressivity was also low. The study concluded that interpersonal difficulties experienced by individuals with ASD may be partially explained by low cognitive empathy and further aggravated by a limited capacity for affective empathy (aan het Rot & Hogenelst, 2014).

Empathy plays an important role in the quality and bonds of intimate relationships and a key role in SWB of intimate partners. As empathy plays a key role in emotional support, it is found to be a positive correlate of relationship satisfaction (Cramer & Jowett, 2010; Rostowski, 2009) and it is theorized that a positive intimate relationship is a strong predictor of SWB (Cummins, October 30, 2012, personal communication).
A further important role played by empathy within intimate partnerships is its contribution towards the important concept of illusion. Some research has found that positive illusions of a partner in a couple dyad is related to relationship quality (Dijkstra, Barelks, Groothof, & van Bruggen, 2014, p. 1). Positive illusion is the concept of inflating the positive characteristics of one’s partner so much so that the positive rating attributed to the partner’s characteristic exceeds the self-assessment of that partner of him or herself (Dijkstra et al., 2014). Some examples are constructs such as kindness, intelligence, and physical attractiveness. When applied to the assessment of a partner’s empathy, positive illusions will contribute to the partner being perceived to have an empathy that is higher or more positive than his/her actual empathy. Perceived empathy has been positively associated with relationship satisfaction whereas accurate empathy was not; and negatively associated with depression and conflict (Cramer et al., 2010). Perceived empathy (a key characteristic of emotional support) can be explained by the notion that one has the feeling of being understood, of having been listened to, valued, respected and cared for or loved (Cramer et al., 2010). This same study found two partner effects by gender. Conflict in women was significantly associated with depression in women and relationship dissatisfaction in men (Cramer et al., 2010). Positive illusions have also been found to be a predictor of more positive relationship satisfaction, love, commitment and trust, and less conflict and ambivalence in both dating and marital relationships (Dijkstra et al., 2014, p. 1; Murray & Holmes, 1997). As partners’ perception of their partners empathy is viewed more positively, their relationship is enhanced and their interactions more meaningful (Dijkstra et al., 2014; Gruhn, Rebucal, Diehl, Lumley, & Labouvie-Vief, 2008). Depression has been found to be a significant mediator between perceived empathy and relationship satisfaction in both men and women, consistent with the cognitive model of depression in which depressed people view their world through a more negative lens (Cramer et al., 2010). Lee et al., (2001) in their study found that cognitive empathy significantly influenced the levels of self-reported stress, threats within the caregiving environment, depression and life satisfaction. Those caregivers who were higher in cognitive empathy reported lower levels of stress, environmental threats and depression, and higher levels of life satisfaction than those caregivers who were low in cognitive empathy. Emotional or affective empathy was found to be negatively correlated to life satisfaction (Lee et al., 2001).

This literature provides for a number of discussion points in relation to the causal implications of NT women’s stated mental and physical health problems and the role of empathy.

Numerous authors have suggested that NT women in intimate relationship with a partner who has AS may not only have an empathy quotient that is ‘higher’ than their AS intimate
partners but also higher than women not in such relationships, and that having an elevated empathy may contribute to the initial attraction of the NT woman to their AS partner and also to assuming the bulk of the responsibility for the maintenance of the relationship and the health and wellbeing of the partner with AS over time (Attwood, personal correspondence, January 6, 2009; Grigg, personal correspondence, November 2, 2009). It has been posited that possessing an elevated empathy quotient may lead to a vulnerability to mental and physical health problems and diminished life satisfaction, as there is a tendency among members of this population to prioritise the needs of others to the detriment of their own health and wellbeing needs. Literature from research in the field of caregiving suggests that caregivers (of a spouse) who have an elevated empathy are more dissatisfied with their romantic relationship with their partner, are vulnerable to experiencing mental, physical and medical health problems and may have a higher mortality rate than their non-care giver counterparts (Capistrant et al., 2012; Hubley, Hemingway, & Michalos, 2003; Lee et al., 2001; Perkins, Howard, Wadley, Crowe, Safford, Haley, & Roth, 2013). It should be noted here that Lee et al.’s (2001) study drew a distinction between cognitive and emotional empathy and found that high cognitive empathy may act as a positive buffer between the caregiver and his/her environment, while low cognitive empathy and high emotional empathy was found to have negative impacts on depression, stress, life satisfaction and environmental threats.

Given that the relationship difficulties experienced by some NT women within their NT-AS partnerships may have a negative impact upon their health and wellbeing, and given what research informs us about the empathy characteristics of persons with AS, it seems reasonable to posit that empathy as a construct may potentially influence both the maintenance of the relationship and the difficulties experienced within the NT-AS relationship by the NT partner. Possessing a high level of empathy as a personal characteristic may contribute to a NT partner being more tolerant and understanding of a partner who has an AS characteristic of low empathy; possessing a low level of empathy as a personal characteristic may contribute to a NT partner being unaffected by their AS partner’s characteristic of low empathy. It is therefore of interest to note whether the NT partners of people with AS have higher or lower levels of empathy than people who do not have AS partners.

Having considered the above, the exploratory nature of this research and the lack of any available empirical evidence on empathy and NT women in relationship with a person who has
AS, it was decided to include a measurement of empathy within this project.

Hogan was one of the early theorists to attempt to further develop a scale to accurately measure empathy (Hogan, 1969). Hogan describes the attributes of an empathic person as ‘pleasant, charming, friendly, dreamy, cheerful, sociable, sentimental, imaginative, discreet and tactful’ and an unempathic person as ‘cruel, cold, quarrelsome, hostile, bitter, unemotional, unkind, hard-hearted, argumentative and opinionated’ (Hogan, 1969, p. 315). Hogan adds ‘… the low scorer … appears somewhat aloof, disaffected, and disposed to alienate those around him’; while the high scorer ‘seems likeable and friendly, possessing considerable charm, poise, and tact. He is outgoing, warm and very much at ease in the interpersonal situation – the term urbane might even be appropriate’ (Hogan, 1969, p. 315).

Professor Simon Baron-Cohen from The University of Cambridge is a contemporary scholar and considered to be one of the leading scholars in the field of autism. Baron-Cohen’s research activities based at the Autism Research Centre have led to the development of a significant number of screening instruments for research purposes. These instruments are made freely available to members of the international research community and other professionals and have been adopted as the instruments of choice by many researchers and clinicians worldwide who are interested in the field of study of autism. It is for a combination of the above-mentioned reasons that the Cambridge Behaviour Scale (EQ) was adopted as the instrument of choice to measure empathy in this study’s populations. Unfortunately, the factor structure of the EQ requires further study to be determined. Currently, the EQ reveals a three-factor structure, cognitive empathy, emotional reactivity and social skills (Lawrence, Shaw, Baker, Baron-Cohen, & David, 2004), and therefore cannot determine an individual’s cognitive empathy and affective or emotional empathy scores.

1.4 Research Hypotheses

Given the exploratory nature of this study, formal hypotheses were not formed; however, two expectations seem plausible, based on the literature that informed this study. First, that the life satisfaction of NT women would be different from the control and normative groups; and second, that the empathy quotient (EQ) of NT women would be different from the control and normative groups.
Chapter 2: Systematic Review

2.1 Background to the Review

A version of this chapter has been published in the *Journal of Relationships Research*, November 2012 (Bostock-Ling, Cumming, & Bundy, 2012). Due to publication page limits, the published review was significantly truncated and some detail lost. Therefore, the longer form of the review is presented here, with the published manuscript reproduced as Appendix A.

Data collection for this systematic review on the topic area ‘Life satisfaction of neurotypical women in intimate relationship with an Asperger syndrome partner’ was run twice due to recognised deficiencies noted within the first draft report. The data for the first systematic review draft report was captured on July 6–8, 2010 and subsequently analysed and finalised into the first draft report on October 27, 2010. The data for the second review was captured on April 7–8, 2011 and subsequently analysed and developed into the second draft report form in August, 2011. The searches were updated again in October 2014 in preparation for inclusion in the thesis document. Data captured from the October 2014 search update identified 62 articles for potential inclusion. Perusal of these 62 articles concluded that none of those articles met the criteria for inclusion based on their study focus, population samples and methodologies; therefore, no further articles were added to the review.

2.1.1 This review is pertinent to the research questions

1. What is the quality of the evidence regarding the nature and impact of AS symptom expression on an NT partner within the context of an intimate partner relationship?

2. What is known about recommended interventions for NT women in intimate partnership with a person who has AS?

2.2 Methods

2.2.1 Article selection

All peer-reviewed journal articles theses that investigated relationships between adult couples where one partner had AS and the other partner did not were identified using the search strategy outlined below (Table 1).
Unpublished articles, opinion pieces, books and other non-peer reviewed/non-scholarly works (e.g., internet pages, commercial publications) were excluded (Table 2).

**Table 1: Final Inclusion Criteria**

<table>
<thead>
<tr>
<th>Types of studies</th>
<th>Types of participants</th>
<th>Types of interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>All journal articles and theses.</td>
<td>Neurotypical (non-AS) adults who have been in or who are in an intimate/romantic relationship with a partner who has, or is suspected of having AS. Acceptable diagnostic criteria for AS will include suspected by spouse, partner or other relative; clinical/expert opinion; reviewer opinion; formal diagnosis and/or a score derived from the administration of the Autism-Spectrum Quotient alone (Baron-Cohen 2001).</td>
<td>All types of interventions or analyses.</td>
</tr>
</tbody>
</table>

**Table 2: Final Exclusion Criteria**

<table>
<thead>
<tr>
<th>Type of studies</th>
<th>Type of participants</th>
<th>Types of interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Books, non-scholarly works (i.e., commercial print publications; internet forums/opinions; newspaper articles); scholarly but nonpeer-reviewed works.</td>
<td>Children only (i.e., not adults or parents); Participants with autism only (i.e., where no participants were neurotypical); Where participants were not in, or had not been in an intimate/romantic relationship with an Asperger-affected partner.</td>
<td>Nil excluded.</td>
</tr>
</tbody>
</table>
2.2.2 Search terms

**Keyword search (any field):** (Asperger* or Autism or Autistic* or HFA) AND (Partner* or de facto or married or marital or marriage or couple* or husband* or wife or wives or spouse* or intimate or intimacy or spousal or fiancé or lover).

2.2.3 Search methods

Electronic searches were performed on April 7–8, 2011, and October 14, 2014 using a number of electronic databases using search terms (Asperger or Autism or Autistic or HFA) AND (Partner or de facto or married or marital or marriage or couple or husband or wife or wives or spouse or intimate or spousal or fiancé or lover).

**Duplicate search.** A review of the references returned from each of the database searches was conducted looking for duplicate references. The searches were conducted by the first and second reviewer both by manual means and also using the duplicate search functions within Endnote. This additional step in the process (a manual review) was undertaken because the Endnote program does not pick up all duplicates. This was confirmed by the manual review. For example, Endnote identified 988 references as possible duplicates, whereas the manual check by the reviewers identified 1,384 actual duplicate references. Differences between the results of each reviewer’s duplicate searches were then reviewed by discussion and comparison and consensus was reached on the final result. References thus identified as duplicates were discarded.

**Titles search.** Titles of all references were then reviewed independently by each reviewer for inclusion. References were discarded if it was deemed to be of no relevance for the present review. References thus discarded by each reviewer were then compared. Where both reviewers had discarded a reference, it remained discarded. Where only one reviewer had discarded a reference, it was placed back into the remaining references for further assessment.

**Abstracts search.** All abstracts from the included titles list were reviewed independently by each reviewer. Where there was no abstract available, the reference was not discarded. If it was deemed that the abstract indicated there was no chance of the article containing information for inclusion in the present review, it was discarded. Criteria for inclusion and exclusion were adopted for this process (see Tables 1 and 2). Abstracts discarded by both reviewers were then compared. Where both reviewers had discarded an abstract, it remained discarded. Abstracts that were discarded by one reviewer but not the other were then reviewed by both reviewers.
together and reassessed against the inclusion and exclusion criteria until a consensus was reached between them. If consensus could not be reached then the abstract was included for further review by full article.

2.2.4 Full article review

All articles were reviewed independently by each reviewer. If it was deemed that the article did not meet the inclusion criteria for the study it was then discarded. Articles discarded by both reviewers were then compared. Where both reviewers had discarded an article, it remained discarded. Articles that were discarded by one reviewer but not the other were then reviewed by both reviewers together with reference to the inclusion and exclusion criteria (Tables 1 and 2) until a consensus was reached. Where no consensus could be reached on the inclusion or exclusion of an article, then the article was retained for inclusion.

2.2.5 Reference list search

The references cited in the reference lists/bibliographies for each of the articles that were included after review of the full article were then subjected to the above methodology and screened for inclusion in the review.

2.2.6 Assessment and evaluation of the evidence

The NHMRC is the recognised peak national government body with responsibility to oversee, guide, fund and inform public health policy within Australia. The NHMRC produces guidelines for evaluating evidence and developing clinical practice guidelines for Australian researchers, practitioners, academics and other relevant parties. The guide has been adopted as protocol for evidence reports by the Australian Psychological Society and as such was deemed a reliable and valid document to inform and guide evaluation of the evidence for this review (Australian Psychological Society Ltd, 2010). A comprehensive list of guiding documents is available to the public through the NHMRC website (http://www.nhmrc.gov.au/). A copy of the NHMRC Body of Evidence Matrix drawn from the NHMRC guiding documents and used to assess and evaluate the results from this review provided in Appendix B.

2.2.7 Results

There were 3,120 references returned in the search (Table 3). Of these, 1,384 were duplicates and were discarded, leaving 1,736 references remaining.
### Table 3: Final Search Results

<table>
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<tr>
<th>Date</th>
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<th>Number of responses</th>
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<tbody>
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<td>07/04/2011</td>
<td>Ageline (viaOvidSP)</td>
<td>6</td>
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<tr>
<td></td>
<td>All EBM Reviews (via OvidSP)</td>
<td>16</td>
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<tr>
<td></td>
<td>AMED (via OvidSP)</td>
<td>25</td>
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<td></td>
<td>Australian Indigenous HealthInfoNet (Not a search engine)</td>
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<tr>
<td></td>
<td>Biomed Central</td>
<td>193</td>
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<td></td>
<td>Cinahl (via EBSCO)</td>
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<td></td>
<td>Embase</td>
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<td>Expanded Academic ASAP</td>
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<tr>
<td></td>
<td>Family and Society Studies Worldwide (via EBSCO)</td>
<td>205</td>
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Reviewer 1 found 1,020 titles to be discarded, and reviewer 2 found 1,044 to be discarded. A joint review by both reviewers of both sets of results resulted in 857 titles finally chosen to be discarded. This left 879 references to be searched by abstract.

Reviewer 1 found 786 references to be discarded by abstract, and reviewer 2 found 785 to be discarded. Of these, consensus was reached to discard 773 of these references, leaving 106 to be reviewed by the full article.

Of the 106 remaining articles, the following list of six theses could not be sourced in full.


2. Ebert, R. R. (1986). Stress and social support in the lives of mothers of handicapped and


Additionally, the following four foreign language articles could not be sourced in English language versions despite considerable effort.


The following article could not be obtained, and therefore was not included:


The following two articles were also not included:


The abstract for this article was a conference abstract that contained information on partners of participants with AS. However, the full journal article, using much of the information contained in the conference abstract, did not contain information on partners of participants with AS. The first author (Hoekstra) was contacted, and she confirmed that she had not published any material that would be relevant to this study review.


This was also an abstract from a conference presentation where no full article could be located. Ms Lieberman was contacted and she advised that she had made no reference to either parent being on the spectrum in her paper or in any other published work.

Eighty-four articles were excluded after a full article review of the 93 articles was conducted by both reviewers and the results compared and discussed. This left nine references that met the inclusion criteria.

The reference lists from these final nine articles contained 531 references. Following the same process for inclusion and exclusion previously outlined, of these 531 references, duplicates and books were excluded, along with those excluded by title or abstract, and those that had already been obtained and reviewed in the previous processes. Three articles were excluded under the exclusion criteria of ‘foreign language’ articles. These articles were all by Ewa Pisula:


Notwithstanding the above, as Professor Ewa Pisula has published in English language journals (e.g., *JIDR*), Professor Pisula was contacted requesting information on the availability of
English version copies of the first two of the three articles listed above. Professor Pisula reported that the papers were not available in the English language and that one was a book. Professor Pisula provided three articles published in English that she thought may assist. One article had already been sourced and the other two were not relevant to NT-AS relationship studies.

Of the remaining 528 articles from the final 9 full articles’ reference lists, only one, Ghaziuddin (1997) was agreed by both reviewers to have met the inclusion criteria. The Ghaziuddin article’s reference list of 21 references was then searched, using the same process as previously outlined. Finally, no references from this reference list of 21 articles met the criteria for a full article review. This brought the final short list of studies that met the final inclusion criteria to 10 (Table 4). 

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3 The reference lists from the final 10 full articles (Table 4) totalled 552. These lists were printed and the printed copies were hand screened by each reviewer for inclusion and marked off accordingly in pen on the printed copy (i.e., if the article was excluded on title it was marked ‘TI’, on Abstract marked ‘AB’, on Book marked ‘Book’). Those references that were obtained already through the initial database search were marked ‘Done’ and those with the ‘first author name circled’ were retained for full article review. This search resulted in 25 articles that met the criteria in this phase of the study for a full article review. A reference list of these 25 full articles is attached. (Att: 5 Reference lists final 25 for full article review) and in the interests of transparency the printed copies of the handsearched reference lists containing the 552 references is also attached (Att 6: Scanned in copies of the reference lists from the 10 final full articles ).
Table 4: References to the 10 Studies Which Met Final Inclusion Criteria

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2.2.8 Characteristics of included studies


**Article type:** Clinical opinion.

**Study focus:** How would you know if one partner of a couple sitting in front of you suffered from Asperger syndrome? (p. 10).

**Methodology:**

**Study design:** N/A.
Participants: Setting: Not reported. Cultural setting: Not reported.
Participants: NT females and AS Males – not clearly described. Inclusion criteria: NT females and AS Males. Exclusion criteria: Not stated.
Interventions: N/A.
Instruments: N/A.
AS diagnosis: Not described.
Data analysis: Not described.

Results relevant to the present study questions. Aston (2013) reports that NT partners:

may appear quite desperate and frustrated by the difficulties and strain that the relationship has placed upon her and say things which include: ‘He can’t talk about his feelings … he treats me like an object … he is obsessed by routine … he constantly accuses me of criticizing him … I think I am going mad’. The NT partner may also be saying that she has brought the children up alone and with no input from their father. It is possible that she will have taken all the responsibility for the running of the home, the finances and any social arrangements. She may say this because she cannot trust him to do anything for her.

Aston also says that if one of the partners in a relationship has AS then that partner will be unable to give or even understand the need for the basic key ingredients fundamental to maintaining a relationship in a workable and functional state: communication and emotional reciprocity.

Intervention outcomes: Not applicable in light of non-peer-reviewed material.

Study bias: Neither scientific methodology nor peer review.

2. Eisenberg, L. (1957)

Article type: journal.

Study focus: This study of the fathers of autistic children was undertaken in an effort to contribute to a broader view of the family dynamics related to the personality development of the child. Special emphasis has been placed on those personality characteristics which involve the ability to form meaningful relationships with other people and which influence marital and parent-child configurations (p. 715).

Methodology:
Study design: Retrospective Descriptive Case Series Level IV (referred to by the author as ‘illustrative vignettes’).
Setting: Not stated.

Cultural setting: Baltimore, Maryland, USA.

Participants: One hundred fathers of autistic children were studied. Three cases were reported in this article.

Inclusion criteria: ‘They exemplify in a heightened and dramatic but nonetheless typical fashion, the features evident in 85 out of the 100 fathers in this series’ (p. 717).

Exclusion criteria: Not stated.

Comparison group: 50 private patients (fathers).

Intervention: Nil.

Instruments: Nil.

AS diagnosis: The results reported are based on a careful review of the material recorded in the case histories about family structure. The case histories were considered to be ‘fairly complete’ and suitable for retrospective evaluation (p 716).

Data analysis: Qualitative.

Relevant results:

Case 1: Descriptions of the NT wife included:
insecure, frightened by his cold and unaffectionate manner, and unable to express her overwhelming resentment, she grew less and less able to bring any matters to his attention. She was intelligent and attractive when they married; she became progressively more of a slave to the household and presented an incongruous appearance for the wife of a leading professional man (a surgeon). Mrs R’s account of her marital situation was indeed pathetic. Her husband had no apparent need for social life himself. As for her friends, ‘he doesn’t care for them. They talk too much’. He displayed affection neither toward her nor the children and had succeeded in isolating her from any possible satisfactions outside of her immediate family.

Case 2:

Her husband, according to her description, rarely showed any affection or even awareness of her presence, except in bed, when he would on occasion arouse from his lethargy, make love in an inept fashion, and roll over to sleep, leaving her unfulfilled and resentful. She became increasingly dissatisfied with her marriage, which compared unfavourably with her sister’s…. Her attempt to create a social life resulted only in annoyance on

---

4 Dr Leon Eisenberg, who conducted some of the first rigorous studies of autism, attention deficit disorder and learning delays and became a prominent advocate for children struggling with disabilities, died on Sept. 15 (2009) at his home in Cambridge, Massachusetts. He was 87. The field of child psychiatry was dominated by Freudian psychoanalysis when, in the late 1950s and 1960s, Dr Eisenberg began conducting medical studies of children with developmental problems. Working at Johns Hopkins University with Dr Leo Kanner, who first described autistic behaviour, Dr Eisenberg completed the first detailed, long-term study of children with autism, demonstrating among other things that language problems predicted its severity (Carey, 2009).
his part and frustration for the invited guests, who rarely returned. His wife was herself a very troubled woman. It is perhaps true as well that only such a person as she would have considered marrying Mr S. But such consideration should not be allowed to obscure the destructive effect on the family of his ineffectualness as father and husband.

Case 3: This account is from the husband only and does not include the wife’s comments so it is excluded from comment. The author does report:

They are no less inadequate as husbands than they are as fathers. Work takes precedence over family life. Marriage seems mostly a convenient arrangement for meals and laundry. Efforts to make day-to-day family decisions a matter for joint concern are resented as unwarranted intrusions upon an evening’s reading. At home, as well as elsewhere, they exhibit a remarkable lack of empathy for and sensitivity to the feelings of others. (p. 722)

Control group: These men were found to have a level of education and professional attainment measurably lower than the study cases; however, Eisenberg noted that the absence of the ‘coldly mechanical attitude toward child rearing and the formalistic approach to marriage so widespread in the autistic group, was striking’ (p. 722). And, in 15 of the 100 members of the case series, the usual pattern was not evident at all. They were described as warm, giving and devoted (p. 722).

Intervention outcomes: N/A.

Study bias:

Note: Eisenberg’s paper was written in 1957 when the predominant opinion held that autism should be properly classified as among the group of childhood schizophrenias; in his introduction, Eisenberg wrote: ‘If this nosologic allocation be granted then early infantile autism is the earliest of the schizophrenic reactions known to occur in man, being evident usually within the first and certainly by the second year of life’ (p. 715). Eisenberg’s article reflected the dominant opinion of the day (though he appears to be open to alternative views) and this opinion is evident in his following reference to work by Lidz, Parker, and Cornelison (1956): ‘based on extensive interviews supplemented by psychological tests (Lidz et al.) concludes that these fathers (of 16 middle-class schizophrenic patients) “exerted seriously pathogenic influences upon the family structure and upon the rearing of children”. And, in their experience there was no single pattern of behaviour common to all’ (p. 723). Eisenberg continues:

Our own observations underscore the insightful comment by the Yale group that the personality difficulties of the fathers of schizophrenic patients
contribute greatly to the disharmonies and eccentricities of the families in which the patients grow up. Some would have made it difficult for any mother to fill her role adequately. The material also emphasizes the need to recognize that the mother can be seriously influenced in her mothering by her spouse (p. 723).


**Article type:** Journal.

**Study focus:**
In the present report, we describe three additional cases of autism with Down syndrome (DS). In all these cases, at least one of the parents had a history resembling the broader phenotype of autism (mild autistic traits without meeting the full criteria for that disorder). We propose that autism-specific genetic factors may be important, even when autism coexists with other disorders such as DS. (p. 88).

**Methodology:**

*Study design:* Case Series Interviews Level IV.

*Participants:* Three Down syndrome (two adults – one male, one female and one 17-year-old male) and their biological parents.

*Setting:* Not reported.

*Cultural setting:* Ann Arbor, Michigan, USA.

*Interventions:* N/A.

*Instruments:* Family History Schedule (Bolton et al., 1994); AS Diagnosis Family History Schedule (Bolton et al., 1994) plus clinical interview.

*Data analysis:* Qualitative.

**Relevant results:**
One wife (GA’s parent) reported that the main reason for her divorce was her husband’s ‘isolative and eccentric tendencies’ (p. 89); SK’s mother reported (of her husband) that ‘she thought of him as a shy man with difficulty in initiating and maintaining conversation in social settings’ (p. 88).

**Intervention outcomes:** N/A

**Study bias:** Interview data was reliant upon the memory of the mother/female spouse only; no collateral informant’s accounts were sought or recorded; two fathers were not interviewed; historical account of one father’s behaviour was obtained from spouse report only where the
couple was divorced at time of interview. Study reported on characteristics of parents rather than the impact of these characteristics on the (other) spouse.


Article type: Journal

Study focus: This study explored romantic attachment style, marital satisfaction and parenthood satisfaction in 157 Australian men and women. There was a focal group of 22 married adults with a clinically confirmed AS diagnosis whose child also had AS, and three NT adult control groups (p. 392).

Methodology:

Study design: Case-control study Level III-3.
Setting: Not reported.
Cultural setting: Australia.
Participants: 157 Australian men and women aged 29–71 years; all were parents from intact couple relationships where the child was still living at home.
Focal group: 22 married adults with a clinically confirmed AS diagnosis whose child also had AS (7 fathers and 15 mothers).
Control groups: Three neurotypical adult groups: (1) those whose spouse and child had AS (11 participants – 1 father, 10 mothers); (2) those whose child had AS but spouse did not (49 participants – 13 fathers, 36 mothers); and (3) non-clinic group, those with no AS family members (75 participants – 16 fathers, 59 mothers). This group of 75 was matched to each of the three clinical groups by respondent’s age, gender and total number of offspring in their families.

The non-clinic control group was a non-random sample. They were recruited via personal contacts, staff and student email and research participants’ pools at a major university.

The study does not report the recruitment procedure for the three clinical groups (82 participants).

Inclusion criteria: An intact couple relationship (married or cohabiting) that had produced at least one child (aged 3–18 years) who was still living at home. Only one respondent per couple who volunteered was included to maintain the statistical independence of all of the group comparisons.
AS diagnosis of the children was conferred independently of the research by a team of clinicians and at least one medically trained pediatrician or psychiatrist and confirmed by DSM-IV criteria.

**Exclusion criteria:** Control group: suspected or diagnosed ASD or other disorder in any family member.

**Interventions:** N/A.

**Instruments:** Hazan & Shaver’s 1987 seminal vignette instrument, as supplemented by more recently devised dimension scales (e.g. Mickelson, Kessler, & Shaver 1997; to measure Adult Attachment Style).

The Quality Marriage Index (Norton, 1983) or the revised Quality Marriage Index (Norton, 1983) (To measure Marital Satisfaction).

Johnston & Mash (1989; as validated by Rogers & Matthews, 2004) – a nine-item measure of parents’ affective feelings of joy or disappointment with parenthood.

**Data analyses:** Quantitative.

**AS diagnosis:** AS diagnosis of the children was conferred independently of the research by a team of clinicians and at least one medically trained pediatrician or psychiatrist and confirmed by DSM-IV criteria (p. 394). AS diagnosis of the focal subgroup of 22 (Group 1) ‘had received a similar clinically-confirmed diagnosis of AS (as their child) … conferred, independently of this research, (sic) clinicians who used DSM-IV criteria’ (APA, 2000, p. 394).

**Intervention outcomes:** N/A.

**Relevant results:** Lau and Peterson (2011) reported attachment style data on NT partners (nine females and one male) with both a spouse and child with AS as 91% (n = 9) Type B (secure); and 9% (n = 1) as Type A (avoidant). These results are not significantly different to the control group. This same NT group had a higher (though not significant) level of secure attachment style than Group 3 where only a child – not spouse – had AS. There is a gender ratio difference between these groups that makes comparisons difficult. This data does not provide information pertinent to the present study questions.

**Study bias:** Mickelson, Kessler, and Shaver (1997, as cited in Lau & Peterson, 2011, p. 395) studying adult attachment styles, found that females had a higher level of secure attachment compared to males, and they found that childhood adversities of an interpersonal nature were
associated with a lower level of secure attachment and higher levels of anxious or avoidant attachment styles in adults. Additionally, there were higher levels of secure attachment in those who were of a higher SES or higher education level. Mickelson et al. also reported that various types of adult psychopathologies and personality traits were also strongly related to adult attachment (p. 1092). Neither SES, education level, race, religiosity and presence or absence of childhood trauma, or personality variables (e.g., self-esteem, locus of control, neuroticism) were reported as having been explored in this present study, and so cannot be excluded as factors for possible bias.

No details of the recruitment process for the three clinic group participants are reported.

The non-clinic control group of 75 participants was drawn from a non-random sample.

In Lau and Peterson’s (2011) study there was also a difference in the gender ratio between Group 2 (NT spouse) and all the other groups and, although not statistically significant, this combined with the low power of the study (due to the low ‘N’ of the NT Group) means that gender bias cannot be excluded as contributing to bias in these results.

Finally, the instruments used in this study have not been normed for the AS population studied by Lau and Peterson (2011).

Group 1 participants’ precise AS diagnostic details are not reported. They are reported as ‘had received a similar, clinically confirmed diagnosis of AS’.

Lau and Peterson (2011) reported that ‘respondent’s responded anonymously to a set of printed materials’ (p 395). The actual procedure for administration of the ‘printed materials’ is not reported and therefore cannot be reviewed for bias.

Notwithstanding the shortcomings of the study as outlined, data for adult attachment styles may be able to be considered (with appropriate caution) to provide data on NT women. All other data for marital satisfaction and parenthood satisfaction was not stratified for this group, that is, Group 2 (NTs) and was combined with Group 3 (NTs with an AS child) for calculation.


