

# **Research and insight into NT/AS relationships**

Collected by: Faaas, Inc and JA Morgan BEd Grad Dip, 2017



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# **1. Executive Summary: Stress, Coping and Resilience: An Investigation into the Well-Being of Partners of Individuals with Asperger's Syndrome** Dr Lisa Abel, Dr Vicki Bitsika, Bond University, Qld, Australia

In 2010 – 2011 we undertook research to investigate the mental health outcomes of individuals in AS-NT relationships. We specifically focused on the influence of fatigue, resilience and stress (coping) on depression and anxiety in NT partners.

Taking a functional analytic approach, we also assessed the extent to which NT partners had experienced reinforcer losses (social, emotional and cognitive) since the onset of their NT-AS relationship. One hundred and 122 partners (113 females) completed the questionnaire component of the research program, and 17 participants completed the interview; 16 of these came from the original sample of 122. The average age of NT partner was 48.6 years, and the average age of their AS partner was 50 years. The average age of the AS partner at diagnosis was 46.5 years. Eighty-one percent of the NT partners taking part in the study were married, and from the interview data the average number of years partners had spent in their NT-AS relationship was 20.5 years (range: 2 years to 46 years). Partners' scores indicated that they were experiencing mild-moderate levels of anxiety and depression, and it was found that fatigue, resilience and (non-productive) coping were all significant predictors of partners' anxiety and depression. The interview data revealed many of the partners had experienced a decrease in, and in many cases a cessation of recreational &/or social activity since the onset of their AS-NT relationship. Many partners also reported experiencing increases in anxiety and depression symptoms since the onset of their relationship with their AS partner.

In relation to planning and decision making for their families and/or partnerships, many partners reported having the sole responsibility for this. Partners also reported an absence of free-flowing exchange and emotional content in their communication with the AS partner. Additionally, due to a lack of understanding and support from others, partners reported having difficulty with communicating their relationship experiences and challenges. Overall, there appears to be a pattern of restriction and control in relation to partners' social, emotional, cognitive and communication behaviours, however, given the nature of AS, partners feel as though they need to maintain these behaviours in order to avoid crises. While these compensatory behaviours are designed to manage the day-to-day challenges of their relationships, the long-term outcome is that these behaviours impact upon partners' health & well-being, as evidenced by partners' reports of increased anxiety, depression and isolation. Recommendations for NT partners is to re-introduce previous reinforcers - physical activity, social interaction, emotional engagement with others - as a way of helping to facilitate positive coping and increase physical and mental well-being.

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## **2. Life Satisfaction of Neurotypical Women in Intimate Relationship with an Asperger's Syndrome Partner: A Systematic Review of the Literature,**

Jennifer S. Bostock Ling, Steven R. Cumming and Anita Bundy [http://journals.cambridge.org/abstract\\_S1838095612000091](http://journals.cambridge.org/abstract_S1838095612000091)

*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. P 96*

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## **3. Conflict resolution and relationship satisfaction in individuals with an autism-spectrum disorder and their neurotypical partner**

MCNEIL, E.C. (Bond University), ABEL, L. M. (Bond University) & DOLEY, R. (Bond University)

The aim of the current study was to examine relationship satisfaction, psychological-wellbeing, and conflict in intimate relationships where one partner has an autism-spectrum disorder and the other partner is neurotypical.

Very few studies have empirically examined NT-ASD relationships and considered the unique challenges of these relationships. The present study examined relationship satisfaction, conflict resolution style (individual's approach to conflict resolution), ineffective arguing (couple's approach to conflict resolution) and psychological well-being (stress, depression, and anxiety) in NT-ASD dyads ( $N=161$ ).

This information was obtained in survey format and participants were recruited from ASD support groups worldwide. An interview component ( $N=19$ ) was also conducted to provide a richer description of the nature of conflict in NT-ASD dyads.

Results reflected reduced relationship satisfaction for NTs and individuals with an ASD. NTs were more likely to use an effective style of conflict resolution than those with an ASD. NT partners and those with an ASD reported greater ineffective arguing in their relationship compared to the control group. Depression scores were significantly higher for NT individuals than the control group.

Thematic analysis revealed that NTs and those with an ASD perceived different causes of conflict in their intimate relationship. Ideals means of resolving conflict were similar for both

groups and reflective of effective strategies. Emotional withdrawal was the strategy described as most commonly used by the NT partner. The strategy most frequently used by the partner with an ASD was avoidance.

These findings indicate that NT-ASD relationships do differ notably from NT-NT relationships. Relationship satisfaction and psychological wellbeing are reduced, and conflict is managed differently. These findings provided evidence that intervention for these couples requires further investigation and should take into account the unique attributes of NT-ASD dyads.

The key limitations of this study pertain to the limited number of participants with an ASD and the use of self-report data rather than observation when investigating conflict.

