The many faces of Asperger syndrome

A study of the education, employment and intimate relationship experiences of adults with Asperger syndrome in South Australia

by

Mr. Matthew Bennett, B.Soc.Sc. (Hons.) M.Soc.Sc.

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Abstract

Asperger syndrome is a condition characterised by limited social abilities, repetitive patterns of behaviour, limited motor movement abilities, sensory sensitivities, a restricted set of interests, compulsive and ritualised behaviour, and verbal communication limitations. People with this syndrome are considered to occupy the higher functioning section of the autism spectrum of disorders. Despite having average to above average intelligence, they typically exhibit a limited awareness of common social understandings and a lack of ability to pick up on social cues.

Despite the vast and growing amount of literature about the autism spectrum, there has been a relatively small amount of research conducted on the lived experiences of adults with Asperger syndrome. Previous research has tended to focus on the experiences of children and their parents. This study seeks to address this gap by focusing on examining the lived experiences of adults with Asperger syndrome. More specifically, this research provides insights into their views and experiences of education, employment, depression and suicidal ideation, parenting and intimate relationships. Twenty-one adults with Asperger syndrome from AutismSA or Community Bridging Services participated in this study. Drawing inspiration from phenomenology, this qualitative study used phenomenological elements to present the participants' views and experiences. Each participant attended two in-depth interview sessions. During the first interview session they were asked to describe their experiences of living with Asperger syndrome and attending school. During the second interview session they were asked about their experiences and views of employment and intimate relationships. Each interview session was transcribed verbatim and then thematically analysed.

An important contribution of this study to the literature is the application of Erikson's Theory of Psychosocial Development to the lived experiences of adults with Asperger syndrome. This theory provides a conceptual framework for understanding how the growth and development of adults with Asperger syndrome can be influenced by their opinions and experiences. For example, this study explains how the participants' job interview experiences have influenced their ability to find employment and their sense of identity and value to the community. In addition, this study proposes a series of recommendations aimed at promoting better opportunities in the future lifespan development of people with Asperger syndrome.

Declaration

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I certify that this work does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any University and that to the best of my knowledge and belief it does not contain any material previously published or written by another person, except where due reference is made in the text.

Signed ....
Mr. Matthew Bennett
Monday, 11th July 2016

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List of Abbreviations

Abbreviation	Long Title
ABS	Australian Bureau of Statistics
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
CBS	Community Bridging Services
CBT	Cognitive Behavioural Therapy
CDC	Centre for Disease Control and Prevention
CMCD	Consistency Management and Cooperative Discipline
DSM-5	Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition - Text Revision
FOCUS	Focus on Autism and Other Developmental Disabilities
GP	General Practitioner
ICD-10	International Classification of Disorders - Tenth Edition
JADD	Journal of Autism and Developmental Disorders
OCD	Obsessive Compulsive Disorder
OECD	Organisation for Economic Co-operation and Development
RRBIs	Restricted and Repetitive Behaviours and Interests
ToM	Theory of Mind
WHO	World Health Organisation

Glossary

APGAR score: The APGAR score was invented in 1952 by Dr. Virginia Apgar as a simple method to quickly assess the health of a newborn child immediately after birth. The APGAR score is determined by evaluating a newborn baby on five simple criteria on a scale from zero to two, then summing up the five values thus obtained. The resulting APGAR score ranges from zero to ten. The five criteria are: Appearance, Pulse, Grimace, Activity and Respiration.

Asperger syndrome: Asperger syndrome was first described in 1944 by Dr Hans Asperger. People diagnosed with Asperger syndrome often display deficits in social interaction and unusual responses to sensory stimuli. However, unlike people diagnosed with autism, cognitive abilities are within the expected range and verbal language abilities are usually an area of relative strength. Highly focused interests are common for people diagnosed with Asperger syndrome and may, for example, present themselves in the form of train schedules, snakes, deep-fry cookers, or Internet routers.

Autism: Autism, also known as Infantile Autism, Early Autism, Autistic Disorder or Kanner's syndrome, was first described by Dr Leo Kanner in 1943. Kanner documented eleven children who exhibited a lack of interest in other people and who were highly interested in certain aspects of the environment. The hallmarks of autism are problems with social interaction, a delayed and deviant verbal and non-verbal communication development, stereotyped motor behaviours (i.e. hand flapping and body rocking), insistence on sameness and resistance to change.

AutismSA: AutismSA, South Australia's peak autism advocacy agency, was founded in 1964. It is a charitable, not-for-profit organisation which provides services to individuals with Autism Spectrum Disorders and their families. AutismSA mission is *"To deliver specialised services and promote community awareness to facilitate an inclusive community that values individuals and families living with an Autism Spectrum Disorder"*.

Co-morbid condition: The term *'co-morbid condition'* refers to the presence of one or more disorders in addition to the primary disorder. For example, if a person with Asperger syndrome has anxiety then anxiety is a co-morbid condition.

De-identification: De-identification is the act of removing any specific data items which could be used to identify the participant, such as the participant's name or their date of birth.

Epoché: In phenomenology the term *'epoché'* is an ancient Greek term which is used to describe the act of a phenomenologist suspending all of their beliefs and judgments about the world.

Informed consent: Informed consent is a process whereby the participant agrees to be in the research project after the researcher has explained to them the general purpose of the study, how their responses will be analysed and presented, any possible consequences of participating in the study and any issues surrounding confidentiality. Typically informed consent is deemed to have taken place once the participant signs the consent form stating that they understand and agree to participate in the study.

Interviews: The elicitation of research data through the questioning of respondents. While quantitative (or 'structured') interviews have a semi-formal character and are conducted in surveys using a standardised interview schedule, by contrast qualitative (or 'semi-structured', or 'depth', or 'ethnographic') interviews have a more informal, conversational character, being shaped partly by the interviewer's pre-existing topic guide and partly by concerns that are emergent in the interview.

Method: A method is a technique used to collect data from participants. For example, surveys, focus groups and in-depth interviews.

Methodology: Methodology is a term which refers to the principles, procedures and strategies used by the researcher for gathering, analysing and drawing conclusions from the data. There are many different types of methodologies, for example: objectivism, action research, case study research and phenomenology.

Participants: Participants are individuals who, once informed consent is obtained, give the researcher data.

Phenomenology: Phenomenology, a methodology created by Edmund Husserl, restricts the researcher's attention to the participant's life experiences.

Thematic analysis: Thematic analysis is a systematic approach to the analysis of qualitative data that involves identifying themes or patterns of cultural meaning; coding and classifying data, usually textual, according to themes; and interpreting the resulting thematic structures by seeking commonalties, relationships, overarching patterns, theoretical constructs, or explanatory principles. Thematic analysis is not particular to any one research method but is used by scholars across many fields and disciplines.

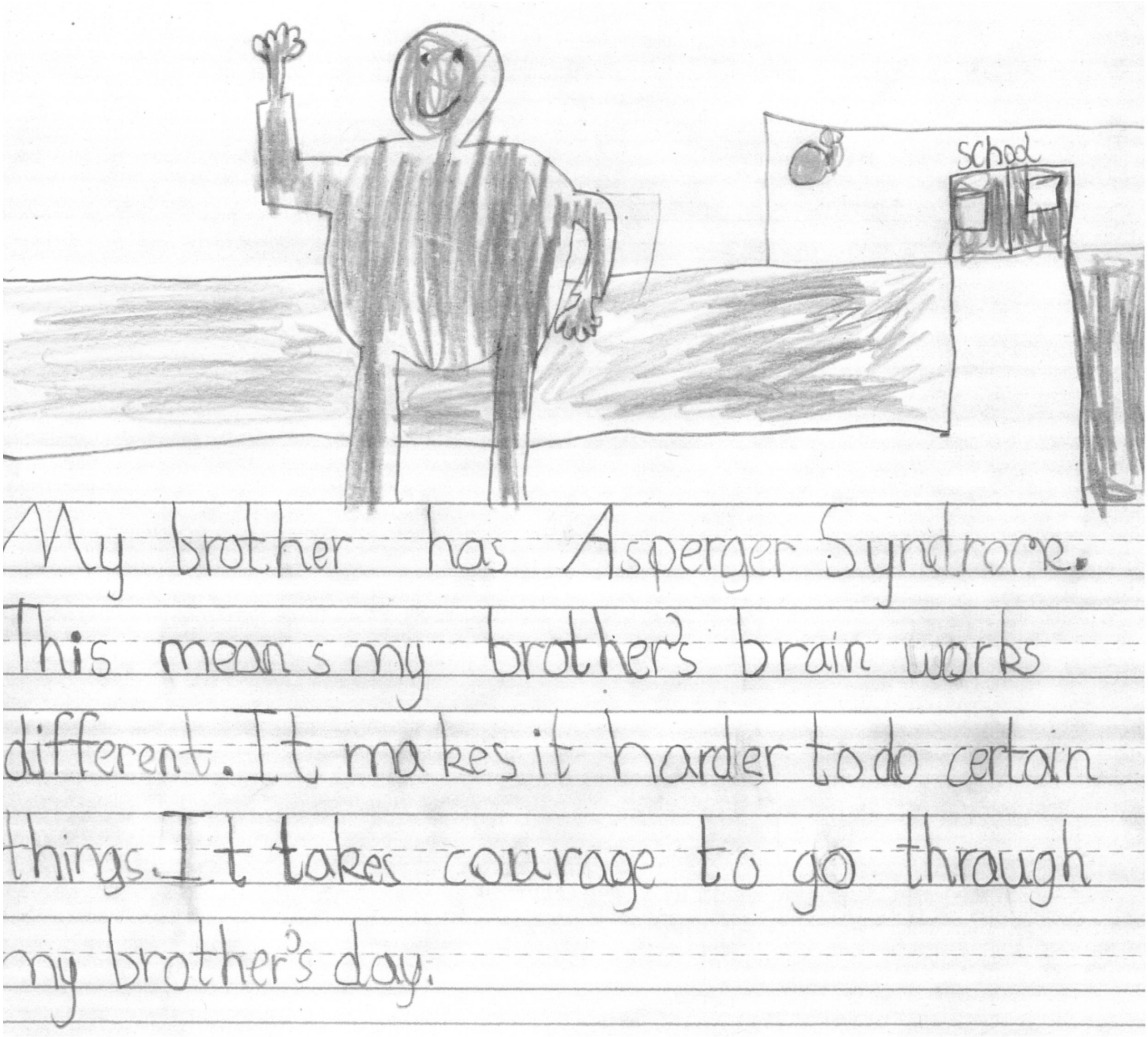
Transcription: Transcription is the act of converting verbal speech into text. However, typographical conventions exist for denoting pauses, hesitations, and laughter. Transcription creates an accurate record for analysis and ensures separation between what the participant actually said from the researcher’s interpretation of that material.

Explanatory note about diagnostic terms

When I started this PhD autism, Asperger syndrome and Pervasive Developmental Disorders - Not Otherwise Specified [PDD-NOS] were classified as three separate conditions in the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition - Text Revision [DSM-IV-TR]. In May 2013 the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders [DSM-5] was released. In the DSM-5 autism, Asperger syndrome and PDD-NOS were amalgamated to form one single diagnostic category called ‘Autism Spectrum Disorder’.

Due to this diagnostic change this thesis uses the terms ‘autism’, ‘High Functioning Autism’, ‘Asperger syndrome’, ‘Asperger Disorder’ and ‘Autistic Spectrum Disorder’ in the following ways:

- The term ‘Asperger syndrome’ is used to refer to the condition discovered by Dr Hans Asperger.
- The term ‘autism’ is used to refer to the condition discovered by Dr Leo Kanner.
- Unless otherwise stated, the term ‘Autism Spectrum Disorder’ is used to encapsulate the terms ‘autism’, ‘Autistic Disorder’, ‘High Functioning Autism’, ‘Asperger Disorder’ and ‘Asperger syndrome’. It does not refer to PDD-NOS.



My brother has Asperger Syndrome. This means my brother's brain works different. It makes it harder to do certain things. It takes courage to go thraugh my brother's day.

<u>A note about the artist:</u>

In 2004 Wesley James Orth was eight years old and in the second grade. He likes reading books, drawing, painting, pottery, collecting seashells and rocks, camping, and astronomy. Wesley's older brother, Chris, has Asperger syndrome. Despite Chris living with Asperger syndrome both brothers share a strong and unique relationship.

Source: Babkie, A. M. (2004). My Brother's Signs of Courage: Wesley James Orth. *Intervention in school and clinic*, 39(3), 183-189, p. 184.

Chapter One

Introduction

1.1 A brief overview of Asperger syndrome

Asperger syndrome, a condition initially called *autistic psychopathy*, was first documented in 1944 by Dr Hans Asperger. His article, ‘Autistic Psychopathy’ in Childhood’, described the disruptive behaviours of four school boys (Lyons & Fitzgerald, 2007a). Asperger kept his clinical observations confidential because he made them during the Second World War and did not want the Nazi regime to use his work and identify children with Asperger syndrome for extermination (Lyons & Fitzgerald, 2007b). Asperger’s work was not published in English until after Wing’s (1981) article ‘Asperger’s syndrome: a clinical account’, in which Wing summarised Asperger’s observations and provided additional clinical illustrations. Wing also coined the term ‘Asperger syndrome’ to enhance the public’s awareness and understanding of the syndrome (Lyons & Fitzgerald, 2007a; Wing, 1981). Since Asperger’s and Wing’s writings, considerable literature has been published on Asperger syndrome (Altschuler, 2013; Giarelli, Ruttenberg, & Segal, 2013; Khor, Melvin, Reid, & Gray, 2014; Osborne, 2002), including articles on its main characteristics (Carrington & Graham, 2001; Smith Myles & Simpson, 2002).

Asperger syndrome is defined by a particular set of characteristics (Smith Myles & Simpson, 2002), which are 1) limited social abilities (Carrington, Templeton, & Papinczak, 2003; Howard, Cohn, & Orsmond, 2006; Macintosh & Dissanayake, 2006); 2) limited fine and/or gross motor movement abilities (Whyatt & Craig, 2012); 3) sensory sensitivities (Dunn, Smith Myles, & Orr, 2002; Elwin, Ek, Schröder, & Kjellin, 2012; Smith & Sharp, 2013); 4) a restricted range of interests and repetitive behaviours (Smith Myles & Simpson, 2002; South, Ozonoff, & McMahon, 2005); and 5) difficulties with verbal communication (Rutherford, Baron-Cohen, & Wheelwright, 2002; Saalasti et al., 2008). Most of these characteristics are included in the *International Classification of Disorders—Tenth Edition* [ICD-10] (World Health Organisation [WHO], 1992) and the *Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition—Text Revision* [DSM-IV-TR] (Linton, Krcek, Sensui & Spillers, 2014) diagnostic criteria for Asperger syndrome (See Appendix 1).

Often, a person is diagnosed with autism or Asperger syndrome after consulting with a clinician who uses a diagnostic test (Risi et al., 2006). However, this approach can be problematic and unreliable (See Table 1.1) (Aspy & Grossman, 2013; Klin, Pauls, Schultz, & Volkmar, 2005; Paris & Philips, 2013; Sharma, Woolfson, & Hunter, 2012; Smith, Graveline, & Smith, 2012; Stoesz, Montgomery, Smart, & Hellsten, 2011; Woodbury-Smith, Klin, & Volkmar, 2005). A clinician's inability to diagnose Asperger syndrome may be due to focusing on a specific set of characteristics (which also belong to another disorder) and not considering the complete diagnostic criteria for Asperger syndrome. Attwood (2007, p. 46) reiterated this point:

> [T]hose who are not referred for a diagnostic assessment for Asperger's syndrome are able to camouflage their difficulties and avoid detection, or a clinician fails to see Asperger syndrome and focuses on another diagnosis.

The consequences of misdiagnosis can include children being diagnosed with Asperger syndrome at 7.2 years of age (van Tongerloo, Bor, & Lagro-Janssen, 2012), which is usually '1.8 years later than children with autistic disorder' (Mandell, Novak, & Zubritsky, 2005, p. 1482). In some situations, another consequence of misdiagnosis is that people with Asperger syndrome can be diagnosed with another condition, such as schizophrenia (Perlman, 2000). Furthermore, the inability to diagnose Asperger syndrome in a timely and accurate manner can create parental stress (Goin-Kochel, Mackintosh, & Myers, 2006) and prevent a researcher from comparing different studies on the syndrome (Kopra, von Wendt, Nieminen-von Wendt, & Paavonen, 2008).

Table 1.1: Common errors when diagnosing Asperger syndrome and associated solutions

Errors	Solution(s)
Diagnostic overshadowing: characteristics of another disorder are evident and mistakenly used to explain the complete diagnostic picture	Trained and experienced teams are able to readily differentiate between ASD and other conditions. They are also able to recognize when ASD occurs along with another disorder
Unremarkable developmental milestones: when developmental milestones are met in a typical time frame, other significant differences (e.g., tantrums, repetitive behaviors) may mistakenly be dismissed	Trained and experienced teams recognize that not all differences associated with ASD are developmental in nature. Experienced teams are also aware that individuals with AS often present with a typical pattern of development in a number of areas
Strong cognitive ability: those with average to above average intelligence often learn to compensate for their differences – especially in familiar situations. The characteristics of ASD often are not apparent until the individual is no longer able to compensate	Trained and experienced teams are able to recognize compensating strategies such as use of scripts, humor, and imitation. They adapt the testing to identify masked limitations
Strong interest in social interaction: an individual with AS may have friends or desire social interaction yet not have the social understanding or social competence that would be expected at his or her age "He's so social he cannot have AS"	Trained and experienced teams know that individuals with AS may have a strong desire for social interaction yet lack the skills to interact successfully. There is a widespread misbelief that individuals with AS are loners. Klin and Volkmar state that persons with AS who are socially isolated are not loners by choice (1995)
Lack of stereotypical signs: the individual does not display some behaviors often seen in individuals with ASD. "She looks just like everybody else"	Trained and experienced teams know that ASD is a pattern of symptoms and is not defined by the presence or absence of any single characteristic
Lack of significant disruptive behaviors: often, significant difficulties are dismissed or explained away when they are not disruptive. This is one of the reasons that fewer females are referred	Trained and experienced teams know that individuals who do not exhibit disruptive behaviors may have AS

Source: Aspy and Grossman, 2013.

Prevalence studies on autism and Asperger syndrome have been conducted worldwide (Elsabbagh et al., 2012). One of the most contemporary Autism Spectrum Disorder [ASD] prevalence statistics, which was published on 28 March 2014, appeared in the Centers for Disease Control and Prevention's [CDC] *Morbidity and Mortality Weekly Report*. In this report, the CDC estimated that 1 in 68 individuals (1 in 42 males; 1 in 189 females) had an ASD (CDC, 2014). However, this prevalence statistic has been criticised by Mandell and Lecavalier (2014) and Durkin, Bilder, Pettygrove, and Zahorodny (2015). Partly in response to multiple prevalence statistics, in May 2013 the American Psychiatric Association [APA] amalgamated Asperger syndrome and autism to form one diagnostic condition, ‘Autism Spectrum Disorder’, in the *Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders* [DSM-5] (APA, 2013).

Since its publication, the DSM-5’s diagnostic category for ASDs has been criticised (Lacasse, 2014). For example, adults with Asperger syndrome have expressed their fears that the DSM-5 may limit their access to disability employment support services (Giles, 2014). Education and health professionals in Australia have also voiced their concerns, such as ‘[T]here is quite a difference between the two [autism and Asperger syndrome] and I feel this should remain distinct’ (Kite, Gullifer, & Tyson, 2013, p. 1696). Despite these concerns, the APA has insisted that the DSM-5’s ASD classification category is beneficial because it ‘will improve the diagnosis of ASD without limiting the sensitivity of the criteria, or substantially changing the number of children being diagnosed’ (APA, 2013, p. 1). Furthermore, there is research which also supports this statement (Kim et al., 2014; Mazefsky, McPartland, Gastgeb, & Minshew, 2013).

1.2 The researcher’s position on this study

In qualitative studies, the researcher’s views and experiences often influence what aspects of the participants’ testimonies are examined. In order to reduce any bias, and to make this study as transparent as possible, the researcher will now share some of his experiences of living with Asperger syndrome in relation to education, employment and intimate relationships.

I live with Asperger syndrome. It is a remarkably complex condition which has been either a blessing or a curse, depending on the situation. My earliest memory of living with Asperger syndrome was from when I was at school in Adelaide, South Australia. I remember moments where I felt socially disconnected from the student cohort. In my opinion, people with Asperger syndrome are often aware that making friends can be difficult and this awareness can create feelings of inferiority, anxiety and depression. I came to the realisation that if I desired friendships, then I would ultimately be depressed because I wanted something which was difficult to obtain. Due to this revelation, I have never made establishing friendships a priority in my life. Furthermore, I have always believed that my social limitations were only a minor inconvenience and were in no way a barrier to achieving my goals in life. These insights helped me understand myself better and also helped me establish my priorities in life.

I have many pleasant memories of school and university, where I learnt useful life skills, such as time management and personal organisation. These important skills have had a positive impact on my academic and personal development beyond my time at school. This phase, however, was not completely without problems. At times, I was bullied. Thankfully, I only experienced school bullying a few times. However, the bullying I encountered at school has prompted me to explore the bullying experiences of other adults with Asperger syndrome.

Being an undergraduate student at the University of Adelaide was an amazing experience. Whilst studying towards a Bachelor of Social Sciences, I learnt a lot about myself—on both a personal and academic level. At school, I had been in a structured academic environment, I knew where and when my classes were held. However, at university, no-one explicitly told me where and when I had to attend lectures and tutorials. At first, I found it difficult to learn in this unstructured learning environment. However, after a short amount of time, I was able to take control of my learning. My time management skills, which I had developed at school, and my desire to obtain a university degree helped me graduate from the University of Adelaide. I went on to continue my learning at the University of South Australia and Flinders University.

Despite my academic achievements, I have only had modest success in the Australian workforce. I have held jobs in South Australian and Australian government departments. Whilst working in these two levels of government, I acquired considerable skills, experience and knowledge. For example, I did learn about policy formulation and how to respond to correspondence from the public. I believe my lack of substantial success, though, can be attributed to organisational factors, such as the attitudes and views of workplace colleagues towards employees with disabilities; and personal factors, such as the characteristics associated with Asperger syndrome not matching the requirements of the job. The main organisational factor which I believe has had a negative impact on my career was my former workplace colleagues' lack of awareness and understanding of Asperger syndrome. Although competent in their respective fields, my colleagues never received *any* disability awareness training or professional guidance on how to work with employees who have disabilities. I frequently encountered colleagues who had no knowledge of Asperger syndrome. Their ignorance about this syndrome is one of the main motivators behind me writing this thesis. I sincerely hope that this research can help educate the public about the challenges which people who live with Asperger syndrome face. It is only through education that people on the autism spectrum will be given the respect, dignity and understanding which they deserve.

Whilst studying for my PhD, I have attended autism-specific functions, such as conferences, gala dinners and charity events. At these events, I meet professionals, parents of children with ASDs, and people who live on the autism spectrum. I have often spoken to parents who, after telling me about their child’s life, ask me questions such as ‘Will my child find suitable employment and live independently?’ or ‘After my child finishes school, will he/she be able to continue his/her education?’ On the surface, these questions appear distinct. Yet they are all different manifestations of the same poignant question, which is ‘Will my child be all right when I am no longer alive?’ When I am placed in these situations, my initial reaction is to reassure the parents that their child will be all right. However, the truth is that I do not know their child’s future and, out of respect for the parent, I usually respond with ‘I don’t know’. After a moment of contemplation, these parents often appreciate that I do not have all of the answers. During these encounters, I also emphasise that as people we are only in control of the possibilities in life, not the actualities. It is *possible* that their child will have a positive life. However, whether or not this happens is out of their control. Nevertheless, there are things which people on the autism spectrum can do to maximise the possibility of success. I sincerely hope that this research will show people that the autism spectrum does not limit one’s potential. In addition, to help convey to the reader the participant’s experiences and views I have utilised my pedantic tendencies to catalogue the relevant information under appropriate headings.

1.3 The contributions this study makes to the literature on adults with Asperger syndrome

This section summarises this study’s contributions to the literature. These gaps will be explained in greater detail in the literature review.

1.3.1 Exploring how adults live with Asperger syndrome

The medical profession, autism charities, the media and the British public often use words such as ‘challenges’ and ‘deficits’ to describe the autism spectrum (Clarke & van Amerom, 2007; Huws & Jones, 2010b; Waltz, 2012; Winter-Messiers et al., 2007). This point has also been expressed by Armstrong (2010, p. 62): ‘the gift for detail among autistic individuals is typically defined by psychologists in terms of deficit rather than strength’. Since the limitations associated with Asperger syndrome have mainly been the focus of research, any benefits that this syndrome can give adults have been under-researched (Baron-Cohen, 2002; Butler & Gillis, 2011; Davidson & Orsini, 2013; Molloy & Vasil, 2002; Wheeler, 2011). To add to our understanding of Asperger syndrome, the participants in this study described how the characteristics associated with their Asperger syndrome have had an impact on their life—both positive and negative.

1.3.2 Discovering new views from adults with Asperger syndrome on how their friends and family emotionally reacted to their diagnosis of Asperger syndrome

Researchers have documented the emotional reactions that people experience when diagnosed with Asperger syndrome (MacLeod, Lewis, & Robertson, 2013; Molloy & Vasil, 2004; Murray, 2006; Punshon, Skirrow, & Murphy, 2009; Rosqvist, 2012). There is also literature on the emotional reactions parents have felt upon learning of their child’s diagnosis of autism or Asperger syndrome (Calzada, Pistrang, & Mandy, 2012; Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Sansosti, Lavik, & Sansosti, 2012). However, there is scant research describing the emotional reactions of family and friends when adults are diagnosed with Asperger syndrome. Similarly, there is little literature on adults describing the processes they went through to obtain their diagnosis of Asperger syndrome. The participants in this study added to this limited amount of literature by describing their experiences of these issues.

1.3.3 Exploring the views that adults with Asperger syndrome have on the Australian public's knowledge of Autism Spectrum Disorders

There is literature on the public's perceptions of ASDs (Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013; Durand-Zaleski, Scott, Rouillon, & Leboyer, 2012; Huws & Jones, 2010b; Mitchell & Locke, 2015; Stewart, 2008). Similarly, there is also research on British adults with ASDs; these adults explain if funding for autism research in Britain addresses their concerns and those of the autistic community (Pellicano, Dinsmore, & Charman, 2014). However, there is very little research on Australian adults with Asperger syndrome commenting on what they think the Australian public knows about the autism spectrum. The participants in this study added to this limited amount of knowledge by sharing their perceptions about what they think the Australian public knows about the autism spectrum.

1.3.4 New insights into how adults with Asperger syndrome live with depression and suicidal ideation

The prevalence and treatment of depression and suicidal ideation in the Asperger syndrome population has been studied broadly (Cassidy et al., 2014; Shtayermman, 2008; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). Researchers have also expressed their views on these issues (Ghaziuddin, 2005; Gillberg, 2002). However, there are only a few articles on adults with Asperger syndrome describing their depression and suicidal ideation experiences. The participants in this study contributed to this small body of literature by describing their experiences of these issues.

1.3.5 Uncovering the school bullying experiences of adults with Asperger syndrome

Literature exists on the types of bullying that students with Asperger syndrome have encountered (i.e., cyber bullying) (Kowalski & Fedina, 2011) and the techniques which they and their teachers have used to reduce bullying (Attwood, 2004; Biggs, Simpson, & Gaus, 2010). However, there is minimal literature on adults with Asperger syndrome describing their school bullying experiences and the techniques they used to avoid school bullies (Fleischer, 2012; Sciutto, Richwine, Mentrikoski, & Niedzwiecki, 2012). The participants in this study added to this literature by describing their bullying experiences and the strategies they employed to avoid bullying.

1.3.6 Exploring the job interview experiences of adults with Asperger syndrome

Although there is substantial research data on the job interview experiences of applicants who are overweight (Kutcher & Bragger, 2004) or pregnant (Cunningham & Macan, 2007; Bragger, Kutcher, Morgan, & Firth, 2002), there is not much literature on job interviews for adults with Asperger syndrome (Bissonnette, 2013a, 2013b; Edmonds & Beardon, 2008; Hendrickx, 2009; Purkis, 2014; Stanford, 2011). The participants in this study described their experiences in job interviews, thereby reducing the shortage of literature in this area.

1.3.7 Understanding how adults tell their workplace colleagues that they live with Asperger syndrome

Peer-reviewed literature on adults with Asperger syndrome in the workforce has described personal testimonies (Baldwin, Costley, & Warren, 2014; Barnhill, 2007; Griffith, Totsika, Nash, & Hastings, 2012; Hurlbutt & Chalmers, 2004); measured employment participation rates (Holwerda, van der Klink, Groothoff, & Brouwer, 2012); and measured the effectiveness of supported employment programs (Howlin, Alcock, & Burkin, 2005). However, only a handful of studies include descriptions of adults telling their workplace colleagues that they live with Asperger syndrome. In contrast, there is literature on employees telling their workplace colleagues that they have the Human Immunodeficiency Virus (Fesko, 2001) or cancer (Pryce, Munir, & Haslam, 2007) or disclosing their homosexual orientation (Griffith & Hebl, 2002; Ragins, Singh, & Cornwell, 2007). This present study contributed to this limited amount of literature by including participants' experiences in telling their workplace colleagues that they live with Asperger syndrome.

1.3.8 Discovering the views and experiences of adults with Asperger syndrome on parenting

Literature has been published on the sexual behaviours and interests of males with Asperger syndrome (Brown-Lavoie, Viecili, & Weiss, 2014; Byers, Nichols, & Voyer, 2013; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007) and of females with Asperger syndrome (Cridland, Jones, Caputi, & Magee, 2014; Simone, 2009, 2010, 2012). There is also literature published to help adults with Asperger syndrome form romantic relationships (Aston, 2009, 2012b, 2014; Thompson, 2008). Yet there are few studies on adults with Asperger syndrome articulating their views and experiences of parenting. The participants in this study expressed their views and experiences on this subject.

1.4 Broader consequences of this research

1.4.1 Dispelling inaccurate media representations of adults on the autism spectrum

Despite adults with Asperger syndrome writing about their life experiences (Ariel & Naseef, 2006; Beardon & Worton, 2011; Dakin, 2005; Santomauro, 2012), the media has mostly published inaccurate stories about people living on the autism spectrum (Huws & Jones, 2010a; Riley, 2005). Huws and Jones's (2010a) study, for example, found that autism stories in British newspapers often sensationalised the abilities of people with autism, often described people with autism as a burden on society, and often failed to recognise the diversity of people with autism. Similarly, Jones and Harwood (2009) examined how autism was reported in the Australian print media between 1996 and 2005. They found that people with autism were frequently described as either dangerous and uncontrollable or unloved and poorly treated. Incorporating the opinions of adults with autism in the media is one approach that may reduce the inaccurate reporting of autism. This view has been voiced by Kang (2013, p. 245), who stated, 'The voices of people with autism need to be covered in the television news media more because they as experts can offer the better understanding of autism'. In essence, this thesis presents the education, employment and intimate relationship experiences of twenty-one adults living with Asperger syndrome. One objective in presenting this information is to focus the public and media's attention on adults with Asperger syndrome.

1.4.2 Improving society’s understanding of the autism spectrum

The general public have inaccurate views of autism and people living on the autism spectrum (Dillenburger et al., 2013; Durand-Zaleski et al., 2012; Huws & Jones, 2010b; Mitchell & Locke, 2015; Stewart, 2008). Giving people on the autism spectrum an opportunity to articulate their views and experiences has the potential to educate the public about the autism spectrum. This view is supported by Huws and Jones (2010a, p. 331) who recommend that ‘interactions between lay people and people with autism may help develop positive conceptualisations of autism’. The notion of people with disabilities speaking for themselves has already been applied to those diagnosed with intellectual disabilities (Callus, 2013) and cerebral palsy (Rousso, 2013). In this present study, the participants will describe their experiences of living with Asperger syndrome; their insights can help improve society’s understanding of Asperger syndrome.

1.4.3 Adding to the limited amount of qualitative research on adults with Asperger syndrome

Academic journals focusing on the autism spectrum, such as *Research on Autism Spectrum Disorders* and *Autism*, have only published a few qualitative studies on people on the autism spectrum (Bölte, 2014). Similarly, research has generally centred on the experiences of children (Huws & Jones, 2010a; Jang et al., 2014). Consequently, there is a paucity of first-person published qualitative research about the experiences of adults with autism or Asperger syndrome (DePape & Lindsay, 2016). This study’s focus, on the life experiences of adults with Asperger syndrome, can help make an important contribution to the limited amount of knowledge on this subject. In addition, through collecting and analysing qualitative information from these adults, this study can create ‘new leads for quantitative studies … and perhaps enhanced societal awareness’ (Bölte, 2014, p. 68).

1.4.4 Helping the next generation of adults with Asperger syndrome

Often, people with disabilities participate in research because they believe that their contributions will help future generations. Sainsbury expressed this sentiment when explaining why she decided to write *Martian in the Playground:*

> [P]eople with Asperger's syndrome are often passionate about sharing our … insights into Asperger's syndrome, in the hope that the next generation … may not have to go through what we did. (MacLeod & Johnston, 2007, p. 83)

This study has the potential to help people living with Asperger syndrome reach a better understanding of their education, employment and intimate relationship experiences.

1.5 Overview of the Remaining Chapters

1.5.1 Chapter Two: A Review of the Literature

This chapter begins with an historical overview of autism, Asperger syndrome and the DSM-5's ASD diagnostic category. It then explores four possible causes of ASDs: 1) maternal and paternal age during a child's birth; 2) suboptimal prenatal conditions, pregnancy complications and obstetric events; 3) maternal exposure to chemicals during pregnancy; and 4) genetic influences. The literature on the prevalence of ASDs in Australia, and on the main characteristics associated with Asperger syndrome, will then be reviewed. This chapter then presents the eight developmental stages in Erikson's Psychosocial Theory of Human Development, hereafter referred to as Erikson's theory. This theory will be used as a theoretical lens to understand how the participants' views and experiences can have an impact on their lifespan development. This chapter then reviews the literature on adults with Asperger syndrome and their 1) emotional reactions towards their diagnosis of Asperger syndrome; 2) views of the public's knowledge of the autism spectrum; 3) depression and suicidal ideation experiences; 4) recollections of school bullying; 5) job interview experiences; 6) experiences of disclosing their syndrome to workplace colleagues; 7) views and experiences of intimate relationships and parenting. The purpose of reviewing these fields of literature is to explain where this study contributes to our knowledge of Asperger syndrome. This chapter concludes with this study's research questions.

1.5.2 Chapter Three: Methodology and Method

Chapter Three explains how the participants' views and experiences were collected and analysed. It begins with an outline of the main theoretical differences which qualitative and quantitative approaches use to study a person's views and experiences. This study is qualitative and draws on phenomenological tendencies. Hence, this chapter discusses the history of phenomenology, an explanation of the sample size used in a phenomenological study, and the main theoretical characteristics of Husserl's approach towards conducting a phenomenological study. This chapter then discusses in-depth interviews (the method used in this study), followed by an explanation of the techniques used to formulate the in-depth interview questions and the participant eligibility criteria. An explanation of the pilot and main study will then be outlined, followed by the ethical steps used to conduct this study, and the analytical technique used to derive meaning from the data collected from the participants.

1.5.3 Chapter Four: Experiences of Living with Asperger syndrome

In this chapter, the participants' experiences of living with Asperger syndrome are presented. It begins with a demographic summary of the sample. It then presents a series of participant quotations on how they obtained their diagnosis of Asperger syndrome and the emotional reactions which they, their family and friends experienced towards their diagnosis of Asperger syndrome. A series of quotations from the participants about how the main characteristics associated with Asperger syndrome have had an impact on participants' lives will then be presented. The main characteristics discussed in this section are as follows: an intense and prolonged focus on a specific topic of interest; sensory sensitivities; limitations interpreting facial expressions and body postures; inability to establish or maintain a verbal conversation; and challenges with social situations. This chapter then presents sections on the participants' views about the Australian community's knowledge of the autism spectrum, their insights on accepting or rejecting their Asperger syndrome diagnosis, and their experiences and views on depression and suicide. This chapter concludes with a section on Nigel and Cody's parent's experiences and views on Asperger syndrome.

1.5.4 Chapter Five: Education, Employment and Intimate Relationships

Chapter Five presents the participants' experiences and views of education, employment and intimate relationships. It begins with four participants describing the bullying they experienced at school and the techniques which they, as well as other participants, used to reduce bullying. It then presents the participants' experiences in employment, particularly their experiences of job interviews and disclosing their diagnosis of Asperger syndrome to workplace colleagues. It then concludes with the participants explaining their views and experiences on intimate relationships and parenting.

1.5.5 Chapter Six: Discussion

This chapter begins by outlining the ways in which this study contributes to our understanding of the lived experiences of adults with Asperger syndrome. It then highlights areas of potential future research and concludes with a summary of the main aspects of the study.

Chapter Two

A Review of the Literature

2.1 Introduction

This chapter presents an overview of the history of autism, Asperger syndrome and the DSM-5's Autism Spectrum Disorder classification category. It then discusses the aetiology of ASDs and reviews the literature on the prevalence of ASDs in Australia and on the main characteristics associated with Asperger syndrome. The eight developmental stages of Erikson's theory are subsequently outlined. The purpose of this theory is to help explain in the discussion chapter how the participants' views and experiences can have an impact on their lifespan development. This chapter will then review the literature on adults with Asperger syndrome and their 1) emotional reactions towards their diagnosis of Asperger syndrome; 2) views of the public's knowledge of the autism spectrum; 3) depression and suicidal ideation experiences; 4) recollections of school bullying; 5) job interview experiences; 6) experiences of disclosing their disability to workplace colleagues; 7) views and experiences of intimate relationships and parenting. The purpose of reviewing these areas of literature is to explain how this study contributes to our knowledge of Asperger syndrome. This chapter concludes with this study's research questions.

2.2 The history of autism and Asperger syndrome

This section explains the history of autism and Asperger syndrome. It begins with an introduction to Dr Leo Kanner, the first person to document autism. The identification of Asperger syndrome and its inclusion in the DSM-IV will then be outlined. It concludes with a review of the literature in the DSM-5 and its potential impact on Autism Spectrum Disorder diagnostic rates.

2.2.1 Dr Leo Kanner: The first person to identify autism

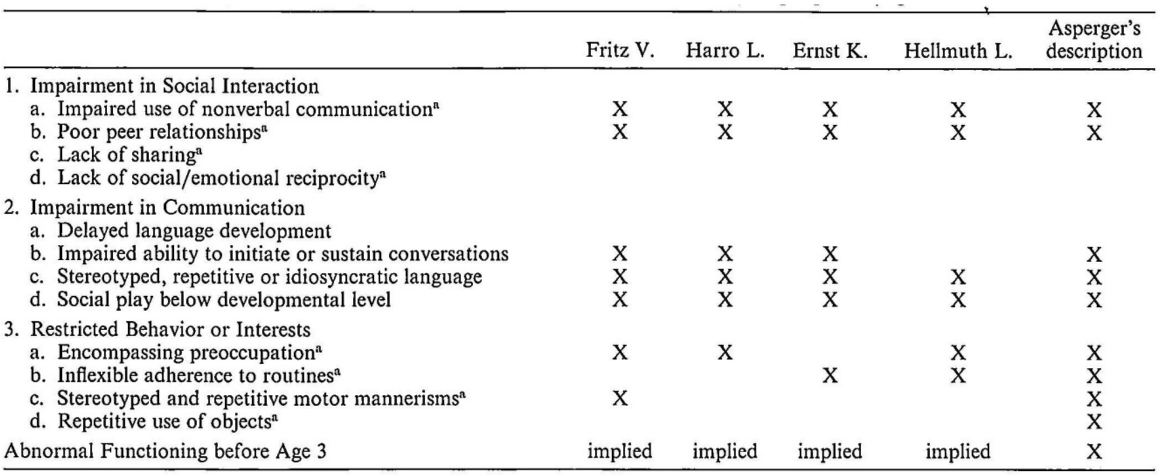
In 1943, Kanner published the article ‘Autistic Disturbances of Affective Contact’, which described the behaviour of eleven children (Kanner, 1943; Lyons & Fitzgerald, 2007a). In this article, Kanner used the term *autism*, which is derived from two Greek words: *autos*, meaning ‘self’ and *ismos*, meaning ‘action or state of being’ (Feinstein, 2010; Irwin, MacSween, & Kerns, 2011). The term autism had been used by Bleuler over thirty years earlier to describe some of the characteristics associated with Schizophrenia. Kanner and Asperger both subsequently used the term autism in their writings. However, only Asperger acknowledged Bleuler’s use of the word autism (Lyons & Fitzgerald, 2007a).

Kanner’s description of autism was based on his observations of eleven children (eight boys and three girls) who all displayed puzzling and deviant behaviour. According to Kanner (1943), this group often displayed ‘autistic aloneness’ (p. 245); an inability to verbally communicate with others (e.g. mutism, echolalia, and overly literal language); repetitive behaviours; an ‘anxiously obsessive desire for the maintenance of sameness’ (p. 245); and ‘good cognitive potential’ and ‘excellent rote memory’ (p. 243) on performance tests. Many of these behaviours Kanner described are still found in modern definitions of autism. Although Kanner’s original clinical description of autism was published in 1943, it was first listed as a diagnostic condition in the *Third Edition of the Diagnostic and Statistical Manual of Mental Disorders* [DSM-III], published in 1980, under the diagnostic label ‘Infantile Autism’. In the DSM-IV, autism was included under the diagnostic label ‘Autistic Disorder’ (Linton et al., 2014).

2.2.2 Dr Hans Asperger: The first person to identify Asperger syndrome

Dr Hans Asperger was the first person to document Asperger syndrome, a condition he initially labelled ‘Autistic psychopathy’, in his 1944 article *Autistic Psychopathy in Childhood* (Lyons & Fitzgerald, 2007b; McPartland, Klin, & Volkmar, 2014). Asperger’s article described four boys who all exhibited limited social abilities; impaired use of nonverbal communication; poor peer relationships; limited communication abilities (*i.e.* impaired ability to initiate or sustain a conversation, stereotyped and repetitive language); and restricted behaviour and interests (*i.e.* inflexible adherence to routines) (See Table 2.1) (Miller & Ozonoff, 1997).

Table 2.1: Number of symptoms of DSM-IV-defined Autistic Disorder demonstrated by Asperger’s original cases



	Fritz V.	Harro L.	Ernst K.	Hellmuth L.	Asperger’s description
1. Impairment in Social Interaction					
a. Impaired use of nonverbal communication[a]	X	X	X	X	X
b. Poor peer relationships[a]	X	X	X	X	X
c. Lack of sharing[a]					
d. Lack of social/emotional reciprocity[a]					
2. Impairment in Communication					
a. Delayed language development					
b. Impaired ability to initiate or sustain conversations	X	X	X		X
c. Stereotyped, repetitive or idiosyncratic language	X	X	X	X	X
d. Social play below developmental level	X	X	X	X	X
3. Restricted Behavior or Interests					
a. Encompassing preoccupation[a]	X	X		X	X
b. Inflexible adherence to routines[a]			X	X	X
c. Stereotyped and repetitive motor mannerisms[a]	X				X
d. Repetitive use of objects[a]					X
Abnormal Functioning before Age 3	implied	implied	implied	implied	X

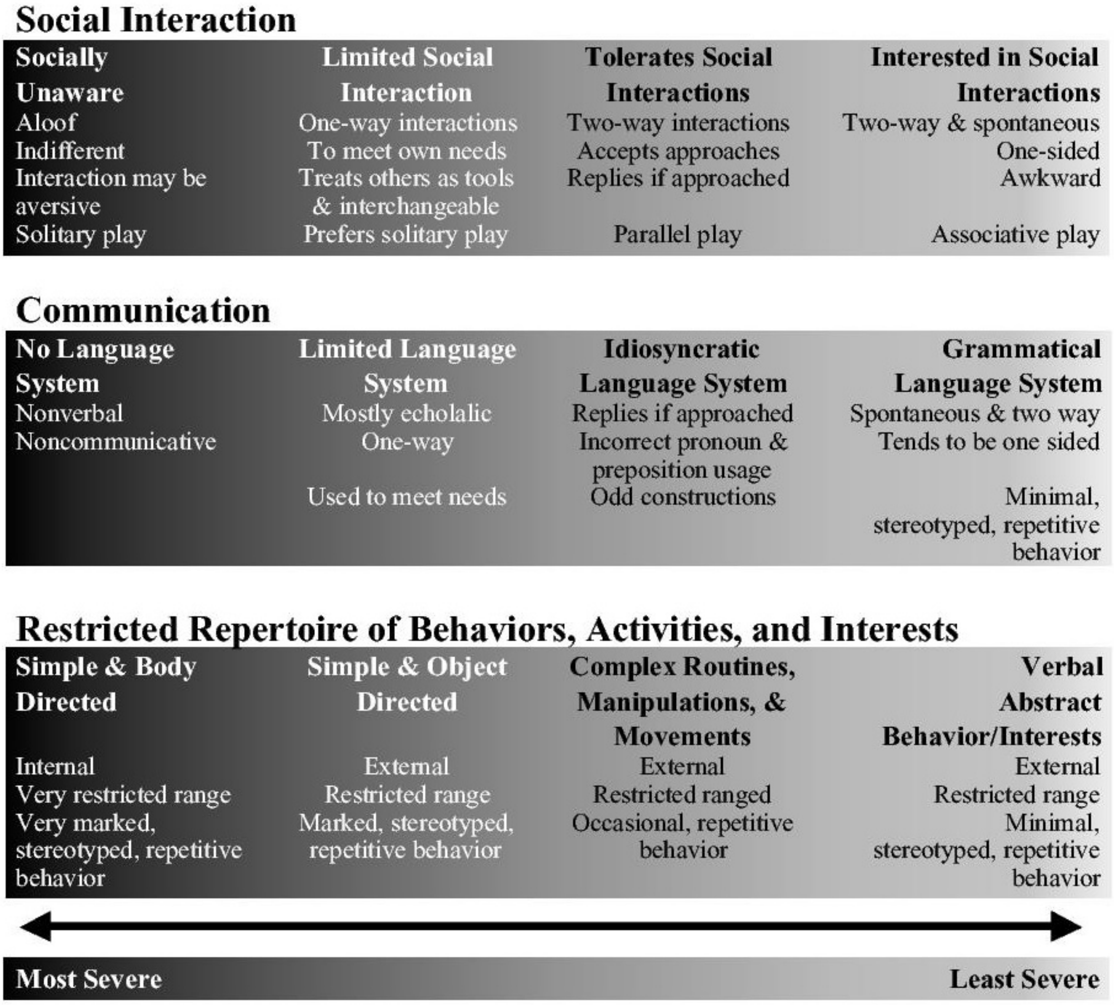
Note: [a] = These symptoms are also included in the criteria for DSM-IV-defined Asperger Disorder.
Source: Miller and Ozonoff, 1997.

Asperger, whilst practising paediatrics in Vienna, was deeply concerned about the welfare of his patients. Although he acknowledged the many negative features of his patients, such as their limited social skills, he also emphasised the many positive features, such as their intellectual giftedness and potential for academic success. There are two plausible reasons for why Asperger highlighted the gifts of his patients. First, he tried to protect them from the Nazi eugenics movement during the Second World War. Second, he realised that he and his male patients shared many of the common problems and characteristics associated with Asperger syndrome. This revelation may have motivated him to find innovative ways to help his patients overcome their difficulties so that they could become successful members of society (Lyons & Fitzgerald, 2007b). Asperger's work, which was originally published in German, started to become recognised in the English-speaking world after Wing described his syndrome in an English language journal and after Frith translated Asperger's writings from German to English (Frith, 1991; Lyons & Fitzgerald, 2007a; Sanders, 2009; Wing, 1981).

In 1981, Wing published one of the first English language articles on Asperger syndrome (Sanders, 2009; Wing, 1981). In Wing's article, she used the term 'Asperger's syndrome' because she thought it was less pejorative than the term 'Autistic psychopathy', which is often associated with sociopathy. According to Wing, the core features of Asperger syndrome are as follows:

1. typical language acquisition for age and sometimes possessing excellent linguistic and vocabulary abilities but with the inability to use speech for social interaction purposes;
2. poor social and emotional relationship development;
3. repetitive activities and resistance to change;
4. clumsy and uncoordinated motor skills;
5. showing a narrow, limited, and intense focus on special interests;
6. showing some extraordinary abilities in some cognitive domains (e.g. mathematics). (Wing, 1981)

There are two main differences between Asperger's and Wing's writings on Asperger syndrome. First, Asperger stated that children with Asperger syndrome often talked before they could walk. However, Wing's (1981) observations were not consistent with this finding. Second, Asperger concluded that many of the children with Asperger syndrome he observed were highly intelligent. Wing (1981), however, found that children with Asperger syndrome had excellent rote memory and this skill misled others into thinking that they were highly intelligent. Despite Wing and Asperger's different views on Asperger syndrome, Wing formulated the 'triad of impairments' as a conceptual model for understanding Asperger syndrome and autism as a spectrum disorder (See Figure 2.1) (Brock, Jimerson, & Hansen, 2006).



Social Interaction

Socially Unaware	Limited Social Interaction	Tolerates Social Interactions	Interested in Social Interactions
Aloof	One-way interactions	Two-way interactions	Two-way & spontaneous
Indifferent	To meet own needs	Accepts approaches	One-sided
Interaction may be aversive	Treats others as tools & interchangeable	Replies if approached	Awkward
Solitary play	Prefers solitary play	Parallel play	Associative play

Communication

No Language System	Limited Language System	Idiosyncratic Language System	Grammatical Language System
Nonverbal	Mostly echolalic	Replies if approached	Spontaneous & two way
Noncommunicative	One-way	Incorrect pronoun & preposition usage	Tends to be one sided
	Used to meet needs	Odd constructions	Minimal, stereotyped, repetitive behavior

Restricted Repertoire of Behaviors, Activities, and Interests

Simple & Body Directed	Simple & Object Directed	Complex Routines, Manipulations, & Movements	Verbal Abstract Behavior/Interests
Internal	External	External	External
Very restricted range	Restricted range	Restricted ranged	Restricted range
Very marked, stereotyped, repetitive behavior	Marked, stereotyped, repetitive behavior	Occasional, repetitive behavior	Minimal, stereotyped, repetitive behavior

Most Severe	Least Severe

Figure 2.1: Triad of impairments in the autism spectrum

Notes: Autistic Disorder symptoms present along a continuum of severity. As one moves along this continuum (from left to right), symptoms have a reduced impact on adaptive functioning and the potential for independent functioning increases. These symptoms change over time, with intelligence and language being the best predictors of movement from most to least severe.

Source: Brock, Jimerson and Hansen, 2006.

Although Wing's (1981) article generated interest in Britain and America, another ten years elapsed before Asperger's article and doctoral thesis were translated from German to English (Sanders, 2009). According to Frith's (1991) translation of Asperger's article, children with Asperger syndrome have extremely limited 'relations with the outside world' (p. 42), 'could not engage in the lively reciprocity of normal social interaction' (p. 45), and have 'abnormal fixations' with objects (p. 81).

2.2.3 The inclusion of Asperger syndrome in academic literature

Asperger's and Kanner's discoveries occurred approximately one year apart. Furthermore, neither professional was aware of the other's work (Sanders, 2009). However, this historical point has been disputed (Chown & Hughes, 2016). The two researchers' papers, which are nearly identical in description, led to the creation of two distinct—albeit similar—disorders in the DSM-IV (Sanders, 2009). However, there is a view in the literature which asserts that Asperger syndrome and autism are not two separate disorders but instead lie at two separate ends of a spectrum (Kamp-Becker et al., 2010). Researchers have published extensively on autism since its discovery by Kanner in 1943. In contrast, from 1944 to 1990, little was published on Asperger syndrome. However, since 1995 onwards there has been an increase in the number of publications on Asperger syndrome (See Figure 2.2) (Matson & Wilkins, 2008).

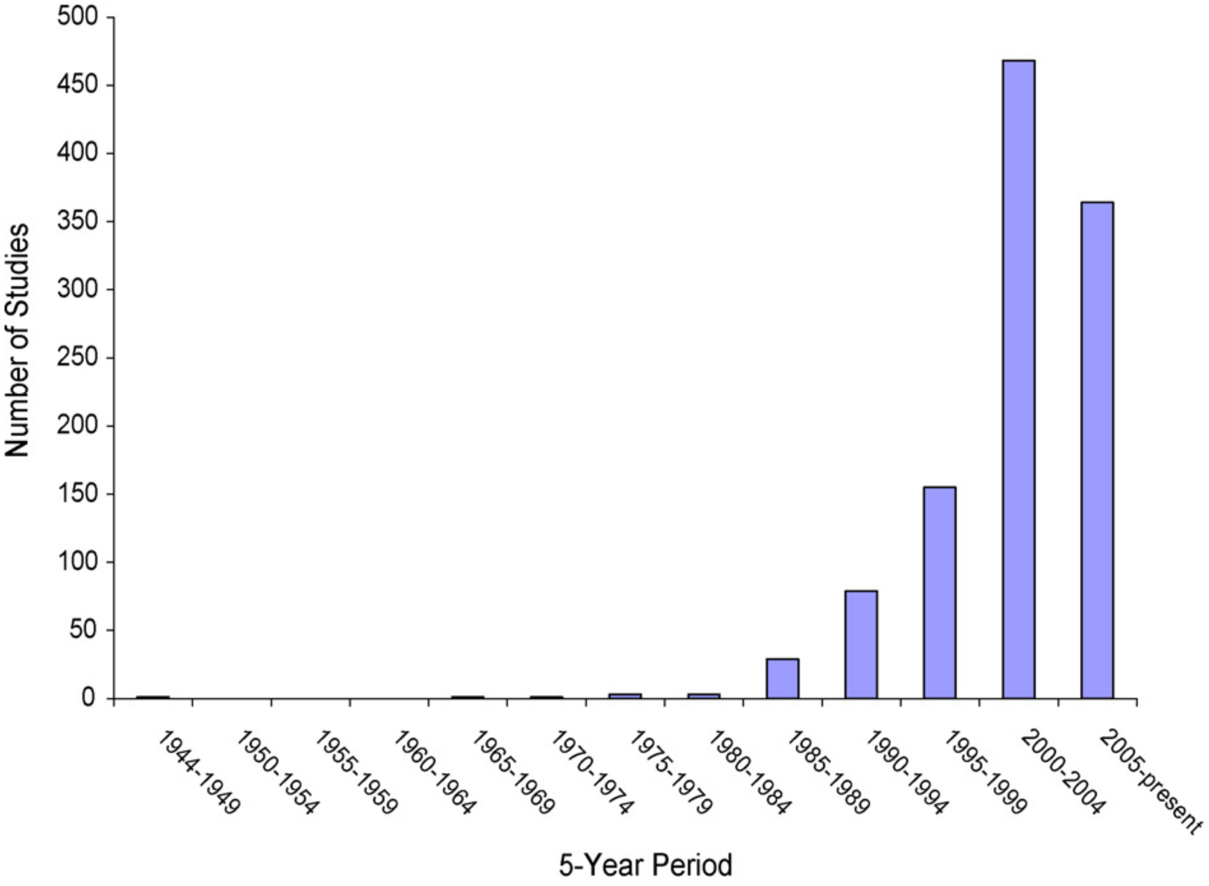


Figure 2.2: Number of articles published on Asperger syndrome from 1944 to 2005

Source: Matson and Wilkins, 2008.

2.2.4 Asperger syndrome and the Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition

In May 2013, the APA published the DSM-5 and in this diagnostic manual, autism and Asperger syndrome were amalgamated to form one condition, called Autism Spectrum Disorders (APA, 2013) (See Appendix 1). This single diagnostic condition has generated scholarly publications (Ghaziuddin, 2010; Kaland, 2011; Leventhal-Belfer, 2013; Nemeroff et al., 2013; Ritvo, 2012; Tsai, 2013, 2014; Verhoeff, 2013; Wing, Gould, & Gillberg, 2011; Young & Rodi, 2014); commentary from the media (Carmack, 2013) and the public (Ohan, Ellefson, & Corrigan, 2015; Parsloe & Babrow, 2016); and positive and negative views from health and educational professionals in Australia (Kite et al., 2013). Some Australian health and educational professionals in Kite et al.'s (2013) study support the DSM-5's Autism Spectrum Disorder diagnostic criteria. For example, one participant made the following comment:

> [P]eople with Asperger's syndrome have a lot of difficulty accessing services that are available for those with Autism. Combining them into one diagnosis would enable more people to receive help and support in schools and for adults who find it extremely difficult to receive support. (Kite et al., 2013, p. 1697)

However, other health Australian professionals and educationalists do not support this change. For example, 'Asperger's syndrome and autism have their unique features. It is just like you can't combine ADHD [Attention Deficit Hyperactivity Disorder] and OCD [Obsessive Compulsive Disorder] together' (Kite et al., 2013, p. 1696).

Some adults with Asperger syndrome have expressed their concern about the DSM-5's Autism Spectrum Disorder diagnostic label (Galligan, Feinstein, Sulkes, Bisagno, & Stein, 2013; Giles, 2014; Linton et al., 2014; Spillers, Sensui, & Linton, 2014). A participant with Asperger syndrome in Linton et al.'s (2014, p. 74) study, for example, stated, 'I don't want to necessarily be called 'autistic', because I don't want to be treated like I have full-on autism'. Similarly, in a 2014 study, a participant with Asperger expressed pragmatic objections:

> Merging AS [Asperger syndrome] with high functioning autism will lead to fewer AS diagnoses, less practical support for AS diagnoses in the workplace, which in turn will

> lead to higher unemployment amongst the undiagnosed who still struggle with the same symptoms and—by extension—a higher rate of alcoholism, heart disease and suicide. (Giles, 2014, p. 190)

Some people with Asperger syndrome have expressed their concerns that under the DSM-5, future generations of people with Asperger syndrome might not receive an Autism Spectrum Disorder diagnosis (Giles, 2014). Similarly, some studies have suggested that fewer people will be diagnosed with an Autism Spectrum Disorder under the DSM-5 (Bennett & Goodall, 2016; Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012; Kulage, Smaldone, & Cohn, 2014; Maenner et al., 2014; Matson, Hattier, & Williams, 2012; Mattila et al., 2011; Mayes et al., 2014; Sturmey & Dalfern, 2014; Young & Rodi, 2014). However, other studies have disputed this claim (Mazefsky et al., 2013; Wilson et al., 2013). In addition, the APA has stated that during their trials of the DSM-5, there has been no reduction in the number of people receiving an Autism Spectrum Disorder diagnosis (APA, 2013).

2.3 The aetiology of Autism Spectrum Disorders

In this section, the following possible causes for ASDs are reviewed: 1) maternal and paternal age during a child's birth; 2) suboptimal prenatal conditions, pregnancy complications and obstetric events; 3) maternal exposure to chemicals during pregnancy; and 4) genetic influences.

The impact of maternal and paternal age on the possibility of a child being born with an ASD has been examined. Maternal studies have found that as a woman's age increases, so does the possibility of her giving birth to a child on the autism spectrum (Bilder, Pinborough-Zimmerman, Miller, & McMahon, 2009; Croen, Grether, & Selvin, 2002; Croen, Najjar, Fireman, & Grether, 2007; Sandin et al., 2012). Likewise, paternal studies have shown that as a man's age increases, the chance of him fathering a child on the autism spectrum also increases (Tsuchiya et al., 2008). Furthermore, research has suggested that a jointly increased paternal and maternal age can increase the likelihood of a child being born with autism (Rahbar et al., 2012).

Studies have been undertaken on the possibility of suboptimal prenatal conditions, pregnancy complications and obstetric events causing a child to be born with an ASD (Dodds et al., 2011; Haglund & Källén, 2011). These conditions, complications and events include assisted reproductive technology (Zachor & Ben Itzchak, 2011); maternal diabetes during pregnancy (Xu, Jing, Bowers, Liu, & Bao, 2014); maternal fever during pregnancy (Zerbo et al., 2013); maternal exposure to intimate partner abuse before birth (Roberts, Lyall, Rich-Edwards, Ascherio, & Weisskopf, 2016); prenatal ultrasound tests (Stoch et al., 2012); neonatal jaundice (Amin, Smith, & Wang, 2011); maternal obesity (Li et al., 2016); low birth weight (Pinto-Martin et al., 2011); brief gestational age (Leavey, Zwaigenbaum, Heavner, & Burstyn, 2013); and low birth weight for gestational age (Lampi et al., 2012).