Article type: Thesis – Doctor of Philosophy

Study focus:
To analyse dynamic representational structures by analysing narrative content, linguistic construction, and the quality of the interaction between the co-participants … an exploration of the experience of a group of autistic individuals who seem to have negotiated a pathway to a higher level of relational functioning … inviting their relationship partners to participate. (pp. 15–16)

Methodology:

Study design: Case Series Level IV

Setting: One couple was interviewed in a non-private space in a retail bookshop (a chosen location near the participants’ home). The settings for the individual and other couple interviews were not specifically reported.

Cultural setting: United States.

Participants: Four married couples. One partner of each couple had a diagnosis of high functioning autism (HFA), AS or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) by a licensed evaluator; NTs were one male and three females; all participants’ IQs were within the normal to superior range, from formal and informal assessments; all participants with autism showed sufficient adaptive functioning to live independently and were able to give voluntary and informed consent; all participants had been in a stable marital relationship for at least 12 years. Participants were interviewed individually for 2 hours and together as a couple for 1 hour.

Inclusion criteria: Not specifically stated.

Exclusion criteria: Not specifically stated.

Recruitment: Participants were recruited through research and treatment facilities, and organisations that provide support and advocacy for individual with this type of disability.

Interventions: N/A.

Instruments: Semi-structured interview questions were adapted from a semi-structured interview formulated to elicit spontaneous reflection on personal and interpersonal experience – similar in content to other instruments that have been used to evaluate representations of self and other (e.g., Main, Kaplan, & Cassidy, 1985; Slade & Cohen, 1996), with a less restrictive format. Author asserts that the flexibility such an instrument allows is necessary to accommodate the autistic idiosyncratic ways of using language (p. 88).

AS diagnosis: Diagnosis of high functioning autism (HFA); Asperger syndrome (AS) or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) were performed by a licensed evaluator.

Data analysis: Qualitative. Grounded theory methodology (Glaser & Strauss, 1967; Strauss &
Corbin, 1998, as cited in Parker-Rosenbaum, 2006, p. 91) was used to analyse the content of the individual narratives (p. 91). The author reported that the grounded theory approach was particularly suited to her study because it involved the development of uniquely tailored coded systems (p. 91). The author further asserted that this approach was particularly suited to her study population ‘because most pre-structured methods of analysis have been developed for use with standardized instruments in a neurologically normal population’ (p. 91). The Oral History Interview and Coding System (Beuhlman & Gottman, 1996, as cited in Parker-Rosenbaum, 2006, p. 93) were used to analyse the data from the couple interview.

**Intervention outcomes:** N/A

**Relevant results:** Parker-Rosenbaum (2006): The relevant reports from this study are very difficult to summarise given its methodology. The thesis is qualitative in nature and includes 316 pages of interview data, summary and (qualitative) analysis alone and a further 16 pages of summary qualitative summary analyses. Furthermore, while Parker-Rosenbaum reports to have underpinned her project with grounded theory methodology, her adherence to this methodology is questionable. Partway through the project, Parker-Rosenbaum reports that her second coders withdrew from the project, and it is also noted that only one round of interviews was conducted, where grounded theory methodology entails conducting subsequent interviews after analysis of each set of interview data until no further questions are raised from the data (Boychuk Duchscher & Morgan, 2004; Glaser & Strauss, 1967). Some examples from the study summary include:

NT partners tend to minimize their needs in order to reduce the potential disruption that both partners acknowledge is lurking nearby.

Tom (NT) seems to work hard to convince both himself and his listener that he is satisfied. He holds tight to an image (one of questionable realism) of his ‘potential’ in his efforts to maintain a positive sense of self. In linking this idea to his relationship with Susan (AS) he seems able to tentatively face the possibility that he will fail to fulfil his dreams.

She (AS) seems to be a catalyst for Tom’s painful self-evaluation and healthy validation.

She (AS) is not shy in letting me (NT) know what she thinks I need … can feel intrusive at times … when we first got married I thought anything was possible … needless to say I’ve been forced to come down to reality … it can be tough at times … a point of conflict between her and me.

There’s a part of it that feels very comforting and feels like I’m being loved and supported and there’s another part that wishes it would just go away and leave me alone (NT partner).
Tom (NT) seems to feel that the negative feedback he tolerates and submissive stance he must assume, are a reasonable trade-off for the narcissistic gratification (as the good enough child) he receives along with his security and trust in the relationship.

The following two excerpts from Parker-Rosenbaum’s thesis capture information relevant to the present study’s review question:

Two (NT) women who characterize themselves as altruistic (Clarissa and Barbara), and find that they must accommodate their partners’ infantile needs and relinquish any hope of being nurtured themselves, are in the least satisfying relationships. Their autistic husbands, in turn, have organized their relational strivings around the need to sustain attachments that keep the desired object in proximity, but not with the mature aim of reciprocating her empathic and nurturing feelings and behaviours.

To be sure, the other two couples struggle with the apportioning of relationship responsibilities, and Susan and Dave (both AS) retain many child-like vulnerabilities, but their relational drives encompass a view of themselves and their (respective NT) partners as linked by a shared affective experience and mutual responsibility to respond to one another’s emotional needs. The degree to which they can represent and aspire to this relational concept, and tolerate awareness of their partner’s affective states, seems almost more important than their actual behaviour toward one another, in creating a positive sense of themselves and their partners in a reciprocal bond (p. 458).

**Study bias:** Small sample size; qualitative analysis only; comorbid disorders in NT and AS participants; some participants were engaging in counselling; participants or their spouses were not matched for developmental disorder severity or type, SES status, personality characteristics (e.g., self-esteem, neurosis) or mood disorders; questionnaire not normed on target group; no second coder was employed to check objectivity of the author; grounded theory methodology principles were not adhered to.

**Notes:** Notwithstanding the many limitations of this article in its offerings to the scientific community, it does provide material that promotes opportunity for the researcher to reflect on the merits of the qualitative process and, in particular, the phenomenological approach, and the rich data that can flow from such an ambitious undertaking. The author does offer her own insights into the significant limitations of the study in terms of its offerings to the scientific community.

**Pisula, E. (2003).**

**Article type:** Journal.
Study focus: Three study areas were examined: (1) genetic determination of the predisposition to autism; (2) parental stress and the parents’ experiences connected with raising the child with autism; (3) studies on the parents’ involvement in the child’s therapy.

Methodology:
Study design: Review of current research – not classifiable under NHMRC Levels of Evidence.
Participants:
AS diagnosis: N/A.
Interventions: N/A.
Instruments: N/A.
Data analysis: N/A.
Intervention outcomes: N/A.

Relevant results: There were no data in this article relevant to the present study.

Study bias: Review was not a systematic review and only captured studies ‘mainly done in the 1990s’.


Article type: Journal.

Study focus: This study investigated possible mechanisms to explain whether and how autistic traits, measured with the AQ, influence relationship satisfaction in a non-clinical sample of 195 married couples (Pollmann et al., 2010, p. 470). It was hypothesised that individuals with more autistic traits are less satisfied with their relationship than individuals with fewer autistic traits (Pollmann et al., 2010, p. 471).

Methodology:
Study design: Cross-sectional Level IV.
Setting: Not stated.
Participants: Non-clinical sample of 195 of 199 original newlywed couples who participated in the second wave of a longitudinal study (SIPA) approximately 10 months after they had married. Husbands’ mean age was 33.05 years (SD = 4.86) and wives’ mean age was 30.11 years (SD = 4.25). Couples had been romantically involved for average of 6.88 years (SD = 3.10) and had been living together for an average of 4.62 years (SD = 2.26).
Cultural setting: The Netherlands.

Inclusion criteria: First (only) marriage; no children from any relationship including current marriage; aged between 25 and 40 years.\(^5\)

Exclusion criteria: Not stated.

AS diagnosis: AQ-short was used to measure autistic traits in the participants.

Interventions: N/A.

Instruments: A Dutch abridged version of the Autism Spectrum Quotient (AQ; Baron-Cohen et al. 2001; Dyadic Adjustment Scale (DAS; Spanier, 1976); Rosenberg Self-Esteem Questionnaire (Rosenberg, 1965); Experiences in Close Relationships Questionnaire (Brennan, Clark, & Shaver, 1998); Relationship-Specific Self-Disclosure Scale (Finkenauer, Engels, Branje, & Meeus, 2004); Responsiveness Scale (Birnbaum & Reis, 2006); Perceived Relationship Quality Components (Intimacy subscale; Fletcher, Simpson, & Thomas, 2000); The Trust Scale (Rempel & Holmes, 1986).

Data analysis: Quantitative.

Intervention outcomes: N/A.

Relevant results: Husbands reported more autistic traits than wives. There was no significant correlation between the relationship satisfaction of the participant and the AQ score of their spouse for either men or women … thus, partners of both men and women with more autistic traits do not report lower relationship satisfaction than partners of people with fewer autistic traits; AQ scores for men only correlated with their own relationship satisfaction, and multiple mediator analysis showed that this effect was explained through lower scores on the scales for responsiveness, intimacy and partner-specific trust. Husbands who report more autistic traits are less satisfied with their relationship than husbands with fewer autistic traits; wives with more autistic traits are not less satisfied with their relationship than wives with fewer autistic traits. More autistic traits among men seem to hamper relationship-specific behaviour and feelings, which in turn reduce their relationship satisfaction.

Study bias:

Culture: The study participants were predominantly Dutch (98.5% of the husbands and 96.4% of the wives). The couples had never had children. The couples were all in their first and only marriage. Couples had only been married for 10 months and had only been romantically involved (on average) for 6.8 years and living together for an average of 4.62 years. The AQ

\(^5\) This information was drawn from a study cited by Pollmann & Finkenauer (2009), which details the Search for Inter-Personal Accuracy Project (SIPA; Finkenauer, 2006).
short was the only measure used to assess for autistic traits.

Notes: Pollmann et al. stated that their paper was the first to investigate the link between relationship satisfaction and autistic traits in a non-clinical sample. Given the cross-sectional study design, causal relations between variables could not be determined.

Noteworthy are Pollmann et al.’s comments:

The finding that partners of people with more autistic traits did not report lower relationship satisfaction than partners of people with fewer autistic traits is inconsistent with research using clinical samples ... it is possible that wives simply perceive husbands with higher scores on the AQ (but still non-clinical) as being 'typical male’ (p. 476); and maybe autistic traits only have a noticeable impact on the relationship if they reach clinical levels. (p. 475)


Article type: Journal.

Study focus: The study focused on the predictive value of stressor severity, received and perceived social support, and coping strategies for individual and marital adaptation as perceived by adult men with ASD and their spouses. It was hypothesised that better individual and marital adaptation would be positively related to the level of informal and formal social support and the use of problem-focused coping strategies and inversely related to autism-specific traits and the use of avoidant coping strategies (p. 1247).

Methodology:

Study design: Cross-sectional Level IV.

Participants: Twenty-one couples recruited through ASD advocacy group newsletter and a newsletter of the Flemish user organisation for ASD.

Setting: Not reported.

Cultural setting: Belgium.

Inclusion criteria: Male spouse fulfilled DSM-IV-TR criteria for autism, AS or PDD-NOS; a formal diagnosis of ASD given by a multidisciplinary team of experienced clinicians. Couples had to be married or cohabiting for at least 1 year. Couples had to have at least one child under 18 who resided at home.

Exclusion criteria: Not stated.

AS diagnosis: DSM-IV-TR criteria met and diagnosis by team of multidisciplinary experienced
clinicians.

**Instruments:** AQ (Baron-Cohen et al., 2001; Ponnet, Roeyers, & Buysse, 2001); Social Provisions Scale (SPS) – source specific version; Cutrona & Russell, (1987); Inventory of Social Supportive Behaviors (ISSB) – source specific version (Barrera, Sandler, & Ramsey, 1981); Camberwell Assessment of Need (CAN) – modified version – (Phelan et al., 1995; McCrone et al., 2000); The Ways of Coping Questionnaire (Lazarus & Folkman, 1984); The Symptom Checklist – 90 (SCL-90; Arrindell & Ettema, 1986; Derogatis, 1977).

**Intervention outcomes:** N/A.

**Relevant results:** For NT women, individual adaptation was strongly related to received social support from family, friends and acquaintances, such that women with higher levels of psychosocial distress received more support. Marital adaptation of the women was inversely related to the degree of autism-specific traits of their husband, while perceived and received support from their spouse was positively related to marital adaptation. Marital adaptation of the women was not related to any coping strategy. Formal support variables were associated with neither individual nor marital adaptation in men or women. Social support accounted for a significant amount of the variance (27–89%) in individual and marital adaptation in both spouses after controlling for demographic information and the degree of autism-specific traits (pp. 1250–1251). Male spouses self-reported significantly fewer AS traits than their spouses perceived them to display.

**Study bias:** Small study size lacking statistical power; non-random sample; participants mainly consisted of those with a high level of education and one or more children with an ASD diagnosis; ASD participants were male and non-ASD were female; no matched control group; participants were all drawn from Belgium.

**Notes:** Given the cross-sectional study design causal relations between variables could not be determined.


**Article type:** Journal – Letter to the Editor

**Study focus:**

When autistic children reach adulthood, can they marry, have satisfactory sexual relations, have children, hold regular jobs? While none of our autistic patients has achieved independence in adulthood, it is our impression that
some of their parents had early developmental delays and symptoms throughout adulthood pathognomonic of autism (p. 139).

Methodology:

Study design: Case Series Level IV.

Setting: N/A. Data was drawn from the authors’ multiple incidence study and epidemiologic survey details of which were not included nor referenced in this article.

Cultural setting: United States.

Participants: 11 possibly autistic parents from 10 families of the author’s autistic patients – 9 males and 2 females: 7 were married; 1 divorced and 1 was in his second marriage. Age range from 38 to 70 years. Four held a degree of BA or higher; three attained high school + 4 years trade school; one achieved high school only; one achieved trade school only; one achieved principal of high school but with no degree status; one where education details not available.

AS diagnosis: DSM-III criteria based on opinion of authors drawn from study of ‘limited’ case notes and spouse reports.

Data analysis: Qualitative.

Intervention: N/A.

Relevant results: Reported comments from NT spouses:

Spouse 1: He definitely has a mild type of autism. No sexual problems, never very interested, mechanical, never with feelings.

Spouse 2: No comments available.

Spouse 3: He is autistic like our children. Always been strange. No sex problems. He learned what he had to do and he did it.

Spouse 4: I think he has autism too.

Spouse 5: He is autistic like our children. Always been strange. No sex problems, not very interested. I have to tell him what to do.

Spouse 6: Not available.

Spouse 7: He knows he is different. Living with him is living alone. He has same problems as my autistic children. No sexual problems but never expresses feelings.

Spouse 8: He was an autistic child himself and had traits similar to our autistic sons.

Spouse 9: Very withdrawn and nonsensical, a serious concern, like an autistic himself.

Spouse 10: Not available.
Spouse 11: No spontaneous social skills, does repetitive activities. Same problems as our kids. Sex drive normal but performed with no feelings, he uses me like an object.

Intervention outcomes: N/A

Study bias: Non-random sample; small sample size; ‘Diagnostic accuracy is woefully inadequate’ (Ritvo et al., 1988, p. 139).

Notes: The authors acknowledge the ‘woefully inadequate diagnostic accuracy’ of the 11 study participants, given they lacked objective early developmental data and relied mainly on mental health status exams. The authors also acknowledge the ‘highly suspect sources’ of their information being the spouses’ reports and the ‘autistic parent reports where memory, cognitive and recall problems are acknowledged’.


Article type: Masters of Science in Psychology thesis.

Study focus: Assessment of the relationship behaviour expectations of the three different relationship types. Five hypotheses were put forward:

H1: Both individuals in a relationship, whether it is a close friendship or a romantic relationship, will perceive their partners as having levels of specific characteristics, such as social skills and communication abilities that are similar to the levels they perceive themselves as having.

H2: Individuals will hold lower expectations for their relationship when their perceptions are that they and their relationship partner are higher in AD symptoms.

H3: If individuals are mismatched on levels of self-perceived AD symptoms, they will also be mismatched in their levels of expectations for one another.

H4: Individuals will have higher expectations for their romantic partners than for their same-sex or cross-sex friends and also have higher expectations for their cross-sex friends as opposed to their same-sex friend, regardless of their level of AD characteristics.

H5: Participants will rate their romantic partners more positive than their close same-sex and close cross-sex friends on Asperger’s traits.
Methodology:

Study design: Case Series Level IV.

Setting: University.

Cultural setting: San Antonio, Texas, United States.

Participants: Non-clinical population of 152 university students enrolled in an Introduction to Psychology course at the University of Texas at San Antonio: 77 males and 75 females; mean age of 19.56 years; either Hispanic-American or Anglo-American ethnicities.

Inclusion criteria: Currently in a romantic relationship; between the ages of 18 and 25 years of age; enrolled in an Introduction to Psychology course at the university; of Hispanic-American or Anglo-American ethnicities.

Exclusion criteria: Not stated.

AS diagnosis: AQ (Baron-Cohen et al., 2001) as a self and partner report instrument

Instruments: AQ (Baron-Cohen et al., 2001); Expectations Scale (Fuhrman, Flannagan, & Matamoras, 2009).

Data analysis: Quantitative.

Intervention: N/A.

Relevant results: Individuals who had lower levels of Asperger’s symptoms had higher expectations for their relationship partner (M = 3.86) and individuals who had higher levels of Asperger’s symptoms had lower expectations for their relationship partner (M = 3.63). However, all couples had significantly higher expectations for emotional closeness and social companionship of their romantic partner than for their same or cross-sex partner.

Of the five Asperger traits measured (social skills level, attention to detail level, communication level, imagination level and attention switching level) those individuals who scored high on AS traits of poor social skills and poor attention switching had lower expectation ratings for emotional closeness, while individuals who rated themselves high on the AS trait of poor attention switching only held lower expectations for social companionship only. Individuals who rated themselves high on the AS traits of both poor attention switching and poor imagination held lower expectations for relationship positivity. The AS traits of extreme attention to detail and poor communication were not related to any relationship expectations.

Vaughn also found an association between participants’ ratings about their own and their close relationship partner’s levels of Asperger’s characteristics, with significant positive correlations between four of the five rated AS characteristics and the fifth subscale (attention switching).
approaching significance.

Vaughn found partial support for H3, which states that individuals will hold lower expectations for their relationship when their perceptions are that they and their relationship partner are higher in AD symptoms.

Mismatching: Partners who were mismatched on their AS ratings of attention to detail were also mismatched on their levels of expectation for emotional closeness; individuals who were mismatched on their levels of expectation for social companionship were mismatched on both AS traits of attention to detail and imagination; and partners who were mismatched on their levels of expectation for relationship positivity were also mismatched on their AS trait of attention switching.

Vaughn found no support for H5.

**Intervention outcomes:** N/A.

**Study bias:** AQ scores were the only measurement for Asperger characteristics. The author does not reveal the AQ score range or detail the ‘median split’, therefore one cannot ascertain the degree of AS traits present in the ‘high AQ scoring group’.

**Non-clinical sample:** Partners only had to be in a romantic relationship for 3 months and the relationship did not have to be a live-in relationship.

### 2.3 Results

The results for Questions 1 and 2 are displayed within the Body of Evidence Matrix, shown in Tables 5 and 6.

#### 2.3.1 Research question 1

What is the nature and impact of AS symptom expression on a NT partner within the context of an intimate partner relationship?
**Table 5: Body of Evidence Assessment Matrix**

<table>
<thead>
<tr>
<th>Component</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Excellent</td>
<td>Good</td>
<td>Satisfactory</td>
<td>Poor</td>
</tr>
<tr>
<td>Volume of evidence</td>
<td>Several level I or level II studies with low risk of bias</td>
<td>One or two level II studies with low risk of bias or aSR/multiple Level III studies with low risk of bias</td>
<td>Level III studies with low risk of bias, or level I or II studies with moderate risk of bias</td>
<td>Level IV studies or level I to III studies with high risk of bias</td>
</tr>
<tr>
<td>Consistency</td>
<td>All studies consistent</td>
<td>Most studies consistent and inconsistency may be explained</td>
<td>Some inconsistency reflecting genuine uncertainty around clinical question</td>
<td>Evidence is inconsistent</td>
</tr>
<tr>
<td>Clinical impact</td>
<td>Very large</td>
<td>Substantial</td>
<td>Moderate</td>
<td>Slight or restricted</td>
</tr>
<tr>
<td>Generalisability</td>
<td>Population/s studied in the body of evidence are the same as the target population for the guideline</td>
<td>Population/s studied in the body of evidence are similar to the target population for the guideline</td>
<td>Population/s studied in body of evidence different to target population for guideline but it is clinically sensible to apply this evidence to target population**</td>
<td>Population/s studied in body of evidence different to target population and hard to judge whether it is sensible to generalise to target population</td>
</tr>
<tr>
<td>Applicability</td>
<td>Directly applicable to Australian healthcare context</td>
<td>Applicable to Australian healthcare context with few caveats</td>
<td>Probably applicable to Australian healthcare context with some caveats</td>
<td>Not applicable to Australian healthcare context</td>
</tr>
</tbody>
</table>

Source: *National Health and Medical Research Council Handbook* (NHMRC, 2000, p. 12). Bold type indicates overall results. **For example, results in adults that are clinically sensible to apply to children or psychosocial outcomes for one cancer that may be applicable to patients with another cancer.

### 2.3.2 Research question 2

What are the recommended interventions for a NT women in intimate partnership with a person who has AS? None of the studies included for final analyses were intervention studies, hence this question cannot be rated using this assessment matrix.
Table 6: Body of Evidence Assessment Matrix

<table>
<thead>
<tr>
<th>Component</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
<tr>
<td>Volume of evidence</td>
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<td>One or two level II studies with low risk of bias or aSR/multiple Level III studies with low risk of bias</td>
<td>Level III studies with low risk of bias, or level I or II studies with moderate risk of bias</td>
<td>Level IV studies or level I to III studies with high risk of bias</td>
</tr>
<tr>
<td>Consistency</td>
<td>All studies consistent</td>
<td>Most studies consistent and inconsistency may be explained</td>
<td>Some inconsistency reflecting genuine uncertainty around clinical question</td>
<td>Evidence is inconsistent</td>
</tr>
<tr>
<td>Clinical impact</td>
<td>Very large</td>
<td>Substantial</td>
<td>Moderate</td>
<td>Slight or restricted</td>
</tr>
<tr>
<td>Generalisability</td>
<td>Population/s studied in the body of evidence are the same as the target population for the guideline</td>
<td>Population/s studied in the body of evidence are similar to the target population for the guideline</td>
<td>Population/s studied in body of evidence different to target population for guideline but it is clinically sensible to apply this evidence to target population**</td>
<td>Population/s studied in body of evidence different to target population and hard to judge whether it is sensible to generalise to target population</td>
</tr>
<tr>
<td>Applicability</td>
<td>Directly applicable to Australian healthcare context</td>
<td>Applicable to Australian healthcare context with few caveats</td>
<td>Probably applicable to Australian healthcare context with some caveats</td>
<td>Not applicable to Australian healthcare context</td>
</tr>
</tbody>
</table>


2.4 Conclusion

The objective of this review was to investigate the quality of the findings in the scholarly peer-reviewed literature on the problems experienced by NT women in intimate relationship with an AS partner, the health and wellbeing implications of those experiences, and any treatment recommendations. The rationale for this review developed from preliminary investigations into the literature base underpinning the recommended diagnostic and practice interventions for NT women in the NT-AS intimate relationship context. The preliminary review revealed a plethora
of anecdotal and scholarly literature in both commercial print and electronic media form, but a
dearth of scholarly, peer-reviewed literature. Scholarly, peer-reviewed literature provides an
esential contribution to the development of best practice models for diagnostic and treatment
interventions and underpins the formation of national health policies in this regard.

2.4.1 Assessment and evaluation of the evidence

The National Health and Medical Research Council (NHMRC) is the recognised peak national
government body with responsibility to oversee, guide, develop, fund and inform public health
policy within Australia. The NHMRC produces guidelines for the evaluation and development
of clinical practice guidelines for Australian researchers, practitioners, academics and other
relevant parties (NHMRC, 2000). The guide has been adopted as protocol for evidence reports
by the Australian Psychological Society (2010) inter alia, and as such was deemed a reliable
and valid document to inform and guide evaluation of the evidence for this review.

Ten studies were agreed by both reviewers to have met the final inclusion criteria. Using
NHMRC Levels of Evidence and grading guidelines, the studies were assessed and the body
of evidence graded.

Two specific questions were formulated to lead this enquiry:

1. What is the nature and impact of AS symptom expression on a NT partner within the context
   of an intimate partner relationship?

2. What are the recommended interventions for NT women in intimate partnership with a
   person who has AS?

The body of evidence examined for this review will be discussed within the context of each of
these study questions.

Question 1. The studies included in this review do not provide robust, scholarly, peer-reviewed
evidence for the nature and impact of AS symptom expression on a NT partner within the
context of an intimate partner relationship. There is insufficient quality evidence to support any
conclusion regarding.

Seven of the studies met level IV criteria; one met level III criteria and two studies did not meet
any of the criteria (one clinical opinion and one review of current research on parents – not a
systematic review).
The body of evidence was assessed to be Grade D or poor, as was the clinical impact and generalisability. Consistency and applicability of the body of evidence was assessed to be Grade C, which is satisfactory.

Although these studies did provide some data on the NT partner’s experience, the studies generally focused on the AS partner in parental/marital/intimate relationship, and not on the NT partner. This focus may go some way toward explaining the quality of the data on the NT partner being insufficiently robust to answer the present study question. Question 1 remains unanswered when assessed within the guidelines provided by the NHMRC and appropriately adopted to assess the quality of the evidence for this project.

**Question 2:** None of the studies included for final analyses were intervention studies, therefore the studies included in this review do not provide scholarly peer-reviewed evidence for recommended interventions for NT women in intimate partnership with a person who has AS. This review concludes that there is no evidence regarding interventions for NT people in NT-AS dyads.
Chapter 3: Empirical Study – Introduction and Methodological Approach

3.1 Introduction

This empirical study conducting an exploratory investigation into the life satisfaction of NT women in intimate relationship with a partner who has AS was conducted to achieve the second and third objectives of the project, which were to explore the life satisfaction and empathy of NT women in intimate relationship with a partner who has AS; and to add to the existing body of evidence-based knowledge regarding the life satisfaction of NT women in relationship with a partner who has AS. There were three research questions formulated to lead this enquiry. First, is the life satisfaction of NT women significantly different from that of women who are not in relationship with a partner who has AS? Second, is the empathy of NT women significantly different from that of women not in relationship with a partner who has AS? And third, what are the predictors of life satisfaction for NT women?

3.2 Choice and Justification of Methods

This section begins with a statement on Study Design, including the adoption of internet-mediated technology (IMT) for data collection; implications of the claim to use of the mixed methods research (MMR) study design label, and the rationale for the terminology and framework adopted to guide the chapter construction. This is followed by an outline of the three key stages of the research process: (1) research formulation, (2) research planning, and (3) the initial stage of research implementation data collection (Collins, Onwuegbuzie, & Sutton, 2006, p. 71; Leech, 2012, p. 871).

3.2.1 Statement of study design

3.2.1.1 Internet mediated technology. This study employed internet-mediated technologies (IMT) for data collection. The rationale for utilising web technology is well captured by Hess-Biber & Griffin, (2013), where the emergent power of Web 2.0 technology in facilitating access by researchers to study issues ‘within and across disciplines and across the global society as a whole’ is discussed:

There are currently 1.5 billion Internet users, which amounts to 22% of the world’s population. In the United States alone, 77.3% of U.S. households are connected to the Internet (Internet World Statistics, 2010) with a
frequency access rate ranging from weekly to daily contact (Horrigan, 2007, as cited in Hesse-Biber et al., 2013, p. 43).

As part of the preliminary investigations into the study group demographics, it was identified that websites organised by members of the affected population and interested clinicians, among others, were numerous, well organised and were readily accessible; and indeed accessed by affected members of the global populations and other interested parties (e.g., professionals and clinicians). Nip (2004) discusses how social movement organisations have “employed” the internet and through their websites and electronic bulletin boards or other conferencing spaces their users can directly interact with each other. The websites for NT women as partners of people with AS are utilised as social networks, support groups, mobilisation of face-to-face meet-up opportunities, and a place of knowledge building and exchange. Carol Grigg (personal communication, November 2, 2009), co-founder of Asperger Partner Information Australia Inc (ASPIA; http://www.aspia.org.au) reported in 2009 that the Aspia group had a mailing list of 300 members, around 25–30 people attending the monthly face-to-face support group meeting (based in Sydney), with around 3–4 new members being welcomed each week. Ms Grigg (2009) further reported that the website was receiving around 1,000 ‘hits’ per week. Internet-based groups such as Aspia facilitate the forming and consolidation of NT women’s sense of being part of a community (both local and global) with a shared identity and purpose. Involvement in the online support group seems to motivate members of this population to utilise and promote IMT as a medium with significant potential to enhance their psychosocial wellbeing, reduce their sense of isolation and promote positive self-evaluation – a necessary component of SWB.

3.2.1.2 Mixed Methods Research (MMR). The rationale for choosing to collect a mix of both quantitative and qualitative data was informed by the anecdotal and other non-scholarly literature and the scholarly peer-reviewed literature summarised in Chapter 2. First, a standardised scale measure was used to explore the life satisfaction of the target population to provide the primary quantitative data source for the project. Second, one open-ended question with a series of prompts was used to investigate ‘the lived reality’ of the participant’s experience of her relationship, with (1) a view to validating the existing body of non-scholarly/non-peer-reviewed literature currently available, (2) to gain a ‘fuller picture’ of the NT woman’s ‘lived reality’, and (3) to further inform the construct under study – life satisfaction (Mason, 2006).

Given that this study design included both quantitative and qualitative data collection and
analyses methods, a review of the relevant literature on MMR (Collins et al., 2006; Denscombe, 2008; Giddings, 2006; Leech, 2012; Mason, 2006; Morgan, 2007; Plano Clark, 2010; Teddlie & Tashakkori, 2012; Teddlie & Yu, 2007) was conducted for fit with the current study design. The literature review process was undertaken to ensure that the correct terminology/nomenclature for use in classification of the study design was adopted for this project and the methodological strategies employed.