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#### **4. Asperger's Syndrome/Autism Spectrum Disorder and Marital Satisfaction: A Quantitative Study** Kim L. Bolling, *Antioch University - New England* **Dissertation Committee**

George Tremblay, PhD, Committee Chair

David Arbeitman, PhD, Committee Member

William Slammon, PhD, Committee Member

**Document Type** Dissertation **Publication Date** 2015

#### **Abstract**

Few empirical studies exist that examine adult Asperger-affected relationships. The purpose of this study was to determine whether the marital satisfaction of individuals in relationships in which at least one partner has Asperger's Syndrome (AS) or Autism Spectrum Disorder (ASD), differs in some significant way from the marital satisfaction of individuals in relationships in which neither partner has AS/ASD. Participants were 126 adults in relationships in which at least one partner had a diagnosis of AS or ASD, recruited from Asperger- and autism-related websites, social media, and organizations from English-speaking countries. Couples consisted of heterosexual and same-sex couples, couples with and without children, and couples in which either the male and/or the female partner had an AS/ASD diagnosis. Members of each couple responded independently. Using an online version of the Marital Satisfaction Inventory, Revised, (MSI R), the mean scores of individuals in AS/ASD-affected relationships were compared with the normative data of the MSI R for males and females on each of 10 dimensions of marital satisfaction, resulting in 20 comparisons. The dimensions of marital satisfaction included global distress, affective communication, problem solving communication, time together, aggression, sexual dissatisfaction, disagreement about finances, family history of distress, dissatisfaction with children, and conflict over child rearing. Comparisons were made using independent samples t-tests. Because of the highly significant results, step-down procedures were not needed to correct for possible inflation of Type 1 errors. Of the 20 comparisons, 15 demonstrated significantly more dissatisfaction among individuals in AS/ASD-affected relationships than those from the normative data sample, at  $p < .001$ . In all cases, individuals in AS/ASD-affected partnerships were more dissatisfied than their normative

sample counterparts. Separate analyses revealed that NT individuals were less satisfied than their AS/ASD partners. Women reported higher levels of sexual dissatisfaction than men. Findings of lower marital satisfaction for AS/ASD-affected relationships replicate those of a similar, prior study, but differ from two other studies that found no difference in marital satisfaction related to partner AS/ASD status. Future research, clinical implications, and alternatives to traditional couples counseling is discussed.

**Recommended Citation**

Bolling, Kim L., "Asperger's Syndrome/Autism Spectrum Disorder and Marital Satisfaction: A Quantitative Study" (2015). *Dissertations & Theses*. 257.

<http://aura.antioch.edu/etds/25>

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## **5. When Eros meets Autos: Marriage to someone with autism spectrum disorder**

by *Rench, Cathryn*, Ph.D., CAPELLA UNIVERSITY, 2014, 264 pages; 3681894

**Abstract:**

While research attention focuses on autism spectrum disorder (ASD) and Asperger syndrome (AS) in children, little is known about the condition in adulthood. The majority of adults with AS/ASD remain undiagnosed and many of these individuals marry, bringing unexplained and significant challenges to the couple's relationship. When a partner or couple seeks therapy, an important source of problematic symptoms remains unrecognized, and therapists who do not discern how AS neurology impacts a family system risk compounding their clients' presenting issues.

Often it is the partner without AS, or neurotypical (NT), who is considered responsible for the relational distress, usually the female due to the heavily male-skewed AS diagnostic ratio of 8:1. Anecdotal and clinical reports consistently underscore serious adverse effects on the physical and psychosocial well-being of NT spouses, yet the lived experience of this population has been remarkably neglected by researchers.

This study used Giorgi's descriptive phenomenological method to investigate what it is like to be married to someone with Asperger syndrome, based on semi-structured individual interviews with 10 current or former NT spouses. Edith Stein's feminist phenomenological theory was applied in order to level power hierarchy, while Finlay's model of "reflexive embodied empathy" served for data collection and "embodied dwelling" for analysis. To illumine the core mental processes involved in adult intimate relationships, attachment and interpersonal neurobiology theory oriented the literature review which served to identify the knowledge gap that this study sought to address.

The results were unexpected, and revealed a pattern of intimate partner abuse so pervasive that it emerged as the lifestyle of the couples. The five forms of domestic violence (emotional, sexual, psychological, economic, physical) characterized the lived experience of the participants.

Based on the results, suggested interventions include: screening for PTSD and complex trauma in distressed NT spouses or former spouses; Korn's integrative psychobiological

treatment approach to trauma; Jordan's mutually empathic relational-cultural model to restore intersubjective processes; and, Brown's feminist therapy to reclaim a sense of self and inform subsequent support strategies.