The relationship between maternal exposure to chemicals and the risk of a child being born on the autism spectrum has been investigated. Studies suggest that a child might be born with an ASD if the mother carrying them has been exposed to lacquer, varnish or xylene (McCanlies et al., 2012); mercury (Olmsted & Blaxill, 2010; Palmer, Blanchard, & Wood, 2009); air pollution generated by traffic (Becerra, Wilhelm, Olsen, Cockburn, & Ritz, 2013); and antidepressants (Croen, Grether, Yoshida, Odouli, & Hendrick, 2011). In contrast, research indicates that maternal exposure to tobacco (Rosen, Lee, Lee, Yang, & Burstyn, 2015) and antibiotics (Atladóttir, Henriksen, Schendel, & Parner, 2012) during pregnancy does not increase the possibility of a child being born with an ASD. Finally, investigators have concluded that more research needs to be conducted on whether low levels of Vitamin D during pregnancy increase the possibility of a child developing an ASD (Whitehouse et al., 2013).

The influence that genetics has on the development of ASDs is another area of research in the aetiology of ASDs. A study has proposed that some cases of ASDs are caused by genes (Fakhoury, 2015). Currently, genetic research, such as data mining and full genome sequencing, is being conducted to try and isolate the specific gene or set of genes responsible for the development of ASDs (Latkowski & Osowski, 2015; Wall et al., 2009).

2.4 Prevalence of Autism Spectrum Disorders in Australia

ASD prevalence studies have been conducted on every continent (Elsabbagh et al., 2012), including Australia (e.g. Barbaro, Ridgway, & Dissanayake, 2011; Parner et al., 2011; Williams et al., 2005). Studies have shown that the prevalence of ASDs in Australia has increased in recent times (Baker, 2002; Icasiano, Hewson, Machet, Cooper, & Marshall, 2004; Nassar et al., 2009). For example, as described in the quotation below, from 1999 to 2004 there has been an increase each year in the number of people receiving an ASD diagnosis in Western Australia (Glasson et al., 2006, p. 4):

> During the period January 1st 2004 to December 31st 2004, 237 people were diagnosed with an autism spectrum disorder in WA [Western Australia]. The (revised) totals for the 1999-2003 years were 160, 174, 212, 216 and 224 cases respectively.

Many factors may have contributed to the rise in the number of people in Australia being diagnosed with ASDs. These include a heightened professional and community awareness of ASDs; an increase in the amount of healthcare services available to people with ASDs; and increased publicity about ASDs in films (e.g. *Rain Man*, *Mozart and the Whale*) and mainstream media (Prior, 2003). Another factor which may have had an impact on reported prevalence rates is changes to diagnostic taxonomies and procedures (Grether, Rosen, Smith, & Croen, 2009; King & Bearman, 2009). Despite an increase in prevalence, often females with ASDs are not researched because the majority of people with ASDs are male (Shefcyk, 2015).

2.5 The main characteristics of Asperger syndrome

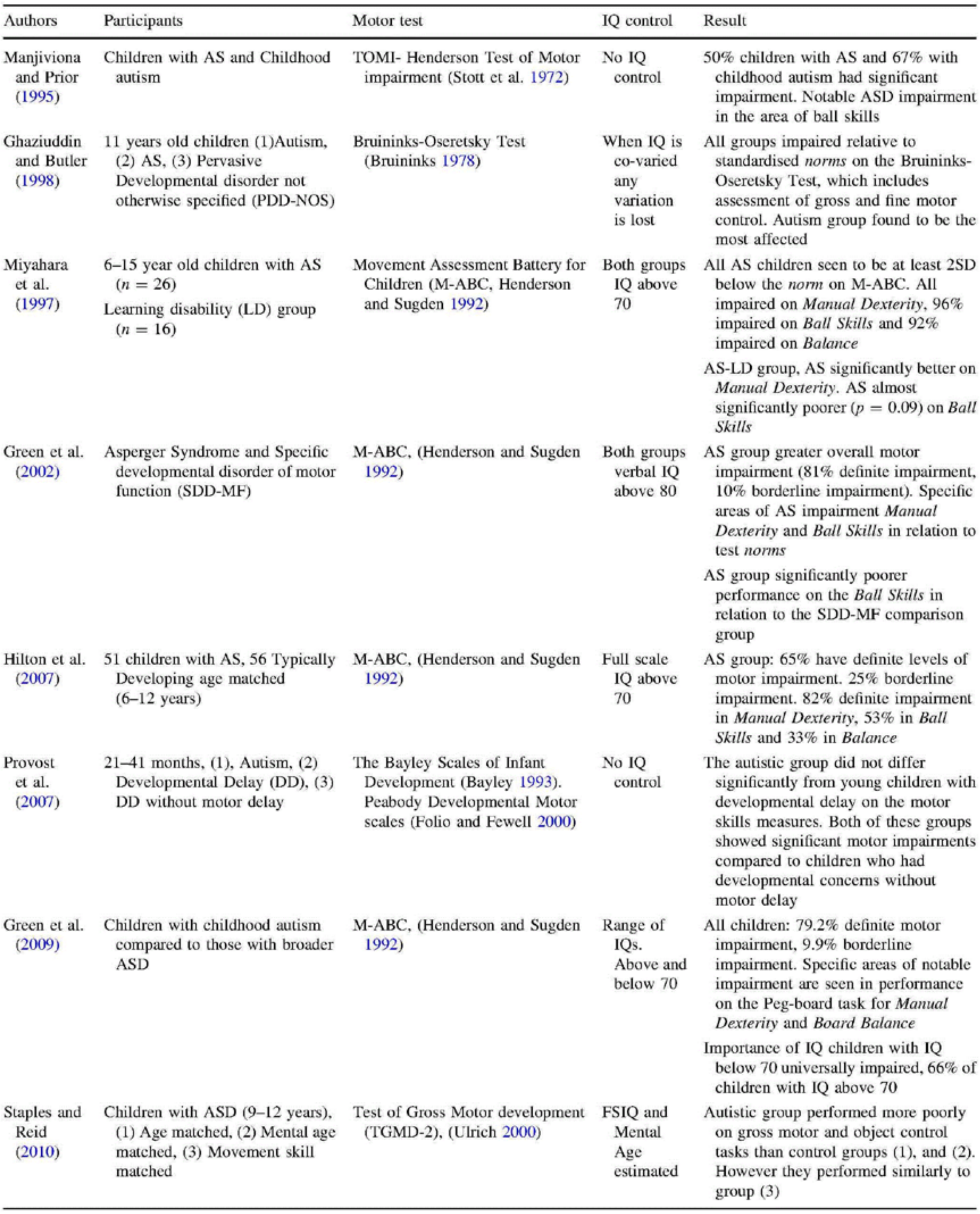
This section presents an overview of the main characteristics associated with Asperger syndrome: limited motor movement abilities; sensory sensitivities; Restricted and Repetitive Behaviours and Interests [RRBIs]; social limitations; and limited verbal communication abilities.

2.5.1 Limited motor movement abilities

The view that people with Asperger syndrome have limited motor movement abilities originated in Asperger's first study (Frith, 1991; Wing, 1981). In addition, 90% of Wing's (1981) sample were 'poor at games involving motor skills, and sometimes the executive problems affect the ability to write or to draw' (Wing, 1981, pp. 116–117). Since Asperger's and Wing's writings, research has examined the motor movement abilities of people with Asperger syndrome (Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Markoulakis, Scharoun, Bryden, & Fletcher, 2012; Price, Shiffrar, & Kerns, 2012; Whyatt & Craig, 2012). Some people with Asperger syndrome exhibit fine motor challenges (i.e. drawing, handwriting, or catching a ball) (Beversdorf et al., 2001; Crippa, Forti, Perego, & Molteni, 2013; Lim & Slaughter, 2008) and/or gross motor challenges (i.e. unstable balance) (Freitag, Kleser, Schneider, & von Gontard, 2007). The DSM-IV-TR and ICD-10's diagnostic criteria for Asperger syndrome have included motor coordination challenges. The DSM-5 has also included delayed motor milestones and clumsiness as symptoms of Autism Spectrum Disorders (Linton et al., 2014).

Despite limited motor movement abilities being incorporated into mainstream taxonomies, the precise prevalence rate for such challenges in the Asperger syndrome population still remains undefined. There are three reasons for why a precise prevalence rate has not been generated. Firstly, studies on the motor movement abilities of people with Asperger syndrome do not use a standardised age range for their samples. For example, Ghaziuddin and Butler's study sampled children aged eleven years while Miyahara et al.'s study sampled people aged six to fifteen years. Secondly, each study had its own unique sample size. For example, Miyahara et al.'s study sampled twenty-six participants with Asperger syndrome while Hilton et al.'s study sampled fifty-one participants. Thirdly, one standardised motor measurement instrument has not been used across all studies. For example, Ghaziuddin and Butler's study used the Bruininks Oseretsky Test of Motor Proficiency while Green et al.'s study used the Movement Assessment Battery for Children test (See Table 2.2) (Whyatt & Craig, 2012).

Table 2.2: Summary of studies investigating motor control in children with Autism Spectrum Disorders



Authors	Participants	Motor test	IQ control	Result
Manjiviona and Prior (1995)	Children with AS and Childhood autism	TOMI- Henderson Test of Motor impairment (Stott et al. 1972)	No IQ control	50% children with AS and 67% with childhood autism had significant impairment. Notable ASD impairment in the area of ball skills
Ghaziuddin and Butler (1998)	11 years old children (1)Autism, (2) AS, (3) Pervasive Developmental disorder not otherwise specified (PDD-NOS)	Bruininks-Oseretsky Test (Bruininks 1978)	When IQ is co-varied any variation is lost	All groups impaired relative to standardised *norms* on the Bruininks-Oseretsky Test, which includes assessment of gross and fine motor control. Autism group found to be the most affected
Miyahara et al. (1997)	6–15 year old children with AS ($n = 26$) Learning disability (LD) group ($n = 16$)	Movement Assessment Battery for Children (M-ABC, Henderson and Sugden 1992)	Both groups IQ above 70	All AS children seen to be at least 2SD below the *norm* on M-ABC. All impaired on *Manual Dexterity*, 96% impaired on *Ball Skills* and 92% impaired on *Balance* AS-LD group, AS significantly better on *Manual Dexterity*. AS almost significantly poorer ($p = 0.09$) on *Ball Skills*
Green et al. (2002)	Asperger Syndrome and Specific developmental disorder of motor function (SDD-MF)	M-ABC, (Henderson and Sugden 1992)	Both groups verbal IQ above 80	AS group greater overall motor impairment (81% definite impairment, 10% borderline impairment). Specific areas of AS impairment *Manual Dexterity* and *Ball Skills* in relation to test *norms* AS group significantly poorer performance on the *Ball Skills* in relation to the SDD-MF comparison group
Hilton et al. (2007)	51 children with AS, 56 Typically Developing age matched (6–12 years)	M-ABC, (Henderson and Sugden 1992)	Full scale IQ above 70	AS group: 65% have definite levels of motor impairment. 25% borderline impairment. 82% definite impairment in *Manual Dexterity*, 53% in *Ball Skills* and 33% in *Balance*
Provost et al. (2007)	21–41 months, (1), Autism, (2) Developmental Delay (DD), (3) DD without motor delay	The Bayley Scales of Infant Development (Bayley 1993). Peabody Developmental Motor scales (Folio and Fewell 2000)	No IQ control	The autistic group did not differ significantly from young children with developmental delay on the motor skills measures. Both of these groups showed significant motor impairments compared to children who had developmental concerns without motor delay
Green et al. (2009)	Children with childhood autism compared to those with broader ASD	M-ABC, (Henderson and Sugden 1992)	Range of IQs. Above and below 70	All children: 79.2% definite motor impairment, 9.9% borderline impairment. Specific areas of notable impairment are seen in performance on the Peg-board task for *Manual Dexterity* and *Board Balance* Importance of IQ children with IQ below 70 universally impaired, 66% of children with IQ above 70
Staples and Reid (2010)	Children with ASD (9–12 years), (1) Age matched, (2) Mental age matched, (3) Movement skill matched	Test of Gross Motor development (TGMD-2), (Ulrich 2000)	FSIQ and Mental Age estimated	Autistic group performed more poorly on gross motor and object control tasks than control groups (1), and (2). However they performed similarly to group (3)

Source: Whyatt and Craig, 2012.

2.5.2 Sensory sensitivities

Another characteristic of Asperger syndrome is sensory sensitivities (Bogdashina, 2003; Dunn et al., 2002; Elwin et al., 2012; Jones, Quigney, & Huws, 2003; Madriaga, 2010; Smith & Sharp, 2013). This characteristic was not included in the DSM-IV or ICD-10 as a symptom of Asperger syndrome. However, it was included in the DSM-5 as a symptom of Autism Spectrum Disorders (Horder, Wilson, Mendez, & Murphy, 2014; Linton et al., 2014).

The literature reveals that people with Asperger syndrome can have hyper- and hypo-sensitive reactions to sensory sensations (Elwin, Ek, Kjellin, & Schröder, 2013). People with hyper-sensitive reactions to sensory sensations often avoid, or have a low tolerance for, sensory inputs. In contrast, people with hypo-sensitive reactions often have a higher sensory threshold and often engage in activities which provide sensory input, such as listening to loud music (Dunn, 1997; Hochhauser & Engel-Yeger, 2010).

The literature shows that people with ASDs experience hyper- and hypo-sensitive sensory sensitivities with at least five senses:

- taste (Bennetto, Kuschner, & Hyman, 2007; Tavassoli & Baron-Cohen, 2012b);
- hearing (Haesen, Boets, & Wagemans, 2011);
- vision (Simmons et al., 2009);
- touch (Cascio et al., 2008);
- smell (Hrdlicka et al., 2011).

This section will now review the literature on these sensory modalities.

2.5.2.1 Tactile sensitivities

> I like heavy pressure, and very often prefer to carry a heavy bag on my shoulders when walking around. (Smith & Sharp, 2013, p. 900)

The quotation above illustrates that some people with Asperger syndrome have tactile sensitivities (Smith & Sharp, 2013). Aside from personal testimonies, there are also studies on people on the autism spectrum and their tactile sensitivities (Abu-Dahab, Skidmore, Holm, Rogers, & Minshew, 2013; Blakemore et al., 2006; Cascio et al., 2008; Foss-Feig, Heacock, &

Cascio, 2012). Some of this literature has shown that people on the autism spectrum—including those with Asperger syndrome—can have hyper-sensitive and/or hypo-sensitive tactile sensitivities. People with ASDs who are tactile hyper-sensitive might express distress while being groomed, react aggressively when being touched, or become irritated while wearing shoes (Blakemore et al., 2006; Lundqvist, 2015). In contrast, people with ASDs who are tactile hypo-sensitive might have a high tolerance for pain, not be aware that their hands and/or face are dirty, or have a preference for touching certain objects, surfaces or textures (Blakemore et al., 2006)

2.5.2.2 Auditory sensitivities

The auditory sensitivities that some people on the autism spectrum experience have been researched (Lucker, 2013; O'Connor, 2011; Stiegler & Davis, 2010). Some of this literature has shown that some people with ASDs can have hyper-sensitive and/or hypo-sensitive responses to sounds. In regard to hypo-sensitive responses, some people with ASDs feel comfortable being immersed in ambient sound (Lucker, 2013). In contrast, some people with ASDs and hyper-sensitive responses cannot tolerate sounds in the low amplitude range, such as the ambient noise generated by a crowd of people. This may result in a person with an ASD having difficulty interacting with more than one person at a time (Müller, Schuler, & Yates, 2008).

2.5.2.3 Taste sensitivities

Some people with Asperger syndrome have taste sensitivities (Kalyva, 2009; Legge, 2004; Roth, Williams, & Paul, 2010), as do some people with autism (Martins, Young, & Robson, 2008; Schreck, Williams, & Smith, 2004; Sharp, Burrell, & Jaquess, 2014). In contrast, other people on the autism spectrum have limited taste identification capabilities (See Figure 2.3) (Bennetto et al., 2007; Tavassoli & Baron-Cohen, 2012b). Specifically, Tavassoli and Baron-Cohen (2012b) found that adolescents (aged between ten and eighteen) with ASDs had difficulties identifying sweet, sour and bitter tastes (See Table 2.3). However, this finding cannot be generalised to younger children with ASDs because, according to Tavassoli and Baron-Cohen (2012b), only adults (Tavassoli & Baron-Cohen, 2012b) and adolescents (Bennetto et al., 2007) have participated in taste identification research. In addition, Tavassoli and Baron-Cohen (2012b, p. 1422) state the following:

> [B]esides taste identification other factors such as texture of the food, presentation and the interaction with olfactory system to create flavour play a role and should be taken into account in future studies.

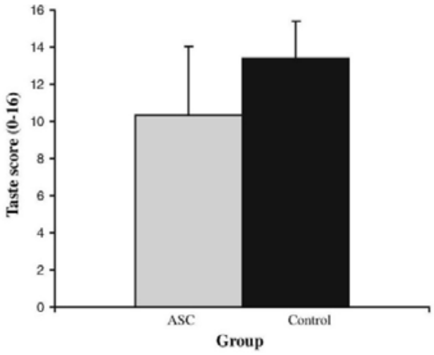


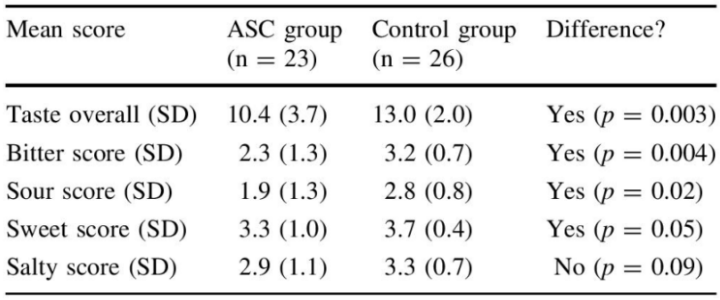
Figure 2.3: Taste identification abilities in adults with and without an Autism Spectrum Disorder

Notes: The bars represent taste identification accuracy scores overall for adults with and without an ASD. The antennas indicate standard error of mean. The overall score can range from zero to sixteen (the higher the better) and is based on identifying sweet, sour, salty, and bitter taste strips. Adults with ASD had significant lower taste identification scores than control participants (p<0.05).

ASC = Autism Spectrum Conditions

Source: Tavassoli and Baron-Cohen, 2012.

Table 2.3: Descriptive characteristics of taste identification scores for adults with and without an Autism Spectrum Disorder



Mean score	ASC group (n = 23)	Control group (n = 26)	Difference?
Taste overall (SD)	10.4 (3.7)	13.0 (2.0)	Yes ($p = 0.003$)
Bitter score (SD)	2.3 (1.3)	3.2 (0.7)	Yes ($p = 0.004$)
Sour score (SD)	1.9 (1.3)	2.8 (0.8)	Yes ($p = 0.02$)
Sweet score (SD)	3.3 (1.0)	3.7 (0.4)	Yes ($p = 0.05$)
Salty score (SD)	2.9 (1.1)	3.3 (0.7)	No ($p = 0.09$)

Key: Taste identification scores overall can range from zero to sixteen. Bitter, sour, sweet, and salty scores can range from zero to four. Taste scores are given as group means. Adults with ASD were less accurate in identifying tastes overall, as well as for bitter, sour, and sweet tastes (p<0.05), ASC = Autism Spectrum Conditions, SD = Standard Deviation.

Source: Tavassoli and Baron-Cohen, 2012.

2.5.2.4 Visual sensitivities

> [M]y bed was surrounded and totally encased by tiny spots which I called stars, like some kind of mystical glass coffin. I have since learned that they are actually air particles yet my vision was so hypersensitive that they often became a hypnotic foreground with the rest of 'the world' fading away. (Donna Williams in Simmons et al., 2009, p. 2707)

Besides the personal testimonies of people with Asperger syndrome, as illustrated in the quotation above, there is also academic literature concerning the visual sensitivities of people on the autism spectrum (Albrecht et al., 2014). As with other sensory modalities, people with ASDs can have hypo-sensitive and/or hyper-sensitive responses. People with ASDs who display visual hypo-sensitive behaviours may be attracted to light; look intensely at objects or people; and be fascinated with reflections and/or brightly coloured objects. In contrast, people with ASDs who display visual hyper-sensitive behaviours may focus on tiny pieces of dust/particles; dislike dark places and/or bright lights; dislike sharp flashes of light; look down most of the time; and cover/close their eyes when facing bright lights (Simmons et al., 2009).

2.5.2.5 Olfactory sensitivities

The olfactory sensitivities of people on the autism spectrum have been studied (Hrdlicka et al., 2011; Legiša, Messinger, Kermol, & Marlier, 2013; May et al., 2011; Suzuki, Critchley, Rowe, Howlin, & McMurphy, 2003; Tavassoli & Baron-Cohen, 2012a). In common with the other sensory modalities, some people on the autism spectrum can have hyper- and hypo-sensitive olfactory sensations. In Jones et al.'s (2003, p. 115) study, for example, Brian expressed his olfactory hyper-sensitivities: 'Chalk hurts my nose, and soap and perfume and aftershave and toothpaste … Almost all types of food smell too sharp'. In contrast, Tavassoli and Baron-Cohen (2012a) claim that there is no difference between people with and without ASDs in relation to their olfactory sensitivities (See Figure 2.4).

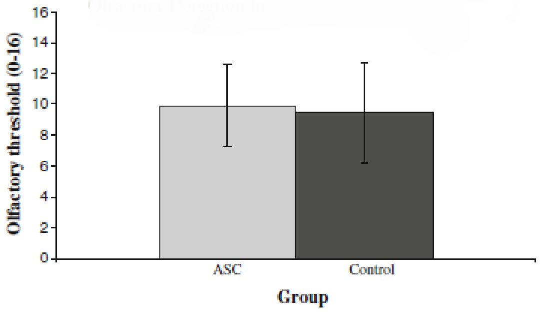


Figure 2.4: Olfactory detection in adults with and without an Autism Spectrum Disorder

Notes: Olfactory detection thresholds in adults with and without an ASD. Bars represent olfactory detection threshold (including error bars). Both groups showed similar olfactory detection.
Source: Tavassoli and Baron-Cohen, 2012a.

2.5.3 Restricted and Repetitive Behaviours and Interests [RRBIs]

RRBIs are a feature of Asperger syndrome (Chowdhury, Benson, & Hillier, 2010; Dewrang & Sandberg, 2011; South et al., 2005; Tanidir & Mukaddes, 2014). RRBIs have been categorised as ‘Repetitive Sensory Motor’ and ‘Insistence on Sameness’ behaviours (Bishop et al., 2013) or ‘lower order’ and ‘higher order’ behaviours (Richler, Bishop, Kleinke, & Lord, 2007; Turner, 1999). Lower order RRBIs are usually considered to be stereotypical and repetitive movements of the body or objects. Higher order RRBIs, however, are predominantly cognitive in nature; for example, rituals and routines, insistence on sameness, and circumscribed interests. They are also characterised by a rigid adherence to some rule or preferred mental state (Tanidir & Mukaddes, 2014; Turner, 1999).

The consequences that RRBIs can have for a person on the autism spectrum can include the inability to socialise with others; problems with getting dressed or maintaining personal hygiene; insomnia; and poor eating habits (Gillberg, 2002). The RRBI behaviours that a child on the autism spectrum displays can also increase parental stress levels (Lounds, Seltzer, Greenberg, & Shattuck, 2007) and create a negative family atmosphere (Greenberg, Seltzer, Hong, & Orsmond, 2006). Conceptualising RRBIs in terms of higher and lower order behaviours has resulted in treatment programs being developed that minimise the negative consequences associated with RRBIs and this seems to be a promising development (Boyd, McDonough, & Bodfish, 2012).

2.5.4 Social limitations

Often people with Asperger syndrome exhibit an inability to socialise with others (Fletcher-Watson, Leekam, & Findlay, 2013; Jones & Meldal, 2001; Macintosh & Dissanayake, 2006; Minne & Semrud-Clikeman, 2011; Stichter et al., 2010). This limitation has been explored within education (Carrington, Papingzak, & Templeton, 2003; Church, Alisanski, & Amanullah, 2000) and employment settings (Jennes-Coussens, Magill-Evans, & Koning, 2006). As illustrated in Figure 2.5, many factors can have an impact on the social abilities of people with Asperger syndrome (Smith Myles & The Ziggurat Group, 2013).

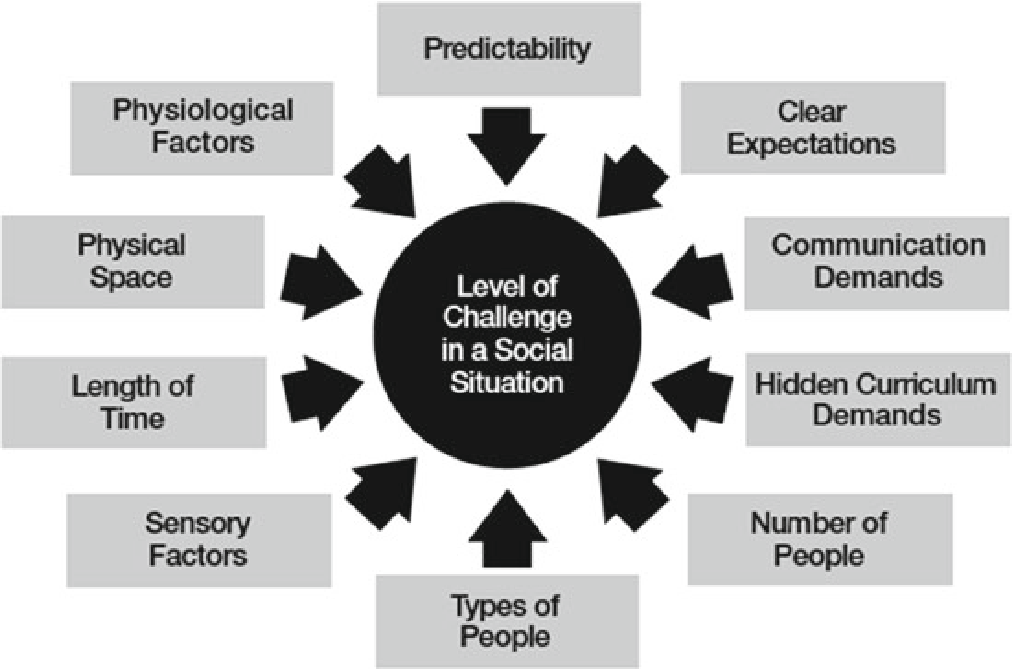


Figure 2.5: Loomis' ten factors that impact on social interactions

Notes: Brief overview of Loomis' ten factors that impact on social interactions

Factor	**Brief description**
Predictability	Routines and regular activities facilitate social success. Activities that are less than predictable can cause anxiety and the learner's focus is on personal stress experiences rather than social exchanges
Clear explanations	Answers to these questions must be provided: Who do you approach? How do you join the activity? When can you talk, sing, yell, etc.?
Communication	Verbal and nonverbal communication, emotions, opinions, jokes, and metaphors relative to an activity must be understood by the learner with Asperger syndrome
Hidden curriculum	Unstated rules, assumptions, and expectations can serve as a roadblock to successful social experiences
Number of people	The fewer people involved, the lower the social challenge

Types of people	Certain individuals are easier to socialise with than others. It is important, especially in new social situations, to ensure that people who are easy to socialise with are included in activities
Sensory demands	All environments have sensory demands and the majority of individuals with Asperger syndrome have sensory challenges. A mismatch between the two can cause regulation problems
Length of time	Social processing can be exhausting for learners with Asperger syndrome. The longer a social event, the more taxing it is
Physical space	Crowded spaces, large open areas, noisy environments, and echoing environments can be difficult and/or exhausting for the individual with Asperger syndrome
Physiological factors	Physiological factors, including fatigue, hunger, thirst, and illness can influence social interactions

Source: Smith Myles and The Ziggurat Group, 2013.

2.5.5 Verbal communication limitations

Some people with Asperger syndrome face certain challenges with verbal communication (Bennett et al., 2008; Paul, Miles-Orlovsky, Marcinko, & Volkmar, 2009; Saalasti et al., 2008). Specifically, these challenges include understanding metaphorical statements (Gold & Faust, 2010; Melogno, D'Ardia, Pinto, & Levi, 2012) and ironic language (Pexman et al., 2011), and inferring the social meaning of verbal communication (Golan, Baron-Cohen, Hill, & Rutherford, 2007; Martin & McDonald, 2004; Rutherford et al., 2002). Similarly, some people with Asperger syndrome have also displayed an inability to stop answering a question once they have conveyed an appropriate amount of information to the listener (Loukusa et al., 2007).

2.5.6 The gap in the literature on adults with Asperger syndrome and the characteristics associated with Asperger syndrome

People with Asperger syndrome have described living with the main characteristics of Asperger syndrome (Smith & Sharp, 2013), as have their family members (Dewrang & Sandberg, 2010, 2011). In addition, negative words such as 'challenges', 'difficulties' and 'limitations' are often used to describe these characteristics (Winter-Messiers et al., 2007). For example, according to Armstrong (2010, p. 62), 'the gift for detail among autistic individuals is typically defined by psychologists in terms of deficit rather than strength'. By portraying these characteristics in negative terms, the benefits such characteristics can provide an adult with Asperger syndrome have been under-researched (Baron-Cohen, 2002; Butler & Gillis, 2011; Davidson & Orsini, 2013; Molloy & Vasil, 2002; Wheeler, 2011; Winter-Messiers et al., 2007). The present study added to this limited amount of literature through asking each participant to describe how the characteristics associated with their Asperger syndrome have had an impact on their life.

2.6 Erikson's Psychosocial Theory of Human Development

Erikson's theory is the theoretical lens used to understand how the participants' views and experiences can have an impact on their lifespan development. This theory proposes that individuals move through eight stages of development, starting with *Trust versus Mistrust* in infancy and finishing with *Integrity versus Despair* in late adulthood. Erikson's theory has variously been applied to lesbian, gay, bisexual, and transgendered individuals (Bennett & Douglass, 2013); Amish, Appalachian, and Mormon women (Cheek & Piercy, 2008); survivors of the Hurricane Katrina disaster (Wiley et al., 2011); and people diagnosed with the Human Immunodeficiency Virus (Merriam, Courtenay, & Reeves, 1997). Yet a review of the available literature failed to locate any studies that have applied Erikson's theory to those on the autism spectrum. In the final chapter, this thesis addressed this lack of research by applying Erikson's theory to the participants' views and experiences.

2.6.1 Stage One: Basic Trust versus Basic Mistrust

The first stage of Erikson's theory is called *Basic Trust versus Basic Mistrust* which it starts when the infant relies on their caregiver to provide basic nourishment. During this stage a sense of trust is instilled in the infant if they are provided with a constant and reliable source of nourishment by their caregiver. The infant generally indicates that they trust their caregiver by showing a sense of ease and relaxation. Alternatively, if an infant is not provided with a constant level of care or support then they can develop feelings of mistrust, deprivation and abandonment towards their caregiver. Generally, the infant conveys these feelings of mistrust by being withdrawn and isolated from their caregiver and other people. Erikson proposed that if an infant has more incidents of trust than mistrust then they are more inclined to develop a sense of hope and confidence in themselves and others (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Vogel-Scibilia et al., 2009).

2.6.2 Stage Two: Autonomy versus Shame and Doubt

The second stage of Erikson’s theory starts during toddlerhood and is called *Autonomy versus Shame and Doubt*. During this stage, autonomy is often expressed through muscular control. Muscular control gives the child the ability to decide about if they want to physically embrace their caregiver. Also during this stage, a toddler learns to say ‘No’—a verbal expression that conveys this new sense of autonomy. If a toddler can be autonomous in situations and exercise a satisfactory level of self-governance, then a healthy personality is more likely to develop. In contrast, if a toddler cannot exercise autonomy during this stage, then they start to experience feelings of shame and doubt (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Vogel-Scibilia et al., 2009).

2.6.3 Stage Three: Initiative versus Guilt

The third stage of Erikson’s theory, *Initiative versus Guilt*, usually occurs when a child is between three to six years of age. According to Erikson, during this stage the child starts to explore the world and where they fit within it. This exploration is partly accomplished by the child socially engaging with other children, starting to imitate and idealise adults, and starting to use the question ‘Why?’ In this stage, a child’s family is the primary source of support and influence. However, the child’s curiosity motivates them to explore the world beyond the family unit. A child’s feelings of guilt develop during this stage, as the child is corrected or disciplined by their caregiver for exercising their physical and mental abilities in a socially inappropriate manner. Feelings of guilt are often expressed in the form of inhibition, over-obedience and repressed hopes and fantasies. The main conflict children encounter during this stage involves overcoming their feelings of guilt and developing a level of initiative. If a child can develop a strong sense of initiative, then they can develop a sense of purpose, which is essentially the self-belief that they can envisage and pursue valued and tangible goals guided by consciousness, rather than being paralysed by guilt or fear of punishment (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Vogel-Scibilia et al., 2009).

2.6.4 Stage Four: Industry versus Inferiority

Children between seven and eleven years old pass through the fourth stage of Erikson’s theory: *Industry versus Inferiority*. Erikson proposes that during this stage, the child’s personality starts to be influenced by social exchanges, friendships and what they have learned by asking questions, such as ‘What is this?’ or ‘What is that?’ If the child is unable to learn from others, then they will start to develop a sense of inferiority. In contrast, if a child is able to establish meaningful friendships, then they develop a positive sense of themselves because they have demonstrated to themselves a sense of competence (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Vogel-Scibilia et al., 2009).

2.6.5 Stage Five: Identity versus Identity Confusion

Between twelve and nineteen, children go through the fifth stage of Erikson’s theory, called *Identity versus Identity Confusion*. The main challenge that confronts children in this developmental stage is finding and establishing a solid identity rather than fostering identity confusion. In Western society, people often ask themselves, ‘Who am I?’ If a person is able to answer this question, then they have formed a solid identity of themselves. However, if an adolescent is not able to answer this question, then they are often placed in a situation where they develop identity confusion (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Vogel-Scibilia et al., 2009).

2.6.6 Stage Six: Intimacy versus Isolation

People between twenty and thirty years of age enter the sixth stage of Erikson’s theory: *Intimacy versus Isolation*. In Erickson’s theory, during this stage people often ask themselves, ‘Who can I share my life with?’ The conflict that occurs in this phase is between one’s desire for intimacy in a long-term relationship and one’s desire for individuality and autonomy. When a young adult fails to satisfy their desire to create an intimate bond with someone else, then their usual tendency is to avoid forming a relationship (Batra, 2013; Beaumont & Pratt, 2011; Berk, 2007; Erikson, 1963; Feldman, 2014; Vogel-Scibilia et al., 2009).

2.6.7 Stage Seven: Generativity versus Stagnation

The seventh stage of Erikson's theory, *Generativity versus Stagnation,* takes place when an adult is between forty and sixty. During this stage an adult often asks themselves, 'Whom or what can I care for?' This question addresses the need to be wanted. If someone is a parent, then their main responsibility during this stage is to take care of their offspring. However, as Erikson explains, if childless, people in this stage can still satisfy their desire to feel needed by helping guide the next generation in society through mentoring. When people do not contribute to the community or their offspring during this stage, then they tend to become stagnant and self-absorbed. This stagnation often presents itself in the form of excessive self-love and worshiping (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Slater, 2003; Vogel-Scibilia et al., 2009).

2.6.8 Stage Eight: Ego Integrity versus Despair

Ego Integrity versus Despair, the eighth and final stage of Erikson's theory, typically begins when an adult reaches sixty and finishes when they die. People in this stage generally ask themselves, 'Has my life been meaningful?' This question typically stems from a psychological preoccupation with facing death. If an adult has nurtured their offspring and partner, has successfully accepted their triumphs and disappointments in life, and can mentally picture their legacy, then they would not fear death. However, if a person cannot mentally picture their legacy and their place in history, then they will usually fear death and express regret at missing opportunities in life (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Hearn et al., 2012; Vogel-Scibilia et al., 2009).

2.7 Emotional reactions adults have had towards their diagnosis of Asperger syndrome

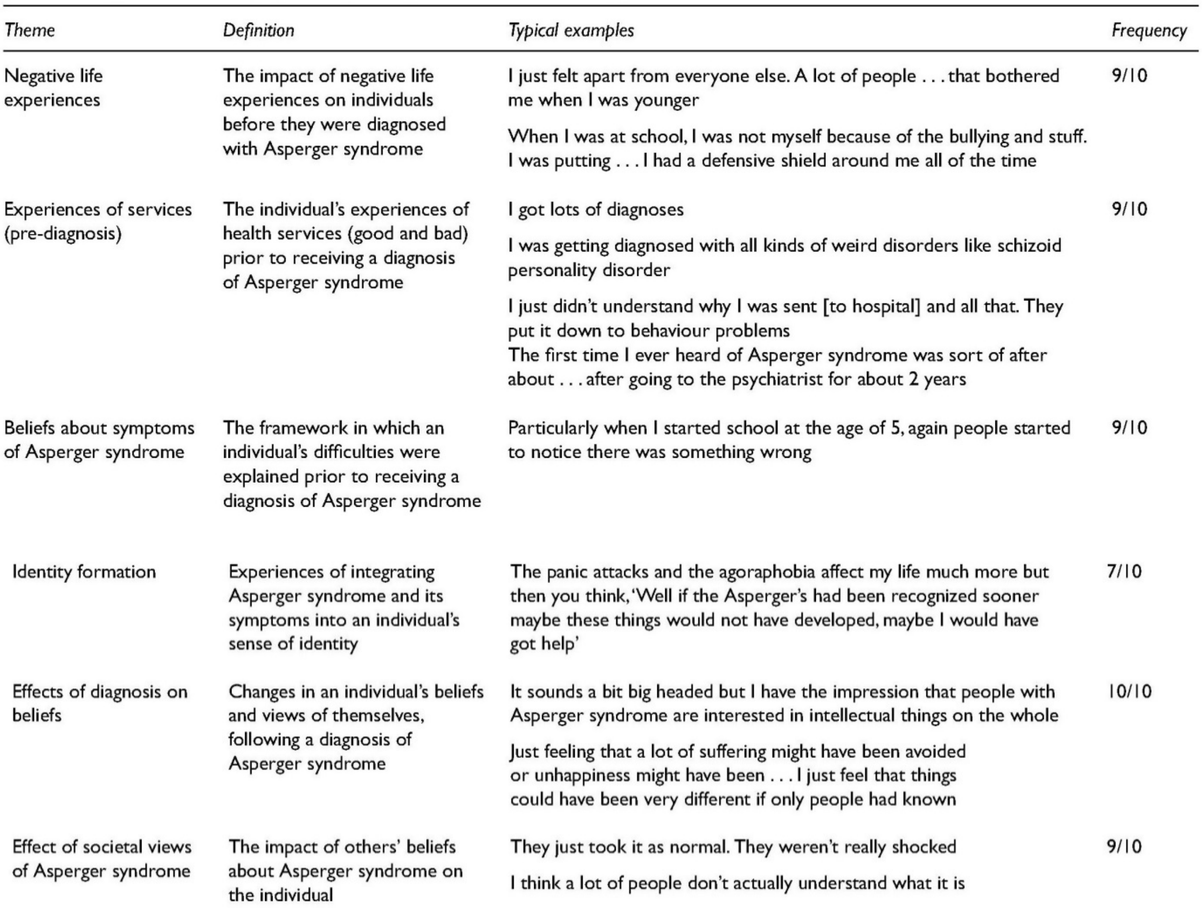
Literature is available about parents describing the emotional reactions they experienced towards their child's diagnosis of Asperger syndrome (Calzada et al., 2012; Pakenham, Sofronoff, & Samios, 2004). This study, however, will focus on reviewing six pieces of literature on the emotional reactions that adults have had towards their diagnosis of Asperger syndrome (i.e., MacLeod et al., 2013; Molloy & Vasil, 2004; Murray, 2006; Powell & Acker, 2016; Punshon et al., 2009; Rosqvist, 2012). Their findings will now be summarised and compared.

MacLeod et al. (2013) interviewed six adults about their experiences with the Asperger syndrome diagnostic process. Their study identified three thematic categories: 1) perceptions of others diagnosed with Asperger syndrome; 2) acquired knowledge of Asperger syndrome; and 3) personal identifications with Asperger syndrome. In the 'acquired knowledge of Asperger syndrome' thematic category, the participants revealed their emotional reactions towards their diagnosis of Asperger syndrome. Some participants found that their diagnosis formed a fundamental part of their identity. For example, Abby stated that 'autism is much more a part of someone's identity in the same way that someone's gender is or someone's sexuality or whatever' (MacLeod et al., 2013, p. 43). In addition, as with the parents of children with Asperger syndrome in Pakenham et al.'s (2004) study, once the adult participants in MacLeod et al.'s (2013) study were diagnosed with Asperger syndrome, they sought information about the condition. For example, Kika stated the following:

> I've read just about every type of information: Books by professionals and autistic people, first-hand accounts on websites and in internet discussions … I tend to disagree with the simplifications in leaflets. (MacLeod et al., 2013, p. 44)

Punshon et al. (2009) also studied the emotional reactions that adults have had towards their diagnosis of Asperger syndrome. Their study interviewed ten adults about their diagnosis of Asperger syndrome in an attempt to answer three research questions. Firstly, what experiences did adults with Asperger syndrome have towards their diagnosis of Asperger syndrome? Secondly, can stage and/or cognitive models of adjustment to diagnosis explain the participants' experiences of being diagnosed with Asperger syndrome? Thirdly, how can community services help adults make sense of, and adjust to, their diagnosis of Asperger syndrome? Punshon et al.'s (2009) study documented six thematic categories (See Table 2.4).

Table 2.4: Emotional reactions from participants in Punshon, Skirrow and Murphy's (2009) study



Theme	*Definition*	*Typical examples*	*Frequency*
Negative life experiences	The impact of negative life experiences on individuals before they were diagnosed with Asperger syndrome	I just felt apart from everyone else. A lot of people . . . that bothered me when I was younger When I was at school, I was not myself because of the bullying and stuff. I was putting . . . I had a defensive shield around me all of the time	9/10
Experiences of services (pre-diagnosis)	The individual's experiences of health services (good and bad) prior to receiving a diagnosis of Asperger syndrome	I got lots of diagnoses I was getting diagnosed with all kinds of weird disorders like schizoid personality disorder I just didn't understand why I was sent [to hospital] and all that. They put it down to behaviour problems The first time I ever heard of Asperger syndrome was sort of after about . . . after going to the psychiatrist for about 2 years	9/10
Beliefs about symptoms of Asperger syndrome	The framework in which an individual's difficulties were explained prior to receiving a diagnosis of Asperger syndrome	Particularly when I started school at the age of 5, again people started to notice there was something wrong	9/10
Identity formation	Experiences of integrating Asperger syndrome and its symptoms into an individual's sense of identity	The panic attacks and the agoraphobia affect my life much more but then you think, 'Well if the Asperger's had been recognized sooner maybe these things would not have developed, maybe I would have got help'	7/10
Effects of diagnosis on beliefs	Changes in an individual's beliefs and views of themselves, following a diagnosis of Asperger syndrome	It sounds a bit big headed but I have the impression that people with Asperger syndrome are interested in intellectual things on the whole Just feeling that a lot of suffering might have been avoided or unhappiness might have been . . . I just feel that things could have been very different if only people had known	10/10
Effect of societal views of Asperger syndrome	The impact of others' beliefs about Asperger syndrome on the individual	They just took it as normal. They weren't really shocked I think a lot of people don't actually understand what it is	9/10

Source: Punshon, Skirrow and Murphy, 2009.

The final study the author found on the emotional reactions that adults have had towards their diagnosis of Asperger syndrome was a 2012 study, in which Rosqvist interviewed twelve participants (three males and nine females) and identified four thematic categories: 1) Receiving the Diagnosis; 2) An Ambivalent Ideal of Openness; 3) Contesting Holders of Knowledge; and 4) Contesting the Diagnostic Criteria. In the thematic category 'Receiving the Diagnosis', participants described how obtaining a diagnosis of Asperger syndrome was an important milestone on the path to self-understanding. For example, the process of obtaining a diagnosis of Asperger syndrome was described by Maria as a 'vital step' and a 'gigantic process of reinterpreting your whole life' (Rosqvist, 2012, p. 122).

Another theme expressed by the participants in Rosqvist's (2012) study, which was also found in Punshon et al.'s (2009) study, was a belief that most of the research literature on Asperger syndrome has only portrayed the condition as a deficit rather than a condition with strengths. For instance, in Rosqvist's (2012) study, Anna argued that training courses should focus more on explaining the strengths and advantages and less on the difficulties and problems associated with Asperger syndrome. The participants in these two studies wanted to emphasise the strengths in the hope that the public, and other people with Asperger syndrome, will not be misled into believing that the syndrome is completely debilitating (Punshon et al., 2009; Rosqvist, 2012).

The three studies explored in this section (i.e., MacLeod et al., 2013; Powell & Acker, 2016; Punshon et al., 2009; Rosqvist, 2012) contain four similar thematic categories. Firstly, the participants in each study claimed that their label of Asperger syndrome was a part of their identity. Secondly, the participants expressed how a diagnosis of Asperger syndrome helped them reach a more accurate and comprehensive understanding of their experiences in life. Thirdly, the participants explained how obtaining a diagnosis of Asperger syndrome motivated them to seek further information about Asperger syndrome. Fourthly, despite a few exceptions (e.g. Baron-Cohen, 2002; Molloy & Vasil, 2002), participants believed that the literature on Asperger syndrome often highlighted the deficits related to the condition and not the strengths.

Aside from studies, two books were also found which focused primarily on the emotional reactions adults have had towards their diagnosis of Asperger syndrome. These books were Molloy and Vasil's (2004) *Asperger syndrome: Adolescence, and Identity: Looking Beyond the Label* and Murray's (2006) *Coming Out Asperger: Diagnosis, Disclosure and Self-Confidence.*

Molloy and Vasil's (2004) book documented the emotional reactions of six adults after being diagnosed with Asperger syndrome. This book identified six thematic categories: trying to make sense of an Asperger syndrome diagnosis; living with a label of Asperger syndrome and identifying as a teenager with Asperger syndrome; socialising and the importance of having good peer relationships; difficulties at school; personal relationships with family; and experiences with other mental health conditions. In the thematic category 'trying to make sense of an Asperger syndrome diagnosis', the participants explained that they thought their Asperger syndrome diagnostic label was an integral part of their character. This finding was also documented in MacLeod et al.'s (2013) study.

In Molloy and Vasil's book, a feeling of 'pure relief' (2004, p. 114) was another emotional reaction the participants expressed after being diagnosed with Asperger syndrome. Similarly, in Murray's book (2006, p. 201), Wendy Lawson also commented on this feeling after she was diagnosed with Asperger syndrome:

> [I]t was a relief to be given a label that made sense to me. After my diagnosis, I had the resources to explore what the label meant and, in particular, what it meant for me.

Molloy and Vasil (2004) postulate that their participants felt a feeling of relief after receiving their diagnosis of Asperger syndrome because it provided them with an understanding of why certain social situations were difficult and why it was hard to converse with some people.

2.7.1 The gap in the literature on the emotional reactions that adults have had towards their diagnosis of Asperger syndrome

The literature review revealed that there is literature on the emotional reactions that adults have had towards their diagnosis of Asperger syndrome (MacLeod et al., 2013; Molloy & Vasil, 2004; Murray, 2006; Punshon et al., 2009; Rosqvist, 2012). There is further literature on parents describing the emotional reactions they experienced towards their child's diagnosis of Asperger syndrome (Calzada et al., 2012; Pakenham et al., 2004). However, there is not much literature on adults with Asperger syndrome describing their families' and friends' emotional reactions to their family member's or friend's diagnosis of Asperger syndrome. Similarly, there is only a small amount of literature on adults describing the processes they underwent to obtain their diagnosis of Asperger syndrome (Molloy & Vasil, 2004). The participants in this study added to this limited amount of literature by describing their experiences of these issues.

2.8 The Australian public's knowledge of Asperger syndrome from the perspective of adults with Asperger syndrome

Several studies have explored the public's awareness and understanding of the autism spectrum (Dillenburger et al., 2013; Durand-Zaleski et al., 2012; Huws & Jones, 2010b; Mitchell & Locke, 2015; Stewart, 2008). For example, Stewart (2008) asked 500 people living in Northern Ireland, aged sixteen years and older, about their knowledge of autism. Most of the participants (89%) were aware of autism, but 90% were unaware of the prevalence of autism. Stewart's (2008) study also found that participants held misconceptions about people with autism. For example, the participants thought that people with autism are mostly children (55%); swear (48%); are intentionally rude (24%); are unable to walk (11%); or have special abilities (62%). In another study, Durand-Zaleski et al. (2012) found that 25% of the sample thought people with autism are unable to work and 8% thought people with autism cannot live in society. Finally, Dillenburger et al.'s (2013) study, which sampled 1204 adults (aged eighteen years and over) from Northern Ireland, found that the majority of respondents (82%) were aware of ASDs. Dillenburger et al. (2013) also found that females are more likely to have heard of ASDs than males (86.2% and 77.18% respectively).

Aside from statistically measuring the respondent's awareness of autism, Dillenburger et al. (2013) also asked their participants to describe the strengths and challenges that they thought people with autism exhibited. The views expressed by the participants are displayed in Word Cloud illustrations. Figure 2.6 is a Word Cloud illustration containing twenty-six words that the participants used to describe the strengths associated with autism. The word most used was 'very-intelligent' (108 responses) and the least commonly used word was 'computers' (ten responses). In addition, just over one third of Dillenburger et al.'s (2013) sample (N = 326) did not comment on what they thought were the strengths associated with autism.

Figure 2.6: Word Cloud illustration of the strengths that participants in Dillenburger et al.'s (2013) study articulated

Note: The word's text size in the Word Cloud visually indicates how often the word was used by the participants to describe autism: the bigger the text size, the more the word was used. In addition, any word used fewer than ten times was excluded from the Word Cloud illustration.

Source: Dillenburger, Jordan, McKerr, Devine and Keenan, 2013.

The participants in Dillenburger et al.'s (2013) study were also asked to comment on what they thought were the best words to describe the challenges associated with autism. Figure 2.7 is a Word Cloud illustration that contains twenty-seven words the participants used to describe the challenges associated with autism. The word most used was 'communication' (293 responses) and the words least used were 'employment' and 'fixation' (ten responses each).

Figure 2.7: Word Cloud illustration of the limitations that participants in Dillenburger et al.'s (2013) study articulated

Source: Dillenburger, Jordan, McKerr, Devine and Keenan, 2013.

Stewart's (2008), Durand-Zaleski et al.'s (2012) and Dillenburger et al.'s (2013) studies have explored the public's perceptions, attitudes, beliefs and views about people on the autism spectrum. However, not many studies were found on adults with Asperger syndrome expressing their views on what they think the *Australian* community in particular knows about people on the autism spectrum. The participants in this study addressed this gap to some extent by commenting on what they think the Australian community knows about the autism spectrum.

2.9 Depression and suicide

People with Asperger syndrome can be diagnosed with co-morbid conditions (Ghaziuddin, 2002; Konstantareas, 2005; Lugnegård, Hallerbäck, & Gillberg, 2011; Mattila et al., 2010; Mazzone, Ruta, & Reale, 2012), including schizophrenia (Waris, Lindberg, Kettunen, & Tani, 2013); anxiety (Dubin, 2009); insomnia (Allik, Larsson, & Smedje, 2006; Paavonen et al., 2008); bipolar disorder (Vannucchi et al., 2014); and epilepsy (Mouridsen, Rich, & Isager, 2013). For brevity, the literature on adults with Asperger syndrome and depression and suicide will only be reviewed since these were the only co-morbid conditions identified in the current study.

This section begins by discussing the causes, treatments and prevalence of depression. It then reviews the literature on the prevalence of depression and suicide in the Asperger syndrome population and cites Gillberg's (2002) and Ghaziuddin's (2005) views on adults with Asperger syndrome committing suicide. It concludes with an explanation of the gap in literature, specifically the limited amount of literature on adults with Asperger syndrome commenting on their depression and suicide experiences and also how Erikson's theory has not been applied to such experiences.

2.9.1 Aetiology and treatments for depression

The onset and progression of depression can be influenced by marital events, financial circumstances, and medical and psychological conditions. Marital events contributing to depression can include divorce (Cano & O'Leary, 2000), a spouse's death (Schoevers et al., 2000), or demanding family responsibilities, such as providing continuous medical care to a sick family member (Ho, Chan, Woo, Chong, & Sham, 2009). Relevant financial circumstances can include living on a limited income or welfare (Gilchrist & Gunn, 2007; Moos, Schutte, Brennan, & Moos, 2005). Medical conditions can include lack of physical exercise (Lee, 1999). Similarly, other possible causes of depression include tobacco use (Lee, 1999), dieting (Kenardy, Brown, & Vogt, 2001), and vegetarian diets (Baines, Powers, & Brown, 2007). Psychological conditions that can make people depressed include poor body image and concerns about being overweight (Al Mamun et al., 2007). Studies have also shown that low levels of serotonin in the brain can cause depression (Willnera, Scheel-Krügerb, & Belzung, 2013).

People who engage in social activities may be able to avoid the onset of depression or make their depression more benign (Uebelacker et al., 2013). However, other studies do not support this finding (Burto, Stice, & Seeley, 2004). Research has also shown that people who engage in regular physical exercise may have less depression than those who live a sedentary lifestyle (Dunn, Trivedi, Kampert, Clark, & Chambliss, 2005; Searle et al., 2011). However, for certain age groups, such as elderly people living in nursing homes, physical exercise may not be an effective treatment for depression (Underwood et al., 2013). Antidepressants, Cognitive Behaviour Therapy (CBT) and psychotherapy are other treatments for depression (Ellis, 2004). Despite the existence of these psychological and pharmacological approaches for treating depression, many people with depression never actually receive these treatments (Cuijpers, van Straten, Andersson, & Van Oppen, 2008; Cuijpers, Van Straten, Warmerdam, & Andersson, 2008; Kessler et al., 2001).

There are many reasons why depression is not treated. Some people never seek treatment because they live in areas where treatments are unavailable; expect negative social repercussions after receiving treatment; are unaware of available treatment programs or options; believe that they are ineligible for treatment; or they prefer a self-help approach to treating depression. There are also reasons why the medical profession fails to treat a patient’s depression. Some medical clinics have a limited number of clinicians who can provide specialised treatment programs for depression. Furthermore, under these circumstances, patients who require treatment for their depression are often left to manage their depression alone. Over time, this may result in increased symptom severity and the need for more intense and prolonged treatment programs (Kessler et al., 2001).

2.9.2 Adults with Asperger syndrome and depression and suicide

As with other segments of society, people with Asperger syndrome can have depression (Barnhill & Smith Myles, 2001; Bennett, 2016; Hedley & Young, 2006; Shtayermman, 2008; Stewart et al., 2006; Whitehouse, Durkin, Jacquet, & Ziatas, 2009) and commit suicide (Fitzgerald, 2007; Hannon & Taylor, 2013; Kocourkova, Dudova, & Koutek, 2013). People with autism can also have depression (Ghaziuddin, Ghaziuddin & Greden, 2002; Mayes, Calhoun, Murray, & Zahid, 2011; Stewart et al., 2006) and commit suicide (Mayes, Gorman, Hillwig-Garcia, & Syed, 2013) (See Appendix 2).

Currently, there is no uniform prevalence rate for depression or suicidal tendencies within the Asperger syndrome population. The rate of depression and suicide in the Asperger syndrome population varies across studies (Stewart et al., 2006; Storch et al., 2013). In regard to depression, Ghaziuddin, Weidmer-Mikhail and Ghaziuddin's (1998) study found that 22% of their sample had depression while Barnhill's (2001) study found that 18% of their sample had depression. In relation to the prevalence rate of suicide in the Asperger syndrome population, Shtayermman (2008) found that 50% of his sample had attempted suicide. Paquette-Smith, Weiss and Lunsky (2014, p. 275) found the following:

> [T]he 36% suicide attempt rate reported in our sample of 50 adults with AS [Asperger syndrome] is much higher than the 4.6% lifetime prevalence rate seen in the general population.

Finally, Cassidy et al. (2014) found that adults with Asperger syndrome were more likely to report experiencing suicidal ideation than adults without Asperger syndrome.

Gillberg (2002) and Ghaziuddin (2005) have commented on both the prevalence of suicidal ideation and the methods that adults with Asperger syndrome use to commit suicide. According to Gillberg (2002, p. 52), 'suicidal thoughts are very common in Asperger syndrome. They appear to be particularly frequent in adolescence and early adult life'. Ghaziuddin (2005, p. 137) expressed a similar view: 'suicidal behavior probably occurs more commonly in adults with high functioning autism/Asperger's syndrome than is generally recognized'. Reflecting on the methods that adolescents with Asperger syndrome use to commit suicide, Gillberg (2002, p. 52) wrote as follows:

> It is not uncommon for boys with Asperger's syndrome to use violent methods if they try to complete suicide that is using hanging, shooting, poisoning, jumping from a bridge or in front of a train.

On a positive note, Gillberg suggested a useful strategy:

> I found it can be very helpful to say to the person with Asperger's syndrome: 'I do not think it is a good idea for you to try to kill yourself. For one thing, if you do not succeed, you may well end up brain damaged, and that would not be good for you.' (Gillberg, 2002, p. 52)

2.9.3 The gap in the literature on adults with Asperger syndrome and their experiences with depression and suicidal ideation

The literature review has shown that studies have measured the rates of suicide for adults with Asperger syndrome (Cassidy et al., 2014; Paquette-Smith et al., 2014; Shtayermman, 2008). Similarly, clinicians have described what it is like to live with Asperger syndrome and attempt suicide (Ghaziuddin, 2005; Gillberg, 2002). However, not much literature was found on adults with Asperger syndrome describing their depression and suicidal ideation experiences (Barnhill, 2001). The participants in this study contributed to the literature by describing their experiences.

2.10 Education

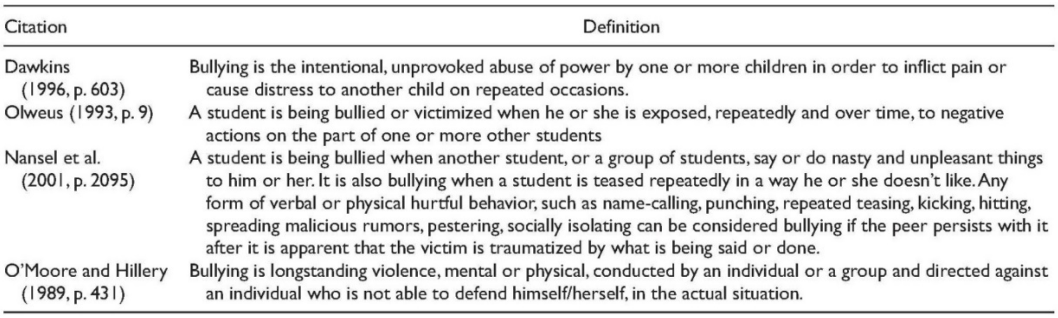
Literature has been published about students with Asperger syndrome in school and university (Ansell, 2011; Martin, 2010; Osborne, 2002; Sciutto et al., 2012; Winter, 2003; Winter & Lawrence, 2011). There is also literature on students with Asperger syndrome's writing (Brown & Klein, 2011; Delano, 2007; Schneider, Codding, & Tryon, 2013) and mathematical abilities (Chiang & Lin, 2007). Yet little is available on adults with Asperger syndrome recalling their bullying experiences at school (Fleischer, 2012; Sciutto et al., 2012). This section begins with a review of the history, prevalence, impact and definitions of school bullying. A statistical overview and the reasons behind why school students with Asperger syndrome are bullied will then be provided. This will be followed by an explanation of the gap in the literature on the connection between education and adults with Asperger syndrome.

2.10.1 History, prevalence, impact and definitions of school bullying

Research on school bullying began in Norway in the 1970s (Green, 2003). Since then, research on this topic has been conducted in Australia (Delfabbro et al., 2006). One finding is that *any* student can be bullied, irrespective of their gender, sexual orientation, age or nationality (Hillard, Love, Franks, Laris, & Coyle, 2014; Nansel, Overpeck, & Pilla, 2007). For girls, the estimated prevalence varies from 5% to 38% and for boys it varies from 6% to 41% (Due et al., 2005). Bullying incidents tend to peak during the transition from middle to high school (i.e. ages twelve to fifteen). After this transitional phase, bullying incidents tend to decrease (Eslea & Rees, 2001). Apart from prevalence, research has also shown that students who are bullied often engage in truancy or, in extreme circumstances, quit school. In addition, students who are bullied often develop depression, anxiety, feelings of rejection, low self-esteem, loneliness and helplessness (Kaltiala-heino, Rimpela, Rantanen, & Rimpela, 2000; Nansel, Overpeck, Haynie, Ruan, & Scheidt, 2003). Originally, school bullying was conceptualised as an activity occurring between the bully and their victim. However, researchers now explore school bullying from the perspective of other school students, family members, and educational institutions (Furlong, Morrison, & Greif, 2003).