This study design would most accurately be defined simply as *utilising both quantitative and qualitative approaches with an emphasis on the quantitative data (QUANqual) as the primary data source to inform the research questions*. It was also concluded from a review of the MMR literature that it was efficient practice to adopt the report writing framework as recommended by Leech (2012), and further informed by Collins et al., (2006), Leech (2012), Tashakkori and Teddlie (2010), Teddlie et al., (2012), and Teddlie et al., (2007).

### 3.3 Research Formulation

#### 3.3.1 Research planning

##### 3.3.1.1 Approach.

The study design adopted for this project included the collection of quantitative data for the two constructs of life satisfaction and empathy. The standardised measures used were the PWI-A (International Wellbeing Group, 2006a) and the Cambridge Behaviour Scale (Baron-Cohen et al., 2004). A Demographic Information Form was constructed to capture demographic data and some qualitative data; however, the single open-ended question provided the main source of qualitative data.

The same survey format was used for both the study group and the control group.

The design of the study emphasised that the quantitative data and categorical variables from demographic information would provide the primary data source for analyses, and the qualitative data drawn from the open-ended question would provide the secondary data source (QUANqual). The philosophy underpinning the rationale for this study is best defined within the mixed methods literature as ‘pragmatic’. Pragmatism (simply framed) rejects the dichotomous nature of the ‘either/or’ options (quantitative or qualitative) (Tashakkori et al., 2010), but rather favours ‘what works’ (Howe, 1988) and:
brings that great strength … to social science research methodology … its emphasis on the connection between epistemological concerns about the nature of knowledge that we produce and the technical concerns about the methods that we use to generate that knowledge … by separating the ‘mechanical issues’ of qualitative methodology … to a larger set of questions about why we do the kind of research that we do’ (Morgan, 2007, p. 73).

3.3.1.2 Sampling strategy. A purposive (nonprobability/judgment) sampling strategy (Handwerker, 2005; Teddlie et al., 2007) was used to: (a) reliably answer the study research questions (Teddlie et al., 2007, p. 83); (b) maximise the potential to recruit members of the target population (Mason, 2002, p. 140); and (c) maximise the potential to yield a large enough sample to mirror the population under study (Neale & Liebert, 1986, p. 33).

Tashakkori and Teddlie (as cited in Teddlie et al., 2007), among others, observed that a probability (random) sampling strategy is the strategy considered most likely to yield a sample representative of the population under study ‘where probability of inclusion for every member of the population is determinable’ (p. 77). Teddlie and Yu’s further comment, acknowledging the important differences between the two sampling positions of probability and purposive, has relevance to the decision to use purposive sampling as the strategy of choice for this study. Of purposive and probability sampling, they state that both are designed to provide a sample that will answer the research questions under investigation, and they both are concerned with issues of generalizability to an external context or population (i.e., transferability or external validity)” (Teddlie et al., 2007).

Maxwell comments that the ‘preference’ for the engagement of probability (random) sampling in research stems largely from studies employing a framework informed by quantitative data analyses/collection methods: ‘Works on quantitative research generally treat anything other than probability sampling as “convenience sampling”, and strongly discourage the latter’ (Maxwell, 2008, p. 235). Maxwell asserts that within qualitative research, neither the probably nor convenience sampling methods appropriately ‘fit’ and that qualitative research sampling methods falls ‘somewhere in between’ – in a third category which he terms ‘purposeful sampling’. A technique that he describes as facilitating the capture of important information that cannot be obtained from any other choice; for example, the choice of particular settings, persons or events (Maxwell, 2008).

3.3.1.3 Sampling frame. A sampling frame within the purposive sampling position is described by Mason as ‘a resource from which you can select your smaller sample’ (Mason, 2002, p.
Teddlie et al., (2007) expand on this definition with the descriptive observation: ‘Purposive sampling frames … are typically informal ones based on the expert judgment of the researcher or some available resource identified by the researcher’ (p. 83).

There is a paucity of peer-reviewed literature on NT women in relationship with men who have AS to provide support or guidance for this study’s sampling techniques (Bostock-Ling et al., 2012). Therefore, it was concluded that an appropriate sampling frame could be based on the judgment of the research team. The resource/s most likely to yield a number of participants sufficient to provide reliable and valid data (Handwerker, 2005, p. 433; Neale et al., 1986, p. 62; Pallant, 2011, pp. 207–208; Stevens, 2002, p. 3) for this study were the support groups and websites to which members of the target population subscribe; and websites, newsletters and reception facilities of known clinical experts in the field of autism and AS. The resources targeted for the control group participants were organisations that provided support to women in general.

3.3.1.4 Resources. Adjunct Associate Professor Tony Attwood was the first point of contact regarding recruitment for this study. Professor Attwood suggested that I advertise the study on his website (Attwood, personal communication, November 2, 2009) and also recommended contact with Ms Carol Grigg, one of the original founders of Asperger Syndrome Partner Information Australia Inc (Aspia). Ms Grigg provided contact details of other persons and organisations that were relevant to the study (personal communication, November 2, 2009). The organisations that agreed to participate in the study provided written confirmation, which was included with the study’s ethics application. The ethics-approved copy of the Research Notification Statement, which contained the appropriate web links for the study, was then provided via email to the organisations that had verbally or in written form agreed to participate in the study. Each participating organisation was also provided with a copy of the letter from the university’s Ethics Committee, which provided authorisation for the study to proceed (see Appendix C).

The participants for the control group study were drawn from resources that were sourced using a similar procedure as for the main study group (cold calling) by personally telephoning or emailing organisations with details of the study and requesting their participation. These organisations were mostly obtained from internet searches using keywords such as women’s health, relationships support, relationship counselling. The organisations that agreed to participate in the study were provided, via email, with a copy of the letter from the university’s
Ethics Committee providing authorisation for the study to proceed and a copy of the Research Notification Statement containing the study web link. In the case of the two medical centres that agreed to participate, the Research Notification Statement containing the study web link was forwarded to the practice managers via email. In the case of the two motorcycle club groups, the Research Notification Statement containing the study web link distributed to interested parties following a presentation delivered to a weekly club group meeting.
Chapter 4: Empirical Study Method

4.1 Participants and Recruitment

4.1.1 Study group participants

Participants were eligible if they were 18 years of age or older and had sufficient command of the English language to complete the survey. Participants in the study group were in or had been in an intimate relationship with a person who they understood to have AS (diagnosed or ‘suspected’); the relationship had spanned 3 years or more; and the participant declared that they themselves did not have or did not suspect that they had AS.

Participants for the study group were recruited via the following resources:

4.1.1.1 Participating organisations and websites:
Asperger Syndrome Partner Information Australia Inc (Aspia) – http://www.aspia.org.au
Research Autism UK – http://www.researchautism.net
Asperger Syndrome Partners and Individuals, Encouragement and Support (Aspires) – http://www.aspires-relationships.com
Coffs Coast Autism – http://www.coffscoastautism.org.au
Autism Spectrum Australia (ASPECT) – http://www.autismspectrum.org.au
Northern Rivers ASD Network (NSW) – http://www.northernriversasdnetwork.wordpress.com
Queensland Association for Healthy Communities (QAHC) – http://www.qahc.org

4.1.1.2 Participating organisation – advertisements displayed in waiting/reception rooms:
Jeroen Decates, Clinical Psychologist, Sydney.

4.1.1.3 Personal emails received: In addition to the targeted resources, 15 eligible participants made contact directly via email expressing an interest in participation after having seen the study advertised on the internet through various search engines, including Google. These participants were forwarded a link to the study via email.
4.1.2 Control group participants

Participants for the control group were eligible if they were 18 years of age or older; had sufficient command of the English language to complete the survey; were in or had been in an intimate relationship that had spanned 3 years or more; do not have or were not suspected of having AS; and their intimate partner does not have (or did not have) or was not suspected of having AS.

4.1.2.1 Participating organisations: electronic newsletters. The following organisations advertised the study containing the study link in their electronic newsletters, which were distributed by email to participants on their regular mailing lists:

Women’s Health Goulburn North East – www.whealth.com.au
Australian Women’s Health Network (AWHN) – www.awhn.org.au
Women’s Information Referral Exchange (WIRE) – www.wire.org.au

4.1.2.2 Participating organisations: Advertisement displayed in waiting/reception rooms (see Appendix D). Two Brisbane-based medical centres displayed the advertisements in their waiting rooms.

4.1.2.3 Participating organisations: Presentations delivered. Two presentations were given and flyers distributed to two Brisbane-based motorcycle clubs at their monthly meetings. There was a high number of female members in both clubs.

4.1.2.4 Newspaper advertisement (see Appendix D). A newspaper advertisement was placed in the Star newspaper, which is a locally produced community newspaper on Brisbane’s north side, in Queensland, Australia. It has a distribution of approximately 70,000 papers weekly and is offered free to community members.

4.2 Data Collection

4.2.1 Collector

The survey was presented online via the Survey Monkey platform (http://www.surveymonkey.com).

The survey comprised the following forms: Participant Information Statement for Neurotypical Women, Participant Consent Form, Participant Demographic Information form, Satisfaction with Life as a Whole and the PWI Scale (Written Format), the Open Ended Question and the Cambridge Behaviour Scale (used to measure the EQ). The measures were uploaded into the
online survey format in the order listed. To enable participation in the study the participants had to have acknowledged having read the participant information statement and acknowledge informed consent by indicating that on the consent form.

The Participant Information Statement provided the participants with instructions for completion of the study. Each survey instrument also contained specific instructions regarding completion of that survey and these instructions included the information that participants could ‘opt out’ at any point during the survey by simply exiting the survey.

Stage 1 of the online data collection process targeted the study group participants (LSNTW). Stage 2 of the process targeted the control group participants (control group). The LSNTW online survey opened on April 16, 2010, with the exclusion of the EQ, which was added on April 23, 2010 due to the need for approval of a slight modification of the Ethics protocol or the study, . The survey closed on February 8, 2011. There were 796 views; 522 completed the Demographic Information form; 518 completed Part 1 of the PWI-A; 515 completed Part 1 and Part 2 of the PWI-A; 420 completed the open-ended question; 416 completed the first half only of the EQ; and 407 completed the EQ. All data from all participants was included, resulting in unequal participant numbers in some analyses.

As the original Ethics approval was only for the NT group, there was a delay between the two data collection phases. The control group survey opened online on the February 14, 2012 and closed on the September 18, 2012. The study attracted 74 views; 56 completed the Demographic Information form; 56 completed Part 1 of the PWI-A; 55 Completed Part 1 and Part 2 of the PWI-A; 55 completed the EQ; and 51 completed the open-ended question.

4.3 Data Management

On completion of the survey, the survey data was downloaded from Survey Monkey directly into SPSS, coded and cleaned in preparation for analyses.

Data cleaning procedures for the LSNTW study group data resulted in 500 completed surveys, of which 419 included a response to the optional open-ended question. For the control group, there were 53 completed surveys and 48 responses to the open-ended question at completion of data cleaning procedures.
4.4 Data Analyses Procedures

4.4.1 Quantitative data

Frequencies were run as part of the data cleaning procedure and to produce descriptive statistics for each of the samples. Correlations were used to explore the strength of the relationships between the SWB and the EQ, for all groups.

Independent sample $t$ tests were used to compare the EQ score of the two LSNTW groups – those EQ data that could be matched with an LSNTW participant and those whose data could not be matched with an LSNTW participant. (These two groups within the LSNTW data set were created as a result of an error in the initial setting up of the survey. When the survey was first uploaded to Survey Monkey, the EQ survey form was uploaded as a separate survey document set apart from the other survey documents, which were grouped together and accessed by one link, while the EQ form was accessed by another link. This error resulted in the EQ standing alone as a survey document and not linked in any identifiable way to the participants’ other survey documents. After this error was corrected within the online survey, and the EQ survey form embedded within the other survey documents link, the survey was completed as one whole set of documents with the EQ matching, or being a part of, an identifiable complete set of survey data.)

Independent samples $t$ tests and one-way between-subjects ANOVA were used to investigate the differences between those participants in the LSNTW group whose partner had been given an AS diagnosis by a professional and those whose partner had been given an AS diagnosis by a non-professional; and also differences between the controls with both the LSNTW groups on SWB and EQ scores.

Correlation and multiple regression were used to estimate the predictive power of the EQ and the demographic variables for SWB and to establish of the construct validity of the PWI-A within the two LSNTW groups, LSNTW group as a whole and the control group.

4.4.2 Qualitative data

Participants responded to a single open-ended question and were provided with a list of prompts to assist them if needed – a Terms Reference Guide. The prompts selected were those drawn from the anecdotal and scholarly literature on NT-AS relationships noted in the Chapter 1, and also those constructs that are known to correlate with SWB:
In your own words how would describe your relationship with your AS partner? (If you have had more than one relationship with an AS partner you may refer to your other AS partnerships here if they spanned 3 or more years.)

Terms Reference Guide: communication, emotional intimacy, sex, responsibility, shared interests, shared activities, leisure, empathy/compassion, equality, domestic duties, health (physical and mental), parenting, organisation, trust, social life, stress, positive aspects, negative aspects, advantages, disadvantages, dependency, and other.

References to AS were removed from the question for the control group participants. Each qualitative response was manually analysed and collated into themes outlined in the Terms Reference Guide, and then evaluated for ‘response type’. The terms for reference were optional for use by the participants: some participants styled their responses using the terms as a subheading, providing data for each of the themes; some participants utilised the terms for some but not all of their response; while other participants presented their response in a narrative form without specific reference to the Terms Reference Guide. Where text was identified that overlapped between two themes, then the relevant text was assigned to both themes, and where data was evaluated as meeting the criteria for more than one response type, then that data was evaluated accordingly.

The data were then categorized into response types – ‘positive’, ‘negative’, ‘no response’ (NR) or ‘neutral’ – for each participant by theme. Where a themed response contained both negative and positive comment, it was assigned to both the ‘positive’ and ‘negative’ column to reflect the dual nature of the response. Each categorized response type was allocated a single score of one. These data were then reviewed independently by the primary supervisor of this thesis to check for rater bias. The Supervisor checked the responses and their allocated categories which were provided to him in spreadsheet format. Where the supervisor disagreed with the assigned coding, we discussed the difference of opinion until a consensus on all categorized data was reached. There were approximately 10 coded responses discussed during this process.

Some example responses coded as both positive and negative are: ‘I taught autistic children and I live with a big one’; ‘He will never grow up, change or be the man of my imagination but he is the man or my dreams, the one put on this earth for me, and I am here for him’; ‘My family loves him, but don't always understand him or his disability’; ‘My husband and I are currently coming to a loving understanding of one another’s quirks and foibles, and learning to work to support one another in our marriage. However, the Asperger’s is still problematic
because the moment my husband stops consciously putting effort into interacting and communicating with me (i.e., he’s tired or feels unwell), he lapses back into that distant, non-communicative, arrogant, critical Aspie’; ‘He can be loving and sensitive, but becomes self-absorbed with what he wants’; and ‘Living with an Aspie has its stresses but it also has its gifts. My husband is talented, really smart and has a wicked sense of humour’.

An example of a neutral response is: ‘Domestic duties are shared for the most part; however, his expectations of how things are done and when are difficult to deal with’.

An additional category of diagnostic/therapeutic issues was added at this stage of the qualitative data analysis, as information was identified within the response data that could prove informative for this category. An example is:

‘I diagnosed him with Aspergers after getting him to do the test, which I downloaded from the Aspia site. I also did it because he could not conceive of there being anything wrong with him, as his IQ allowed him into Mensa. He scored 32 (and lied on some answers and I scored 10). I made an appointment with a psychiatrist who was recommended by Aspia, but when the appointment time came he was gone. I wish it hadn’t taken me so long to figure him out. I have missed 37 years of happiness with the husband and father he might have been, but never was’.

4.5 Measures

4.5.1 The Demographic Information form

The 23-item Demographic Information form was developed for the purposes of this study and informed by the scholarly, non-peer-reviewed and non-scholarly literature reviewed for this study. Some changes to the form were necessary to adapt the content to fit the Survey Monkey web format design. These changes included rewording of items (which then resulted in another seven items being added to the form) and an introductory instruction paragraph. These changes were approved by the primary and associate supervisors of this thesis, who jointly considered that the new content and format rendered the form insufficiently different to the ethics-approved version to warrant resubmission to the Ethics Committee (Appendix E). The introductory statement read:

Participant Demographic Information

To be eligible for participation in this study, you must complete this form.
If you have lived in relationship with more than one AS partner, please choose to refer to one relationship only when completing this section. You may refer to your other AS partnerships in the Open-Ended Question.

The 23 items on the Demographic Information form were:

Q1: Age: (years and months)
Q2: Age of partner: (years and months)
Q3: Gender of your partner: M/F
Q4: Marital status: married, defacto, separated, divorced
Q5: Length of time living in relationship up to the present time or up to time of separation: (years and months)
Q6: Currently living with partner: Y/N
Q7: Number of children of the relationship:
Q8: Number of children with disabilities or disorders:
Q9: If your child/children have disabilities or disorders please provide details:
Q10: Partner accepts children’s disabilities or disorder diagnosis? Y/N
Q11: Does your partner have a disability or a diagnosed disorder? Y/N
Q12: If you answered ‘Yes’ to Q11 please provide details of the disability or disorder:
Q13: If you answered ‘Yes’ to Q11, did you know that your partner had this disorder or disability prior to entering into the relationship? Y/N
Q14: If you answered ‘Yes’ to Q11, was your partner’s disability or disorder diagnosed by a professional person and if so please state that person’s profession (e.g., GP, Psychologist etc.)?:
Q15: If your partners’ disability or disorder was not diagnosed by a professional then who made the diagnosis:
Q16: Are you currently engaged in counselling for difficulties associated with your relationship?
Q17: If you answered ‘No’ to Q15 when did you cease counselling for your relationship difficulties?
Q18: Current occupation:
Q19: Previous occupation/s:
Q20: Have you ever been employed in a helping profession?
Q21: Have you ever been in relationship with a partner who had Asperger syndrome? Y/N
Q22: What is the highest level of education that you have achieved? (primary school, secondary school, matriculation, certificate, diploma, degree)
Q23: My geographic area of residency is: (e.g., North Coast NSW; Sydney; Brisbane; regional SEQ; Nth Qld; Florida; London)

The Demographic Information Form was positioned as the third form within the web survey design. The Participant Information Statement (see Appendix F) was the first form, followed by the Consent Form (see Appendix G).

4.5.2 Personal Wellbeing Index – Adult (PWI-A)

The Personal Wellbeing Index – Adult (PWI-A; International Wellbeing Group, 2006a) is the instrument of choice for this study to measure Life Satisfaction. It is asserted that the SWB theoretical model which underpins the PWI-A, as proposed by Cummins (2010) and discussed in the following paragraphs, provides an appropriate theoretical model with which to inform this particular study (Cummins, 2010). Importantly, the PWI-A offers normative data for Australian women on the construct under study, *life satisfaction*, thereby providing valuable comparison data (see Appendix H).

The theoretical underpinnings of SWB posit that a management system of psychological devices has evolved for the purposes of targeting the protection of Homeostatically Protected Mood (HPMood), the major component of SWB. HPMood, theorised to consist of the combination of three constructs, contentment, happiness and positive arousal, results in us experiencing a ‘normally positive’ view of ourselves. When faced with a negative challenge (or set of challenges) that are of an overwhelming nature, this theory proposes that we ‘lose contact’ with HPMood and experience a dominance of negative arousal and, when of a chronic nature, results in people experiencing depression (Cummins, 2010). The mechanism of homeostasis comprises two kinds of buffers – *external* and *internal*. The two major external buffers are wealth and relationships and a relationship with another adult that involves mutual sharing of intimacies and support is almost universally supported by research literature as having sufficient power to moderate the influence of real and potential stressors on an individual’s SWB (Cummins, 2010). When the external buffers are insufficient to prevent a negative event from occurring Cummins suggests that automatic processes of adaptation and habituation act as internal protective devices and are assisted by a set of cognitive buffers using cognition to restructure reality and minimise the impact of such negative experiences (Cummins, 2010). Cummins asserts that the core role of the homeostatic system is to maintain a positive sense of wellbeing that is both non-specific and highly personalised; the homeostatic system is concerned only with the abstract core feelings that the individual has about
themselves and only in the most general sense, therefore people need to be ‘imbued with a “positivity bias” in relation to themselves’ (Cummins, 2010).

The Australian Unity Wellbeing Index Survey Report 24.0 (Australian Unity et al., 2008; Cummins, 2010) contained appropriate comparison data and cumulative data and therefore was considered an appropriate resource for this study (Cummins, October 30, 2012, personal communication).

The PWI-A scale consists of an eight item ‘end defined 0–10 scale’ (which is anchored by completely dissatisfied and completely satisfied (Jones & Thurstone, 1955). Bendig and Hughes (1953) posit that anchoring has been shown to increase the reliability of preference responses and to increase the amount of information, in the technical sense, transmitted by responses. The eight items comprise the eight domains of life satisfaction, with each of the eight items corresponding to one of the eight quality of life domains: standard of living, health, achieving in life, relationships, safety, community-connectedness, future security, and spirituality/religion’ (International Wellbeing Group, 2006a). Participants are invited to rate each of the eight items on a 0–10 scale, where 0 represents completely dissatisfied, 5 represents neither satisfied nor dissatisfied and 10 completely satisfied. ‘The data are then averaged across the eight domains for each respondent and the result transformed onto a 0–100 scale’ (Cummins, 2010, p. 2). One additional optional item – representing a global life satisfaction rating ‘Life as a whole’ – is also offered on the scale. The eight domains are ‘theoretically embedded, and constitute the minimum set of domains that represent first level deconstruction of the global question: “How satisfied are you with your life as a whole”’ (International Wellbeing Group, 2006a, p. 8).

Reliability and Validity: A psychometric overview of the scale reveals that typically 30 – 60% of the variance can be explained when the eight domains are collectively regressed against ‘Satisfaction with Life as a Whole’ (International Wellbeing Group, 2006a).

The domains of ‘Safety’ and ‘Spiritual or religious wellbeing’ make no unique contribution in Australian populations.

As at 2004, 16 surveys of the Australian population had revealed a maximum variation of 3.2 percentage points in SWB. Cummins and Lau (2005) report a Cronbach alpha of between .70 and .85; interdomain correlations moderate at around .30 to .55; item-total correlations are at least .50 in Australia and a level of sensitivity between demographic groups that is consistent with the theory of subjective wellbeing homeostasis.
Agha Yousefi, Alipour, and Sharif (2011) in their study on mothers of mentally retarded students in north of Tehran-Iran using the 7 item PWI-A scale demonstrated a high scale reliability with a Cronbach’s alpha of 0.90.

A correlation of .78 with the Diener et al.’s Satisfaction with Life scale (SWL) was reported by Thomas (2005, as cited in International Wellbeing Group, 2006a, p. 9).

4.5.3 Cambridge Behaviour Scale

The Cambridge Behaviour Scale measures the EQ (online version; Baron-Cohen et al., 2004). It is a Likert scale questionnaire comprising 40 items (see Appendix I). A respondent is asked to rate each item using the following format: strongly agree, slightly agree, slightly disagree, strongly disagree. Each item attracts a score of 2, 1, or 0, permitting a maximum score of 80 and a minimum score of zero. Some limitations in the measurement of Empathy are accepted. Of measurement of the empathy construct using the EQ, Baron-Cohen comments on the limitations of using self-report measures for measuring empathy traits, including that the EQ measures a person’s beliefs about their own empathy and that improvement in the accuracy of the score could be obtained by having significant others or observers complete the measure for a respondent. He also comments that empathy may be comprised of both state and trait components and that state components may be subject to fluctuation depending upon life events and mood, and that genetic or early learning factors could influence the trait component (Baron-Cohen et al., 2004, pp. 170–171).

People with AS generally score significantly lower on the EQ (mean 20.4, SD 11.6) than controls, while female adults from the general population score (mean 47.2, SD 10.2) significantly higher than males from the general population (mean 41.8, SD 11.2) and significantly higher than AS adults (Baron-Cohen & Wheelwright, 2004, pp. 168, 170). Given the exploratory nature of this study, the empathy within the target population relative to controls and people with AS was investigated, as well as its relationship to life satisfaction, and also as a function of key demographic variables.

A study by Davis (1980) examining the reliability, validity and factor structure of the EQ found the questionnaire’s reliability across samples to be similar to those stated by Baron-Cohen and Wheelwright (2004). High test-retest reliability was found, as were sex differences similar to the original authors. However, Davis’s (1980) study saw women scoring slightly higher (but not significantly higher) than the original sample. Concurrent validity of the EQ was supported
by (as expected) moderate correlations with Davis’s Interpersonal Reactivity Index (IRI) on its two subscales, ‘empathic concern’ and ‘perspective taking’. The authors concluded that the EQ would appear to have utility in studying at least two clinical groups: people with AS and those with neurotic conditions such as depersonalisation disorder (DPD), which includes anxiety and depressive symptoms. Further use in clinical research would appear to be worthwhile (Davis, 1980, p. 919). Rasch analysis of the EQ found that the EQ is a unidimensional measure of empathy, and does not discriminate between the two major components of empathy, affective and cognitive (Allison, Baron-Cohen, Wheelwright, Stone, & Muncer, 2011).

4.5.4 Open-ended question

One open-ended question was constructed to allow participants to describe their relationship in their own words: ‘In your own words how would you describe your relationship with your AS partner?’ This question was accompanied by a Terms of Reference guide to act as prompts for the participants (Appendix J). The responses to this question provided the qualitative data for the study. Milberg and Strang (2000) in their article ‘Met and unmet needs in hospital-based home care: qualitative evaluation through open-ended questions’, proposed that a potential drawback to the use of quality of life instruments is that ‘it is possible to miss relevant aspects’ (Milberg & Strang, 2000, p. 533). Their findings suggested ‘that a combination of standardized quantitative questions and open-ended qualitative questions is one way to improve the value of questionnaires for follow-up’ (Milberg & Strang, 2000, p. 534). Hearn and Higginson (1998), in their comprehensive review article, ‘Outcome Measures in Palliative Care for Advanced Cancer Patients: A Review’, concluded that ‘no single measure covers physical, psychological and spiritual domains in a format that will provide sufficient or reliable information’ (Hearn & Higginson, 1998, p. 198). Other findings of note regarding the positive value of including open-ended questions to supplement quantitative measures of satisfaction include: Law, Ray, Knapp, and Balesh (2003, p. 399), who found that problems that patients reported in the open-ended question from their survey were not addressed in the quantitative instrument and, importantly, reaffirmed concerns that had been reported in other public health literature; Riiskjaer, Ammentorp, and Kofoed (2012), whose study demonstrated ‘that most patients were able to put their perceptions into words’ and that qualitative data provides an important supplement to quantitative results providing a way to ‘broaden the channel from patients’ perceptions to quality improvement’ (p. 515). Marcinowicz, Chlabicz, and Grebowski’s (2007) results found that some of the respondents who answered “‘good or very good” to the closed questions expressed negative views in their two open-ended questions’ and ‘Answers to open-ended questions add
value to a patient satisfaction survey by providing information that answers to closed questions may not elicit’ (p. 86).

4.5.5 Ethics

Given the exploratory nature of this study, the original application to the University of Sydney’s Ethics Committee included a screening assessment for autistic traits of either the NT participant or their AS partner.

An assessment instrument for this purpose, the AQ, is available for downloading and research use from the Autism Research Centre website. The AQ is an instrument developed at the Autism Research Centre to measure the degree of autistic traits of adults with normal intelligence. Baron-Cohen stresses that the instruments on the Autism Reseach Centre website are not for diagnostic purposes (University of Cambridge, 1999).

The inclusion of the AQ in this study was rejected by the University of Sydney Ethics Committee on the grounds that no follow-up counselling or support would be available to participants who may have experienced psychoemotional difficulties as a consequence of the outcome of their AQ score. The AQ was therefore not used in the present study following advice from the Ethics Committee. Resource constraints at that stage of the project dictated that the Ethics Committee’s advice be accepted. However, it would be ideal for any future research in this area to give consideration to the inclusion of the AQ scale as this would be consistent with clinical experts’ advice/opinion (e.g., Professor Attwood).
Chapter 5: Results

The primary aim of this study was to explore the life satisfaction and empathy of neurotypical (NT) women in intimate relationship with a partner who has AS. Analyses used were linear regression and independent groups T-Tests.

5.1 Research Questions and Expected Results

5.1.1 Research questions

Three research questions were formulated to lead this enquiry:

1. Is the life satisfaction of NT women in intimate relationship with a partner who has AS significantly poorer than that of women not in such relationships?

2. Is the empathy of NT women in intimate relationship with a partner who has AS significantly different to that of women not in such relationships?

3. What are the predictors of life satisfaction of NT women?

5.1.2 Anticipated results

Given the exploratory nature of this study, formal hypotheses were not formed; however, the following two outcomes were anticipated, based on the literature that informed this study:

1. That the LSNTW group would have a lower overall SWB than the control and normative groups.

2. That the LSNTW group would have a higher level of empathy than the control and normative groups.

5.2 Scoring Procedures

5.2.1 PWI-A

The PWI individual domain scores for each respondent were converted to a standard form by multiplying each of the scores by 10 to provide domain scores ranging from 0–100 and producing the SM% score. The PWI total score was computed by adding the individual domain scores and then obtaining an average to produce the PWI total SM% score. The LSNTW group was further separated into two groups – those whose partner’s AS was diagnosed by a professional practitioner (prof dx) and those whose partner’s AS was diagnosed by a non-professional person (non-prof dx) in order to answer assumption 4 outlined above.
5.2.2 Cambridge Behaviour Scale (EQ)

Due to a design error described in the previous chapter, 106 of the 403 valid responses for the EQ could not be matched to an LSNTW participant’s PWI and demographic survey data. This left 297 EQ surveys that could be matched. For exploratory purposes, given the method variance, a decision was made to explore the relationship between the two groups of EQ data – matched and unmatched. An independent samples t test was conducted and showed an unexpected finding of a significant difference between the two EQ data sets. The matched group, \( M = 62.33, SD = 9.766 \), reported significantly higher empathy than the unmatched group, \( M = 52.52, SD = 21.301 \); \( t(4.574), df \ 401, p = .05 \), two-tailed with the substantive significance considered medium to large (Cohen’s \( d = 0.4568 \)). The author can only speculate as to the reasons for this difference. Two points from the two data sets were noted: the unmatched group was the first group to participate in the study, and the distribution of the unmatched grouped contained approximately 14 very low scores. The matched data set was the data set used for analyses.