**Adviser** Leslie Korn  
**School** CAPELLA UNIVERSITY  
**Source Type** Dissertation  
**Subjects** [Neurosciences](#); [Mental health](#); [Women's studies](#); [Clinical psychology](#)  
**Publication Number** 3681894

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## **6. Relationships, Sexuality, and Intimacy in Autism Spectrum Disorders**

Maria R. Urbano<sup>1</sup>, Kathrin Hartmann<sup>1</sup>, Stephen I. Deutsch<sup>1</sup>, Gina M. Bondi Polychronopoulos<sup>1</sup> and Vanessa Dorbin<sup>1</sup>

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**Conclusion:** In summary, our literature review and ample experiences of the families in our clinical practice show that, while every person has the innate basis for developing sexuality in a multitude of expressions and experiences, individuals with disabilities (and especially individuals with an Autism Spectrum Disorder) most often require additional education and help to become able to express their sexuality in a socially appropriate way. While most neurotypically developing peers form intimate relationships beginning in adolescence and into adulthood, along a variety of experiences from dating to partnering in committed relationships, many individuals with an Autism Spectrum Disorder remain living with their family of origin into their adulthood and have significant difficulty navigating the social expectations surrounding relationships. Their difficulty may pertain to recognizing their own needs and wants, as well as to recognizing their partner's wishes coupled with more inexperience than their peers in this arena. Individuals with ASD and their parents and caregivers frequently identify this difficulty when directly asked about it. Sexuality education in a supportive format that includes the individual's family and their particular values and background will be most effective. Interventions need to be individualized with a long-range goal that matches the cognitive, social, and emotional developmental level of the person with ASD. As the prevalence of persons with ASD increases in our society, we are more than ever called to support their ability to mature into adults capable of functioning in all areas of life, including sexuality and intimacy.

[Relationships, Sexuality, and Intimacy in Autism Spectrum Disorders](#)

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## 7. Naomi Millar-Powell Macquarie University: **Relationship satisfaction, communication, social support and caregiver burden in Autism Spectrum Disorder**

Autism Spectrum Disorder (ASD) is a developmental disorder featuring difficulties with socio-emotional reciprocity and communication (DSM-5, 2013). Symptoms vary among individuals therefore, some people can live independently (Hofvander et al., 2009) and develop intimate relationships. Relationship satisfaction, communication patterns, social support and caregiver burden were quantitatively assessed among ASD-neurotypical (NT) couplings. Relationship satisfaction was low and caregiver burden was high and negatively related to relationship satisfaction among NT partners. A moderating pattern related to social support was identified and themes related to caregiving, social support and communication, as well as disconnection and grief were identified in the qualitative data.

[www.psych.usyd.edu.au/pgconf2015/wp-content/uploads/.../SPPC2015\\_Abstracts.pdf](http://www.psych.usyd.edu.au/pgconf2015/wp-content/uploads/.../SPPC2015_Abstracts.pdf)

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## 8. **Lighting Up Family Law In Blue: Autism's Impact on the Family and Family Courts**

### **Conclusion:**

Autistic individuals often exhibit an “obsessive need to control their environment, especially caregivers or providers on whom they depend” and may attempt to do so through manipulation. When a divorcing spouse is also autistic, this need for control over the former spouse may continue after separation and throughout post-divorce custody arrangements. Many cases of stalking have been observed in these situations. Further, “[t]he obsessed parent may also seek frequent access and shared custody through the courts, using transitions and negotiation to re-engage control over the other parent. If the other parent resists such manipulation, high conflict often results.” Safety concerns of a neurotypical parent based on the other parent’s autism may also cause conflict. Insensitivity or altered sensitivity to pain and illness often seen in autistic individuals can result in situations where “pain and illness may be neither reported nor recognized because the neurosensory disturbances of autism often block the recognition of pain or illness in the self or in others.” [Autism in Children and Parents](#).

“When one parent is committed to defend the child’s best interest and the other parent is committed to his/her own best interest, high conflict is likely to occur. It may be difficult for the professional to recognize which parent is accurately advocating for the best interest of the child, if the parent with [autism] has the intellectual and verbal skills to portray his/her own preferences as if they were the child’s.” [Autism in Children and Parents](#).

### **[Lighting Up Family Law In Blue: Autism's Impact ... - Payne Law, PLLC.](#)**

<https://www.paynelawpllc.com/lighting-up-family-law-in-blue-autisms-impact-on-the-...>

## 9. Effects of Differing Neuro/Developmental Levels on Neurotypical/Autism Spectrum Adult Relationships.

A comprehensive chart delineating mature developmental milestones, milestones reached by adults with ASD and the impact of these variances on both parties in a relationship.

<https://theneurotypical.com/effects-on-differing-nd-levels.html>

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## 10. Excerpt from “Counselling for Asperger Couples”, Barrie Thompson, Jessica Kingsley Publishers, UK, 2008.

Pages 54-55.

### Stage Four: Acknowledging Different Perspectives “Cassandra phenomenon”

I want to conclude this chapter by giving some recognition to a debilitating condition that can be experienced by the spouses of people with AS (often at the hands of family members, friends and colleagues), that is referred to as the Cassandra phenomenon. I think the following quote from the Families of Adults Affected by Asperger Syndrome (FAAAS) website ([www.faaas.org/doc.php?40](http://www.faaas.org/doc.php?40)) aptly explains the naming of this syndrome.