There are many different definitions of school bullying (See Table 2.5) (Rose, Monda-Amaya, & Espelage, 2010). Bullying can present itself in the form of physical violence (e.g. shoving, tripping, aggressive fighting, and damage to personal property); verbal abuse (e.g. teasing, threats of violence, intimidation, abusive language, mimicking, and discriminatory remarks); indirect bullying (e.g. spreading lies and rumours or ignoring and isolating the victim); and sexual abuse (e.g. using sexually explicit language and/or sexually abusive actions) (Rose & Monda-Amaya, 2012). Bullying can also occur in cyberspace (Chadwick, 2014) and there is published research on students with Asperger syndrome being cyber bullied (Kowalski & Fedina, 2011). In addition, all of these bullying definitions share three commonalities. Firstly, there must be an emotional, physical or social power imbalance between the bully and their victim. Secondly, the bully must intend to cause emotional or physical harm towards their victim. Thirdly, the bully must harass their victim continuously over a sustained period of time (Espelage & Swearer, 2003; Rose & Monda-Amaya, 2012).

Table 2.5: Definitions of bullying



Citation	Definition
Dawkins (1996, p. 603)	Bullying is the intentional, unprovoked abuse of power by one or more children in order to inflict pain or cause distress to another child on repeated occasions.
Olweus (1993, p. 9)	A student is being bullied or victimized when he or she is exposed, repeatedly and over time, to negative actions on the part of one or more other students
Nansel et al. (2001, p. 2095)	A student is being bullied when another student, or a group of students, say or do nasty and unpleasant things to him or her. It is also bullying when a student is teased repeatedly in a way he or she doesn't like. Any form of verbal or physical hurtful behavior, such as name-calling, punching, repeated teasing, kicking, hitting, spreading malicious rumors, pestering, socially isolating can be considered bullying if the peer persists with it after it is apparent that the victim is traumatized by what is being said or done.
O'Moore and Hillery (1989, p. 431)	Bullying is longstanding violence, mental or physical, conducted by an individual or a group and directed against an individual who is not able to defend himself/herself, in the actual situation.

Source: Rose, Monda-Amaya and Espelage, 2010.

2.10.2 Bullying of school students with Asperger syndrome

There is literature on students on the autism spectrum being bullied at school (Attwood, 2004; Cappadocia, Weiss, & Pepler, 2012; Chen & Schwartz, 2012; Dubin, 2007; Humphrey & Lewis, 2008; Kowalski & Fedina, 2011; Little, 2001, 2002; Sofronoff, Dark, & Stone, 2011; van Roekel, Scholte, & Didden, 2010). Only two studies were found, however, that have statistically measured the rate of bullying for students with Asperger syndrome in secondary school (Little, 2001, 2002).

Little's (2001) study found that about 75% of their sample (N = 411) of students with Asperger syndrome were bullied at school. Little (2001) also found that students with Asperger syndrome had bullying rates four times higher than those without Asperger syndrome (55% vs. 13% respectively). In a similar study, Little (2002) interviewed the mothers of children with Asperger syndrome about their child's school bullying experiences in the past year. Little (2002) found that 94% of mothers sampled reported that their child had been victimised. In addition, Carter (2009) found that 65% of the parents sampled reported that their child had been bullied by their peers at school. Another focus of study has been the factors that cause students with Asperger syndrome to be bullied at school.

Essentially, there are two main reasons why students on the autism spectrum might be bullied at school. Firstly, due to their limited social and communication abilities, school students with Asperger syndrome often struggle to form and sustain relationships with other students, which subsequently places them at an increased risk of being bullied (Humphrey & Symes, 2010a, 2010b). On the other hand, if a school student has good peer relationships, then their peers can protect them from being bullied (Delfabbro et al., 2006; Pellegrini & Bartini, 2000; Pellegrini, Bartini, & Brooks, 1999). Secondly, a school student with Asperger syndrome may not be able to register that they are being bullied because they may not notice that another student's actions are aggressive and directed towards them. Students on the autism spectrum also have Theory of Mind [ToM] deficits that may limit their ability to recognise bullying and aggressive behaviours (Baron-Cohen, Jolliffe, Mortimore, & Robertson, 1997).

2.10.3 The gap in the literature on adults with Asperger syndrome and their school bullying experiences

Existent studies have statistically measured the rate of bullying which students with Asperger syndrome encounter in secondary school (Little, 2001, 2002). There are also studies on the types of bullying that students with Asperger syndrome have experienced at school (i.e. cyber bullying) (Kowalski & Fedina, 2011). However, there are only a small number of studies in which adults with Asperger syndrome articulate their experiences of being bullied at school (Fleischer, 2012; Sciutto et al., 2012). The participants in this study contributed to this limited field of research by explaining their bullying experiences at school and the techniques they used to avoid such bullying.

2.11 Employment

This section reviews the literature on job interviews for adults with Asperger syndrome and explores some factors an employee needs to consider before revealing their disability to colleagues. It then discusses the benefits that employment can give people with disabilities and outlines the employment participation rates for adults on the autism spectrum. It concludes with an explanation of the gap in the literature on adults with Asperger syndrome and employment.

2.11.1 Experiences with job interviews

A job interview is considered an efficient, fair and useful tool for selecting a suitable applicant for an employment opportunity (e.g. Gray, 2011; McKay, 2009; Rogers, 2011). There is literature pertaining to the job interview experiences of applicants who are physically disabled (Hebl & Skorinko, 2005; Jans, Kaye, & Jones, 2012), overweight (Kutcher & Bragger, 2004; Pingitore, Dugoni, Tindale, & Spring, 1994), pregnant (Cunningham & Macan, 2007; Bragger et al., 2002), or mature-aged (Morgeson, Reider, Campion, & Bull, 2008). Yet in spite of this body of literature, not much literature was found on the job interview experiences of adults with Asperger syndrome. Rather, there is literature about adults on the autism spectrum performing in simulated job interviews (Morgan, Leatzow, Clark, & Siller, 2014). To add to this limited amount of literature, the participants in this study recalled their experiences in real life job interview situations.

2.11.2 Disclosing disabilities in the workplace

Literature is available about employees telling their workplace colleagues that they are homosexual (Griffith & Hebl, 2002; Ragins et al., 2007) or that they live with cancer (Pryce et al., 2007), the Human Immunodeficiency Virus (Fesko, 2001), or a disability (Brohan et al., 2012; Ellison, Russinova, MacDonald-Wilson, & Lyass, 2003; Goldberg, Killeen, & O’Day, 2005; Irvine, 2011; Jans et al., 2012; Pennington, 2010). However, no literature was found on employees informing their colleagues that they live with Asperger syndrome. Despite this shortfall in the literature, this section has outlined the types of disclosure an employee can use to tell their colleagues about their disability and has stated several factors that might influence an employee’s decision to tell their colleagues about their disability.

2.11.2.1 Types of disclosure

From an elementary perspective, disclosing a disability can be viewed as a dichotomous choice: that is, either you tell other people that you have a disability or you keep this information confidential. However, in reality, the act of disclosing one’s disability is not a dichotomous choice and can instead be a long and complex process.

2.11.2.1.1 Full disclosure

Full disclosure occurs when an employee tells every colleague in the workplace about their disability. Employees who use full disclosure take no action to conceal their disability because they often view their disability as an integral part of their identity. Employees who use full disclosure often inform their colleagues of any limitations they may experience in the workplace; medication or treatment options for their disability; and necessary accommodations or assistive technology requirements (MacDonald-Wilson et al., 2011).

2.11.2.1.2 Selective disclosure

Selective disclosure occurs when an employee only tells a few colleagues about their disability or when they only reveal a limited amount of information about their disability to their colleagues (Ellison et al., 2003). For example, instead of revealing their specific condition, such as, ‘I have Asperger syndrome’, an employee with Asperger syndrome might say to their colleagues ‘I have a disability’ (Goldberg et al., 2005).

2.11.2.1.3 Strategically timed disclosure

Strategically timed disclosure refers to an employee telling their colleagues about their disability after a certain period of time from the point of being hired has elapsed. For example, an employee might tell colleagues that they live with Asperger syndrome after they have developed good working relationships and demonstrated their competence in the job (Goldberg et al., 2005).

2.11.2.1.4 Targeted disclosure

Some organisations have disability employment targets. People with disabilities who apply for a job within these organisations are often required to disclose their disability to the organisation prior to commencing employment (Goldberg et al., 2005).

2.11.2.1.5 Non-disclosure

Non-disclosure occurs when an employee does not tell any of their colleagues that they live with a disability. In some circumstances, an employee who does not disclose their disability may have a better chance of blending into the organisation. However, non-disclosure may prevent an employee from requesting workplace support and accommodations. Either way, non-disclosure may be appropriate in employment situations where no workplace accommodations can be offered or where negative ramifications are likely after disclosure (Goldberg et al., 2005).

2.11.2.1.6 Forced disclosure

Unlike the previous types of disclosures, where the employee can choose if they will tell their colleagues about their disability, forced disclosure refers to when an employee is required by law or company policy to tell their employer about their disability. For example, under Australian workplace law, in order for an employee with a disability to access workplace accommodations, he or she must disclose their disability to their employer (Ellison et al., 2003).

2.11.2.2 Factors which might influence an employee's decision to tell their colleagues about their disability

This section discusses some factors employees need to consider before telling their colleagues about their disability. These factors are employee factors (i.e. disability-related characteristics, previous experience with telling workplace colleagues about a disability); workplace factors (i.e. nature of workplace accommodations); and societal factors (i.e. knowledge of disability employment legislation, workplace culture, attitudes towards people with disabilities).

2.11.2.2.1 Disability characteristics

An employee's decision to inform his or her colleagues about their disability is influenced by the disability's severity, type and visibility. If an employee's disability prohibits optimum work performance, then he or she is often more inclined to tell their colleagues about their disability. For example, if an employee has an epileptic seizure at work, then this incident may force the employee to tell their colleagues about their epilepsy. In contrast, according to Banks, Novak, Mank and Grossi (2007), if an employee has a mental health condition, which is not visible, then they are less inclined to tell his or her colleagues about their disability. In short, if an employee's disability is severe and/or physically visible, then they are more inclined to tell their colleagues about it in order to explain low work performance and request appropriate workplace accommodations. However, if an employee's disability is not severe and/or physically visible, then he or she is less likely to tell their colleagues about it because they do not require any workplace accommodations or need to explain any incidents of under-performance (MacDonald-Wilson et al., 2011).

2.11.2.2.2 Previous workplace disability disclosure experiences

Previous workplace disability disclosure experiences can influence an employee's decision to tell his or her workplace colleagues about their disability. If an employee's disability disclosure experience was negative, then he or she is less likely to tell their future colleagues about their disability—especially during the hiring process (Ellison et al., 2003; Goldberg et al., 2005).

2.11.2.2.3 The personalities of workplace colleagues

Another factor that can influence an employee's decision to tell colleagues about their disability is the personalities of other colleagues. Research has shown that if an employee perceives his or her colleagues to be supportive, open-minded and caring, then they are more inclined to tell them about their disability (Ellison et al., 2003). In contrast, if an employee perceives his or her colleagues to be insensitive or hostile towards people with disabilities, then they are less inclined to tell their colleagues about their disability (Dalgin & Bellini, 2008; Ellison et al., 2003; Goldberg et al., 2005).

2.11.2.2.4 Nature of workplace accommodations

An employee is less inclined to tell his or her colleagues about their disability if they perceive a workplace accommodation to be costly or difficult to implement. In certain circumstances, however, these employees might be able to obtain workplace accommodations without informing their colleagues of their disability. For example, an employee who is vision impaired and requires a large computer screen might be able to upgrade their screen size when the office is refurbished instead of obtaining a larger screen as a result of disclosing their disability. In addition, in order to minimise the risk of negative outcomes in the workplace, case workers who help clients with disabilities in employment need to discuss with their clients the need for workplace accommodations, what types of workplace accommodations are needed, and who in the workplace should be consulted about workplace accommodations. Finally, before disclosing a disability and requesting workplace accommodations, an employee needs to examine the tasks in their job, the length of time they have been in the job, and their perception of job security (MacDonald-Wilson et al., 2011).

2.11.2.2.5 Knowledge of disability rights legislation and policies

There are international and Australian policies, treaties and laws designed to protect people with disabilities in the workforce. The Convention on the Rights of Persons with Disabilities is an example of an international treaty from the United Nations, intended to protect the rights of people with disabilities (Harpur, 2012; Muir & Goldblatt, 2011; Ollerton & Horsfall, 2013). In Australia, the *Disability Services Act* and the *Disability Discrimination Act 1992* are laws that protect the rights of people with disabilities in the workforce and society (Dempsey & Ford, 2009; Lantz & Marston, 2012; Stancliffe, 2014). These laws have been created to assist people with disabilities in all areas of employment, including recruitment, access, training, promotion, and dismissal. There are also Australian policies, such as *Bridging Pathways* and *Australians Working Together*, which are designed to maximise the employment outcomes of people with disabilities. These policies are nationwide and they are meant to increase the number of people with disabilities participating in education and employment (Dempsey & Ford, 2009).

2.11.2.2.6 Workplace culture

A workplace culture can influence an employee’s decision to tell his or her colleagues about their disability. However, despite workplace culture being a relevant factor, very little research has been conducted in this area. It appears, from the limited amount of literature available on this topic, that if an organisation has positive and flexible disability and diversity policies, and takes an active interest in implementing workplace accommodations, then the likelihood of an employee telling his or her colleagues about their disability increases. Furthermore, if an employer is familiar with disability discrimination legislation then he or she is more inclined to hire an employee with a disability (MacDonald-Wilson et al., 2011).

2.11.3 Benefits that employment can provide people with disabilities

Studies have shown that people with disabilities can attain both psychological and financial benefits from employment. Employment can give employees with disabilities financial independence, coping strategies for psychiatric symptoms, feelings of pride and self-esteem, and a pathway towards recovery (Dunn, Wewiorski, & Rogers, 2008). Employment can also give socially isolated employees with disabilities opportunities to socialise with their colleagues (Borg & Kristiansen, 2008). However, before people with disabilities can access these benefits, they must first overcome the barriers associated with finding, maintaining and sustaining employment. These barriers include the following:

1. Finding the right balance between having too many or too few tasks to perform at work;
2. Coping with any particular physical demands in the workplace;
3. Coping with the psychological demands in the workplace, such as establishing and maintaining social and professional relationships with colleagues and managers;
4. Managing the side-effects associated with medication;

5. Finding the right time and place to tell colleagues about their disability;
6. Overcoming the fear of losing their job and financial income;
7. Confronting stigmatisation from colleagues and/or supervisors. (Provencher, Gregg, Mead, & Mueser, 2002)

Despite the societal and organisational benefits employers obtain from employing people with disabilities (Hartnett, Stuart, Thurman, Loy, & Batiste, 2011), and the personal benefits that employment can give people with disabilities (Paul & Moser, 2009), the overall rates of employment for people with disabilities remain low (Organisation for Economic Co-operation and Development [OECD], 2010). For people living on the autism spectrum rates of unemployment or under-employment are particularly high (Burke, Andersen, Bowen, Howard, & Allen, 2010).

2.11.4 Employment participation rates for adults with Asperger syndrome

Studies have compared the rates of employment between people with and without disabilities. The *World Report on Disability*, a publication by the World Health Organisation, drew a disturbing conclusion:

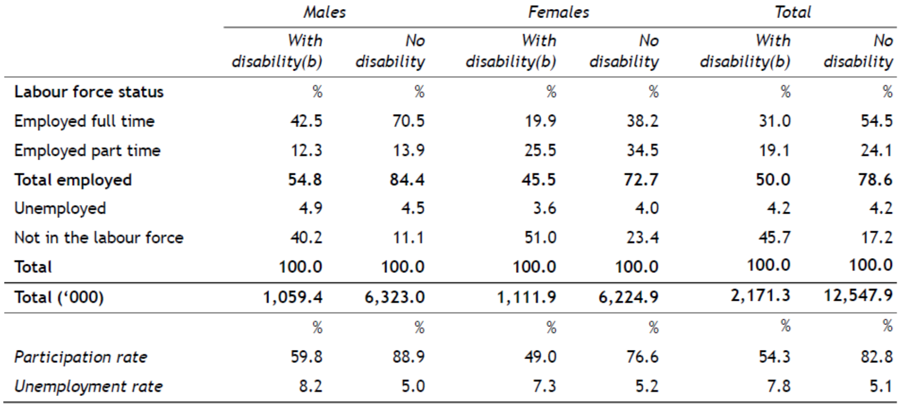
> [An] analysis of the World Health Survey results for 51 countries gives employment rates of 52.8% for men with disability and 19.6% for women with disability, compared with 64.9% for non-disabled men, and 29.9% for non-disabled women. (WHO, 2011, p. 237)

Similarly, another study comparing the rates of employment between people with and without disabilities, which was published by the OECD, found the following:

> [E]employment opportunities of people with health problems or disability are limited. In the late-2000s, on average across the OECD their employment rates were just over 40% compared with 75% for people without disability. (OECD, 2010, p. 50)

In Australia, according to the Australian Bureau of Statistics [ABS] (2012), the rate of employment for people with disabilities is considerably less than for those without disabilities (See Table 2.6). In addition, in regard to specific disability types, those with psychological disabilities are most likely to be unemployed in Australia. People with sensory and speech disabilities, on the other hand, are more likely to be employed (ABS, 2012).

Table 2.6: Disability status[a] by labour force status as at 2009



	Males		*Females*		*Total*	
	With disability(b)	*No disability*	*With disability(b)*	*No disability*	*With disability(b)*	*No disability*
Labour force status	%	%	%	%	%	%
Employed full time	42.5	70.5	19.9	38.2	31.0	54.5
Employed part time	12.3	13.9	25.5	34.5	19.1	24.1
Total employed	**54.8**	**84.4**	**45.5**	**72.7**	**50.0**	**78.6**
Unemployed	4.9	4.5	3.6	4.0	4.2	4.2
Not in the labour force	40.2	11.1	51.0	23.4	45.7	17.2
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Total (‘000)	1,059.4	6,323.0	1,111.9	6,224.9	2,171.3	12,547.9
	%	%	%	%	%	%
Participation rate	59.8	88.9	49.0	76.6	54.3	82.8
Unemployment rate	8.2	5.0	7.3	5.2	7.8	5.1

Notes: (a) People aged 15–64 years and living in households.

(b) Includes those who may not have a specific limitation or restriction.

Source: Australian Bureau of Statistics [ABS], 2012.

When compared to people with other disabilities, those on the autism spectrum have some of the lowest employment participation rates (Burke et al., 2010) (See Appendix 3). For example, in relation to autism, studies have shown that between 11 to 56% of participants sampled were in some form of employment (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996; Taylor & Seltzer, 2011). Engstrom, Ekstrom and Emilsson (2003) found that only 2% of their sample, people with Asperger syndrome, were employed. The overall conclusion to be drawn from these studies is that people on the autism spectrum are less engaged in employment than those not on the autism spectrum.

2.11.5 The gap in the literature on adults with Asperger syndrome and their employment experiences

There are books to help adults with Asperger syndrome gain employment (Bissonnette, 2013a, 2013b; Edmonds & Beardon, 2008; Hendrickx, 2009; Purkis, 2014; Stanford, 2011). There is also literature available on the rates of employment for adults with Asperger syndrome (Engstrom et al., 2003; Holwerda et al., 2012); supported employment programs for these adults (Howlin et al., 2005; Mawhood & Howlin, 1999; Strickland, Coles, & Southern, 2013; Walsh, Lydon, & Healy, 2014); and the personal testimonies of these adults about their employment experiences

(Baldwin et al., 2014; Barnhill, 2007; Griffith et al., 2012; Hurlbutt & Chalmers, 2004; Jennes-Coussens et al., 2006; Nesbitt, 2000). No studies were located by the author on adults with Asperger syndrome describing either their job interview experiences or their experiences disclosing to colleagues their diagnosis of Asperger syndrome. The participants in this study reduced these gaps in the literature by describing their experiences with these issues.

2.12 Intimate relationships and parenting

This section reviews the literature on how people find a partner; marital and non-marital relationships in Australia; parenthood; and the sexual behaviours of adults with Asperger syndrome. This section concludes with an explanation of the gap in the literature concerning adults with Asperger syndrome and their intimate relationships and parenting.

2.12.1 Finding a partner and developing a sexual relationship

2.12.1.1 Finding a partner

Often when people reach early adulthood, they begin their search for a partner. In Western society there are many popular myths about how people find a suitable partner, such as ‘opposites attract’ or that people ‘meet a stranger across a crowded room’. In reality, most people first encounter their future partner through a mutual friend or at a gathering of like-minded people. When potential partners meet under these circumstances, their friends and families often approve and support the relationship. This approval and support from each partner’s family and friends often contributes to the longevity of the relationship. However, meeting at a particular place or through a mutual friend are not the only ways in which people meet each other. Sometimes people develop a sexual relationship after meeting at a non-predetermined place, such as at a hotel bar. However, very few people develop sexual relationships after such encounters and if they do develop a sexual relationship, then it is often brief (Hoffnung et al., 2013).

2.12.1.2 Qualities people seek in romantic partners

Research has shown that people who share certain similar characteristics, such as ethnicity, age and educational level, are more likely to form a sexual relationship. A study by Sprecher and Regan (2002) found that the most desirable qualities in a potential partner were warmth and kindness, expressiveness and openness, and a sense of humour. Sprecher and Regan (2002) concluded that these intrinsic qualities might be more important and fundamental to forming a long-lasting relationship than attributes which are culturally considered important, such as financial assets and physical attractiveness.

2.12.2 Marriage

For brevity, this study will only review the literature on heterosexual marriage because no participants reported any same-sex relationship experiences.

When most Australians reach early adulthood, they begin their search for a person they may eventually marry. Since 1990 in Australia, the age at which a person marries has been increasing (See Figure 2.8) (ABS, 2012). Furthermore, as with other Western societies, in Australia a person often decides who they wish to marry. However, this pattern is not always observed in other cultures. For example, in some Asian cultures, marriages are usually arranged (Allendorf & Ghimire, 2013; Ghimire & Axinn, 2013; Peterson, Kim, McCarthy, Park, & Plamondon, 2011).

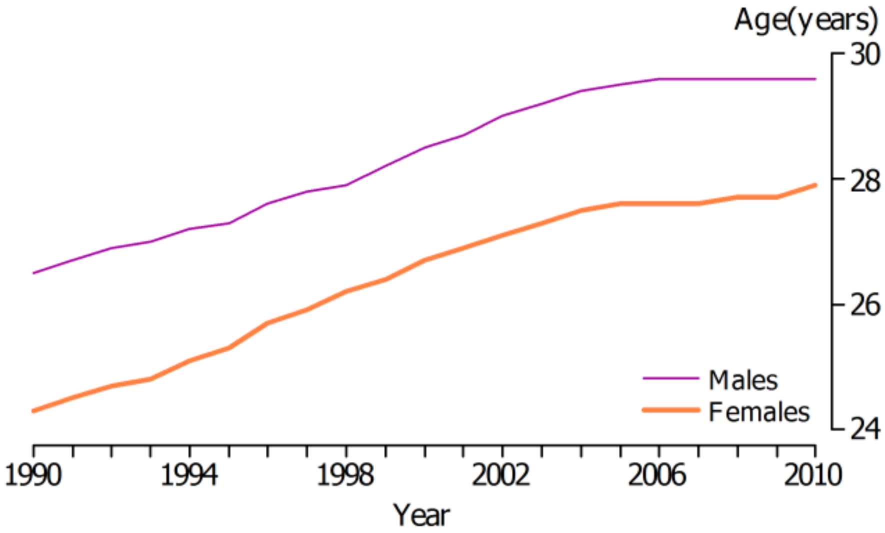


Figure 2.8: Median age at first marriage in Australia from 1990 to 2010

Source: Australian Bureau of Statistics [ABS], 2012.

When people marry, they can enter into an ‘equal partnership marriage’, a ‘conventional marriage’, or a ‘junior partnership marriage’. Equal partnership marriages are marriages where every issue in the marriage, such as household responsibilities and financial decisions, is negotiated and shared equally between partners (Blaisure & Allen, 1995; Risman & Johnson-Sumerford, 1998). Conventional marriages are where the responsibilities are clearly defined and allocated between the husband and wife. In most conventional marriages, the husband is expected to be the sole economic provider and the wife is expected to nurture the children and undertake domestic tasks. Finally, junior partnership marriages contain both elements of equal partnership and conventional marriages. In junior partnership marriages there is a ‘junior’ partner, who is typically the wife, and a ‘senior’ partner, who is typically the husband (Hoffnung et al., 2003).

2.12.3 Parenthood

Children can be raised in a variety of different family types, such as same-sex families (Goldberg, 2012; Mallon, 2004; Rivers, 2013; Ruspini, 2013;), opposite-sex families (Deave & Johnson, 2008; Halle et al., 2008), and single parent families (Collings, Jenkin, Carter, & Signal, 2014). Most of the studies on parenthood have not researched the experiences of fatherhood (de Montigny, Lacharité, & Devault, 2012; Halle et al., 2008). However, research on fatherhood is important because, according to Deave and Johnson (2008), men often do not feel prepared to confront the challenges that await them when they become fathers.

Since 1987, the number of single-parent families in Australia has increased. Over half of all single parents rely solely on Australian government pensions and financial subsidies. In addition, single parents who are Indigenous Australians are more inclined to rely solely on government benefits and financial subsidies than any other single-parent ethnic type (ABS, 2007). Single parents also have greater rates of psychological distress than parents in two-parent families (Collings et al., 2014). Collings et al.’s (2014) study found that single mothers (15.7%) and single fathers (9.1%) had higher rates of psychological distress than partnered mothers (6.1%) and partnered fathers (4.1%). Similarly, Weitoft, Hjern, Haglund and Rosén (2003) found that children living in single-parent families have an increased risk of mortality, severe morbidity and injury than children living in two-parent families.

2.12.4 Adults with Asperger syndrome and their intimate relationships

Research is available on adults with Asperger syndrome in intimate relationships (Ariel, 2012; Aston, 2012a, 2012b, 2014; Bentley, 2007; Brown-Lavoie et al., 2014; Byers & Nichols, 2014; Byers et al., 2013; Edmonds & Worton, 2005; Estelle & McCabe, 2003; Hellemans et al., 2007; Hénault, 2006; Hendrickx, 2008; Holmes & Himle, 2014; Howlin, 2004; Mehzabin & Stokes, 2011; Moreno, Wheeler, & Parkinson, 2011; Slater-Walker & Slater-Walker, 2002; Stanford, 2008; Stokes & Kaur, 2005; Thompson, 2008; Weston, 2010) (See Appendix 4). Most of this literature has explored the sexual interests and behaviours of males with Asperger syndrome. However, there is also some literature on these issues in relation to females (Cridland et al., 2014; Simone, 2009, 2010, 2012).

The literature indicates that adults with Asperger syndrome engage in socially appropriate sexual behaviours, such as masturbation, kissing, intimate touching of others, and consensual sexual intercourse (Hellemans et al., 2007; Konstantareas & Lunsky, 1997; Ousley & Mesibov, 1991). Some adolescents and adults with Asperger syndrome also date, marry and procreate (Aston, 2003, 2009, 2012a, 2012b, 2014; Byers, Nichols, Voyer, & Reilly, 2013; Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Van Nieuwenhuizen, 2015; Lau & Peterson, 2011). In contrast, some adults with Asperger syndrome engage in socially inappropriate sexual behaviours (Griffin-Shelley, 2010; Ray, Marks, & Bray-Garretson, 2004; Shahani, 2012; Stokes, Newton, & Kaur, 2007). For example, Chesterman and Rutter (1993) described a twenty-two-year-old male with Asperger syndrome who used to steal women's cotton lingerie and masturbate while holding women's nightdresses. Similarly, Kohn, Fahum, Ratzoni and Apter (1998) described a sixteen-year-old male with Asperger syndrome who tried to make women his girlfriends by fondling them in public. Finally, Milton, Duggan, Latham, Egan and Tantam (2002) described a Caucasian male in his early thirties with Asperger syndrome who publicly fondled women, covertly watched women in public toilets, impersonated a gynaecologist and asked women sexual questions over the telephone. The socially inappropriate sexual behaviours mentioned above, however, are based on individual case studies and should not be considered representative of the sexual activities found in the Asperger syndrome population.

2.12.5 The gap in the literature about intimate relationships and adults with Asperger syndrome

There have been some studies on adults with Asperger syndrome engaging in sexual behaviours (Chesterman & Rutter, 1993; Griffin-Shelley, 2010; Kohn et al., 1998; Milton et al., 2002; Ray et al., 2004; Shahani, 2012; Stokes et al., 2007). Similarly, there is literature demonstrating that adults with Asperger syndrome also date, marry and procreate (Aston, 2003, 2009, 2012a, 2012b, 2014; Byers et al., 2013; Dewinter et al., 2015; Lau & Peterson, 2011). However, there is not a lot of literature on adults with Asperger syndrome describing their experiences with forming intimate relationships, marrying and parenting (Lau & Peterson, 2011). The participants in this study contributed to this limited amount of literature by describing their experiences and views on these issues.

2.13 Research questions

Based on the literature review, the following research questions have been formulated:

1. From the participants' perspective, how did their family and friends emotionally react to their diagnosis of Asperger syndrome?
2. How do the characteristics associated with Asperger syndrome have an impact on the participants' daily life?
3. What are the participants' views about the Australian community's knowledge of Asperger syndrome?
4. What were the participants' experiences of depression and suicide?
5. What bullying experiences did the participants have in secondary school?
7. What are the participants' experiences with job interviews and disclosing their diagnosis of Asperger syndrome to workplace colleagues?
8. What are the participants' experiences and views about dating and parenting?

2.14 Conclusion

This chapter began with an overview of the history of autism, Asperger syndrome and the DSM-5's Autism Spectrum Disorder classification category. It then discussed the aetiology of ASDs. This was followed by an overview of the literature on the prevalence of ASDs in Australia and the main characteristics associated with Asperger syndrome. The eight developmental stages of Erikson's theory were subsequently outlined in order to help explain, in the upcoming discussion chapter, the impact that the participants' views and experiences can have on their lifespan development. In the following order, this chapter then reviewed the academic literature on adults with Asperger syndrome and the following: 1) their emotional reactions towards their diagnosis of Asperger syndrome; 2) their views of the public's knowledge of the autism spectrum; 3) their depression and suicidal ideation experiences; 4) their recollections of school bullying; 5) their job interview experiences; 6) their experiences of disclosing their disability to workplace colleagues; 7) their views and experiences of intimate relationships and parenting. These areas of literature were reviewed in order to illustrate the contributions to knowledge on Asperger syndrome that this study makes. This chapter then concluded with the research questions that this study attempts to answer.

The next chapter, called *The Research Methodology and Method*, explains the procedures and techniques used to collect and analyse the participants' views and experiences.

Chapter Three

Methodology and Method

3.1 Introduction

This chapter explains how the participants' experiences and views were collected and analysed. It begins with an explanation of the qualitative and quantitative approaches used to study human behaviour. It then presents the historical origins and theoretical components of a qualitative phenomenological approach and the rationale for using it as this study's methodology. An introduction and rationale for using in-depth interviews, which is also used in this study, will then be presented. The three approaches used to formulate the interview questions are then discussed, followed by an overview of the pilot and main study and the ethical considerations before, during and after the interview sessions. The final section outlines the steps used to conduct a thematic analysis, the technique used to analyse the data collected.

3.2 Quantitative and qualitative approaches towards researching human behaviour

3.2.1 Four main differences between quantitative and qualitative research

Quantitative and qualitative researchers approach the study of human behaviour in essentially four different ways (Bryman, 2012; Denzin & Lincoln, 2011; Nayar & Stanley, 2014; Rubin & Rubin, 2012). First, quantitative researchers often use observations and surveys to collect data from people (Rubin & Rubin, 2012). In contrast, qualitative researchers often collect this data by reading written records (e.g. interview transcripts, diaries, letters), listening to or watching tape recordings (e.g. movies, television shows), reviewing images (e.g. paintings, photographs), conducting interviews, or facilitating focus groups (Rubin & Rubin, 2012; Nayar & Stanley, 2014; Sarantakos, 2013). Second, quantitative researchers are often concerned with discovering facts and statistics about humans. Qualitative researchers, however, are often concerned with understanding people's experiences from the perspective of the participants (Denzin & Lincoln, 2011; Hicks, 2009; Silverman, 2013). Third, quantitative researchers often randomly sample large groups of people (Denzin & Lincoln, 2011; Minichiello & Kottler, 2010; Nayar & Stanley, 2014; Rubin & Rubin, 2012). Qualitative researchers, on the other hand, have small samples who are often selected based on a specific set of criteria (Denzin & Lincoln, 2011; Rubin & Rubin, 2012). Fourth, quantitative researchers use numerical values and statistical analysis to report their findings. Qualitative researchers, however, often report their findings using words or sections of text catalogued and presented under thematic categories (Bryman, 2012; Denzin & Lincoln, 2011; McMurray, Pace, & Scott, 2004; Minichiello & Kottler, 2010; Nayar & Stanley, 2014; Rubin & Rubin, 2012; Silva, Healey, Harris, & Broeck, 2015).

3.2.2 The benefits of qualitative research

As mentioned previously, in an attempt to explain human behaviour, qualitative researchers often collect information from written records (e.g. interview transcripts, diaries, letters), tape recordings (e.g. movies, television shows), images (e.g. paintings, photographs), interviews, and focus groups (Bryman, 2012; Denzin & Lincoln, 2011; Rubin & Rubin, 2012; Silverman, 2013). The benefits of using this data can include exploring unchartered or underdeveloped territory in areas where phenomena are poorly understood; examining experiences, behaviour and phenomena in a social context that takes into account various perceptions and realities; discovering new ways of understanding the world and its inhabitants; and intensively studying single cases of phenomena that represent unique or meaningful examples of interest (Denzin & Lincoln, 2011; Minichiello & Kottler, 2010; Silverman, 2013).

Although qualitative research has produced rich and revealing insights about human behaviour, it has also been criticised for ‘being too soft and unscientific to have a place within academic disciplines’ (Minichiello & Kottler, 2010, p. 16). In order to refute such criticisms, qualitative researchers have argued that there is no fixed way to observe the world because different people perceive and interpret the same events differently (Bryman, 2012; Denzin & Lincoln, 2011; Jackson & Mazzei, 2012; Rubin & Rubin, 2012). For example, Browne and Minichiello’s (1995) study on sex workers and their clients having sexual intercourse found that despite both people being engaged in the same physical activity (i.e. having sex) their experiences of this activity were quite different. From the clients’ perspective, the act of sexual intercourse resulted in feelings of intense sexual gratification and intimacy. The sex workers, on the other hand, reported feelings of boredom and aversion during sexual intercourse, and described the encounters as just going through a routine day.

3.3 The research methodology: Phenomenology

This study draws on elements of phenomenology for data collection and analysis. The following section will outline the history of phenomenology; recommended sample size for a qualitative study that uses elements of phenomenology; the main distinctions between Husserl's and Heidegger's views about phenomenology (Denzin & Lincoln, 2011); and the rationale behind why a phenomenological approach was used in this study.

3.3.1 The history of contemporary phenomenology

Edmund Husserl is regarded by many researchers of phenomenology to be the founder of the modern phenomenological movement (Bryman, 2012; Denzin & Lincoln, 2011; Rubin & Rubin, 2012; Sarantakos, 2013). Before his death in 1938, Husserl wrote many books and articles—and even 45 000 pages of handwritten notes—about phenomenology (McLeod, 2001). The concepts embedded in his writings are considered complex and difficult to understand and in 1962 Merleau-Ponty, in his book *Phenomenology of Perception*[1], posed the question, 'What is Phenomenology?' One possible explanation for the complexity of Husserl's work is that he wanted to publish a comprehensive phenomenological understanding of the world—ultimately an ambitious and impossible task (Bryman, 2012; Denzin & Lincoln, 2011; McLeod, 2001). Since Husserl's death, many authors have published books explaining their interpretations of Husserl's views of phenomenology (Babich & Ginev, 2014; Creswell, 2007; Friesen, Henriksson, & Saevi, 2012; Moustakas, 1994; Polkinghorne, 1989). One theme to emerge from these books is that there are different versions of phenomenology, such as existential, social, transcendental, descriptive, interpretative, and hermeneutic (Bryman, 2012; Denzin & Lincoln, 2011; Hicks, 2009; Saldana, 2013).

For this present study, the researcher adopted Husserl's interpretation of phenomenology, called transcendental phenomenology, which proposes that understanding human behaviour can only be

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[1] *Phenomenology of Perception* was originally published in French in 1945 by Maurice Merleau-Ponty. The first English language translation was published in 1962.

achieved after the phenomenologist has separated all of her or his preconceived knowledge of the human behaviour from the actual human behaviour being investigated (Bryman, 2012; Jackson & Mazzei, 2012; McMurray et al., 2004; Silverman, 2013; McWilliam, 2010). For this study, as a means of helping him separate his views on Asperger syndrome from the participants' views and experiences, the researcher wrote in a diary all of his views on adults with Asperger syndrome.

3.3.2 Sample size in qualitative studies that use elements of phenomenology

Usually the number of participants sampled for a qualitative study that uses elements of phenomenology are quite small to allow for a depth of research (Denzin & Lincoln, 2011; Silverman, 2013). According to Morse (2000), factors that can influence the sample size include the study's research questions; the nature of the topic under investigation; the quality of the data collected; and the use of shadow data.

3.3.2.1 The study's research question

The study's research question can influence a qualitative study's sample size (Bryman, 2012; Denzin & Lincoln, 2011; Silverman, 2013). If a study has a specific focus, then the number of participants recruited may be small (McMurray et al., 2004; Rubin & Rubin, 2012; Sarantakos, 2013). For example, a study on what it is like to be the Prime Minister of Australia would only attract a few participants. In contrast, if a study adopts a more general focus, then a large number of participants could be recruited in order to generalise the conclusions reached (Morse, 2000; Saldana, 2013; Sarantakos, 2013).

This study's sample size was twenty-one participants because the focus of this study was broad justifying a large sample size. However, the researcher's time and resources were limited which prevented the recruitment of a larger sample size.

3.3.2.2 The nature of the topic under investigation

The nature of the topic under investigation can influence the sample size in a qualitative study that draws upon phenomenological elements (Jackson & Mazzei, 2012; Saldana, 2013; Denzin & Lincoln, 2011; Silverman, 2013). If the topic being studied is considered to be taboo, then the prospect of recruiting participants might be highly unlikely (Rubin & Rubin, 2012). For example, in Western society paedophilia is considered controversial and, as a consequence, the possibility of recruiting paedophiles to discuss this topic might be unlikely. Conversely, noncontroversial topics, such as raising a child, are considered to be acceptable within Western society. Thus, a researcher would most likely find it easy to recruit participants (Jackson & Mazzei, 2012; Morse, 2000; Saldana, 2013).

3.3.2.3 The quality of the data collected

Another factor that can influence the sample size in a qualitative study which uses elements of phenomenology is the quality of the data collected (Denzin & Lincoln, 2011). If participants are able to articulate elaborate responses to interview questions, then the number of participants sampled would most likely be small (Bryman, 2012; Jackson & Mazzei, 2012; Rubin & Rubin, 2012). However, if participants do not express detailed answers, then the size of the sample might need to be increased in order to obtain additional data for analysis (Bryman, 2012; Morse, 2000; Rubin & Rubin, 2012).

3.3.2.4 The use of shadow data

The term *shadow data*, according to Morse (2000) and Jackson and Mazzei (2012), refers to participants discussing the experiences of others from their own perspective. For example, shadow data could consist of participants describing how their life experiences are similar to or different from others. Shadow data is very important because it can give a researcher more data than just the participant’s personal experience. If participants generate shadow data, then the researcher might only need to interview a small number. On the other hand, if they do not provide any shadow data, and only describe their own life experiences, then the researcher may need to sample a large number of participants (Jackson & Mazzei, 2012; Morse, 2000).

3.3.3 The main theoretical characteristics of Husserl’s approach to conducting a phenomenological study

In this section, Husserl’s theoretical position on essences and phenomenological bracketing will be explained.

3.3.3.1 Essences

According to Husserl, phenomenologists aim to reveal the essence of a participant’s experience of a phenomenon by obtaining a comprehensive description from the participant (Bryman, 2012; Jackson & Mazzei, 2012; Polkinghorne, 1989; Silverman, 2013). In phenomenology, the term ‘essence’ refers to the characteristics that make the experience what it is. However, a phenomenologist can never directly observe the essence of the experience, but only its physical manifestations, which are illustrated in the participants’ accounts. Consequently, the essence of an experience can never be *completely* explored; therefore, the results of a phenomenological study can never possibly present a universal or absolute truth of the essence. Instead, a phenomenologist can only uncover and present a snapshot of the essence of the participant’s experience from a specific point in space and time, as manifested in the participant’s mind and as seen from the perspective of the phenomenologist (Bryman, 2012; Denzin & Lincoln, 2011; McMurray et al., 2004; Moustakas, 1994; Silverman, 2013).

3.3.3.2 Phenomenological bracketing

Husserl proposed that the phenomenologist and the phenomenon that they are studying are separate entities (Bryman, 2012; Sarantakos, 2013; Silverman, 2013). This seemingly simple notion is a fundamental cornerstone of Husserl’s writings on phenomenology. To perceive the phenomenon being studied, the phenomenologist must first suspend all of their own knowledge, beliefs, assumptions, and biases about the phenomenon (Bryman, 2012; Silverman, 2013). The researcher’s act of suspending their own knowledge, beliefs, assumptions, and biases is called ‘phenomenological bracketing’ (Denzin & Lincoln, 2011; Dowling, 2007; Silverman, 2013). In the quotation below, Husserl (1970, p. 152) describes the process of engaging in phenomenological bracketing:

> It is from this very ground that I have freed myself through the epoché; I stand above the world, which has now become for me, in a quite peculiar sense, a phenomenon.

Heidegger, Husserl's protégé, thought that Husserl's view that a phenomenologist could perceive a phenomenon without any prior knowledge was flawed. According to Heidegger, all human knowledge is acquired from living in the world and, therefore, it is impossible for a phenomenologist to bracket all of their knowledge of the phenomenon and see it as if they were seeing it for the very first time. Heidegger suggested that, at best, only a partial bracketing could be undertaken, as opposed to a complete bracketing, which was proposed by Husserl (Denzin & Lincoln, 2011; Mulhall, 2005). Thus, arguing against Husserl's notion, Heidegger claimed as follows:

> Understanding is never without presuppositions. We do not, and cannot, understand anything from a purely objective position. We always understand from within the context of our description and involvement in the world. (Johnson cited in McConnell-Henry, Chapman, & Francis, 2009, p. 9).

Before commencing the thematic analysis process, the researcher wrote in a personal diary all of his views on adults with Asperger syndrome. The purpose of this task was to help highlight any beliefs that could influence the identification of data in the interview transcripts. It was also used to suspend the researcher's preconceptions from influencing data collection.

3.3.4 Rationale for using phenomenological elements in this study

Before conducting a qualitative study, a researcher has to choose one of many methodologies, such as grounded theory, ethnography, narrative inquiry, or phenomenology (Chesnay, 2015; Denzin & Lincoln, 2011; Nayar & Stanley, 2014; Silverman, 2013). Each methodology has its own unique strengths and limitations (Bryman, 2012; Denzin & Lincoln, 2011). For example, a study using ethnography to explore the social networks in physical fitness centres can give the researcher an opportunity to explore this topic in its natural environment (Hicks, 2009; Jackson & Mazzei, 2012; Rubin & Rubin, 2012; Sarantakos, 2013). Yet conducting an ethnographic study in a physical fitness centre may be inappropriate, especially if people are there just to exercise (Denzin & Lincoln, 2011; Silverman, 2013). Similarly, a case study project on an old man recovering from a traumatic event can give the researcher an opportunity to conduct a comprehensive analysis. However, a researcher who uses this methodology can only explore a small number of participant disclosures and thus cannot create generalisations to the entire population (Minichiello & Kottler, 2010; Rubin & Rubin, 2012; Nayar & Stanley, 2014; Sarantakos, 2013).

Initially, this study was going to use a case study methodology because this methodology would have given the researcher an opportunity to explore each participant's views and experiences in elaborate detail (Rubin & Rubin, 2012; Sarantakos, 2013). However, acknowledging the differences between people with Asperger syndrome the researcher concluded that a larger sample size was warranted. The researcher also contemplated using an ethnographic methodology, as it would have enabled the researcher to enter the participants' natural environment. However, this methodology was not used because the researcher felt that a much longer-term engagement with the participants would have been required (Nayar & Stanley, 2014; Rubin & Rubin, 2012). After some consideration, the researcher adopted a qualitative study with phenomenological aspects. This is because it enabled the researcher's focus to be on in-depth views and experiences of the participants. It also provided a framework that assisted the researcher from imposing his own interpretation on the participants' experiences and views, for he could only present the participants' words to describe their views and experiences (Bryman, 2012; Denzin & Lincoln, 2011; Jackson & Mazzei, 2012; Minichiello & Kottler, 2010; Sarantakos, 2013).

3.4 The research method: In-depth interviews

From all the data collection methods available, such as surveys (Mowbray & Yoshihama, 2001) and focus groups (Barbour, 2010; Rosaline, 2008b), the researcher selected in-depth interviews (Bryman, 2012; Goodman, 2001; Leavy, 2014; Rubin & Rubin, 2012; Tracy, 2013). There were two reasons for this decision. Firstly, the researcher initially considered using surveys because they can be distributed to a large sample of people. However, they were not used because they only ask specific and/or short-answer questions that prevent the researcher from collecting detailed experiences and views from the participants (Bryman, 2012; Leavy, 2014; Mowbray & Yoshihama, 2001; Rubin & Rubin, 2012; Tracy, 2013). Secondly, focus groups were considered because they would have given the participants opportunities to express their views and experiences in a supportive environment. This data collection method was not used, however, as some of the interview questions in this study were deemed sensitive and inappropriate to ask in a group setting (Barbour, 2010; Bryman, 2012; Rosaline, 2008b). Based on the limitations of these data collection methods, and the objectives of research based on phenomenology, the researcher decided to use in-depth interviews.

To ensure the accessibility and understanding of interview sessions for participants who may experience social communication difficulties, such as a literal interpretation of language and auditory processing difficulties, the questions were trialled in a pilot study.

An in-depth interview approach was used because, unlike fully structured or unstructured interviews, it gave participants the freedom to express their views and experiences (Bryman, 2012; Jackson & Mazzei, 2012; Leavy, 2014; Nayar & Stanley, 2014; Rubin & Rubin, 2012; Silverman, 2013). This approach also gave the researcher the ability to probe for additional information through altering the order of the questions asked (Goodman, 2001; Rubin & Rubin, 2012; Silverman, 2013; Tracy, 2013). Nevertheless, during the in-depth interview session there was a possibility that the researcher’s personal views on adults with Asperger syndrome could have influenced the follow-up questions to answers. To avoid this situation from occurring, the researcher familiarised himself with his own views on adults with Asperger syndrome and then recorded these views in his personal diary before the interview session (Rubin & Rubin, 2012; Silverman, 2013). This approach helped the researcher focus the interview session and provided an opportunity for this rarely consulted group of adults to express their views and experiences to the academic community.

3.5 Interview question development

3.5.1 Reading the literature on Asperger syndrome

The interview questions were designed to elicit detailed responses from the participants. The questions were developed after the researcher read websites, autobiographical literature, self-help books, and peer-reviewed journal articles on Asperger syndrome. A selection of this literature is presented below.

Websites on Asperger syndrome

1. AutismSA (http://www.autismsa.org.au): AutismSA is a community organisation in South Australia for people living with an Autism Spectrum Disorder. Their website contained information on Asperger syndrome and autism, in particular prevalence, causes and symptoms.
2. Autism Spectrum Australia [Aspect] (https://www.autismspectrum.org.au): Aspect's website contained information about diagnostic assessments for autism and Asperger syndrome and information about behavioural support programs for people on the autism spectrum.

Personal accounts by adults with Asperger syndrome

1. Ariel, C. N., & Naseef, R. A. (2006). *Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals share their wisdom*, London: Jessica Kingsley Publishers.
2. Beardon, L., & Worton, D. (2011). *Aspies on Mental Health, Speaking for Ourselves*, London: Jessica Kingsley Publishers.
3. Dakin, C. J. (2005). Life on the outside: A personal perspective on Asperger syndrome. In K. P. Stoddart (First Edition), *Children, youth and adults with Asperger syndrome: Integrating multiple perspectives*, (pp. 352–361). London: Jessica Kingsley Publishers Ltd.
4. Santomauro, J. (2011). *Autism All-Stars: How We Use Our Autism and Asperger Traits to Shine in Life*, London: Jessica Kingsley Publishers.

Self-help books on Asperger syndrome

1. Ansell, G. D. (2011). *Working with Asperger syndrome in the classroom: An insider's guide*, London: Jessica Kingsley Publishers Ltd.
2. Aston, M. (2014). *The other half of Asperger syndrome (Autism Spectrum Disorder): A guide to living in an intimate relationship with a partner who is on the Autism Spectrum (Second edition)*, London: Jessica Kingsley Publishers.
3. Bissonnette, B. (2013b). *The complete guide to getting a job for people with Asperger's syndrome: Find the right career and get hired*, London: Jessica Kingsley Publishers.

4. Hendrickx, S. (2009). *Asperger syndrome & employment: What people with Asperger syndrome really really want*, London: Jessica Kingsley Publishers Ltd.
5. Martin, R. (2010). *Top tips for Asperger students: How to get the most out of university and college*, London: Jessica Kingsley Publishers.
6. Simone, R. (2012). *22 things a woman with Asperger's syndrome wants her partner to know*, London: Jessica Kingsley Publishers.
5. Slater-Walker, C., & Slater-Walker, G. (2002). *An Asperger Marriage*, London: Jessica Kingsley Publishers Ltd.

Journal articles on Asperger syndrome

1. Baldwin, S., Costley, D., & Warren, A. (2014). Employment Activities and Experiences of Adults with High-Functioning Autism and Asperger's Disorder. *Journal of Autism and Developmental Disorders*, *44*(10), 2449–2449.
2. Baron-Cohen, S. (2002). Is Asperger syndrome Necessarily Viewed as a Disability? *Focus on Autism and Other Developmental Disabilities*, *17*(3), 186–191.
3. Byers, E. S., Nichols, S., & Voyer, S. D. (2013). Challenging Stereotypes: Sexual Functioning of Single Adults with High Functioning Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *43*(11), 2617–2627.
4. Byers, E. S., Nichols, S., Voyer, S. D., & Reilly, G. (2013). Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship. *Autism*, *17*(4), 418–433.
5. Calzada, R. L., Pistrang, N., & Mandy, W. P. (2012). High-Functioning Autism and Asperger's Disorder: Utility and Meaning for Families. *Journal of Autism and Developmental Disorders*, *42*(2), 230–243.
6. Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *Lancet Psychiatry*, *1*, 142–147.

7. Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). ‘I just don’t fit anywhere’: support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, *16*(5), 532–546.
8. Jennes-Coussens, M., Magill-Evans, J., & Koning, C. (2006). The quality of life of young men with Asperger syndrome: A brief report. *Autism*, *10*(4), 403–414.
9. Kite, D. M., Gullifer, J., & Tyson, G. A. (2013). Views on the Diagnostic Labels of Autism and Asperger’s Disorder and the Proposed Changes in the DSM. *Journal of Autism and Developmental Disorders*, *43*(7), 1692–1700.
10. Lau, W., & Peterson, C. C. (2011). Adults and children with Asperger syndrome: Exploring adult attachment style, marital satisfaction and satisfaction with parenthood. *Research in Autism Spectrum Disorders*, *5*(1), 392–399.
11. Molloy, H., & Vasil, L. (2002). The Social Construction of Asperger Syndrome: The pathologising of difference? *Disability & Society*, *17*(6), 659–669.
12. Müller, E., Schuler, A., Burton, B. A., & Yates, G. B. (2003). Meeting the vocational support needs of individuals with Asperger Syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation*, *18*, 163–175.
13. Nesbitt, S. (2000). Why and why not? Factors Influencing Employment for Individuals with Asperger Syndrome. *Autism*, *4*(4), 357–369.
14. O’Halloran, M., Sweeney, J., & Doody, O. (2013). Exploring fathers’ perceptions of parenting a child with Asperger syndrome. *Journal of Intellectual Disabilities*, *17*(3), 198–213.
15. Punshon, C., Skirrow, P., & Murphy, G. (2009). The ‘not guilty verdict’: Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, *13*(3), 265–283.
16. Sciutto, M., Richwine, S., Mentrikoski, J., & Niedzwiecki, K. (2012). A Qualitative Analysis of the School Experiences of Students with Asperger Syndrome. *Focus on Autism and Other Developmental Disabilities*, *27*(3), 177–188.

3.5.2 Consulting with an expert employed at AutismSA

To maximise the prospect of this study being conducted successfully, after consulting with the literature and people with the lived experiences of Asperger syndrome, the researcher sent a copy of the interview questions to an expert on Asperger syndrome employed at AutismSA. After meeting the expert, in January 2011, the researcher finalised his interview questions.

3.5.3 Consulting with the primary and secondary supervisors

In the interests of creating a comprehensive list of interview questions, the researcher shared his list of interview questions with his primary and secondary supervisors. These supervisors reviewed the list and provided feedback on the order and wording of the interview questions.

3.6 Participant eligibility criteria

The main objective of any qualitative study based on phenomenological aspects is to capture and present from a relatively homogeneous group of participants their views and experiences of a phenomenon (Bryman, 2012; Denzin & Lincoln, 2011; Jackson & Mazzei, 2012; Silverman, 2013; Tracy, 2013). Yet it is important that the researcher only sample participants who have relevant knowledge and experience of the phenomenon under examination (Bryman, 2012; Denzin & Lincoln, 2011; Jackson & Mazzei, 2012; Polkinghorne, 1989). Accordingly, criterion sampling is the most suitable approach for recruiting participants for a qualitative study based on phenomenological aspects because it involves only recruiting individuals who completely fulfil an entire predetermined list of eligibility criteria (Creswell, 2007). Nevertheless, it is important that when adopting criterion sampling that careful consideration is given to formulating the eligibility criteria for identifying potential participants (Creswell, 2007; Polkinghorne, 1989). To participate in this study, each participant had to have a diagnosis of Asperger syndrome from AutismSA and be eighteen years of age or over.

3.7 Pilot study: Community Bridging Services [CBS]

Community Bridging Services [CBS], a community-based organisation supporting people with disabilities in employment, was contacted to nominate the participants for the pilot study. CBS generated a list of people who were 1) aged eighteen or over; and 2) had a diagnosis of Asperger syndrome from AutismSA. Once a contact list had been created, a CBS staff member telephoned the adults on this list and, on behalf of the researcher, gave them an opportunity to participate in the pilot study. When telephoning the potential participants, the CBS staff member used a telephone script that the researcher had created (See Appendix 5).

After the potential participants had been contacted and provided with an overview of the study, the CBS staff member then asked them if they wanted to be participants in the pilot study. If they decided to participate, then the CBS staff member recorded their name on the final contact list. The final contact list only had the name, telephone number and date of birth of the adults who decided to participate in the pilot study.

Before the researcher received the final contact list, the CBS staff member who had telephoned the potential participants signed and dated the final contact list. This was done to show any authority auditing the study that the clients were initially contacted by a CBS staff member and not by the researcher.

Six participants (five males and one female) were recruited for the pilot study. The age range of these participants was between nineteen (19) to thirty-five (35) years, with an average age of twenty-four (24) years.

The pilot study, which was conducted from July to September of 2011, helped the researcher test the in-depth interview questions and the transcription process. The participants gave detailed responses to the interview questions used in the pilot study, and as a result, they were incorporated into the main study. Since the interview questions remained unchanged, the data from the pilot study and main study were combined for analysis. However, the process used to transcribe the data failed during the pilot study and had to be altered.

During the pilot study, Microsoft Text-to-Speech software was used to create a verbatim transcript of each interview session. Unfortunately, due to this software producing typographical errors, this approach did not create an accurate transcription. Instead, a manual transcription process was used, which involved the researcher listening to the audio recording and then typing the speech into a Microsoft Word Document. The researcher then ensured the interview transcript and all of the dialogue on the recording were identical by simultaneously listening to the audio recording and reading through the interview transcript. Once the interviews were transcribed and checked, the researcher posted a copy of the transcript to the relevant participant for verification. No participants disagreed with the accuracy of any of the transcripts.

Pilot studies serve many purposes, such as testing the suitability of the data collection method and interview questions (Sarantakos, 2013). The interview questions used in the pilot study generated detailed answers from the participants and as a consequence the same interview questions were used in the main study. Since the interview questions did not change, the data collected from the participants in the pilot study and main study was combined.

3.8 Conducting the main study: AutismSA

Only adults registered with AutismSA as having a diagnosis of Asperger syndrome were eligible to participate in this study. To be registered with AutismSA as an adult with Asperger syndrome two separate diagnosis of Asperger syndrome, one diagnosis from a psychologist or psychiatrist not affiliated with AutismSA and one diagnosis from a psychologist affiliated with AutismSA, had to be given.

AutismSA, a community organisation for people on the autism spectrum in South Australia, used three approaches to recruit participants for the main study. These approaches are explained in detail below.

3.8.1 Electronic advertisement on AutismSA’s website

The first recruitment approach involved AutismSA placing a small advertisement on the ‘Latest Research Projects and Surveys’ section of their website (See Appendix 6). This recruitment approach did not yield any participants (See Table 3.1).

3.8.2 Speaking to the men’s and women’s support groups

The second recruitment approach involved giving the researcher ten minutes at the start of AutismSA’s men’s and women’s support group sessions to speak about the researcher’s study and to see if anyone was interested in participating. This recruitment approach gave potential participants the opportunity to meet the researcher and to ask any questions they had regarding the study. These are some of the questions asked by potential participants:

1. Who has access to the interview transcript and audio recording?

2. Where is the interview transcript and audio recording stored?
3. How will my personal details remain confidential?
4. Where will the interviews take place?

When the participants asked these questions, the researcher gave spoken answers. No male participants were recruited via this approach. However, one female was recruited after the researcher spoke to the female-only support group (See Table 3.1).

3.8.3 Advertising in AutismSA's electronic newsletter

The third recruitment approach involved AutismSA distributing an advertisement in their fortnightly email newsletter. This newsletter, established in 2006, was disseminated to about 3000 people or organisations in South Australia. This recruitment approach yielded sixteen participants (eight males, eight females) (See Table 3.1).

Table 3.1: The number of male, female and total participants recruited using the three recruitment approaches used by AutismSA

Recruitment technique	**Total number of male participants recruited**	**Total number of female participants recruited**	**Total number of participants recruited**
Electronic advertisement on AutismSA's website	0	0	0
Speaking to the male and female AutismSA support groups	0	1	1
Advertising in AutismSA's electronic newsletter	8	8	16
TOTAL	**8**	**9**	**17**

Note: Table 3.1 illustrates the total number of participants who were recruited using AutismSA's three recruitment approaches. Overall, seventeen participants (eight males and nine females) were recruited from AutismSA. The age range for these recruited participants was from twenty (20) to sixty-two (62) years, with an average age of thirty-five (35) years.

3.9 Analysing the views and experiences of the participants' parents

The sole focus of this study was on interviewing adults with Asperger syndrome about their views and experiences of education, employment and intimate relationships. Two participants, however, wanted their parents to attend the interview sessions. In line with the University's ethics policies and rules, the researcher was able to invite these family members to attend when the participants requested their support. Although the testimonies of these family members were excluded from the discussion chapter, because they contradicted the study's focus, they have been included at the end of Chapter Four for additional contextual information.

3.10 Ethical considerations when collecting data from the participants

A researcher must follow ethical rules when collecting data from people (Brinkmann & Kvale, 2008; Flick, 2007; Gibbs, 2007b; Mertens & Ginsberg, 2009; Miller & Salkind, 2002; Reamer, 2001; Rosaline, 2008a; Stark & Hedgecoe, 2010). One ethical rule enforced in Australia is that research studies on people must be ethically approved by the University Ethics Committee prior to the studies' commencement (National Health and Medical Research Council, 2013). Adhering to this rule, the researcher sought and obtained ethics approval for his study from Flinders University's Social and Behavioural Research Ethics Committee (See Appendix 7) and from AutismSA's Professional Practice Committee (See Appendix 8). This section will highlight the main ethical issues before, during and after the interview sessions.

3.10.1 Before the interview session

3.10.1.1 Obtaining the participant's consent

3.10.1.1.1 Explaining the study to the participants

The participant's decision to be interviewed was voluntary and was made after they read a copy of the *Participant Information Sheet* (See Appendix 9). The purpose of this handout was to help foster a mutual understanding between the researcher and the participant about the study's objectives, methods, risks and potential benefits. However, explaining this study was not considered a simple administrative process. Each participant's understanding of the study was unique. To accommodate these differences, the researcher ensured that each participant understood through constant checking the following:

1. the Participant Information Sheet;
2. that their participation was voluntary and that they could withdraw from the study at any time without needing to give a reason and that after withdrawing, all of the data collected from them would be deleted;
3. that they, the researcher and the researcher's supervisors were the only people who would have access to their information.

3.10.1.1.2 Audio recording

Before each interview session, the participant was given a choice about whether or not they wanted the interview session audio recorded (See Appendix 10). If they declined to have it audio recorded, then the researcher planned to write interview notes. Every participant, however, gave permission to be audio recorded.