The EQ was scored by applying a score of 2 to definitely agree and 1 to slightly agree to selected item responses, in accordance with the scale scoring directions. The scoring procedures included reverse scoring for 20 of the 40 items to accommodate potential for response bias. The scores were then summed to provide an overall EQ score. (Scoring procedures are outlined in Appendix K.)

There were 500 life satisfaction of NT women (LSNTW) study group participants and 53 control group participants who provided valid survey data. Of the LSNTW participants, 256 were from Australia (51.2%); 5 from New Zealand (1%); 165 from the United States of America (33%); 28 from Canada (5.6%); 31 from The United Kingdom (6.2%); 3 from The Netherlands (0.6%); 2 from Spain (0.4%) and 1 each (0.2%) from Norway; Germany, Vietnam, Israel, Iceland, Middle East, Ireland, Slovenia, France and South Africa. Of the LSNTW participants, 346 were married, 61 were de facto, 61 were separated and 32 were divorced. The separated and divorced participants \( (N = 93; 18.6\%) \) were all living apart and the married and de facto participants \( (N = 407; 81.4\%) \) were living together. Twenty-nine (5.8%) LSNTW participants knew of their partner’s AS prior to the commencement of their relationship, while 471 (94.2%) did not. Three hundred and twenty-one (64.2%) LSNTW participants reported that their partner had a professional diagnosis of AS; 177 (35.4%) were either self, partner or ‘other’ diagnosed and 2 (0.4%) participants did not respond to this question. Two hundred and
ninety-two (58.4%) LSNTW participants reported that their partner accepted their diagnosis of AS, while 208 (41.6%) reported that their partner did not accept their diagnosis. There were 8 (1.6%) reported same-sex partnerships within the LSNTW group and 5 (9.4%) within the control group. Table 7 reports the descriptive statistics for both the LSNTW and the control group.

Table 7: Descriptive Statistics for LSNTW and Control Group Participants

<table>
<thead>
<tr>
<th></th>
<th>LSNTW N = 500</th>
<th>Control N = 53</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age M</td>
<td>47.82</td>
<td>46.77</td>
</tr>
<tr>
<td>SD</td>
<td>9.95</td>
<td>11.48</td>
</tr>
<tr>
<td>Age of partner M</td>
<td>49.65</td>
<td>49.58</td>
</tr>
<tr>
<td>SD</td>
<td>10.62</td>
<td>12.59</td>
</tr>
<tr>
<td>Years spent in relationship M</td>
<td>18.1</td>
<td>16.08</td>
</tr>
<tr>
<td>SD</td>
<td>10.95</td>
<td>11.64</td>
</tr>
<tr>
<td>Years spent in relationship before diagnosis of AS M</td>
<td>15.12</td>
<td>N/A</td>
</tr>
<tr>
<td>SD</td>
<td>10.94</td>
<td></td>
</tr>
</tbody>
</table>

Note. LSNTW = Life Satisfaction of Neurotypical Women; M = mean; SD = standard deviation.

5.3 Anticipated Results

5.3.1 Anticipated Results 1

That the NT group (LSNTW) will have lower overall SWB than the control and normative groups

The data analyses included treating members of the sample group whose partner had a professional diagnosis of AS and those participants whose partner did not have a professional diagnosis as two separate groups, as well as the group as a whole. For data analyses, Country of origin was separated into two groups: Australia and New Zealand (52.2%) were treated as one group and the remaining countries (47.8%) as one group.

The LSNTW group as a whole (inclusive of both diagnostic types) showed significantly lower PWI total score than the control group sample (t = 7.1589, df 551, p < .05), with a substantive
significance of large (Cohen’s $d = 0.609$), and the normative sample ($t = 28.1722, df 1472, p < .05$), with a substantive significance of large (Cohen’s $d = 1.468$). There was no significant difference between the two LSNTW diagnostic groups ($t = 1.4126, df 498, p > .05$), with no substantive significance (Cohen’s $d = 0.126$). The control group showed no significant difference to the normative sample ($t = -1.9591, df 1025, p > .05$), with no substantive significance (Cohen’s $d = 0.122$). The LSNTW professional diagnostic group showed a significantly lower PWI total score than the controls ($t = -7.3904, df 373, p < .05$), with the substantive significance of medium approaching large (Cohen’s $d = 0.7653$); and significantly lower PWI total score than the normative sample ($t = 26.4219, df 1294, p < .05$), with a substantive significance of large (Cohen’s $d = 1.469$).

Across each of the seven domains both the LSNTW professional diagnostic group and the LSNTW non-professional diagnostic groups showed significantly lower PWI scores than the normative sample and the control group ($p < .05$). The Cronbach alpha for PWI1- PWI8 is 0.87, which indicates very good internal consistency.

### 5.3.2 Anticipated results 2

**That the LSNTW group would show a higher level of empathy than the control and normative groups**

The LSNTW group as a whole showed a significantly higher EQ score than both the control group sample ($t = 5.8539, df 348, p < .05$), with a substantive significance of medium (Cohen’s $d = 0.6276$), and the normative sample ($t = 14.3752, df 421, p < .05$) with the substantive significance large (Cohen’s $d = 1.4012$). The control group also showed a significantly higher EQ compared to the normative sample ($t = 3.8521, df 177, p < .05$) with the substantive significance medium (Cohen’s $d = 0.57908$). The LSNTW professional diagnostic group showed significantly higher total EQ scores than the control group ($t = 6.6251, df 240, p < .05$), with the substantive significance large (Cohen’s $d = 0.855$), and the normative sample ($t = 14.7592, df 313, p < .05$), with the substantive significance large (Cohen’s $d = 1.668$). The LSNTW non-professional diagnostic group showed significantly higher total EQ scores than the control group ($t = 3.7569, df 159, p < .05$), with the substantive significance medium (Cohen’s $d = 0.596$), and the normative sample ($t = 9.6834, df 232, p < .05$), with the substantive significance large (Cohen’s $d = 1.2715$).

To the extent that it matters as regards the source of diagnosis, the only statistically significant difference was that those whose partner had been diagnosed by a health professional
(professional diagnosis) had higher EQ scores \((t = 6.6251, df = 240, p < .05, M = 63.47, SD = 9.15)\) than those whose partner was not diagnosed by a health professional (nonprofessional diagnosis). This result however has a substantive significance of small \((Cohen’s d = .312)\). No other differences between the two LSNTW groups approached significance.

Table 8 shows the mean scores for the LSNTW group and the control group against published normative data for both the EQ and the PWI-A.

**Table 8: Means and Standard Deviations for SWB and EQ for the LSNTW Group, the Control Group and the Normative Data**

<table>
<thead>
<tr>
<th></th>
<th>LSNTW group</th>
<th>Control</th>
<th>Normative sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total EQ score</td>
<td>62.33 (9.766) N = 297</td>
<td>53.68 (10.7) N = 53</td>
<td>47.2 (10.2) N = 126</td>
</tr>
<tr>
<td>PWI Total</td>
<td>52.45 (20.33) N = 500</td>
<td>73.10 (16.04) N = 53</td>
<td>76.6 (12.46) N = 974</td>
</tr>
<tr>
<td>PWI 1 Standard of Living</td>
<td>61.83 (25.23) N = 499</td>
<td>75.85 (14.86) N = 53</td>
<td>78.7 (16.97) N = 974</td>
</tr>
<tr>
<td>PWI 2 Health</td>
<td>50.95 (26.33) N = 499</td>
<td>73.02 (19.07) N = 53</td>
<td>74.8 (19.1) N = 974</td>
</tr>
<tr>
<td>PWI 3 Achieving in life</td>
<td>53.36 (26.67) N = 499</td>
<td>70.00 (20.38) N = 53</td>
<td>74.6 (17.3) N = 974</td>
</tr>
<tr>
<td>PWI 4 Personal relationships</td>
<td>42.13 (26.440) N = 499</td>
<td>69.06 (24.59) N = 53</td>
<td>80.9 (20.54) N = 974</td>
</tr>
<tr>
<td>PWI 5 (Safety)</td>
<td>58.37 (29.29) N = 499</td>
<td>83.77 (19.92) N = 53</td>
<td>79.5 (17.08) N = 974</td>
</tr>
<tr>
<td>PWI 6 (Being part of your community)</td>
<td>53.50 (27.683) N = 499</td>
<td>72.45 (21.11) N = 53</td>
<td>74.4 (18.76) N = 974</td>
</tr>
<tr>
<td>PWI 7 (Future security)</td>
<td>47.38 (29.258) N = 499</td>
<td>67.55 (23.36) N = 53</td>
<td>72.3 (19.08) N = 974</td>
</tr>
</tbody>
</table>

**Note.** SWB = Subjective Wellbeing; EQ = Empathy Quotient; LSNTW = Life Satisfaction of Neurotypical Women; PWI = Personal Wellbeing Index.

### 5.3.3 Predictors of SWB

Standard multiple regression was used to test which variables best predicted SWB in the LSNTW group. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity (Pallant, 2011). The data revealed five predictors of significance for SWB, four were predictors of lower SWB, and one a predictor of higher SWB. Women whose partner did not accept their AS diagnosis had a lower SWB than those whose partner accepted their diagnosis \((\beta = -5.19, p < .05)\). Further findings predicting lower SWB were having at least one child with AS \((\beta = -6.82, p < .05)\), living in a country other than Australia or New Zealand \((\beta = -4.76, p < .05)\) and not being in
paid employment ($\beta = -4.58$, $p < .05$). Those who were divorced from their AS partner had higher SWB than those who were not divorced ($\beta = 8.24$, $p < .05$). Table 9 displays these results.

**Table 9: Regression Analysis for the LSNTW Group Demographic Variables Predicting Subjective Wellbeing**

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>95% CI</th>
<th>$p$ value</th>
<th>Adjusted $B$</th>
<th>95% CI</th>
<th>$p$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (Ref: School)</td>
<td>[-41.45, 15.22]</td>
<td>.36</td>
<td>-4.36</td>
<td>[-31.91, 23.19]</td>
<td>.76</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>[0.04, 11.78]</td>
<td>.05</td>
<td>5.06</td>
<td>[-0.81, 10.93]</td>
<td>.09</td>
</tr>
<tr>
<td>Graduate/Diploma/Cert</td>
<td>[-5.43, 5.2]</td>
<td>.97</td>
<td>-0.40</td>
<td>[-5.6, 4.8]</td>
<td>.88</td>
</tr>
<tr>
<td>Acceptance by partner of diagnosis (Ref: Yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>[-8.86, -1.66]</td>
<td>&lt;.001</td>
<td>-5.19**</td>
<td>[-8.84, -1.55]</td>
<td>.01</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced (Ref: Married)</td>
<td>[-0.9, 13.77]</td>
<td>.09</td>
<td>8.24*</td>
<td>[1.08, 15.39]</td>
<td>.02</td>
</tr>
<tr>
<td>Separated</td>
<td>[-6.31, 4.71]</td>
<td>.78</td>
<td>-0.33</td>
<td>[-5.81, 5.14]</td>
<td>.90</td>
</tr>
<tr>
<td>De facto</td>
<td>[-1.81, 9.29]</td>
<td>.19</td>
<td>1.54</td>
<td>[-4.26, 7.33]</td>
<td>.60</td>
</tr>
<tr>
<td>Current occupation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not in paid employment</td>
<td>[-11.07, -2.51]</td>
<td>&lt;.001</td>
<td>-4.58*</td>
<td>[-8.85, -0.3]</td>
<td>.04</td>
</tr>
<tr>
<td>Other paid employment</td>
<td>[-9.05, -0.32]</td>
<td>.04</td>
<td>-2.64</td>
<td>[-7, 1.72]</td>
<td>.23</td>
</tr>
<tr>
<td>Country (Ref: Aus/NZ)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (Ref: Helping professions employment)</td>
<td>[-6.92, 0.22]</td>
<td>.07</td>
<td>-4.76**</td>
<td>[-8.28, -1.23]</td>
<td>.01</td>
</tr>
<tr>
<td>Offspring (Ref: No child)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least one child with AS</td>
<td>[-13.13, -3.64]</td>
<td>&lt;.001</td>
<td>-6.82**</td>
<td>[-11.84, -1.8]</td>
<td>.01</td>
</tr>
<tr>
<td>Children but none with AS</td>
<td>[-8.72, -0.14]</td>
<td>.04</td>
<td>-2.44</td>
<td>[-7.25, 2.38]</td>
<td>.32</td>
</tr>
<tr>
<td>Years spent in relationship with AS partner</td>
<td>[-0.36, -0.03]</td>
<td>.02</td>
<td>-0.10</td>
<td>[-0.28, 0.09]</td>
<td>.30</td>
</tr>
<tr>
<td>Number of years respondent had been in relationship with AS partner BEFORE diagnosis of AS became known</td>
<td>[-0.31, 0.01]</td>
<td>.07</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>[-0.21, 0.15]</td>
<td>.78</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior knowledge of partner AS (Ref: Yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>[-9.15, 6.1]</td>
<td>.70</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional diagnosis (Ref: Yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>[-1.29, 6.17]</td>
<td>.20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ever been in helping occupation (Ref: Yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>[-8.57, -1.44]</td>
<td>.01</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer</td>
<td>[-21.52, 10.47]</td>
<td>.13</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5.4 Qualitative Data

5.4.1 Open-ended question

Examination of the individual categories within the LSNTW group and the control group qualitative responses yielded the results that are displayed in Table 10. For the LSNTW group overall, 17% of the total responses were positive; 71% negative, and 12% were recorded as neutral responses. The overall response rate for the terms of reference was 46%. The ‘Top 5’ terms for reference that attracted the highest percentage of negative responses for the LSNTW Group were Stress (97%), Communication (94%), Health (91%), Empathy/Compassion (89%), and Sex (88%). The ‘Top 5’ terms for reference that attracted the highest response rates were: Emotional Intimacy (77%), Communication (71%), Stress (70%), Sex (59%), and Social Life (56%). Disadvantages attracted a 6% response rate, of which 100% were negative and Negative Aspects attracted a 23% response rate, of which 96% were negative. Positive Aspects attracted a 46% response rate, of which 85% of the comments were positive; and Advantages attracted an 11% response rate, of which 83% were positive.

For the control group, 57% of the total responses were positive, 35% negative, and 8% were recorded as neutral responses. The response rate for the terms of reference was 33%. The ‘Top 5’ constructs attracting the highest percentage of negative responses were: Stress (79%), Health (56%), Sex (50%), Emotional Intimacy (47%), and Social Life (40%) (see Table 10).

The ‘Top 5’ terms for reference that attracted the highest response rates were: Communication (67%), Emotional Intimacy (61%), Trust (53%), and Social Life and Domestic Duties both attracting a 52% response rate. Disadvantages attracted a 0% response rate and Negative Aspects attracted a 15% response rate of which 100% were negative. Positive Aspects attracted a 48% response rate, of which 100% of the comments were positive; and Advantages attracted a 0% response rate.
### Table 10: Qualitative Responses for LSNTW Group and Control Group for Each Construct by Category and Listed in Alphabetical Order

<table>
<thead>
<tr>
<th>Construct</th>
<th>Positive LSNTW</th>
<th>Control</th>
<th>Negative LSNTW</th>
<th>Control</th>
<th>Neutral LSNTW</th>
<th>Control</th>
<th>Response rate LSNTW</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advantages</td>
<td>83%</td>
<td>0</td>
<td>17%</td>
<td>0</td>
<td>0%</td>
<td>0</td>
<td>11%</td>
<td>0</td>
</tr>
<tr>
<td>Communication</td>
<td>3%</td>
<td>68%</td>
<td>94%</td>
<td>26%</td>
<td>3%</td>
<td>6%</td>
<td>71%</td>
<td>67%</td>
</tr>
<tr>
<td>Dependency</td>
<td>9%</td>
<td>50%</td>
<td>62%</td>
<td>25%</td>
<td>29%</td>
<td>25%</td>
<td>34%</td>
<td>8%</td>
</tr>
<tr>
<td>Diagnostic/therapeutic issues</td>
<td>5%</td>
<td>75%</td>
<td>17%</td>
<td>25%</td>
<td>77%</td>
<td>0</td>
<td>58%</td>
<td>9%</td>
</tr>
<tr>
<td>Disadvantages</td>
<td>0%</td>
<td>0</td>
<td>100%</td>
<td>0</td>
<td>0%</td>
<td>0</td>
<td>6%</td>
<td>0</td>
</tr>
<tr>
<td>Domestic duties</td>
<td>37%</td>
<td>56%</td>
<td>60%</td>
<td>24%</td>
<td>3%</td>
<td>20%</td>
<td>35%</td>
<td>52%</td>
</tr>
<tr>
<td>Empathy/compassion</td>
<td>8%</td>
<td>60%</td>
<td>89%</td>
<td>40%</td>
<td>3%</td>
<td>0</td>
<td>44%</td>
<td>10%</td>
</tr>
<tr>
<td>Emotional intimacy</td>
<td>2%</td>
<td>53%</td>
<td>67%</td>
<td>47%</td>
<td>30%</td>
<td>0</td>
<td>77%</td>
<td>61%</td>
</tr>
<tr>
<td>Equality</td>
<td>14%</td>
<td>56%</td>
<td>84%</td>
<td>25%</td>
<td>2%</td>
<td>3%</td>
<td>32%</td>
<td>33%</td>
</tr>
<tr>
<td>Health (mental and physical)</td>
<td>8%</td>
<td>36%</td>
<td>91%</td>
<td>56%</td>
<td>1%</td>
<td>8%</td>
<td>55%</td>
<td>49%</td>
</tr>
<tr>
<td>Negative aspects</td>
<td>4%</td>
<td>0</td>
<td>96%</td>
<td>100%</td>
<td>0%</td>
<td>0</td>
<td>23%</td>
<td>15%</td>
</tr>
<tr>
<td>Organisation</td>
<td>31%</td>
<td>25%</td>
<td>69%</td>
<td>38%</td>
<td>0%</td>
<td>38%</td>
<td>24%</td>
<td>17%</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
<td>47%</td>
<td>22%</td>
<td>33%</td>
<td>68%</td>
<td>20%</td>
<td>42%</td>
<td>31%</td>
</tr>
<tr>
<td>Parenting</td>
<td>23%</td>
<td>56%</td>
<td>75%</td>
<td>38%</td>
<td>2%</td>
<td>6%</td>
<td>52%</td>
<td>33%</td>
</tr>
<tr>
<td>Positive aspects</td>
<td>85%</td>
<td>100%</td>
<td>13%</td>
<td>0</td>
<td>3%</td>
<td>0</td>
<td>46%</td>
<td>48%</td>
</tr>
<tr>
<td>Responsibility</td>
<td>16%</td>
<td>76%</td>
<td>83%</td>
<td>18%</td>
<td>1%</td>
<td>6%</td>
<td>53%</td>
<td>35%</td>
</tr>
<tr>
<td>Sex</td>
<td>11%</td>
<td>42%</td>
<td>88%</td>
<td>50%</td>
<td>1%</td>
<td>8%</td>
<td>59%</td>
<td>50%</td>
</tr>
<tr>
<td>Shared interests/activities/leisure</td>
<td>28%</td>
<td>82%</td>
<td>71%</td>
<td>18%</td>
<td>1%</td>
<td>0</td>
<td>51%</td>
<td>23%</td>
</tr>
<tr>
<td>Social life</td>
<td>11%</td>
<td>48%</td>
<td>87%</td>
<td>40%</td>
<td>2%</td>
<td>12%</td>
<td>56%</td>
<td>52%</td>
</tr>
<tr>
<td>Stress</td>
<td>3%</td>
<td>21%</td>
<td>97%</td>
<td>79%</td>
<td>0%</td>
<td>0</td>
<td>70%</td>
<td>29%</td>
</tr>
<tr>
<td>Trust</td>
<td>34%</td>
<td>73%</td>
<td>64%</td>
<td>27%</td>
<td>2%</td>
<td>0</td>
<td>40%</td>
<td>53%</td>
</tr>
<tr>
<td>Total comments by category</td>
<td>17%</td>
<td>57%</td>
<td>71%</td>
<td>36%</td>
<td>12%</td>
<td>8%</td>
<td>46%</td>
<td>33%</td>
</tr>
</tbody>
</table>
5.4.1.1 Sample of LSNTW group individual participant responses to the ‘Top 5’ variables

The section below includes five participant response examples from each of the Top 5 variables:

**Stress:**

- I let a lot of things slide to avoid arguments and his fascination with Warhammer, Star Trek etc are annoying to me.

- So what has my life been like..in a few words … a living hell ...!!! a nightmare.

- Living, and running a business with my partner turned my life into a mirror that had been attacked with a stiletto. Shards all there, but a fractured view, where some things matched up, and others didn’t. No congruence between what was said and what was lived out. Persistent physical threats to myself and my daughters. VERY short fuse … liable to go off the deep end. We landed up being very careful … walking around on egg shells around him, so as not to antagonise.

- He likes everything planned or gets frustrated easy. He works off my emotions, so if I am in a bad mood, he is in a bad mood. He can’t multitask and has a hard time keeping a job.

- I feel completely alone and overwhelmed. AS partner has never moved out of home with his mother but wants complete control over my household and raising the children. He visits us for about 20 minutes a week as he says the kids are too noisy. He does not contribute financially as he is obsessive about money and possesions. Children get very little from him in regards to presents etcetera.

**Communication:**

- I have rage at him one minute and forgive him the next. I compare talking with him to talking to a tree; actually, I feel more connected with the trees’ ability to communicate back.

- I am having a hard time partly because too often I forget and expect to be able to communicate in a normal way with him … even though I understand he is unable to do this I find myself wanting or expecting it to be easier. I am looking for validation, some sort of credit for the fact I live in this situation.

- At times, mostly, I feel totally on edge due to communication issues. My ASH does not seem to ‘hear’ me, and sometimes he has an iPod in his ear. Even without it, I generally repeat things several times. Sometimes I don’t get an answer and have to ask again, or tell him something again. He doesn’t say things like ‘that’s nice’ or ‘okay’. He will not look in my eyes when he talks to me. He talks to me like he knows everything (professor-like); I
feel he wants to impress me with his knowledge and sometimes he goes on and on. I get bored with this type of interaction. He sometimes says I ask too many questions, so I guess I’m overloading his senses, but sometimes I just talk because he doesn’t talk.

- In the last 5 years there has been increasing misunderstandings and at times verbal aggression, which seems to come from nowhere. I miss the experience of touch too. This is a much under-valued means of communication and it is very difficult for him as he is not ‘wired’ in the same way as me.

- Very hard to communicate with. He does not like ‘chatter’, for him there has to be a purpose to talking. I am told off many times for not being precise enough when talking to him. This leads me to not starting any discussion at all.

**Health:**

- Life is hard for him, I understand that, life is hard for everyone involved with AS – I try to make allowances, I appreciate it is a disability, but the situation affects my mental and physical health.

- I worry that if something happens to me he will be in real trouble. I have way more responsibility and stress than I can easily handle and it has taken a serious toll on my health. I am paying the price physically for his inability to deal with so many things.

- Over the years, due to my need for vigilance and egg-walking (and lack of neurotypical recognition) I have developed a panic disorder (plus depression, plus PTSD). I know, about myself, that my sense of self has been disintegrating over the years. Before marrying him (at age 39) I was an exceptionally outgoing person (for an introvert) with the energy and interest to explore life. I was happy on my own terms just being ‘me’.

- We lead completely separate lives, having no social life or friends or activities together. If we have visitors about once a year, hubby ‘hovers’ and copies everything I do and say until I get to the point where I politely chase the visitors away just to get some peace. Our lives have shrunk to watching TV most days and going to our separate appointments. It is the only way I can survive in this stultifying, crippling relationship: to just drop out of life. I have suffered as a result of this abusive relationship. I have been dx’d with clinical depression. I have severe ongoing traumatic responses to small situations; for example, I cannot bear anyone to touch me, particularly men. I don’t enjoy NT social events any more because they require an emotional effort I can’t muster. Life is just one long slog each day. My life has shrunk to staying home most days. Some days I don’t even get out of my pyjamas. Having a shower is too much effort. And through all this, hubby’s life continues to be enjoyable for him and his own interests.
My health and physical wellbeing need my careful monitoring and require mindful participation on my part, along with my conviction that this is my role by me and for myself.

**Empathy/Compassion:**

- Empathy: I would hate to say that he has none because this is not true; in fact, he seems to get very riled when he perceives a situation where someone is an underdog or a victim. He sees this quite clearly as being innately unfair. On the other hand, say in a more complex situation, that is, whenever I express how lonely and unloved I feel in the relationship – he shows almost zero empathy and places the blame squarely with me for even feeling that something is not right. Although he would never see himself as doing this, if he gets it into his head that one person has done something wrong then he will automatically generalise that most people from this person’s sexual orientation/social standing or whatever will be the same. He generalises to the nth degree.

- Empathy/compassion: not much. Was unable to put himself in my position. Often used my feelings of guilt to manipulate an outcome.

- As time went by I started to notice the need to prompt for things like giving a hug when I was upset, or saying something supportive, him not knowing how to respond beyond trying to find a practical thing to do to help, he often did not know what to say and therefore said nothing and did nothing.

- He is very empathetic for his loved ones. Beyond that, he doesn’t seem to be bothered by travesties concerning others. He simply can’t think of such a thing if it doesn’t concern him.

- Empathy/compassion – is very limited, we see a very small amount towards immediate family members but rarely any.

- He can’t read people and runs into them all the time. He seems to have little empathy for people’s situations. He has difficulty helping people and isn’t aware of what goes on around him.

**Sex:**

- Sex – BAD, never improves. No amount of talking or education helps. He just does the same awful things over and over and over till I want to kill him. We rarely have sex now, and when we do it’s just me giving him a pity fuck. I will probably start an affair. As an interesting side note, he has no concept of jealousy and is aware that I plan to start having sex outside of the marriage. This does not seem to bother him, nor does it seem to motivate him to become a better lover. Also, no amount of criticism seems to phase his enthusiasm or motivate him to get better. He is so sexually inept it is not even funny, despite the fact that he is hung like a horse. He is pitiful and he drives me crazy. We have an
almost non-existent sex life, not because of disinterest on his part but because for five years now we have been having the same type of sexual experience that you would expect from a virgin male. I can give him that once, maybe even a few months to get the swing of things. But FIVE years? OMFG!

- Communication is the most difficult aspect as it permeates all aspects of the relationship – emotional intimacy, sexual intimacy (of which there is almost none); social interactions; my feelings of being validated and valued as a spouse, etc.

- People think I’m married to such a sweet, gentle man, but if they had to depend on him for sex, they might change their minds! After being the sole initiator in the bedroom for over a quarter of a century, I gave up because it was too hard on my self-esteem to have to ‘beg’ for sex – every time.

- Sex was frequent and mechanical … no playfulness or fun.

- Sex. Always same position (usually he was behind me not looking at me), and was not experimental. Always had to be in the bed. Was not very frequent.

- The deep intimacy he craves, including sexual connection, comes as a result of reciprocal communication and a balance between giving, receiving, yielding, and asking. Without some of these elements, there really isn’t much intimacy. Though I can initiate, explain, and model any of these behaviours, it goes nowhere if my partner cannot understand how to do them and why they are important. It is very hard to accept that the contributions I’ve made to our lives and to our relationship will never be acknowledged, because they will never be understood.

**Positive Aspects/Advantages:**

- I want to start off by saying that he is a very sweet, gentle person. He has always been shy, very intelligent, and very talented. He tries to overcome and compensate for his AS very hard. He often falls short, and feels like a failure. I wish I could help him see the man I see, underneath all of that.

- Positive aspects – trustworthy, faithful, predictable.

- Advantages – loyal, however I have a dog. (This response was coded as dual response type – positive for ‘loyal’ and negative for ‘however, I have a dog’).

- He retired early and his investments provide well for us but he still worries about money.

- He has always been a good provider.
My only advantage is that my former husband became obsessed with properties and then shares (I do not use obsessed lightly, as you will appreciate) which has enabled me to provide for the two adult children of this marriage without financial stress).

**Diagnostic/Therapeutic issues:**

- Well I will begin with the day of dawning, when it was suggested to me that my AS may indeed have AS. I had heard of the syndrome but really just related it to children, how wrong, as these children do grow up and become adults, taking their peculiar traits with them. We have move to WA from SA as AS could not maintain permanent employment. He is an engineer. We have been here 16 years. My daughter is in the health/psych area and said to me ‘He has AS’, well I was onto the computer and read and read and cried and yes he certainly does have it, reading the signs, characteristics, etc, I would say he is on the top end of the scale … Going back over the past 30 years it all falls into place.

- Prior to the confirmation of the Asperger’s, we had struggled greatly with what I perceived was his ‘jerk’ persona, and with what he felt were his personal failings. I struggled with alcohol, gained 30 kilos and was treated for clinical depression. Since the confirmation of the ASD, however, much of the pressure has been relieved as we learn to both work through the trials and tribulations of this disorder as a committed couple.

- The ‘diagnosis’ was a pretty amazing and difficult time. It validated my feelings that I was OK and that I wasn’t crazy and difficult. At the same time, almost on a daily basis, it challenges me to face what is the reality of my relationship – my husband won’t ever really love me in a way that I need and want to be loved – he just isn’t wired that way.

- Given my increased understanding of our relationship and communication issues following the diagnosis of AS, I describe our relationship as a successful NT/AS relationship. Understanding makes all the difference.

- There are no advantages in living with someone with Aspergers if they refuse to even think about how they can make things better – I am not sure if he even accepts the diagnosis, but will use it as the excuse to get out of anything he doesn’t want to do.

- Understanding AS has helped enormously in the acceptance of what goals, boundaries and tasks are realistic.
Chapter 6: Discussion

This study had one objective and two expected outcomes. The objective was to obtain empirical evidence for the life satisfaction of NT women in an intimate relationship with a partner who has AS and the two expected outcomes were that the life satisfaction of NT women would be different from the control and normative groups; and that the empathy quotient (EQ) of NT women would be different from the control and normative groups.

It was found that NT women scored significantly lower across each of the seven domains when compared to the normative data and the control sample, these domains being: Standard of Living, Personal Health, Achieving in Life, Personal Relationships, Personal Safety, Community Connectedness and Future Security. These results provide some evidence that NT women’s perception of the quality across many of the most significant aspects of her life is of a significantly depressing nature. The study findings also supported the hypothesis that empathy quotient (EQ) for the NT study sample would be higher than that of both the normative sample and the control group sample.