*I ended up feeling that no one would listen to me and came up with a name for the ‘syndrome’ that affects the non-AS spouse: The CASSANDRA PHENOMENON, Cassandra being the Greek mythological character who was given the gift of prophecy, but also the curse of having no one believe her even though she was right! (Anonymous, Massachusetts, 1999).*

It is usually both a blessing and a relief when an NT spouse learns about AS (perhaps from a magazine article or a TV programme) and feels she now has an explanation for her husband’s unusual behaviours. But it is demoralizing and extremely frustrating if the AS husband rejects her theory out of hand. Imagine then, as a next step the NT spouse seeks support from the extended family; ‘Perhaps mum-in-law might be able to give me some childhood history of my husband?’ She optimistically thinks this might help, only to be told quite firmly, ‘There’s nothing wrong with my son, I suggest you look a bit closer to home!’ Not only have the NT spouse’s hopes been dashed with regard to gaining support from her mother-in-law, but the relationship between herself and all of her in-laws has probably now been seriously damaged and even more tension may be generated at home between her and her husband.

Still intent on gaining credibility for the theory that her husband exhibits Asperger-type behaviours, she then seeks the support of people in her and her husband’s social network. The problem here might be that the AS husband (assuming the wife’s theory is indeed correct), is one of those ‘chameleon-like’ people that can fit in reasonably well in certain situations. A typical type of response in these circumstances from the NT spouse’s friend

might then be, 'I think he's a little different to other men, but I think that's kind of cute. I don't think he's as bad as you are making out.' Ironically, it may have been the 'cute difference' that initially attracted the NT partner to her AS spouse when they first met!

No way forward here, then for our NT partner as people outside the relationship only see a limited part of the AS man. They don't experience him in an emotional context; they don't witness his rituals, his routines or his inflexible lifestyle that occur for the most part within the confines of the home. FAAAS gave further credence to this problem in 1997 when they described it thus:

FAAAS came up with the term "Mirror Syndrome" to explain the way NT spouses and the NT family members adversely affected by AS behaviors, over time, begin to reflect the persona of AS behaviours we live with, twenty-four seven. We are isolated, no one validates us, we lose friends and family, and we feel like 'hostages' in our own homes. (FAAAS website)

My reasons for drawing attention to this condition, be it named Cassandra phenomenon or Mirror Syndrome, is to let NT partners who are in this plight know that their situation is recognised. It is known that loneliness, anxiety and depression can result when they try to tell people about their AS situation, but they are not listened to or are thought of as being melodramatic or even paranoid. I also hope that family members, friends and colleagues may in future take notice and be more prepared to hear what 'Cassandra' has to say."  
[https://theneurotypical.com/cassandra\\_phenomenon.html](https://theneurotypical.com/cassandra_phenomenon.html)

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## 11. Annotated Bibliography Helping Couples Manage Asperger's Syndrome

Sheryl R. Braun Massey University 253.750 Sheryl Braun ID 96154739 2

**Introduction** As late as the 1990s, Asperger's Syndrome (AS) was considered to be a relatively new field of study. It is named for Hans Asperger, a Viennese paediatrician of the earlier twentieth century, who noted particular similar patterns of behaviour in some of the children who came to his clinic, and recorded his findings (Asperger, 1944).

AS is not an illness, but might be better described as a neurological condition in which the brain has been "wired" a little differently to that of someone without AS, who, in turn, is often referred to as a "neurotypical" or NT individual. AS has previously been considered a high functioning form of autism, with the acknowledgement that its presence can vary in both severity and manifestation of symptoms, and some aver that it should be classed in a category all of its own.

It was not until 1994 that Asperger's Syndrome (also sometimes referred as Asperger Syndrome) was officially recognized by the American Psychiatric Association (APA), under the umbrella of Pervasive Developmental Disorder (PDD). The most recent release of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), published by the APA in 2013, has acknowledged that AS can be diagnosed as a disorder separate from autism.

Regarding the disorder itself, there are some common elements which can aid in its identification: The most common and severe of all is difficulty in social interactions and relationships, understanding social cues, misunderstanding of even simple communication (such as taking words very literally) and difficulty making friends.

In addition to this, people with AS usually have a need to adhere to a strict routine, where unannounced change can cause huge stress and distress to the individual concerned. They often also have an extreme sensitivity to certain sounds, light, textures, smells and tastes. At the same time, they may be particularly gifted in a certain area, and often have a liking for collecting certain things to the point of appearing obsessive. They may have a habit of “tuning out” into a mental fantasy world to escape the reality of a situation they find difficult to cope with at a given moment.

Depending on the severity of the condition, some people with AS may learn to cope and adjust to their social world without ever being diagnosed, while others can be taught to manage. In either case, the presence of AS can cause great strain in marital and other adult relationships, particularly if the condition is undiagnosed, or if one partner doesn’t have AS or is unfamiliar with it. Because the thinking processes can be quite different in the minds of a couple impacted by AS, conflict can become a major issue.