3.10.1.2 Replacing the participant's name with a pseudonym

To help establish confidentiality, each participant was asked, prior to the start of the first interview session, to select a pseudonym. The participants were also verbally informed before the first interview session that if they used their real name during the interview sessions, then it would appear in the interview transcripts, but in the thesis it would be replaced with their selected pseudonym.

The participants were also verbally informed that any features of the interviews that could identify them would be removed or replaced with a pseudonym in the thesis. Examples of such features that were replaced with a pseudonym included the names of the participant's friends and family; the participant's residential location; and facilities or organisations associated with the participant.

3.10.1.3 Collecting the participant's contact details

Once a transcript of the interview session was created, the researcher posted it to the participant in an interview package. As part of this process, the researcher recorded the participant's postal address and telephone number in a small notebook. The researcher was the only person who had access to the small notebook and it was stored in a locked filing cabinet at Flinders University.

3.10.2 During the interview session

3.10.2.1 Asking interview questions

The interview sessions lasted between one to two hours (See Appendix 11). This included time for obtaining informed consent at the beginning and a debriefing period at the end. However, since the participants had different levels of understanding the interview questions, the time allocated for the interview session varied widely (Harrington, Foster, Rodger, & Ashburner, 2013). The researcher also helped the participants express their views and experiences in the following ways:

1. pacing the interview dialogue at a comfortable rate for the participant;
2. restating, summarising or paraphrasing the answers articulated by the participant in order to ensure that what they said during the interview session was correct;
3. ensuring questions were worded in a way that encouraged maximum participation in the interview session;
4. avoiding broad, abstract or double-barrelled questions. For example, instead of asking, ‘How did that make you feel?’, a more appropriate question asked was, ‘Can you tell me how you felt when your work colleagues bullied you?’

3.10.2.2 Declining to answer interview questions

Each participant was informed before the start of the interview session that he or she could decline to answer any interview question and that he or she did not need to give a reason for their decision. During the interview sessions, several participants declined to answer questions about depression, school bullying and suicide.

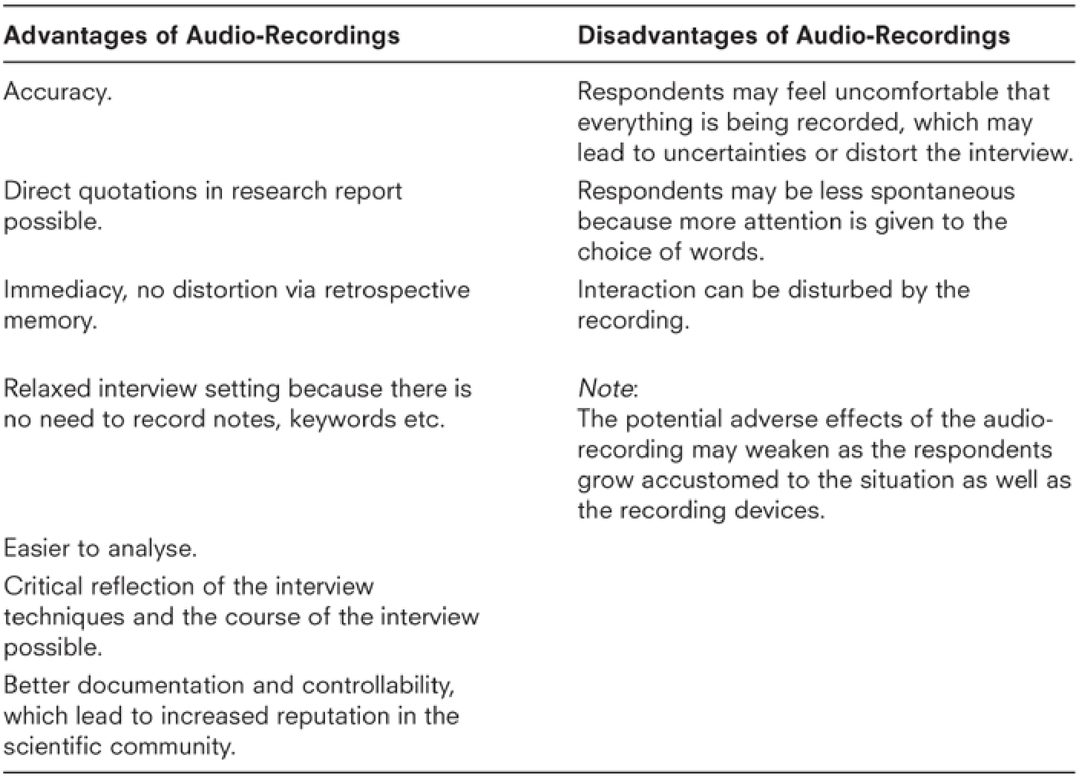
3.10.2.3 Withdrawing from the interview session

Before each interview session, the participant was verbally informed that she or he could end the interview at any time and that she or he did not need to give a reason for their decision. The participants were also informed that after the interview session was terminated, the audio data captured by the digital audio recorder would be erased. No participant decided to end the interview session prematurely.

3.10.2.4 Audio recording the interview sessions

Studies recommend that during the interview session the interviewer should use an audio recording device instead of relying on their memory to recall information. However, there are several advantages and disadvantages associated with using audio recording devices (See Table 3.2) (Kuckartz, 2014b; Rubin & Rubin, 2012; Saldana, 2013).

Table 3.2: Advantages and disadvantages of using audio recordings



Advantages of Audio-Recordings	**Disadvantages of Audio-Recordings**
Accuracy.	Respondents may feel uncomfortable that everything is being recorded, which may lead to uncertainties or distort the interview.
Direct quotations in research report possible.	Respondents may be less spontaneous because more attention is given to the choice of words.
Immediacy, no distortion via retrospective memory.	Interaction can be disturbed by the recording.
Relaxed interview setting because there is no need to record notes, keywords etc.	*Note*: The potential adverse effects of the audio-recording may weaken as the respondents grow accustomed to the situation as well as the recording devices.
Easier to analyse.	
Critical reflection of the interview techniques and the course of the interview possible.	
Better documentation and controllability, which lead to increased reputation in the scientific community.	

Source: Kuckartz, 2014b.

3.10.3 After the interview session

3.10.3.1 Financial reimbursement for the participant's time and effort

As is standard practice in Australia, before each interview session, the participant was told that they would receive a $25.00 shopping voucher as compensation for their time and effort. Funding for the shopping vouchers came from the Research Student Maintenance Fund.

3.10.3.2 Replacing data that could identify the participant with pseudonyms

Interview transcripts often contain information that can identify the participant. Examples of such information include the participant's name or home address. The researcher adopted a three-step process to replace all of the data identifying the participant in the transcript with an appropriate pseudonym. Firstly, the researcher carefully and methodically read through the entire transcript and identified all of the data items that could potentially identify the participant. Secondly, the researcher replaced with pseudonyms all such data items. For example, specific places where the participant had lived (e.g. Sydney, Brisbane or Melbourne) were replaced with a very general pseudonym, such as 'city'. After all the identified data items in the transcript were replaced with pseudonyms, the researcher then created a table to summarise these changes. The purpose of this table was to ensure that if a researcher in the future required specific details, then these could be accessed via the table (Kuckartz, 2014b; Rubin & Rubin, 2012; Silverman, 2013).

3.10.3.3 Participant verification of the interview transcript

After the interview session was transcribed and checked for typographical errors, the researcher posted it to the participant for verification. The participant was requested to read the transcript and then to sign section seven of the consent form[2]. All participants were satisfied with the transcript's content and typographical accuracy and consequently signed section seven (See Appendix 10).

3.10.3.4 Provision of counselling services

The participants were asked for their views and experiences concerning education, employment and intimate relationships. The researcher anticipated that participants might disclose sensitive information that might create psychological distress. To mitigate this risk, the researcher gave each participant a list of counselling services before the start of each interview session (See Appendix 12).

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[2] Section seven of the consent form stated, 'I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained'.

3.10.3.5 Storing the data collected from the participants

With official University research, the researcher must store all of the data collected from the participants, such as consent forms and interview transcripts, in accordance with the University's data retention policies. After this study, all audio recordings, consent forms and participant correspondence letters were sent to a secure storage section in the Department of Disability and Community Inclusion at Flinders University, to be kept for a period of five years.

3.11 Thematic Analysis

Out of the different analytical techniques available to researchers, such as semiotics (Manning, 2004) or conversational analysis (Clayman & Gil, 2004; Wilkinson & Kitzinger, 2008), the researcher used a manual thematic analysis approach (Gibbs, 2007a; Marks & Yardley, 2004). There are seven steps involved in conducting a thematic analysis and these steps will now be outlined (See Figure 3.1) (Kuckartz, 2014a).

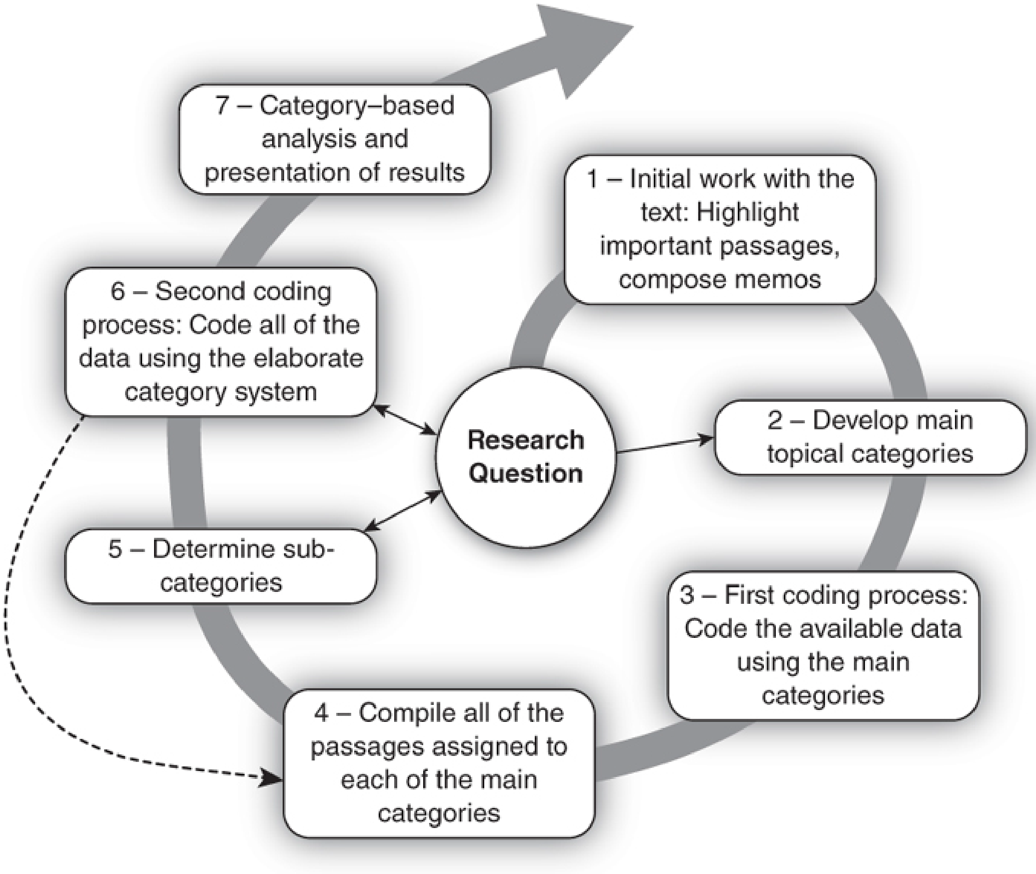

Figure 3.1: The seven steps used in the thematic analysis process

Source: Kuckartz, 2014a.

3.11.1 Stage One: Initial reading of the text, highlighting important text passages and writing memos

As Denzin and Lincoln (2011) suggest, the first stage of the thematic analysis process begins with the researcher carefully reading the interview transcript and highlighting sections of text that they consider interesting or important. Once a section of text has been highlighted, the researcher then writes a comment next to it, explaining why it was selected. If the interview transcript is complex and/or lengthy, then they might need to read it more than once in order to gain a general sense of what the participant was conveying (Denzin & Lincoln, 2011; Kuckartz, 2014a; Rubin & Rubin, 2012).

3.11.2 Stage Two: Develop main thematic categories

The second stage of the thematic analysis process begins when the researcher constructs main thematic categories (Denzin & Lincoln, 2011). There are two approaches that a researcher can use to create main thematic categories. The first approach involves the researcher using the study's research question(s) to formulate the main thematic categories. For example, a study on adult women and their experiences with depression might pose the research question 'What were the participants' experiences with depression and suicide?' Based on this research question, the researcher might create the following thematic categories: 'depression', 'sadness', 'suicide', and 'anxiety'. The second approach researchers can use to create main thematic categories involves their reading and examining the literature to help them formulate main thematic categories. A researcher conducting a study on single parents living in Australia, for example, would read the literature on this subject to help formulate the following possible main thematic categories: 'children', 'divorce', 'poverty' and 'low wage' (Denzin & Lincoln, 2011; Kuckartz, 2014a; Silverman, 2013). For this study, the researcher read the literature on adults with Asperger syndrome to help him formulate the main thematic categories.

After the thematic categories have been developed, irrespective of which approach was used to formulate them, the researcher should search for them in a sample of the data collected. This trial run of the thematic analysis should be conducted before the researcher reads through all of the collected data for the thematic categories developed. The purpose of this trial run is to make sure that the thematic categories formulated can be applied to all of the data collected. The researcher, as a guide, should use 10 to 20% of the entire data collected in the trial run (Bryman, 2012; Jackson & Mazzei, 2012; Kuckartz, 2014a; Rubin & Rubin, 2012).

3.11.3 Stage Three: First Coding Phase: Code all of the data using the developed thematic categories

The third stage of the thematic analysis process involves the researcher reading and thematically coding the entire interview transcript. During this stage, the researcher must decide if a piece of text can be coded and put into a main thematic category. If it cannot be placed into a main thematic category, then it is left un-coded. When undertaking this stage, passages of text can be assigned to more than one main thematic category (Jackson & Mazzei, 2012; Kuckartz, 2014a; Rubin & Rubin, 2012). For instance, a passage of text about an adult telling their workplace colleagues that they live with Asperger syndrome can be coded under the main thematic categories ‘workplace disclosure’ and ‘workplace colleague interactions’.

Often during this stage, the researcher asks one or more of their colleagues to thematically code the same interview transcript. The term used to describe multiple researchers independently coding the same piece of text is ‘consensual coding’. Consensual coding can improve the quality of the analysis because with two or more researchers examining the same piece of text independently, the possibility of data being left un-coded is reduced. So that all researchers conducting the consensual coding task do not experience any ambiguities when coding, all main thematic categories are clearly listed with descriptions (Jackson & Mazzei, 2012; Kuckartz, 2014a; Thyer, 2001). See Table 3.3 for the coding list used in this study.

Table 3.3: The coding list used in this study

Main thematic category	***Description of the main thematic category***
Getting a diagnosis of Asperger syndrome	The participants’ experiences of obtaining diagnoses of Asperger syndrome are placed in this thematic category. Examples of these experiences include a self-instigated diagnosis of Asperger syndrome, family or friends helping with the Asperger syndrome diagnosis process, and tests for Asperger syndrome.
Emotional reactions to a diagnosis of Asperger syndrome	The emotional reactions that the participants, their family and friends, had towards the Asperger syndrome diagnostic process are placed in this thematic category. Examples of these emotional

	reactions include shock, surprise, relief, and anger.
Characteristics of Asperger syndrome and daily functioning	Experiences of how the characteristics associated with Asperger syndrome have had an impact on the participant’s life are placed in this thematic category. Examples of these characteristics include an intense focus on a special interest, sensory sensitivities, verbal challenges, and social difficulties.
The Australian public’s perception of Asperger syndrome	The participants’ views on the Australian public’s knowledge and perceptions of Asperger syndrome are placed in this thematic category. Examples of these perceptions can include ‘Asperger syndrome only affects children’ and ‘lack of knowledge about Asperger syndrome’.
Would the participant choose to keep their Asperger syndrome?	The participants’ views on if they want to live with Asperger syndrome are placed in this thematic category.
Depression and suicidal ideation experiences	The participants’ experiences with depression and suicidal ideation are placed in this thematic category. The methods used to commit suicide are also placed in this thematic category.
Experiences with school bullying	The participants’ experiences with school bullying are placed in this thematic category. Examples of these experiences include physical bullying and verbal abuse.
Techniques used to avoid the school bully	The techniques which the participants used to avoid school bullies are placed in this thematic category. Examples of these techniques include ignoring the bully, sitting at the front or back of the classroom, and telling the teacher.
Experiences with job interviews	The participants’ experiences with job interviews are placed in this thematic category. Examples of these experiences include answering interview questions, not knowing where to place hands during the job interview session, and having difficulties making eye contact.
Workplace colleague reactions to a diagnosis of Asperger syndrome	The participants’ recollections of the emotional reactions which their workplace colleagues had towards their diagnoses of Asperger syndrome are placed in this thematic category. Examples of these emotional reactions include shock, disbelief, and acceptance.
Social challenges in employment	The participants’ recollections of social challenges with workplace colleagues are placed in this thematic category. Examples of these social challenges can include difficulties with interpreting social situations and difficulties at office meetings and parties (i.e. staff meetings, Christmas parties).
Experiences and views of dating and intimate relationships	The participants’ recollections and views about intimate relationships are put in this thematic category. Examples of these recollections and views include social difficulties, inability to interpret a partner’s intentions, and relationship breakdowns.
Decisions and views on parenting	The participants’ decisions behind wanting to have or wanting not to have children are placed in this thematic category.

Problems understanding partners	The participants' recollections of problems with understanding partners are placed in this thematic category.

The consensual coding process usually comprises two steps (Jackson & Mazzei, 2012; Rubin & Rubin, 2012; Silverman, 2013). The first step, called 'independent coding', involves two or more researchers examining and coding the same piece of text independently without any collaboration (Silverman, 2013). Once this step is complete, the researcher then begins the second step, which is called 'collaboration' (Rubin & Rubin, 2012). In this phase, the researchers meet and discuss the pieces of text identified and coded (Jackson & Mazzei, 2012). During such discussion, the researchers attempt to reach a consensus about the most appropriate thematic code for the piece of text. However, if the researchers are unable to reach consensus, then more members of the research team are brought into the discussion to help resolve the conflict (Jackson & Mazzei, 2012; Kuckartz, 2014a). For this study, the researcher and two other colleagues in the Department of Disability and Community Inclusion conducted a consensual coding exercise.

3.11.4 Stage Four: Compile all the text passages that belong to the same main thematic category

Once the entire transcript has been coded, whether using an isolation or consensual coding process, the researcher begins the fourth stage of the thematic analysis process. This stage involves the researcher collating all of the highlighted pieces of text under their respective main thematic categories (Jackson & Mazzei, 2012; Kuckartz, 2014a; Rubin & Rubin, 2012). In this study, all of the highlighted sections of text relating to a main thematic category were placed into separate Microsoft Word documents.

3.11.5 Stage Five: Create minor thematic categories based on the data

Once all of the sections of text have been allocated to their main thematic categories, the fifth stage of the thematic coding process can begin. This involves the researcher reading all the sections of text under the main thematic category and then deciding if they can be further sub-catalogued (Kuckartz, 2014a; Rubin & Rubin, 2012). For example, Müller, Schuler, Burton and Yates's (2003) study, which explored the vocational support needs of adults with Asperger syndrome, had a main thematic category called 'workplace experiences'. Under this main thematic category, these researchers created the following minor thematic categories: ‘Diverse vocational interests’; ‘Patterns of unemployment and underemployment’; ‘Work as a generally negative experience’; and ‘Exceptions to the rule: The isolated positive vocational experience’. See Table 3.4 for a list of major and minor thematic categories identified in this study.

Table 3.4: Major and minor thematic categories in this study

Main thematic category	***Minor thematic category***
Getting a diagnosis of Asperger syndrome	• Self-diagnosis • Family/friends helping with the diagnostic process
Emotional reactions to a diagnosis of Asperger syndrome	• Participant reactions • Reactions from the participant’s family • Reactions from the participant’s friends
Characteristics of Asperger syndrome and daily functioning	• Intense focus on a topic of interest • Interpretation of facial expressions or vocal tones • Sensory sensitivities (i.e. auditory, tactile, and olfactory) • Inability to establish or maintain a verbal conversation • Challenges with socialisation
The Australian public’s perception of Asperger syndrome	• International perspective • Only children have Asperger syndrome • Ignorance and non-awareness of Asperger syndrome
Would the participant choose to keep their Asperger syndrome?	• Yes • No • Unsure
Depression and suicidal ideation experiences	• Depression experiences • Suicidal ideation experiences
Experiences with school bullying	• Physical bullying • Emotional bullying
Techniques used to avoid the school bully	• Ignoring the school bully • Fighting the school bully • Telling the teacher or principal about the school bully • Avoiding the bully by sitting at the front or back of the classroom
Experiences with job interviews	• Inability to answer job interview questions • Group interviews • Inability to make eye contact • Knowledge of where to place one’s hands during the job interview session • Difficulty convincing an employer that an employment experience was real • Work trials
Workplace colleague reactions to a diagnosis of Asperger syndrome	• Positive reactions (i.e. acceptance) • Negative reactions (i.e. rejection) • Non-disclosure
Social challenges in employment	• Difficulty reading social situations

	• Limited social contact • Limited promotional opportunities • Difficulties at office meetings and parties (i.e. staff meetings, Christmas parties)
Experiences and views of dating and intimate relationships	• Marriage • Wanting a partner • Physical intimacy • Inability to read body language • Time for courtship
Decisions and views on parenting	• Reasons for wanting to have children • Reasons for not wanting to have children
Problems understanding partners	• Yes • No

3.11.6 Stage Six: Second Coding Phase: Code all of the data using the elaborate category system

The sixth stage of the thematic analysis process, the ‘second coding phase’, begins after the researcher has developed sub-categories. Here, the researcher applies the sub-categories to all of the data collected. It is important during this stage that there is a sufficient amount of data that can be used to clearly differentiate the developed sub-categories. If the researcher created the sub-categories from a small amount of data, then they might need to re-define the sub-categories. Although it is easy to re-define sub-categories, by way of merging the sub-categories together, it is harder to create new sub-categories because it would require the researcher to re-read all of the collected data again (Denzin & Lincoln, 2011; Kuckartz, 2014a; Rubin & Rubin, 2012).

3.11.7 Stage Seven: Writing the final report

Stage seven is the final step in the thematic analysis process and this is the stage in which the researcher writes a written report. The purpose of this report, whether in the form of a journal article or an academic dissertation, is to explain how the participants experienced the phenomenon under investigation (Denzin & Lincoln, 2011). It is important that the report is written in a way that is concise, coherent, logical, and engaging for the reader. In addition, the written report should not be just a random collection of participant quotations. Rather, the quotations need to be organised so as to logically illustrate the story of the phenomenon and support an argument in relation to the research question (Denzin & Lincoln, 2011; Kuckartz, 2014a; Rubin & Rubin, 2012; Silverman, 2013). In addition, in this study, to support the logical illustration of the participant’s views and experiences an extensive number of subheadings was used.

3.12 Conclusion

This chapter explained how the participants’ experiences and views were collected and analysed. It began with an introduction to the qualitative and quantitative approaches used to study human behaviour. It then presented the historical origins, theoretical components and rationale for using a qualitative phenomenological approach, which was this study’s methodology. An introduction and rationale for using in-depth interviews, this study’s data collection method, was then introduced. The three approaches used to formulate the interview questions were then outlined. This was followed by an overview of the pilot and main study and the ethical considerations before, during and after the interview sessions. The final section of this chapter outlined the steps used to conduct a thematic analysis, the technique used to analyse the qualitative data collected from the participants.

The next chapter is called *Experiences of Living with Asperger Syndrome* and in the following order it presents the participants’ views and experiences of getting diagnosed with Asperger syndrome; how the characteristics associated with Asperger syndrome have had an impact on their lives; what they think the Australian public knows about Asperger syndrome; depression; and suicidal ideation. This chapter will conclude with the views and experiences of Cody and Nigel’s parents on Asperger syndrome.

Chapter Four

Experiences of Living with Asperger Syndrome

4.1 Introduction

The views and experiences presented in this chapter fill some of the gaps in the research illustrated in the literature review. This chapter begins with a demographic summary of the participants, outlining their education, employment, and relationship characteristics. The participants' experiences in obtaining their diagnosis of Asperger syndrome, along with participants' recollections of the emotional reactions their family and friends had to their diagnosis, are then presented. Next, this chapter discusses how the characteristics associated with Asperger syndrome have had an impact on the participants and then presents participants' views on the Australian community's knowledge of Asperger syndrome. It then outlines the participants' experiences of and views on depression and suicide. Finally, the parents of participants Nigel and Cody explain their views of and experiences with Asperger syndrome.

4.2 Demographic summary

4.2.1 Overview of participants

There were 21 participants in this study: 12 males (57%) and 9 females (43%). The average age of participants in the sample was 34 years (males 34 years, females 34 years). The age range of the sample was 19–62 years (male age range 19–62 years, female age range 21–53 years). Participants' average age when they received their diagnosis of Asperger syndrome was 27 years (males 26 years, females 28 years). The average number of years participants had been living with their diagnosis of Asperger syndrome was 7 (males 7 years, females 6 years). There were 14 participants (7 males, 7 females) who had initially been diagnosed with Asperger syndrome and the remaining 7 participants (5 males, 2 females) initially received an alternative diagnosis, such as Obsessive Compulsory Disorder or Bipolar Disorder (See Table 4.1).

4.2.2 Employment background

There were 10 participants (6 males, 4 females) who were employed; 9 participants (5 males, 4 females) were unemployed but had previously worked, and 2 participants (1 male, 1 female) had never worked. Participants reported working in the following roles: video and supermarket clerk; government employee; community care and support employee; pizza delivery worker; landscape contractor; information technology contractor; university tutor; postal clerk; medical doctor; garden centre worker; music teacher; nightclub guard; fast food operator; gallery assistant; and hospitality worker.

4.2.3 Relationship status

Of the participants, 5 (2 males, 3 females) were involved in a sexual relationship and 16 participants (10 males, 6 females) were not. Out of these 16 participants, 7 (5 males, 2 females) had previously been involved in a sexual relationship and 9 participants (5 males, 4 females) had never been involved in a sexual relationship. In addition, 5 participants (3 males, 2 females) had sons and no participants reported having daughters.

4.2.4 Education background

In regard to education, 6 participants (6 males) were studying at college, 7 participants (2 males, 5 females) were studying at university, and 8 participants (4 males, 4 females) were studying at TAFE (Training and Further Education). Areas of study that the participants reported include the following: agriculture, horticulture, sociology, history, art and craft, diversional therapy, disability and aged care, business administration, fine arts, automotive engineering, drama, retail, biochemistry, microbiology, psychology, economics, medicine, clinical toxicology, microbiology, and computer graphics.

Table 4.1: Participant demographics

Participant pseudonym	**Participant gender**	**Participant age at the time of the interview session**	**Number of years the participant has been diagnosed with Asperger syndrome**	**Was the participant initially diagnosed with Asperger syndrome?**	**If 'No', what was the participant initially diagnosed with?**
Philip	Male	19	5	Yes	
Sam	Male	35	10	No	• Obsessive Compulsive Disorder
Kyle	Male	20	3	No	• Attention Deficit Disorder • Attention Deficit Hyperactivity Disorder
John	Male	19	10	Yes	
Tim	Male	20	15	No	• Autism
Alison	Female	24	2	Yes	
Jake	Male	59	3	Yes	
Dave	Male	21	3	No	• Autism
Adam	Male	35	18	No	• Autism
Linda	Female	53	11	Yes	
Shelby	Female	34	2	Yes	
Kylie	Female	21	3	Yes	
Sebastian	Male	47	5	Yes	
Charlotte	Female	50	4	Yes	
Imogen	Female	28	3	No	• Borderline Personality Disorder • Bipolar Disorder
Justin	Male	22	5	Yes	
Peggy	Female	41	Under 1 year	Yes	
Isabelle	Female	28	1	Yes	
Travis	Male	62	2	Yes	
Nathan	Male	44	7	Yes	
Sheryl	Female	24	23	No	• Generalised Anxiety Disorder with Depression and a Social Phobia

4.3 Obtaining a diagnosis of Asperger syndrome

Few studies have been published on adults describing the events that led to their diagnosis of Asperger syndrome. To help contribute to this limited amount of literature, the participants were asked to describe their experiences of being diagnosed with Asperger syndrome. Eleven participants could not describe these experiences. For example, John stated, 'I can't really remember. My mum would know.' In contrast, ten participants *were* able to describe the steps they went through. Two participants explained how they received their diagnosis with assistance from their family and/or friends, six participants explained how they got their diagnosis by themselves, and three participants explained how they were initially diagnosed with another condition before receiving a diagnosis of Asperger syndrome. The six participants who received their diagnosis without any assistance were typically triggered into seeking a diagnosis after learning about Asperger syndrome from books, Internet websites or television programs, or through meeting family members or friends diagnosed with the syndrome. In the quotation below, Charlotte explains how her interest in discovering if she had Asperger syndrome started after she read the autobiography, *Nobody Nowhere* by Donna Williams:

> I read the book *Nobody Nowhere* by Donna Williams … and I noticed there were some similarities between the two childhoods, hers and mine, and so I went to the Internet and I looked up autism but it didn't really fit, but one of the sites had Asperger on it and I looked at that and I thought that fits better.

Unlike Charlotte, Imogen wanted to see if she had Asperger syndrome after watching the television show *Britain's Got Talent:*

> I was watching *Britain's Got Talent* … and I saw a few performances and one of them stood out to me. It was a little boy called Callum Francis and I thought he reminded me of what I was like at his age … Something that I read about him was that he had High Functioning Autism and I thought, 'Oh, I didn't learn about that. What's that?' Because I thought everyone with autism sits in front of the wall and hits their head into it … So I read more and more about it and I discovered that it was also synonymous with Asperger's syndrome … the more I read the more I realised that it sounds just like me … I looked up diagnostic tests and found that while there's not a lot of diagnostic tests there's the A.Q. [Autism Quotient] Test. I sat it and I got forty-six out of fifty and I thought that was quite high and I thought that if I sat it with a friend that it

> might be a bit lower but when she held me accountable to my answers my score went up to forty-nine out of fifty.

Another participant, Kylie, decided to consult with a neuropsychologist:

> Basically a few members of my friendship group, one of whom has Asperger's syndrome himself, kind of thought that I had Asperger's syndrome and when I turned eighteen I kind of wanted to know for myself. So the next time I had a doctor's appointment … I asked for a referral to see someone who could see whether I had it or not … So he referred me to someone and I got diagnosed by a neuropsychologist.

Isabelle wanted to see if she had Asperger syndrome after encountering a friend's son with Asperger syndrome and reading an interview with an adult woman diagnosed with Asperger syndrome:

> I first heard about it [Asperger syndrome] when I was first introduced to the son of one of my friends who has Asperger syndrome and I read an interview with an adult woman with Asperger syndrome. That was where I first realised that a lot of the things that she described as her quirks were also things that I had as well … Things like wearing socks inside out because of the irritation of the seams, being unable to really cope with certain stimuli and also the social side of things. So occasionally just not being able to follow what's going on.

For Linda, her decision to see if she had Asperger syndrome was made after she used the Internet to find information about the syndrome:

> I looked on the Internet at the description [of Asperger syndrome] and I wondered whether or not I had it … and I tried to find somebody who could diagnose me but the psychologists were looking at children and in the end, through Internet searching, I found a lady and so I got in touch with her … I spent three days almost full-time doing different psych tests and on the last afternoon she told me that I did have Asperger's.

Peggy wanted to check whether she had Asperger syndrome after her son was diagnosed with the condition. Peggy initially thought her son's Asperger syndrome was inherited from his father and not her:

> The only reason we suspected it [that Peggy had Asperger syndrome] is that my son got diagnosed with it … and I always thought it came from my husband's side of the family, and the

> more I got to know about Asperger’s and the more I understood it, and also watching my son and his formative years and then recalling my experiences, I started to think again.

Philip and Adam had quite different experiences from the aforementioned ones: they required more formal prompting and support from their family to seek their diagnosis. Philip stated the following:

> Well, I do believe it was my mum [who] suggested … Cause I’ve been seeing a psychologist a little while beforehand … Just behavioural oddities … That would eventually be diagnosed as Asperger syndrome.

Adam had this to say of his diagnosis:

> My mother picked up that I wasn’t quite up with the learning at school … I remember sitting in a room and being given a whole series of questions and puzzles and things like that and then it came up that it was actually really high functioning, like borderline autism/Asperger syndrome, and whether I should be given that label or not but it was so borderline.

Another diagnostic experience which three participants recounted was that they were initially diagnosed with another condition, such as Bipolar Disorder, before receiving a diagnosis of Asperger syndrome. Kyle commented on this:

> It’s a common mix-up between ADD [Attention Deficit Disorder], ADHD [Attention Deficit Hyperactivity Disorder] and Asperger’s. They [Kyle’s psychiatrist] ruled out those and decided okay it was Asperger syndrome all along … Basically she stripped off all the layers and said, ‘Right, you are just diagnosed with Asperger syndrome,’ and because she put me through a few tests, a few examinations and one of the test[s] specifically was to put you into a percentile of Asperger’s and work out whether you have it or not … and it turns out I’ve actually got it … Especially with the fact that I find it hard to fit in, I find it hard to talk to people, and I also find it hard to be with people around my own age.

Imogen had a similar experience:

> The first one was Bipolar Disorder, which I didn’t actually agree with even when I was given it … I didn’t really fit it for Bipolar Disorder but I’d taken a lot of questions quite literally in my interviews and they said, ‘Do you ever have times where you’re more energetic than other times?’ and I’m thinking, ‘Well, of course I do. Everyone actually does.’ I now realise but at

> twenty odd years old when that happened I gave all of the right answers basically to get diagnosed with that … We now know that it was all coming down to communication difficulties and sensory overload and that sort of thing were linked to being on the autism spectrum but because I would run away or have meltdowns, nobody was looking for autism. So they saw what they thought was quite bad behaviour or they thought that I was trying to be manipulative because why would a really intelligent student have meltdowns when presenting with depression? So they labelled me with Borderline Personality Disorder and said that I had it despite the fact that I didn't actually meet the diagnostic criteria and that was damaging because essentially everywhere I went I didn't receive medical treatment even when I was physically unwell. I just got labelled for Bipolar Disorder. I was put on goodness knows how many drugs for it and I had adverse reactions to 90% of them and I had withdrawal seizures when I finally came off the one that I'd been on long-term.

Sheryl was another participant who was misdiagnosed:

> Prior to it being suggested that I had Asperger's, I was diagnosed with Generalised Anxiety Disorder, with depression and a social phobia … I was seeing a psychologist who was treating me for that but when certain Aspie traits were sort of hinted at in my interactions in all areas of life, she suggested that I go to a Community Sector Organisation and get a proper diagnosis. This psychologist actually deals with a lot of adults with Asperger's, which is why it was so good. I actually have her as a psychologist even now.

In this section, ten out of twenty-one participants interviewed for this study described the steps they went through to obtain their diagnosis of Asperger syndrome. Six participants explained how they obtained their diagnosis by themselves, two participants explained how their family or friends helped them get their diagnosis, and three participants explained how they were initially diagnosed with another condition before receiving their diagnosis of Asperger syndrome. In the next section the participant's emotional reactions to their diagnosis of Asperger syndrome are outlined.

4.4 Emotional reactions to a diagnosis of Asperger syndrome

4.4.1 The participants' emotional reactions

Few studies were found on adults describing the emotional reactions that they experienced towards their diagnosis of Asperger syndrome. The participants' experiences presented in this section add to the existing literature and help place into context the results provided in other sections. Each participant was asked, 'What were your initial thoughts after receiving a diagnosis of Asperger syndrome?' In this section, eight participants describe their initial emotional reactions, such as relief or shock, after being diagnosed with Asperger syndrome. The remaining thirteen participants could not remember their emotional reactions. Philip, Charlotte, Jake and Peggy described a feeling of 'relief' after being diagnosed. Philip found it a relief because he does not believe Asperger syndrome is a disability:

> It was quite a relief I must say. It's not a disability per se. Asperger's isn't really a disability in the same way that say Dyslexia is a disability. It does come with strengths as well as weaknesses.

Charlotte also felt relief after her diagnosis because it gave her an explanation for the way she was:

> Absolute feeling of relief … because there was finally an explanation as to why I was the way I was.

Similarly, Jake was also relieved to be diagnosed with Asperger syndrome because his diagnosis gave him an explanation for his character. However, unlike Charlotte, Jake's relief was replaced with a sense of trying to understand the consequences associated with a diagnosis of Asperger syndrome.

> Relief because it [a diagnosis of Asperger syndrome] explained so much … and then there was a long period of sort of looking at things again and then reassessing things and by the time I'd got through to the formal diagnosis part, my self-image had crumbled completely and I'd been almost afraid to go out for a year or so and since then I sort of started to put it back together a bit.

Peggy was raised in a family who thought she was mentally ill and she internalised this belief. However, she felt relieved after receiving a diagnosis of Asperger syndrome because it helped invalidate her family's opinion of her.

> It was a relief when they told me that [I had Asperger syndrome] because it was like, you know, I'm not stupid because that's what my brothers and sisters used to call me: 'Oh you are just stupid. Stop being stupid,' and it's like, 'Well I'm not.' I won't stop being stupid because this is just who I am. It's like saying to a blind person to stop being blind, it's not their fault that they can't see … So it's more or less the same thing and it was a relief. It was like well, you know, it's like my character isn't in question.

Imogen was yet another participant whose diagnosis led to a sense of relief. Unlike the other participants, however, after feeling relieved, Imogen became angry because she realised that the health system did not support her:

> I did get relief but I was also quite cross because I'd been through the mental health system with quite a few misdiagnosis [sic] that were quite damaging and that I knew would probably continue to be until people got used to the idea that they weren't actually mine. I'd also got quite cross because I had actually been telling people that I thought there was something, I didn't know what, since I was at least in Junior High School. There was something different and that I wasn't just being difficult and that sort of stuff and I just copped a lot of crap basically every time I said to people, 'I think I'm different and there's a reason,' but I was a bit annoyed that all of that had been thrown in my face.

Nevertheless, not all participants reported feeling relief after being diagnosed with Asperger syndrome. For example, Kyle explained how shocked he was after he received his diagnosis:

> It was just a shock really that I'd been diagnosed with Asperger syndrome because I volunteer at a Community Sector Organisation and I know a lot about what Asperger's is like and I thought to myself, 'I'm not like that am I?' Like that was the first reaction that went in my head, without thinking, without trying to even get the realistic idea of what I've just been diagnosed with and how bad it was. I instantly thought of the worst-case scenario, which was several of the kids over at the Community Sector Organisation that I've actually volunteered for because they're quite severe on the Asperger's scale and it was just comparing myself to those. I was like, 'I'm not like that am I?', and it turns out I'm not like that but it's just that shock.

Another emotional reaction felt after being diagnosed with Asperger syndrome was regret. John expressed this emotion:

> Sometimes I regret ever getting it [a diagnosis of Asperger syndrome] … because if you've got Asperger's you get automatically declined to join the Defence Force, no questions asked … and that's any form of Asperger's. No matter how serious or mild it is, they just say, 'No' … Cause apparently people with Asperger's can't handle different cultures or loud noises.

Depression was another emotional reaction and Linda described such a reaction:

> I felt depressed … because at that time a lot of what you could read about it [Asperger syndrome] said that it was a lifelong disability and it was very severe and it was a very negative kind of picture.

In this section, eight out of twenty-one participants interviewed for this study described the emotional reactions they felt after being diagnosed with Asperger syndrome. The most common reaction reported was relief. There are different reasons why the participants felt this emotion. For example, Peggy felt relief because it meant that her family's character assessment of her was incorrect. For Charlotte, however, her diagnosis of Asperger syndrome gave her a sense of relief because it finally gave her an explanation for her experiences in life. Other emotional reactions reported by the participants were shock, regret and depression. In the next section, the participants explain the emotional reactions that their family members exhibited towards their diagnosis of Asperger syndrome.

4.4.2 Participants' perceptions of their families' emotional reactions towards their diagnosis

The participants in this study were asked to describe what emotional reactions they thought their families exhibited to their diagnosis of Asperger syndrome. Six participants explained their families' reactions and fifteen participants could not describe their families' emotional reactions. John and Kyle encountered patronising attitudes from their families, Philip's and Isabelle's families did not treat them any differently, and Sam's and Alison's parents could not initially accept that their children were diagnosed with Asperger syndrome. Below, Philip explains how his father does not accept the notion that he should use his Asperger syndrome as 'an excuse'.

> He [Philip’s father] prefers the idea that it’s not a disease, it’s not a disorder: it’s something you work through yourself … he doesn’t agree that I should ever try and ‘use it’ … I should never use it as an excuse. I shouldn’t say, ‘I can’t do this; I have Asperger syndrome,’ or anything like that. If I don’t think I can do something because of Asperger syndrome, I should try it anyway.

Although Philip’s father believes that Philip should never use his Asperger syndrome ‘as an excuse’ or say to himself, ‘I can’t do this; I have Asperger syndrome,’ Philip perceives that his mother does not completely share this view:

> My mother has the same attitude but she’s not as strong about it … I think it’s more that Mum thinks that I should do what I can and … what I want. While … my dad thinks that I should, even if I know I can’t do it, try it anyway … and often he ends up being right and I end up actually succeeding. I’m not sure if that means that my mum is unconfident … I’m not entirely sure about their points of view. I’m not exactly brilliant at reading people.

Isabelle expressed the opposite view about how her family treated her after she told them that she had Asperger syndrome:

> For the people that I have told [that I have Asperger syndrome] who have been family, absolutely nothing has changed. They’ll still ask me to do things, they’ll still ask me all of the same questions that they normally would have. So I don’t believe anything has changed.

Unlike Philip’s and Isabelle’s families, who were either positive or neutral to a diagnosis of Asperger syndrome, Kyle and John experienced family members who were condescending. According to Kyle, his mother’s opinion of his capacity for independence was lowered after he was diagnosed:

> I remember the main reaction from Mum is the fact that ever since I’ve been diagnosed … my mum tries to make me be more dependent on her than I was before I was diagnosed.

John also found that after receiving his diagnosis, his grandmother and auntie started to treat him with disrespect.

> My grandmother and my auntie I don’t have contact with because of the things they say about me and people with disabilities behind my back … My grandmother treats me like a retard … just because I have Asperger’s and says I can’t think like a normal person and stupid things like

> that … That's why I just refuse to talk to her … She actually works with helping people with disabilities, so she should know better.

Another finding was that two participants, Sam and Alison, reported that their families did not initially accept their diagnosis. This is what Sam reported:

> In 1996 I was seeing a psychologist and telling him my life story and he suggested, for the first time, that I might have Asperger syndrome and gave me a sheet … and I subsequently took that [information sheet] home and my mother, who is a social worker for people with disabilities, heard of it but didn't know much about it and she had a very bad reaction to it and was sort of like, 'You don't have Asperger's,' and so I put that away for a few years … As I got a bit older I kept thinking about Asperger syndrome and I started to think that maybe it is something that makes sense and my mum was coming more around to the idea of it and she sort of learnt more about it and she said, 'Oh maybe you *do* have it.' So then I decided to get a diagnostic assessment.

Alison also reported a similar experience:

> It's a little bit of a complicated story. I've got a younger brother who's diagnosed with autism … and my parents came home from that diagnosis pretty much saying we think we've found out more than we were going to … and so they sort of suspected I was interested in getting diagnosed at that point but they weren't interested in going through the process again. So I left it for a few years and then I had a conversation one day with someone who has a young son with autism who encouraged me to get formally assessed.

The participants' recollections of their emotional reactions towards their diagnosis of Asperger syndrome was explained in this section. John and Kyle explained how they encountered negative attitudes from their family. In contrast, Philip and Isabelle explained that they were not treated any differently by their family. Finally, Sam's and Alison's parents did not accept their diagnosis. However, after some time, their parents did accept their diagnosis. In the next section, four participants explain the emotional reactions that their friends exhibited towards their diagnosis of Asperger syndrome.

4.4.3 Participants' perceptions of the emotional reactions from their friends

There is not much literature about adults describing the emotional reactions their friends exhibited towards their diagnosis of Asperger syndrome. In an attempt to increase the amount of literature available, each participant was asked, 'Have you told your friends that you have Asperger syndrome?' Four out of the twenty-one participants answered this interview question. Two participants, Linda and Kyle, did not tell all of their friends. Linda explained as follows:

> No, I don't think it's any of their business … because I want to be me and I don't want to be that person that has a disability … I don't really think that it's any of their business. However, if somebody raised this with me, and I don't think they ever would, 'Do I have Asperger's?' Then yes I don't see it as being something to worry about either.

Unlike Linda, who kept her diagnosis of Asperger syndrome a secret from *all* of her friends, Kyle was selective in whom he told that he lived with Asperger syndrome:

> Yes, most of my friends do know. Some of them don't and I don't tell everyone for the specific reason that I know they're going to question me about it and then they're going to all of a sudden judge me and compare me to other people with Asperger syndrome and I really don't want that from my friends … and all my really, really close friends know.

Linda's and Kyle's choice of not telling all of their friends about their Asperger syndrome was not shared by the other two participants who answered this question. Adam and Sam told their friends that they lived with Asperger syndrome. Adam had this to say:

> I have told friends around me that I have Asperger syndrome … They were actually quite good with it cause the friends around me, we're all friends that I have kept from school.

Sam's experience was unlike Adam's. One of Sam's friends gave him a response that was based on a stereotypical notion that all adults with Asperger syndrome have a special talent:

> I've told a friend and she didn't really know what it meant and she was like, 'What's your special talent?' Because that's all she knew about autism … Well, I said that not everybody with autism has a special talent. I said, 'I guess in a lot of ways my special talent is people, like figuring them out and relating to them. I have a pretty good idea of doing that' … but then she went on to go, 'Well, at least you are not like this and at least you are not like that,' kind of

> thing and it was alright but it was comparing me to people who are really bad and stuff like that. But I mean there was no malice: she was trying to be nice.

This section presented the emotional reactions that four participants encountered from their friends after they told them about their diagnosis of Asperger syndrome. Linda did not inform her friends that she lived with Asperger syndrome. Kyle only disclosed his diagnosis to a few friends. Finally, Adam and Sam told all of their friends that they lived with Asperger syndrome. Irrespective of the participants' experiences, their testimonies have supplemented the small amount of literature on adults describing the emotional reactions that their friends exhibited towards their diagnosis of Asperger syndrome. In the next section, the participants explain how the characteristics of Asperger syndrome have had an impact on their lives.

4.5 Characteristics of Asperger syndrome and their impact on daily functioning

Few studies exist in which adults describing how they have lived with the characteristics associated with Asperger syndrome. In order to add to this small amount of literature, the participants were asked to provide some examples of negative and positive aspects of their Asperger syndrome and its impact on them. The characteristics outlined in this section are an intense focus on a specific topic of interest; challenges reading body language; sensory sensitivities; challenges with verbal conversations; and challenges with socialisation.

4.5.1 An intense focus on a specific topic of interest

An intense focus on a specific topic of interest is a characteristic of Asperger syndrome (Tanidir & Mukaddes, 2014; Winter-Messiers et al., 2007). However, the literature review showed that there are not many studies on adults describing how this characteristic can have an impact on their lives. To investigate this further, the participants were asked if they have ever had an intense focus on a specific topic of interest. Three participants chose to describe either their views or experiences in this area and eighteen participants did not describe any instances of an intense focus on a specific topic of interest. Below, Peggy expresses her view on people with Asperger syndrome and their ability to maintain focus on a specific topic of interest:

> As far as what their special interest is, they [people with Asperger syndrome] become absolute specialists in whatever field they choose to do, whether it is arts, science, music or even acting or comedy. They can become experts in their field, whether it is studying the mating habits of the Swahili moth … or whether it's finding a cure for cancer, you know? They can just stay focused and stay on track and they are very good attributes to have. Not everyone has that and most people go, 'Ah stuff it,' but you know Aspies like us, like whatever your special interest is, you become a professional at whatever it is that you love.

In the quotation below, Isabelle expresses a similar view, discussing how she could focus on her studies:

> I could focus on that [Isabelle's studies] from the moment I get up till the moment I go to bed … to the point where I will forget to eat and move and that kind of thing.

Finally, Adam describes how his intense focus on a specific topic of interest helped him find a suitable career after leaving school:

> In terms of positive aspects, what I've found is that Asperger's people have like a tunnel vision, like a focus on a particular subject. Mine was sprinklers when I was back in Junior Primary/Primary School. Then it turned out to be lights and that used to be like football lights on football ovals, stage lights … When I was at High School and we were looking at career choices and what we would like to do when we leave High School after graduating, the two things that we came up with were hospitality industry and computing … So what I did was I turned my obsession or focus on computing into my career path … So rather than being a negative thing … I spend every day and at night-time just researching and looking into the emerging technologies.

An intense focus on a specific topic of interest is a characteristic of Asperger syndrome (Tanidir & Mukaddes, 2014; Winter-Messiers et al., 2007). In this study, three out of twenty-one participants sampled outlined their views or experiences concerning this characteristic. Participants suggested that people with Asperger syndrome can also change their topic of special interest as they age. This was illustrated in Adam's story, where his topic of special interest was garden sprinklers, which shifted to lighting and then computing.

4.5.2 Interpreting facial expressions and/or vocal tones

An inability to interpret facial expressions and vocal tones is a characteristic of Asperger syndrome. However, the literature review revealed that not many adults have articulated their experiences of living with this characteristic. To help supplement this literature, the participants were asked if they have ever had any difficulty interpreting another person's facial expressions and/or vocal tones. Three participants explained their difficulties and eighteen participants did not explain any difficulties interpreting facial expressions and/or vocal tones. John stated succinctly his inability to interpret facial expressions:

> Sometimes I just have trouble understanding whether people are angry, when people tell jokes. Sometimes I can't get if they are being serious or if they are joking.

The other two participants gave more elaborate descriptions. Below, Philip reveals how his Asperger syndrome renders him incapable of distinguishing between similar facial expressions, such as anger and disgust. He also explains how he can only perceive facial expressions that are emotionally opposite, such as happy and sad:

> I've always found it incredibly hard to decipher body language and facial expressions … I can tell sort of basic facial expressions, like I can tell when someone's happy or sad, but when you get into the more subtle things like different kinds of happiness or sadness, I find that very difficult. I can't tell the difference between someone who's frustrated at me or someone who's frustrated at something I'm doing. I can't tell the difference between various forms of surprise or anything like that … I know there is a huge range of different types of happiness, huge range of different types of sadness. I find it very difficult to distinguish between them … Most of the time certain ones are more difficult to distinguish than others: anger and disgust in particular always get mixed up.

Philip's inability to distinguish between similar facial expressions was also shared by Adam:

> I normally describe Asperger's to people that haven't met someone who's got Asperger's before, that you have a lot of trouble with social skills, understanding facial expressions and recognising the tones in people's voices and moods and stuff like that. One of the big things I've had with life is understanding what people are thinking, how they are feeling. Unless it's actually explained to me, 'I'm feeling cross at the moment,' then I wouldn't know that you were feeling cross. So explaining to people what Asperger syndrome is, I say pretty much Asperger's

> people are in their own world, don't recognise the expressions that most people in life can easily understand and you know, I'm not anti-social: I just can't socialise.

The inability to interpret facial expressions and/or vocal tones is a characteristic of Asperger syndrome. Three out of twenty-one participants interviewed for this study described this characteristic. Each participant had their own unique set of strengths and weaknesses in regard to these interpretative abilities. For example, Philip only had problems reading another person's facial expressions, while Adam had problems reading facial expressions and vocal tones.

4.5.3 Sensory sensitivities

Sensory sensitivities are a characteristic of Asperger syndrome. However, there are not many studies on adults with Asperger syndrome describing their experiences of this characteristic. To address this gap in the literature, the participants were asked if they have ever had any sensory sensitivity experiences. Not all participants experienced sensory sensitivities. For example, Sam stated, 'I don't think I have ever felt overwhelmed sensory. So I don't think that is necessarily an aspect for me.' Fifteen out of twenty-one participants interviewed for this study revealed their sensory sensitivities. Each participant who reported experiencing sensory sensitivities had their own unique sensory profile. For example, Philip had sensory sensitivities to texture, sound and light but not to taste or smell. Adam, however, had sensory sensitivities to touch and sound but not to taste, smell or light. The participants' sensory sensitivity experiences with touch, sound, light and smell will be presented. The literature review showed that some people with Asperger syndrome have taste sensitivities. However, none of the participants revealed any experiences relating to this sensory sensitivity.

4.5.3.1 Tactile sensitivities

People with Asperger syndrome can experience tactile sensitivities. However, the literature review showed that there is a paucity of literature on adults with Asperger syndrome describing their tactile sensitivity experiences. The participants in this study were asked if they have had any tactile sensory experiences. Ten participants explained these experiences and eleven participants did not describe any tactile sensitivity experiences. In the quotation below, Philip explains how he dislikes wearing gloves because the physical pressure of them against his hands causes him some discomfort:

> I often wear gloves but I often don’t like the texture of them because I don’t like the feel of something constantly touching my hands … I find it difficult to ignore … The gloves I wear mostly are woollen gloves, which while I do generally enjoy the texture of wool, it’s actually the sensation of something always touching my hands that I don’t like. I mean I wear it when I go skiing or in the snow but most of the time I prefer not to wear it … I find it hard to ignore sensations that most people seem to be able to just completely ignore … It’s always there and most people can get used to it. I can’t get used to it.

Philip outlined how he had difficulty wearing gloves because he constantly felt the pressure of them against his hands. No other participants, however, described any issues regarding the physical pressure of clothing. Another reference that the participants made about clothing was the texture of the clothing’s fabric. Adam, for example, stated, ‘I have noticed that things that are microfibre or soft materials like work pants or work shirts and stuff, I tend to like feel more comfortable in.’ Similarly, Linda explained how she purchased a soft cotton top that she felt was pleasant to touch against her skin:

> I have on occasion bought clothes not because I particularly liked the clothing but because the fabric is so beautiful to touch … and it feels so lovely next to your skin … I remember one in particular. It was a very soft voile and it was a top … such a beautiful soft cotton, it just made my skin just want to wear it all the time … and unfortunately because it was a lighter fabric it didn’t last that long. It tore.

Charlotte was another participant who preferred soft clothing:

> Clothes: I like them soft … Most of the time I don’t buy them new. I buy a lot of my stuff from opp shops already worn in … Already with the tags out, washed a hundred times.

Charlotte, Linda and Adam described their tactile sensory sensitivities about clothing fabric. Charlotte did not wear any clothing with washing instruction tags. Similar comments were also made by Isabelle and Travis, with Isabelle stating as follows:

> I've got to be very careful with what I wear because if it's got seams in the wrong place I just can't physically wear it. I've been known to just tear the tags out of clothes because after ten minutes they are annoying me to the point that I can't stand them anymore.

Travis expressed a similar experience:

> [F]irst thing she [the psychologist] asked, 'Do you have any labels on your clothes?' and I went like that to her [shows that the label on the t-shirt is cut off] … No I cut it off … because it irritates me and I said to her, 'I can't show you my underwear for obvious reasons,' but I said 'There is no label on the underwear as well.' The thing is I like to keep my labels on to wash them, you know, and it tells you the temperature and the wash and roughly say forty degrees or whatever but I like to see the label to see how to wash them or whatever, you know, but they are so uncomfortable, it's just like unbelievable and I've got to go home and get the scissors and snip them off but … all of my clothes' labels gone if it is against my skin. If I have got a jacket and it's got a label on—of course a jacket you wear it over a t-shirt or a shirt there's no problem— but t-shirts, underwear, shorts, label goes.

Four participants identified jewellery and wrist watches as a source of tactile irritation. Jake, Isabelle and Peggy briefly described this irritation. Jack typified this:

> Jewel, I can't wear jewellery … or watches or things like that.

Isabelle stated something similar:

> One out of every two pieces of jewellery I buy, I find I can't wear. I've got a few pieces that I know don't bother me.

Finally, Peggy had this to say:

> I have got a wedding ring, I have got an engagement ring and I have got like an eternity ring but I don't wear it—like I have got necklaces and ear rings that I don't wear.

Travis expanded upon the above insights by giving a detailed explanation as to how jewellery caused him skin irritation:

> Overseas I used to wear a watch because it's colder there. The reason why I don't wear a watch here [Australia] is because it irritates and the sweat … pours off me all of the time and wearing a watch it's too painful … It just flops about, it won't stay in one place because the sweat is

> running off me because of this Asperger's heat thing that it sweats under the strap and the thing is moving all over the place. It is just irritation beyond comprehension.

Another cause of physical discomfort reported by the participants was hugging. One participant, Peggy, was not able to be hugged: 'I'm not a hugger … Like I want to push them away.' Other participants reported preferring a firm hug instead of a soft hug. For example, Kylie stated, 'I don't like light touch … Someone like touching on my shoulder lightly, I tend to get all jumpy and it's just pretty awful. Heavy touch is fine.' Imogen expressed a similar view:

> I'm fine with people hugging me so long as it's really firm and really tight and stuff like that. My friend's dad is great because he can read when I actually need a hug but you pretty much squeeze me until I can't breathe … The light hugs it's like 'I'm going to kick you in the nuts if you do that again' type of reaction.

Imogen explained further:

> I'll squirm a lot more and I'll just push away. The actual gut instinct is to just push them away like, you know, get off but I learnt quite young girls, if you haven't noticed, girls are a lot more cuddly when they are younger in terms of like they go up and they hug their friends … I had to learn quite young that people are going to get really upset if you just throw them off. They get a little offended by that and that sort of thing. So I kind of just squirm and people pick up but the squirming is like a 'Come on please. Just get off me. I can't throw you off but you need to know that it's frustrating and uncomfortable.'

Interestingly, Imogen then explained how even extreme physical pressure could be reassuring:

> [T]here are times where I absolutely crave deep pressure … I swear half of the times I tried to run away, when I was a patient, was because I didn't mind having five security guards piled on top of me. They were like a weighted blanket, minus the whole bad reaction that comes with it, but, you know, that particular moment in time it's like, 'Oh, yeah!' It's like, 'That's quite calming. Thank you.'

Sensory sensitivity to physical texture and pressure is a characteristic of Asperger syndrome. Ten out of twenty-one participants who were interviewed for this study reported a range of tactile sensitivities, such as problems with gloves, washing instruction tags, jewellery, and hugging. This section began with Philip describing how he did not like wearing gloves due to the physical pressure they exerted against his hands. This was followed by Adam, Linda and Charlotte explaining how they preferred certain types of clothing fabric. Isabelle and Travis then described how washing instruction tags caused them irritation. Jake, Peggy and Travis then explained how they could not wear jewellery. Imogen, Peggy and Kyle's preference for either not being hugged or having a tight hug concluded this section.

4.5.3.2 Auditory sensitivities

Some people with Asperger syndrome have auditory sensitivities. However, there are not many studies on adults with Asperger syndrome describing their auditory sensation experiences. The participants added to this literature by describing their auditory sensations. Eleven participants reported experiencing auditory challenges and ten participants did not describe any auditory sensitivities. Some of the auditory sensitivities reported include the inability to focus on a single conversation whilst in a crowd or the inability to be around household appliances, such as clocks or vacuum cleaners that generate noise. Tim, Kyle, Philip and Imogen described their inability to sleep next to a ticking clock. In relation to this, Philip stated:

> I can't sleep next to a clock … because the ticking, which is generally very rhythmic and most people can ignore, I can never get past that. I have always got it in my head, it's always annoying.

Philip's view, that he can hear the noise of a ticking clock in his 'head', was also shared by Kyle:

> I can't sleep if I can hear a clock ticking back and forth. I hear it echo really loud in my head … Simple story is that I can hear it in my head echoing twice as loud as what it actually is. It's just that really dark echoed sound because I'm dead tired, yet I can't sleep because the noise is keeping me awake.

Tim was another participant who found that a ticking clock prevented him from sleeping:

> Sometimes when I'm out in my room and I'm sleeping I don't really like hearing the clock tick because it will keep me awake.

Unlike the other participants, Imogen was able to find a solution to the noise generated by a clock ticking:

> I have a ticking clock that does not tick at night because its battery gets taken out and that's in my kitchen, which is away from my bedroom. My mum bought me a little clock when I moved to college, where you just get a small, like, two-by-three metre bedroom if that and I threw it in the bin and I got in a lot of trouble with her because she thought it wasn't very nice but it was ticking. I recently got a puppy dog and I was told that a ticking clock in her bed would be good for her in the initial nights and I said, 'No,' and I said, 'Cause I need to sleep'.