This discussion chapter has three sections, beginning with a discussion of the study findings for the life satisfaction of NT women, followed by a discussion on the findings of empathy and the implications of these findings for the life satisfaction of NT women, concluding with a discussion on the findings from the qualitative data analyses and the implications of these findings on the life satisfaction of NT women.

6.1 Life Satisfaction

Cummins’ theory of subjective wellbeing proposes that failure of the homeostatic process denies individuals access to their HPMood which then leads them to experience dominant feelings of NA over PA. When the negative challenges leading to this failure are chronic or long lasting, people experience the clinical state of depression (Cummins, 2010).

Through the lens of SWB homeostasis theory, this study informs us of three points of note: (1) that this study sample of 500 NT women in intimate relationship with a partner who has AS are faced with long-lasting or chronic challenges of an overwhelming nature; (2) that the set of internal and external buffers to which these women have access are inadequate to protect them against the magnitude of these challenges; and (3) that this study sample of women would be experiencing depression or other mood disorders of a clinical nature as a consequence of the failure of their homeostatic process.
Buffers key to the moderation and maintenance of HPmood within the positive range include income and satisfying personal/intimate relationships. Theoretically, low income of itself is found to not necessarily lead to low wellbeing. It may be that for this sample of NT women their intimate relationship with their AS partner is the key variable leading to their significantly low SWB. This assumption would be supported by SWB theory as described in Chapter 1. Alternately, or additionally, there may be personal characteristics of these NT women which make them more vulnerable than other NT women in relationship with partners who have AS to the challenges posed by the symptom expression of AS, potentially aggravating the impact of these challenges. No data on the personal characteristics of the NT women was sought in this study therefore this assumption can only be considered as noteworthy for future research.

Research has found that marital relationship quality and life satisfaction for the male partner is ‘buoyed’ by his wife’s self-report of a happy marriage and ‘flattened’ by his wife’s self-report of an unhappy marriage (Carr et al. 2014). Carr et al.’s findings when applied to the present results may suggest that the NT’s partner’s diminished SWB affects the mood of her male partner and the altered mood state of the AS partner perpetuates the low marital quality of the NT woman partner and the cycle continues resulting in lower SWB for both partners. This same concept model could be applied to further research of the NT woman and her AS partner with potential for application of the findings to therapeutic interventions.

Study findings from research with carers (discussed in Chapter 1) demonstrated similarities to the findings from this study and the following examples describe these similarities. Dunkle et al., 2014 found that wives as carers of their spouse or children experienced greater depressive symptoms than non-caregiver spouses, stress related disorders were even greater in middle and older age, and the detrimental effects of these stress related disorders were even greater for this group than for caregiving wives who care for relatives other than their spouse or children (Penning et. al., 2015). Carer activities of ADL management (again, for a spouse by a spouse) was found to be a significant predictor of hypertension when controlling for period of caregiving (Capistrant et al., 2012) while the van den Berg et al., 2014 study of over 10,000 Australian caregivers found that number of informal (non-paid) weekly caregiving hours (>20 hours) correlated negatively with life satisfaction.

NT women often define themselves as unpaid (informal) carers, mothers and parents to their AS partners as well as ‘sole parenting’ their children. These NT women reports reflect a perception of the ‘less than equal’ distribution of day to day relationship responsibilities and
activities and domestic and family related duties within their NT-AS relationship with their spouse. This NT ‘role definition and burden perception’ would hold similarities to the role performed and burden experienced by those caregiver spouses who formally identify themselves as informal spousal carers. Another similarity between these two groups and worthy of note may be the nature of their voluntary approach to being a caregiver to their spouse or children. Whilst considered informal, there may be particular stressors related to the caregivers unexpected role of becoming a caregiver to their spouse, having similarities to the situation that NT women often find themselves in, not having expected to become an informal caregiver to their spouse because their AS characteristics were not so obvious during courtship and prior to marriage. This may lead to the nature of the caregiving being informal and involuntary. The involuntary/voluntary nature of the role of caregiving in the health and wellbeing of NT spouses warrants further investigation. Further reference to spousal caregiver populations research may prove to be of assistance here.

NT spouse’s number of caregiving hours’ would also be greater than 20 hours per week, and similar to those of spousal carers of husbands. Being employed outside the home/caregiving environment, either in a voluntary or paid position, resulted in higher rates of happiness for spousal caregivers (van Campen et al., 2012) similar to the present NT participants where results found that being employed outside the home was one of five significant predictors of life satisfaction.

Other variables studied within the caregiver population, but not in the present NT-AS study, and found to have implications for carer health and wellbeing include personality (trait similarities in couples are positively correlated with SWB in males but not in females), personality facet of agreeableness (specifically trust and compliance) in care recipients positively correlated with physical health of the caregiver (Riffin et al., 2013), marriage stability and marriage quality (positively correlated) (Arrindell et al., 2000). Findings from the study of caregivers by Haley et al., (2001) for depression and life satisfaction indicated that female gender, caregiver health problems and negative social interactions were risk factors for diminished wellbeing, while caregiver personal characteristics of finding meaning and subjective benefits in caregiving combined with more social resources showed higher life satisfaction and lower depression. Each of these findings from the caregiver research may have utility for future research studies investigating the NT-AS intimate partnership. The available clinical and self-report publications on the present population of women leads us to suspect that marriage stability and marriage quality are both impaired and warrant further investigation.
to explore this hypothesis.

It is already known that social resources play a mediating role between stress and health and wellbeing. What is not known is the nature of the social resources that would enhance the health and wellbeing of NT women. The theory of SWB predicts that PA and NA are independent constructs, therefore if social resources do play an important role in alleviating stress and promoting health and wellbeing in some populations, it may be that those populations are not exposed to challenges of such an overwhelming and chronic nature that they produce NA that is higher than the PA. The present findings inform us that NT women in this study are experiencing challenges of such an overwhelming and chronic nature that any experiences or events which may result in an elevation of their PA are not the type of events or experiences that impact on reducing their NA and are therefore insufficient to have a positive impact on their SWB. Further research could investigate the nature of the resources that are most likely to produce a reduction of NA in NT women and explore whether the introduction of these resources enhance the SWB of these NT women by reducing their NA.

As discussed in the introductory chapter of this thesis, Cummings reported on the influence of Tesser et al.’s self-evaluation maintenance (SEM) model upon HPMood where they found that only failures in valued dimensions of life negatively impact on an individual’s SEM, negatively influencing self-evaluation, internal buffers and, in turn, HPMood. Further enquiry into exploring valued dimensions of life of NT women may shed further light on some factors that are influencing their diminished SWB; For example, if NT women self-evaluate being empathic and caring as valued dimensions of their self and something that they are ‘good at’, despite employing these valued attributes within their relationship with their partner who has AS they fail to produce any positive change within the relationship, then their perceived failed performance will negatively threaten their self-evaluation, reduce internal buffers and ultimately their HPMood, leading to diminished SWB. 6.1.2 Other findings

The data from the study found that there was no significant difference between the SWB of NT women whose partner had received a professional diagnosis of AS and those whose partner’s AS had been ‘suggested’ as a result of information gleaned from other resources to which the person with AS or their partner or relative or friends had access. These study findings indicate the significantly low levels of SWB for all NT women in the study whether professionally or non-professionally diagnosed.

This outcome may be important in terms of its contribution to the assessment, future care and
therapeutic needs of NT women. The non-peer reviewed literature reviewed for this study revealed that there are numerous barriers placed before NT women seeking therapeutic intervention for themselves and or their AS partner. One of the reported barriers is the significantly limited access to available health professionals who are qualified to assess and diagnose AS and, of those few professionals who are available, for some NT women and their families the cost of diagnosis with additional costs associated with travel and accommodation (potentially necessary for regional and remote community members) may be prohibitive.

The absence of a professional diagnosis of AS may be problematic for NT women. Some report that they are often not believed by friends, relatives or health professionals when they disclose that they suspect that their husband has AS adding to the burden that they are already experiencing.

Therapeutic interventions for this group of women or their family members cannot be formulated or empirically tested if we first cannot identify ‘what the clinical problem is’, for which we need to formulate those clinical interventions (Voils & Maciejewski, 2011). This study has provided supportive evidence that some NT women in intimate relationship with a partner who has AS experience impairment to their mental health and wellbeing. Specifically, the NT participants in this study demonstrated that they experience a sense of being overwhelmed by the negative challenges that they face, such that the internal and external resources that normally act as buffers to protect their mood stability and maintain it within a positive range are insufficient to combat the effect of those negative challenges. One result of that experience evidenced by these study results is a diminished SWB which is indicative of the presence of a clinical level of depression.

A number of NT women reported that their partner whom they suspected of having AS was ‘in denial’ of their AS, or their partner did not consider it necessary to have a formal diagnosis and they were content with their informal diagnosis.

Non-acceptance of diagnosis by the AS partner was a statistically significant predictor of the NT sample’s SWB. This finding was not supported by the non-peer-reviewed literature explored for this study, however it is an important factor worthy of further discussion. First, if an individual denies the existence of AS as part of their profile of characteristics, then they cannot contribute towards finding solutions to the problems that their AS characteristics bring to their intimate relationship, thereby contributing to the chronic nature of the NT partners negative challenges. Second, this denial or ‘lack of empathy’ from the partner with AS provides
another negative challenge for the NT partner further diminishing her already burdened buffers. Third, an AS partner’s acknowledgement of their AS characteristics may lead to an increase in the availability of buffers for the NT partner by way of perceived personal relationship support, which the NT partner could utilise to mediate the impact of the negative challenges.

6.2 Empathy

The construct of empathy was anticipated to be elevated in the profile of the NT women in relationship with a partner who has AS for reasons of its potential for relationship initiation and relationship maintenance, particularly given the low empathy reported to be part of the profile of AS. Attwood, among others, suggests that a part of the initial attraction that a NT woman may find in a potential partner who has AS characteristics (known or unknown to either or both parties) is the perception that the partner with AS needs to be nurtured, protected and ‘helped’, and that elevated empathy in NT women, relative to women not in such NT-AS relationships, may predispose them to wanting to help and assist others who are perceived to be ‘less capable’. Additionally, Attwood proposes that elevated characteristics of empathy may contribute to the longer-term maintenance of the NT-AS relationship (Attwood, personal communication, November 2, 2009), given that they endow the NT woman with an above average ability of ‘being able to identify the emotions and thoughts in others, and to respond appropriately’ (Lawson, Baron-Cohen, & Wheelwright, 2004, p. 302). The present study did include the variable ‘have you ever been employed in the helping professions’. This variable was found to not be a significant predictor of SWB.

The study findings confirmed the anticipated result as the EQ score for the NT study sample was statistically significantly higher than both the normative sample and the control group sample. This finding may be an important finding and is worthy of further investigation. We know that empathy has an important positive association with relationship quality and life satisfaction, and a negative association with depression and conflict, however research suggests that similarities within the intimate partnership are necessary for positive relationship quality, reduced depression and relational conflict (Riffin et al., 2013).

Empathy and sympathy as constructs are not easily disentangled. Explanation for this may be that sympathy is considered similar to, or a component of both dimensions of empathy, affective and cognitive. The component factors of empathy, affective and cognitive, are considered to overlap and also ‘not easily disentangled’ (Baron-Cohen et al., 2004). Davis (1994) describes sympathy as an observer’s emotional response to another’s distress and a
desire to take action to alleviate that distress though not necessarily acting on this desire, the appropriate affective and cognitive responses to another’s distress mirror that of empathy. In response to the Davis study (Davis, 1994), Baron Cohen asserts that the essential difference between sympathy and empathy is the action response to another’s suffering, that is when the observer of another’s suffering feels an appropriate empathic reaction and a desire to take action then acts on his/her desire to take action to alleviate the suffering, then this is sympathy. When an observer does not act on the desire to take action to alleviate another’s suffering then this is empathy (Baron-Cohen et al., 2004). Rasch analysis of the instrument used for this study to measure empathy, the Cambridge Behavior Scale (EQ), found that the EQ measures a single dimension of empathy and does not discriminate between cognitive and affective empathy (Allison et al., 2011). Studies with carer populations found that those carers with higher affective empathy and lower cognitive empathy experienced higher depression and lower life satisfaction than those carers whose affective empathy was low and cognitive empathy was high (Lee, et al., 2001). As discussed in Chapter 1 Lee et al.’s study drew a distinction between cognitive and emotional empathy and found that high cognitive empathy may act as a positive buffer between the caregiver and his/her environment, while low cognitive empathy and high emotional empathy was found to have negative impacts on depression, stress, life satisfaction and environmental threats (Lee, et al., 2001).

When we compared the EQ scores between those LSNTW participants whose partner had a professional diagnosis of AS and those whose partner did not have a professional diagnosis, we found a statistically significant difference, however, as the substantive difference was small (Cohen’s $d = .312$), we do not consider this finding as warranting further investigation at this point in time.

The dimensional structure of empathy as measured by the EQ made it not possible to compare our study data with that of those carer studies investigating the impact of empathy on that population. Further exploration of empathy using a multidimensional approach to empathy that includes both cognitive and affective or emotional empathy within the NT populations is warranted.

Another confounding factor to the understanding of our study findings is both the varying definitions of sympathy and the overlap of sympathy with the construct of empathy (Davis, 1994, Baron-Cohen, et al., 2004). NT women’s behaviour indicate that they take on extra responsibilities, alter their behaviours so as to reduce the number of stressors that their AS
partner is exposed to and take on a parent/carer/protector role within their relationship with their AS partner. This behaviour could be understood as an action taken by the NT partner as a consequence of their observation of their AS partner’s difficulties and motivated by a desire to help and alleviate their ‘suffering’. This understanding of the NT partners ‘behaviour does not reflect Baron-Cohen’s definition of empathy, rather it reflects Baron-Cohen’s definition of sympathy and the definition of empathy proposed by that of Davis (Baron-Cohen et al., 2004., Davis, 1994). Further exploration of the constructs empathy and sympathy within the population of NT women is warranted.

Empathy is known to make a contribution towards the concept of illusions within an intimate partnership. Positive illusions of a partner in a couple dyad is related to relationship quality (Dijkstra et al., 2014), and we know that relationship quality is a significant predictor of SWB. Positive illusion is the concept of having an inflated positive perception of one’s partner’s characteristics to the extent that this inflated positive perception exceeds the partner’s self-reported positive perceptions of his or her characteristics. Described in Chapter 1, when the positive illusion concept is applied to a partner’s empathy, then that partner will be perceived to have an empathy that is higher or more positive than his or her actual empathy and will have a positive effect on the other partner’s perception of the relationship quality, even more so than the partner’s actual empathy (Dijkstra et al., 2014). This conceptual model may be worthy of further investigation as applied to the NT-AS couple dyad as it may have potential for implications in therapeutic models of relationship counselling for this group of intimate partners and provide further explanations for the difficulties within the NT-AS relationship.

6.3 Qualitative Data

Outcomes were only formulated for the quantitative data. There was uncertainty surrounding what to anticipate in relation to the open-ended question, save for the research cited in preceding chapters which indicates that the provision of this open-ended question to complement quantitative data collection methods might result in the collection of data that otherwise would be lost (Law et al., 2003; Marcinowicz, Chlabicz, & Grebowski, 2007; Riiskjaer, Ammentorp, & Kofoed, 2012). The design of the study emphasised that the quantitative data from the survey forms and the categorical variables from the demographic information would provide the primary data source for analyses, and the qualitative data drawn from the open-ended question would provide the secondary data source.
6.3.1 Outcome from the open-ended question

The qualitative data did prove to be a rich source of data and also provided information that was not captured by the quantitative data sources, as suggested by the research. Utilisation of the terms developed from the literature resources reviewed for the study and provided by members of the affected population, clinicians and other interested contributors proved to be a valuable method for capturing data pertinent to this study focus, and also permitted a relatively easy method of analysis or collation of the data.

The collated data informed how the key areas that were considered problematic for NT women in their relationship with their AS partners reflected the core characteristics of AS, these being impairments in communication, empathy, and social interactions; limited interests and rigid/fixed beliefs. Some participants responded to these terms for reference as they applied to themselves, while others responded to the terms as they applied to their AS partner; however, sex and stress were clearly predominantly responded to from the NT women’s perspective of how these terms related to themselves. Throughout the review of the terms, elements of stress as experienced by the NT participants were evident. Of the total number of responses that were collected and collated, there was a dominant negative theme that could be identified throughout the LSNTW data set that was not present within the control sample. Interestingly, the control sample participants did reflect similar responses in their relationship problems that were rated in the ‘Top 5’ and these were stress, communication and sex; however, we note that the significance of these problems is not indicated by the level of stress reflected in their responses, nor the SWB of members of this sample. This may suggest that members of this sample have a greater genetic component to positively contribute to their HPMood, or they have greater resources feeding their internal and external buffers, or their dominant empathy ‘type’ may be cognitive therefore consistent with Lee, et al’s, 2001 findings acts as a buffer protecting them from ‘over-caring/over-identifying’ with others’ problems at the expense of their own needs. Further, it may be that the degree of the challenges within their relationships are not of such an overwhelming and chronic nature so as to cause homeostatic failure.
Chapter 7: Conclusions

During the conceptualisation of this study, evidence-based guidelines with which to inform clinicians about NT women in intimate partnership with a person who has AS were sought. It was found that guidelines and intervention practices had not been investigated within the available published literature. This study then sought to initiate research that would lead to defining the problems faced by NT women in these relationships and encourage further research.

This study concluded that the SWB (life satisfaction) of NT women in intimate relationship with a partner who has AS is more likely to be significantly poorer than women who are not in such relationships. Those women whose partner does not accept their diagnosis of AS are more likely to have significantly poorer SWB than those NT women whose partner does accept their diagnosis. Having a professional diagnosis of AS is associated with a higher level of empathy in the NT partner but does is not associated with relationship stressors. Partners and relatives of people with AS may be as likely to diagnose AS characteristics as a professional person trained to do so. Women who have a child with AS are more likely to experience lower SWB than those women who do not have a child with AS. Those women who are divorced from their partner who has AS are more likely to experience a higher SWB than those who are not divorced from their partner.

The findings indicate that the characteristics of the stressors experienced by NT women in relationship with a partner who has AS may have an association with the known deficits that form part of the AS profile (e.g., empathy, communication skills, social skills, rigid beliefs, and inflexibility). More research is needed to explore these associations.

A further finding of this study was that NT women in relationship with a partner who has AS are more likely to have elevated empathy as part of their profile of characteristics than those not in such relationships.

When NT women were asked an open-ended question about their relationship, they were willing to reveal deeply intimate details of the difficulties that they face in their relationship with their AS partner and these details are likely to provide important information that has utility for clinicians and researchers alike, in addition to any quantitative measures used to assess these women. Furthermore, as a number of participants expressed gratitude at being
given the opportunity to express how they feel, it is likely that NT women derive some therapeutic benefit from being invited to tell their story and going through the process of having their story heard.

The study’s results lend validity to the reported experiences of some NT women – that the problems that they experience in their intimate relationship with their AS partner make a significant negative contribution to their life satisfaction, to such a degree that they experience mental health problems of a clinical nature.

Noteworthy, is that these findings (both qualitative and quantitative) lend validity to the findings and opinions expressed by contemporary clinical experts and noted in Chapter 1 (e.g., Attwood, Aston, Garnett). These study results also resonate with findings and expressed opinions of pioneers in the field of both research and clinical practice (e.g., Eisenberg, 1952; and Ritvo, 1988). Accepting the limitations of some of the 10 included studies reported on in Chapter 2, those of Aston, Parker-Rosenbaum, Lau and Peterson, Eisenberg, Ritvo and Pollman, particularly when referenced against the qualitative data from this study, report very similar findings to this study.

These comparisons may also lend some support to the understanding that the characteristics of Autism (including Asperger’s Syndrome) remain relatively stable over the lifespan (Bolte & Bosch, 2004).

7.1 Implications of These Findings

7.1.1 Subjective wellbeing homeostasis model

The findings of this study suggest that the model of subjective wellbeing homeostasis provides a plausible model with which to explain and explore the experiences reported by NT women in intimate relationship with a partner who has AS. The findings can be explained by the model in that NT women, due to the overwhelming and chronic nature of the negative challenges they face within their relationship, lose contact with HPMood, experience the domination of NA rather than PA, resulting in a significantly low SWB and may be diagnosed as being clinically depressed (Cummins, 2010, p. 1).

This result informs us that female partners of males whom they suspect have AS experience an equally statistically significantly low SWB as those women whose partners with AS have received a professional diagnosis. The implications of this finding are inconclusive. Although there was no difference found between these two groups, this does not mean that a diagnosis
is irrelevant. It seems important to make the point that more than half of the sample were diagnosed by a professional. The professional disciplines within this group of diagnosticians varied however, and they included nurses, therapists, GP’s, psychologists and psychiatrists, psychotherapists, counsellors and teachers. It is unknown how many of these professionals were formally qualified to diagnose AS as this data was not sought.

Coping mechanisms such as those published by Weston (2010) and Martin and Hendrickx (2011), and to a lesser extent those of Bentley (2007), viewed within the context of the findings of this study, may not reflect the experiences reported by the women in the present study and if applied to this group, may perpetuate their difficulties, or make no significant difference to enhancing their SWB.

7.1.2 Empathy

The study findings indicate that the EQ of NT women deviate from women who are not in relationships with men who have AS in that they indicate significantly elevated empathy as a personal characteristic. The nature of this characteristic of NT women and the implications for their life satisfaction warrants further investigation.

Having this knowledge about themselves may provide some useful information to NT women. If clinicians and other helping professionals in the field have an awareness that members of this population of women may have an elevated empathy as part of their personal characteristics, then they can utilise this information in the formulation of treatment plans. For example, women with this characteristic of elevated empathy may find that they often place their needs as secondary to the care needs of others and to the detriment of their own health and wellbeing. Having the knowledge about potential contributions to their behaviour may assist in better understanding themselves and so develop strategies to ‘take time out’ from being a helper and a carer and see this as a necessary coping strategy (i.e., additional external buffer), without associated feelings of guilt by ‘not caring enough’.

7.2 Limitations and Criticisms of the Study

The results of this study should take into account the following limitations.

This study comprised NT women who self-reported that they were in intimate relationship with a partner who has AS. No assessment of the autistic characteristics of the participants was undertaken (due to recommendations from the Ethics Committee) and no confirmation of the
partners’ AS characteristics was undertaken or evidence requested to support this.

It is unclear how these results can be generalised to all non-AS women in intimate relationship with a partner who has AS. The participants were procured predominantly through NT women’s support group websites and those organisations that provide support and intervention to NT women, thereby capturing a sample who are experiencing or who have experienced significant difficulties in their relationship. The participants were women who wanted to tell their story, and there may be certain characteristics of these women that are different to those women who do not want to tell their story, or who are content in their relationship with their partner who has AS. The population of women who volunteered for the study may have characteristics that differ from women who do not volunteer for research studies. Additionally, the population of women who volunteered for the study may have access to resources that other NT women do not (e.g., high speed internet, computers, resources to access support groups, strong command of the English language).

This study only sought to measure SWB and empathy and did not include any other self-report measures such as depression, anxiety, or personality. The study was designed as an exploratory study to provide preliminary data around a specific issue, life satisfaction, and has left numerous questions unanswered.

The study findings cannot imply ‘linear causality’ - that the cause of the NT partners low SWB is the behavioural expression of the AS characteristics of her partner who has AS.

The study data was compared to normative data on Australian women; however, although the geographic location of women who participated in the study was predominantly Australia (51.2%), 5 were from New Zealand (1%); 165 from the United States of America (33%); 28 from Canada (5.6%); 31 from The United Kingdom (6.2%); 3 from The Netherlands (0.6%); 2 from Spain (0.4%) and 1 each (0.2%) from Norway; Germany, Vietnam, Israel, Iceland, Middle East, Ireland, Slovenia, France and South Africa. As living outside of Australia was found to predict lower SWB, comparisons should be interpreted with some caution.

Some research studies have found that sympathy (defined as the action taken as a consequence of an observer’s empathic response to an individual’s suffering) is a component of empathy and more likely associated with affective empathy than cognitive empathy. The Cambridge Behavior Scale provides a unidimensional measure of the empathy construct even though substantial research has found empathy to be a multidimensional construct. It may have been
useful to use a different instrument to measure empathy in the present study population in order to attempt to ‘tease out’ the components of empathy that influence the behaviour of NT women.

The Cambridge Behaviour Scale (EQ) does not provide normative data for Australian women; however, the control group was recruited to provide the main source of normative data, so this factor was not considered to be of significance, just noteworthy.

The control group participants were not stratified or random; rather, they were recruited through a process of snowballing and social processes, so they may not be typical of the Australian population of women.

Email addresses of participants were not requested; therefore, this group of women cannot be called upon to participate in further research and cannot be personally delivered the findings of the study.

7.3 Recommendations for Future Research

It is recommended this study be replicated, with the inclusion of measures for stress, depression, anxiety and hopelessness, using NT-AS married and defacto couples as participants.

An investigation of various intervention techniques (e.g., stress management) may optimise SWB within a population of NT women in intimate relationship with a partner who has AS.

Further research of the knowledge of medical and allied health professionals (e.g., GPs, psychologists, counsellors) on the issues facing NT women in relationships with a partner who has AS – with and without a child who also has AS – is also recommended.

An investigation of the personality profile of NT women and their AS partners, as well as the empathy of NT women and their AS partners that uses an instrument to measure the construct using a multidimensional approach, which includes measurement of cognitive empathy and affective or emotional empathy, is recommended.

The investigation of sympathy in NT women should also be included in future research, along with the marital relationship quality and stability of NT women and their AS partners.

Investigation of the type of social resources most desired by NT women in relationship with a
partner who has AS would be of assistance to clinicians and counsellors.

As discussed in the introductory chapter of this thesis, Cummings reported on the influence of Tesser et al.’s SEM model upon HPMood, where they found that only failures in valued dimensions of life negatively affect an individual’s SEM, which negatively influences self-evaluation, internal buffers and, in turn, HPMood. An enquiry into exploring valued dimensions of life of NT women may shed further light on some factors that are influencing their diminished SWB. For example, if NT women self-evaluate being empathic and caring as valued dimensions of their self and something that they are ‘good at’, and despite employing these valued attributes within their relationship with their partner who has AS they fail to produce any positive change within the relationship, then their perceived failed performance will negatively threaten their self-evaluation, reduce internal buffers, and ultimately their HPMood, leading to diminished SWB.

The medical problems (e.g., hypertension, cardiac disease, obesity) that NT women experience and have had proof of diagnosis by a medical professional should be explored in further research.

Finally, an investigation of the financial literacy in NT women and their partners who have AS is also important.

7.4 Contributions Toward the Development of Guidelines for Treatment

This research study’s findings must be viewed with some caution until further research is undertaken on this topic. Given that, to our knowledge, this is the first empirical investigation of women in relationship with a partner who has AS that focuses on their SWB, further studies focusing on replicating these findings are warranted. Some suggestions, however, seem plausible to propose even at this early stage in the empirical investigation of this population.

From a therapeutic intervention perspective, the literature searches and systematic review steps undertaken as part of this study indicate that there are no evidenced based interventions available to clinicians who treat NT women. Most importantly, therapeutic interventions cannot be formulated or empirically tested if we first cannot identify ‘what the clinical problem is’, for which we need to formulate clinical interventions (Voils et al., 2011).

This study has provided some insight at an empirical level into the nature of the problems that NT women in relationship with a partner who has AS may experience. They may
experience a sense of being overwhelmed by the chronic nature of the negative challenges that they face, such that the internal and external resources that normally act as buffers to protect mood stability and maintain it within a positive range are insufficient to combat the effect of those negative challenges. One result of that experience is impairment in mental health that may be measured at a clinical level. These findings indicate that a therapist/health professional should be encouraged to include assessments for stress, depression and anxiety during an initial interview of NT women within a therapeutic setting.

The present findings suggest that the impact of empathy upon the NT women’s mental health and wellbeing needs further investigation before the nature of this impact can be more clearly defined. However, assessment of the empathy component of the NT women’s profile within the treatment setting may be appropriate.

Medical and allied health professionals may consider approaching all women who present as NT women with partners who have AS, as women in need of treatment, placing less reliance on having a formal diagnosis of the partner’s AS, at least in the initial stages of treatment.


Appendix A: Conferences and Publications Arising From This Thesis

The following published paper was first submitted to the editor of the *Journal of Relationships Research* on March 2, 2012; returned for review by the authors on August 16, 2012; resubmitted to the editor on September 19, 2012; and accepted for publication online on November 27, 2012.

**Life Satisfaction of Neurotypical Women in Intimate Relationship with an Asperger’s Syndrome Partner: A Systematic Review of the Literature**


This systematic review explores the psychosocial wellbeing of neurotypical (NT) women in intimate relationship with persons with Asperger’s Syndrome (AS), and intervention models for such relationships. Over 20 pertinent scholarly databases were searched in April 2011. The initial search yielded 1,736 unique items. Articles were eligible if they were a peer-reviewed journal article or a peer-reviewed thesis investigating adult couple relationships where only one partner had AS. Ten studies were agreed by both reviewers to have met these final inclusion criteria. Utilising the National Health and Medical Research Council (NHMRC) guidelines the body of evidence comprising the final 10 studies was assessed to be of an overall grade D or ‘weak’. None of the studies included for final analyses were intervention studies.

**Keywords:** life satisfaction, neurotypical women, Asperger’s syndrome, partner, relationship
A substantial body of both scholarly and nonscholarly, peer-reviewed and nonpeer-reviewed literature has been published on Asperger’s syndrome (AS) since its recognition as a separate diagnostic category in the 10th edition of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10) in 1992 (World Health Organization, 1992a, 1992b) and the *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV* in 1994 (American Psychiatric Association, 1994). It is beyond the scope of this article to chart the history of the typology of AS; however, it is important to note that the classification of AS as a separate diagnostic category within the DSM-IV has not been without its detractors. There has been much debate among academics, nosologists, researchers, clinicians and members of the affected populations both challenging and defending the validity of this disorder (American Psychiatric Association, 2010, 2012; Attwood, 2007; Frith, 2004; Frombonne, 2008; Ghaziuddin, 1992; Hartley & Sikora, 2009; Kim, 2011; Lawson, 2008; Lord, 2011; Macintosh & Dissanayake, 2004; Wazana, Bresnahan, & Kline, 2007; Witwer & Lecavalier, 2008; Wolff, 1996). This debate has resulted in a recommendation by the DSM-5 Neurodevelopmental Work Group that AS be subsumed into the diagnostic category of the Autism Spectrum Disorders (ASD), losing its distinction as a previously held separate diagnostic category within the Pervasive Developmental Disorders (PDD; American Psychiatric Association, 2012). The DSM-5 was published in 2013.