There is a wide range of resources in which children with AS are the focus of AS literature and research, but much less that is relevant to the practical life of adults who are already in a long-term relationship. As Lozzi-Toscano (2004) says, “... all of these studies address the biomedical model of assessment with Asperger’s and not the practical, clinical, and familial aspect of the syndrome. Researchers have focused most of their attention in finding out the biological and neurological roots of the syndrome and hardly address the “real-life” experience of living with the disorder.” The purpose of this bibliography is to suggest some resources for counsellors and couples being impacted by AS that can provide insight and offer strategies and suggestions through which a couple can learn to cope more effectively with the neurological differences present in their relationship.

Initial searches on both the Massey library search as well as the standard Google site, for “Asperger” AND “adult” AND “relationship” yielded a number of academic articles which were mostly about brain function or were child-related. Adding the word “counselling” and trying a few other combinations yielded some more useful results.

Overall, though, by far, the greatest number of relevant results yielded from both online searching and the physical library Dunedin were autobiographies of people who either have AS or have been impacted by a family member having it. This would indicate that there is still quite a need for academic resources to be published about the topic of long-term relationships and AS.

Hopefully some more of these will emerge in the years to come.

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## 11 A. ANNOTATION TOPIC: Helping Couples Manage Asperger's Syndrome

Reference: Aston, M. C. (2003). **Asperger's in love: Couple relationships and family affairs**. London: Jessica Kingsley.

### Annotation:

Maxine Aston is a counsellor qualified in Psychology who specializes in Asperger's Syndrome. She published this book in order to provide a comparison of the differences between someone who has Asperger's Syndrome and their partner who does not, and how those differences can then affect their relationships.

Her findings were obtained from researching the relationships of forty-one adults with AS and thirty-five partners of the former. Interviews, questionnaires and case studies were utilized to obtain her information. Aston covers the usual range of AS symptoms such as routine, social interaction and sensitivity to various senses, but she takes her study further in that she addresses more disturbing topics such as verbal and domestic abuse, and their prevalence in relationships where AS is present.

She also includes a chapter about the area of counselling people with AS, acknowledging that many who seek counselling come away dissatisfied with the outcome, mostly due to a lack of awareness and understanding of AS on the part of the counsellor. This reinforces the idea that a counsellor needs to have a good background knowledge of understanding the perspective of someone either with AS or living with someone who has it, to establish an effective therapeutic relationship, as described in Annotation 11H.

The book is an extremely relevant source of helpful material for anyone who is in a long-term adult relationship with someone who has AS, or who may find themselves counselling someone in that situation. While the book contains much very helpful information, it is important to note that many of the difficulties described in the anecdotal examples given may also occur in relationships where AS is not present.

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## 11 B. ANNOTATION TOPIC: Helping Couples Manage Asperger's Syndrome

Reference: Aston, M. C. (2003). **Asperger syndrome in the counselling room**. Cpj: Counselling & Psychotherapy Journal, 14(5), 10-12.

Retrieved from

[http://www.maxineaston.co.uk/published/AS in the Counselling Room.pdf](http://www.maxineaston.co.uk/published/AS%20in%20the%20Counselling%20Room.pdf)

In this article, Aston explains how a couple may present when approaching a counsellor for the first time. She points out some typical body language, such as an AS man avoiding eye contact, followed by a typical verbal exchange which exposes the very different viewpoints that each person may have of the relationship.

From the beginning of the article she stresses that a relationship between a couple impacted by AS is highly likely to face problems in interaction and understanding, which

outsiders may not even be able to see. Aston goes on to caution counsellors about counselling couples with AS if the counsellor is not familiar or experienced with the condition, and suggests some approaches the counsellor can take initially to move the couple towards a path which will assist them in understanding the situation and eventually being able to make an informed decision about whether they can somehow learn to manage the relationship or whether they decide it is not going to improve. She mentions counselling situations where the non-AS, or NT, person has felt frustrated, disbelieved and targeted due to the counsellor not understanding the dynamics of an AS relationship.

Like many other writers on the subject, Aston emphasizes that a person with AS may be so rigidly set in their thinking, responses and routines, and often quite unaware of the effect their actions (or lack of actions) are having on their partner, that any “change” to bring about improvement may fall largely upon the shoulders of the NT partner, in order to accommodate the condition which, the AS person is not capable of changing, since they are “wired” into it.

The article is not long, but it succinctly makes the reader aware of the potential frustration an uninformed counsellor can bring to an already difficult situation along with the potential avenue to be of valuable assistance to such a couple. Aston has written many other documents about Asperger Syndrome, and this one may be a good starting point for a counsellor who suspects they have encountered a relationship of this nature in their counselling room.

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### **11C. ANNOTATION TOPIC: Helping Couples Manage Asperger’s Syndrome**

Reference: Attwood, T. (2007). **The complete guide to Asperger’s Syndrome.** London, England: Jessica Kingsley Publishers.

Tony Attwood is a highly qualified clinical psychologist who currently operates out of his home in Brisbane, Australia. He has become renowned for his knowledge of Asperger’s Syndrome and has written several publications on it, along with contributing forewords to a number of other authors who have written about the subject.