Other household appliances that participants Kylie and Imogen reported causing discomfort were kettles, televisions and vacuum cleaners. Kylie stated the following:

> My family members have to tell me to get out of the room because they are turning the kettle on, which can be really annoying. If watching T.V. and the kettle gets turned on, I yell at them before leaving because that noise is just horrible and I can't really stop myself yelling … Um, vacuum cleaner they tend to do it when I'm not home … That one's pretty easy to work with though because vacuum cleaning doesn't need to be done every day. People are always having cups of tea or coffee or something like that so I don't really notice that one so much. Um, hair dryer though. I can't sleep sometimes at night because Mum puts the dryer on at night and although it's not that loud, I can't sleep. Like, it won't send me into meltdown mode. I just would not be able to sleep until the dryer has finished.

Imogen had this to say:

> Loud noises: I'll be the first to jump. You know, vacuums, lawnmowers and particularly floor cleaners in hospitals. I can't focus. I want to run away. It's been enough to make me run away—before I had a bit more insight—when I've been a patient and people have gone, 'Oh, she's absconding,' and it's like, well, there's that big horrible machine making that noise. What do you expect?

The final auditory sensation the participants recounted was an inability to tolerate the noise generated by a crowd. However, not all participants experienced this, as Philip illustrated:

> Well, I'm actually very good in a crowd … So that doesn't annoy me so much, especially considering most of the sounds you hear in a crowd are generally very brief. You know, here's a noise and then it goes away.

Despite having to 'listen harder', Adam expressed a similar view to Philip in that he was able to tolerate and listen to a single conversation while being engulfed by the noise of a crowd talking:

> I’ve been in a noisy crowd at a restaurant or a conference and there’s been all people around me and I’ve got to listen harder, but I hadn’t found myself getting frustrated or having great difficulty blocking out those other sounds around me. Even with music and stuff going on in the background. Once someone’s helped me start the conversation or someone, who I’ve met before then, I hadn’t found any difficulties focusing just on that conversation.

Sebastian, Alison and Sheryl, unlike Adam and Philip, did have auditory difficulties in crowds. Sebastian shared his experience:

> If there were two other people here talking to each other, I couldn’t concentrate on you … I can’t follow even in a small crowd, you know, even if it’s four or five people. If there’s a couple of conversations going on I can’t go from one to the other myself and I can’t just focus on one and tune the others out.

Alison also had difficulties when more than one conversation was taking place:

> [G]oing out to restaurants with people, I can find it quite hard to follow conversations. Like if there’s three conversations going on at the table, I’ll hear all of them. I won’t be able to focus on any of them quite enough to be able to follow everything that was said in such a way that I have also got room in my head to work out what I’m going to say and contribute to the conversation.

Finally, Sheryl had similar problems with multiple conversations:

> If there’s too much sound, I can’t really cope. So I have learnt to shut out things … If there’s too many people talking to me at once, loudly especially, I get confused but even if I’m having a one-on-one conversation I can think to the side for a second and not hear them.

Charlotte and Peggy also experienced difficulty with the ambient noise generated by a crowd. Yet they were able to find innovative solutions to this problem, as Charlotte explained:

> It [the sound of a crowd] can engulf me … quite easily. It just becomes a total muddle of sound of just people talking and cars whizzing past and an alarm going off here or an ambulance going past and the trams going up and down the main street and it just becomes a jumble of noise, but I have little havens in the city where I can escape to and get away for a while. So, yeah, I’ve sort of managed to find some quiet places.

Peggy had her own solution to too much noise:

> I would often go up and climb in the old peach tree we had in the back yard and sit in the top of the tree and I preferred it up there than to be around the noise of people.

In this section, eleven out of twenty-one participants interviewed described their auditory sensitivity experiences. Philip, Kyle, Tim and Imogen explained how they were unable to sleep next to a ticking clock. Kylie and Imogen then described their inability to be around noisy household appliances. Philip and Adam explained how they were able to tolerate being in a noisy crowd of people, while Sebastian and Alison were not able to tolerate such noises. Charlotte's and Peggy's explanations of how they were able to tolerate noisy environments concluded this section.

4.5.3.3 Visual sensitivities

Some people on the autism spectrum, including those with Asperger syndrome, can have visual sensitivities. Yet the literature review did not reveal many studies on adults with Asperger syndrome describing their visual sensitivity experiences. In an attempt to address this gap, the participants in this study were asked to describe their experiences of this sensory sensitivity. Sixteen participants did not describe any visual sensitivity experiences and five participants articulated their visual sensitivity experiences. Four participants found sunlight a major source of discomfort. For Peggy and Charlotte, this discomfort also occurred during winter, where there is often a diminished level of sunlight. Peggy said, 'I wear sunglasses a lot, even in winter.' Similarly, Charlotte wore sunglasses most of the time:

> I always wear sunglasses year round … The only time I don't wear sunglasses is in the dark. Like, my house is fairly dark … I keep the blinds half down the rest of the time I wear sunnies.

Philip and Isabelle also wore sunglasses. Philip stated the following:

> I'm not very good with very bright light—like a very bright sunny day—that's why I have transition lenses just to keep the glare out: because it is awful.

Isabelle also wore sunglasses extensively:

> I don't go anywhere without my sunglasses … So, particularly strong sunlight I often find very unpleasant if I don't have my sunglasses with me.

While sunglasses offered Philip, Isabelle, Peggy and Charlotte comfort and protection from sunlight, Imogen stated that she had problems wearing sunglasses because of the pressure they placed on her nose:

> Bright sunlight … I'm not good and I have to pull over if it's too bright … when I'm driving, but sunglasses, I have a sensory issue with having them actually on my nose.

Another light sensitivity that Imogen referred to was the inability to cope under flickering fluorescent lights:

> I don't know if you can see them but they [the fluorescent lights in the interview room] actually flicker in a cycle and these ones are doing it … If you get the movie *Mozart and the Whale*, they've actually deliberately done it on film there to show what he's experiencing. I showed one of my friends and I said, 'Look, you know this is coming up on the T.V. screen.' And she was able to see it and I said, 'That, that is what it looks like to me when I'm in a hospital,' and she said, 'Oh my gosh! I'd throw up after half an hour.'

In this section, five out of twenty-one participants interviewed for this study explained their visual sensitivity experiences. Philip, Isabelle, Peggy and Charlotte outlined how they were unable to cope with bright sunlight. Imogen then explained how she could not tolerate fluorescent lighting.

4.5.3.4 Olfactory sensitivities

Some people with Asperger syndrome have olfactory sensitivities. However, few studies exist in which such adults describe their olfactory sensations. This study added to the limited amount of literature by getting the participants to describe their olfactory sensitivities. Three participants reported experiencing olfactory sensitivities and eighteen participants did not describe any olfactory sensitivity experiences. Below, Charlotte, Imogen and Sebastian report their inability to enter certain shops due to this sensory sensitivity. Charlotte, for example, was unable to enter manicurist shops:

> You know those manicurist shops? … I can't stand them … I can't walk past them. It nauseates me: that smell. Whenever I see a manicurist shop I'll cross over the road, or in Westfield I just look for a way of getting around it. I hate the smell of those places.

Imogen, who had a similar experience to Charlotte, described how she was unable to enter a particular shop:

> Do you know the store ‘Dusk’? They sell pretty candles, smelly stuff … I can’t even walk past it without getting a headache and without feeling like I’m going to vomit.

In a similar vein, Sebastian said he was able to enter shops but not the pet aisle in a supermarket:

> I avoid the pet aisle because of the smell of the pet food and things like that because it annoys [me] a little bit.

Unlike the other sensory sensitivities presented in this chapter, olfactory sensitivities were the least discussed. Charlotte, Imogen and Sebastian were the only participants who discussed this sensory sensitivity and their accounts were all related to particular smells in retail outlets and the impact of their daily life.

4.5.4 Inability to establish or maintain a verbal conversation

The inability to establish or maintain a verbal conversation is a characteristic of Asperger syndrome. Yet there is scant literature on adults with Asperger syndrome describing their experiences of this characteristic. To enhance the existing literature, the participants were asked if they have ever had any difficulties with establishing or maintaining a verbal conversation. Five out of twenty-one participants explained their verbal communication difficulties, such as interpreting metaphors, knowing when to stop a conversation, or knowing how to answer questions tactfully in order to maintain social cohesion. The inability to interpret metaphors was the most common verbal challenge reported by the participants. Kylie recalled how her inability to interpret a metaphorical expression in a university tutorial had an impact on her ability to follow a conversation:

> First year uni, I think someone said something like, ‘And the judge threw the book at the defendant,’ and I spent the tutorial going, ‘That seems really strange for a judge to just get a law book and throw it. Wouldn’t someone stop the judge from doing that?’ Then it suddenly hit me towards the end of the tutorial that they meant that the judge was sort of being really hard in the sentence that the defendant got. But I mean if I’ve heard metaphors once, I can normally get it the second time.

Isabelle also commented on an inclination to interpret metaphors literally:

> Often if people are using a phrase that I haven't heard before … I will usually attempt to process that literally and if I can't immediately understand it, I will probably just give them a confused look.

One participant, Justin, described his inability to use verbal expressions effectively:

> When you see a T.V. show and you think something's funny and a really good quote, you'd quote it in a conversation or something like that. I used to do that a little bit and I used to get embarrassed when I did not get any laughs for it.

Another verbal challenge that participants revealed was an inability to know when to terminate a conversation or when to answer personal questions with tact. Philip spoke of not knowing when to terminate a conversation:

> I've talked to people about history and I assume that people know and they just don't, like, people often seem to be quite ignorant about the political state of the world before World War I … I like to think that I have developed a skill of detecting when people don't care, although it's probably less I don't detect when people don't care and more the fact that I will actually stop myself and ask, 'Do you care about this?' Or 'Am I boring you?'

In relation to knowing how to answer personal questions with tact, Peggy had this to say:

> I can easily offend people when I don't really mean to. Like if somebody asks me, 'Do I look fat?' Well, I'll tell them … and why are you getting upset? You asked me if you were fat and I told you the truth … If you wanted me to lie, you should have told me, 'Can you please lie after this question?' And if you didn't want the answer, why the hell did you ask the question? You know, it doesn't make any sense to me.

The literature review showed a limited number of studies on adults with Asperger syndrome describing their verbal conversation abilities. The participants in this study added to these studies by describing their verbal communication experiences. This section began with Kylie's and Isabelle's accounts of how they cannot interpret metaphors. It then presented the conversational challenges that Justin, Philip and Peggy experienced.

4.5.5 Challenges with socialising

Limited social abilities are a characteristic, and even a stereotypical feature, of Asperger syndrome. Surprisingly, however, there is not much literature on adults with Asperger syndrome describing their experiences of socialising. To address this gap, the participants were asked to describe any social difficulties they have experienced. Three participants shared their experiences of socialisation and eighteen participants did not describe these experiences. Charlotte likened her limited social abilities to being ‘in a room full of engineers’. She explains this comparison further:

> When I talk to my G.P. [General Practitioner], I imagine saying to her, ‘Imagine that you are the only doctor in a room full of engineers, okay, and they are all talking engineer talk and you … are the only doctor and you are wandering around and looking at all these people talking and you have got no idea what they are going on about. You know what you’re going on about but you have no idea what they are talking about and for most of your life you are in that room. You are stuck in that room … and for some reason you find a door and you leave that room and in the room next door there’s a whole heap of doctors and all of a sudden you find someone who speaks your language and you understand what they are talking about. All of a sudden you think, “Wow! There are other people like me, but for most of your life you’ve lived in a room full of engineers that you don’t understand.”

Travis, another participant who explained his limited social abilities, said how he gravitated towards Mr Spock’s character in the original *Star Trek* television series.

> I immediately took to the character of Mr Spock and I didn’t know why: I just thought I like Mr Spock. Mr Spock was a Vulcan from another planet and I feel like I’m from another planet and I always have done. Captain Kirk would say to him, ‘Listen Spock. You have got this love and hate.’ ‘Captain what is love?’ ‘Well it’s when you bla, bla, bla, bla,’ and he said, ‘No I don’t understand this human stuff,’ and ‘What is an emotion, Captain?’ And the Captain explained what an emotion is and he said, ‘Well, what is hate?’ ‘Oh, Spock. Hate is this.’ And I gravitated towards this character. I thought, Jesus, that is just like me … I just gravitated towards Spock and he was my favourite character out of all of this *Star Trek* stuff. When I go back and look at Spock and I think, ‘God, that could be me really, you know?’

The final participant who reflected on her social limitations was Peggy:

> Misunderstanding and not being able to read a social situation … not getting the subtle nuances of a party … I got invited to a Christmas party at my son’s family day care and just feeling you are so isolated.

In this section Charlotte, Travis and Peggy described their views or experiences of limited social abilities. In the next section, six participants explain their views on the Australian public’s knowledge of Asperger syndrome.

4.6 The Australian public’s knowledge of Asperger syndrome

There is literature on the public’s knowledge and perceptions of the autism spectrum. In contrast, no studies were found on adults with Asperger syndrome expressing their views on the Australian public’s knowledge of Asperger syndrome. In order to investigate this area further, each participant was asked, ‘What do you think the Australian public knows about Asperger syndrome?’ Six out of twenty-one participants answered this question and two participants, Philip and Dave, answered it from an international perspective. Philip had this to say:

> Considering that I’m not generally a social person, [it’s] quite difficult to say, but if I take it from the point of view of the Internet, instead of Australia, it is generally there’s nothing wrong with you—you are just lying as an excuse to behave badly, which admittedly is something that happens quite a lot with Asperger syndrome, but it does mean that you have to be a little bit careful about who you tell.

Dave commented on what he felt was a negative perception of Asperger syndrome in Australia:

> They [Australian people] see it as more as a disorder. People from around the world, outside of Australia or beyond, see it as more of a unique way of a person.

Another view, expressed by Jake, was that the Australian public believes only children have Asperger syndrome:

> It [Asperger syndrome] is something that kids have … is a very strong perception in the minds of people and something that adults tend not to have.

Isabelle expressed a similar view to Jake:

> I think there’s a perception that it’s a problem that children get.

The Australian public’s ignorance of Asperger syndrome was another view participants voiced. Linda expressed this view succinctly: ‘I think there’s a lot of ignorance in the Australian community but that’s just my perception.’ This was discussed in more detail by Kyle:

> It [Asperger syndrome] is judged more as a mental disability than intellectual and most people say, ‘Oh, he’s got Asperger syndrome: he’s retarded,’ when that’s not the case. As a matter of fact, every time they even so much as think that we’re retarded, they are insulting us and could very well be insulting themselves because these days they said that one in every three or four people could have Asperger syndrome because it’s on such a wide scale. I mean, a lot of people don’t even see it in me until I tell them and then they look into it and say, ‘Oh, well, he really does have it.’ … I’m not that severe compared to most people and honestly a lot of people just can’t seem to tell.

In this section, six out of twenty-one participants interviewed for this study expressed their views on the Australian public’s knowledge of Asperger syndrome. Philip and Dave answered this question from an international perspective. Jake and Isabelle thought that the Australian public considers Asperger syndrome to be a condition that only affects children. Finally, Linda and Kyle thought that the Australian public held misperceptions about Asperger syndrome. In the next section, eight participants explain whether or not they have accepted their diagnosis of Asperger syndrome.

4.7 Self-acceptance of Asperger syndrome

The issue about whether or not adults *want* to live with Asperger syndrome has not been widely researched. To address this small amount of literature, each participant was asked ‘If you were given a choice, would you choose to keep your Asperger syndrome?’ Eight participants answered this question and thirteen participants did not answer this question. Linda, Charlotte and Tim, however, were not able to answer this question, with Linda stating:

> ‘I think that’s too hard a question.’

Charlotte reacted to the question in a similar fashion:

> That is absolutely impossible to answer … I can never look at it from a person’s viewpoint who hasn’t got it.

Finally, Tim was also unable to answer how he would feel without Asperger syndrome:

> If I had my Asperger syndrome taken away. Oh, I'm not too sure on that one … I'm a bit of a fence sitter on that one.

In contrast, Sam, Philip and Peggy stated that they wanted to live with Asperger syndrome. Peggy and Sam considered the syndrome to be an integral part of their identity, with Peggy stating as follows:

> It's [Asperger syndrome] a part of me … It's like would I choose to be born under a different star sign or would I choose to be born with black hair? It's just a part of me … I wouldn't know who I would be if I didn't have it.

Sam also felt Asperger syndrome was part of his identity:

> If I was given the choice to get rid of it [Asperger syndrome] or keep it completely, um, yeah, I'd probably keep it … It makes me who I am.

Philip was not sure about which aspects of his Asperger syndrome formed part of his character. Due to this uncertainty, he did not want to live without his Asperger syndrome; he did not want to lose any unknown skills or abilities the syndrome may give him.

> Someone with Asperger syndrome, who's better with words than myself, once said, 'I personally would choose to keep my Asperger syndrome because I like what I can do, but I can clearly see that someone else without Asperger syndrome would not want to give up what they have.' I would choose to keep my Asperger syndrome.

Sam, Philip and Peggy wanted to keep their Asperger syndrome. However, Sebastian and John wanted to live without this condition. Sebastian wanted to live without his Asperger syndrome because he wanted to be more social:

> I think until a year or two ago, I probably would of said, 'No, I don't want to be cured. I like who I am. I'm different, I'm creative, I'm quirky, I'm weird.' And I really like all that kind of stuff about me, but right now I would change it in a minute. If you could cure me and make me more social and I don't care if I'm boring and I don't care if I like sports, but I wouldn't be me anymore.

John wanted to live without his Asperger syndrome in order to serve in the Australian Defence Force:

> Probably ‘No,’ as I said for the jobs [Avionics Technician and Military Dog Handler] I wanted to do … If I didn’t have it [Asperger syndrome] I would probably be in Queensland or somewhere training … I think the Australian Defence Force should really change their views about it … because the British Defence Force, the New Zealand Defence Force, the United States Armed Forces, they let people with Asperger’s in … I don’t know, maybe they’ve [the Australian Defence Force] had some people with Asperger’s stuff up and they think that all people with Asperger’s are like that.

In this section Linda, Charlotte and Tim were not able to answer if they wanted to live with Asperger syndrome. Peggy, Sam and Philip were reluctant to live without their Asperger syndrome and, for social and career reasons, Sebastian and John were happy to live without their Asperger syndrome. In the next section, eight participants explain their depression and/or suicidal ideation experiences.

4.8 Depression and suicidal ideation

Few studies have been published on adults with Asperger syndrome articulating their depression and/or suicidal ideation experiences. In an attempt to augment this limited amount of literature, each participant was asked ‘According to several studies, depression is very common for adults with Asperger syndrome. Have you ever experienced any episodes of depression?’ Thirteen participants did not have any depression or suicidal ideation experiences and eight participants revealed their experiences of this issue. John, however, did not want to discuss these experiences: ‘I’ve just put it in the back of my head and forgot about it.’ Tim, Travis and Philip did not have any depression or suicidal ideation experiences. Tim said:

> I haven’t actually experienced ongoing depression. Maybe I’ve felt a bit down in the dumps at times but I haven’t felt really depressed.

In a similar vein, Philip had this to say:

> I’ve experienced what may be depression but it’s never been anything diagnosed and it’s never been anything too severe or lasted any longer than a day.

Finally, Travis reported that he had not experienced extreme depression:

> Depression: never had it … I've maybe been depressed when something's not gone right but I've never had depression.

Kyle, Peggy, Charlotte, Imogen and Sebastian disclosed their depression and suicidal ideation experiences. Kyle metaphorically described his depression as 'Hell'.

> Depression was, how do I put it, depression was Hell … Hell is the one thing that lingers in all of our minds. I mean I'm not religious or anything but I do know Hell exists where Heaven doesn't and Hell is inside all of our heads and depression is an example of that Hell, hate is an example of that Hell and it's all the negative thoughts that are in our heads and all those negative emotions and feelings because they have such an impact on how we see the world, how they affect us and for me, I didn't want to be around anymore. I had enough. I started to cut. I tried to bleed out on several occasions. I tried hanging myself. I've literally been down the path of trying to eliminate myself from existence as such, failed on multiple attempts and, in the end, after I started getting help, it was after I'd been diagnosed with Asperger syndrome, I actually started to stop. Before then I've tried to off myself on so many occasions. What shocked me the most was that not even my mum had picked up the fact that I'd tried to end it several times beforehand until I actually came clean about it one day and scared the absolute crap out of her. But depression affected my grades. It affected me socially. I didn't want to even so much as look at another person, let alone talk to them. All I wanted to do was lock myself up in my room and play my music up really loud so no-one could hear me, block out everything around me. It was all doom and gloom. It was just shades of black and grey. There was no other colour and it was just a really, really, really hard time for me.

Peggy also described her depression and suicidal ideation experiences:

> Our son got diagnosed with Asperger's and we had problems infinitum with the school and I'd felt so much responsibility that I had let him down and that I had let my husband down and I'd let my mother down and that I was basically poison and that I had black tar flowing through my veins. At the time when you are in these episodes, people think, 'Oh, don't do anything silly.' Well, when you are in that zone, ending it all is not a silly thing to be deciding and you actually think that people would benefit without you in their lives … and I think a lot of people who know about suicide think that there's just this hysterical leap, but for me it's, you get to a point

> where it’s very calm and you logically come to the conclusion that the world would be a better place without you in it.

Imogen and Sebastian also described their depression and suicidal ideation experiences. However, unlike other participants, they discussed the process they went through to try and commit suicide. Imogen had this to say:

> I’ve tried to kill myself so many times I’ve lost count and we’re talking self-harming like you see where you’ve gone out and you’ve bought 700 aspirin tablets and you’ve taken as many as you can until you puke because they’re fizzy and then you waited for that to stop, realise that you’re going to hurt one particular person and that’s been enough motivation to go, ‘Crap. I should go get this dealt with,’ but you still don’t actually want to live so you wake up in I.C.U. [Intensive Care Unit] going ‘Drats!’ and you kind of go there going well, *at least they’ll think that I tried to live* … and then you do live and you kind of go, ‘Yeah, well, that’s not really what I wanted.’ So I have tried to kill myself so many times it’s not funny.

Sebastian also spoke of attempting to commit suicide:

> There was one other time where I took a lot of pills and I used to stockpile a lot of my medication. It would change often and I would just save the rest and there was this one time where I took a shitload of pills … sleeping pills and anti-depressants and all kinds of shit and it just knocked me out and I was in bed for about forty hours or something like that and everything went back to normal and I just recovered and it was nothing. I didn’t go to hospital or anything, so that was the only serious attempt.

The final participant who spoke about their depression and/or suicidal ideation experiences was Charlotte. During the in-depth interview, she did not disclose if she had ever wanted to commit suicide. However, she did reveal how her Asperger syndrome has had an impact on her treatment for depression:

> The treatment for depression is, or part of it is, to not isolate yourself … I like my solitude but because I like to be on my own, a lot of doctors would see that as you’re depressed. You don’t want to be with people; therefore, you are depressed. You don’t want to join groups; therefore, you are depressed. You don’t want to do; *therefore*, you’re depressed. Whereas I don’t want to be with people because I have got Asperger’s, I don’t want to join groups because I have got

> Asperger’s, and that can be hard to get across to a doctor because they only look at what depression is and you are showing these symptoms; therefore, you have got depression.

In this section, Kyle, Peggy, Imogen, Charlotte and Sebastian revealed their depression and suicidal ideation experiences. John and Sam also disclosed that they had experienced depression, but they did not want to provide much detail. Kyle described his experiences of depression from a metaphorical perspective, describing depression as ‘Hell’. In addition, Kyle, Peggy, Imogen and Sebastian recounted instances where they tried to commit suicide. This section concluded with Charlotte’s account of how her doctor’s treatment of her depression—which was to encourage her to be more social—clashed with her desire to be isolated and anti-social, which was caused by her Asperger syndrome.

4.9 Views and experiences of Asperger syndrome from the participants’ parents

The focus of this study was on adults with Asperger syndrome and their experiences and views on intimate relationships, education and employment. Before the start of the interview session, each participant was given the opportunity to have a support worker or family member present. Cody and Nigel were the only two participants who wanted their parents to attend the interviews. As a consequence of their attendance, the information in Cody’s and Nigel’s transcripts was not analysed. However, the data collected from these interviews is still valuable and will be presented in this section.

This section will now present the views and experiences of Cody’s Asperger syndrome from the perspective of Cody’s mother, Sally. Below, Sally explains how Cody was diagnosed with Asperger syndrome:

> **Matthew:** Can you describe the process you went through to obtain a diagnosis of Asperger’s syndrome?
>
> **Cody:** I really can’t explain it. Mum?
>
> **Sally:** … When he was at school, he was having the guidance officer visit … and the guidance officer called me in to the room to talk about Cody and she said, ‘Have you thought of Asperger’s syndrome?’ and I said I hadn’t even heard of Asperger’s syndrome. And she said,

> ‘The only reason why I say that is because my son has it and Cody presents as a boy with Asperger’s.’ So after that I went to a community organisation where he had an assessment done and that’s when the diagnosis was made.

During the first interview session, Cody was asked to describe the positive and negative consequences of living with Asperger syndrome. Below, Sally prompts him to discuss his ability to identify minute details:

> **Sally:** What about an eye for detail?
>
> **Cody:** Eye for detail, yeah. We can just pick up on so many little things and even hear things like from far away, like which other people can’t hear. Like, you know, I can hear my mum’s phone going off or Mum’s partner’s phone going off and I’m going, ‘Your phone’s going off, your phones going off,’ and they both are going, ‘What? We can’t hear anything,’ you know.

Aside from audio sensitivities and the ability to identify minute details, Sally describes Cody’s desire to wear tight shoes:

> **Matthew:** Do you have any problems with wearing denim at all? Because it’s quite thick.
>
> **Cody:** Yeah, I used to have a real problem, but now I don’t have a problem.
>
> **Matthew:** Can you describe that for me?
>
> **Sally:** Was it clingy?
>
> **Cody:** Yeah, you know, clinging feeling and I just hated it—even with the big clothes … I hated it. That’s why I was always in shorts and a t-shirt.
>
> **Matthew:** Yep.
>
> **Sally:** I remember with your shoes, when he used to wear lace-up shoes for school, but they always had to be really tight … So we used to have big issues if they weren’t tight enough … So every morning was a nightmare to get his shoes on and get the laces so tight.

After Sally described Cody’s fondness for tight-fitting shoes, Cody was then asked to recall how his Asperger syndrome has had an impact on him at school. However, since Cody was unable to answer this question, Sally explained her perceptions of Cody’s experiences at school:

> **Matthew:** Can you give me some examples of how your Asperger syndrome has had an effect on you at school?

> **Cody:** I’m a bit lost on that one.
>
> **Sally:** Do you remember they used to have that system where you could go out of the room. Do you remember that?
>
> **Cody:** Yeah.
>
> **Sally:** They set up that system … When Cody felt he was getting frustrated or was overwhelmed, he was allowed to sit outside.
>
> **Cody:** Or get a drink.
>
> **Sally:** Or get a drink, just to have a break. Lots of times the principal would take him to his office if he was really getting upset … Not as a punishment but just simply to remove him from the situation and let him calm down.

Sally then told of another experience that Cody had at school:

> **Sally:** He [Cody] went to a Catholic school and they put in an awful lot of supports for him. I know that in Year Seven they actually took Cody out of the classroom.
>
> **Cody:** Yeah.
>
> **Sally:** Because I was there that day and I stayed.
>
> **Cody:** Still angry about that up till this day.
>
> **Sally:** And the teacher then talked to the class about Cody’s Asperger so that the kids understood that if Cody was not made to do something that it wasn’t preferential treatment: it was because of his Asperger syndrome that some allowances had to be made … and I think they were quite supportive.

During the second interview session, Cody was asked to discuss his employment experiences. Sally helped Cody explain how his Asperger syndrome has had an impact on his experiences in employment:

> **Matthew:** How did your Asperger syndrome affect you in the workforce?
>
> **Sally:** It caused you some anxiety, didn’t it?
>
> **Cody:** Yeah, anxiety … It was kind of bad.
>
> **Sally:** I think the sensory overload, or something like that, causes the anxiety and then the anxiety causes, well, in Cody’s case in particular, to avoid the situation.

Cody was then asked to describe his experiences of telling his workplace colleagues about his Asperger syndrome. However, he was reluctant to answer this question. Consequently, Cody's mother, Sally, answered on his behalf:

> Cody doesn't really like disclosing that he's got Asperger, but we felt that it was important that employers know so that they can make adjustments in the workplace … I think what we have found is that employers really do not understand the complexities of Asperger syndrome. I will say things like, 'Cody needs short and simple instructions,' because there's a whole range of things that he needs to be able to cope with in the workplace, and they are full of good intentions but when it actually comes time to start working, a lot of it gets forgotten.

Cody was then asked if he has ever had any difficulties communicating with other workplace colleagues:

> **Matthew:** In the workplace, it is often important to communicate with other employees and your employer. Have you ever experienced any communication difficulties in the workplace?
>
> **Cody:** Oh, yeah.
>
> **Matthew:** Could you give me an example of that?
>
> **Cody:** Um, oh well, if I think back it's like—
>
> **Sally:** Well, I guess the fact that I often go with Cody isn't … I am his spokeswoman.
>
> **Cody:** Yeah.
>
> **Sally:** I sit back and let him say what he wants, but if I think he's floundering I'll step in because it's important that people get the information … So I guess I'm like his translator … but I am also a bit concerned because as I get older, I know I won't be there in the future. I mean, I think his communication has improved a lot but there are still situations where he has trouble expressing himself.

Above, some of Sally's recollections of Cody's life experiences are presented. Nigel was another participant who wanted his parents to attend the interview sessions. Below are some examples of Nigel's parents' views and experiences of Asperger syndrome.

At the start of the first interview session, Nigel was asked to describe how he was diagnosed with Asperger syndrome. He could not recall this information, so Nigel's mother and father, Mary and David, explained how their son received a diagnosis of Asperger syndrome:

> **David:** What happened was that when Nigel was young he didn't respond as a normal child would. He was our third child and he wasn't responding as we expected a child to and one of our family members, who was a nurse, said when he was about two, 'You need to have him referred somewhere,' and so it was quite a lengthy process. It took about nine months before he actually got to the diagnosis stage.
>
> **Matthew:** Yep.
>
> **Marie:** We went through deaf hearing people.
>
> **David:** Yes.
>
> **Marie:** But—
>
> **David:** We knew he wasn't deaf.
>
> **Maire:** Yeah.
>
> **David:** Because if anybody clapped their hands behind his head he wouldn't respond, but I could be in the next room and unwrap a lolly paper and he'd come running.
>
> **Matthew:** Okay.
>
> **David:** So we knew he wasn't deaf but we didn't know what it was.
>
> **Marie:** We had never heard of autism and—
>
> **David:** So we first went to the deaf and they said that they couldn't test him because he wouldn't respond and then we went to—
>
> **Marie:** A hospital.
>
> **David:** A hospital to—
>
> **Marie:** And they did a whole lot of tests.
>
> **David:** With you know, putting puzzles together and they said, 'Well, instead of being two, he was really at the level of a four-year-old.'
>
> **Matthew:** Yep.

> **David:** They said that there was nothing cognitively wrong and then they suggested that we go to a psychologist … and he [the psychologist] said let's start with the letter A and we'll cross them off the list. So under the category 'autistic' he read out the diagnosis, like, 'Does he sit in the corner and rocking in the chair?' and we said, 'No he doesn't do that,' so he said he's probably not autistic but let's test him anyway and will take that one out.

After Nigel's parents related the process their son went through to obtain his diagnosis of Asperger syndrome, Nigel was then asked to voice his thoughts about his Asperger syndrome. However, since he was unable to answer this question, his parents interjected and described their views on this subject:

> **David:** If he [Nigel] had a tantrum or something like that at say, a shopping centre, I just turned around and told people that he's autistic and that really made a big difference.
>
> **Marie:** Yeah.
>
> **David:** And you would get people who weren't sure. Nowadays, they would know much more about it.
>
> **Marie:** They never heard of it.
>
> **David:** They might not have heard of it but they said, 'Oh, well.'
>
> **Marie:** He had something.
>
> **David:** He's got something.
>
> **Matthew:** Okay.
>
> **David:** And they might not know what it is, but they were much more accepting of the behaviour if we told them. If we just carried on without telling people around us what was happening … they might either thought he was a very disobedient child or they would think that I was a—
>
> **Marie:** Bad parent?
>
> **David:** Bad parent.

Nigel was then asked to describe some of the positive and negative impacts that his Asperger syndrome has had on his life. He was not able to answer this question and Nigel's mother, Marie, decided to explain her perceptions of how Nigel’s Asperger syndrome has had an impact on his life:

> **Marie:** … Quite often when he [Nigel] was young, part of the problem is when you give him the instruction like, ‘Don’t cross the road,’ he’d hear ‘Cross the road,’ because he doesn’t hear the ‘Don’t’.
>
> **Matthew:** Okay.
>
> **Marie:** Because of the way his auditory processing works, often he would get into trouble. I’d say, ‘Don’t cross the road,’ and he would cross the road and I would stop him and he would get upset and say, ‘You told me to,’ and I would say, ‘No, I didn’t tell you,’ and that would cause a lot of problems.

David then provided another example of Nigel’s auditory sensitivities:

> **David:** An example of how sensitive to noise he [Nigel] is: one day Marie was out walking with him, going home from school.
>
> **Marie:** That’s right.
>
> **David:** ‘Hear those kids? They are calling me that name again,’ and there’s a particular name that upsets him.
>
> **Marie:** They know they would stir him up.
>
> **David:** She [Marie] said, ‘I can’t hear anything,’ but as she got closer to the children, she could hear it.
>
> **Marie:** I couldn’t hear it but he could already hear it from miles away. I couldn’t hear it but he could hear it at the shopping centre. He could hear them calling him that name. I thought he was just imaging it, you know.
>
> **Matthew:** How far away were the kids from your location when you heard that?
>
> **Marie:** Well, we were in the car park on one side of the road and the people were in the shopping centre on the other side of the road.

Another sensory sensitivity Nigel experienced, aside from auditory sensitivities, was sensitivity to taste. Marie explained how her son’s sensitivity to taste limits him to only eating certain brands of food:

> We often explain to people that he [Nigel] has got to eat this brand of food. This makes life quite difficult because some shops don't make particular brands of food anymore. So I have had to ring up the manufacturers and say, 'Can you please tell me where you sell them?' or 'Where can I order a bulk or something and have it sent to me?' Some people have said to me, 'The last one I have is in the showroom. Do you want to come and pick it up?'

Marie then gave another example of Nigel's taste sensitivities:

> He [Nigel] has a set meal on Wednesday, Friday and Sunday at the moment. Before you [Nigel] used to be much more rigid than that. For example, if we ordered chicken it had to be from that particular shop and not another shop and that used to be really difficult. Now, he will eat the chicken from other shops. He only started eating chicken a few years ago … Other than that, he is really a fruitarian. He's not a vegetarian, and we call him a fruitarian because he eats a lot of fruits.

Nigel was then asked to outline some of the techniques he has used to avoid school bullies. In the passage below, he was unable to answer this question in detail and his parents interjected to help him:

> **Matthew:** Could you share with me some of the coping tools you used to help you get through school? So how did you get through the bullying?
>
> **Nigel:** I tried counting to ten, but how can you count when people try to tease you?
>
> **Marie:** That was the technique we said: take a deep breath and count.
>
> **David:** What happened when they gave you a book and said, 'Write down every time somebody bullies you.' What happened then?
>
> **Marie:** Does it help?
>
> **Nigel:** It comes in handy to report bullying to teachers with some proof, yes.
>
> **David:** Yeah, so how many reports would you give the teacher in a day?
>
> **Nigel:** Everyday?
>
> **David:** Yes. How many reports in one day? When the teacher asked you to write down every time you were bullied, make a report. How many reports would you make in a day?
>
> **Nigel:** Roughly ten I think.

Marie then explained another technique that school authorities used to help Nigel handle school bullying:

> They [school authorities] would give him [Nigel] a timeout room so that he can do his work. If he finds it too hard in the classroom, he can go to this place, but not every teacher liked this idea because he needs somebody to supervise him. I once made a request for a camera or something of that nature to be placed in the timeout room but the school doesn't have that sort of thing.

David also explained how the school helped his son manage school bullying:

> … Nigel didn't realise that he was harassed when he was very young but the principal helped him by finding the biggest bully in Year Seven and said, 'At recess time, your responsibility is to look after Nigel and make sure nobody bullies him,' and he solved two problems in one.

Nigel was then asked about his experiences in employment. After a period of silence, Marie gave an example of Nigel's difficulties in the workforce:

> Part of the problem was that if they change him [Nigel] from one job to another job and if they are not organised enough that would cause a problem for him because he doesn't like hanging around waiting … He thinks every minute counts and you should be working.

Marie then referred to how she helps her son Nigel in employment:

> **Marie:** In the previous job he [Nigel] would go and look for the supervisor quite often and they would say to him, 'Go back and carry on with your work.' They never used to act on whatever he was complaining about. So he used to get rather upset because it's like, 'It is no use if I go and tell them because they are still not going to come and help me.'
>
> **David:** So what Marie devised is a communication book … with the supervisor.
>
> **Marie:** Yep.
>
> **David:** And Marie and the supervisor both have a discussion from time to time on the phone, but most of their communication is done by writing notes in this book … So if he's had a bad day at work, they'll write a note in the book and explain what happened and then if he complains to Marie and she sees that there's nothing in the book, she'll write a note in the book and send the book back to them.

In this section, Cody's and Nigel's parents explained the views of their children's experiences with Asperger syndrome. The data presented in this section will not be analysed in the discussion chapter because this study is focused on presenting and analysing the views and experiences of adults with Asperger syndrome. However, due to the detail of the parents' views and experiences, it was deemed important to include them in this study.

4.10 Conclusion

This chapter began with a demographic overview of the sample. The participants' recollections of how they received their diagnosis of Asperger syndrome and the emotional reactions they, their family and friends experienced after obtaining a diagnosis was then presented. An overview was then provided of how the main characteristics of Asperger syndrome have had an impact on the participants' lives; the participants' views on what they thought the Australian public knows about Asperger syndrome; and the reasons behind wanting to live or not live with Asperger syndrome. This chapter then outlined the participants' accounts of living with depression and suicidal ideation. The final section of this chapter presented the views and experiences of Nigel's and Cody's parents on Asperger syndrome.

The next chapter is called *Education, Employment and Relationships* and it presents the participants' experiences of education, employment and intimate relationships.

Chapter Five

Education, Employment and Intimate Relationships

5.1 Introduction

The purpose of this chapter is to present the voices of adults with Asperger syndrome describing their education, employment and intimate relationship views and experiences. The chapter begins with accounts of the verbal and physical bullying four participants experienced in school and the coping strategies that they, along with other participants, used to avoid school bullying. The participants' experiences with the job interview process, their experiences after they had told their workplace colleagues about their Asperger syndrome, and the social challenges they have experienced at work will then be presented. It concludes with a presentation of the participants' experiences of and views on parenting, dating, and intimate relationships.

5.2 Education experiences

5.2.1 School bullying experiences

Not many studies are available on adults with Asperger syndrome describing their school bullying experiences. The participants added to the small number of studies by recalling and explaining their school bullying experiences. Each participant was asked to respond to the following:

> There is some literature which suggests that children with Asperger syndrome are bullied at school. Bullying can include being called names, being physically assaulted or being placed into positions where you feel intimidated or threatened. Whilst at school were you bullied?

Out of twenty-one participants asked this question, sixteen participants (seven males, nine females) reported being bullied; four participants (four males) reported no bullying experiences; and one participant, Tim, did not want to reveal if he had been bullied:

> I don't really want to talk about that … Like sometimes I just feel a bit uncomfortable when people ask me, 'What kind of ways that you were bullied?' Like, I just feel a bit uncomfortable with that.

This section presents Kyle's and Adam's experiences of being physically bullied and concludes with Linda's and Isabelle's experiences of being verbally bullied. Below, Kyle discusses how he was physically bullied at school.

> One day, when I was in either Year Nine or Year Ten, I was at my locker and people were throwing fifty-cent pieces. I'm not going to list any names but … there was a group of boys standing by the sink … and they were throwing fifty-cent coins at me and hitting me in the head, again and again and again and again … and because I wasn't reacting, one of the boys came up behind me and said, 'Hey, how's it going?' and just tried to act cool and act friendly and being a bit of a dick and you could see it, you could really hear it in his voice … and he's trying to stir something up and … he just came up behind me, grabbed me by my hair and just pushed the front of my head into my locker.

Kyle then described the teacher's response:

> Oh, the teachers responded but me having Asperger syndrome, they decided to suspend me but give him [the bully] time-out because I went to the extreme length of snapping and over-reacting and basically being just as bad as what he was. I suppose, driving his face into the ground after I literally grabbed him by his neck and throwing him downwards after he had slammed my head into the locker. But the way I see it, I wouldn't have done that if he hadn't pushed me to that breaking point by pushing my head into the locker. I mean, I was fine with objects being thrown at me, I was fine with people having laughed behind my back … It was the physical fist-on-fist contact I just couldn't take. The minute someone had aggressively pushed me or tried to hurt me, it was that which would set me off to over-reacting and looking after myself, taking matters into my own hands. Because every time I'd been bullied, there would have been a teacher there, there be students there and they would do nothing and they would just stand there and gawk. And when I'd react, the teachers would step in, kick me out of the school for a few weeks and the other kid would be out of school for maybe a day or two while they filled out paperwork on their side of the story and then they'd be back in before I was back in and the whole system was just a load of crap.

Kyle experienced physical bullying at school and his teacher's response was to give the bully a time-out and to suspend Kyle from school. Adam disclosed a similar experience:

> I didn't like the bullying … I've had my fair share of bullying … Two or three students, I think, could see that there was a weakness in me and it resulted in me being bullied and what I found was that there was absolutely no support from the principal … I reported this bully one day for kicking me in the back while I was getting changed in the change rooms for P.E. [Physical Education] and I said, 'Oh, look, you know, so-and-so kicked me in the back,' … and the principal turned around and said, 'Well, no, you need to tell me the truth; otherwise, I'm going to give you a one day of suspension,' … and I knew I was telling the truth. Hey, this kid kicked me in the back and I ended up having to, you know, cover the bully's back by saying, 'Oh no, he didn't do that. I must of misunderstood it,' because I certainly didn't want to have any record of being suspended for a day or a number of days, and I found that was pretty unfair and so I certainly didn't like that aspect of the school environment.

Kyle and Adam experienced physical bullying. However, not all participants reported being physically bullied. Isabelle and Linda mentioned how they were socially bullied at school. For Isabelle, her Asperger syndrome made it difficult for her to understand social situations and made it possible for other students to call her names:

> I found myself often not understanding social concepts and people would be calling me names and I would not be understanding what they were calling me. In some cases I actually thought that they were complimenting me.

Linda also disclosed how her social naivety, which was partly caused by her Asperger syndrome, resulted in her being bullied. Below, she describes a schoolyard hazing experience:

> I think, looking back, I mistook the girls that I hung around with as being friends. So there's a group of us when I was very little, like infant school, who used to hang around together and they decided to have a club that met after school and they decided at some point they told me that if I want to be in the club, and all of my friends I thought were in this club, that you had to pass a test and I said, 'Oh, what's that?' 'Oh there's three things that you have to do,' and I said, 'Oh, well, what are they?' 'Oh, first thing you have to do is—' I had to run around some huge distance in a certain amount of time and one of the girls in the club who was a really outstanding runner would run with me and, well, they timed it so that I wouldn't get into the

> club, except the only thing was that I surprised them and I came in within time. So I said, 'What do I have to do next?' and I passed all three, and so then they had to put up with me being in it but it had been designed so that I wasn't supposed to be in it … but I didn't see that as being kind of bullying cause I was socially naive and this sort of thing happened time and time again and I would be really naive about that stuff.

In this section, four out of twenty-one participants interviewed for this study described their bullying experiences at school. Both male participants, Kyle and Adam, described being physically bullied and both female participants, Isabelle and Linda, described being socially bullied. The next section presents the techniques that seven participants used to avoid school bullying.

5.2.2 Coping strategies used in school to avoid the bully

Little has been published on adults with Asperger syndrome recalling how they used to manage or avoid school bullying. In order to add to this limited literature, the participants were asked, 'Can you share with me [the researcher] some of the coping tools you used to help you get through school?' Seven participants answered this question and fourteen participants did not answer this question. The strategies that the participants used were ignoring the bully; fighting the bully; telling a staff member; and avoiding the bully by sitting at the front or back of the classroom. These strategies will now be discussed.

In regard to ignoring the bully, Adam stated as follows:

> I simply just ignored it … I tried to not let it faze me at all and I had the support of the teachers that were saying, 'Just ignore it. Just get on with it,' and I did just that: I ignored it.

However, sometimes Adam did report bullying to the principal:

> I pretty much just ignored it or went and told the principal. I wouldn't go and tell the teacher; I would go straight to the principal and tell the principal about it.

Similarly, Dave informed the teacher when bullying occurred: 'I would go to a teacher. I would go to the teacher straight away.' Another technique that Linda and Peggy used to avoid school bullying was going to an area away from the bully, such as the library. Linda explained this strategy:

> I guess that for me the coping tool was avoidance … I coped by doing things like joining the orchestra that met at lunch time; reading in the library.

Peggy also found refuge from bullying in the library:

> I lived in the library: that was one of my quiet places … and I would volunteer to help the librarian put books away so that people wouldn't come up to me and talk to me because I am busy doing something.

While Linda and Peggy tried to avoid bullies, Travis used words to defend himself from bullying attacks:

> I am particularly good with words and so I used semantics on them [the bullies]. I say the right thing and I say it in the right tone and it's like it really is that difficult to explain but what I found out when somebody wants to bully you, you say as little as possible. You don't go into a spiel: you say, it's like something out of a Clint Eastwood movie. He says as little as possible and when he does speak, what does he say? He holds up a magnum and he said, 'What you've got to ask yourself is do I feel lucky? Well do ya punk?' And that's what he says. There's a couple of lines before that, you know, and you have to watch how you speak and you have to speak in a menacing tone and say as little as possible but you have to mean it and you can't back down, never ever back down and never take a step backwards. You have to stand your ground and I learnt that when I was a kid at school and I was never bullied.

The final strategy used to avoid the school bully was to sit either at the front or back of the classroom. Imogen stated, 'I liked the back of the classroom because nobody could be looking at me and throwing stuff at me.' Kyle explained his anti-bullying strategy:

> I used to try and be one of the cool kids by sitting in the back of the class, lean up against the wall. I didn't cope very well because leaning up against the wall at the back of the class, sure, you stand out, but you're also in the target range of all the 'cool kids' sitting around the back as well. So they would be scrunching up the paper and throwing it at you, passing notes, harassing you behind your back and you, of course, are right in the middle of it all, and around Year Ten I decided to sit in the front. I sat right up close to the teacher and sure, I copped teacher's pet a lot doing that, but at least the teacher got to keep an eye on me being right up the front where everything's noticeable.

Unlike Kyle and Imogen, Peggy decided to sit by the window to avoid school bullies:

> Not right at the back because the cool kids used to sit at the back and not at the front because that means you are in the line of fire. So I tried and hide myself in plain sight like in the sort of middle to the side … You know, I like being near the window so I could look out the window.

This section presented the techniques which seven out of twenty-one participants who were interviewed for this study used to avoid school bullies. The techniques outlined were ignoring the bully; fighting the bully; telling a staff member; and avoiding the bully by sitting at the front or back of the classroom. In the next section, the participants reveal their experiences with job interviews, disclosures to their workplace colleagues that they live with Asperger syndrome, and social difficulties at work.

5.3 Employment experiences

5.3.1 Job interview experiences

There are an insubstantial number of studies on adults with Asperger syndrome describing their experiences with job interviews. To increase this body of knowledge, each participant was asked to respond to the following question:

> The job interview process is a set of complex social interactions between the employer and the prospective employee. Have you ever experienced any social difficulties with the job interview process?

Ten participants answered this question and eleven participants did not answer this question. Travis, Sheryl and Imogen recounted scenarios where they could not understand the job interview questions being asked or they could not tailor their answers to the job interview questions. Travis had this to say:

> Horrible git says to me, ‘What would you do if the customer came in and we had to take the wheels off of the car and put the wheel back on and they didn’t tighten up,’ he said, ‘and they are driving down the road and they get to the Entertainment Centre … and the wheel falls off. What would you do?’ I said, ‘Well, you mean on the job?’ ‘No, what would you do in regards to having words to the mechanic?’ I said, ‘Sack him.’ ‘What?’ I said, ‘Yeah, immediately.’ ‘Oh, you can’t sack somebody for leaving a loose wheel on a car?’ And I said, ‘Well, you wouldn’t work in the aircraft industry, that’s for sure. The aviation industry wouldn’t put up with that.’

> And I said, ‘That car, the wheels could of come off and shoot through the air and hit a pram and kill a baby. The driver might of veered off and killed someone else and they might have been killed.’ And he says, ‘Tell me,’ he says. ‘How many wheels have you taken off cars in your lifetime and put back on?’ I said, ‘It’s hard to estimate: ten, twenty thousand.’ And he said, ‘You are telling me that you’ve never left a wheel loose?’ ‘Never ever.’ ‘Ha!’ he said. ‘I don’t believe it.’ And I said, ‘Never,’ and I said … ‘He’d be out of a job.’ I said, ‘If he caused an accident he might find himself in court.’ ‘Oh,’ he said. ‘We can’t employ people like you.’

Sheryl also shared her view about being honest in the interview process:

> One thing I have noticed about the interview process is they don’t actually mean what they say. There’s hidden implications which, unless you are aware of them, you can completely miss and say the wrong thing and I mean that’s difficult and I wish people would say what they mean. I mean, that’s the whole point of the Aspie things is that we say what we mean as opposed to imply the meaning. I don’t like to imply the meaning because it insinuates a level of dishonesty, but apparently one thing that I have noticed about social interactions in general, even with friends and even with family, there is always some level of dishonesty, for whatever reasoning society has. There’s this level of dishonesty that either saves face prior to whatever the motivation is; there’s this level of dishonesty that is never going to go away because apparently we need it to interact with each other.

Imogen commented on her problems applying for jobs:

> When I was an intern … I was allowed to apply for jobs … I had five interviews … and I got offered all of the interviews based on my C.V. [Curriculum Vitae] which is very good. Most people are lucky if they get offered one, so getting offered five was kind of like, ‘Wow! This person’s really good.’ And I did badly in all five.

Imogen explained her job application problems further:

> Yep, one of them … apparently if you are a junior doctor you have to play their game and not be confident at your interview about your medical skills, but I was confident about my medical skills. I didn’t read into it that you’re meant to basically say, ‘I know nothing. I’m a junior doctor.’ But the fact is that I know a lot more than a lot of senior doctors and I was quite happy to say that I would be confident managing certain situations and that was misinterpreted that I don’t know my weaknesses, when in fact *they* didn’t know my skill level. I didn’t know how to

> play the game … I had another one that went badly because they seemed to think I was far too academic and because I'm so open about things. They were really just looking for apparently a junior doctor who'd be happy to run around the wards and didn't really have any career aspirations or goals, and I was already enrolled in several Masters, and they just went, 'Yeah, no. Too academic.' There was another one where they basically saw me as too advanced at the interview, so not so much academic, but they went, 'Oh, well, you know too much for the position that you've applied for so we wouldn't want to have you get bored.'

An inability to master the social skills required to answer job interview questions was also found to have an impact on Philip's confidence in applying for employment opportunities:

> I've never actually had a proper job interview … but the idea of getting one is quite terrifying to me … I really don't like going into a situation where I'm not sure what they're going to ask and I'm not even sure of what they really want. I mean I have a basic idea they want a good employee but I'm not sure of what they really want me to do and I have no clues about the questions and there's this other problem. I worry quite a lot about sounding arrogant. I spend a lot of time just being quite self-depreciating only because I feel it helps me sound humble cause with Asperger syndrome, I've seen that it's quite easy to accidentally sound arrogant and I don't want to.

In the quotation above, Philip explained how he was reluctant to undertake a job interview because he could not anticipate the questions he would be asked. However, not all participants faced Philip's challenge. For instance, Peggy spent some time and effort formulating answers to potential job interview questions that a prospective employer might want to hear:

> [I]t's all rehearsed really. It's just actors on a stage and so I just learnt the responses to as many questions as I could and I would interview myself beforehand … They would ask me an open question and I would give them a closed answer and every job that I've ever gone for I've actually gotten … I'd put it down to being able to set the scene in my head first, rehearse the script in my head and then execute it correctly.

Isabelle was another participant who did not have any particular difficulty with answering job interview questions:

> Job interviews, whilst they might be complex, most interviewers use a very fixed formula. By the time you've gone to a job website and have gone through twenty or so of their practice

> questions, you know pretty much everything that they are going to ask you because everyone asks the same questions. So as long as I have the answers to the ten most common questions, I can do a job interview brilliantly … The problem comes when someone asks me a question that I don't have a pre-prepared answer … The one that I always fall over on is when they ask, 'Give an example of a time where you have shown leadership.' I have no leadership qualities. So the story I used to use was completely made up.

For some participants, applying for a job only required them to submit a résumé and then engage in a relatively quick and simple face-to-face job interview. However, for other participants, the job application process required them to participate in a group interview where they had to simultaneously compete with other applicants for a limited number of employment opportunities. Alison and Kyle reported that competing with other applicants in a group interview was a stressful event. Alison shared her experience of a group interview:

> Recently I did an assessment centre interview for doing the summer internship with one of the major banks … and that was quite a complicated process … Well, you got quite a lengthy application and then you got to do like a set of psychometric tests over the Internet and if you did well in that, then you got invited to not just an interview but an interview day pretty much … So I got through that and we had an hour-long interview with two people from the bank. There were six of us going through this process. We had to do an abstract reasoning test and we had to do a group task where we're doing this mock board meeting and we had to negotiate and make decisions while there were six psychologists and H.R. [Human Resources] people watching us and taking notes … and I got feedback from that and apparently I did about the best the person had ever seen anyone do on the group activity, which was rated on seven or eight different things … I got well above average on the psychometric testing, completely messed up the interview.

Kyle felt very flustered by his group interview experience:

> One was a group interview. I was told to step up in front of a whole group and the whole time I looked up at the roof. I couldn't talk. I was stepping from side to side. I was moving my hands about and just waving them around and not holding them behind my back and I started to sweat. I started to panic. I started to freak out. I started going quiet on them … and in the end I went back to my seat red, flustered. I was panicking. I was shaking. I was freaking out mainly because I had basically felt exposed to the whole group, being put up the front of the whole

> group and that was pretty much awkward. I've never been in panel interviews and one-on-one interviews and with them, it's the fact that when they're interviewing me it's like something in my head is being picked apart bit by bit as they learn more about you as they ask you questions and that process also makes me feel uncomfortable and I can't give them direct eye contact. I'm often looking down or [up at] the roof. I'm fiddling with my hands. I'm trying to keep my cool, trying to keep my temper and it just gets to the point where I want nothing more than to be out of there.

Being unable to maintain eye contact with a prospective employer, knowing where to place one's hands during a job interview, and knowing how to convince a prospective employer that participants' employment experience was genuine were other job interview challenges that participants reported. Jake stated the following in relation to eye contact:

> It is impossible to maintain the correct level of eye contact: you are either making too much or too little … and you start and stop it at the wrong times because I hadn't a clue and yes, I know making eye contact is important. So I will stare fixedly at people and then I will realise that I am not supposed to be doing it.

Kyle expressed a similar view:

> Often I'm looking at the table, looking at the side, looking at the roof or looking at inanimate objects around me, trying to keep myself mentally distracted from their gaze. It's just trying to avoid having to look at the other person and I just look at something else in the room. It could be one of the most random and most weirdest objects in the room or it could be something as simple as a bit of paper sitting in the middle of the table.

In regard to knowing where to place one's hands during a job interview Sebastian stated as follows:

> I mean, everyone gets nervous and uncomfortable … So I would read up on what's expected at a job interview and dress accordingly. And they say, 'Don't fidget and don't cross your legs,' and I would stick to those things and try to relax and answer the questions and provide feedback and I was uncomfortable and it was hard. It wasn't easy for me.

The final challenge with job interviews, revealed by Jake, was the inability to master the social skills required to convince a prospective employer that an employment experience was truthful:

> Well, I did a course in behavioural interviewing techniques during last year … and I was interested to learn that when you're scoring someone on their behaviour at interviews, if their hand movements are unusual, you score them down, if their eye movements are unusual, you score them down. This is the techniques that my organisation teaches its interviewers and instructs them to practise and I think it is blatantly discriminatory against people with Asperger's because hand movements and eye movements are amongst the most noticeable signs … I do interviews for jobs I think I would be bloody good at and never hear from people again, so I assume that I've done something in the interview that turned them off … In this behavioural interviewing style where they say, 'Tell us about a situation where you dot, dot, dot, dot, dot,' and you have to tell it in the right way that they can see that you are reliving a natural experience and when you're autistic, it's bloody hard to get that impression across.

Despite the social challenges expressed above, Jake and Alison stated that they might be able to bypass a job interview and obtain employment if they were first given a work trial to demonstrate their capacity to do the job. Jake had this to say:

> I would prefer to be able to qualify for jobs by taking the work on and doing some of it than by trying to explain to people who don't understand what the job is.

Alison expressed a similar view:

> I know I don't come across as well in an interview as I would do if you kind of did like a work trial thing where you got to show how to actually do the job instead of how you can talk up the fact that you could do the job.

In this section, ten out of twenty-one participants interviewed for this study explained their experiences with job interviews. The experiences outlined included having problems answering interview questions and engaging in a group-based job interview. In the next section, five participants explain the emotional reactions that their workplace colleagues exhibited towards their diagnosis of Asperger syndrome.

5.3.2 Disclosing Asperger syndrome to workplace colleagues

Not many studies have been published concerning adults telling their workplace colleagues that they live with Asperger syndrome. To address this gap in the literature, each participant was asked, 'Do your work colleagues know that you have Asperger syndrome?' Five participants answered this question and sixteen participants did not answer this question. Adam and Imogen recalled that their workplace colleagues had a positive reaction to their diagnosis of Asperger syndrome. Two participants, Kyle and Sam, did not tell their workplace colleagues that they lived with Asperger syndrome, and one participant, as seen below in Sebastian's account, did not have a positive reaction:

> I was involved with a Community Sector Organisation and decided to do the City to Bay Fun Run and raise a bit of money and I actually wrote to Australia Post and asked for them to sponsor me and I wrote to our union and I asked them to sponsor me and they had a fair bit of money and so I kind of came out and then I went and visited the guys at Australia Post that I used to work with, and I remember one of the guys said, 'Oh, I am really sorry about your Asperger's,' and I said, 'Well, nothing's changed. It just explains who I am and why I have behaved how I have all my life,' and I thought the apology [from the Australia Post colleague] was weird … His pity was weird, feeling sorry for me.

Sebastian reported a negative experience with a former workplace colleague after he had revealed his diagnosis of Asperger syndrome. However, Adam and Imogen had different experiences. Adam's workplace colleagues were very positive towards him after he told them that he lived with Asperger syndrome:

> My work colleagues do now [know that I have Asperger syndrome]. They didn't at the start. I mean, there's been some new colleagues that we've got cause of staff changes and I've been fairly confident at this stage in my life now to say to them, 'Look, you know, I'm going to be slow at putting the books away in the library or I'm going to be slow at trouble-shooting a problem because I have Asperger's and it takes me longer to go through that process.' We have a new principal and so one of the things I've done is I have gone back to them and said, 'Look, I know it doesn't affect my job. It doesn't affect me apart from a tiny little niggling thing like checking the door four times before I leave and that can be seen by anyone just as a security consciousness person but I do have Asperger's and it is going to take me a little bit longer to complete some tasks,' and I mean, it's been received fairly good. I guess the biggest thing I've always had is that fear of 'Okay, so you've told us that you have a disability, now we can no longer have you.'

Adam was afraid that after telling his workplace colleagues about his Asperger syndrome his employment as a technology support officer at school would be terminated. However, after Adam disclosed his Asperger syndrome, it did not result in any negative workplace repercussions or termination of his employment. Imogen also did not encounter any negative repercussions after revealing her diagnosis of Asperger syndrome to her workplace colleagues:

> At our store it's actually probably helped but that's actually because we have a very Asperger/autism friendly store. All of the staff members either have a son with Asperger's or little brothers with either autism or Asperger's or they have it themselves. So I kind of just fit in there … If I'd been in another store I don't know but in our store it basically just means that everyone understands where I'm at and it's kind of helped them warm to me a little bit. I think because they see a little bit of something that they see in their family members, whereas in other places it might have been the opposite. They might have gone, 'Oh, she's not really with it,' but there are several of us with Asperger's: all girls.

In contrast, Kyle decided not to tell his workplace colleagues that he lived with Asperger syndrome because he feared how they might react:

> The best example of this would be my employers. I don't tell my employers because I don't want to be judged for having such a disability.

Sam also chose not to tell his workplace colleagues that he had Asperger syndrome because he did not want to be judged:

> I guess it's just the old chestnut of stigma … and judgement and also lack of knowledge on their part, you know? I mean if you tell someone that there's actually something wrong with your brain and they didn't know anything about it and they have never been exposed to disability, then they may just have a stereotypical opinion of you.