Notwithstanding the above, the core psychosocial characteristics of AS are generally agreed to be a triad of impairments: (1) *difficulties with social interaction*, (2) *difficulties with communication*, and (3) *the presence of restricted repetitive and stereotyped patterns of behaviour, interests and activities* (American Psychiatric Association, 1994). People with AS generally fall in the average or above average range for intelligence quotient (IQ) and some may experience *impairment in sensory sensitivities* (Attwood, 1998, 2006; Attwood & Garnett, 2010; Bentley, 2007; Bliss & Edmonds, 2008; Hénault, 2006; Lawson, 2005, 2008; Slater-Walker & Slater-Walker, 2002).

**Intimate Relationships**

A corollary of the increase in the general awareness of AS is the recognition among members of the affected population, clinicians and academics that adults with AS can and do form intimate partnerships. They marry and have children and participate in and pursue mainstream employment and career opportunities despite their characteristic social and interpersonal peculiarities, and contrary to earlier held beliefs (Aston, 2001; Attwood, 2007; Bentley, 2007;
Bolte & Bosch, 2004; Eisenberg, 1957; Lawson, 2005; Lucas, 2001; Ritvo, Brothers, Freeman, & Pingree, 1988; Slater-Walker & Slater-Walker, 2002; Stanford, 2003; Willey, 1999). Interest in the difficulties that the core characteristics of AS may present for the NT partner within intimate relationships has also increased. (A person who does not have AS is commonly referred to within the AS body of literature as neurotypical or NT.)

**Neurotypical partners**

Numerous anecdotal, non-scholarly and non-peer-reviewed scholarly accounts of NT partners’ experiences within the NT-AS intimate relationship dyad have been published. These publications represent a range of views, perspectives and coping recommendations for the NT partner. Author profiles include: NT women and men who are in or who have been in intimate relationship with a partner who has AS, expert clinicians drawing on their extensive clinical practice and academic experience, and others with personal and/or professional and nonprofessional experience and interest in the field (Aston, 2001; Bentley, 2007; Bliss & Edmonds, 2008; Griffiths, 2008; Hadcroft, 2005; Hendrickx, 2008; Jacobs, 2006; Jessica Kingsley, 2012; Lawson, 2005; Slater-Walker & Slater-Walker, 2002; Stanford, 2003; Weston, 2010).

A second source of anecdotal narrative accounts of living in an AS-NT partnership is the self-help and support resources available online and via various social media (e.g., www.aspia.org.au; www.aspartners.org; www.asperger-marriage.info; www.meetup.com/neurotypicals; www.kmarshack.com).

Most of these sites encourage users to share their stories, providing a rich, albeit highly selected, source of experiential material.

**Gray literature content**

A scan of the content contained within the available gray literature, published books and articles, as well as those expressed on AS partner support group websites and other internet discussion forums and blogs reveal that NT partners share a belief that their experience is unique, and in all but a few cases can only be understood by those who share the experience. The English idiom ‘Only the wearer knows where the shoe pinches’ seems to capture this belief. In some cases there is expressed distrust and strong disappointment held towards members of the helping professions for their lack of recognition, knowledge, skills, expertise and understanding of the issues facing NT women.
The personal, practitioner, clinician and other expert opinions and experiences expressed and contained within this literature suggest that some female NT partners experience a decline in mental and physical health, wellbeing and quality of life, which they attribute to the symptom expression of their partner’s AS. Feelings of loneliness, confusion, frustration, isolation and, at times, of ‘going insane’ are reported, as are disorders of mood (e.g., depression and anxiety), problems with sexual intimacy and sexual activity, and other medical complaints. Reports that the NT-AS intimate relationship is marred by the unwillingness or inability of their partner to engage in shared activities, to provide appropriate emotional support, to effectively communicate, to reciprocate, or to be spontaneous or flexible in their beliefs and behaviours and to learn from their mistakes, seem commonplace. These accounts also suggest that misunderstandings in communication are commonplace, and empathy is often perceived by the NT partner as non-existent. Problematic social lives, as well as hardships resulting from financial mismanagement or their AS spouse’s inability to effectively engage in stable employment, are also reported. A small number of these women reveal that they have ‘become physical’ towards their AS partner and they further report a sense of personal shame associated with this and other ways they use to cope with their relationship problems (e.g., yelling, arguing, name-calling, threatening).

While NT women whose experiences are noted in this literature do demonstrate a shared experience, there is also a variability that can be identified within those shared experiences. This variability can best be explained by the intensity, frequency and type of behaviour expressed by the AS partner. For example, some women report difficulties with financial security resulting from the AS partner’s inability to manage finances appropriately, while another reports that money is not a problem as the AS partner is meticulous when it comes to managing finances. Some report that their AS partner is verbally aggressive and sometimes violent, while another reports that their AS partner has a very gentle and quiet nature and has never been verbally abusive towards them. Similarly with employment, some women report that their AS partner has always found difficulty finding and keeping a job, while another reports that their AS partner has only ever held one job in his entire lifetime. Stephen Shore’s often-quoted statement: ‘If you’ve met one person with autism – you’ve met one person with autism’ (http://www.autismasperger.net/) eloquently captures this theme, found throughout this body of literature, and may contribute to the difficulties in identification of the presence of AS.

**Current Study**
The consistency across the reporting of these personal accounts and professional contributions provides some evidence of converging knowledge within this particular relationship field of study and provides interesting insights into the experiences of some NT women. What is unknown, however, is the extent to which this knowledge is generalisable to other NT-AS relationships.

We conducted a systematic review to investigate findings in the scholarly peer-reviewed literature on the experiences of NT women in intimate relationship with an AS partner and the treatment intervention recommendations for any identified problems.

Two specific questions informed this enquiry:

1. What is the nature and impact of AS symptom expression on the psychosocial wellbeing of NT female partners within the context of an intimate NT-AS relationship?

2. What are the recommended interventions for NT women who share an intimate relationship with a person who has AS?

**Method**

**Article selection**

All peer-reviewed journal articles and peer-examined theses investigating relationships between adult couples where only one partner had AS were identified using the search strategy outlined below (see Table 1). The authors adopted the routinely accepted practice of accepting non-formal diagnostic procedures (e.g., self-diagnosed, partner-diagnosed, partner or self ‘suspects one has AS’) as evidence of AS. This practice has been adopted and is evident throughout the published scholarly non-peer-reviewed literature, largely due to the relatively recent recognition of the disorder and the reluctance of people to seek formal diagnosis due to embarrassment, lack of resources or not feeling the need for a formal diagnosis (Attwood, 2007, pp. 29–39). Screening instruments such as the AQ, The Adult Asperger Assessment (AAA), The Empathy Quotient (EQ), the Systemizing Quotient (SQ) and the Friendship and Relationship Quotient (FQ) have been developed by the Autism Research Centre. These tests are frequently reviewed and are freely available from the internet website of the Autism Research Centre at the University of Cambridge to both professionals and other members of the global community (http://www.autismresearchcentre.com/arc_tests).

Members of the affected populations report having accessed these tests for self- or partner-
diagnostic purposes; also, professionals commonly report the use of these test instruments for research assessment purposes, as evidenced in the studies uncovered by this review.

Unpublished articles, opinion pieces, books and other non-peer-reviewed and non-scholarly works (e.g., internet pages, commercial publications) were excluded (see Table 1).
Table 1: Inclusion Criteria

<table>
<thead>
<tr>
<th>Types of studies</th>
<th>Types of participants</th>
<th>Types of interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>All journal articles and theses</td>
<td>NeuroTypical (non-AS) adults who have been in or who are in an intimate/romantic relationship with a partner who has, or is suspected of having AS. Acceptable diagnostic criteria for AS will include: suspected by spouse, partner or other relative; clinical/expert opinion; reviewer opinion; formal diagnosis and/or a score derived from the administration of the Autism-Spectrum Quotient alone (Baron-Cohen 2001).</td>
<td>All types of interventions or analyses</td>
</tr>
</tbody>
</table>

Search methods: The databases searched on particular dates are listed in the results section (see Table 2). All searches included all languages, and all dates until the date of the search.

Table 2: Exclusion Criteria

<table>
<thead>
<tr>
<th>Type of studies</th>
<th>Type of participants</th>
<th>Types of interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Books, nonscholarly works (i.e., commercial print publications; internet forums/opinions; newspaper articles)</td>
<td>Children only (i.e., not adults or parents) Participants with autism only (i.e., where no subjects/participants were neurotypical) Where subjects/participants were not in, or had not been in an intimate/romantic relationship with an Asperger-affected partner</td>
<td>Nil excluded</td>
</tr>
</tbody>
</table>
Keyword searches for the different databases were formulated to maximise the potential to identify relevant articles with slight variations due to differences in database search functions. A comprehensive list of search criteria is available from the author. Keywords were generally combined in the following way: (Asperger* or Autism or Autistic* or HFA) and (Partner* or de facto or married or marital or marriage or couple* or husband* or wife or wives or spouse* or intimate or intimacy or spousal or fiancé or lover). Appropriate subject heading terms were also searched in those databases that provided them.

The references returned from each of the database searches were then subjected to the following process by two reviewers. One (the first) reviewer was the first author; the other (the second) reviewer was a medical practitioner.

**Duplication and relevance**

All items identified by both reviewers as duplicates were excluded. All items which on the basis of title were agreed by both reviewers as being irrelevant to the present study were excluded, as were those where there was agreement that the item was irrelevant on the basis of the content of the abstract. Items where the reviewers agreed that the content was relevant, or where there was no consensus that it was irrelevant, were retained for review.

Both reviewers evaluated each remaining item against the inclusion criteria. Articles discarded by both reviewers were then compared. Where both reviewers had discarded an article, it remained discarded. Articles that were discarded by one reviewer, but not the other, were then reviewed by both reviewers together until a consensus was reached. Where no consensus could be reached on the inclusion or exclusion of an article then the article was retained for inclusion.

**Reference list search**

The references cited in the bibliographies of each of the articles included after review of the full article were then subjected to the above methodology and screened for inclusion in the review.

**Assessment and evaluation of the evidence**

The NHMRC is the recognised peak national government body with responsibility to oversee, guide, fund and inform public health policy within Australia. The NHMRC produces guidelines for evaluating evidence and developing clinical practice guidelines for Australian researchers, practitioners, academics and other relevant parties. The guide has been adopted as protocol for
evidence reports by the Australian Psychological Society and as such was deemed a reliable and valid document to inform and guide evaluation of the evidence for this review (Australian Psychological Society Ltd, 2010). A comprehensive list of guiding documents is available to the public through the NHMRC website (http://www.nhmrc.gov.au/).

Author contact

Where incomplete reporting of study methods or results was identified, where further clarity was needed and where details for author contact could be sourced then author contact was attempted through email.
Results

The keyword search returned 3,120 items (Table 3). Figure 1 outlines the refinement of the literature set through the consensus process outlined above, leaving 106 references to be reviewed by full article. Of these 106 items, six dissertations could not be sourced (Ebert, 1986; Herron, 1985; Olsson, 2004; Rzepka, 1991; Sanders, 1994; Tunali, 1989). Four foreign language articles could not be sourced in English or adequately translated, despite considerable effort (Garcia, 2010; Kosecka, 1999; Kubo, 1986; Takatomi, Suzuki, Dendo, & Watanabe, 1974), and one further article (Corfman, 1979) could not be obtained despite exhaustive attempts.

Table 3: Search Results

<table>
<thead>
<tr>
<th>Date</th>
<th>Database searched</th>
<th>Articles returned</th>
</tr>
</thead>
<tbody>
<tr>
<td>07/04/2011</td>
<td>Ageline (via OvidSP)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>All EBM Reviews (via OvidSP)</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>AMED (via OvidSP)</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Australian Indigenous HealthInfoNet (not a search engine)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Biomed Central</td>
<td>193</td>
</tr>
<tr>
<td></td>
<td>Cinahl (via EBSCO)</td>
<td>119</td>
</tr>
<tr>
<td></td>
<td>Embase</td>
<td>342</td>
</tr>
<tr>
<td></td>
<td>Expanded Academic ASAP</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td>Family and Society Studies Worldwide (via EBSCO)</td>
<td>205</td>
</tr>
<tr>
<td></td>
<td>Informit</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>ISI Web of Knowledge</td>
<td>590</td>
</tr>
<tr>
<td></td>
<td>Medline and Premedline (via OvidSP)</td>
<td>310</td>
</tr>
<tr>
<td></td>
<td>PsycCritiques</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>PsycInfo</td>
<td>636</td>
</tr>
<tr>
<td></td>
<td>Sage Journals Online</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Science Direct</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Scopus</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Social Work Abstracts (via OvidSP)</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Sociological Abstracts (via CSA)</td>
<td>79</td>
</tr>
<tr>
<td></td>
<td>Women’s Studies International (via EBSCO)</td>
<td>5</td>
</tr>
<tr>
<td>08/04/2011</td>
<td>Proquest 5000</td>
<td>460</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>3120 references</td>
</tr>
</tbody>
</table>

Of the 95 remaining articles, 86 were excluded by consensus of the two reviewers. There was a range of reasons for exclusion. Most commonly, articles used keywords in the title and abstract with a different connotation to that required for this project in a way that was only evident upon reading the full article (e.g., the keyword ‘relationship’ not referring to an
intimate relationship between human adults; the acronym ‘HFA’ referring to Homes for the Aged; and the acronym ‘ASD’ referring to acute stress disorder). Other excluded items included one conference abstract (Hoekstra, Vinkhuyzen, Der Sluis, & Posthuma, 2010) containing information regarding NT-AS relationships. The full journal article, however, did not contain NT-AS relationship information. Hoekstra (personal communication, June, 22, 2011) has confirmed that she has not published any material that would be relevant to this study review. Similarly, Lieberman (personal communication, June 11, 2011) advised that she had made no reference to either parent being on the autism spectrum in her presentation or any other published work. Nine items were eventually included.

Figure 1. Review results.

The reference lists from these final nine articles contained 531 references. Following the same process for inclusion and exclusion previously outlined, of these 531 references, only one (Ghaziuddin, 1997) was agreed by both reviewers to have met the inclusion criteria. Finally, no references from this article’s reference list of 21 met the criteria for full article review. This brought the final review list of studies meeting the inclusion criteria to 10 (Table 4).
<table>
<thead>
<tr>
<th>Author/Year</th>
<th>NHMRC level</th>
<th>Participants and AS diagnosis</th>
<th>Instruments used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pisula, 2003</td>
<td>N/A Non-systematic review article</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Aston, 2003</td>
<td>Level IV Case descriptions</td>
<td>NT females coupled with AS males Author’s clients Diagnostic procedures not stated</td>
<td>N/A</td>
</tr>
<tr>
<td>Eisenberg, 1957</td>
<td>Level IV Case descriptions</td>
<td>100 fathers of autistic children No AS diagnosis made. AS suspected from case descriptions</td>
<td>N/A</td>
</tr>
<tr>
<td>Ghaziuddin, 1997</td>
<td>Level IV Case descriptions</td>
<td>3 couples with a Down Syndrome child No AS diagnosis made Diagnosis suspected from case descriptions</td>
<td>N/A</td>
</tr>
<tr>
<td>Ritvo et al., 1988</td>
<td>Level IV Case descriptions</td>
<td>11 parents of autistic children: 9 males, 2 females. AS diagnosis based on author’s opinion and DSM-III criteria</td>
<td>N/A</td>
</tr>
<tr>
<td>Parker-Rosenbaum, 2006</td>
<td>Level IV Case descriptions Thesis</td>
<td>4 couples: one spouse with a diagnosis of HFA, AS or PDD-NOS by licensed evaluator</td>
<td>Semi-structured interview questions; Grounded Theory Methodology; Oral History and Coding System</td>
</tr>
<tr>
<td>Vaughn, 2010</td>
<td>Level IV Cross-sectional study Thesis</td>
<td>152 University students: 77 males, 75 females. Non-clinical sample (i.e. no AS diagnosis</td>
<td>Autism Quotient (AQ); Expectations Scale</td>
</tr>
<tr>
<td>Pollmann et al., 2010</td>
<td>Level IV Cross-sectional study</td>
<td>195 newly-wed couples Non-clinical sample</td>
<td>AQ Short; Dyadic Adjustment Scale; Rosenberg Self-esteem Questionnaire; Experiences in Close Relationships Questionnaire; Relationship-specific Self Disclosure Scale; Responsiveness Scale Perceived Relationship Quality Components; The Trust Scale.</td>
</tr>
<tr>
<td>Renty &amp; Roeyers, 2007</td>
<td>Level IV Cross-sectional</td>
<td>21 couples; male spouse fulfilled DSM-IV criteria for autism, AS or PDD-NOS by experienced multidisciplinary team.</td>
<td>AQ; Social Provisions Scale; Inventory of Social Supportive Behaviours; Campberwell Assessment of Need – Modified Version; The Ways of Coping Questionnaire The Symptom Checklist-90 Dyadic Adjustment Scale</td>
</tr>
<tr>
<td>Lau &amp; Peterson, 2011</td>
<td>Level 111-3 Case-controlled study</td>
<td>157 persons; married or cohabitating, with at least one child. Adult AS diagnosis made by independent clinicians using DSM-IV criteria.</td>
<td>Quality Marriage Index Hazan &amp; Shaver’s Instrument for Adult Attachment Style; Johnston &amp; Mash’s Instrument for Parental Satisfaction.</td>
</tr>
</tbody>
</table>
The studies by Aston (2003), Eisenberg (1957), Ghaziuddin (1997) and Ritvo et al. (1988) are all case series in which the main focus of the study was not the NT spouse. All contained some comments or observations of the NT spouse of possible AS (not formally diagnosed), and the content of the articles was of a descriptive nature only. No data analysis of these data was performed.

The review article by Pisula (2003) did not contain any information from studies of NT-AS relationships, and Pisula reported that she had not undertaken studies of this nature (personal communication, July 3, 2011). Results from the remaining seven articles are summarised below.

Parker-Rosenbaum (2006) stated that qualitative data analysis was performed using grounded theory methodology with four participants. However, the extent to which the methodology complies with the methods of grounded theory is unclear. Only one round of interviews was conducted by Parker-Rosenbaum, whereas grounded theory method entails conducting subsequent interviews after analysis of each set of interview data until no further questions are raised from the data (Boychuk Duchscher & Morgan, 2004; Glaser & Strauss, 1967). Results from this thesis can therefore only be considered descriptive information from its four cases.

Pollmann, Finkenauer, and Begeer’s (2010) cross-sectional study found there was no significant correlation between relationship satisfaction and the Autism Spectrum Quotient (AQ) score of their spouse for either men or women. Thus, partners of both men and women with more autistic traits did not report lower relationship satisfaction than partners of people with fewer autistic traits. They also found that husbands who reported more autistic traits were less satisfied with their relationship than husbands with fewer autistic traits. Wives with more autistic traits were not less satisfied with their relationship than wives with fewer autistic traits. More autistic traits among men seemed to hamper relationship-specific behaviour and feelings, which in turn reduced their relationship satisfaction. The 195 participants in this study were newly-wed couples. AQ scores were interpreted dimensionally, and the extent to which any participant would meet criteria for categorical AS is unclear. These results may not hold true for the NT-AS relationship.

The thesis by Vaughn (2010) is also a case series of couples without a formal AS diagnosis. were assessed for AS characteristics to evaluate what effect these might have on relationship expectations. Seventy-seven males and 75 females aged 18–25 years and were enrolled in an Introduction to Psychology course at the University of Texas, San Antonio. Instruments used
were the AQ and the Expectations Scale.

Vaughn found that individuals who had lower levels of AS symptoms had higher expectations for their relationship partner (M = 3.86) and individuals who had higher levels of AS symptoms had lower expectations for their relationship partner (M = 3.63). Of the five Asperger traits measured (social skills level, attention to detail level, communication level, imagination level, and attention switching level), those individuals who scored high on AS traits of poor social skills and poor attention switching had lower expectation ratings for emotional closeness, while individuals who rated themselves high on the AS trait of poor attention switching held lower expectations for social companionship only. Individuals who rated themselves high on the AS traits of both poor attention switching and poor imagination held lower expectations for relationship positivity. The AS traits of extreme attention to detail and poor communication were not related to any relationship expectations.

Vaughn also found an association between participants’ ratings of their own and their close relationship partner’s levels of AS characteristics with four of the five rated AS characteristics, and with the fifth subscale of attention switching approaching significance. This study found partial support for the hypothesis that individuals will hold lower expectations for their relationship when they believe that they and their relationship partner are higher in AS symptoms. Partners who were mismatched on their AS ratings of attention to detail were also mismatched on their levels of expectation for emotional closeness; individuals who were mismatched on their levels of expectation for social companionship were mismatched on both AS traits of attention to detail and imagination; and partners who were mismatched on their levels of expectation for relationship positivity were also mismatched on their AS trait of attention switching.

Renty and Roeyers (2007) studied 21 couples from Belgium who were recruited through two support organisations for people with ASD. The male of each couple was diagnosed as having autism, AS, or PDD-NOS by a multidisciplinary team using DSM-IV-TR criteria. Couples had to be cohabitating for at least 1 year, and have at least one child younger than 18 years of age living at home. For NT women, individual adaptation (as measured with the Symptom Checklist – 90 (SCL-90; Derogatis, 1977) was strongly negatively correlated to received social support from family, friends and acquaintances (i.e., those women who received more social support had higher levels of distress – lower adaptation). Given the cross-sectional nature of the study, it cannot be determined whether higher distress leads to engagement in more social
support, or more social support leads to higher distress. Higher levels of autism-related traits in the husband were associated with lower levels of marital adaptation on the Dyadic Adjustment Scale (Spanier, 1976), and perceived and received support from their spouse was positively related to marital adaptation. Marital adaptation of the women was not related to any coping strategy. Formal support variables were associated with neither individual nor marital adaptation in men or women. Social support accounted for a significant amount of the variance (27–89%) in individual and marital adaptation in both spouses after controlling for demographic information and the degree of autism-specific traits (pp. 1250–1251). Male spouses self-reported significantly fewer AS traits than what their spouses perceived them to display.

Lau and Peterson’s (2011) study is the only research identified for this review that included control and comparison groups. However, the main focus of the study was to explore romantic attachment style, marital satisfaction, and parenthood satisfaction in 157 Australian men and women within four subject groups. Diagnoses were made independently by a team of clinicians and confirmed using DSM-IV criteria. The study contained one small group of 11 NT in which their spouse and child had been diagnosed with AS (one father and ten mothers in the NT-AS group). The other three groups were: (1) 22 AS (7 fathers, 15 mothers) in which both spouse and child were diagnosed with AS; (2) 49 NT (13 fathers, 36 mothers) in which the spouse was NT and the child was diagnosed AS; and (3) a control group of 75 NT (16 fathers, 59 mothers) in which none of the family had been diagnosed with AS. Participants for the NT control group were obtained via personal contacts, staff and student email, and research participant pools at a major university. Recruitment procedures for the other three groups were not stated.

Results from parenthood and marital satisfaction scores were not available for the in a NT-AS relationship as data analysis was performed by grouping this data with the NT-NT couple with AS child group data. The only data available for the NT-AS group pertained to adult attachment style. Ten (91%) of this group were assessed as having a secure attachment style, and one (9%) as having an avoidant attachment style, as measured with an instrument devised by Hazan and Shaver (1987) and Mickelson et al. (1997). The control group (NT-NT couple with AS child) had lower levels of secure attachment style (57%), but this result did not reach significance. Additionally, Mickelson et al. (1997) found that females were more likely to have a secure attachment style, but these gender differences were not noted in the Lau and Peterson (2011) study. Mickelson et al. (1997) also found that with higher socio-economic status or education level were more likely to have a secure attachment style; subjects with past childhood
adversities of an interpersonal nature were less likely to have a secure attachment style; and
diverse types of adult psychopathologies and personality traits were also strongly related to
adult attachment. Each of these factors may have had an impact on Lau and Peterson’s results.

Seven of the ten studies met Level IV of the National Health and Medical Research Council
(NHMRC, 2008) Levels of Evidence criteria; one study met level III criteria; and two studies
did not meet any of the criteria (one clinical opinion and one review of current research on
parents — not a systematic review).

Application of the NHMRC grading recommendations to the overall body of evidence resulted
in the assignment of an overall grade of ‘D’ or ‘weak’ to the body of evidence (NHMRC, 2008,
p. 12; see Table 5). This grading recommendation is assigned to the literature reviewed seeking
to answer the first research question only: What is the nature and impact of AS symptom
expression on the psychosocial wellbeing of NT female partners within the context of an
intimate NT-AS relationship? The second research question pertained to intervention studies,
none of which were found within the literature reviewed, hence no grading could be applied to
this question.
Table 5: Body of Evidence Assessment Matrix

<table>
<thead>
<tr>
<th>Component</th>
<th>A</th>
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Note. *For example, results in adults that are clinically sensible to apply to children or psychosocial outcomes for one cancer that may be applicable to patients with another cancer (NHMRC, 2008). Source: NHMRC (2000), p. 12.

Discussion

The objective of this review was to investigate the current state of knowledge available within the scholarly, peer-reviewed published literature regarding the psychosocial wellbeing of NT adult women in intimate relationship with an AS partner, and to appraise the strength of the evidence regarding the provision of clinical practice interventions for this group.

Two specific questions informed this enquiry:
1. What is the nature and impact of AS symptom expression on the NT female partner’s psychosocial wellbeing within the context of an intimate NT-AS relationship?

2. What are the recommended interventions for NT female partners in an intimate relationship with a person who has AS?

Ten studies were agreed by both reviewers to have met the final inclusion criteria. Utilising the NHMRC Levels of Evidence and Grading Guidelines (NHMRC, 2008, p. 12), the studies were assessed and the body of evidence graded. The outcome of the assessment and grading process has shown that the studies which met the criteria for inclusion in this review do not provide reliable evidence for the nature and impact of AS symptom expression on a NT female partner within the context of an intimate partner relationship. Although these studies did provide some data on the female NT partner’s experience, the studies generally focused on the AS partner in parental/marital/intimate relationship, not on the NT partner. This focus may go some way toward explaining the quality of the data on the female NT partner’s experience. Question 1 remains unanswered by the studies included in this review.

None of the studies included for final analysis were intervention studies. Therefore, no evidence was found within this body of research to recommend any interventions for NT women in intimate partnership with a person who has AS. Question 2 remains unanswered by the studies in this review.

This review identifies a paucity of good quality, evidence-based literature on which to base any conclusions regarding the psychosocial wellbeing of the female NT partners of people with AS, and, as a corollary of this, there is no empirical basis for any proposed interventions in this area. One conclusion that cannot be drawn from this review is that the female partners of people with AS do not experience impairment in their psychosocial wellbeing.

Academics, clinicians and other professionals feature in the scholarly but non-peer-reviewed literature on this topic area (Aston, 2001; Attwood, 2007; Hendrickx, 2008; Lawson, 2005; Stanford, 2003; Thompson, 2008) and other contributors to this literature include members of the affected populations themselves, some of whom are also have professional backgrounds and occupations (Bentley, 2007; Hendrickx, 2008; Jacobs, 2006; Slater-Walker & Slater-Walker, 2002; Stanford, 2003; Weston, 2010). This literature base clearly identifies that there are negative impacts of the symptom expression of AS on an NT female partner within the context of an intimate partner relationship, and recommendations for treatment are offered. The
negative impacts reported include disorders of mood, social isolation, physical health decline, financial worries or concerns, critical self-appraisal, negative self-concept/self-image, impaired sexual health functioning, relationship breakdown, confusion and hopelessness. Aston (2009) reports on the development of Cassandra affective deprivation disorder (CADD) as representing a cluster of clinical signs and symptoms experienced by NT partners and other family members affected by AS. Recommendations for treatment include education about AS, communication skills development, social engagement rules development and CBT.

The producers of knowledge from this non-peer-reviewed literature base (experts, expert clinicians and consumers/end users) are recognised by the peak public health body within Australia (NHMRC), and other organisations within the health sector empowered with ethical responsibilities, as invaluable and indeed necessary contributors to and participants in the development, translation and dissemination of new knowledge (Charman & Barkham, 2005; Jackson, 2005; NHMRC, 2012; Thomas, 2008).

**Conclusions**

This systematic review has identified that there is neither academic nor clinical evidence to develop practice-based guidelines for this subpopulation of women. One key role of the academic researcher is to develop and translate scholarly, peer-reviewed scientific research and (ideally) practice-based evidence into evidence-based practice guidelines. One key role of the research practitioner is to develop and translate knowledge from practice-based evidence and (ideally) evidence-based practice into best practice guidelines.

Given that this review identifies that non-evidence-based literature is currently utilised by clinicians to diagnose, treat and inform those NT women in intimate relationship with an AS partner who present with personal and relationship difficulties, and is also utilised by members of the affected population to self-diagnose, treat and inform themselves and their friends and relatives, then some action is clearly needed to address the deficiencies within this standard of practice.

A step forward would be to foster and encourage research targeting the development and translation of knowledge through evidence-based practice and practice-based evidence. This process will entail corroboration between academic researchers, research practitioners, practitioners/clinicians, other stakeholders and members of the affected population. Such a process, while ambitious, would indeed be in line with a key recommendation of the NHMRC
(2012), which supports a ‘comparative effectiveness research’ model (p. 57). Alternately, Voils and Maciejewski (2011) importantly point out that ‘prior to developing interventions, however, we must know what the clinical problem is and to what extent it must be addressed. What outcomes could be improved?’ (p. 39). Perhaps an important and readily achievable next step forward would be to conduct empirical research into this group of NT women, with the aim of identifying what the clinical problem is and what outcomes could be improved.

Acknowledgments

Nicholas Bostock-Ling for his contribution as the second reviewer, and Elaine Tam, John Paul Cenzato, and Kate Masters, Librarians, University of Sydney, Australia.