The Complete Guide to Asperger’s Syndrome is a textbook written from a professional standpoint to both professionals and laypeople to assist in their search for answers about AS. It contains information about the terminology used in this and other disorders, which are sometimes mistakenly diagnosed instead of AS, as well as providing a wealth of information about the typical struggles that people with AS, or those living with someone who has AS, go through from childhood to maturity, school years and adulthood. Chapter 13 of the text particularly focuses on long-term adult relationships.

Attwood offers explanations and insights about the kind of people with AS are drawn to, and goes on to describe the typical problems such couples might face. There are suggestions for strategies to help the couple manage the relationship. While the book in its entirety is a rich resource in terms of providing knowledge of AS, the section on adult long-term relationships is rather brief.

This particular section could have been expanded with more typical scenarios described and more strategies offered to couples when facing daily conflicts and differences. Attwood has a web site with other publications included, but many of these relate to children with AS.

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#### **11D. ANNOTATION TOPIC: Helping Couples Manage Asperger's Syndrome**

Reference: Bradshaw, S. (2013). **Asperger's Syndrome – that explains everything: Strategies for education, life and just about everything else.** London, England: Jessica Kingsley Publishers.

**Annotation:** Stephen Bradshaw has produced a comprehensive text addressing the topic of Asperger's Syndrome, and it is probably one of the most recent in the field. The book contains subsections of nearly every area relating to life and AS, from childhood through to adulthood, professional explanations of the symptoms of AS, its historical recognition, strategies for education and counselling, and anecdotal inclusion of parental experiences.

It also includes an extensive bibliography, a glossary and index, with links to relevant web sites as well. The book is a little different to others, regarding long-term relationships, in that it focuses more on the perspective of what an AS person may experience when first encountering the area of sexual knowledge and romantic relationships, but this is useful in that he points out the pitfalls such people may fall into, due to their tendency to take information very literally and not understand or be able to "read" the person they are approaching for intimacy or romance.

There are some valuable inclusions of experiences had by counsellors when talking to a young person with AS which have resulted in misunderstandings by the client with potentially disturbing results. Bradshaw relates how these counselling "gaffes" honed the skills of the counsellors concerned, by helping them become more careful how they communicated with people with AS. Because of the wealth of information contained in the book, it could be considered as a useful handbook when used in conjunction with the other resources suggested in this bibliography.

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#### **11 E. ANNOTATION TOPIC: Helping Couples Manage Asperger's Syndrome**

Reference: Edmonds, G. & Beardon, L. (Eds.). (2008). **Asperger Syndrome & social relationships.** London, UK: Jessica Kingsley Publishers.

**Annotation:** In this edited book, fourteen individuals, both male and female, who have Asperger's Syndrome share their experience in life particularly with regard to social awareness and relationships. The editors have contributed comments here and there, some on a cautioning note to the reader, reminding the latter that the perspective offered may be

quite different to how a person without AS might think about it. Each contributor approaches the subject of social life from a slightly different perspective, from making friends, to online social environments, to how to be understood by those who don't have AS.

While the book does not specifically address long-term romantic relationships, the contributions are written by adults who describe their thinking processes and expectations from the adult AS point of view, and in some cases, they describe how their thought processes impacted romantic endeavours and experiences in their lives.

One of the typical idiosyncrasies often found in people with AS also becomes apparent in the book; for many people with AS, effective and reciprocal verbal communication may be difficult, but the written word appears to come a lot more easily, to the point of pedantic detail, which may become somewhat tedious for the reader! Because the book presents an example of a group of similarly-wired AS people who think on a slightly different wavelength to those without AS, it may provide insight in understanding how to counsel such a person; the routines, trusts and literal interpretations can explain to an NT person the actions and reactions of someone with AS.

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## **11 F. ANNOTATION TOPIC: Helping Couples Manage Asperger's Syndrome**

Reference: FAAAS, Inc. (2010). **Ongoing Traumatic Relationship Syndrome/Cassandra Phenomenon (OTRS/CP)** Families of Adults Affected by Asperger's Syndrome.

Retrieved from <http://faaas.org/otrscp/>

**Annotation:** More recently, symptoms have been noted in some neurotypical (NT) people (those who do not have AS), who have been living long-term with an AS partner, that show evidence of ongoing trauma and suffering on the part of the NT person. FAAAS, Inc. initially attributed the name "Mirror Syndrome" to this condition but later revised it to "Cassandra Syndrome", with it still later being revised to "Cassandra Affective Deprivation Disorder" (CADD). The name was derived from the mythical figure Cassandra, in Greek mythology, who was given the gift of foreseeing the future, but which gift was accompanied by the curse of no one believing her when she told them what was going to happen – even though she proved to be correct.

The NT partner of the AS person can find themselves in a similar position – trying to explain to others how the AS person is in the home and being met with incredulity on the part of those who do not live with the person. Because of the nature of AS, and the fact that some AS people can adapt to certain environments, it can be difficult for the NT partner to find someone who will believe them when they explain that there is a darker side to the AS person. When they try to discuss it with others, they may be met with disbelief, contempt, ridicule and can eventually experience ongoing feelings of invalidation, depression, feelings of being abused and isolation. If a counsellor does not know about AS or this aspect of its

effect on another person in the home, they can unwittingly be an exacerbator of the NT person becoming more isolated and more traumatised.