In this section, five out of twenty-one participants who were interviewed for this study reported the emotional reactions that their workplace colleagues expressed towards their diagnosis of Asperger syndrome. Adam and Imogen experienced no negative repercussions after they told their workplace colleagues about their Asperger syndrome. Sebastian did encounter a patronising comment from a former workplace colleague. Finally, Kyle and Sam did not tell their workplace colleagues that they lived with Asperger syndrome. In the next section, the participants describe the social challenges they have experienced in employment.

5.3.3 Social challenges in employment

Few studies exist in which adults with Asperger syndrome describe their social experiences in the workplace. To help add to this body of knowledge, each participant was asked to respond to the following: ‘Often in the workplace it is important to communicate with other employees and your employer. Have you ever experienced any communication difficulties in the workplace?’ Eight participants answered this question and thirteen participants did not answer this question. The participants described having difficulties with understanding the political dynamics of the workplace, conducting team meetings, or attending workplace social functions, such as Christmas parties. Below, Philip explains how his social limitations, which are associated with his Asperger syndrome, made him feel more comfortable around animals instead of people whilst doing work experience at a wildlife centre:

> When I was at a wildlife centre, I spent a bit of time actually working with the animals just feeding and keeping the enclosure clean, which was a bit difficult. I like being around animals. I actually feel in many situations more comfortable with animals than with people … I know what an animal is thinking. Like you show a dog food and you know it’s thinking about that. You know its thinking, ‘He’s got food. I want that. Maybe I can get him to give it to me. Maybe if I do what he tells me to do, I’ll sit, I’ll beg, I’ll run around in a circle because I want the food.’ It’s very simplistic, very easy to understand and that’s not something that people do. People always have ulterior motives. I know that I am a person but I can’t tell what other people are thinking.

Linda also explained her social challenges in the workforce:

> [W]hile it may be true that people will always have difficulties with some of the core so-called ‘deficiencies of Asperger’s or Autism Spectrum Disorders’, you can actually do a lot of work on yourself with regard to many, many things. You can change if you are prepared to be honest with yourself. So in my case, it was a matter of suddenly realising that it wasn’t everyone else at work that was an absolute idiot and hard to get on with. There was a common thing and it was me and it was a matter of asking for help at that time and getting coaching and I found that there

> were many people who were very, very willing to be helpful and show you different ways of doing things.

Despite seeking help for her social difficulties, Linda still has trouble communicating with other employees:

> [O]ne thing that I still have a huge amount of trouble with, and it doesn't matter how hard I work on it, is interrupting other people because if I've got something I want to ask, I want to know the answer now and I will go up to that person. I'm so focused on what I want to say that I don't notice that they're on the phone, they're in the middle of a conversation, they're reading something or they're thinking about something. I will blurt out my question. I'm a lot better than I used to be but I am still nowhere near normal. That's probably my biggest thing that I'm working on at the moment.

Imogen also experienced social difficulties being a pizza delivery worker:

> There was a lot of time alone in the car having Asperger's … I still had some contact with people and I only tended to be friendly for short bursts. Not that I'm unfriendly at other times but I only had to act all sociable when I was going in and picking up the next delivery or organising it and stuff like that. I think they picked up that there was something different about me at the place where I was doing it, but they actually quite liked that. It did affect it when they tried to take me off deliveries and tried to put me onto waitress work in the actual restaurant attached because they thought, 'Oh, she's a girl. It might be nicer for her,' but I told them that I was quite clumsy as a lot of people with Asperger's are and they didn't really believe me until I dropped four plates of dinner onto the ground and then they let me go back to the pizza delivery cause I dropped a whole table's worth of dinners on the ground in front of the whole restaurant. But yeah, it was actually quite good because I had so much time to myself, I could drive where I wanted to go. I just had to get the pizza there and get back because I was really good at working out the shortest way on the road maps and stuff. I got a lot more deliveries done than other drivers, which saved them money, which meant I got more tips. So it was really good.

In another situation, Peggy stated that she thought that her limited social abilities hindered her chances of getting a promotion:

> I've always wanted to do something in management. I've always wanted to manage people, directing people. I can do that. For some strange reason, people tend to follow my direction,

> whether it is like if you are in a lift and it breaks down, I'll be the one that people will look at and say, 'What do we do?' And I have no problems saying, 'This is what you are going to do.' … But finding somewhere to do that is hard because it requires lots of social sucking up … Oh, you know, the management goes out and has drinkies and that sort of stuff: talking over a coffee at a meeting on a personal level about things. I can't read it, I just can't read them, and if I was just maybe a general in an army just dishing out orders, I'd be okay, but not even the army's like that anymore.

Peggy then described the social challenges she experienced in work:

> I could handle lot of things. I could handle seizures and clients throwing up on me; people waking up in the morning with poo being everywhere and you being the one to clean it up. I can handle that: I have got a strong stomach. What I couldn't handle was the emotional stuff, the social stuff with the other carers. They'd leave little notes to each other or they'd buy Nutrimetics off each other or, you know, they'd expect some sort of emotional response from you.

The inability to use appropriate social skills in a crowd was another workplace social challenge and was discussed by Charlotte, Linda and Peggy. Linda's social challenges resulted in her having difficulties conducting a university tutorial:

> Part of the tutorial, they [students] have to field and answer questions in their lab book … and at the end I am supposed to go through the answers with them so they understand what the answers are. And what happened was that I would ask people, like I would try and make sure every person in my tutorial was asked one question … So I would say, 'And so the lady on the desk at the back with the pink top on,' and then I would ask the question and then I would go, 'Oh, the lady next to her: the Asian lady,' and apparently that was very offensive because I described the person by their race and much to my surprise, my work supervisor went to my aid and said that they were sure that there was nothing offensive meant by it, but I did have a few people misunderstand and drop out. So I was just told that you just don't do it that way and, in fact, you don't single out students. You can say, 'Somebody at the table in the corner,' but you are not supposed to actually make the kids work for their answers or you just ask and if nobody answers, then you answer.

Charlotte also had social challenges in the workplace:

> The other thing was team meetings … I would just sit there and I wouldn't say a thing. I hated them. I absolutely hated them. I did what I would do at school: I just did not contribute to discussions and as soon as they were over, I was out of there. I just can't deal with people.

Charlotte's social challenges in team meetings, however, did not have an impact on her public speaking ability:

> For some reason I can do public speaking but if I have to contribute in a team environment I can't … I don't do public speaking anymore, but when I was doing that, the biggest audience I spoke to was over one hundred people and I didn't find that all that difficult because there was no interaction and you don't require anything from the audience and they listen, but if it was sort of public speaking that's interactive where they can ask questions and you have to answer their questions, I couldn't do that.

Peggy also explained the social challenges she had within a group of people in her workplace:

> I found it very difficult dealing with people. I could either deal with them en masse—like speaking to a group of people, I had no issues with—but social chit chat, I'd rather stick a fork in my eye, you know? It's just that I don't have the social niceties and they just thought I was being a little bit rude … and like one-on-one I'd be okay if the people were genuine, but if it was, 'Let's talk about the weather,' I was at a loss. I would just either go have my mandatory free wine and cheese and then I would quickly walk around the gallery and get the Hell out of there as fast as I could before anybody could start to talk to me about current events or something that I just don't care about.

The inability to engage in informal socialising at workplace functions was another social challenge that participants described. Below, Adam explains his social challenges at Christmas parties:

> The one thing that I don't do and I keep getting reminded that I should do is go to the staff room, go to Christmas functions, all because of the communication. Like, you know, I just feel uncomfortable and if I went to a Christmas function or into a staff room, I would have to make conversation and for someone with Asperger's the hardest thing is to start or have the conversation starters and that's one of the reasons why I avoid the staffroom. In recent times, I have made a real effort to go down to the staffroom on a Friday after assemblies and that's

> mostly been because I have been looking for feedback of how the assembly has gone because I have to support the functions of the audio-visual and computing aspects of the assembly.

Unlike Adam, Peggy developed a strategy to help her socially manage Christmas parties and other work functions.

> Wine … That's how I'd deal with it. I'd have a glass of wine or a glass of champagne and that would be an excuse for any jokes that were inappropriate or, you know, mouthing off at the wrong time or being just you know a bit of an ass: 'Oh, she's had a couple and considering what she does for a living, you know, we'll allow that'. So people were quite understanding and even saw me as a bit of a character, you know, a bit of a character and that's how I dealt with it.

The final social challenge that the participants reported experiencing in the workplace was instances of workplace bullying. Isabelle explained how her limited social abilities and disagreement with another administrative officer at a school resulted in her becoming a target of workplace bullying:

> Looking back now, I think someone actually tried to get me into a bit of trouble with the database. I had a disagreement with the receptionist at one point and she did a bit of data entry as well and at one point, we had a whole heap of errors that were quite critical ones … They made some parents very, very upset … they were personal detail errors. One of them meant that mail was being sent out with the father's name and the ex-wife's name … one was being sent to the person's previous name and they changed their name due to racial discrimination … I could attribute these errors back to the receptionist. I had access to data she didn't and I could see that she made the changes, but she said that she had no memory making them and I just initially thought they must of been mistakes but looking back on it I think she did it deliberately to try and get me into trouble.

In contrast to Isabelle, who was a victim of workplace bullying, Travis's account below shows that some adults with Asperger syndrome can be bullies in the workplace:

> She's useless as anything but she drew a self-portrait of herself … on a piece of paper with a biro and it was actually very good and then she stuck it on the cabinet and then she wrote on it, 'This is how beautiful I am and Mum says I'm a really beautiful girl and I am so beautiful and all of the boys love me.' And I'm like, 'Oh, I am going to be sick,' and then everyday she put another comment on it: 'I am so beautiful. I am the best-looking girl in the whole world,' and

> after three weeks, I couldn't take any more of the comments. And then one night I was leaving and I thought, 'I am going to fix her. I am going to fix her in less than five seconds,' Black pen and draw a Hitler moustache on her and then I put a swastika on her forehead … and I laughed about it all the way home and when she came in the [following] morning the first thing she noticed was the Hitler moustache and the swastika and she went absolutely berserk and ripped it off.

This study addressed the limited amount of research on workplace social experiences of adults with Asperger syndrome by asking the participants to explain their workplace social experiences. Eight out of twenty-one participants interviewed provided explanations. Participants discussed having challenges with understanding the political dynamics of the workplace; conducting team meetings; or going to workplace social functions such as Christmas parties. In the next section, eighteen participants present their experiences of and views on dating, intimate relationships and parenting.

5.4 Experiences of and views on dating, intimate relationships and parenting

5.4.1 Experiences of and views on dating and intimate relationships

There are only a small number of studies on adults with Asperger syndrome describing their experiences of, and views on, dating and intimate relationships. This study contributed to the existing research. Each participant was asked, 'Do you have a partner?' and 'Would you like a partner and/or what are your hopes/plans for future relationships?' Eighteen out of twenty-one participants interviewed shared their experiences of and views on dating and intimate relationships. Two participants, Tim and Sam, described these experiences and views in brief detail. For example, Sam stated, '[O]bviously I do want to meet someone and I would like to get married and I would like to have kids,' and Tim stated, 'One day I'd like to have a partner because I get lonely … I'd like to have a girlfriend.' The other participants explained their views and experiences in greater detail. Imogen related how her desire to have an intimate relationship motivated her to register with an Internet dating website:

> When I was in the fifth year of my university degree I went *'Oh this is too hard' trying to find Mr. Right.* I'll go to one of those agencies where they find the right type of guy for you and you

> pay them several thousand dollars and you have a profile and they go through matching the things that you look for in a person and what they look for. They come up with all of these lame, lame matches for me. I have sent them an email three years ago now saying, ‘Look, I don’t actually want to be sent a potential match unless he’s genuinely a potential match. That means you can’t send me a guy that’s got a definite ‘no’ on my list because that’s just going to get my hopes up when I open your email.’ I haven’t received any matches since. I don’t think it’s because I’m a perfectionist because I’m actually not looking for Mr Perfect.

Imogen then explained in greater detail the fifty-point checklist that she used to find a potential partner:

> When I was little, I used to have a fifty-point criteria for a boyfriend/husband written out that I used to carry around with me and any guy that got close to a high score—and most of them had Asperger’s when I look back—I was just, ‘Na, you don’t meet point number forty-eight. See ya.’ So that was probably not the best thing to do but I still got it [the fifty-point checklist] and it’s quite amusing when I read it. I go, ‘They’re all quite practical things,’ and I was onto a good thing there. Maybe it was a bit unrealistic, but it was a pretty good criteria for a twelve- or thirteen-year-old.

Imogen then described an experience where her social difficulties had an impact on her ability to form a relationship:

> There was a really gorgeous guy behind me at the checkout yesterday and I was wearing my friend’s dress because I was staying at her house and the only clothes I had with me were my pajamas. I was like, ‘Oh, you want me to go to the shop to get tuna? I am not wearing Elmo pajamas, no.’ I put on her dress and I don’t do dresses and I’m at the checkout and this guy starts talking to me. He’s drop-dead gorgeous, six pack, and he’s like, ‘So you like tuna, then?’ … and I was like, ‘No, my friend’s mum does.’ ‘Yes, I really like your dress,’ and I’m like, ‘It’s not mine,’ and the checkout chick is looking at me like, ‘How could you put him off more?’ … The guy was making a real effort and I could see that and I cut him off at every chance. I was like, going, ‘What’s wrong with me He’s cute.’ And I’m like, ‘Na, cut him off, cut him off. There will be something that’s not okay.’

Unlike Imogen, Sheryl was not as ready to find a partner:

> I probably should be more proactive about it [finding a partner]. I am really, really interested in finding someone but at the moment I'd rather focus on trying to be every kind of person I need to be: a sister, a daughter, a friend, a best friend. All of those kinds of things. I don't really want to add a partner to it because a partner requires looking after that other person to some degree as well and I am not really in a place where I can sit there and babysit another person … However, if that happened in the next six months and if I found someone that I liked and it worked, then yeah, we'll see where it goes.

Kylie has never been in an intimate relationship. However, despite her lack of experience, she did not think forming an intimate relationship was important:

> I'm constantly being questioned, you know, why I don't have a partner and there have been a couple of people interested—funnily enough, also autistic—but my sister's questioned it, other people have asked me on campus. I mean, it's just one of those social norms I suppose … In Year Twelve, especially, people could never understand why I didn't want [a partner]. I don't see the point. People generally get partners and then they ignore their friends for so long and then if they and their partner break up, then they come back to their friends but who would want to spend all of their time with one person anyway? … I mean, I have met plenty of other people, especially girls, that have Asperger syndrome that are my age who didn't want a partner anyway. I suppose it's a bit of a relief knowing that I fit in somewhere.

Charlotte also did not consider the goal of finding a partner enticing:

> I was trying to be normal, you know, have a partner. It's not really normal for a woman to live on her own all of her life: that's not normal, you know? You have to pretend to be that way and I did that for a long time … So I don't have to pretend to be normal anymore and I like being on my own and that's how the rest of my life will be.

Unlike Charlotte, who was previously married, Linda was never married. However, in her previous relationship she wanted to get married:

> I had another relationship much later on and I was heading for forty and I wanted to have a family and I wanted a bit of commitment and he wasn't ready to commit … I think I was too busy trying to push him into that and I think I got some wrong messages from my family and I think he wanted me to move in with him: he had asked me on a few occasions. He was the child of a divorcee. His parents had divorced and he felt that he wouldn't want to get into a permanent

> relationship unless he had lived with the person first and because I've lived with someone earlier, I didn't want to be one of those people that lived with a few different men. I would of got what my mother would of called 'used merchandise'. So I think it would have had a much stronger chance of working if I had moved in with him and just taken my time, which is what his wife did, but in the end I broke it off because I was going to do lab work for my Master's … and I kind of gave him an ultimatum and, this was pre-diagnosis, he said that he could never marry me because it was something to do with more my attitudes, black and white thinking at the time.

After some personal development and self-reflection, Linda reached a stage in her life where she wanted to find a partner and get married:

> I'm ready to get married now but that's because it's taken me this long to get all of the things in place that I wanted and to be the kind of person and live in the kind of area that I wanted and have the kind of job I want to do. Now that I've got my external picture congruent with my own personal values and I like myself a lot more, now I would like to find a partner … I think that I probably would have reached this sort of stage in my twenties if I didn't have Asperger's.

Despite Linda's personal development and a desire to get married, she still finds it difficult to flirt with the opposite sex:

> Has Asperger's syndrome affected my ability to form intimate relationships? I would say, 'Yes,' cause I don't have a clue how to flirt … I had a friend interstate who was trying to teach me how to flirt and it just bored me. She'd practised stuff like licking her lower lip and putting her foot up and she used to practise in front of the mirror and practise on her friends and flicking her head and trying to be sexy and stuff and it just looked so fake.

Sebastian was another participant who has never been married. However, he did have short-term intimate relationships:

> The only long-term relationship I have ever had was in 2009 and it lasted about a year and that was a bit strange in itself but that was after I was diagnosed and it was with a girl that had Asperger. Prior to that [relationship] the only relationships I only ever really had was with one-night stands or sometime they might last a few weeks in my twenties. Around my twenties, I'd go out and get really pissed and meet someone and last a couple of weeks but I wouldn't follow

> through and I never felt comfortable with it. The girls probably saw how quiet and shy I was and not very communicative and so the relationships never lasted a year.

Dave, who has 'always been single', was very selective about the partner he wanted:

> I would be very picky with who the person is [Dave's potential partner], which could result in me never finding a partner but it's best to be safe than sorry … Loyalty is one of the most important things I would like. Looks in a person as well, cause that's the only way you can find yourself sexually attracted to that person. I'm a visual person and I like if a person looks quite exotic.

Dave then explained more:

> Yes, definitely. I would like to settle down and have a family and earn a decent income and the Asperger's syndrome will slow me down … but I suppose I can't base myself on wanting too much and never achieving what I wish, but you just have to find the right one. You don't want to find one that's not right. You don't want to find someone that's just going to use you … like the respect you give that person and then they don't give you the respect back at all. Like, for example, having an affair behind your back and things like that.

One of the reasons why Dave was so careful in the selection of his future partner was because of his brother's past experiences with intimate relationships:

> I think relationships are seriously very overrated myself. I have always seen it that way. My brother's different: he had a girlfriend for two and a half years and she was never worth trusting and my dad didn't like her.

Due to Dave's selectivity, and his brother's past experiences with intimate relationships, he has studied relationship etiquette:

> I suppose around eighteen or nineteen, I started studying off the Internet, interacting with women and watching movies like *The 40-Year-Old Virgin* … I've taught myself how not to act with girls.

Philip was another participant who wanted to find a partner and get married. As with Dave and Imogen, he stressed the importance of selecting a partner who has high standards:

> I've never actually been able to ask a girl out and I must say I have never actually been that attracted to anyone that I have ever known … I've got this sort of thing: I don't really want to

> go out with someone unless I've known them beforehand, unless I've been their friend; otherwise, it feels like I am just letting people into something that I don't know anything about … I've been asked about this before by my friends. I would probably say onwards up to six months at the minimum, probably a year.

John also wanted 'to have a partner one day' so that he was 'not so lonely'. Like Philip, he stressed the need to allow for plenty of time to get acquainted with a potential partner:

> I'm very cautious and even with relationships, I don't want to rush it … That's the kind of person that I'm looking for, someone who wants to take their time … Not those stupid short-term relationships like three months, a year most probably … cause by then if you have been going out with someone for a year, then you know them for a pretty good while.

John also stated that he wanted to 'settle down' before living with a partner:

> Well, I would actually prefer to settle down, have a good job, and go on a few holidays before I even think about having a partner.

Unlike John and Philip, who were single at the time of the interview session, Kyle had a girlfriend. She did not believe that he had Asperger syndrome:

> Yeah, she knows … She doesn't believe that I've got it [Asperger syndrome] … Basically, one of her relatives has Asperger's and I'm nothing like her relative so she sees it as a comparison and not on a spectrum … So I've left her with a rather plausible argument, saying that 'I don't act anything like your brother and we're all different and it's also on such a broad spectrum you can never really narrow it down to comparing me to someone who's completely and utterly overwhelmed with Asperger's to the point where they can't even spell their own name.' … I mean, you can look at some of my social difficulties, you can look at some of the things that I excel in and some of the things that I don't excel in, you can look at it and then you can compare me to a normal person and you can hardly tell the difference, but if you study me and you get to know me long enough you will see that I'm a little bit different.

Unlike Kyle's girlfriend, who did not believe that he had Asperger syndrome, Alison's boyfriend did believe that she had Asperger syndrome:

> He [Alison's boyfriend] was actually kind of excited because his best friend who lived interstate, who he's been friends with since he was in reception, pretty much has Asperger's.

Below, Jake and Shelby explain how their sensory sensitivity to human touch prevented them from being physically intimate with their partners. Shelby stated the following:

> With dating, which was many moons ago, you do things that are expected because you want to be liked and you want to appear normal. You hold hands and you kiss and all of that. I hate kissing every time. I kiss my children. I'll ask them for a kiss because I want them to have a normal life. So sometimes I'll say, 'Hey, come and give me a kiss today,' but as they are approaching my mouth I'll think, 'You got to do it, you got to do it, you got to do it.' Yeah, I really hate it. I don't like kissing my husband and … my mum told me that as a little baby she always felt frustrated because as soon as I'd feed I just wanted to go and I'll be off and she never had cuddle time with me … When my kids jump, I'll hate it. Like I'll say, 'Come and give me a cuddle.' That's fine and they'll come and lay down and give me a cuddle, but I hate it when people come and climb on me or if my husband comes and puts his arm. Na, I hate it. The end.

Shelby then provided another insight about her difficulties with physical intimacy:

> [I]n the initial bit of dating you put up with things because you … want someone to like you but once you get together, then you show your true colours and then it's like, 'Don't touch me.' … I think it is hard for him [Selby's husband] because he does want someone who cuddles, kisses and touches and who is more intimate and this is just not me.

Jake was another participant who revealed how his sensory sensitivities to human touch prevented him from being physically intimate with his partner:

> We don't have much physical contact in my current relationship … and yeah, I don't miss it … It's one of the areas where our mutual understandings diverge.

Another limitation that inhibited the participants from forming an intimate relationship was the inability to read a partner's body language or anticipate a partner's sense of humour. Adam described how he cannot read his partner's body language and therefore needs constant reassurance and clarification from her:

> The characteristics that I'd like to point out is around the social thing. It often is to do with the fact that because I can't interpret people's body language and facial expressions, I've often got to get reassurance. I've often got to ask, you know, 'Why don't you hold my hand? Why don't you give me a hug? Don't you love me? Do you want to separate?' and it's because I can't read

> those body languages. She may well be expressing how much she loves me, how much I mean to her, but I can’t pick up on that and I often have to ask for clarification. I often have to say, you know, ‘Tell me how much I mean to you. Tell me that you love me. Come here and give me a hug.’

Adam’s experience, of not being able to read his partner’s body language, was also expressed by Peggy:

> It’s been a very rocky road … Well before the Asperger was diagnosed and it wasn’t in our vernacular, it was kind of like I couldn’t read what was going on with him [her husband] … I couldn’t tell when he was cross unless he was yelling.

Unlike Peggy and Adam, who mentioned their social challenges with reading their partner’s body language, Isabelle describes how she could not understand her former partner’s sense of humour.

> I was previously married and it was my husband’s belief that if he made enough jokes at my expense I would eventually learn to laugh at myself … but [that] did not work and eventually I got so sick of that and quite a number of other aspects of the relationship that I walked out … Some of them related to my abilities and my lack of social skill but sometimes they got outright creepy. Like he would be joking about all of the ways he could kill me and hide my body and he used to think that this was perfectly humorous. I was quite disturbed … but to him this was humour. But I’d have a go at him for something that he was saying and he would go, ‘No, no, I’m joking.’ ‘But I can’t tell when you are joking.’

In this section, eighteen out of twenty-one participants interviewed expressed their experiences of and views on dating and intimate relationships. These views and experiences were diverse. For example, Imogen’s desire to find a partner motivated her to register with an Internet-based dating agency. In contrast, Dave and Philip were in no hurry to find a partner. In the next section, the participants explain their decisions and views about parenting.

5.4.2 Decisions and views about parenting

Few studies have been published on adults with Asperger syndrome describing their decisions and views about parenting. To help address this gap in the literature, each participant was asked, ‘Do you have any children?’ If the participant answered ‘yes’ to this question, then they were asked if their offspring had a diagnosis of Asperger syndrome and if their Asperger syndrome has had an impact on their parenting. If the participant answered ‘no’ to this question, then they were asked if they wanted children and the reasons behind their decision. Eleven out of twenty-one participants explained their decisions and views about parenting. Kyle, Sheryl, Dave, Sam, Philip, and Sebastian explained their reasons for wanting children. Charlotte, Linda, Isabelle, John, and Kylie explained their reasons for not wanting children. This section will begin with the six participants who wanted children.

Kyle wanted children so that he could treat them better than he was treated:

> I’ve kind of always just wanted to be a father I suppose … more or less. I’ve kind of wanted to be the father that I never had. I mean, my dad was a penniless, abusive drunk all the time. He stayed at home and watched the footy. He was never really employed. Spent whatever my mum gave him on petrol, booze and cigarettes. He’d sit at home all day and watch the footy. I had my Nintendo in the lounge-room and when I came home from school, he had basically spent all day playing it, trying to beat my records just cause he got bored and he wouldn’t actually go out and help with groceries … He hardly went out shopping for my mum. He cooked at home every now and then. My mum still did a fair bit of the cooking. The only other thing I think my dad really did was after being nagged time and time and time again by my mum, he did actually get up and do some maintenance to the house like cleaning the gutters … fixing a big crack down the wall, fixing something up in the roof or fixing something electrical. Very rarely would he do that. Most times he spent at home drinking, smoking and not doing much at all and that’s obviously one of the reasons why mum divorced him.

Kyle then provided additional insights on why he wanted children:

> You know, it’s really hard to explain … I think the main two is the fact that I enjoy seeing the happiness that comes from the kids. Like, it’s just, you know, watching them laugh, watching them smile, watching them play around and all the rest of it and then there’s always the fact that my dad basically treated me like shit … treated me like absolute shit. He gave me, you know, lifts to school and he’d pick me up from home, but at the age of eight, I basically started taking my bike and running away from home. Well not so much running away. I was gone for four or five hours to blow off steam and I caught up with some school friends and I started hanging out with them for the day and all the rest of it and when I got home, I was grounded for two weeks.

Another reason for wanting children, which Sheryl, Dave, Sam, and Philip articulated, was a desire to give their parents the opportunity to be grandparents. Sheryl had this to say:

> I am not good with kids but I think that is more with not really understanding them … I don't really spend a lot of time with little kids … I don't know how to talk to them because I have never really been exposed to them. I mean, most of the people I interact with are adults, but at the same time, I do want to have kids and I don't want to adopt and I want them to be mine … I think part of it is sort of passing on family things, passing on my values, having someone be exposed to things that I have experienced and sort of seeing how they go … I kind of want to see how Mum and Dad would do as grandparents and I know my grandparents would probably be ecstatic if I had kids because they are very, very old school Catholics.

Despite her view, Sheryl expressed apprehension about raising children:

> I don't really understand children. I do in some aspects than in other aspects … If you are talking to a kid or if you are responsible for a kid, the idea of screwing that up is … fighting and I mean, especially if it's not my kid. So there have been times where I have been made responsible for one to two [children] and it was for five minutes and I am sitting there and I am going, 'I don't really want to do something that will screw this kid up,' because even people's best intentions can cause problems. I mean Mum and Dad have always had the best intentions but in a lot of ways, they have screwed up and I mean they are people and people make mistakes and I'm probably going to screw my kids up.

Dave, Sam, and Philip also wanted children so their parents could become grandparents. Dave said the following:

> Well, I think my parents would love to be grandparents and my family have passed that generation onto the next generation and I would like to pass my generation on as well … but kids are very expensive and I feel I'd like to have a daughter and a son and that's it, but you know, like when I'm absolutely ready financially.

Sam also wanted to have a child:

> You know wanting to, you know, have someone to carry on so you can have grandchildren and all that and have the experience of raising a child.

Philip was another participant who valued the idea of children carrying on his legacy:

> Raising a child sounds nice, obviously quite a bit later on in my life, and I'm not quite sure I'm quite ready for that yet. On top of that, I would like to continue my lineage. Genetics has always been quite interesting and I've been quite interested in making sure that my family line continues. I've looked back over who my ancestors are. I'm their descendant and I kind of want to continue the family line. So there's the social aspect of 'I want a family' and then there's the colder aspect of 'I want my lineage to continue'.

Philip then explained that due to the possibility of overpopulation, he only wanted to raise two children:

> I don't want any more than that [two children] because the world is overpopulated as it is and having two children does not add to that: it simply keeps it the same.

The final participant who wanted to have children was Sebastian. When asked the question, 'Do you want to have children?', Sebastian initially did not want to:

> I don't think I could cope with the responsibility basically … the financial side of it concerns me and kids are really expensive to bring up and that but I'm forty-seven now and I am starting to feel old and I have the odd pain and kids need a lot of energy and I don't have that and like I get stressed out and I'm not sure. I think I might have been able to be a Godfather but no, it's too hard basically … it's just a huge responsibility and lots of yeah, they are children and they keep you up at night and you worry about looking after them and their health and so many things can go wrong and it's just I have enough stress in my life.

However, Sebastian subsequently changed his view and expressed a desire to have children:

> I realise that not all Aspies have been through what I have been through but I wouldn't want to put any children of mine through the same experience. The world is geared towards people without Asperger's, people with good social skills, and life is hard; it's been hard for me. So I wouldn't want to put my kids through it. So no, I wouldn't want to have kids if I knew definitely that I was going to pass it [Asperger syndrome] onto them … Having said that and sorry for interrupting, but having said that, I regret, if that's the right word, being diagnosed so late and I think now in 2011 things are getting better. We are still not there yet but if kids are diagnosed at three or four years old and the right services and support systems are in place I think they wouldn't have the same problems that I did. I haven't considered this issue but I

> guess I would have to consider it now because perhaps I would have kids now because it's different if they were diagnosed early.

Kyle, Sheryl, Dave, Sam, Philip, and Sebastian explained their reasons for wanting children. Kyle wanted them so he could have the opportunity to be a better father than the father who raised him. Sheryl, Dave, Sam, and Philip wanted them so that they could give their parents the opportunity to be grandparents. Finally, Sebastian was initially reluctant to raise children. However, he changed this view after realising that society's knowledge of Asperger syndrome had increased and that if his offspring had Asperger syndrome, then they would receive adequate support and respect.

Five participants (i.e. Charlotte, Linda, Isabelle, John, and Kylie) explained their reasons for not wanting children. Isabelle decided early in her life that she did not want children:

> I made the decision very early in life that having kids was not really for me … I think parenting is not something that you can go into half-heartedly and I don't think I could fully apply myself to being a parent. I have got too much other stuff that I want to do.

Charlotte also expressed a similar view:

> When I was eleven I knew that I did not want to have children. It just came into my head. I was eleven years old and this idea flittered through my head which said that I did not ever want to have children and I have never had children.

Linda was another participant who did not want children:

> I think they're [children] fun and I think they also make you think about somebody other than yourself … if you are single the whole world is wrapped up in yourself and all of this stuff

Unlike Charlotte and Isabelle, who made the decision early in their lives not to have children, Linda decided at a later stage in her life that she did not want children:

> I don't think I would have been a good parent. I think parenting if you're on the spectrum, if you had a neurotypical child particularly, would be very, very challenging and it's physically very demanding and it's very tiring being a parent and trying to maintain a relationship and these days a job as well.

John was another participant who did not want children:

> I don't really like young kids … they just annoy me and get on my nerves … and I think it would be better not to become a parent.

John, however, then explained further:

> If I had a son that had Asperger's it would be easier to help them and understand what they were going through cause I have it.

The final participant who did not want children was Kylie. She was apprehensive about having them because she did not think she could provide continuous care for them:

> I don't think I'd be the best person to have responsibility for children, um, you know 24/7, because I'd get to a point where I'd just be like 'Aagggh!' and I just want to be alone … you can't really have the child growing up in that sort or environment but I mean, again, that may change in the future. I guess I'm going to get more mature and stuff but I mean, I can't even cook for myself yet.

In this section, Kyle, Sheryl, Dave, Sam, Philip, and Sebastian explained their reasons for wanting children. Charlotte, Linda, Isabelle, John, and Kylie expressed their reasons for not wanting children. In addition, Isabelle and Charlotte made the decision early in their lives not to raise children. In contrast, Linda made this decision at a late stage in her life. In the next section, ten participants describe the impact that their diagnosis of Asperger syndrome has had on their parenting decisions.

5.4.3 The impact of Asperger syndrome on parenting decisions

Very few studies exist on adults explaining the impact that their Asperger syndrome has had on their parenting decisions. To add to this small amount of research, each participant was asked to respond to the following statement and question: 'There is some evidence within the literature which suggests that Asperger syndrome has a hereditary component. Would/or did this influence your decision to have children?' Ten participants expressed their views on this subject and eleven participants did not express any insights about this subject. At the time of this study, two participants, Shelby and Adam, were raising children and the other eight participants were childless. All ten participants did not consider the possibility of passing their Asperger syndrome to their children a deterrent to conceiving children. Philip stated that he did not consider Asperger syndrome to be a disability and because of this belief, he was not deterred from having children:

> I don't see it [Asperger syndrome] as being a problem … Asperger syndrome isn't really a disability. It's more of an abnormality … I don't see anything wrong with it. So there's no real reason why I'd be happier or sadder if my child did or did not have Asperger syndrome.

Similarly, Kylie thought that Asperger syndrome was not a serious disability and as a result, she was not concerned if her child had Asperger syndrome:

> I don't see Asperger syndrome as being entirely negative … I don't think it's a tragedy or whatever like it's portrayed in some media so it wouldn't have an impact I don't think.

Kyle was another participant who did not consider the possibility of passing on his Asperger syndrome to his children to be a deterrent to conceiving children. Below, Kyle explains how his volunteering at a community organisation prepared him for raising children with Asperger syndrome:

> It wouldn't have an influence on it [Kyle's decision to father children] but I would be aware and I would know what to look for … I'm in my fourth year at a community organisation now. I've learnt a lot about other disabilities, whether it be Asperger's, whether it be people that are blind, whether it be people who have physical disabilities like Spina Bifida. I've learnt a lot about them and I know what signs to look for in a disability and I'm also learning how to deal with them and things I can do to improve it.

Kyle was confident that his experience volunteering at a community organisation would prepare him for raising a child with Asperger syndrome. Sam also expressed a similar sentiment:

> It would influence my decision not to get married to someone else who has got Asperger syndrome [laughter] … I think my desire to have kids sort of outweighs that concern, even though I'm very aware that that's a big possibility [passing on the characteristics of Asperger syndrome to offspring] and that's sort of another reason why I'd want to be a father … because if I did have a child on the spectrum, I think I would do a lot better job than my parents.

Kyle joked about not conceiving a child with someone with Asperger syndrome. Sheryl made a similar point:

> I think autism is in my family on both sides. So if I find a partner, and I mean, this is assuming that genetics works in a particular way—who has a history of autism in their family—I probably wouldn’t want to have kids with them because I don’t want my children to go through the things that I have gone through … the experiences that I have gone through as a girl with Asperger’s. I don’t want my daughters to go through the same thing. I would rather that they were neurotypicals.

Sheryl then clarified her position:

> I am a female and I went to an all-girls school … There is a different kind of social atmosphere between girls and it requires intuition that Aspies seem to lack with the social-related stuff and communication and considering I struggled, they [Sheryl’s children] would struggle too and I don’t want them to turn out like I did … It’s probably a terrible thing to say, but I don’t think I could have the level of devotion that other people seem to have if I had a kid who was autistic and had some kind of intellectual disability, and the kid that I mentioned before, who’s my cousin, who has autism, I think he has an intellectual disability as well … so if I had a little boy or girl who was like that or the potential for that, I don’t know if I want that in my life for the rest of my life because that requires a level of responsibility and devotion that I don’t really have at the moment. Mind you, I am in my early twenties.

Dave also discussed the possibility of his children inheriting Asperger syndrome:

> I don’t think it’s so bad. I don’t think it’s hereditary. I don’t think my kids would get it. I think it could pass on to, like, a niece or a nephew from my brothers or a great grandchild.

Dave then elaborated on this point:

> [J]ust because they [Dave’s potential children] could have Asperger’s syndrome off me doesn’t mean that I’m going to avoid having kids. I think early diagnosis is the best help if they did have it [Asperger syndrome] but na, it wouldn’t stop me from having kids … I don’t think it should be a reason to stop you from having kids.

Imogen was another participant who did not allow her diagnosis of Asperger syndrome to deter her from having children. Unlike the other participants who voiced their views on this issue, Imogen believed that she had the knowledge to raise a child on the autism spectrum:

> Now that I know a lot about it [Asperger syndrome] and I know a lot of the management strategies and I know a lot of the benefits, I think that I could help them overcome the obstacles and let them enjoy the pros of it and that they would not necessarily have the same issues now that there's becoming greater awareness. I don't think they'd be up for quite the same amount of Hell that people our age went through in school. I think the fact is that with all of it, I don't see that they would be faced with the same issues, they would have a lot more understanding, and they'd be picked up a lot sooner. I would have the skills that other people didn't have to help me and I don't see Asperger's as all bad. I'd almost prefer that I had a child on the autism spectrum … than a neurotypical kid who just wants to go and play with make-up if she's a girl or go and lift weights at the gym and not think about life if it's a boy.

Below, Alison shared a similar view to that of Imogen:

> If I did have kids who were autistic, then with what I know about it and how it presents in younger children, then they'd actually get diagnosed and have intervention and stuff early. They probably wouldn't go through some of the stuff I did … I have always wanted children. There's not necessarily a particular … reason. I mean it is someone to pour all your knowledge and so forth into.

Unlike the participants above, who were childless at the time of the interview sessions, Adam and Shelby already had children. Below, Adam explains how his child was diagnosed with autism, the reactions from his family to this diagnosis, and his thoughts on fathering a child with autism:

> I've got very borderline Asperger's and we wanted to check and make sure whether there was any form of Autism Spectrum Disorder there at all. Our eight-year-old certainly showed signs back in kindy … we put it down to having a learning difficulty back then because it was too early to interpret what sort of autism it might be, whether it was Asperger or just autism spectrum. When he started school, he had a lot of anxiety separation that continued on and we thought, 'No, this is not right … No, there is definitely something here,' and so we booked him in to be assessed and back in March he was officially assessed at hospital and was found to have

> autism … and that's very sad cause I mean he lives in his own world and he doesn't understand what's going on in the world.

Adam then described his extended family's reactions to his son's diagnosis of autism:

> One thing that we found is that my side of the family has been extremely supportive and Mum's always there to look after one or both … With my partner's side of the family, we find that there is no support. Since he was diagnosed in March, one of my parent's sisters back in February was saying, 'If you want to have a break and catch up on the movies or go out for a meal, I'll come and look after the boys'. Since March, we've found that she's been making excuses for not wanting to look after the boys, and I suspect it is probably that diagnosis of him having autism.

Despite the difficulties Adam and his partner encountered from their extended family, Adam did not regret having a son on the autism spectrum:

> We [Adam and his wife] knew that there's always a chance of one of them [Adam and his partner's children] having Asperger's or autism but it certainly didn't influence the decision. I mean, we both wanted to have children. We both loved children and we were prepared for it.

Shelby was another participant who had children. Unlike Adam, who already had a diagnosis of Asperger syndrome prior to becoming a father, Shelby obtained her diagnosis of Asperger syndrome after she had given birth to three children:

> I kind of look at it and think that with every pregnancy you are worried about Down's syndrome and you are worried about heart conditions, congenital deficits. You still go on to have a child knowing that 'Oh, it could have Down's syndrome or that it could have a congenital heart.' … If I had two children and they were both autistic … then I don't know. Would I have had a third had my first two had autism or something severe? I mean, I know Asperger's: I'm a good person and I can be lovely and there is no reason why I shouldn't be born. I just think that if I had two children with Asperger's, yeah, I would probably have a third one but if I had two children with severe autism, no, I probably would not have risked having another one.

In this study, ten out of twenty-one participants interviewed expressed their views about the impact of their Asperger syndrome on their parenting decisions. Despite the diversity of views, all ten participants did not consider their diagnosis of Asperger syndrome an impediment to having children.

5.5 Conclusion

This chapter presented the participants' education, employment and relationship views and experiences. It began with four participants explaining their verbal and physical bullying experiences in school and the strategies that seven participants used to cope with school bullying. The participants' recollections of the job interview process, their disclosure of Asperger syndrome to workplace colleagues, and their social challenges at work were then presented. It then presented the participants' relationship experiences, in particular their experiences of and views on dating and intimate relationships and their views on the impact that Asperger syndrome has had on parenting decisions.

The next and final chapter of this thesis begins by explaining the eight contributions that this study makes to our understanding of Asperger syndrome. It will then explain eight areas where future research can be conducted. It concludes with a summary of the contents of this thesis.

Chapter Six

Discussion

6.1 Introduction

This chapter outlines the ways in which this study has contributed to our understanding of the lived experiences of adults with Asperger syndrome. Areas of potential future research are highlighted and concludes with a summary of the main aspects of the study.

6.2 This study's contributions to our knowledge on Asperger syndrome

Prior to this study, in the following areas concerning life as an adult living with Asperger syndrome, there was limited published research:

1. daily life and managing the characteristics associated with Asperger syndrome
2. experiences with depression and suicidal ideation
3. how friends and family reacted to their friend's/family member's diagnosis of Asperger syndrome
4. experiences of school bullying
5. job interview experiences
6. perspectives on the Australian public's knowledge of Asperger syndrome
7. experiences of telling their workplace colleagues about their Asperger syndrome
8. views on intimate relationships and parenting.

When commencing the literature search, there were limited published studies exploring the eight areas mentioned above. As such, this study has provided some increased understanding around the gaps in the literature: participants' views and experiences and the potential impact of this information on the development of future services and supports. In order to help further explore the impact of the findings of this study, Erikson's theory is used as a theoretical framework with which to consider how these findings can be applied and further understood. Each subsection will conclude with suggestions about how to help adults with Asperger syndrome to better engage with other people.

6.2.1 The characteristics associated with Asperger syndrome and their impact on daily functioning

The literature review outlined the main characteristics associated with Asperger syndrome, such as sensory sensitivities (Kalyva, 2009; Legge, 2004; Smith & Sharp, 2013) and limited motor movement abilities (Whyatt & Craig, 2012). However, not many studies were found in which these adults describe how these and other characteristics have had an impact on their life.

In this study participants described how the characteristics associated with Asperger syndrome have had an impact on their lives. The main characteristics participants identified as having an impact on their lives were an intense focus on a specific topic of interest; challenges reading body language; sensory sensitivities; challenges with verbal conversations; and challenges with socialisation. Based on the data collected, it appears that an intense focus on a topic of interest was the characteristic that has had the most positive impact on daily life. Two participants, Adam and Isabelle, explained how this characteristic has helped them in life. For example, Adam described how this feature has helped him find a suitable career. In contrast, it appears that the majority of participants suggested that the most detrimental characteristic of Asperger syndrome was sensory sensitivities. Fifteen participants explained their difficulties with this characteristic. Participants reported experiencing difficulties with wearing certain types of clothes (e.g., gloves); problems walking near certain shops; challenges being near household appliances (e.g., clocks); and problems walking through crowds of people. In addition, each participant reported a unique sensory profile. For example, Philip disclosed having sensory sensitivities with texture, sound and light. In contrast, Adam reported experiencing sensory sensitivities to touch and sound but not with taste, smell and touch.

In regards to adults with Asperger syndrome interpreting facial expressions, the results in this study have concurred with some of the findings in the literature (Baron-Cohen, Wheelwright, & Jolliffe, 1997). In this study three participants expressed their inability to interpret another person’s facial expressions. The revelations of these three participants have added to the findings in the existing literature, which show that some people with Asperger syndrome cannot immediately interpret facial expressions accurately (Baron-Cohen et al., 1997; Doi et al., 2013; Rueda, Fernández-Berrocal, & Schonert-Reichl, 2014).

The characteristics associated with Asperger syndrome can have an impact on employment prospects. Studies have shown that those on the autism spectrum who have conversational abilities similar to typical people have a greater chance of obtaining employment than those on the autism spectrum who have poor conversational abilities (Roux et al., 2013). In addition, under certain circumstances, especially when an employee's skills fulfil the job's expectations, an adult with Asperger syndrome might be an ideal employee. For example, adults with Asperger syndrome who have fine attention to detail skills might make excellent quality assurance officers (Giarelli et al., 2013). There are also other factors that can increase the employment prospects of adults on the autism spectrum. These factors include high perceived support from parents and a supportive work environment (Holwerda, van der Klink, de Boer, Groothoff, & Brouwer, 2013). In order to reduce the negative impact perceptions may have on employment outcomes, it is important that employers and workplace colleagues receive awareness training about people on the autism spectrum (Wilczynski, Trammell, & Clarke, 2013). In addition, if workplaces do not support people with Asperger syndrome, then the latter's lifespan development could be impacted. For example, during the fifth stage of Erikson's theory, called 'Identity versus Identity Confusion', an adolescent develops their sense of identity through work and independent living. If they are unable to sustain paid employment, then this could have a negative impact on their identity (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Slater, 2003; Vogel-Scibilia et al., 2009).

Data from this study aligns with research conducted by Matson, Hattier and Belva (2012), detailing how some characteristics associated with Asperger syndrome can cause difficulties in domestic situations. For example, Kylie's experiences of living at home, expressed below, support Matson et al.'s (2012) findings:

> My family members have to tell me to get out of the room because they are turning the kettle on, which can be really annoying.

The characteristics associated with a person's disability can influence her or his lifespan development and confidence. For adults with Asperger syndrome, their confidence and lifespan development can also be influenced by the characteristics associated with their syndrome. According to Erikson (1963), when people age, they begin to develop their identity by exploring their abilities and limitations. For example, Adam described how his focus on a specific topic of interest, which is a characteristic of Asperger syndrome, has enhanced his confidence. In contrast, John did not appear to have a positive self-image because his Asperger syndrome prevented him from joining the Australian Defence Force. John's negative view of himself might have a detrimental impact on his identity formation and if his negative identity development continues, then it could have an impact on his ability to transition through to the latter stages of Erikson's theory (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Slater, 2003; Vogel-Scibilia et al., 2009).

According to Erikson's theory, when a person is not able to form a comprehensive identity about themselves through their work, then they often tend to develop role confusion (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014). Role confusion is often accompanied by feelings of inferiority, failure and incompetence. Such emotions can often have a detrimental impact on a person's confidence which, as a consequence, can lead to problems transitioning through later lifespan development stages, such as forming a relationship and reflecting on one's accomplishments in life (Erikson, 1963; Feldman, 2014).

6.2.2 Depression and suicidal ideation experiences

There is literature about people with Asperger syndrome and their depression and suicidal ideation experiences (Bennett, 2016; Cassidy et al., 2014; Paquette-Smith et al., 2014; Shtayermman, 2008; Storch et al., 2013). However, there are not many studies on adults with Asperger syndrome describing what it is like to live with depression and/or suicidal ideation (Bennett, 2016). To help augment this small amount of literature, the participants were asked, 'Have you ever experienced any episodes of depression?'

Of the participants who disclosed their depression and/or suicidal ideation experiences Kyle described depression as 'Hell' and Sebastian, Peggy and Imogen outlined the methods they used to try and commit suicide. Charlotte did not disclose whether she had attempted suicide. However, she did reveal how her Asperger syndrome inhibited her doctor's ability to treat her depression. Charlotte's self-reporting elucidates our understanding because the literature currently does not present any explanations from adults on the autism spectrum about whether or not their doctor's treatment for depression is effective.

The majority of studies about depression and Asperger syndrome, reviewed for this study, have obtained their data from parents completing questionnaires about their children. For example, in Hedley and Young's (2006) study, parents completed the Social Comparison Scale and the Children's Depression Inventory. While questionnaires can give researchers the ability to quickly and easily collect data from a large group of people they do, however, have drawbacks. One limitation is that researchers are never entirely certain if the respondents understand the questions or if the researchers have obtained accurate answers (Rowley, 2014). By using in-depth interviews, the researcher was able to ensure that the participants understood the questions posed on depression and suicidal ideation.

This study showed that five out of twenty-one participants experienced depression and/or suicidal ideation, which is a higher proportion than the general Australian population. This finding appears to be consistent with the literature. For example, in Cassidy et al.'s (2014) study on adults in Britain with Asperger syndrome, who experienced depression and/or suicidal ideation, 66% reported suicidal ideation; 35% of respondents reported plans or attempts at suicide; and 31% of respondents reported depression. Their study concluded that adults with Asperger syndrome were more likely to experience suicidal ideation and/or depression than members of the British population not living on the autism spectrum.

When a person commits suicide it usually has detrimental consequences on his or her family. According to Cerel, Jordan and Duberstein (2008), family members who are exposed to a relative's suicide often become guilty about the death, blame themselves for hostile words they said to the person before the suicide, and often struggle to reconcile their inability to anticipate or prevent the suicide from occurring. No studies were found on parents or siblings describing matters related to suicidal ideation or suicide attempts by the family member on the autism spectrum. However, in the current study, one participant, Kyle, recalled how his family reacted to his suicide attempt.

A person's depression and/or suicidal ideation experiences can inhibit their lifespan development. According to Erikson's theory, as a person ages they pass through different stages of development (Berk, 2007; Erikson, 1963; Feldman, 2014). If people experience depression and/or suicidal ideation, then this can have an impact on their ability to progress through the stages Erikson outlines. For example, according to Erikson, when a person reaches his or her early twenties, they typically reach stage six, which is called 'Intimacy versus Isolation'. During this stage, they contemplate living alone or living with another person in an intimate relationship. If they want to be in a relationship and if they develop depression during this stage or earlier, then their depression can prevent them from achieving this personal goal (Erikson, 1963; Feldman, 2014). If they continue to live alone, contrary to their desires for a relationship, then when they reach the final stage of Erikson's theory, 'Ego Integrity versus Despair', they might decide that their life has not been successful since they have not been in an intimate relationship (Berk, 2007; Erikson, 1963; Feldman, 2014).

In conclusion, depression and/or suicidal ideation often have a detrimental impact on society and families. In order to reduce the rates of depression and/or suicidal ideation experienced by adults with Asperger syndrome, perhaps staff in mental health services need specialised training to understand the unique needs of people living with Asperger syndrome. Whilst it is likely that some people with Asperger syndrome may benefit from generic programs aimed at treating depression, it also seems likely that specific depression treatment programs for people on the autism spectrum could also be beneficial.

6.2.3 Disclosing a diagnosis of Asperger syndrome to workplace colleagues

The literature reviewed on Asperger syndrome and employment, which was presented in Chapter Two, showed that there are few studies about the experiences of adults telling their workplace colleagues that they live with Asperger syndrome. In contrast, there are studies on the experiences of employees telling their workplace colleagues that they have the Human Immunodeficiency Virus (Fesko, 2001); Multiple Sclerosis (Kirk-Brown & Van Dijk, 2014); or cancer (Pryce et al., 2007). Similarly, there are also studies on the experiences of employees telling their workplace colleagues that they are homosexual (Griffith & Hebl, 2002; Ragins et al., 2007). To provide further understanding, participants in this study were asked to recall their experiences of disclosing their Asperger syndrome to workplace colleagues.

In this study five participants described their experiences of disclosing their diagnosis of Asperger syndrome to their workplace colleagues. Adam and Imogen recalled that their workplace colleagues had a positive reaction to their disclosures. In contrast, Sebastian did not receive a positive reaction. Finally, Kyle and Sam did not tell their workplace colleagues that they lived with Asperger syndrome because they feared the consequences of disclosing this information. The remaining sixteen participants did not disclose any experiences of revealing their diagnosis of Asperger syndrome to their workplace colleagues. Reasons offered by these participants included 1) never being employed and therefore never being placed in a situation where they had to disclose; 2) being employed in organisations that already knew of their diagnosis; and 3) being in employment situations where disclosing a diagnosis was not appropriate or warranted.

According to Johnson and Joshi (2014, p. 278), researchers have mainly focused on the disability disclosure experiences of employees with other particular disabilities, such as ‘chronic illnesses, sensory challenges, learning disabilities, mental illness, and psychological disorders’. Consequently, few researchers have studied the experiences of employees disclosing their autism spectrum diagnosis to workplace colleagues. The limited amount of literature on adults disclosing their diagnosis of Asperger syndrome to workplace colleagues has explored the negative consequences that these adults encounter after disclosing their condition to workplace colleagues, such as termination of employment and demotion (Baldwin et al., 2014). The participants in the current study expanded our knowledge of these issues by presenting more examples of disclosing Asperger syndrome during employment and revealing their views on disclosing their disability during job interviews.

This study and the literature on adults with Asperger syndrome and workplace disability disclosure share similarities in relation to the use of an advocate. In Griffith et al.’s (2012) study, participants thought that it would be beneficial to use an advocate to help explain the characteristics of Asperger syndrome to colleagues and employers. This point was also expressed by Sheila, who stated during the interview session, ‘Obviously I can go in and explain about Asperger syndrome, but maybe information would be best coming from somebody else, other than me. It might have more impact.’ However, in some situations, research has suggested that the use of an advocate could be detrimental, possibly resulting in stigmatisation and/or harassment by workplace colleagues (MacDonald-Wilson et al., 2011).

Disclosing a diagnosis of Asperger syndrome to workplace colleagues can be a factor that can result in an employee with Asperger syndrome becoming unemployed and reliant on welfare (Baldwin et al., 2014). According to Buescher, Cidav, Knapp and Mandell (2014), the total cost of supporting an unemployed individual on the autism spectrum across his or her entire life in the United States of America in 2011 was $1.4 million USD or $50 319 USD per annum. Similarly, Knapp, Romeo and Beecham (2009) found that in 2009 in Britain, it cost approximately £0.80 million to support a person on the autism spectrum throughout his or her life. In Australia, in certain circumstances, people with Asperger syndrome are entitled to receive support from the Australian Government, in the form of unemployment benefits (i.e. a Newstart payment) or the Disability Support Pension (Morris & Wilson, 2014). This welfare expenditure, which companies and taxpayers fund, can be reduced if employers retain employees with Asperger syndrome after they have disclosed their disability.

Parents who have adult offspring with Asperger syndrome can also be disadvantaged if their offspring become unemployed after disclosing their disability to workplace colleagues. Adults with Asperger syndrome who are unemployed often rely on their parents for support. This support often increases parents’ levels of stress (Smith, Greenberg, & Mailick, 2012); emotional hardship (Smith et al., 2010); and physical health problems, such as fatigue, joint pain, and headaches (Smith, Seltzer, & Greenberg, 2012). To help minimise the possibility of parents being placed in these situations, it is important that employers continue supporting adults with Asperger syndrome after they have disclosed their disability.

The lifespan development of an adult with Asperger syndrome can be influenced by his or her workplace disability disclosure experiences. According to Erikson, a person’s occupation can form an integral part of his or her identity (Berk, 2007; Erikson, 1963; Feldman, 2014). If an adult with Asperger syndrome has a negative experience of workplace disability disclosure, then they might become unemployed, experience financial hardship and develop low confidence. In addition, negative experiences in employment can also have a detrimental impact on an adult's ability to successfully establish a solid identity, which is often developed during stage five of Erikson's theory, called 'Identity versus Role Confusion'. A failure to establish a comprehensive identity can result in feelings of inferiority, failure and incompetence (Berk, 2007; Erikson, 1963). These negative consequences can also have an impact on people's transition through the latter stages of Erikson's theory, in particular the final stage of Erikson's theory when people reflect on their achievements in life.

In conclusion, adults who become unemployed after disclosing their diagnosis of Asperger syndrome in the workplace often rely on welfare and their families for support. This leads to an increase in public and company taxes. Furthermore, parents who support their adult offspring on the autism spectrum face increased levels of stress and physical illness. To help avoid these possible negative outcomes, adults might like to ask themselves the following questions before they disclose their Asperger syndrome diagnosis to workplace colleagues: 1) Why should I disclose my disability?; 2) Who should I tell about the disability (i.e. supervisors, workplace colleagues)?; 3) What should I say about my disability (i.e. symptoms)?; and 4) When should I disclose my disability (i.e. during the job interview, during probation)? (MacDonald-Wilson et al., 2011).

6.2.4 School bullying experiences

There is a small amount of literature published which has examined adults with Asperger syndrome recalling their school bullying experiences (Fleischer, 2012; Sciutto et al., 2012). Instead, the main focus of literature on school children with Asperger syndrome has explored their writing and mathematical abilities (Brown & Klein, 2011; Chiang & Lin, 2007; Schneider et al., 2013). To develop an understanding of adults with Asperger syndrome and their bullying experiences at school, the participants were asked, 'Whilst at school were you ever bullied?'

The majority of participants did not wish to disclose their school bullying experiences, for they stated that these experiences were still very painful. However, of the participants who were willing to discuss their experiences. The two female participants described indirect forms of bullying (i.e. spreading lies) and the two male participants experienced physical bullying (i.e. shoving, tripping, and aggressive fighting). This finding appears consistent with the literature on gender and school bullying in the general school population, which shows that male students often experience physical bullying and female students often experience indirect bullying (Rose & Monda-Amaya, 2012).

There are similarities between the bullying situations expressed by the participants and the bullying situations documented in the reviewed literature about school students living with Asperger syndrome. For example, in this study, Kyle explained an instance where he was lured by bullies into a situation that would eventually lead to his suspension from his school. Kyle's experience has parallels with the experiences documented in Sciutto et al.'s (2012) article. In that particular article, an adult participant with Asperger syndrome recalled the following:

> I wish they [teachers] understood that the reason I was always in trouble wasn't that I was bad, it was that the other kids did all kinds of things outside the view of the teacher, and then provoked me into a response that was in front of the teacher, and laughed when I got in trouble. (Sciutto et al., 2012, p. 5)

Kyle's bullying experience also provides an insight into some of the strategies that students on the autism spectrum might employ to mitigate bullying (Biggs et al., 2010). No examples of adults with Asperger syndrome recalling how they verbally defended themselves against school bullies were found in the reviewed literature. One study, however, was found which described adolescents on the autism spectrum using verbal threats against potential bullies (Fisher & Taylor, In press). One adolescent in Fisher and Taylor's (In press, p. 6) study stated:

> Um, my responses were at times not the best. [Ok, why do you say that?] Well, threatening to cut someone up and describing in detail of what you would do, not the smartest thing to do.

In this present study, Travis explained how he used a verbal tactic against school bullies. During the interview session, he did not provide an example of a bullying situation where he used verbal tactics against the bully. Instead he gave a general explanation. Travis suggested that verbal aggression was an effective strategy to defend himself against bullying. However, for adults on the autism spectrum in this study, such as Travis, their memories of school bullying appeared to be very traumatic. Despite the passage of time, their recollection of school bullying events did not appear to lessen, possibly because of a perseverative thinking style that has been reported by people on the autism spectrum (Griffith et al., 2012). It may be worth future investigation into the long-term impacts of school bullying on adults on the autism spectrum and how to help such adults reconcile these events in their lives. Fisher and Taylor’s (In press) study also explained that verbal bullying was used by adolescents on the autism spectrum as a strategy for preventing bullying. In contrast, in this study, Travis explained how he used verbal bullying to retaliate against the school bullies.

Linda’s recollections of her bullying experiences indicate difficulty in understanding the intentions of peers. Linda recalled how while she was at school, she was told that she could be friends with a group of girls after she completed a series of tasks. However, in hindsight, she explained, ‘I think, looking back, I mistook the girls that I hung around with as being friends.’ Participants’ experiences of school bullying align with the literature which proposes that students with Asperger syndrome have difficulties immediately perceiving the intentions of peers (Baron-Cohen et al., 1997; Doi et al., 2013).

School bullying can have negative consequences for victims after they have finished school (Allison, Roeger, & Reinfeld-Kirkman, 2009; Bender & Losel, 2011; Crozier & Skliopidou, 2002; Ttofi, Farrington, Losel, & Loeber, 2011b). Some possible negative consequences include increased use of tobacco and illegal drugs; a lower satisfaction with intimate relationships (Sigurdson, Wallander, & Sund, 2014); difficulties in employment (Smith, Singer, Hoel, & Cooper, 2003); and increased levels of depression and anxiety (Boulton, 2013; McCabe, Antony, Summerfeldt, Liss, & Swinson, 2003; Ttofi, Farrington, Losel, & Loeber, 2011a). Despite these possible negative consequences, a small amount of research was found on the long-term effects that school bullying has on students with Asperger syndrome, and this area needs more research (Fleischer, 2012; Sciutto et al., 2012).