Appendix

Body of Evidence Assessment Matrix

<table>
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**Source:** *National Health and Medical Research Council Handbook* (NHMRC, 2000, p. 12). Bold type indicates overall results. **For example, results in adults that are clinically sensible to apply to children or psychosocial outcomes for one cancer that may be applicable to patients with another cancer.*
Statement from Co-Authors

Faculty of Health Sciences
Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD candidate “As co-authors of the paper Life Satisfaction of Neurotypical Women in Intimate Relationship with an Asperger Syndrome Partner: A Systematic Review of the Literature we confirm that Jennifer Shirley Bostock-Ling has made the following contributions. In particular, the candidate’s contribution to the following items should be noted:

• conception and design of the research
• analysis and interpretation of the findings
• writing the paper and critical appraisal of content

Signed…………………………………Steven Cumming      Date 7 Jan 2015.

Signed……………………………………………………………Date 8 Jan 2015
### Appendix B: Body of Evidence Assessment Matrix

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Appendix C: Ethics Approval

RESEARCH INTEGRITY
Human Research Ethics Committee
Web: http://sydney.edu.au/ethics/
Email: ro.humanethics@sydney.edu.au

Address for all correspondence:
Level 6, Jane Foss Russell Building - G02
The University of Sydney
NSW 2006 AUSTRALIA

Ref: PB/PE

29 March 2010

Dr Alex Broom
Faculty of Health Sciences
Cumberland Campus - C42
The University of Sydney
Email: a.broom@usyd.edu.au

Dear Dr Broom

Thank you for your correspondence dated 8 March and 21 March 2010 addressing comments made to you by the Human Research Ethics Committee (HREC). After considering the additional information, the Executive Committee at its meeting held on 23 March 2010 approved your protocol entitled “Life satisfaction of neurotypical (NT) women in relationships with Asperger Syndrome (AS) Men.”

Details of the approval are as follows:

Protocol No.: 12437
Approval Period: March 2010 to March 2011
Authorised Personnel: Dr Alex Broom
Professor Anita Bundy
Ms Jennifer Bostock-Ling

The HREC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans-March 2007 under Section 5.1.29.

The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed. Your report will be due on 23 March 2011.

Chief Investigator / Supervisor’s responsibilities to ensure that:

1. All serious and unexpected adverse events should be reported to the HREC within 72 hours for clinical trials/interventional research.
2. All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.
3. All changes to the protocol must be approved by the HREC before continuation of the project.
4. All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The following statement must appear on the bottom of the Participant Information Statement: Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager.
Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

5. Copies of all signed Consent Forms must be retained and made available to the HREC on request.

6. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

7. The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.

8. A report and a copy of any published material should be provided at the completion of the Project.

Please do not hesitate to contact the Human Ethics Office should you require further information or clarification.

Yours sincerely

[Signature]

Associate Professor Philip Beale
Chair
Human Research Ethics Committee

Copy: Jennifer Bostock-Ling jbos8611@uni.sydney.edu.au

Approved Documents:
Advertising Flyer Version 2 04/03/10
Participant Information Statement Version 2 04/03/10
Satisfaction with Life as a Whole and the PWI Scale (Written Format)
Open-Ended Question
Participant Demographic Information
Participant Consent Form
Letter of Invitation
The Adult Autism Spectrum Quotient (AQ) Ages 16+
The Adult Autism Spectrum Quotient (AQ) Ages 16+ Scoring Key
The Cambridge Behaviour Scale
The Cambridge Behaviour Scale Scoring Key
Revised Cambridge Personality Questionnaire
Revised Cambridge Personality Questionnaire: Scoring Key
Appendix D: Advertisement displayed in waiting/reception rooms and published in newspapers

RESEARCH NOTIFICATION

Volunteers needed for Research Project

If you are a FEMALE

- In relationship with, or have been in a live-in relationship for at least three years with, a partner who has Asperger Syndrome (Aspie)

- Are NeuroTypical (NT) or do not have, or are not suspected of having, Asperger Syndrome (AS)

- Aged 18 years and above and

- Can speak, read and write English

....then you may wish to participate in a research project being conducted by the University of Sydney titled:

Life satisfaction of NeuroTypical (NT) women in relationship with men with Asperger Syndrome (AS)
Some NeuroTypical women in relationships with men with Asperger Syndrome report negative implications for their health and wellbeing.

**Research Aim:** This study aims to investigate the Life Satisfaction of NeuroTypical (NT) women who are currently in, or have been involved in, a relationship with a male person who has AS (an Aspie). The relationship must have been a live-in relationship and for a period of at least 3 years.

You are invited to participate by completing a survey form *The Personal Wellbeing Index (PWI-A)*. The PWI-A consists of 9 questions (8 + 1). You will be asked to rate on a scale from zero to 10 how satisfied you are with each of the 9 items. No time limit is set for completion of the survey however it can be completed in as little as 2 minutes. You will also be asked to respond in your own words to one open-ended question. You may write as little or as much as you want in your response to this question. If your partner has not been formally (clinically) diagnosed then you will be requested to ask your partner to complete some questionnaires. Should your partner not wish to complete the questionnaires, you will still be eligible to participate in the study. Participation in the research is voluntary and you may discontinue your participation at any time. Non-identifying demographic information including age, current occupation, previous occupation/s, relationship status, time in relationship (years), number of children and geographic area of residency (e.g. North Coast NSW; S.E. QLD) will be collected.

If you are interested in participating in this study, please contact Jennifer Bostock-Ling at jbos8611@uni.sydney.edu.au or phone 0411 824 944 for further information and/or a copy of the relevant forms and questionnaires.

The study is being conducted by Jennifer Bostock-Ling under the supervision of Dr. Russell Shuttleworth and Dr Gomathi Sitharthan, Faculty of Health Sciences, University of Sydney and approved by the Human Research Ethics Committee at the University of Sydney.

**Jennifer Bostock-Ling**
MSc Masters
Faculty of Health Sciences
University of Sydney
Ph 0411 824 944
jobs@uni.sydney.edu.au

**Dr Russell Shuttleworth**
Lecturer, Sexual Health
Faculty of Health Sciences
University of Sydney
Ph. 02 9351 9647
r.shuttleworth@uni.sydney.edu.au

**Dr Gomathi Sitharthan**
Senior Lecturer in Psychology
Discipline of BSSH
University of Sydney
Ph: 02 9351 9584
G.Sitharthan@uni.sydney.edu.au
Appendix E: Participant Demographic Information Form

Participant Demographic Information

To be eligible for participation in this study you must complete this form

Q1: Age: \( \text{years and months} \)

Q2: Age of partner: \( \text{years and months} \)

Q3: Gender of your partner: \( M/F \)

Q4: Marital status: married, defacto, separated, divorced

Q5: Length of time living in relationship up to the present time or up to time of separation: \( \text{years and months} \)

Q6: Currently living with partner: \( Y/N \)

Q7: Number of children of the relationship:

Q8: Number of children with disabilities or disorders:

Q9: If your child/children have disabilities or disorders please provide details:

Q10: Partner accepts children’s disabilities or disorder diagnosis? \( Y/N \)

Q11: Does your partner have a disability or a diagnosed disorder? \( Y/N \)
Q12: If you answered ‘Yes’ to Q11 please provide details of the disability or disorder:

Q13: If you answered ‘Yes’ to Q11, did you know that your partner had this disorder or disability prior to entering into the relationship? Y/N

Q14: If you answered ‘Yes’ to Q11, was your partner’s disability or disorder diagnosed by a professional person and if so please state that person’s profession (e.g., GP, Psychologist etc.)?:

Q15: If your partners’ disability or disorder was not diagnosed by a professional then who made the diagnosis:

Q16: Are you currently engaged in counselling for difficulties associated with your relationship?

Q17: If you answered ‘No’ to Q15 when did you cease counselling for your relationship difficulties?

Q18: Current occupation:

Q19: Previous occupation/s:

Q20: Have you ever been employed in a helping profession?

Q21: Have you ever been in relationship with a partner who had Asperger syndrome? Y/N

Q22: What is the highest level of education that you have achieved? (primary school, secondary school, matriculation, certificate, diploma, degree)

Q23: My geographic area of residency is: (e.g., North Coast NSW; Sydney; Brisbane; regional SEQ; Nth Qld; Florida; London)

Thank you for completing this form. Please continue to the survey.
Appendix F: Participant Information Statement

PARTICIPANT INFORMATION STATEMENT FOR NEUROTYPICAL WOMEN

Title: The Asperger – NeuroTypical Relationship: Investigation of the Life Satisfaction (Wellbeing) of NeuroTypical Women in Relationship with an Aspie partner.

(1) What is the study about?

This study is about identifying, exploring and examining the life satisfaction/personal wellbeing of NeuroTypical (NT) women who are or who have lived in a relationship with a partner who is self, partner or clinically diagnosed with Asperger Syndrome (an Aspie). In this context a NeuroTypical woman is a woman who does not have, or is not suspected of having, Asperger Syndrome. As a NeuroTypical woman you must have lived with your Asperger partner for a minimum of three years.

(2) Who is carrying out the study?

The study is being conducted by Jennifer Bostock-Ling and will form the basis for the degree of Master of Applied Science at The University of Sydney under the supervisory team of Dr Russell Shuttleworth and Dr.Gomathi Sitharthan.

(3) What does the study involve?

The study involves you completing a survey questionnaire comprising of 9 questions. You will be asked to rate each of the 9 items on a scale of zero to 10 depending upon your belief. You will be asked to answer one open-ended question in your own words. You will be asked to provide non-identifying
demographic information (e.g. age, marital status, number of children, time in relationship, time in relationship prior to diagnosis, husband’s acceptance of diagnosis y/n). If your partner has not been formally/clinically diagnosed then you will be asked to request him to complete some questionnaires. Your partner’s participation is voluntary. You will be eligible to participate in the study even if your partner does not wish to complete the questionnaires. Participation is voluntary. You may withdraw at any time. You will not be paid for your participation.

If you would like to participate in this study please follow the link. .................
If you would like further information about this study please contact Jennifer Bostock-Ling jbos8611@uni.sydney.edu.au

Any person with concerns or complaints about the conduct of a research study can contact the Manager, Ethics Administration, University of Sydney on (02) 8627 8175 (Telephone); (02) 8627 8180 (Facsimile) or gbriody@usyd.edu.au (Email).

Jennifer Bostock-Ling  Dr Russell Shuttleworth  Dr Gomathi Sitharthan
MSc Masters  Lecturer, Sexual Health  Senior Lecturer in Psychology
Faculty of Health Sciences  Faculty of Health Sciences  Discipline of BSSH
University of Sydney  University of Sydney  University of Sydney
Ph: 0411 824 944  Ph: 02 9351 9647  Ph: 02 9351 9584
jobs@uni.sydney.edu.au  r.shuttleworth@uni...sydney.edu.au  G.Sitharthan@uni.sydney.edu.au
PARTICIPANT CONSENT FORM

I,…………………………………give consent to my participation in the research project.

TITLE: Life Satisfaction of NeuroTypical (NT) women in relationship with Asperger Syndrome (AS) men.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

3. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

4. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
5. I understand that I can withdraw from the study at any time during the process of completion of the questionnaire if I do not wish to continue and any information that I may have given to the interviewer up to this point will be destroyed.

6. I understand that I cannot withdraw my consent for my questionnaire to be used in the study following completion and submission of the questionnaire.

I agree with the conditions set out in the Participation Information Form.

Any person with concerns or complaints about the conduct of a research study can contact the Manager, Ethics Administration, University of Sydney on (02) 8627 8175 (Telephone); (02) 8627 8180 (Facsimile) or gbriody@usyd.edu.au (Email).
Appendix H: Satisfaction with Life as a Whole and the PWI Scale

Satisfaction with Life as a Whole and The PWI Scale
(Written Format)

Instructions for Written Format (i.e. test items answered in written questionnaire)

The following questions ask how satisfied you feel, on a scale from zero to 10. Zero means you feel completely dissatisfied. 10 means you feel completely satisfied. And the middle of the scale is 5, which means you feel neutral, neither satisfied nor dissatisfied.”

4.2 Test Items

Part 1 [Optional Item]

1. “Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?”

Part 2

1. “How satisfied are you with your standard of living?”

2. “How satisfied are you with your health?”

3. “How satisfied are you with what you are achieving in life?”

4. “How satisfied are you with your personal relationships?”
5. “How satisfied are you **with how safe you feel?**”

![Dissatisfied to Satisfied Scale](image)

6. “How satisfied are you **with feeling part of your community?**”

![Dissatisfied to Satisfied Scale](image)

7. “How satisfied are you **with your future security?**”

![Dissatisfied to Satisfied Scale](image)

8. “How satisfied are you **with your spirituality or religion?**”

![Dissatisfied to Satisfied Scale](image)
Appendix I: Cambridge Behaviour Scale

THE CAMBRIDGE BEHAVIOUR SCALE

Please fill in this information and then read the instructions below.

ALL INFORMATION REMAINS STRICTLY CONFIDENTIAL

Name:................................................................. Sex:.........................

Date of birth:.......................... Today's date:..........................

How to fill out the questionnaire

Below is a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer. There are no right or wrong answers, or trick questions.

IN ORDER FOR THE SCALE TO BE VALID, YOU MUST ANSWER EVERY QUESTION.

Examples

E1. I would be very upset if I couldn’t listen to music every day. strongly agree slightly agree slightly disagree strongly disagree

E2. I prefer to speak to my friends on the phone rather than write letters to them. strongly agree slightly agree slightly disagree strongly disagree

E3. I have no desire to travel to different parts of the world. strongly agree slightly agree slightly disagree strongly disagree

E4. I prefer to read than to dance. strongly agree slightly disagree strongly disagree
1. I can easily tell if someone else wants to enter a conversation.  
2. I find it difficult to explain to others things that I understand easily, when they don't understand it first time.  
3. I really enjoy caring for other people.  
4. I find it hard to know what to do in a social situation.  
5. People often tell me that I went too far in driving my point home in a discussion.  
6. It doesn’t bother me too much if I am late meeting a friend.  
7. Friendships and relationships are just too difficult, so I tend not to bother with them.  
8. I often find it difficult to judge if something is rude or polite.  
9. In a conversation, I tend to focus on my own thoughts rather than on what my listener might be thinking.  
10. When I was a child, I enjoyed cutting up worms to see what would happen.  
11. I can pick up quickly if someone says one thing but means another.  
12. It is hard for me to see why some things upset people so much.  
13. I find it easy to put myself in somebody else’s shoes.  
14. I am good at predicting how someone will feel.  
15. I am quick to spot when someone in a group is feeling awkward or uncomfortable.  
16. If I say something that someone else is offended by, I think that that's their problem, not mine.  
17. If anyone asked me if I liked their haircut, I would reply truthfully, even if I didn’t like it.
18. I can’t always see why someone should have felt offended by a remark.

19. Seeing people cry doesn’t really upset me.

20. I am very blunt, which some people take to be rudeness, even though this is unintentional.

21. I don’t tend to find social situations confusing.

22. Other people tell me I am good at understanding how they are feeling and what they are thinking.

23. When I talk to people, I tend to talk about their experiences rather than my own.

24. It upsets me to see an animal in pain.

25. I am able to make decisions without being influenced by people’s feelings.

26. I can easily tell if someone else is interested or bored with what I am saying.

27. I get upset if I see people suffering on news programs.

28. Friends usually talk to me about their problems as they say that I am very understanding.

29. I can sense if I am intruding, even if the other person doesn’t tell me.

30. People sometimes tell me that I have gone too far with teasing.

31. Other people often say that I am insensitive, though I don’t always see why.

32. If I see a stranger in a group, I think that it is up to them to make an effort to join in.

33. I usually stay emotionally detached when watching a film.

34. I can tune into how someone else feels rapidly and intuitively.

35. I can easily work out what another person might want to talk about.
36. I can tell if someone is masking their true emotion.  
   strongly agree  slightly agree  slightly disagree  strongly disagree

37. I don’t consciously work out the rules of social situations.  
   strongly agree  slightly agree  slightly disagree  strongly disagree

38. I am good at predicting what someone will do.  
   strongly agree  slightly agree  slightly disagree  strongly disagree

39. I tend to get emotionally involved with a friend’s problems.  
   strongly agree  slightly agree  slightly disagree  strongly disagree

40. I can usually appreciate the other person’s viewpoint, even if I don’t agree with it.  
   strongly agree  slightly agree  slightly disagree  strongly disagree

Thank you for filling in this questionnaire.
Appendix J: Open-Ended Question

Open-ended Question

**Instructions:** Please answer the following question. There is no word limit or time limit for the completion of this task. Some terms have been provided to assist you to respond to this question. The terms are to be referred to as a guide only. You may wish to consider all, some, or none of the terms when preparing your response.

*In your own words how would you describe your relationship with your AS partner?*

**Terms Reference Guide**

- Communication
- Emotional Intimacy
- Sex
- Responsibility
- Equality
- Domestic Duties
- Health (physical and mental)
- Parenting
- Organisation
- Trust
- Social life
- Other
Appendix K: Cambridge Behaviour Scale: Scoring Key

The Cambridge Behaviour Scale: Scoring Key


Please note that this version for the questionnaire has 40 items as the 20 filler items discussed in the paper have been removed.

*Responses that score 1 or 2 points are marked. Other responses score 0. For total score, sum all items.*

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<tr>
<td>1.</td>
<td>I can easily tell if someone else wants to enter a conversation.</td>
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<td>2.</td>
<td>I find it difficult to explain to others things that I understand easily, when they don’t understand it first time.</td>
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<td>3.</td>
<td>I really enjoy caring for other people.</td>
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<td>4.</td>
<td>I find it hard to know what to do in a social situation.</td>
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<td>5.</td>
<td>People often tell me that I went too far in driving my point home in a discussion.</td>
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<td>6.</td>
<td>It doesn’t bother me too much if I am late meeting a friend.</td>
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<td>7.</td>
<td>Friendships and relationships are just too difficult, so I tend not to bother with them.</td>
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<td>8.</td>
<td>I often find it difficult to judge if something is rude or polite.</td>
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<td>9.</td>
<td>In a conversation, I tend to focus on my own thoughts rather than on what my listener might be thinking.</td>
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<td>10. When I was a child, I enjoyed cutting up worms to see what would happen.</td>
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<td>11. I can pick up quickly if someone says one thing but means another.</td>
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<td>12. It is hard for me to see why some things upset people so much.</td>
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<td>13. I find it easy to put myself in somebody else’s shoes.</td>
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<td>14. I am good at predicting how someone will feel.</td>
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<td>15. I am quick to spot when someone in a group is feeling awkward or uncomfortable.</td>
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<td>16. If I say something that someone else is offended by, I think that that’s their problem, not mine.</td>
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<td>17. If anyone asked me if I like their haircut, I would reply truthfully, even if I didn’t like it.</td>
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<td>18. I can’t always see why someone should have felt offended by a remark.</td>
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<td>19. Seeing people cry doesn’t really upset me.</td>
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<td>20. I am very blunt, which some people take to be rudeness, even though this is unintentional.</td>
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<td>21. I don’t tend to find social situations confusing</td>
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<td>22. Other people tell me I am good at understanding how they are feeling and what they are thinking.</td>
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<td>23. When I talk to people, I tend to talk about their experiences rather than my own.</td>
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<td>24. It upsets me to see animals in pain.</td>
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<td>25. I am able to make decisions without being influenced by people’s feelings.</td>
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<td>26. I can easily tell if someone else is interested or bored with what I am saying.</td>
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<td>27. I get upset if I see people suffering on news programs.</td>
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28. Friends usually talk to me about their problems as they say I am very understanding. 2 1
29. I can sense if I am intruding, even if the other person doesn’t tell me. 2 1
30. People sometimes tell me that I have gone too far with teasing. 1 2
31. Other people often say that I am insensitive, though I don’t always see why. 1 2
32. If I see a stranger in a group, I think that it is up to them to make an effort to join in. 1 2
33. I usually stay emotionally detached when watching a film. 1 2
34. I can tune into how someone else feels rapidly and intuitively. 2 1
35. I can easily work out what another person might want to talk about. 2 1

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36. I can tell if someone is masking their true emotion. | 2 1          |
37. I don’t consciously work out the rules of social situations. | 2 1          |
38. I am good at predicting what someone will do. | 2 1          |
39. I tend to get emotionally involved with a friend’s problems. | 2 1          |
40. I can usually appreciate the other person’s viewpoint, even if I don’t agree with it. | 2 1          |
Appendix L: Open-Ended Question Response Examples

Stress

- I find the relationship very difficult as I do love him and want the family to stay together, and yet at times I feel I am sinking beneath an unnameable weight.

- Hello, I am completely at my wits end. My husband has had 12 jobs in the last 16 years. Our financial situation is terrible. His instability in the workforce causes strain in our relationship and insecurity for me. I am constantly worrying about our debt. If I can describe our relationship in two words they would be ‘frustrating’ ... and ... ‘disappointing’.

- He also hid from me before our marriage his severely addictive nature, especially to sex (XXX materials), and marijuana. I endured years of his stopping and starting his addictions before he went into rehab, for the smoking only. I worry about how our son will do if he wants to marry someday. But honestly, our 17-year-old son is much better socially than our husband, he can call up friends and make plans, etc. I don’t know what to do as we approach our 25th anniversary; I grew up through four divorces, he had two to go through growing up. Also, we both are professing Christians, that is why I did not choose divorce. But I honestly cannot endure another 25 (or even 1 year!!!!) like the past 25. I’d rather be single the rest of my life. Sometimes it is all I can do not to hit him. I yell at him sometimes, I just can’t help it. He loses my clothes. He ruins my clothes. I have not been able to maintain a single nice piece of clothing since we met. He can’t smell anything, is hypersensitive to pain, associates colours with letters and numbers, I can’t read his handwriting, sometimes he writes backwards and upside down. The house is covered in electronics paraphernalia and circuit diagrams. I love him, but he drives me crazy and I will probably die of a heart attack or aneurism from the stress of dealing with his shit.

- Never receive praise or compliments and feel that basic human connection is lacking in relationship – Miserable, lonely, stressed, grieved, feel on the point of nervous breakdown when trying to communicate feelings. Concern for the safety of children when he gets distracted driving, cooking, etc. Concern they will not connect with him emotionally as teenagers and adults and they will suffer from that. But instead of receiving understanding and appreciation for all my extra efforts I am criticised for being disrespectful both by AS spouse and by clergy.

- The whole relationship is a stress there is not much good about it so needs are unmet frustration is high and my anger hurts me as much as it hurts him.

- Is obsessed with what everyone else does (i.e. driving) and sees no fault with his own. Maintaining the relationship and family is full on. Partner is in and out of depressive type episodes and has at least one significantly negative relationship in all workplaces. It is all too hard sometimes: gave up my career to look after our children. Since then, I
have just had temporary work fitting in with school hours and his work. I am constantly told to find work and that I don’t contribute to the family.

- Have come to the conclusion that the majority of our stress stems from communication. HE DOES NOT UNDERSTAND/MISINTERPRETS ME – AND I AM THE SAME WITH HIM. Which makes having a ‘simple’ – ‘serious’ conversation with him impossible! Then this trickles down to the children. Our 11-year son has Asperger's – so when he goes ‘into a meltdown’ – Dad follows. Which causes our 3-year-old stress and 16 year to feel 11-year-old is getting treated ‘spoiled’. So I HAVE 4 PEOPLE ‘FREAKING OUT ON ME @ ONCE & DON’T KNOW WHAT THE HECK TO DO!!”

- This is all not good for my health as I find it difficult to sleep and have stress-related stomach cramps and he is suffering from lack of sleep too. I do find myself assessing if I can continue working or maybe just need to take a break for a while, the threat to his job is weighing heavy on my mind, he appears indifferent about the whole situation.

- I walk on eggshells a lot. Unfortunately my AS spouse had little coping skills so when life got tough he would drink and drink. The added stress was awful. I felt alone and abandoned.

- I think to myself sometimes that it would be easier to deal with if he didn’t have an IQ of 145. Then I wouldn’t be so frustrated that he doesn’t evaluate his behaviour and make a change, but I know because he’s told me that it’s not an intelligence thing it’s a stubbornness issue. He recently is talking about stepping down from his position at work because he likes the lesser degree of responsibility that a recent health crisis provided. Eventually the financial comfortableness we have will be eroded as well. He now believes that the answer to his issues is to help others. It’s not that I don’t believe that he has something to offer because I do, but I know that this will be one more way to avoid facing the growth that might repair some of the rifts in our marriage.

- He spreads this tension like a poison gas and changes the energy in the room to that of a black hole. I feel like all the excitement and joy are siphoned out of me.

- I see myself as his special interest and I am wholly responsible for his happiness. I have felt like an emotional punching bag, controlled, stressed, confused, lonely crazy, co-dependant, frigid, unloved. All of these emotions and feelings have been a part of my life. It is only that I am strong and self-sufficient most of the time that I am able to process my feelings and maintain my self-esteem. He has been unable to follow any new routines and unable to cope with my ongoing auto-immune disease.

- Completely stressed and not sure what will come next. Ups and downs and meltdowns make life exhausting. I am apprehensive about how he sees the kids and does not see emotional cues if they have a need. Feels rejection on the slightest disagreement. Has to change jobs when personal conflict happens. Uses very good vocab. to win argument or confuse issue. Can be aggressive when not liking a question.
I was married to my partner for 10 years after going out together for 3 years. We remained friends for 2 years after I left him so the relationship lasted 15 years all together. It was a second marriage for both of us. He was kind, gentle, if a little naive, during our courtship but 3 months after we were married he went into his first rage (with me that is – I later heard from his family members about his rages with them). It is impossible to describe the shock and devastation I felt. I thought he was possessed. For many reasons I tried to make our marriage work, not least of which I am a relationships therapist and I felt responsible to make it work. The rages became more and more frequent, happening about 3 times a week. STRESS: He lived under constant stress and, needless to say, so did I. He was always anxious. In fact, he knew he didn’t have the same feelings as other people. His feelings were: anxious, worried, suspicious and angry. He was never happy. He would say ‘I just want to be happy’. He had everything that most people could ever want – his health, a wife who loved him, a beautiful home on the river that was the envy of most, more than enough money to last the rest of his life, friends, a job he loved, success and lots of travel. But he was never happy.

Communication

I found that I have to work hard at looking after myself, keeping in touch with friends, working and having hobbies, joined a support group as well. Because it so easy to lose the skills to communicate, holding a conversation, eye contact, crowds and panicking about who or what will upset him or being embarrassed by him. No small talk, no intimate conversations – no idea of my routine – doesn’t remember when I work days/time etc even though these are set days and times for whole year – he will not ring if late or has had a change of plans – says ‘if there is a problem that the police will knock on the door and let me know’. Can’t see how this is distressing to me;

Communication is difficult unless about the most mundane things as the normal banter that other couples/people share is very uncomfortable for him. Any sort of discussion/animation/challenge – he becomes defensive. He has to be right. Like we don't talk about AS. He thinks not talking about things is better than discussing/arguing. When I watch other couples – even our grown children with partners – I realise how much I have missed out on – with caring looks/gestures/words. We do have some good times together but there is always a sense of loss/loneliness as there is no deep discussions or sharing.

I do not have an ‘interactive partner’ in my marriage. He never matured out of parallel play. He dictates rather that teachers or suggests.

Communication – extremely poor unless we talk about what he is personally interested in, then he will open up. He likes to answer questions about topics where he has interest. He wants other people to see him as smart and successful.

Our communication can only be either what things happened at work, what things he made (computer whiz), what things he wants to do around the house. He is not interested in my philosophising about anything or theorising either. He says I talk too much. We have very high IQs yet I irritate him with my deep interests in many directions.
My husband had a lot of knowledge in his interest areas and I enjoyed talking to him about them. Mainly I asked questions and he answered them in detail. He didn’t ask me about my life experiences or interests and trying to just have an impromptu conversation was almost impossible. He would usually say, ‘I will have to think about that’ or ‘I don’t know what to think about that’. End of conversation. I was often confused by his answers and the answers didn’t match his actions. I tried many times to explain that I needed him to hug me, kiss me goodnight or hold my hand. He would walk right by me to go to bed, but said he couldn’t remember to kiss me or say goodnight. The last few years of the marriage he openly said that he could not deal with any type of conflict, however small, so I just gave up.

Communication, intimacy, shared interests and activities, shared leisure time all appeared normal. After 1½ years we got engaged, and I began to hit the Aspie brick wall of emotional unavailability. He had no social script for being a fiance, and after the ring went on my finger, his goal had been achieved. He began to dabble in various other special interests (which I knew nothing of before!), and he went back to graduate school around that same time. We went from daily 2-hour long conversations to barely speaking at all. We barely speak any more.

Used to beg for 10 minutes of communication per day, but that was 20 years ago.

Our battle’s in our marriage are firstly communication. It is an effort for him to talk about the day’s events. People have always come to me and said ‘did ____ tell you what happened the other day’ and it is often quite a story that he hasn’t told me.

He was totally unable to express any frustration he had in an adult way. He could only do it if he flew into a rage. Nor could I express any frustration I may have without him flying into a rage no matter how caring I tried to be. So I felt I was never heard or understood. He is intelligent, has a PhD and was the managing director of a company employing several hundred people so he is a very capable person. If his colleagues saw him at home they wouldn’t believe it. He could also be very childish at home and talk like a young child. Sometimes he talked like a computer but he didn’t know he was doing it. When I asked him why he was talking like that he said ‘I don’t know what you mean’ in a computer like voice. Nobody but me saw this. In spite of all of this, we talked about non-personal things in a normal manner. He was totally unable to look me in the eyes and hold a conversation. If I insisted he look at me, he just stared in an unblinking, fixed fashion.

He gets irritable and angry but never verbalises. In attempted counselling, he would ‘make up’ events or miscontrue, bringing up issues five years earlier that he was still angry about. We could never communicate.

One-sided communication – he appears unable to provide emotional support. He tends to ‘lecture’ rather than converse and is always right. We never argue. If we have a disagreement he retreats into himself.
• Communication – one sided. Any comments I make unless they are overwhelmingly positive are viewed as critical, which he cannot handle. He, however, is quick to offer criticism at any available moment.

• A constant struggle on my end to maintain something like a normal level of communication that would be expected in a relationship.

• Have never communicated on a deep level. He would always brush over things as being not important. If we did talk it was mainly about him and his.

Health

• Loss of sense of self-esteem; depression, hopefulness dashed.

• As far as my health is concerned, I have been on antidepressants for 15 years – since the birth of our youngest child. I believe the stress of raising children with such limited support from him has contributed to this.

• I find that I am being degraded verbally on a daily basis without my partner being aware of this or the impact he has.