In this article, FAAAS, Inc. explains the finer points of Cassandra Syndrome, pointing out that it is the result of ongoing, unrelenting trauma. The article states that such individuals eventually feel “isolated, no one validates us, we lose friends and family, and we feel like ‘hostages’ in our own homes” (FAAAS, Inc., 2010). FAAAS, Inc. strongly recommended that Cassandra Syndrome be incorporated into DSM-5, which was released in 2013 and is currently being refined, but they were met with some resistance and it is unclear at this point in time whether it has actually been included.

There do not yet appear to be any peer-reviewed studies on the phenomenon. However, that does not mean it simply does not exist. So, it may be important that potential counsellors are aware of the possibility that they may encounter a non-AS partner suffering from such a condition in the course of a counselling and be ready to support and assist the non-AS person as well as the AS person.

The webpage actually contains three documents about Cassandra Syndrome, with the first two contributed by FAAAS, Inc. itself and the third being an excerpt from another author who has noted the same condition when counselling. The first one is recommended as a good overview.

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## **11 G. ANNOTATION TOPIC: Helping Couples Manage Asperger’s Syndrome**

Reference: McCabe, P., McCabe, E. & McCabe, J. (2003). **Living and loving with Asperger Syndrome: Family viewpoints.** London, England: Jessica Kingsley Publishers.

**Annotation:** Living and Loving with Asperger Syndrome: Family Viewpoints is unique in that it has been written by each member of an entire family: the father, Patrick, who has Asperger’s Syndrome, Estelle, his wife, and Jared, their son, who was seventeen years old at the time of writing. The entire family has a deep interest in writing, with Patrick having published articles for years as well as a lengthy university level thesis and Estelle worked as an editor part-time from home. Jared, too, has embarked on a career in writing.

The family wrote this book to help other families understand the dynamics of Asperger’s families, how it can impact families, and how families can learn to work with it successfully. They describe the struggles and frustrations they went through for years, before Patrick was finally diagnosed with AS.

Ironically, it was the son, Jared, who as a teenager, pointed out to his mother that his father did not seem quite “normal”. It was this observation that prompted the couple to get answers. Once the diagnosis was obtained, like many other families in similar positions, they learned what they could about the disorder and learned how to understand and accommodate Patrick’s processing differences, particularly his rigidity with regard to routine, and the social challenges from both his point of view of needing “space” and his wife’s point of view of having to cope with what others considered “rudeness”. The

inclusion of Jared's experience as a child of a father with AS adds a valuable dimension to this account. He relates, for example, how difficult it was to explain to his peers that if he was only five minutes late home, it would be enough to cause great anxiety to his father and result in him being grounded, regardless of how reasonable and true his explanation for the minor lateness was.

While this book has not been endorsed by some of the well-known experts in the same way many other autobiographies have been, it provides a rich background of anecdotal experience consistent with many of the common symptoms that people with AS typically have. This being the case, it may prove to be worthwhile as a resource for a potential counsellor to understand how overall family dynamics and child-raising can be affected by AS.

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#### **11 H. ANNOTATION TOPIC: Helping Couples Manage Asperger's Syndrome**

Reference: Morgan, J. A. (2012). **Marriages/relationships between non-Asperger partners and Asperger partners are extremely difficult.** FAAAS, Inc.: Families of Adults Affected by Asperger's Syndrome. (January, 2012).

Retrieved from <http://faaas.org/2012/01/premise-marriagesrelationships-between-non-asperger-partnersand-asperger-partners-are-extremely-difficult/>

In this online article, Morgan refers to published research that has shown what kinds of skills and strategies contribute to a successful marriage, pointing out that even for a non-AS person marriage can be a challenge, then goes on to explain that when AS is present in either or both partners, the challenge becomes even more difficult. For each skill or aspect of the relationship mentioned, she explains how the same aspect is often perceived and acted on quite differently by a partner who has Asperger's Syndrome.

The article highlights the need for each partner to learn how to understand each other's thinking, if possible, in order to put the success principles into practice. Like other authors, Morgan mentions the paucity of helpful information from the academic community in these matters, when she says, "What is particularly disturbing is that in the 16 or so years that Autism spectrum has been identified there has been very little acknowledgement by the medical and psychiatric/psychological community that those with AS do desire to have relationships and that many of them marry. The difficulties of AS with social interaction compound the difficulties in the relationship; especially when there is a non-AS partner."

The article paints a rather dire picture for marriages where AS is present, emphasising the likelihood that to be successful will take ongoing years of hard work, and in some cases the difficulties may never be overcome.