It appears that school bullying can have an impact on a person’s lifespan development. According to Erikson’s theory, during adolescence children develop their sense of identity (Berk, 2007;

Erikson, 1963; Feldman, 2014). If children with Asperger syndrome are bullied, then they might develop a distorted sense of their own identity (e.g. a view that they are inferior to others). This negative self-perception can have an impact on their life after school, such as the ability to obtain meaningful employment (Howlin et al., 2005; Sigurdson et al., 2014). In addition, if school bullying distorts a student with Asperger syndrome's sense of identity, then this distortion can have an impact on their transition through the adolescent and adult stages of Erikson's theory. For instance, during adolescence, Erikson claims that children usually go through the fifth stage of development, called 'Identity versus Role Confusion' (Erikson, 1963). If they were bullied at school, then they might not be able to develop an accurate self-identity, thus developing role confusion. This sense of role confusion can also have an impact on their transition through the final stage of Erikson's theory, 'Ego Integrity versus Despair'. During this stage, adults often reflect on their achievements in life. If they were bullied at school and consequently did not achieve their goals in life, then when they reach the final stage of Erikson's theory, they might experience a sense of despair and depression (Berk, 2007; Erikson, 1963; Feldman, 2014).

Applying Erikson's theory would suggest that if students with Asperger syndrome are bullied at school, they will be less likely to develop a comprehensive understanding of themselves, which can result in decreased levels of self-confidence and pride. On the other hand, this would also suggest that having good relationships with peers, such as friendships, would result in increased levels of self-confidence and well-being. These positive benefits often consequently result in higher academic attainment, increased levels of self-confidence, and a realistic self-appraisal of one's abilities (Berk, 2007; Erikson, 1963).

In summary, school bullying can have a detrimental impact on the lifespan development of students with Asperger syndrome (Howlin et al., 2005). To help reduce these and other negative consequences, it is suggested that schools implement anti-bullying programs to help minimise the prevalence of school bullying. Examples of such programs include Responding in Peaceful and Positive Ways (Farrell, Meyer, & White, 2001; Farrell, Meyer, Sullivan, & Kung, 2003; Tuab & Pearrow, 2013); the Resolving Conflict Creatively Program (Aber, Brown, & Jones, 2003; Tuab & Pearrow, 2013); and the Good Behaviour Game (Kleinman & Saigh, 2011; Lannie & McCurdy, 2007; McCurdy, Lannie, & Barnabas, 2009; Tuab & Pearrow, 2013). It does seem likely, however, that aspects of these programs may need to be tailored more closely to the needs of students with Asperger syndrome. This would also be a useful focus for future research on students with Asperger syndrome and school bullying.

6.2.5 Intimate relationships and parenting

Sexual behaviours of adults with Asperger syndrome have been explored (Cridland et al., 2014; Kohn et al., 1998). However, most research about sexuality and Asperger syndrome is quantitative in nature. Consequently, there is a small amount of qualitative research about adults with Asperger syndrome and their experiences of, and opinions on, intimate relationships and parenting. In an attempt to expand our understanding of this area, during the second in-depth interview session, the participants were asked to describe their views and experiences concerning these issues.

In this study, participants explained their views and experiences of intimate relationships. Twelve participants had been single for a substantial period of time and they did not have any children or express any interest in being a parent. However, five out of these twelve participants expressed a desire to have a relationship at some point in the future.

Erikson's theory implies that people with Asperger syndrome who decide to be single are denying themselves the opportunity to be in an intimate relationship, which is a prerequisite for fulfilment (Berk, 2007). However, some people in this study expressed a preference for isolation and did not wish to be involved in an intimate relationship. Their revelations do not align with Erikson's theory and suggest that the application of Erikson's theory, in this stage at least, may be problematic for people with Asperger syndrome.

Of the participants who explained their reasons for wanting children. Kyle stated that he wanted children so that he could treat them better than he was treated when he was a child. Dave and Philip expressed a desire to have children so that their parents could have the opportunity to be grandparents. Imogen and Alison also wanted children, stating that the possibility of their children inheriting Asperger syndrome was not problematic because of the increased community awareness of autism. Sebastian initially did not want children. However, he reversed this decision because he came to believe that society's awareness of Asperger syndrome had increased and that his children might not experience the same problems that he experienced when he was a child.

In this study some participants explained their reasons for not wanting children. For example, according to Kylie: 'I don't think I'd be the best person to have responsibility for children, um, you know 24/7, because I'd get to a point where I'd just be like 'Aagggh!' and I just want to be alone'.

The literature review showed that there was a paucity of research on adults with Asperger syndrome describing their parental experiences. Lau and Peterson (2011, p. 393) have also expressed this point when describing the value of their study:

> [T]o the best of our knowledge, this study is the first to systematically explore satisfaction with marriage and parenting in groups of couples where one spouse has a clinically-confirmed AS [Asperger syndrome] diagnosis.

In this study, the participants' experiences of parenthood support those in the published literature. For example, in both this study and Lau and Peterson's (2011) article, the majority of participants with Asperger syndrome who were raising children did not express any regrets about having children.

In Lau and Peterson's (2011) study, respondents with Asperger syndrome described instances where they felt unsure about their social interactions with their partners. This finding is similar to the views voiced in this study, in particular Adam's and Peggy's accounts. These participants described how their inability to interpret their partner's body language caused difficulties in the relationship. Adam's experience provides an insight into some of the real-life consequences that people with Asperger syndrome encounter when they are unable to interpret their partners' intentions. It appears that the majority of literature sampled for this study has only measured the inability of people with Asperger syndrome to interpret facial expressions and body postures, with little consideration for how these limitations can have an impact on real-life situations, such as intimate relationship situations (Baron-Cohen et al., 1997; Doi et al., 2013; Doody & Bull, 2011; Reed et al., 2007). By getting the participants to explain their inability to interpret the intentions of others in intimate relationships, which is an example of a real-life situation, this study has expanded our current understanding of some of the limitations people on the autism spectrum encounter in life.

The sixth stage of Erikson's theory is 'Intimacy versus Isolation'. During this stage, people often make a decision about whether they want to be in an intimate relationship and raise children or live alone and childless (Berk, 2007). In this study, Charlotte stated: 'When I was eleven I knew that I did not want to have children. It just came into my head'. Her decision about parenting appears to contradict the developmental timeline outlined in Erikson's theory.

Some participants seemed to think that their personal goals of finding a partner and being a parent were hampered by their Asperger syndrome. This point was illustrated by Linda, a woman in her forties, who explained how her Asperger syndrome delayed her aim of getting married. In this study Linda described her insights into how the characteristics of her Asperger syndrome have inhibited her ability to form an intimate relationship. According to Erikson, a person who develops intimacy at a later age will experience a delay in reaching the latter stages of human development, such as reflection on one's achievements and accepting of one's life (Berk, 2007). However, Linda's insight appears to illustrate her ability to reflect on and accept her circumstances. This demonstrates the problematic nature of applying Erikson's theory to participants. Linda appears to be in the final stage. However, she has not yet traversed the penultimate stage.

In an attempt to help adults with Asperger syndrome achieve their desired relationship goals, this study proposes the use of an adult version of social stories. For example, video blogs may aid in the development of skills required for intimate relationships. Currently, social stories are used to help children with Asperger syndrome improve a range of interactions and daily skills, such as mealtime behaviours (Bledsoe, Smith Myles, & Simpson, 2003) and conversational skills (Scattone, 2008). In regard to sexual education, there are studies on people with autism using social stories to help them develop the skills needed to form intimate relationships and raise children (Klett & Turan, 2012; Tarnai & Wolfe, 2008). However, no studies were found on social stories being used to help adults with Asperger syndrome understand sexual relationships and parenting. Despite this lack of research, adult versions of social stories may have considerable potential for aiding these adults to learn the basic skills needed to form and maintain an intimate relationship and this would seem to be another useful area for future research.

For adults with Asperger syndrome who want a sexual relationship yet find face-to-face dating approaches socially difficult, this study suggests that the use of online dating services may be useful, as evidenced by Roth and Gillis (2015). They asked adults with autism to explain the benefits and drawbacks associated with online dating. The convenience of writing and reading dating profiles was the most commonly reported advantage. Avoiding public places where social anxiety could arise was another benefit. This point was explained by a participant in Roth and Gillis' (2015, p. 138) article: '[I] can meet people and talk to them without dealing with the anxiety of going to places like clubs.' Finally, participants explained that online dating services gave them opportunities to access a wide range of potential dating candidates. However, the participants also mentioned the drawbacks associated with these services. A lack of personal safety was the most frequently cited drawback. For example, a participant explained their concerns about 'people presenting false images' of themselves on dating websites, which was 'troublesome especially for Aspies as [we] tend to be a bit naive and trusting' (Roth & Gillis, 2015, p. 139). Despite these drawbacks, the potential benefits that online dating services can provide adults with Asperger syndrome should not be disregarded and should be the subject of further research.

6.2.6 Job interview experiences

There is literature about adults with Asperger syndrome and job interview training programs, such as interview skills curriculum, JobTIPS, and virtual reality job interview training (Giarelli et al., 2013; Morgan et al., 2014; Müller et al., 2003; Smith et al., 2014; Strickland et al., 2013). However, only a few pieces of research have given voice to the job interview experiences of adults with Asperger syndrome (Hendrickx, 2009). In order to expand on our limited understanding of the job interview experiences of adults with Asperger syndrome, the participants were asked to describe their job interview experiences.

Of the participants who discussed their job interview experiences, seven explained the difficulties they experienced with job interviews; two participants did not have any problems; and twelve participants had never experienced a job interview. Generic issues such as being anxious and unable to tailor their answers to the job interview questions were described by Travis and Imogen. Similarly, Philip was reluctant to participate in job interviews because he said that he was not able to anticipate the questions a prospective employer would ask. Alison and Kyle reported how they could not compete with other applicants in a group interview setting because they perceived their social difficulties to be a factor that made them less employable. Jake stated that during a job interview, he could not establish eye contact with a prospective employer. He believed that by failing to establish eye contact, his prospective employer would not interpret his answers as genuine. Finally, Sebastian had difficulty knowing where to place his hands during a job interview. He attributed this inability to his social limitations. In some situations, this inability can cause anxiety, which can have a further impact on job interview performance. However, the formulaic nature of some job interviews suited some of the participants. Peggy and Isabelle, for example, found that they were able to anticipate likely job interview questions and formulate appropriate responses and then practise these responses in preparation for the job interview.

John and Kyle described experiences where they were not able to establish and/or maintain eye contact during a job interview. Their revelations are similar to a male in his thirties with Asperger syndrome in Hendrickx's (2009, p. 106) book who stated, 'I think my weaknesses are that I'm not good at looking people in the eye during interviews'. In Western society, the inability to look people directly in their eyes has the implication of conveying intentions that are not genuine and is generally considered to be a sign of disrespect (Hendrickx, 2009).

The inability to quickly compose detailed responses to job interview questions was expressed by some participants and was one of the difficulties highlighted in the reviewed literature on adults with Asperger syndrome participating in job interviews. According to Barnhill (2007, p. 119), while individuals with Asperger syndrome may indeed 'possess the technical skills required for a job, they may not be able to engage in reciprocal conversation or think and quickly respond to questions during a job interview.' This point was illustrated by Alison, who said a potential employer told her she demonstrated the skills and abilities to fulfil the requirements of the advertised position but that her inability to answer job interview questions prevented her from being employed. In contrast, Hendrickx's (2009) writings described a male with Asperger syndrome who would often use a list of his employment achievements to answer job interview questions. This was similar to the experiences described by Peggy and Isabelle in this study. These two participants revealed how before the actual job interview itself, they formulated and rehearsed answers to anticipated job interview questions.

The inability to anticipate or interpret a prospective employer's motives or intentions during a job interview was an experience articulated by Sheryl. Sheryl's experience reflected the experiences of other adults with Asperger syndrome in Giarelli et al.'s (2013) and Müller et al.'s (2003) studies. In these studies, participants explained how they were unable to obtain employment because they could not perceive or interpret the intentions of employers during job interviews.

The difficulties adults with Asperger syndrome face in job interviews can influence their lifespan development and identity. According to Erikson's theory, a person's identity is influenced by his or her contribution to society, such as their employment status (Berk, 2007). If an individual cannot perform during the job interview, then her or his employment opportunities would be limited. With limited employment opportunities, their ability to construct part of their identity, based on their occupation and contribution to society, would be limited and may result in stagnation (Erikson, 1963). In addition, the inability to obtain meaningful employment can also have an impact on an adult's transition through the latter stages of life. For example, in the final stage of Erikson's theory, an adult reflects on their life and assesses their contributions to society. If they believe that they have not made a meaningful contribution, then they are more likely to become depressed (Erikson, 1963; Feldman, 2014).

Although no research was found on helping adults with Asperger syndrome navigate job interviews, there was research found on helping adults on the autism spectrum succeed in job interviews. According to López and Keenan (2014), vocational practitioners should educate individuals on the autism spectrum about appropriate social skills to help them overcome challenges during the job interview process. Langford, Lengnick-Hall and Kulkarni (2013) proposed that, if possible, adults on the autism spectrum should use their family and/or friends to circumvent the job interview process to obtain work. These authors also suggested that adults on the autism spectrum should receive job interview training to help them understand how to successfully navigate the job interview process. Examples of these training programs include interview skills curriculum, JobTIPS, and virtual reality job interview training (Morgan et al., 2014; Smith et al., 2014; Strickland et al., 2013). Job interview training programs might be especially effective for adults on the autism spectrum who cannot find suitable employment via their family and/or friends. Additionally, employers should receive from the government disability awareness training, tax credits and other financial incentives for hiring people with disabilities (Houtenville & Kalargyrou, 2012).

This study also suggests one reason why adults with Asperger syndrome collectively experience higher rates of unemployment when compared to people with other disabilities. It is likely that their social and communication limitations may prevent them from obtaining employment opportunities via job interviews, and this aligns with Howlin et al.'s (2005) study. In addition, more research on why adults with Asperger syndrome do not obtain employment opportunities at the same rate as people with other disabilities needs to be undertaken in order to explain this complex concept further.

6.2.7 The Australian public's knowledge about and views on Asperger syndrome

There are contemporary studies on the public's views on and knowledge about the autism spectrum (Dillenburger et al., 2013; Durand-Zaleski et al., 2012; Huws & Jones, 2010b; Mitchell & Locke, 2015; Stewart, 2008). In addition, recent research that has canvassed the views of Australian health and education specialists on autism, Asperger syndrome and the DSM-5 has been conducted (Kite et al., 2013). When this study began in 2010, the DSM-IV-TR was used in Australian clinical settings and this diagnostic manual contained the diagnostic condition, Asperger syndrome. However, in May 2013, an updated edition of the DSM was released, DSM-5. In the DSM-5, Asperger syndrome and autism were replaced with the diagnostic condition, Autism Spectrum Disorder. This change has complicated this present research because some clinicians and researchers who use the DSM no longer refer to Asperger syndrome in their research. However, despite this change, people with Asperger syndrome still feel that their diagnosis exists (Spillers et al., 2014). It appears that very little research has been conducted on asking people on the autism spectrum, including adults with Asperger syndrome, describing their perceptions of what they think the general public knows about the autism spectrum. The participants were given an opportunity, during the first in-depth interview session, to express their opinions on the Australian public's perceptions and understanding of Asperger syndrome.

Prior to this question being asked, the majority of participants did not consider the public's perception of Asperger syndrome. However, six participants commented on this issue. According to Jake and Isabelle, the Australian public perceives Asperger syndrome to be a condition that only affects children. Linda and Kyle thought the Australian public were unaware of the existence of Asperger syndrome. Philip and Dave explained how Australians' perceptions of Asperger syndrome fit within an international context.

The participant views in this study are distinct because no available literature was found on adults with Asperger syndrome describing their views on the Australian public's perceptions of Asperger syndrome. There are, however, similarities between the views expressed by the participants and the views found in the literature concerning the public's perceptions of autism. For example, in this study Jake stated: 'It [Asperger syndrome] is something that kids have … is a very strong perception in the minds of people and something that adults tend not to have'. Jake's opinion is similar to the opinions documented in Stewart's (2008) study, which found that the majority of the public sampled believed that autism was a condition that mostly affected children.

It is apparent that a person's sense of identity is influenced both by internal factors and societal beliefs and an individual is limited in the degree to which she/he can change these factors (Bao & Swaab, 2011). However, it does seem likely that becoming familiar with the Neurodiversity movement may have a positive effect on identity. This movement, as with the Gay Pride movement and the Civil Rights movement, has the potential to empower a marginalised group of adults and help the Australian public understand the nature, symptoms and challenges of living on the autism spectrum (Butler & Gillis, 2011; Newheiser & Barreto, 2014).

'Neurodiversity' is a term conveying that autism and other neurological conditions, such as dyslexia and epilepsy, are part of being human and should not be considered disabilities (Jaarsma & Welin, 2012; Langan, 2011). This term was coined by Judy Singer, an author with Asperger syndrome. She used this term in her honours thesis and in her article, ‘Why Can’t You Be Normal for Once in Your Life?’ (Cascio, 2012; Krcek, 2013; Runswick-Cole, 2014). Supporters of neurodiversity claim that people on the autism spectrum are unique and are a part of naturally occurring human diversity. They suggest that society should accept neurodiverse strengths and limitations just like other human characteristics, such as ethnicity, gender, and sexuality (Jaarsma & Welin, 2012; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Krcek, 2013). Some neurodiversity advocates also claim that people on the autism spectrum are not just a part of human diversity, but that their neurological profile can contribute to society and the economy (Runswick-Cole, 2014). As Temple Grandin, an advocate for people on the autism spectrum and inventor of a humane cattle chute for abattoirs in the United States of America, explained:

> In some ways, I credit my autism for enabling me to understand cattle. After all, if I hadn’t used the squeeze chute on myself, I might not have wondered how it affected cattle. I have been lucky, because my understanding of animals and visual thinking led me to a satisfying career in which my autistic traits don’t impede my progress (Jaarsma & Welin, 2012, p. 5).

The neurodiversity movement can offer many benefits to people on the autism spectrum. This movement may encourage a sense of belonging and acceptance that may support people on the autism spectrum’s development through Erikson’s Identity versus Role Confusion and Ego Integrity versus Despair stages (Berk, 2007; Erikson, 1963). This movement may also help them implement strategies to help overcome the challenges associated with living on the autism spectrum (Jaarsma & Welin, 2012).

A search of the available literature did not find any research on the neurodiversity movement in Australia. However, overseas literature suggests this movement has empowered people on the autism spectrum and has helped educate the public in other countries about the autism spectrum. There is a potential for the same positive impacts to occur in Australia and because of this, it would seem prudent for the neurodiversity movement to be adopted and supported in Australia.

6.2.8 Emotional reactions to a diagnosis of Asperger syndrome

The emotional reactions which adults have had towards their diagnosis of Asperger syndrome have been analysed (MacLeod et al., 2013; Molloy & Vasil, 2004; Murray, 2006; Punshon et al., 2009; Rosqvist, 2012). There are also studies on parents describing their reactions towards their child's diagnosis of Asperger syndrome (Calzada et al., 2012; Pakenham et al., 2004). However, no research was found on adults describing the reactions they thought their family and friends exhibited towards their diagnosis of Asperger syndrome. To try and gain an insight into their lived experiences, the participants were asked to recall how their friends and family responded to their diagnosis of Asperger syndrome.

The majority of the participants were not able to recall how their friends and family emotionally reacted to their diagnosis of Asperger syndrome. Reasons provided included obtaining their diagnosis after having left home, or not perceiving any reaction to their diagnosis.

In this study eight participants described the emotional reactions that they thought their family and/or friends had towards their diagnosis of Asperger syndrome. Sam and Alison thought that their parents did not initially accept their diagnosis of Asperger syndrome, John and Kyle recalled patronising attitudes from their family, and Philip and Isabelle thought their family did not treat them any differently. In addition, two participants, Adam and Sam, discussed the emotional reactions that they thought their friends had towards their diagnosis of Asperger syndrome. However, not all of the participants told their friends about their diagnosis of Asperger syndrome. Linda, for example, stated, 'I don't really think that it's any of their [her friends'] business.' However, she added that if her friends asked her if she had Asperger syndrome, then she would reveal her diagnosis. Kyle expressed a similar view. However, unlike Linda, he told some of his friends that he had Asperger syndrome.

Since no studies were found on adults describing how their family and/or friends reacted to their diagnosis of Asperger syndrome, the participants' recollections are unique and have provided a new perspective of the diagnostic experience. One possible reason why researchers have not asked adults with Asperger syndrome to comment on how their friends and family reacted to their diagnosis is because researchers may believe that adults with Asperger syndrome cannot perceive or contemplate another person's emotional state; this belief is otherwise known as Theory of Mind limitations (Montgomery, Stoesz, & McCrimmon, 2012; Shimoni, Weizman, Yoran, & Raviv, 2012). However, some participants conveyed articulate answers that described their perceptions of their family's and friend's reactions to their diagnosis of Asperger syndrome. Their answers illustrate that people with Asperger syndrome are capable of understanding other people's feelings, thoughts and perspectives. Furthermore, participants' answers on this subject appear to challenge the widely held view within the literature that people with Asperger syndrome are incapable of perceiving the emotional states of others; thus, this area requires more research.

An adult's sense of identity can be influenced by their perceptions of their family and/or friends emotional reactions towards their diagnosis of Asperger syndrome. If a person experiences negative reactions, then it would seem likely that he or she would have an increased possibility of developing depression (Butler & Gillis, 2011). In contrast, if she or he experienced a positive reaction, then she or he could develop a more positive self-perception. Developing a positive self-perception can have a beneficial impact on the movement of people with Asperger syndrome through the latter stages of Erikson's theory. For instance, with a positive sense of identity, the person is more likely to develop intimate relationships rather than remain isolated (Erikson, 1963). In addition, with a positive sense of self, an adult with Asperger syndrome would be more likely to experience a sense of ego integrity and reach the conclusion that their life has been positive and productive (Batra, 2013; Berk, 2007; Erikson, 1963; Feldman, 2014; Slater, 2003; Vogel-Scibilia et al., 2009).

This study suggests that autism awareness campaigns that include adults describing their lived experiences of being on the autism spectrum may support the development of a positive self-identity for adults with Asperger syndrome. Showing a realistic and unbiased portrayal of the lived experience of Asperger syndrome may help people with Asperger syndrome overcome feelings of isolation because it would be easier to realise that their experiences are shared by others and this may aid in the development of positive interpersonal relationships (Erikson, 1963; Huws & Jones, 2010a). Autism awareness campaigns are well-established throughout the developed world and these have been shown to increase public interest and knowledge about people on the autism spectrum (Butler & Gillis, 2011; DeVilbiss & Lee, 2014; Huws & Jones, 2010b).

6.3 This study’s contributions to the broader research agenda

The broader consequences of this study, such as improving society’s understanding of the autism spectrum or adding to the limited amount of qualitative research on adults with Asperger syndrome, were outlined in the first chapter of this thesis. According to Dillenburger et al. (2013) and Mitchell and Locke (2015) the public generally do not accurately understand autism or people on the autism spectrum. Similarly, the media often publish inaccurate stories about people on the autism spectrum (Huws & jones, 2010a). To help educate the public about the autism spectrum, and to help dispel inaccurate media portrayals of people on the autism spectrum, Huws and Jones (2010a, p. 331) suggest that ‘interactions between lay people and people with autism may develop positive conceptualisations of autism’. Furthermore, Kang (2013, p. 245) suggest that ‘the voices of people with autism need to be covered in the television news media more because they as experts can offer the better understanding of autism’. The experiences and insights of adults with Asperger syndrome presented in this study could help the public understand autism and dispel inaccurate media portrayals of the autism spectrum.

Bölte (2014) asserted that academic journals which publish research about the autism spectrum, such as *Autism* and *Journal of Autism and Developmental Disorders*, rarely publish qualitative studies about people who live on the autism spectrum. Consequently, there are a handful of first-person published qualitative studies about the experiences of adults with autism or Asperger syndrome (DePape & Lindsay, 2016). This study used qualitative accounts from participants to explain what it is like to live with Asperger syndrome. The use of such qualitative information addresses the limited amount of qualitative research about the autism spectrum.

6.4 Limitations of this study

This section outlines the limitations of this research into adults with Asperger syndrome and their education, employment and intimate relationship views and experiences.

6.4.1 Geographical limitations

With the exception of one participant, all the participants lived in the metropolitan areas of Adelaide. If this study interviewed people who lived in rural Australia, then it would have been possible to compare the impact that rural and metropolitan areas can have on the participants’ life experiences. For example, by interviewing participants from rural areas, the researcher could have explored how limited employment and education opportunities in country towns have had an impact. A larger sample of participants from rural Australia may also have highlighted the benefits of living in these communities, such as increased levels of community support. More research is required to investigate this further.

6.4.2 Cultural limitations

In an attempt to have a sample that was representative of the Australian population, the researcher sampled participants from both genders and all ages. However, the researcher did not take into consideration recruiting participants from non-Caucasian ethnicities (e.g. Asian or Indigenous-Australian). If the researcher had taken this into consideration, then the impact that ethnicity has had on the participants' life experiences could have been explored. For example, participants from non-Caucasian ethnicities could have discussed potential experiences of racism; immigration to Australia; culture shock; cultural heritage and practices; and difficulties with the English language.

6.4.3 Data collection limitations

Each participant had to attend two face-to-face interviews with the researcher at a mutually agreed location and time. During the interview sessions, some participants responded with long statements that did not answer the interview question. When these situations arose, the researcher interjected and directly asked the participant, 'How is your answer relevant to the interview question?' Although this assertive approach helped most participants answer the interview question, it did not completely alleviate the social and verbal challenges that participants experienced. With future research studies, an asynchronous method of communication, such as email or text messaging, might help adults with Asperger syndrome answer interview questions succinctly. Such methods of communication can give these adults the opportunity to take a large amount of time contemplating their answers before conveying them to the researcher. However, there are also drawbacks to these communication methods. For example, the interaction between the researcher and the participant can be prolonged (Evans, Elford, & Wiggins, 2008; Fielding, Lee, & Blank, 2008). However, this method of research has rich potential for gaining a better understanding of people on the autism spectrum. Studies on adults with Asperger syndrome that have used asynchronous methods of communication have found that adults with Asperger syndrome are capable of explaining in elaborate detail their experiences in life (Benford & Standen, 2009, 2011; Clarke & van Amerom, 2007; Durkin, Whitehouse, Jaquet, Ziatas, & Walker, 2010).

The researcher did not collect any details from the participants about their living arrangements (e.g. living with family members, living alone, living in private rental accommodation, living in government housing, or living in private ownership). Similarly, the researcher did not document if participants were receiving support from AutismSA, government disability service providers or employment assistance agencies; receiving counselling or psychological treatment; or receiving income support from the government (e.g. Disability Support Pension or unemployment benefits). In retrospect, collecting this information would have placed the participants' comments into a more detailed context and perhaps enabled a deeper insight. In addition, this information could have helped the researcher ask additional questions. For example, if the participant stated that they were receiving income support from the government, then additional interview questions about interacting with welfare agencies and budgeting could have been asked.

6.5 Suggestions for future research

6.5.1 Depression and suicidal ideation

This study touched on the depression and suicidal ideation experiences of participants. It found that often family and friends were unaware of the presence of depression and/or suicidal ideation. In these instances, participants were more likely to attempt suicide because they were not accessing any support. With future research, it may be beneficial to explore how depression and suicidal ideation present in people with Asperger syndrome. This research may highlight differences in presentation between the general population and people with Asperger syndrome, which could lead to easier recognition and support for people with Asperger syndrome who are experiencing depression and suicidal ideation.

6.5.2 Community and a sense of belonging

There were instances where the participants expressed similar experiences and used similar strategies in daily life (e.g. the difficulty of sleeping next to a ticking clock). However, it appeared that participants did not feel a sense of belonging to the Asperger syndrome community, for they did not describe anyone else with Asperger syndrome sharing similar experiences. Their sense of isolation may compound their feelings of isolation and depression. It may be useful to investigate how a sense of belonging can be practically implemented through the neurodiversity movement in Australia. Further research could also be conducted on whether this movement will have a positive impact on these people. For example, measuring the impact of this movement on the rates of suicidal ideation could be examined.

6.6 Summary of this thesis

This thesis presented twenty-one adults with Asperger syndrome and their views on and experiences of education, employment and intimate relationships. To present these views and experiences effectively, the researcher used a phenomenological framework. This methodology was used because it placed the participants' statements at the centre of the study and reduced the researcher's opportunity to incorporate his own views and experiences. The method used to collect the participants' views and experiences was in-depth interviews because it gave the participants the opportunity to articulate detailed responses. This method also gave the researcher the flexibility to change the order of the interview questions in order to probe for additional information or seek clarification on the answers provided.

The participants' experiences and views seemed to impact on the participants' movement through the adult stages of Erikson's theory. At times, Erikson's theory was problematic in the context of this study. For example, Charlotte's decisions about motherhood appear to contradict the developmental timeline outlined in Erikson's theory. Similarly, other findings suggest that the linear nature and stages framework of Erikson's theory may not be universally applied to adults with Asperger syndrome. However, this theory was useful in helping to conceptualise the challenges adults with Asperger syndrome face in life and introduce a series of recommendations to help people with Asperger syndrome engage with society.

The recommendations presented were based on the participants' expression of their lived experiences and their views. For example, in this study participants explained the difficulties they had in disclosing their diagnosis of Asperger syndrome to their workplace colleagues. It was recommended that to overcome these difficulties, adults with Asperger syndrome might want to ask themselves four questions and evaluate their answers before they decide to tell their colleagues about their Asperger syndrome.

The proportion of adults with Asperger syndrome in this study who experienced depression and suicidal ideation concurs with the findings by Cassidy et al. (2014). Research by Cassidy et al. (2014) indicated that adults with Asperger syndrome were disproportionately likely to experience depression and suicidal ideation compared to the general population. To help other adults with Asperger syndrome who have similar experiences, it is suggested that society needs to support organisations that educate people about depression and suicide in ways that may be effective for these adults. In addition, it is proposed that more research is needed in this area to explore the presentation of depression and suicidal ideation.

Although this study has contributed to our knowledge about adults with Asperger syndrome, there are some limitations which could be addressed should a similar study be conducted. This research would need to interview participants from rural Australia and non-Caucasian ethnicities. Interviewing participants from these backgrounds would give greater depth and breadth to understanding the lived experience of adults with Asperger syndrome in Australia.

This thesis explored and presented the lived experiences of adults with Asperger syndrome and it compared these experiences with the general academic literature about Asperger syndrome. The majority of the current literature presents the views of clinicians regarding their interpretations of the lived experiences of adults with Asperger syndrome. It is possible that there is a paucity of research detailing these lived experiences because clinicians may have believed that these adults are not capable of expressing themselves (Rutherford et al., 2002). However, this research indicates that adults with Asperger syndrome are not just capable of expressing themselves but that they are also capable of introspective awareness. In addition, this research indicated that adults with Asperger syndrome are aware of and can articulate the impact of their actions on the lives of other people around them.

In conclusion, this thesis has achieved its overall objective: namely, to present a collage of education, employment and intimate relationship views and experiences from a sample of adults with Asperger syndrome and to subsequently extend our understanding of their lived experience. Hopefully, continued research exploring ‘the voice’ of people with Asperger syndrome will provide a better understanding of the challenges they face, their potential contributions to society and, subsequently, promote more accurate and supportive community awareness.

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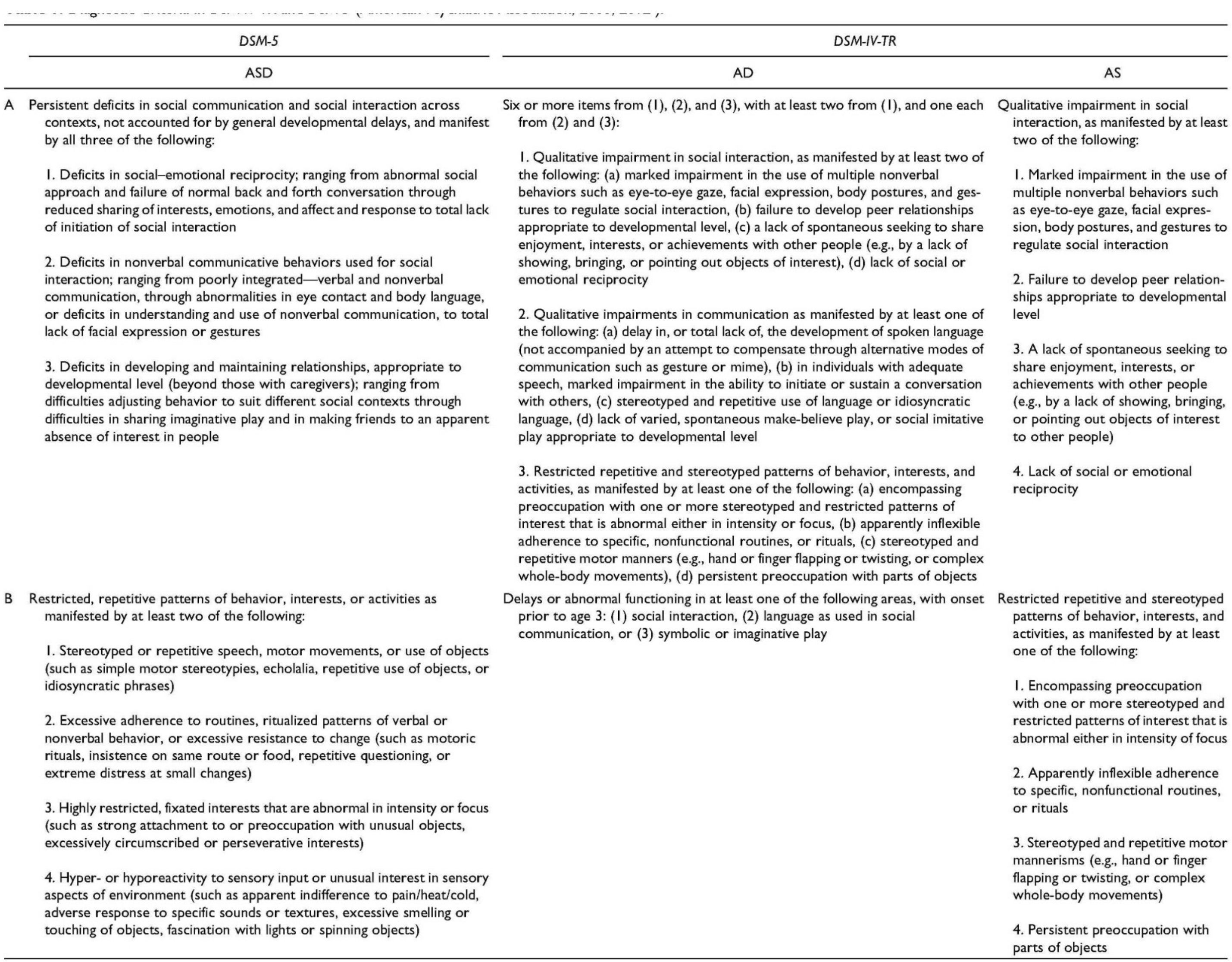
Appendix 1: Autism Spectrum Disorder [ASD] diagnostic criteria in the DSM-IV-TR and DSM-5



	DSM-5	*DSM-IV-TR*	
	ASD	AD	AS
A	Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all three of the following: 1. Deficits in social–emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction 2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated—verbal and nonverbal communication, through abnormalities in eye contact and body language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people	Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3): 1. Qualitative impairment in social interaction, as manifested by at least two of the following: (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction, (b) failure to develop peer relationships appropriate to developmental level, (c) 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), (d) lack of social or emotional reciprocity 2. Qualitative impairments in communication as manifested by at least one of the following: (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime), (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others, (c) stereotyped and repetitive use of language or idiosyncratic language, (d) lack of varied, spontaneous make-believe play, or social imitative play appropriate to developmental level 3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following: (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus, (b) apparently inflexible adherence to specific, nonfunctional routines, or rituals, (c) stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements), (d) persistent preoccupation with parts of objects	Qualitative impairment in social interaction, as manifested by at least two of the following: 1. Marked impairment in the use of multiple nonverbal behaviors 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 patterns of behavior, interests, or activities as manifested by at least two of the following: 1. Stereotyped or repetitive speech, motor movements, or use of objects (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases) 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change (such as motoric rituals, insistence on same route or food, repetitive questioning, or extreme distress at small changes) 3. Highly restricted, fixated interests that are abnormal in intensity or focus (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests) 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of environment (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects)	Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play	Restricted repetitive and stereotyped patterns of behavior, 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 of focus 2. Apparently inflexible adherence to specific, nonfunctional 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

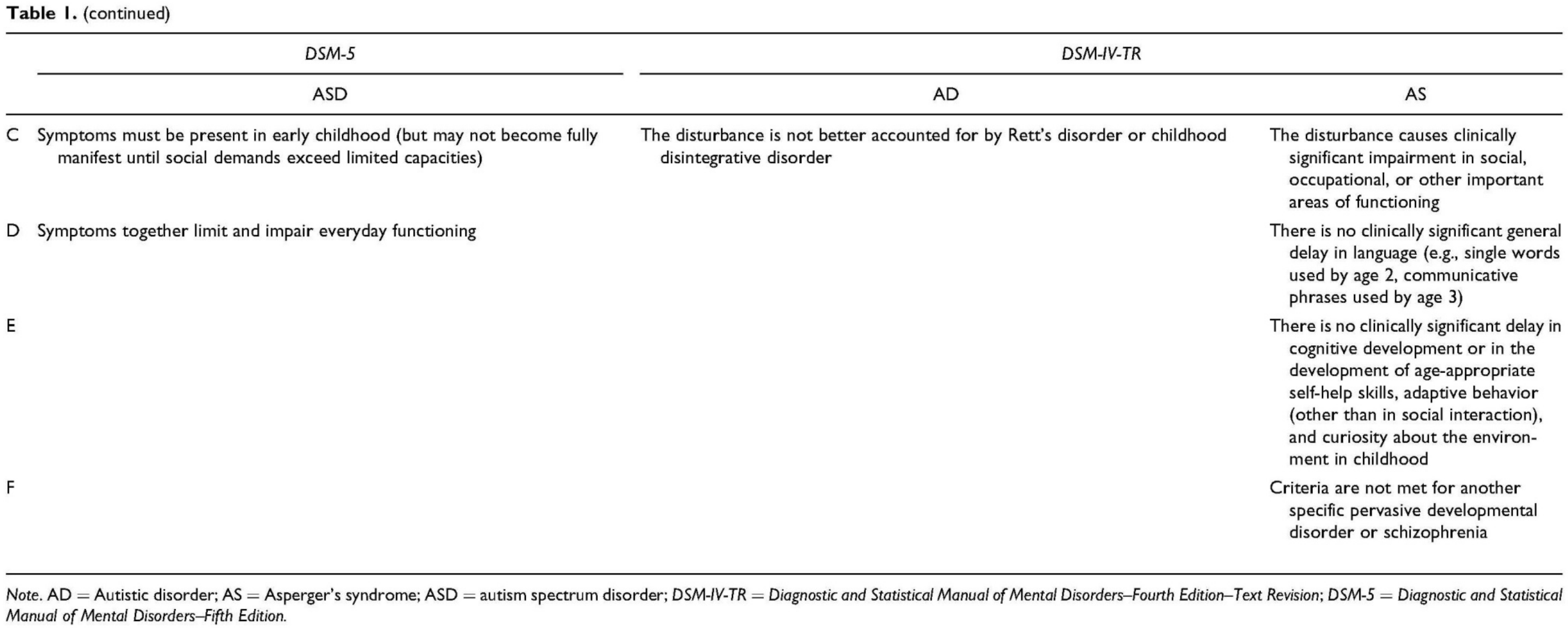


Table 1. (continued)

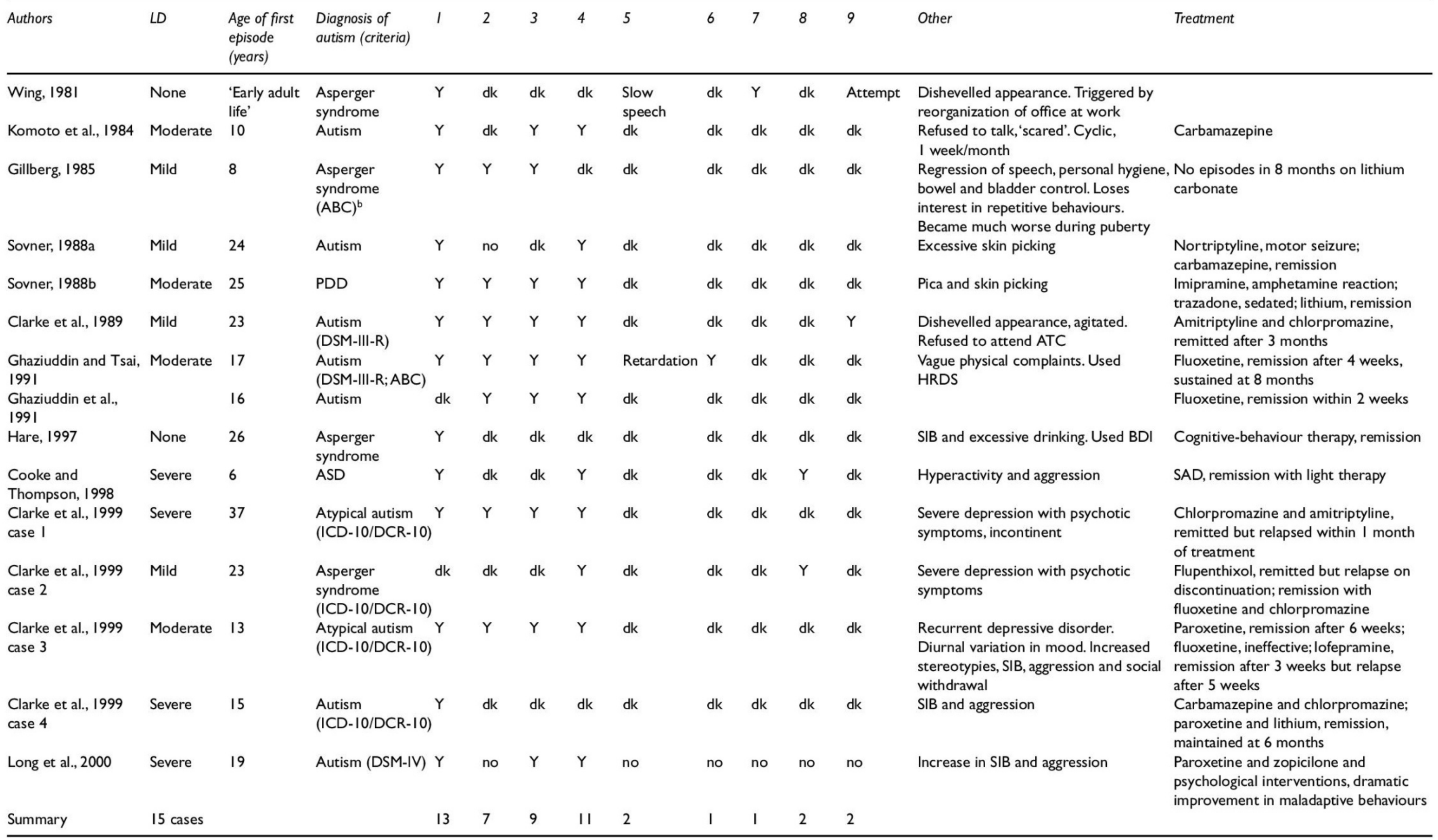
	DSM-5	*DSM-IV-TR*	
	ASD	AD	AS
C	Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)	The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder	The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning
D	Symptoms together limit and impair everyday functioning		There is no clinically significant general delay in language (e.g., single words used by age 2, communicative phrases used by age 3)
E			There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood
F			Criteria are not met for another specific pervasive developmental disorder or schizophrenia

Note. AD = Autistic disorder; AS = Asperger's syndrome; ASD = autism spectrum disorder; *DSM-IV-TR* = *Diagnostic and Statistical Manual of Mental Disorders–Fourth Edition–Text Revision*; *DSM-5* = *Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition.*

Source: Linton, K. F., Krcek, T. E., Sensui, L. M., & Spillers, J. L. H. (2014). Opinions of People Who Self-Identify With Autism and Asperger's on DSM-5 Criteria. *Research on Social Work Practice*, *24*(1), 67-77, pp. 69-70.

Appendix 2: A table of studies on depression in people with autism or Asperger syndrome

Table 1: Summary of case studies that describe depression in autism and Asperger syndrome



Authors	*LD*	*Age of first episode (years)*	*Diagnosis of autism (criteria)*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*Other*	*Treatment*
Wing, 1981	None	'Early adult life'	Asperger syndrome	Y	dk	dk	dk	Slow speech	dk	Y	dk	Attempt	Dishevelled appearance. Triggered by reorganization of office at work	
Komoto et al., 1984	Moderate	10	Autism	Y	dk	Y	Y	dk	dk	dk	dk	dk	Refused to talk, 'scared'. Cyclic, 1 week/month	Carbamazepine
Gillberg, 1985	Mild	8	Asperger syndrome (ABC)[b]	Y	Y	Y	dk	dk	dk	dk	dk	dk	Regression of speech, personal hygiene, bowel and bladder control. Loses interest in repetitive behaviours. Became much worse during puberty	No episodes in 8 months on lithium carbonate
Sovner, 1988a	Mild	24	Autism	Y	no	dk	Y	dk	dk	dk	dk	dk	Excessive skin picking	Nortriptyline, motor seizure; carbamazepine, remission
Sovner, 1988b	Moderate	25	PDD	Y	Y	Y	Y	dk	dk	dk	dk	dk	Pica and skin picking	Imipramine, amphetamine reaction; trazadone, sedated; lithium, remission
Clarke et al., 1989	Mild	23	Autism (DSM-III-R)	Y	Y	Y	Y	dk	dk	dk	dk	Y	Dishevelled appearance, agitated. Refused to attend ATC	Amitriptyline and chlorpromazine, remitted after 3 months
Ghaziuddin and Tsai, 1991	Moderate	17	Autism (DSM-III-R; ABC)	Y	Y	Y	Y	Retardation	Y	dk	dk	dk	Vague physical complaints. Used HRDS	Fluoxetine, remission after 4 weeks, sustained at 8 months
Ghaziuddin et al., 1991		16	Autism	dk	Y	Y	Y	dk	dk	dk	dk	dk		Fluoxetine, remission within 2 weeks
Hare, 1997	None	26	Asperger syndrome	Y	dk	dk	dk	dk	dk	dk	dk	dk	SIB and excessive drinking. Used BDI	Cognitive-behaviour therapy, remission
Cooke and Thompson, 1998	Severe	6	ASD	Y	dk	dk	Y	dk	dk	dk	Y	dk	Hyperactivity and aggression	SAD, remission with light therapy
Clarke et al., 1999 case 1	Severe	37	Atypical autism (ICD-10/DCR-10)	Y	Y	Y	Y	dk	dk	dk	dk	dk	Severe depression with psychotic symptoms, incontinent	Chlorpromazine and amitriptyline, remitted but relapsed within 1 month of treatment
Clarke et al., 1999 case 2	Mild	23	Asperger syndrome (ICD-10/DCR-10)	dk	dk	dk	Y	dk	dk	dk	Y	dk	Severe depression with psychotic symptoms	Flupenthixol, remitted but relapse on discontinuation; remission with fluoxetine and chlorpromazine
Clarke et al., 1999 case 3	Moderate	13	Atypical autism (ICD-10/DCR-10)	Y	Y	Y	Y	dk	dk	dk	dk	dk	Recurrent depressive disorder. Diurnal variation in mood. Increased stereotypies, SIB, aggression and social withdrawal	Paroxetine, remission after 6 weeks; fluoxetine, ineffective; lofepramine, remission after 3 weeks but relapse after 5 weeks
Clarke et al., 1999 case 4	Severe	15	Autism (ICD-10/DCR-10)	Y	dk	dk	dk	dk	dk	dk	dk	dk	SIB and aggression	Carbamazepine and chlorpromazine; paroxetine and lithium, remission, maintained at 6 months
Long et al., 2000	Severe	19	Autism (DSM-IV)	Y	no	Y	Y	no	no	no	no	no	Increase in SIB and aggression	Paroxetine and zopicilone and psychological interventions, dramatic improvement in maladaptive behaviours
Summary	15 cases			13	7	9	11	2	1	1	2	2		

Key:

1 = Depressed mood as indicated by subjected report or observation (e.g. tearful).

2 = Diminished interest or pleasure in all or almost all activities.

3 = Significant weight loss or gain, or significant change in appetite.

4 = Insomnia/hypersomnia.

5 = Psychomotor agitation/retardation.

6 = Fatigue or loss of energy.

7 = Feelings of worthlessness, or excessive or inappropriate guilt..

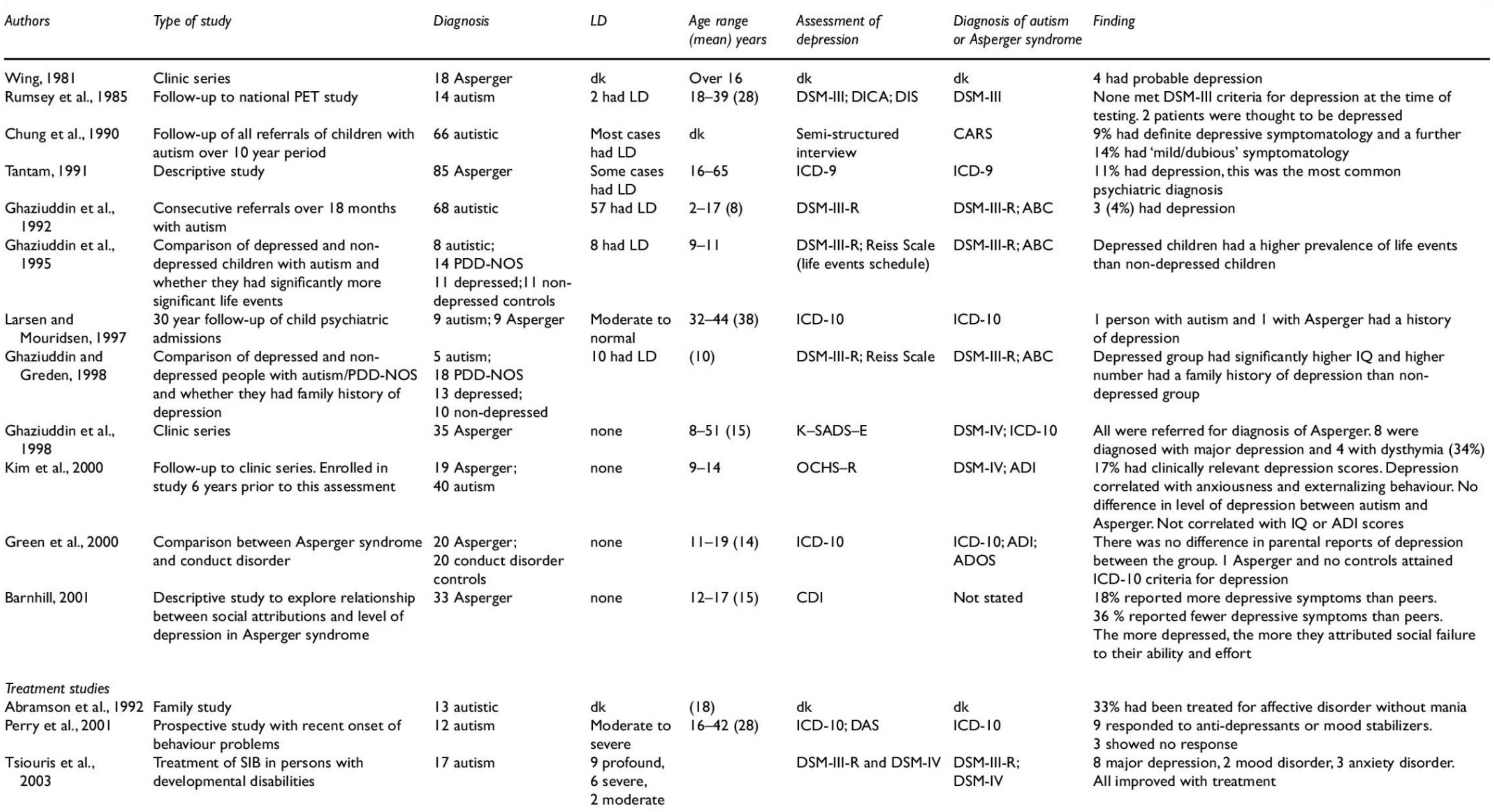
8 = Diminished ability to think/concentrate, or indecisiveness.

9 = Recurrent thoughts of death, suicidal ideation, suicidal attempt or plan.

[a] This case was also described in Ghaziuddin et al. (1991). [b] Did not meet criteria on this scale. ‘dk’ means that the symptom/sign was not discussed in the article, not that the authors were unable to assess it. Similarly, ‘no’ means that the behaviour was discussed in the article, and either was not a problem or could not be assessed.

Source: Stewart, M. E., Barnard, L., Pearson, J., Hasan, R., & O’Brien, G. (2006). Presentation of depression in autism and Asperger syndrome: A review. *Autism*, *10*(1), 103-116, p. 106.

Table 2: Summary of studies describing depression in autism and Asperger syndrome (excluding single case studies)



Authors	*Type of study*	*Diagnosis*	*LD*	*Age range (mean) years*	*Assessment of depression*	*Diagnosis of autism or Asperger syndrome*	*Finding*
Wing, 1981	Clinic series	18 Asperger	dk	Over 16	dk	dk	4 had probable depression
Rumsey et al., 1985	Follow-up to national PET study	14 autism	2 had LD	18–39 (28)	DSM-III; DICA; DIS	DSM-III	None met DSM-III criteria for depression at the time of testing. 2 patients were thought to be depressed
Chung et al., 1990	Follow-up of all referrals of children with autism over 10 year period	66 autistic	Most cases had LD	dk	Semi-structured interview	CARS	9% had definite depressive symptomatology and a further 14% had 'mild/dubious' symptomatology
Tantam, 1991	Descriptive study	85 Asperger	Some cases had LD	16–65	ICD-9	ICD-9	11% had depression, this was the most common psychiatric diagnosis
Ghaziuddin et al., 1992	Consecutive referrals over 18 months with autism	68 autistic	57 had LD	2–17 (8)	DSM-III-R	DSM-III-R; ABC	3 (4%) had depression
Ghaziuddin et al., 1995	Comparison of depressed and non-depressed children with autism and whether they had significantly more significant life events	8 autistic; 14 PDD-NOS 11 depressed; 11 non-depressed controls	8 had LD	9–11	DSM-III-R; Reiss Scale (life events schedule)	DSM-III-R; ABC	Depressed children had a higher prevalence of life events than non-depressed children
Larsen and Mouridsen, 1997	30 year follow-up of child psychiatric admissions	9 autism; 9 Asperger	Moderate to normal	32–44 (38)	ICD-10	ICD-10	1 person with autism and 1 with Asperger had a history of depression
Ghaziuddin and Greden, 1998	Comparison of depressed and non-depressed people with autism/PDD-NOS and whether they had family history of depression	5 autism; 18 PDD-NOS 13 depressed; 10 non-depressed	10 had LD	(10)	DSM-III-R; Reiss Scale	DSM-III-R; ABC	Depressed group had significantly higher IQ and higher number had a family history of depression than non-depressed group
Ghaziuddin et al., 1998	Clinic series	35 Asperger	none	8–51 (15)	K–SADS–E	DSM-IV; ICD-10	All were referred for diagnosis of Asperger. 8 were diagnosed with major depression and 4 with dysthymia (34%)
Kim et al., 2000	Follow-up to clinic series. Enrolled in study 6 years prior to this assessment	19 Asperger; 40 autism	none	9–14	OCHS–R	DSM-IV; ADI	17% had clinically relevant depression scores. Depression correlated with anxiousness and externalizing behaviour. No difference in level of depression between autism and Asperger. Not correlated with IQ or ADI scores
Green et al., 2000	Comparison between Asperger syndrome and conduct disorder	20 Asperger; 20 conduct disorder controls	none	11–19 (14)	ICD-10	ICD-10; ADI; ADOS	There was no difference in parental reports of depression between the group. 1 Asperger and no controls attained ICD-10 criteria for depression
Barnhill, 2001	Descriptive study to explore relationship between social attributions and level of depression in Asperger syndrome	33 Asperger	none	12–17 (15)	CDI	Not stated	18% reported more depressive symptoms than peers. 36 % reported fewer depressive symptoms than peers. The more depressed, the more they attributed social failure to their ability and effort
Treatment studies							
Abramson et al., 1992	Family study	13 autistic	dk	(18)	dk	dk	33% had been treated for affective disorder without mania
Perry et al., 2001	Prospective study with recent onset of behaviour problems	12 autism	Moderate to severe	16–42 (28)	ICD-10; DAS	ICD-10	9 responded to anti-depressants or mood stabilizers. 3 showed no response
Tsiouris et al., 2003	Treatment of SIB in persons with developmental disabilities	17 autism	9 profound, 6 severe, 2 moderate		DSM-III-R and DSM-IV	DSM-III-R; DSM-IV	8 major depression, 2 mood disorder, 3 anxiety disorder. All improved with treatment

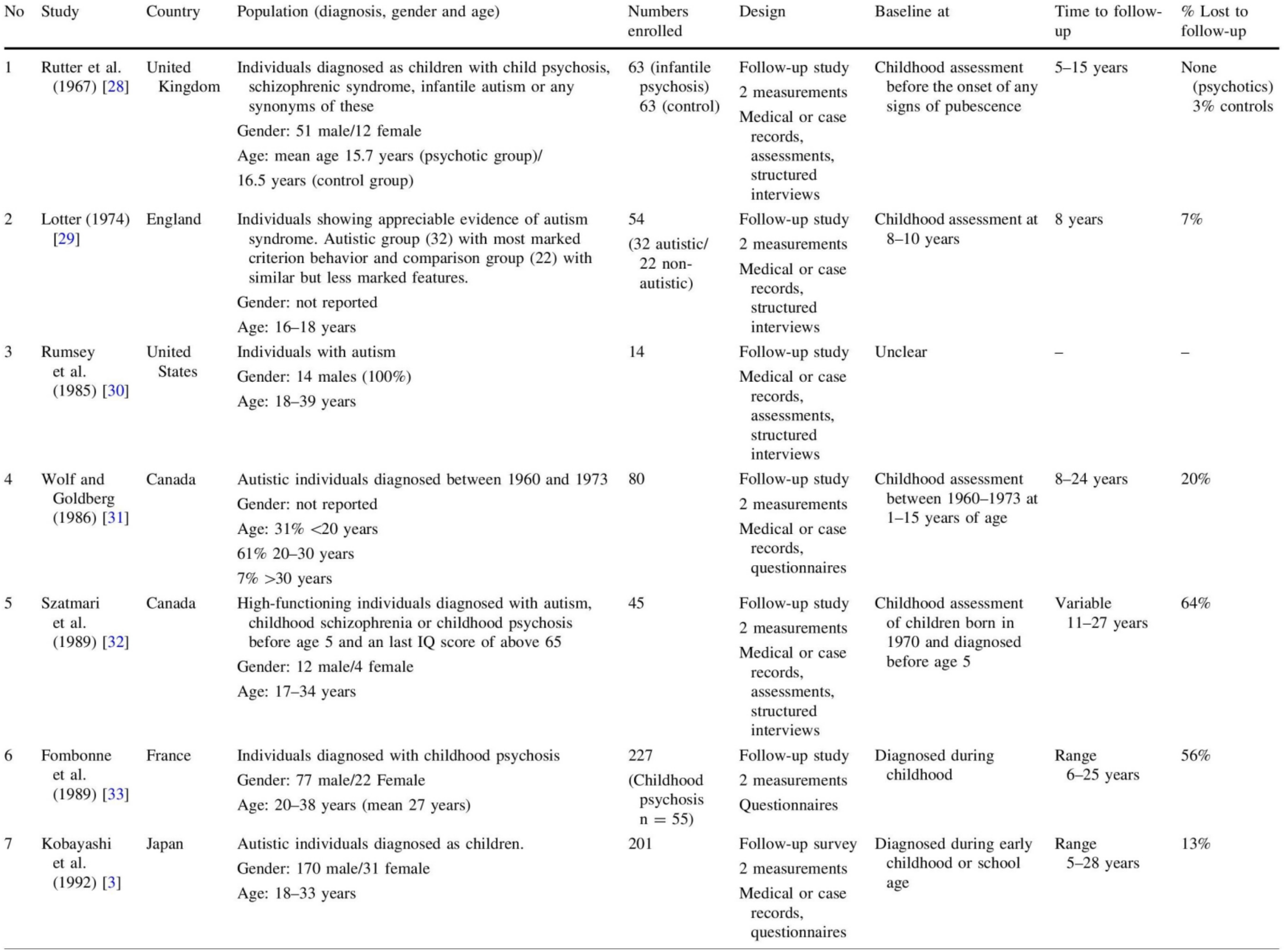
Key:

ABC = Autism Behaviour Checklist. ADI = Autism Diagnostic Interview. ADOS = Autism Diagnostic Observation Scale. CDI = Children's Depression Inventory. DAS = Disability Assessment Schedule. DICA = Diagnostic Interview for Children and Adolescents. DIS = NIMH Diagnostic Interview Schedule. K-SADS-E = Kiddie-Schedule for Affective Disorders and Schizophrenia-Epidemiological Version. OCHS-R = Ontario Child Health Study-Revised, Current age - not clear at what age symptoms started and treatment commenced. 'dk' means that the symptom/sign was not discussed in the article, not that the authors were unable to assess it. Similarly, 'no' means that the behaviour was discussed in the article, and either was not a problem or could not be assessed.