• My health has suffered badly throughout the years and my challenge has been to stay ‘strong’, which I have somehow managed to do.

• It hurts me financially, emotionally, physically. I live in exhaustion.

• Extremely stressful – has led unsuccessful attempts at separation. Stressful to the point of feeling like I am losing my mental and physical health. Feeling trapped and desperate unless I can create long periods away from my husband. I now have an explanation for so many of our relationship problems and yet they cannot be addressed.

• Seven years since our separation (at my initiative) I am still struggling to recover a sense of peacefulness and well-being and leave behind my tendency to be hyper-vigilant and easily traumatised. I am constantly aware of feelings of anxiety, and am very prone to stress and becoming overwhelmed by life and people. Thankfully, due to some personal achievements and relatively new but solid friendships, I am rapidly gaining confidence and self-respect. My children are flourishing within a home environment of acceptance, warmth and emotional safety.

• Living with this level of stress has caused me incredible health problem, physically and emotionally, terrible damage to my self-esteem by his emotional and verbal abuse, and just never knowing when my ‘walking on egg shells’ isn’t going to be enough and he’ll ‘go off’ and flip out again ... I live in constant fear. It is sad, lonely, depressing, the despair and anguish are excruciating, but because we cannot sell our home, owe a lot of money in debt, and he is 24 months away from retirement, I am hanging in until he retires, at which time I will take my half of his retirement, plus his pension and I will move away and divorce him.

• I have been on antidepressant therapy due to his lack of insight and emotional support. As for the professional assistance/therapy – I think he was more interested in the process than the outcomes.
Since the birth of our son nearly two and a half years ago things have deteriorated rapidly and to the point where I have nearly left on several occasions. Everything to do with the care of our child, and my apparent post-natal depression (which I’m now seriously questioning and wondering whether it was just the stress of having so little support from my AS husband) was so stressful for him that all the difficult behaviours became so much worse and unbearable. He has gone to buy nappies once in all that time, he has probably taken our son out two or three times by himself, and has almost never prepared a meal for him. All these things just appear to be beyond him, although I can only see them as simple and more importantly, things that would be helpful to me.

He experienced a high stress level, which in turn made me feel very anxious and eventually I felt very depressed and lonely.

I have some guilt about the likelihood that I will dump him. However, my other option is to be a robot like him. Maybe he will do better when the daily pressures of family life are somewhat lessened.

He lies and lies, and watches as my mental health deteriorates.

Have had CFS for 21 years – 3 weeks after our engagement. Took me 8 years to realise it was because my I hated my husband – couldn’t admit it to myself. Although I do remember the third blow-up in the first week of our marriage when I went and hid under the covers and cried, wondering how on earth this had become my life. My health has prevented me from being able to take an active role in our financial picture. We have not had resources for therapy, and the help our child needs. So, there’s the truth of it – I’m not proud of what I write – as I record this I just feel selfish and unloving … definitely not Christian. No wonder I’m sick with all this going on – who can stand the emotional pain and guilt of feeling that way. I marvel at all the people who LOVE their AS husbands because I don’t … as much as I want to … I am full of bitterness and anger and feel like I was deceived. I didn’t even know about autism when we married and had no idea that he carried a genetic predisposition that would force me to have to be a mental health expert. I just wanted to be a wife and mom … I didn’t sign up for this.

When I met him, his first wife had died suddenly aged 23, I was dating him eight weeks later and never saw any grief; looking back now, I question my own sanity. I guess I was lonely; he is good looking and has stayed loyal to me, but it is not enough, and I don’t know what the future holds for me, I cannot break up my family and it’s not in me to be unfaithful, my own mental health is suffering greatly and sometimes I break down but I have to get up again I have three people to take care of.

Doesn’t eat properly, drinks too much milk and alcohol, won’t eat salads or green vegetables or fruit. Too fat. Eats too much meat. Poor diet contributed to heart attack at age 61. I have left him nine or ten times. I have rented another house four times. He is so horribly distressed by the thought that he might have to live without me and cope with drastic change that I always go back. I have suffered terrible depression but I am resigned to my fate now. I do love him and care for him.
I became sick with one illness after another, which I put down to living in constant stress. I was unable to stay well within the marriage and moved out.

Most of the time I am scared and sad in the relationship.

I am very physically and mentally unhealthy. I am overweight, don’t eat right and don’t exercise. I suffer from ongoing major depression and anxiety. I had breast cancer four years ago. His health is not the best either. He had a lot of depression after he found out about my unfaithfulness. He has high blood pressure, is also overweight, and has had LAP band surgery to lose weight.

We both enjoy good physical health. My husband is mostly depressed and suffers from severe stress at work. He sleeps poorly. I suffered postnatal depression but have learnt to get on with achieving goals that fulfill me and am well now. I feel desperately lonely and unloved. I have to work really hard to maintain my self-esteem and keep myself out of depression.

I felt he was not taking enough responsibility for himself in regards to his depression – in the end had to leave for my own mental health.

My relationship with my partner just seems to get harder and harder. I am at a point where I feel so run down that I don’t think I can do it anymore. I love him, I just don’t think I can deal with it. I feel so very alone, even when he is around, I feel lonely.

I am obese these days, unkempt, and almost have to force myself to shower daily. I was always thin, socially aware of correct dress etiquette, wore meticulous make-up, held down high paying employment etc. Somewhere along the way, the lack of care, lack of eye contact, has made me disconnect from myself. It is very difficult to describe in words, but because he gives such fleeting eye contact, the deep intimacy between us is missing. and when I look in the mirror to brush my hair or apply make-up, I don’t really see myself. I feel that this point is very important, and I would be extremely interested to know if other women have experienced this feeling of ‘non-existence’ in co-existing with an AS husband. I’m struggling to get through each and every day, with very little reward at the end of it, and by reward, I mean ‘social’ reward. I find that when I socialise out in the community, I’m elated at the stimulation of chatting to people, strangers, and the normal eye contact fulfills me enough to feel a moment of happiness in a day. I find with my AS de facto and ASD child, I don’t get this natural reward of human contact, and our day-to-day life feels so rigid with rules and routines, that there is no light relief. I hope this describes what it feels like. My life feels very empty living with the two of them, and I suspect I’ve gained the body weight by filling the void by eating. On the issue of health care, my AS de facto regularly visits dentists, doctors, specialists, and sets reminders for check-ups every six months. Although we have a health fund, he uses Medicare wherever possible to save money. He does not seem bothered that I have not done any of the above for myself for years and years, nor thinks to question it. As far as emotional support goes, there is very little of this from my AS de facto. I see a counsellor once a month to debrief. I try hard not to bother my
friends too much, however, they do provide me with some emotional support.

- He is using finances as a weapon against me becoming economically abusive ... and in all of this he feels justified and supported and encouraged by his therapist (thinking he’s implementing her guidance.) My stress level as a consequence is high. I feel like I need to be wearing a flak vest (at least emotionally, etc.) here more than I did in Iraq. I feel like I am under constant attack and the enemy is in my camp. My sleep sucks. I wake every night and spend at least several hours awake (usually between 0100 and 0400). I ‘battle’ with him in my dreams. Sometimes I will just wake up with a sense of foreboding or panic … I am not sure whether that is the PTSD from combat coming through or the reality of my home life. I am weary and I am worn, and it’s not getting better. It is getting worse.

**Empathy/Compassion**

- I believe I am really the one who suffers the most because he acts indifferent no matter how I plead, cry, scream, etc.

- Empathy-compassion 2%.

- Empathy/Compassion – he shows very little if any, unless he has personally experienced it recently or remembers it vividly from childhood.

- He shows no compassion.

- Decreased capacity to have empathy towards children and I.

- He has learned empathy with the kids and the two times he showed it to me without a doubt were the two times I was very very sick and he was actually worried I might die.

- I have two children with severe mental health issues (bipolar and schizophrenia) from an ex-husband with a significant personality disorder. This has brought to the surface my husband’s lack of empathy (only for the cats), and inability to cope with any stressful situation. I cannot express my feelings about the mental health situation of my kids because they are viewed as being negative. This puts me in a very difficult position because I must literally keep all my frustrations, worries, fears, anxiety, depression, and any other feelings I might experience inside. It’s getting to the point that merely asking him to help out with something, which would be considered neutral, such as computer problems, meets with anything from refusal to ignorance. There is little to no compassion for my struggles in dealing with the bureaucracy in order to obtain assistance for my kids.

- If I become emotional he does not respond.

- Also being there when I need him, he doesn’t know how to offer emotional support at all.

- No empathy … the physical changes I have since breast cancer/menopause have made a difference to me. He doesn’t see menopause as a shared change – it’s me. And we don’t talk about it.
• He is blunt and shows very little empathy. No outward strong feelings.

• Empathy/Compassion – Says all the right words but nothing really from the heart. Has more empathy, compassion and concern for our old dog than me

• Little compassion except when we lost pets.

• He had no empathy or compassion for other people or even imagined what could possibly be going on with other people. Also he tries to be compassionate or empathetic with our son, but it comes across as baby talk.

• Negligible empathy/compassion for me or others – his ‘needs’ come first – I have had many stress related health problems – he has no interest in my health status.

• He responds inappropriately when I am looking for comfort or reassurance – I usually get a lecture – a helpful lecture, but nonetheless – a lecture when all I want is a cuddle.

• He rarely or never shows empathy/compassion with me or others. He lacks empathy and can never put himself in the other person’s situation.

• He can also say the most unkind things, without knowing he is hurting you. He still has no idea of his impact on me and the family, even though he did recognise this briefly with psychologist. He is not a bad person, he just doesn’t know how he affects people.

• He lacks empathy especially where my older children are concerned, he forgets that I am their mother and love them equally to our son. I found this to be true at work also as we worked together for 6 years which caused all sorts of conflict between us.

• Have had to learn to accept the fact that my husband simply does not have the ability to show empathy in what many would consider a ‘normal’ way

• Nor does he have much empathy.

• I tell him how I feel and what I need from him, and he just stares at me.

• My husband is in no way able to empathise with me or with anyone else. He doesn’t seem to notice if I am upset – although he does recognise if I am cross. Compassionate is not a word I would associate with him, although he has certainly demonstrated compassion in matters regarding myself on a handful of occasions.

• Rage toward his absolute lack of empathy is a daily occurrence. He has as much empathy as someone with Antisocial Personality Disorder, and his weirdness often makes me wonder about the similarities between AD and Schizoid.

• Not only does he lack empathy, you can also have a long discussion and clearly point out how and why he is wrong and you are right, using all the evidence at your disposal (e.g., the thinking question) and you will appear to have convinced him, BUT tomorrow, he will be back to where
you started from, and he’ll have his little fixed idea in place again. He lacks empathy for others (me!) on one hand but reaches out to take care of elderly people or people in need. He volunteers on a regular basis, but says it’s because he is expected to, not because he wants to or gets anything out of it.

Sex

- Our sex life is as much a routine to him as his morning routine of how he gets dressed and brushes his teeth. There is little to no spontaneity.

- Sexuality is a huge area of difference as is communication and the reciprocity of emotion.

- Sex is well … lonely and silent. He says he is concentrating, so he can’t look at me or talk to me (I guess I believe him), but I need more.

- Sex, physically satisfying, emotionally distant.

- He is constantly emotionally flat, does not want, or seemingly need anyone other than himself and his computer (Also see below?). For the whole of my marriage I have effectively lived alone – mentally, emotionally, sexually. After our first year of marriage he was, to all intents and purposes, gone. We have no emotional or sexual intimacy – he believes that 30 second, roll on-roll off-fall asleep sex is normal, and will brook no discussion as to why he believes this. He thinks we have not had sex for 15 years because I am frigid. He cannot tolerate being touched, gives rigid hugs, but only because he believes that men must their wives, but doesn’t like to. I recently found that he thinks men get married because they need housekeepers, and to get free sex.

- He is content to watch as much TV as possible every day, not needing any intimacy with me, except ironically sexual even totally ignoring me and/or taking me for granted. He has even cheated on me a total of six times with prostitutes (I found out about the first five at one time when he confessed back in’91 in rehab). He seemed truly repentant, I chose to forgive and move on … then 2½ years ago or so I intercepted a credit card bill in mail that had a charge to a brothel in Nevada on it. He admitted to seeing another prostitute then but swore he’d been faithful all the years before then. He cried, was really sorry, got counselling after we separated, and once again I found myself forgiving him and letting him come back home.

- The little emotional intimacy that we had is gone now, and as a result sex is practically non-existent. I used to enjoy making love to him because there was an element of naivete on his part, but I had to initiate it 99% of the time because he could not bring himself to do because despite of assuring me that he thought about it and wanted it, he felt ‘dirty and ashamed’ about it.

- Sex was a bit awkward (in the beginning), but I assumed it would improve as the relationship progressed. Sex became less frequent – It has been 10 years since we’ve had sex – I had a realisation around that time that, while he said he loved me, he had no idea what that even
meant. I’ve also discovered he needs deep pressure and certain preferred visual stimuli, neither of which do anything for me, so it’s easier for him to masturbate on his own anyway.

- Sex dropped off hugely, it seemed he had just kind of gotten it out of his system if I can put it that way. Where sex was/is to me an integral part of a relationship and a source of physical and emotional closeness, to him it was something that was not so important, and he found my reaction of distress very confusing and still does not entirely understand. In some ways he is adventurous, in others not – for example he maintains that the bed is the place for sex and is almost comically bewildered by the suggestion that it take place elsewhere.

- Sex? He hates to be touched. That pretty much precludes sex. We don’t have it. Oh we tried in the beginning of our marriage but it was abysmal. It was like trying to make love to a robot who had never been programmed for it, or who had a really big glitch in his program. Take your pick. I once let several years go by without any touch; finally I broke down and asked him for a hug and he said he had to think about it! I just go up to him a few times a year and tell him to brace himself, that I need a hug. He tolerates it somewhat sweetly since he knows this means I love him. He got married, we don’t have sex, so now he has a free maid. Yuk.

- When things are going well between us then sex is generally okay and normal, however if there is unresolved conflict between us we can go for weeks on end without any intimacy whatsoever. He doesn’t understand or want to know how to please me, how to keep the marriage alive, he doesn’t understand the intricacies of intimacy.

- Sex has NO emotional attachment for him; I had always known that he had not felt emotional intimacy during sex prior to our relationship, but during counselling he disclosed that he had never felt satisfied with me despite appearing to enjoy himself. He developed a secret cybersex habit that exceeds 20 hours per week – He has stated that he must attend church to remain moral and faithful.

- My partner is mostly disinterested, and only interested in self-satisfaction.

- Our sex life is sporadic, it is too much ‘pressure’ on him to preform more than a few times a month. It has to be ‘his idea’ my suggestion does not ‘count’.

- He can’t sleep with anyone in his bed. I have been sleeping in another room for six or seven years now.

- We have not been intimate for quite a while now.

- There is no sex or emotional intimacy.

- No sex life for the past 6 years.

- No sex for most of marriage.
Love-making, for the first two years of marriage, was great. Sex has been non-existent since. We have been married for seven years. He refuses to touch me and will not allow me to touch him intimately. I did have an average to high sex drive. These sex-less years have been very difficult for me to handle. For several years, I tried to ‘manipulate’ (his word) him into wanting me/sex. (Romantic – candles, baths, wine, dinner, movies, toys, nighties, lighting, etc.) He thought my actions were ‘sneaky’ because I had a ‘hidden agenda’. How can a wife wanting love-making from her husband have a ‘hidden agenda’? Can sexual intimacy be a blind spot in the brain? This has never made any sense to me – but this is what I have been told by him. Ultimately, my plans to seduce my husband made him become distrustful of me and my intentions in ‘all’ matters. Social, money, planning for the future, etc. I eventually gave up, and now I cannot see him in a sexual way. I only have sisters, so I see him as maybe an older brother – but I cannot date. I cried and grieved for over a year due to the loss of my sexuality and told him of my anger and sorrow. He does not care. He can only sense/satisfy his own needs. God did not intend for me to find intimacy love. He does not like smells – like perfume or a woman. He does not like lotions or gels – hates the feeling. He does not like to snuggle, does not want to be touched. He will sleep in his recliner until 1.00–3.00 am, then comes to bed and sleeps for a few hours without touching me. He only comes to bed when he knows that I am asleep. If we go out of town to a hotel, he sleeps on the couch. To deal with my sexless life, I have had to stop reading and watching romantic novels/movies. To stay away from man/men/situations where an ‘attraction’ to another may arise. I believe that I have started menopause early due to the lack of intimacy. I am told by most that I am attractive; 5’6”, blonde hair, blue eyes, size 4, physically fit from regular exercise, and well educated. He stole from me the very thing he was to give me when he asked me to marry him – unconditional intimate love and my self-confidence as a wife/woman. I was told by the marriage therapist that we sought to help us that, unless he wants to change, I need to look at my role in this marriage as being married to a man who has a prolonged illness and cannot physically relate sexually. This made him feel better, but I just wept and felt loss.

• Sex. He was not interested in sex. We did have sex during our courtship but I suspect that is because he knew you were supposed to do that. He was unable to look at me or to say anything during foreplay or intercourse. Naively thought that when he felt more safe and relaxed he would be able to do these things. Instead we stopped having sex 3 months after we were married.

• Very demanding on sex. Often wondered if he had multiple secret partners, or was swinging … some very strange requests and fantasies.

• No sex life anymore as I can’t do this without intimacy anymore and the physical changes I have since breast cancer/menopause have made a difference to me.

• Sex was satisfying, but lacking intimacy – task oriented.

• No sex for more than 10 years, prior to that just for his physical relief then premature ejaculation diminishing to impotency.

• There has been no physical contact for about 25 years.
• Emotional intimacy, sex, empathy/compassion: We have argued over ‘him’ not wanting to ‘make love’, over the years it has gotten less and less. He said ‘It’s not you – it’s me and I don’t know why I feel this way.’ I don’t want it to be a chore.

• My health has suffered in that I have gained 70 lbs over the course of our marriage and can’t seem to lose weight. This, in turn, has affected my sex drive, and for the past 2 years, I have had no interest in sex whatsoever. My husband has a high sex drive, and 90% of the time I give in to his sexual needs, but I rarely feel any emotional intimacy during our sexual encounters, and instead feel it is more of a physical release for him. My anger toward him for not helping out more, or for how he yells and snaps at our son, also greatly kill my sex drive.

• Sex – either every day or 10 days will go by and he will be completely disinterested as if it is not worth it any more.

• I tried many times to explain that I needed him to hug me, kiss me goodnight or hold my hand. He would walk right by me to go to bed, but said he couldn’t remember to kiss me or say goodnight.

• I feel so alone within my marriage and this caused by and effects communication, emotional intimacy, sex, responsibility for our children and home duties, empathy/compassion, trust, health, equality, domestic duties, organisation, stress and so on.

• He never takes the initiative. Unless it’s for sex. I am having much trouble feeling in the mood with someone who is like a perpetual teenager. I just can’t get myself to respond.

• Oh, and you mentioned sex in your list … that had been the only positive aspect of our relationship. The ONLY way I could really connect with him. He was under extra strain at work, so when we went 3 weeks with no intimacy, I chalked it up to that. But one night, I became concerned there was more to it than that. The next morning, after a good night’s sleep, I asked if he was angry at me. ‘NO!’ he assured me. Oh, I replied, ‘I thought maybe you were, as I’ve noticed you seem to be avoiding me.’ To my dismay, he rapidly began to nod his head up and down, with a ‘uh hum’. He then proceeded to tell me, he’d ‘had to teach me a lesson’!! All because, after moving back he’d assured me he now had a whole new attitude about me, and marriage, and would I please be patient as he overcame a ‘lifetime of bad habits’ (which FLOORED me as he never before had even hinted anything was his responsibility!) but after 3 months of no change at all, I had told him all I seemed to matter to him was in the bedroom, and I needed more. I needed to know I mattered more than that. How dare I?! Then, by golly, even the bedroom closeness would be taken away. Which he did.

Positive Aspects/Advantages

• The other positive is that he is not greedy about money, and doesn’t show any sort of jealousy if I go out, talk to other men, etc. This for me is the only saving grace – that I can go out (albeit by myself) and at least
socialise with men and women without having to deal with jealous husband syndrome. I wouldn’t be able to survive otherwise.

- We have a very comfortable life which is intellectually stimulating and allows me to go off and do my own thing.

- The positives are that I can do whatever I like (as long as I make no demands on him) – this is what attracted me to him in the first place. As soon as my youngest finishes her HSC, I am travelling. He won’t come ‘You get bird flu in Vietnam!’ He is stable, dependable and reliable (to forget to give me phone messages lol!).

- Advantages: he seems to want to be with me and he is generous (i.e. he never asks me what I spend; he never says I can’t have something; he is always accommodating when I want to have friends over and puts in a special effort to please them).

- He has a good income and provides well materially and endeavours to ‘compensate’ financially.

- He has always been a good provider financially and holds a responsible job as an engineer.

- There are some advantages I guess. He is loyal – would take kids to events. Always be on time, will fix up things around the house when asked. And did practical things for the kids. Lets me do all the finances. Happy for me to go out/away with my own friends. Good sense of humour. Can be life of the dinner party if someone in interested in his interests. Can be very entertaining.

- He calms me down, helps me think logically.

- I guess that’s one advantage: finding inner strength and meaning, and defining with ever increasing clarity what I hold most important in life.

- In terms of positive things/advantages? There are many. He is unbelievably smart and gifted. So many things come so easily for him (computers, cooking, handicrafts, gardening, car care, the list goes on …) and he is good at almost everything he does. He is fiercely loyal and would die for me. He is protective, safe, a good friend, neighbour, employee, son, brother, pet owner. I think he is less ready to get help because of these things: he is a highly intelligent and capable person, and believes he can ‘fix’ himself.

- I think that my relationship with my AS husband is really good. I mean no relationship is perfect but he treats me well, shares more than half the household responsibilities – pays the bills, does things that most guys couldn’t be bothered with like ring up insurance companies and patiently wait for quotes and have all this logically organised in a list.

- My Aspie is guaranteed faithful, compliant, pleasant in social company (he can say silly, embarrassing things at times), will do anything for me, loves me unconditionally – even if I don’t feel loved, I do know that he does love me and would never leave me.
What’s weird is that all these years, he has given me the most lovely cards and signed Love xxx, etc. bought me nice presents when required, etc. In February of this year, even though things were going downhill, he asked me to attend a Valentine’s Day concert (????). He gave me a lovely V Day card. On Mother’s Day, he gave me flowers and a lovely card. My counsellor says that when he does that, it doesn’t mean the same thing to him as it would to me. I call it ‘love by the checklist’ – Mother’s Day card – check! It doesn't make any sense – our marriage was toast and yet he still continued on this track.

I like his intelligence and I am proud of him. He is also quite funny with a good sense of humour but he is extremely cynical.

I love his organisation skills, I am very organised but he is way, way better.

He is a professional competent workaholic who is calm and honest (except for his denial of AS-like condition). He is a high school principal, and deals with stressful emotions of students and staff every day … he calmly ploughs through this and comes out looking very competent.

My husband is extremely intelligent and is the director of R&D for a communications company. He loves his job, which is very structured and contains no emotional component. He works with so many people that are just like him – introverted and nerdy – that he feels perfectly ‘normal’ while at work. He feels his life is stable, which to him is the most important thing.

My husband is very ‘high functioning’ and has consistently provided excellent financial security for us. He is also a kind and generous man. Though most who meet him find him very likable.

He has a good soul. The root of him is good. Loves his kids to bits. One great advantage is that he is better at getting the kids out of their meltdowns than I am. I am learning from him in this way.

My relationship with my spouse is extremely strong. We both have very logical viewpoints and are able to view our differences objectively and talk without charge about what we’re feeling.

My partner has many positive aspects; he is great at organising and researching things he is interested in which in turn I benefit from as well. He is very trusting and loves me dearly.

At best he was, and is, very amusing, trustworthy, talented, sweet, ego-driven, handsome, kind, romantic and hard working, a perfectionist who hated going out to work, so he renovated houses. He is a Yorkshireman.

We are comfortable with our status as a neuro-diverse/atypical family, while striving to continue growing and changing as we manage our differences, relationally. My husband holds two masters degrees and is about a third of the way through a doctorate. He has always excelled at academics and generally does well in the university setting, with perhaps one or two kinks coming about per semester that would likely be attributable to the HFA/AS. We try, in our family, to talk out
feelings, view mistakes as learning opportunities, and to reach out to external resources when problems become a stress nightmare. My husband feels bad when he finds himself mired in a quandary that he’s experienced before, but failed to heed. It is especially trying for him that he, with an unusually high IQ, and our oldest son, who is developmentally and intellectually disabled (IQ: 70), both have patterns of behaviour that they’ve thus far been unable to conquer. I also must strive to be of assistance, w/o mothering my husband or rushing in to fix problems that his behaviour’s created. It’s a tightrope I walk, but I am a naturally optimistic personality in temperament, so we balance one another, and I am able to see all the wit and wonder my husband brings to day-to-day life.

- There were two major advantages: I bought a house around the corner from him in a gentrifying area, so I have a house that I would not have had; he was good at editing appeals, and that has helped my career as an attorney. Finally, he helped me to be more objective about many of my clients, which also helped my career.

- He drives the eight hours when we visit California (sorry, cheap vacation to same place … relatives’ houses). He has great medical and dental benefits. He has an excellent retirement plan and investments. He is gone from 4 am to 5 pm. There is and never has been any physical abuse.

- He is very smart and amazing with any kind of electronics. He is a mechanic by occupation. He can fix anything you give him by just looking at it for a few minutes, it’s quite amazing the things he figures out.

- He was a great fixer of things and got a great deal of satisfaction from mending machinery, rebuilding cars, adding a balcony to the house. He was a hard worker for as long as he was interested in what he was repairing or building, but quick to drop it when something he considered more interesting came along.

- Yes I would not change him for the world. He comes with some bad and lots of good points. Yes, I will always be the one doing the changing, but I am prepared to be the peacemaker. If I had to choose again, I would choose an Aspie. He is witty, very clever, articulate in his areas of expert knowledge, fun to be with and challenging.

- Lovely family, great support and feel loved by children, good.

- On the positive side, he is very supportive of anything I want to do. He believes I can do anything. He totally accepts me as I am and never asks me to change, but if I want to change he will help me in any way he can. Life is never boring with him.

- But he was /is a good man who put himself totally into school and cared for us in his way. I sometimes envied his ability to focus to the exclusion of all else. Recently B and I went to South America for the wedding of the second youngest and his brother above and bro below went too, very satisfying and fun. I can’t complain. They are happy and generally settled and very supportive of each other. A great comfort for us both. More benefits – B has allowed me space – by default! to grow,
and do my thing, sort of. He is strong on social justice – in theory and so intelligent and knowledgeable about so much. He is the father of my kids. Neither of us enjoys too much TV and can enjoy listening to music and/or reading. We both have a good/quick sense of humour. That has been a lifesaver for us. I have my garden. He now has crosswords and we both bike ride each Sunday at 9 am with friends. And we walked the Camino 2 years ago – 770 km across the top of Spain, with backpacks and each other! At times I feel disloyal to him with my story, but it is my story.

- Positives as – loyalty!!! 1000% if I tell him he HAS to listen /do or whatever he will – but I HAVE to TELL him. Advantages/disadvantages – I will NEVER want for anything material! But at the end of the day – I love him. I would have had a completely different life if I had not married him and 95% of the time I am very happy.

- My husband and I are divorcing amicably and we still love each other. He has been a very good provider for me and our kids.

- Since he worked continuously, he did pay off the house mortgage quickly … the one positive aspect.

- I have respect for his financial stability. I am so glad I have one son (15) who is neurotypical but I do not want to have him feel he has to make right the misadventures others. I’m sorry he has had to be raised without a ‘hands on’ Dad but he has had a stable home life, his Dad has dignity and my son can appreciate his Dad has demonstrated responsibility in his own limited way.

- My husband is a honourable, quality, loving man; he would never be unfaithful (NOTE: Also included in Trust).

- My life is so happy, I regularly laugh until I cry, as I see new twists and turns through the eyes of Aspergers. I am more patient and a better person by far for my experiences. I like to help others and altruism is the best high! I am also selfish and make time for me, which keeps me sane! I am grateful as I have so much love in my life and I consider myself fairly lucky.

- We have a loyal and faithful relationship and have always been friends.

- I love him. On the positive side, he is a caring and devoted husband and father, and he helps out around the house.

Diagnostic/Therapeutic Issues

- Could not understand a lot of things about my partner until AS was mentioned.

- Like all long-term couples, we have shorthand for things, and our communication has vastly improved since the understanding of Aspergers Syndrome. He practises phrases and situations that he thinks that work, however using a script doesn’t usually work, because he can’t follow that up with the normal chit chat and off-the-cuff remarks
that NTs are so good at. He can’t perceive situations or garner a correct response, so he often creates issues where he thinks people have disbed him, or that they are laughing at him. So the dynamic is, that he wishes to fit into NT world, but at the same time, can’t stand it.

- Communication was awful previously but since my diagnosis, clear, concise and direct is the only way to speak.

- I have been in therapy for this relationship after our combined therapy failed. My therapist suggests divorce because he has severe financial issues that he refuses to resolve. He has had the support of my family, the veterans administration, doctors, lawyers, accountants, financial advisors, psychiatrists, etc, many pro bono yet he will refuse to let them help him. He initially agrees and acts even thankful and relieved then will not cooperate and give them the paperwork that is needed to file papers, etc. He has not filed taxes in the past 7 years, bounces cheques each month, refuses to work over a few hours a day and has no inner motivation. Why do I stay? I ask myself the same thing every day.

- The last straw for me was when my husband left me the week my father died: my ONLY relative who would even acknowledge the AS diagnosis, and due to some experience with AS, was my only help, my mental ‘backdoor escape route’ if things ever got to the point I could not go on. Our counsellor, trying to prevent my husband’s past cruelty when dealing with my family deaths, was able to convince my husband he needed to go with me and adopt the attitude and behaviour of a servant. Just be and do whatever was needed. Like a small boy, my husband stared at him, at 8 am as we literally were prepared to hit the road for the long trip straight from his office, that solemnly declared he ‘could do that’. Mind you, at our regular appointment the previous day, the doctor was so concerned over what might happen, he asked us to come in the next morning, on his day off, just to meet with us again. That’s when he came up with the plan how to ‘program’ civil behaviour. (Post-AS partner seeking AS therapeutic intervention/education) I can see that sex may even be possible once again!