However, it contains an excellent list of principles and suggestions through which some couples and counsellors may have a better understanding of the typical issues faced, and therefore ways in which some of those issues can potentially be addressed. Morgan refers

to actual couples, with anecdotal examples of their experiences in marriage. It is clear that she has developed a good understanding of the nature of AS, particularly in regard to social interaction and empathy difficulties, and the pedantic kinds of conflict many couples find themselves in. The article provides a means of comparison between relationships with and without AS and may be useful for that reason.

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### **11 I. ANNOTATION TOPIC: Helping Couples Manage Asperger's Syndrome**

Reference: Ramsay, J., Brodtkin, E. S., Cohen, M. R., Listerud, J., Rostain, A. L., & Ekman, E. (2005). **'Better strangers': Using the relationship in psychotherapy for adult patients with Asperger Syndrome.**

**Annotation:** One of the terms used in counselling is “therapeutic alliance” or, as in this article, “therapeutic relationship”. This refers to the establishment of a good working relationship, or a bond, between a counsellor and his or her client, where empathy, trust and a sense of well-being occur that promote an effective and rewarding counselling environment where progress can be made in terms of transparency and goals (McLeod, 2013).

The authors of this article explain that therapeutic relationship is of great importance when counselling a person with Asperger's Syndrome, and yet by the very nature of AS, establishing that relationship can be unexpectedly challenging, because the very way in which the AS person may interpret what is said may result in a misunderstanding. So, it is important that a counsellor approaches such a session with a clear understanding of how typical AS people function; in other words, the counsellor should already have a good knowledge of Asperger's Syndrome.

Suggestions are made about how to initially approach the person with AS in order to relieve any initial anxiety they may have. They also point out potential pitfalls that may occur in conversation.

While the article is not directly about helping couples manage their issues, it is certainly important in raising a counsellor's awareness of the differences in thought processes they may encounter. This awareness may help a counsellor establish a background understanding of the communication challenges he or she may face when counselling a couple where AS is present.

However, the authors also caution that, “We should state at the outset that psychosocial treatment paradigms for adult AS are just now emerging and are based wholly on anecdotal evidence, as there are no extant studies of clinical effectiveness.” This, again, highlights the fact that the area of AS is still a relatively new area of study and plentiful evidence of research-based solutions to the problems faced by those impacted by AS may be yet to come.

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## 11 J. ANNOTATION TOPIC: Helping Couples Manage Asperger's Syndrome

Reference: Simone, R. (2010). **Asperger's on the job**. Texas, USA: Future Horizons Inc.

**Annotation:** One might wonder why this particular book has been included in this bibliography. The reason is that in the workplace adults are usually interacting with adults, with social relationships to navigate on a daily basis for several hours at a time, just as they are in the home, if the AS person lives with an adult partner or other adult person. So, the same kinds of difficulties may be encountered to some degree in the workplace as they are in the home.

This book pinpoints some of the difficulties employees with AS may experience, and offers insight to both them and their employer in learning to maximize the benefit of the working relationship. In some instances, focusing on the gifts of the person with AS and what they have to offer the workplace could be equally beneficial when applied to a home situation.

For example, many AS people just like to get on with things without too much discussion about it. Simone suggests ways the employer can work with this to his or her advantage. In the home, if a non-AS partner recognized the gift and desire of their partner to complete a job to the point of perfectionism, they may be able to then understand their partner's "single-mindedness" and encourage it in a positive direction without feeling ignored, disrespected or frustrated.

The foreword of the book was written by Dr. Temple Grandin, another recognized early authority on the subject of autism and Asperger's Syndrome. Dr. Grandin is currently a Professor at Colorado State University.

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**11 K. Conclusion:** Peer-reviewed results of academic research, focussing on what has been shown to help couples manage an adult relationship where AS is present, has proven to be rather scarce at the current time.

Many of the authors of the autobiographies referred to mentioned their frustration at the lack of informed, official and useful information available to them as they sought both a diagnosis as well as answers to the problems they were facing in their relationships. There is an increasing number of academic research articles about AS being published, but as mentioned earlier, nearly all of these address the medical side of AS, such as brain activity.

In addition, the majority of the research has been carried out in relation to children, with much of that research also pertaining to childhood education. As parents sought diagnoses and answers to the problems their children were having, many also found there was a dearth of information available, with academic and peer-reviewed literature being almost absent as late as the year 2000.

Some parents published autobiographies in order to share their struggles and findings with other families who were also having trouble finding “expert” information. Indeed, one parent writes, “One of the things that irked me was the rush of clinicians who had read a little about the disorder, treated one or two patients, and then hit the lecture tour as ‘experts’. Sometimes, it was obvious that the parents (spouses and partners) in the room knew more about Asperger Syndrome than the speaker.” (Fling, 2000).

Most parents and couples explained that the reason they published their life experiences of living with Asperger’s was to help fill this gap; to make available some practical suggestions for other families, based on their own experiences. For a potential counsellor to be successful in treating couples who are impacted by AS, or at least, to be somewhat helpful, it is clear that such a counsellor needs to do his or her homework in regard to learning as much as possible about Asperger’s Syndrome, and its related disorders and effects on others.

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