Source: Stewart, M. E., Barnard, L., Pearson, J., Hasan, R., & O'Brien, G. (2006). Presentation of depression in autism and Asperger syndrome: A review. *Autism*, *10*(1), 103-116, p. 108.

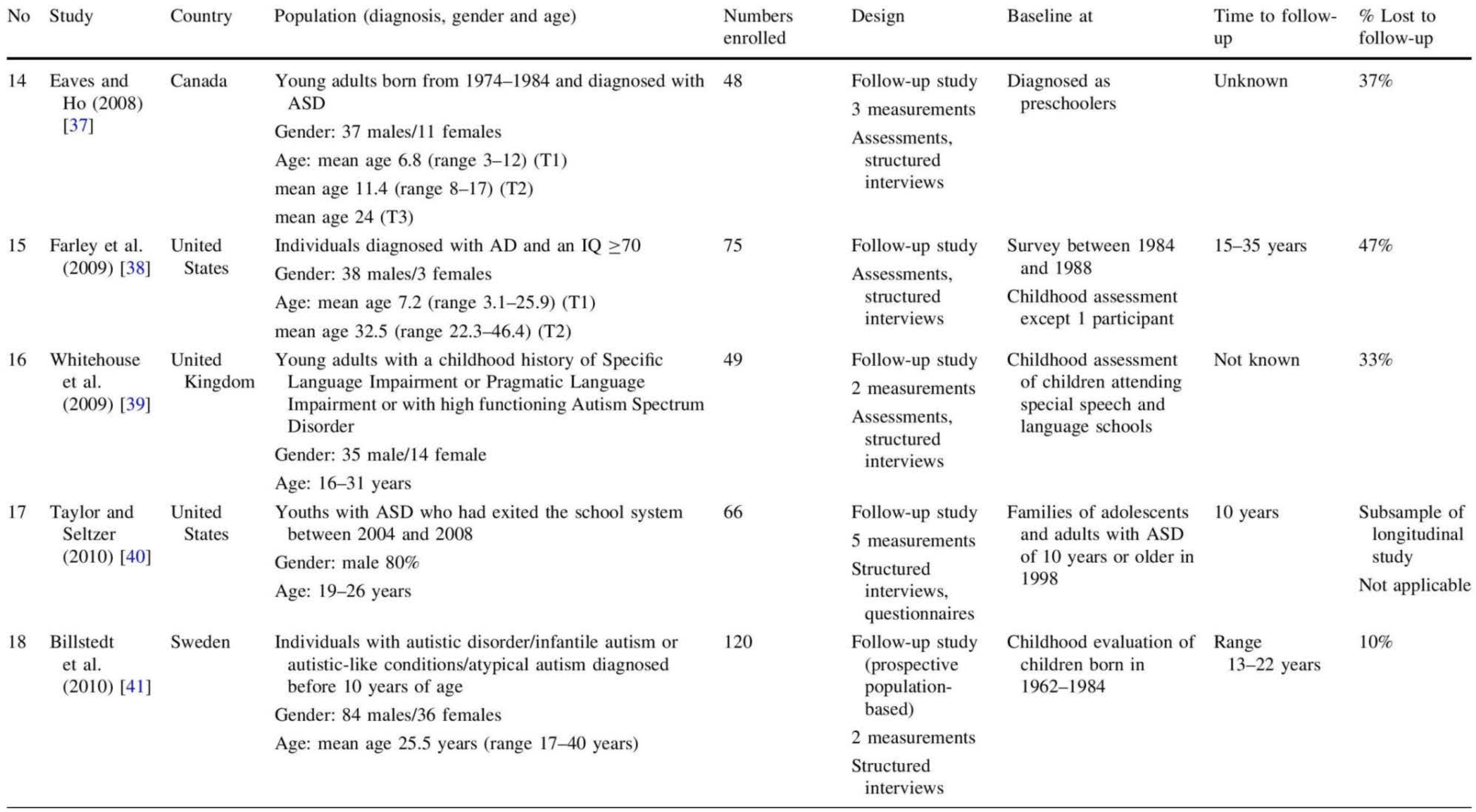
Appendix 3: A table of studies on employment participation for people with autism or Asperger syndrome

Table 1: Characteristics of studies on the employment participation for people with autism or Asperger syndrome



No	Study	Country	Population (diagnosis, gender and age)	Numbers enrolled	Design	Baseline at	Time to follow-up	% Lost to follow-up
1	Rutter et al. (1967) [28]	United Kingdom	Individuals diagnosed as children with child psychosis, schizophrenic syndrome, infantile autism or any synonyms of these Gender: 51 male/12 female Age: mean age 15.7 years (psychotic group)/ 16.5 years (control group)	63 (infantile psychosis) 63 (control)	Follow-up study 2 measurements Medical or case records, assessments, structured interviews	Childhood assessment before the onset of any signs of pubescence	5–15 years	None (psychotics) 3% controls
2	Lotter (1974) [29]	England	Individuals showing appreciable evidence of autism syndrome. Autistic group (32) with most marked criterion behavior and comparison group (22) with similar but less marked features. Gender: not reported Age: 16–18 years	54 (32 autistic/ 22 non-autistic)	Follow-up study 2 measurements Medical or case records, structured interviews	Childhood assessment at 8–10 years	8 years	7%
3	Rumsey et al. (1985) [30]	United States	Individuals with autism Gender: 14 males (100%) Age: 18–39 years	14	Follow-up study Medical or case records, assessments, structured interviews	Unclear	–	–
4	Wolf and Goldberg (1986) [31]	Canada	Autistic individuals diagnosed between 1960 and 1973 Gender: not reported Age: 31% <20 years 61% 20–30 years 7% >30 years	80	Follow-up study 2 measurements Medical or case records, questionnaires	Childhood assessment between 1960–1973 at 1–15 years of age	8–24 years	20%
5	Szatmari et al. (1989) [32]	Canada	High-functioning individuals diagnosed with autism, childhood schizophrenia or childhood psychosis before age 5 and an last IQ score of above 65 Gender: 12 male/4 female Age: 17–34 years	45	Follow-up study 2 measurements Medical or case records, assessments, structured interviews	Childhood assessment of children born in 1970 and diagnosed before age 5	Variable 11–27 years	64%
6	Fombonne et al. (1989) [33]	France	Individuals diagnosed with childhood psychosis Gender: 77 male/22 Female Age: 20–38 years (mean 27 years)	227 (Childhood psychosis n = 55)	Follow-up study 2 measurements Questionnaires	Diagnosed during childhood	Range 6–25 years	56%
7	Kobayashi et al. (1992) [3]	Japan	Autistic individuals diagnosed as children. Gender: 170 male/31 female Age: 18–33 years	201	Follow-up survey 2 measurements Medical or case records, questionnaires	Diagnosed during early childhood or school age	Range 5–28 years	13%

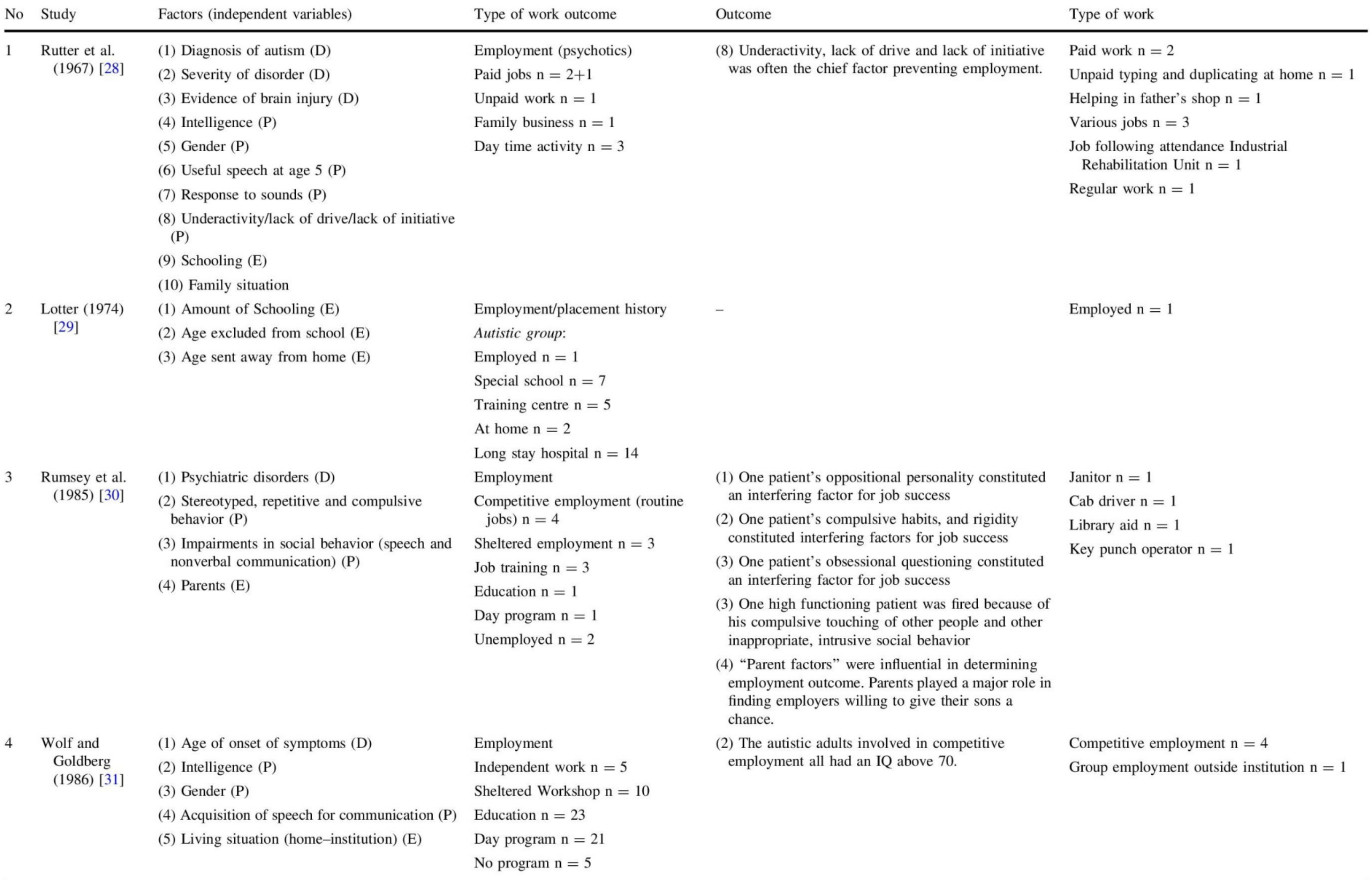
No	Study	Country	Population (diagnosis, gender and age)	Numbers enrolled	Design	Baseline at	Time to follow-up	% Lost to follow-up
8	Ruble and Dalrymple (1996) [34]	United States	Individuals diagnosed with autism meeting DSM-III-R criteria Gender: 33 male/13 female Age: mean age 8.5 years (range 2–19) (T1) mean age 17.1 years (range 7–26) (T2)	46	Follow-up study (retrospective) 2 measurements Medical or case records, structured interviews	Diagnosed in childhood (mean age at diagnosis 5.2 years)	Mean follow-up time 8.6 years	–
9	Ballaban-Gil et al. (1996) [4]	United States	Adolescents and young adults with autistic disorder Gender: not reported Age: 12 years or older (T2)	163	Follow-up study 2 measurements Medical or case records, structured interviews	Childhood evaluation from May 1966 to May 1988: mean age 5 years and 2 months	Range 3.2–22.7 years	39%
10	Larsen and Mouridsen (1997) [5]	Denmark	Individuals considered to be either psychotic or borderline cases and diagnosed with Pervasive Developmental Disorder (childhood autism or Asperger syndrome) Gender: 10 male/8 female Age: 32–44 years	18	Follow-up register study 2 measurements Medical or case records	Childhood assessment between 1949–1970	30 years	11%
11	Howlin et al. (2000) [35]	United Kingdom	Individuals (all male) with autism or with developmental language disorders Gender: 47 male (100%) Age: 23–24 years on average	47	Follow-up study (comparative) 2 measurements Assessments, structured interviews	Childhood assessment at 7–8 years	Around 15 years	17%
12	Howlin et al. (2004) [7]	England	Individuals diagnosed as having an autistic disorder. Gender: 61 males/7 females Age: 21–49 years	79 (68 participants)	Follow-up study 2 measurements Medical or case records, assessments, structured interviews	Childhood assessment prior to 16 years (range 3–15 years)	Variable (minimal 6 years)	14%
13	Cederlund et al. (2008) [36]	Sweden	Individuals with Asperger Syndrome and normal intelligence (IQ >70) and individuals diagnosed with autism or atypical autism before age 10 with different IQ levels Gender: 140 male (100%) Age: 16–38 years of age	140	Follow-up study (prospective) 2 measurements Medical or case records, assessments, structured interviews	*AS group*: Diagnosed between 1985–1999 at ages 5.5–24.4 years and born 1967–1988 *Autism group*: diagnosed before age 10	More than 5 years	30.0% in AS group 16.7% in autism group



No	Study	Country	Population (diagnosis, gender and age)	Numbers enrolled	Design	Baseline at	Time to follow-up	% Lost to follow-up
14	Eaves and Ho (2008) [37]	Canada	Young adults born from 1974–1984 and diagnosed with ASD Gender: 37 males/11 females Age: mean age 6.8 (range 3–12) (T1) mean age 11.4 (range 8–17) (T2) mean age 24 (T3)	48	Follow-up study 3 measurements Assessments, structured interviews	Diagnosed as preschoolers	Unknown	37%
15	Farley et al. (2009) [38]	United States	Individuals diagnosed with AD and an IQ ≥70 Gender: 38 males/3 females Age: mean age 7.2 (range 3.1–25.9) (T1) mean age 32.5 (range 22.3–46.4) (T2)	75	Follow-up study Assessments, structured interviews	Survey between 1984 and 1988 Childhood assessment except 1 participant	15–35 years	47%
16	Whitehouse et al. (2009) [39]	United Kingdom	Young adults with a childhood history of Specific Language Impairment or Pragmatic Language Impairment or with high functioning Autism Spectrum Disorder Gender: 35 male/14 female Age: 16–31 years	49	Follow-up study 2 measurements Assessments, structured interviews	Childhood assessment of children attending special speech and language schools	Not known	33%
17	Taylor and Seltzer (2010) [40]	United States	Youths with ASD who had exited the school system between 2004 and 2008 Gender: male 80% Age: 19–26 years	66	Follow-up study 5 measurements Structured interviews, questionnaires	Families of adolescents and adults with ASD of 10 years or older in 1998	10 years	Subsample of longitudinal study Not applicable
18	Billstedt et al. (2010) [41]	Sweden	Individuals with autistic disorder/infantile autism or autistic-like conditions/atypical autism diagnosed before 10 years of age Gender: 84 males/36 females Age: mean age 25.5 years (range 17–40 years)	120	Follow-up study (prospective population-based) 2 measurements Structured interviews	Childhood evaluation of children born in 1962–1984	Range 13–22 years	10%

Source: Holwerda, A., van der Klink, J. J. L., Groothoff, J. W., & Brouwer, S. (2012). Predictors for Work Participation in Individuals with an Autism Spectrum Disorder: A Systematic Review. *Journal of Occupational Therapy*, *22*(3), 333-352, pp. 337-339.

Table 2: Work outcome and related factors of studies listed in Table 1

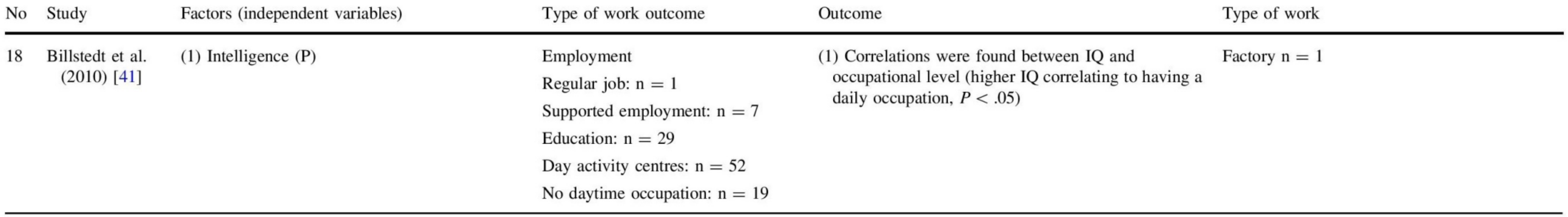


No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of work
1	Rutter et al. (1967) [28]	(1) Diagnosis of autism (D) (2) Severity of disorder (D) (3) Evidence of brain injury (D) (4) Intelligence (P) (5) Gender (P) (6) Useful speech at age 5 (P) (7) Response to sounds (P) (8) Underactivity/lack of drive/lack of initiative (P) (9) Schooling (E) (10) Family situation	Employment (psychotics) Paid jobs n = 2+1 Unpaid work n = 1 Family business n = 1 Day time activity n = 3	(8) Underactivity, lack of drive and lack of initiative was often the chief factor preventing employment.	Paid work n = 2 Unpaid typing and duplicating at home n = 1 Helping in father's shop n = 1 Various jobs n = 3 Job following attendance Industrial Rehabilitation Unit n = 1 Regular work n = 1
2	Lotter (1974) [29]	(1) Amount of Schooling (E) (2) Age excluded from school (E) (3) Age sent away from home (E)	Employment/placement history *Autistic group*: Employed n = 1 Special school n = 7 Training centre n = 5 At home n = 2 Long stay hospital n = 14	–	Employed n = 1
3	Rumsey et al. (1985) [30]	(1) Psychiatric disorders (D) (2) Stereotyped, repetitive and compulsive behavior (P) (3) Impairments in social behavior (speech and nonverbal communication) (P) (4) Parents (E)	Employment Competitive employment (routine jobs) n = 4 Sheltered employment n = 3 Job training n = 3 Education n = 1 Day program n = 1 Unemployed n = 2	(1) One patient's oppositional personality constituted an interfering factor for job success (2) One patient's compulsive habits, and rigidity constituted interfering factors for job success (3) One patient's obsessional questioning constituted an interfering factor for job success (3) One high functioning patient was fired because of his compulsive touching of other people and other inappropriate, intrusive social behavior (4) "Parent factors" were influential in determining employment outcome. Parents played a major role in finding employers willing to give their sons a chance.	Janitor n = 1 Cab driver n = 1 Library aid n = 1 Key punch operator n = 1
4	Wolf and Goldberg (1986) [31]	(1) Age of onset of symptoms (D) (2) Intelligence (P) (3) Gender (P) (4) Acquisition of speech for communication (P) (5) Living situation (home–institution) (E)	Employment Independent work n = 5 Sheltered Workshop n = 10 Education n = 23 Day program n = 21 No program n = 5	(2) The autistic adults involved in competitive employment all had an IQ above 70.	Competitive employment n = 4 Group employment outside institution n = 1

No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of work
5	Szatmari et al. (1989) [32]	(1) Aspects of cognition (P) (2) Impairments in social behavior (P) (3) Deviant language (P) (4) Bizarre behaviors (P)	Occupation or placement Paid employment n = 6 Family business n = 1 Sheltered work n = 4 Education n = 3 Unemployed n = 2	–	Teacher-tutor n = 1 Librarian n = 1 Salesman n = 2 Library technician n = 1 Factory n = 1 Family business n = 1 Workshop n = 4
6	Fombonne et al. (1989) [33]	(1) Age of admission (P) (2) Length of stay (E) (3) Gender (P) (4) Intelligence at time of admission (P) (5) Treatment (E) (a.o. psychotherapie, speech therapy, remedial gymnastics) (6) Medication	Employment 55%	–	–
7	Kobayashi et al. (1992) [3]	(1) IQ at age 6 (P) (2) Level of speech development at age 6 (P)	Employment (21.8%) Paid jobs (mainly manual or industrial workers) n = 41 Family business n = 2 Education n = 11 Sheltered workshop n = 27 At home n = 18	–	Laundry n = 4 Bus conductor n = 1 Chikuwa maker n = 1 Paper maker n = 1 Food maker n = 9 Tatami maker n = 2 Civil servant/office worker n = 3 Auto mechanic n = 1 Helper n = 2 Industrial worker n = 9 Physical therapist n = 1 Printer n = 1 Trash collector n = 2 Tile roofer n = 1 Confectionary maker n = 1 Construction/Assistant plasterer n = 2 Dressmaker n = 1
8	Ruble and Dalrymple (1996) [34]	(1) Cognitive level (IQ) (P) (2) Communication (P) (3) Challenging behavior (P)	Employment (adults) Supported employment n = 1 Sheltered employment n = 7 Daily living programs n = 3 No program n = 4 In institution n = 2	–	–

No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of work
9	Ballaban-Gil et al. (1996) [4]	(1) Intelligence (P) (2) Language (P) (3) Behavior (P) (4) Social deficits/impairment (P)	Employment adults (n = 45) Open employment (menial jobs) n = 5 Sheltered workshops n = 6 Self employment n = 2 Education n = 7	–	Only 11% of adults were employed on the open market, all in menial jobs such as stock boy or mail clerk (n = 5) Sheltered workshops n = 6
10	Larsen and Mouridsen (1997) [5]	(1) Diagnosis of autism (D) (2) Intensity of autistic symptoms (D) (3) Intelligence (P) (4) Psychiatric morbidity (D) (5) Pharmacotherapy (E)	Employment *Asperger group*: Paid job n = 1 Sheltered employment n = 2 Disability pension n = 5 *Childhood autism group*: Paid job n = 2 Sheltered employment n = 1 Daytime program n = 5	(1) In middle adulthood the Childhood Autism group has a much poorer outcome regarding education and employment than the Asperger group.	Insulator n = 1 Porcelain painter n = 1 Kindergarten teacher n = 1 Received vocational training n = 4 Before working as a driver/fish industry n = 1 Fully-paid unskilled work before n = 4
11	Howlin et al. (2000) [35]	(1) Diagnosis of autism (2) Intelligence (P) (3) Psychiatric problems (D) (4) Early language abilities (P) (5) Autistic-like stereotyped and repetitive behavior patterns (P)	Education and employment histories *Autism group*(*n = 19*): Independent jobs n = 1 Fulltime education n = 2 Voluntary work n = 3 Daytime centres n = 12 No occupation n = 1	–	Laboratory technician n = 1
12	Howlin et al. (2004) [7]	(1) Childhood IQ (P) (2) Gender (P) (3) Speech at 5 years (P) (4) Autistic-type behaviors (P) (5) Social functioning (P)	Employment Independent jobs n = 8 Self employed n = 1 Sheltered employment n = 11 Daily activities by centre n = 15 Family based work activities n = 2 Voluntary work n = 1 No work activities n = 28 Not known n = 2	(1) Individuals with a stable IQ from childhood to adulthood above 70 were more often in some form of employment (paid, voluntary or sheltered) ($P = .005$)	Scientific officer oil company n = 1 Electrical work n = 1 Cartographer n = 1 Postal assistant n = 1 Factory work n = 5 Computing n = 1 Accounts n = 1 Fabric design n = 1 Washing up n = 1 Grave digger n = 1 Office/accounts assistant n = 1 Charcoal burning/gardening n = 1 Administrative assistant n = 1 Data input n = 1 Supermarket trolleys n = 1 Electronic work n = 1 Special shop n = 1 Decorating with father n = 1 Office with parents n = 1

No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of work
13	Cederlund et al. (2008) [36]	(1) Diagnosis of autism (D) (2) Intelligence (P) (3) Psychotic disorder (D)	Employment *Asperger group*: ordinary jobs n = 7 "daily occupational activities" in a group centre n = 6 no organized daily activity n = 12 *Autism group*: ordinary job n = 1 "daily occupational activities" in a group centre n = 4 regular individually tailored daily activities n = 33 no organized daily activity n = 13	–	Ordinary jobs n = 8 Daily occupational activities n = 10
14	Eaves and Ho (2008) [37]	(1) Diagnosis (autism score) in adolescence (D) (2) Childhood and adolescence intensity of autistic symptoms (CARS) (D) (3) Childhood and adolescence verbal and Performance IQ (P)	Employment 56% (n = 27) had ever been employed, most in volunteer, sheltered or part time work Independent job n = 2 Daytime activity n = 19 (40%)		Delivering papers Meals on wheels Sorting recycle
15	Farley et al. (2009) [38]	(1) Psychiatric disorders (D) (2) Epilepsy (D) (3) Other medical disorders (D) (4) Historical full scale IQ (P) (5) Level of speech development at age 6 (P) (6) Adaptive behavior (P)	Employment Independent paid jobs n = 22 Supported employment n = 3 Voluntary work n = 2 Day programs n = 10 Unemployed n = 4	(1) In spite of high IQ scores and adequate practical skills, some participants were unable to seek employment due to difficulties with anxiety.	–
16	Whitehouse et al. (2009) [39]	(1) Diagnosis of autism (D) (2) Intensity of autistic symptoms (D) (3) Psychiatric problems (D) (3) Language ability (pragmatic or structural problems) (P) (4) Stereotyped and repetitive behaviors (5) Social impairments	Employment *Autism group* (*n = 11*): Education n = 5 Paid employment n = 5 Never employed n = 1	(1) Stable employment proved to be an area of difficulty for the ASD group.	Factory workers n = 2 Cleaners n = 3
17	Taylor and Seltzer (2010) [40]	(1) Autistic symptoms (D) (2) Intellectual disability (P) (3) Comorbid psychiatric diagnoses (D) (4) Maladaptive behaviors (P) (5) Functional independence (P) (6) Family income (E)	Employment College/university n = 9 Competitive employment n = 4 Supported employment n = 8 Adult day services n = 37 No regular activities n = 8	(1) Young adults who were competitively employed had fewer autism symptoms than those who had a supported job or were receiving adult day services ($P < .01$) (2) There was a significant relation between employment/day activity categories and ID status ($P < .001$)/Adults without ID were three times more likely to be competitively employed than those with ID, although percentages in supported employment were similar (4) Adults who were receiving adult day services had significantly more maladaptive behaviors than individuals who were in a post-secondary education program or competitively employed ($P < .05$)	Competitive: Bus boy Replacing dirty glasses with clean ones Salvation Army Bead business (self employed) Supported: Rolling silverware into napkins in restaurant Folding towels in hotel Shredding confidential information Washing dishes at a nursing Working in a grocery store

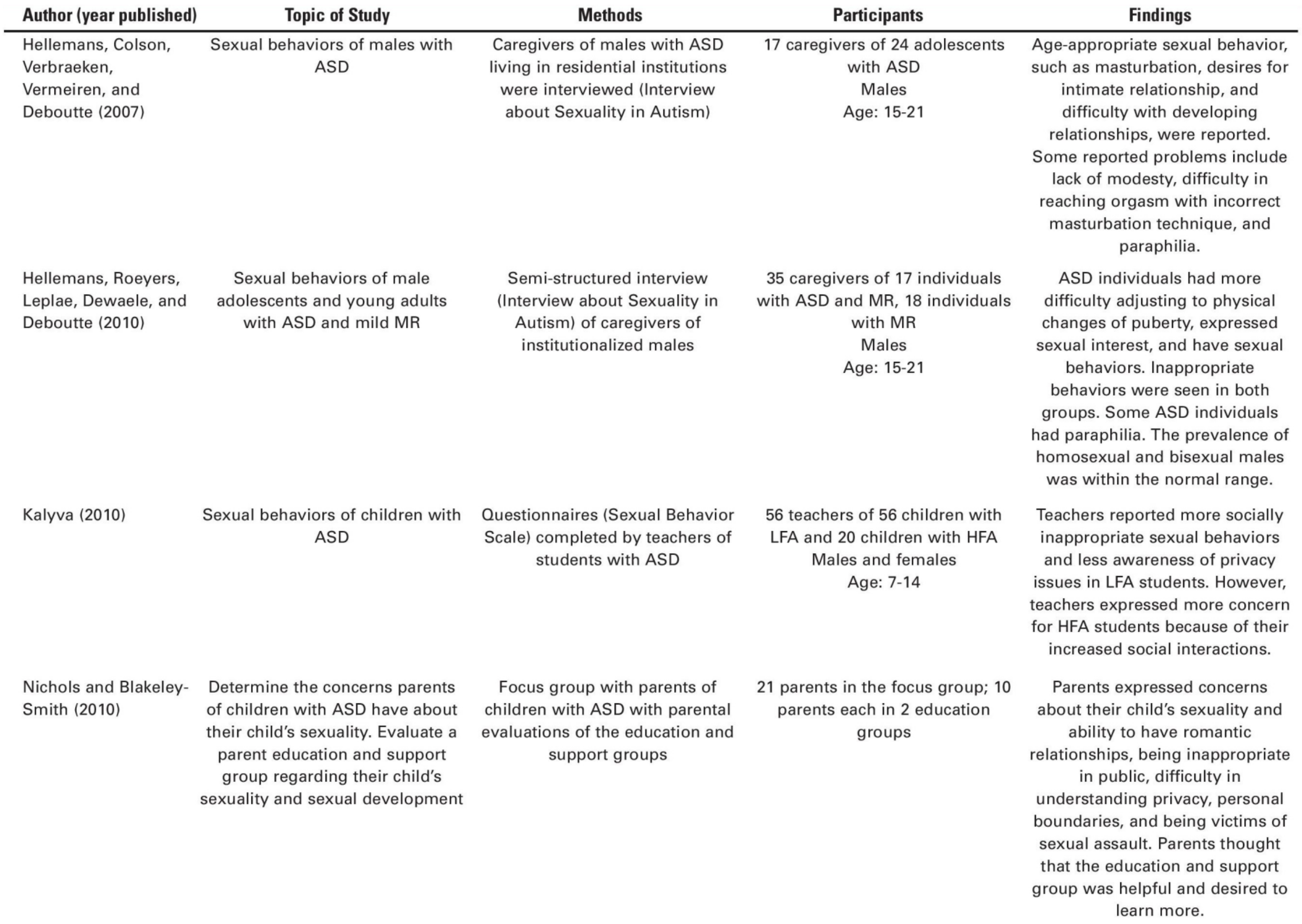


No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of work
18	Billstedt et al. (2010) [41]	(1) Intelligence (P)	Employment Regular job: n = 1 Supported employment: n = 7 Education: n = 29 Day activity centres: n = 52 No daytime occupation: n = 19	(1) Correlations were found between IQ and occupational level (higher IQ correlating to having a daily occupation, $P < .05$)	Factory n = 1

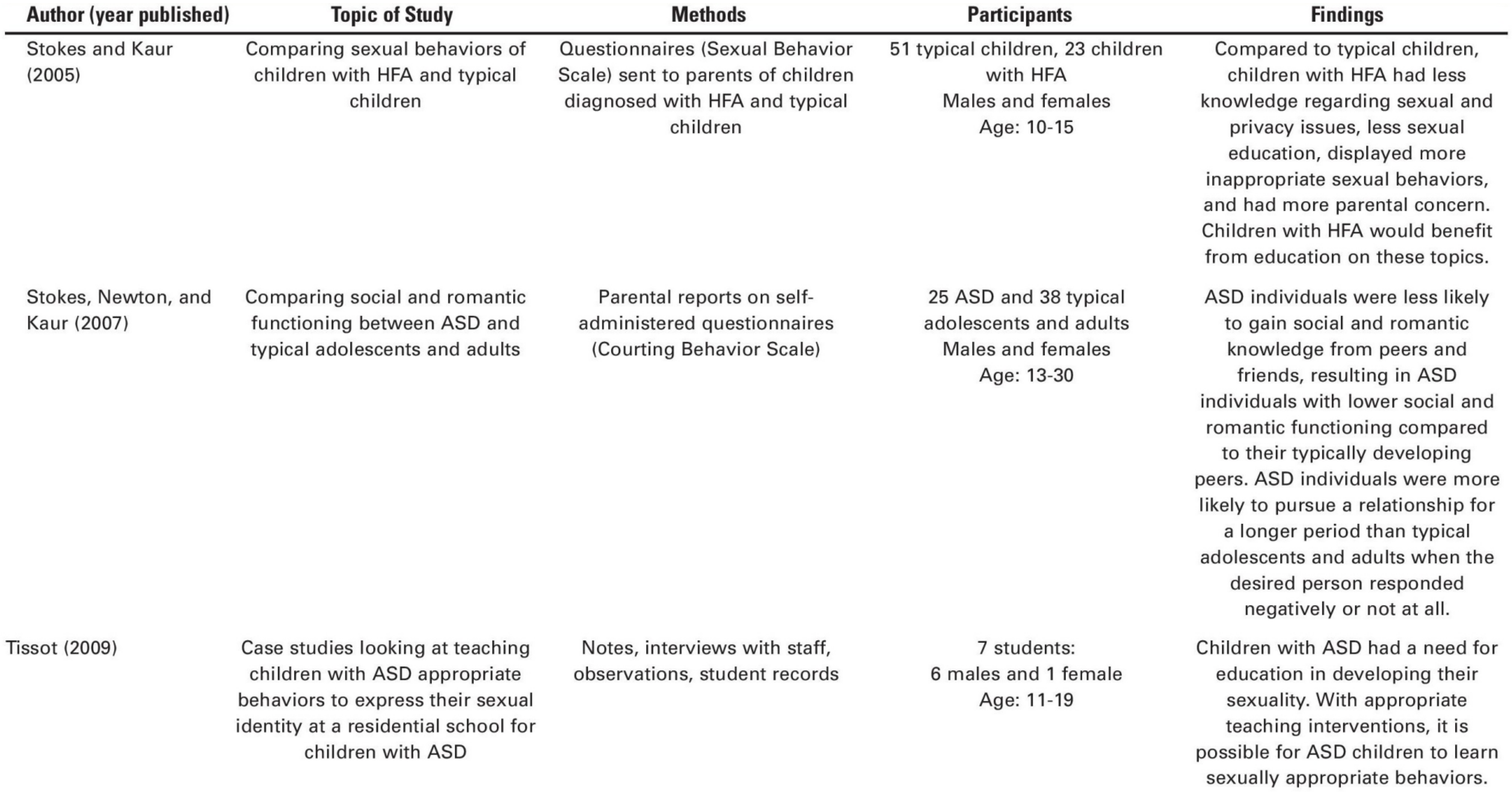
Key: D = Disease/disorder related factor, P = Personal factor, E = External factor.

Source: Holwerda, A., van der Klink, J. J. L., Groothoff, J. W., & Brouwer, S. (2012). Predictors for Work Participation in Individuals with an Autism Spectrum Disorder: A Systematic Review. *Journal of Occupational Therapy*, *22*(3), 333-352, pp. 342-346.

Appendix 4: A table of studies on people with autism or Asperger syndrome and their sexual behaviours



Author (year published)	Topic of Study	Methods	Participants	Findings
Hellemans, Colson, Verbraeken, Vermeiren, and Deboutte (2007)	Sexual behaviors of males with ASD	Caregivers of males with ASD living in residential institutions were interviewed (Interview about Sexuality in Autism)	17 caregivers of 24 adolescents with ASD Males Age: 15-21	Age-appropriate sexual behavior, such as masturbation, desires for intimate relationship, and difficulty with developing relationships, were reported. Some reported problems include lack of modesty, difficulty in reaching orgasm with incorrect masturbation technique, and paraphilia.
Hellemans, Roeyers, Leplae, Dewaele, and Deboutte (2010)	Sexual behaviors of male adolescents and young adults with ASD and mild MR	Semi-structured interview (Interview about Sexuality in Autism) of caregivers of institutionalized males	35 caregivers of 17 individuals with ASD and MR, 18 individuals with MR Males Age: 15-21	ASD individuals had more difficulty adjusting to physical changes of puberty, expressed sexual interest, and have sexual behaviors. Inappropriate behaviors were seen in both groups. Some ASD individuals had paraphilia. The prevalence of homosexual and bisexual males was within the normal range.
Kalyva (2010)	Sexual behaviors of children with ASD	Questionnaires (Sexual Behavior Scale) completed by teachers of students with ASD	56 teachers of 56 children with LFA and 20 children with HFA Males and females Age: 7-14	Teachers reported more socially inappropriate sexual behaviors and less awareness of privacy issues in LFA students. However, teachers expressed more concern for HFA students because of their increased social interactions.
Nichols and Blakeley-Smith (2010)	Determine the concerns parents of children with ASD have about their child's sexuality. Evaluate a parent education and support group regarding their child's sexuality and sexual development	Focus group with parents of children with ASD with parental evaluations of the education and support groups	21 parents in the focus group; 10 parents each in 2 education groups	Parents expressed concerns about their child's sexuality and ability to have romantic relationships, being inappropriate in public, difficulty in understanding privacy, personal boundaries, and being victims of sexual assault. Parents thought that the education and support group was helpful and desired to learn more.



Author (year published)	Topic of Study	Methods	Participants	Findings
Stokes and Kaur (2005)	Comparing sexual behaviors of children with HFA and typical children	Questionnaires (Sexual Behavior Scale) sent to parents of children diagnosed with HFA and typical children	51 typical children, 23 children with HFA Males and females Age: 10-15	Compared to typical children, children with HFA had less knowledge regarding sexual and privacy issues, less sexual education, displayed more inappropriate sexual behaviors, and had more parental concern. Children with HFA would benefit from education on these topics.
Stokes, Newton, and Kaur (2007)	Comparing social and romantic functioning between ASD and typical adolescents and adults	Parental reports on self-administered questionnaires (Courting Behavior Scale)	25 ASD and 38 typical adolescents and adults Males and females Age: 13-30	ASD individuals were less likely to gain social and romantic knowledge from peers and friends, resulting in ASD individuals with lower social and romantic functioning compared to their typically developing peers. ASD individuals were more likely to pursue a relationship for a longer period than typical adolescents and adults when the desired person responded negatively or not at all.
Tissot (2009)	Case studies looking at teaching children with ASD appropriate behaviors to express their sexual identity at a residential school for children with ASD	Notes, interviews with staff, observations, student records	7 students: 6 males and 1 female Age: 11-19	Children with ASD had a need for education in developing their sexuality. With appropriate teaching interventions, it is possible for ASD children to learn sexually appropriate behaviors.

Key: ASD = Autism Spectrum Disorder; MR = Mental Retardation; LFA = Low Functioning Autism; HFA = High Functioning Autism

Source: Chan, J., & John, R. M. (2012). Sexuality and Sexual Health in Children and Adolescents with Autism. *The Journal for Nurse Practitioners*, *8*(4), 306-316, pp. 308-309.

Appendix 5: The telephone script used by the support staff at Community Bridging Services [CBS]

Please note this is a guide as each telephone conversation will be different.

1. **Greeting**

    - Good morning/afternoon.

    - My name is XXXX from XXXXX Services.

    - Is this a good time to speak to you?
        - If "YES": Go to section 2 "Introduce the research and the researcher"
        - If "NO": Ask if you can telephone back later and at what time.

2. **Introduce the research and the researcher**

    - Mr. Matthew Bennett is a Flinders University PhD candidate and he would like to ask you about your life experiences of living with Asperger syndrome.

    - He would like to interview you twice and each interview session will be between 45 minutes to an hour in length.

    - At the end of each interview session you will receive a 25 dollar Myers, JB HI-FI or Westfield gift voucher.

    - Participation in this project is voluntary and you can withdraw from the project at any time without any repercussions to yourself or anyone else.

    - Your information will be kept confidential and XXXX Services will not have access to the information you disclose to Mr. Matthew Bennett.

    - Would you be interested in participating in this project?
        - If "YES": Do you agree for Mr. Matthew Bennett to contact you?
            - If "YES": CBS staff member to place a tick next to the name on the contact list.
            - If "NO": End the telephone call.

        - If "NO": End the telephone call.

        - If "UNSURE": If the participant is unsure then ask them whether Mr. Matthew Bennett can get in contact?
            - If "YES": CBS staff member to place a tick next to the name on the contact list.
            - If "NO": End the telephone call.

Appendix 6: The advertisement placed on the ‘Latest Research Projects and Surveys’ section of AutismSA’s website

Project title: A life span perspective of Asperger syndrome: a phenomenological study which explores the life experiences of twelve adults with Asperger syndrome

Status: Currently Recruiting Participants!

Primary researcher: Matthew Bennett

Institution(s): Flinders University

Project summary: This project will explore the life experiences of adults with Asperger syndrome. The life experiences, which will be explored, include marriage, family relations, education, employment, health and welfare and self-perceptions of Asperger syndrome. The adults recruited will be interviewed twice and each interview session will last between thirty-five to sixty minutes in length. In the first interview session the participants will be asked a series of questions about their life experiences. In the second interview session the participants will review their answers from the first interview sessions and will discuss some more of their life experiences. If you are interested, please download the information sheet and contact Matthew Bennett on 0431 154 925 or email benn0299@flinders.edu.au.

Eligible participants: People aged 18 years and over with a diagnosis of Asperger syndrome

Further information: Download Information Sheet

Date posted: September 2011 **ID:** PP201103

Appendix 7 - Ethics approval from Flinders University

Flinders University and Southern Area Health Service

SOCIAL AND BEHAVIOURAL RESEARCH ETHICS COMMITTEE

Research Services Office, Union Building, Flinders University
GPO Box 2100, ADELAIDE SA 5001
Phone: (08) 8201 3116
Email: human.researchethics@flinders.edu.au

FINAL APPROVAL NOTICE

Principal Researcher:	Mr Matthew Bennett
Email:	matthew.bennett@postgrads.unisa.edu.au
Address:	68 Buucaut Avenue, Klemzig SA 5087
Project Title:	A life span perspective of Aspergers syndrome. A phenomennological study which explores the life experiences of twelve adults with Asperger syndrome

Project No.:	**5113**	Final Approval Date:	10 February 2011	Approval Expiry Date:	**4 June 2018**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

If you have any outstanding permission letters (item D8), that may have been previously requested, please ensure that they are forwarded to the Committee as soon as possible. Additionally, for projects where approval has also been sought from another Human Research Ethics Committee (item G1), please be reminded that a copy of the ethics approval notice will need to be sent to the Committee on receipt.

In accordance with the undertaking you provided in your application for ethics approval for the project, please inform the Social and Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion.

You are also required to report anything which might warrant review of ethical approval of the protocol. Such matters include:

- serious or unexpected adverse effects on participants;
- proposed changes in the protocol (modifications);
- any changes to the research team; and
- unforeseen events that might affect continued ethical acceptability of the project.

To modify/amend a previously approved project please either mail or email a completed copy of the Modification Request Form to the Executive Officer, which is available for download from http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-and-behavioural-research-ethics-committee/notification-of-committee-decision.cfm. Please ensure that any new or amended participant documents are attached to the modification request.

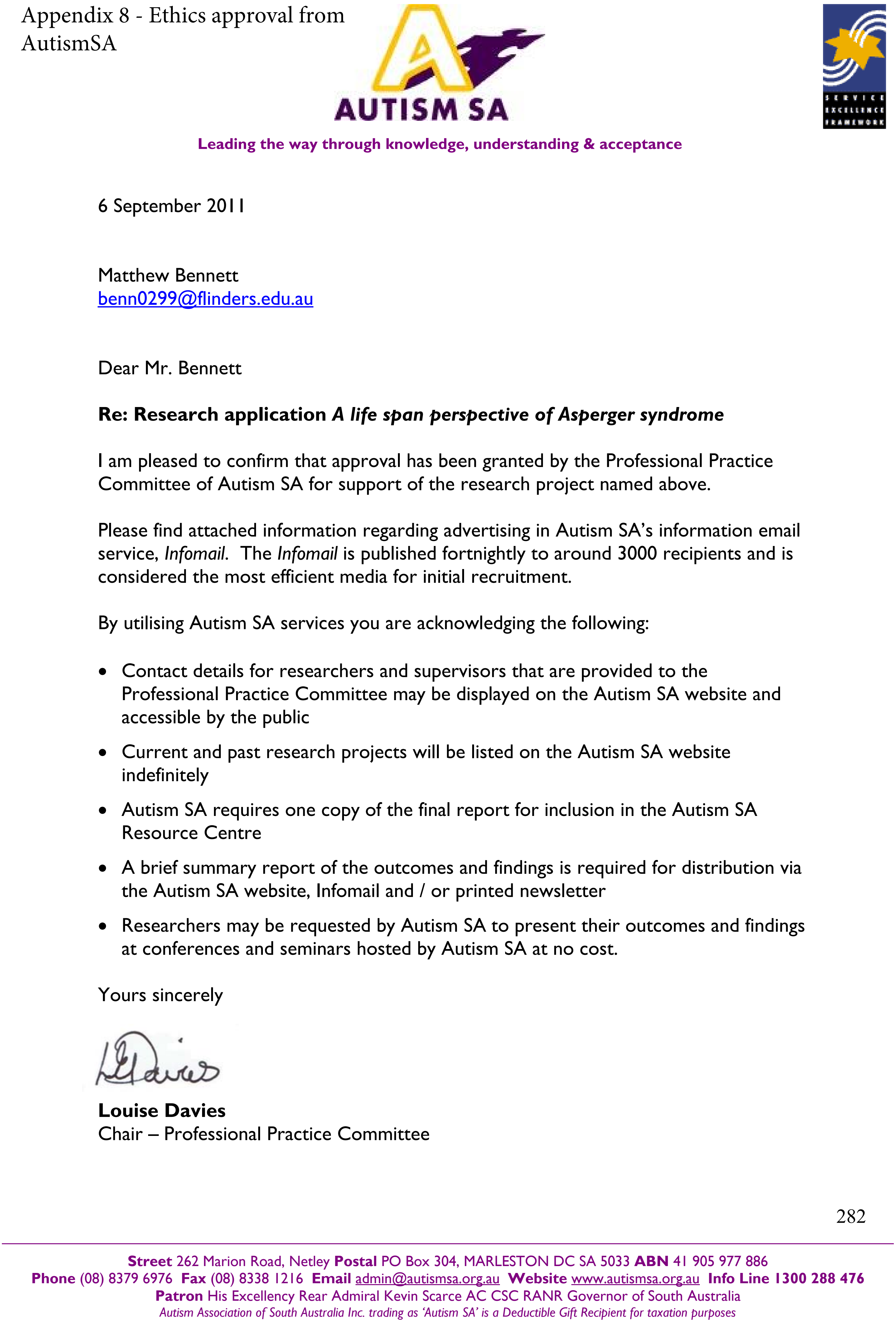
In order to comply with monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress and/or final report must be submitted. A copy of the pro forma is available from http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-behavioural.cfm.

Your first report is due on **10 February 2012** or on completion of the project, whichever is the earliest. *Please retain this notice for reference when completing annual progress or final reports.* If an extension of time is required, please email a request for an extension of time, to a date you specify, to human.researchethics@flinders.edu.au before the expiry date.

Andrea Mather (formerly Jacobs)
Executive Officer
Social and Behavioural Research Ethics Committee
11 February 2011

c.c Dr Brian Matthews, brian.matthews@flinders.edu.au
Dr Caroline Ellison, caroline.ellison@flinders.edu.au

Appendix 8 - Ethics approval from AutismSA



AUTISM SA

SERVICE EXCELLENCE FRAMEWORK

Leading the way through knowledge, understanding & acceptance

6 September 2011

Matthew Bennett
benn0299@flinders.edu.au

Dear Mr. Bennett

Re: Research application *A life span perspective of Asperger syndrome*

I am pleased to confirm that approval has been granted by the Professional Practice Committee of Autism SA for support of the research project named above.

Please find attached information regarding advertising in Autism SA's information email service, *Infomail*. The *Infomail* is published fortnightly to around 3000 recipients and is considered the most efficient media for initial recruitment.

By utilising Autism SA services you are acknowledging the following:

- Contact details for researchers and supervisors that are provided to the Professional Practice Committee may be displayed on the Autism SA website and accessible by the public
- Current and past research projects will be listed on the Autism SA website indefinitely
- Autism SA requires one copy of the final report for inclusion in the Autism SA Resource Centre
- A brief summary report of the outcomes and findings is required for distribution via the Autism SA website, Infomail and / or printed newsletter
- Researchers may be requested by Autism SA to present their outcomes and findings at conferences and seminars hosted by Autism SA at no cost.

Yours sincerely

Louise Davies
Chair – Professional Practice Committee

Street 262 Marion Road, Netley **Postal** PO Box 304, MARLESTON DC SA 5033 **ABN** 41 905 977 886
Phone (08) 8379 6976 **Fax** (08) 8338 1216 **Email** admin@autismsa.org.au **Website** www.autismsa.org.au **Info Line 1300 288 476**
Patron His Excellency Rear Admiral Kevin Scarce AC CSC RANR Governor of South Australia
Autism Association of South Australia Inc. trading as 'Autism SA' is a Deductible Gift Recipient for taxation purposes

Appendix 9: Participant information handout

Flinders University and Southern Adelaide Health Service
Social and Behavioural Research Ethics Committee

Participant Information Sheet

- ***A description of the project in language appropriate to the audience***

The aim of this project is to explore the life experiences of adults with Asperger syndrome. The life experiences, which will be explored, include marriage, family relations, education, employment, health and welfare and self-perceptions of Asperger syndrome.

The participants will be interviewed twice and each interview session will last between thirty-five to sixty minutes in length. In the first interview session the participants will be asked a series of questions about their life experiences. In the second interview session the participant will review their answers from the first interview session and will discuss some more of their life experiences.

- ***An explanation of the participant's role in the project***

The participant's role is to provide in-depth information about their life experiences of having Asperger syndrome.

- ***Alternatives to participation***

The participants are expected to attend two interview sessions. There are no alternatives to participation.

- ***How the research will be monitored***

The progress of this research will be monitored by the researcher's Principal Supervisor, Dr. Brian Matthews, who can be contacted via the following contact details:

Postal Address
Dr. Brian Matthews
Disability and Community Inclusion
Faculty of Health Sciences
GPO Box 2100
ADELAIDE
SA 5001

Telephone number
08 8201 3448

Fax Number
08 8201 3646

Email
Brian.Matthews@flinders.edu.au

- ***Provision of services to participants adversely affected by the research, ie a list of free counselling services***

Prior to the beginning of the first and second interview session the participant will be provided with a list of counselling services.

- ***Contact details of the researchers***

Please find enclosed below the researcher's contact details:

Postal Address
Dr. Brain Matthews care of Mr. Matthew Bennett
Disability and Community Inclusion
Faculty of Health Sciences
GPO Box 2100
ADELAIDE
SA 5001

Email address
benn0299@flinders.edu.au

Phone number
0431 154 925

- ***How the participant's privacy and confidentiality will be protected***

The researcher will maintain the participant's confidentiality by replacing any specific data items which could be used to identify the participants with pseudonyms.

Among other things the specific data items which will be replaced with pseudonyms in the final thesis include the following:

1. The personal name and age of the participants or their immediate friends and family.
2. The participant's residential location. For example, a street address or suburb.
3. Named facilities or service providers. For example, the name of the participant's employer.
4. Important participant dates. For example, date of a hospital operation.
5. Unique characteristics of the participant. For example, a rare health condition or occupation.
6. Highly visible characteristics of the participant. For example, ethnicity or a visible disability.

- ***The participant's right to withdraw from further participation at any stage, along with any implications of withdrawal, and whether it will be possible to withdraw data***

The participants are advised that they can withdraw from the study at any time during the interview sessions and do not need to give any reason for their decision.

Upon withdrawing from the study the participants can have their responses to the interview questions removed from the thesis and from all electronic storage devices (i.e. USB Drives and Hard Disk Drives) and Hardcopy storage unites (i.e. Flinders University and the researcher's locked filing cabinets).

- ***Amounts and sources of funding for the research***

Please note that all funding for this research project will come from the Flinders University Student Maintenance Fund.

- ***Re-imbursement of costs to participants***

The participant will receive one $25.00 gift voucher for the first interview session and another $25.00 gift voucher for the second interview session. They will receive a total of $50.00 in gift vouchers. The gift vouchers offered include either a JB HI-FI Gift Voucher or a Westfield Gift Voucher.

- ***The likelihood and form of dissemination of the research results, including publication***

The participants' responses to the interview questions will be placed into the final thesis and into any journal articles in a de-identified form.

- ***Expected benefits to the wider community***

The expected benefits of this project to the wider community include:

1. Highlight the benefits which adults with Asperger syndrome bring to their society.
2. Contribute to the current body of scientific knowledge about Asperger syndrome.
3. Create and share knowledge, strategies and ideas which will enhance the public's understanding of Asperger syndrome.

Appendix 10: Consent form

CONSENT FORM FOR PARTICIPATION IN RESEARCH

by interview

I ………………………………………………………………………………………………………

being over the age of 18 years hereby consent to participate as requested in the letter of introduction for the research project on adults with Asperger syndrome and life experiences.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio and/or video recording of my information and participation.
4. I am aware that I should retain a copy of the Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I agree/do not agree to the tape/transcript being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.

Participant's signature……………………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name Mr. Matthew Bennett

Researcher's signature………………………………………..Date……………………

NB: Two signed copies should be retained.

7. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature……………………………………………Date…………………...

Appendix 11: Interview questions

First Interview Session - *Asperger syndrome and self-perceptions*

1. How old were you when you were diagnosed with Asperger syndrome?

2. Can you describe the process you went through to obtain a diagnosis of Asperger syndrome? (i.e. Did someone like a family member or friend suggest you get a diagnosis?, What were your initial thoughts on the subject?)

3. How would you describe Asperger syndrome to someone who has never heard of it before?

4. Throughout my research I have discovered both positive and negative aspects of having Asperger syndrome. Can you provide some examples of some:

   (4.1) Positive aspects?

   (4.2) Negative aspects?

5. Have you told your friends that you have Asperger syndrome?

   (Yes: 5.1) If yes, how did they respond?

   (No: 5.1) If no, why have you not told them?

   (Addition: 5.1) Are there any people who you have not told and why?

6. Do you think other people's expectations of you have changed when they found out that you had Asperger syndrome?

   (Yes: 6.1) If yes, what has changed? (ie. How do they respond to you differently from the way they did before?)

   (No: 6.1) If no, what things have you noticed about their behaviour which makes you think that their expectations of you have not changed?

7. What do you think the Australian community's perception of Asperger syndrome is? That is, what types of statements do you think an average person would make about someone with Asperger syndrome?

8. If you were given a choice would you choose to keep your Asperger syndrome?

   (Yes: 8.1) If yes, what is it that would make you want to keep the condition?

   (No: 8.1) If no, what is it that would make you want to reject the condition?

9. According to several studies depression is very common for adults with Asperger syndrome. Have you ever experienced any episodes of depression?

   (Yes: 9.1) If yes, can you describe what depression has been like for you?

Education

1. Tell me about your school days? (i.e. What was your favourite subject, teachers and things you didn’t like?)

2. Describe, with examples if possible, some of the ways your Asperger syndrome has had a negative impact upon your experiences in education?

3. What are some of the ways your Asperger syndrome has had a positive impact upon your experiences in education? Please give examples.

4. Can you give any other examples of how Asperger syndrome affected you at school?

5. There is some literature which suggests that children with Asperger syndrome are bullied at school. Bullying can include being called names, being physically assaulted or being placed into positions where you feel intimidated or threatened. Whilst at school were you bullied?

   (Yes: 5.1) If yes, do you think that your Asperger syndrome contributed to you being bullied at school? Please give examples

   (Yes: 5.2) If yes, can you share with me some of the coping tools you used to help you get through school?

   (No: 5.1) If no, what were some of the protection strategies used at school to protect you from being bullied? For instance, supportive teachers, school bullying reporting procedures or any other strategies that you remember.

6. Have you done any studies at University or TAFE?

   (Yes: 6.1) If yes, what did you study and what were you hoping to achieve?

   (Yes: 6.2) If yes, how has your Asperger syndrome impacted upon your studies? (i.e., has it had an impact upon your concentration, attention to detail or memory? Please give examples of any positive or negative affects you experienced)

   (No: 6.1) If no, would you like to study and what would you aim to achieve through this?

7. Often people with Asperger syndrome have a fixation on routines. Whilst at school/University or TAFE did you have any routines (i.e., having a particular lunch meal on a particular day)?

   (Yes: 7.1) If yes, can you describe how you felt and what you did when those routines were disrupted?

Second Interview Session

Use twenty minutes to ask supplementary and clarifying questions for the first interview

Employment

1. Are you currently employed?

    (Yes: 1.1) If yes, how has your Asperger syndrome affected you in your job?

    (Yes: 1.2) If yes, what are some of the tasks you like doing in your current job?

    (Yes: 1.3) If yes, what are some of the challenges you have within your current job? (i.e. social difficulties, sensory difficulties)

    (Yes: 1.4) If yes, do your work colleagues know that you have Asperger syndrome?
    If yes, what was it that made you decide to tell them?
    If no, what was it that made you decide not to tell them that you have Asperger syndrome?

    (Yes: 1.5) If yes, often in the workplace it is important to communicate with other employees and your employer. Have you ever experienced any communication difficulties in the workplace?
    If yes, can you provide me with examples of these difficulties?
    If no, what is it about the behaviour of your work mates that makes you think you have not experienced any communication difficulties in the workplace?

    (No: 1.1) If no, have you ever worked?

2. What are some of the jobs that you have had in your career?

3. Have you experienced a job that really suited you?

    (Yes: 3.1) If yes, what was it that you liked about it?

    (No: 3.1) If no, what job would you like to do and what would you hope to achieve or experience in this job?

4. The job interview process is a set of complex social interactions between the employer and the prospective employee. Have you experienced any social difficulties with the job interview process?

    (Yes: 4.1) If yes, what happened?

    (No: 4.1) If no, what is it that makes you think you have not experienced any difficulties?

5. Overall, has Asperger syndrome had an impact upon your ability to find employment and what was the impact?

6. What would you like to be doing as a career within the next five years?

Family planning and relationship experiences

1. Can you please describe your immediate family? For instance, are your parents still living and how many brothers and/or sisters do you have?

2. Do you have any other family members who have a disability?

   (Yes: 2.1) If yes, can you describe his/her disability?

3. Can you give examples of the ways in which your Asperger syndrome has had an effect (positive or negative) upon your relationships with your immediate family?

4. Do you have a partner? (i.e. spouse, boyfriend, girlfriend)

   (Yes: 4.1) If yes, have you told your partner that you have Asperger syndrome?
   If yes, when did you tell your partner that you had Asperger syndrome?
   If yes, what did they say or do in response to this?
   If no, what is it that encouraged you to not tell them that you have Asperger syndrome?

   (Yes: 4.2) If yes, what effects does your Asperger syndrome have on your relationship?

   (No: 4.1) If no, would you like a partner and/or what are your hopes/plans for future relationships?

5. Do you currently have any children?

   (Yes: 5.1) If yes, do your children have a diagnosed condition such as Asperger syndrome?
   If yes, can you tell me about behaviour related to their condition?
   If yes, what did people say to you or how did they respond when your child/children were diagnosed?

   (Yes: 5.2) If yes, do you think your Asperger syndrome has affected your parenting skills?
   Could you give examples of how Asperger syndrome has affected your parenting?

   (No: 5.1) If no, would you like to have any children?
   If yes, what is it that makes you want children?
   If no, what is it that makes you not want children?

6. There is some evidence within the literature which suggests that Asperger syndrome has a hereditary component. Would/or did this influence your decision to have children?

7. Has Asperger syndrome affected your ability to form intimate relationships?

   (Yes: 7.1) If yes, what is it that has affected you?

   (No: 7.1) If no, what has enabled you to develop a relationship?

Appendix 12: A list of counseling services provided to the participants

Support Agencies

Should the interview session result in you needing to seek professional advice the following agencies can provide assistance.

1. Lifeline

Lifeline provides access to crisis support, suicide prevention and mental health support services. The phone number for Lifeline's 24 hour crisis support service is **13 11 14.**

2. Relationships Australia

Whether it's a relationship with our partner, family members, work mates, community or our self, relationships can have a big affect on our lives. Relationships Australia helps people to develop their own ability to strengthen relationships and enhance wellbeing by adopting a holistic range of services that provide support across a diverse range of areas. The phone number for Relationships Australia is **1800 182 325**.

3. UnitingCare Wesley, Disability and Mental Health Services

UnitingCare Wesley Adelaide has a long history in supporting and advocating for the mental health needs of children, adolescents, adults, families and older people in South Australia.

All UnitingCare Wesley Adelaide programmes are open to people who may also be experiencing issues around their social and emotional well-being (usual eligibility criteria apply). The phone number for UnitingCare Wesley, Disability and Mental Health Services is **(08) 8202 5158**.

4. Your local General Practitioner, Psychologist or Psychiatrist