Special Interests and Mental Health in Autism Spectrum Disorders

by

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Abstract

The pursuit of restricted or special interests (SIs) in Autism Spectrum Disorders (ASDs) is a well-known though relatively under-researched phenomenon. Several different theories conceptualise the pursuit and function of SIs including homeostasis theory, weak central coherence theory, theory of mind and empathising-systemising theory. The present study had three central aims. The first was to examine the characteristic features of SIs in individuals with ‘higher-functioning’ ASDs. The second was to investigate the relationship between engagement in SIs and levels of depression, anxiety and stress. It was hypothesized that individuals with higher levels of anxiety and stress would pursue their SIs for longer periods of time, compared to individuals with lower levels of anxiety and stress; and that individuals with higher levels of depressive symptoms would spend less time pursuing their special interest, compared to individuals with lower levels of depression. The third aim was to explore the subjective experience of individuals who pursue SIs. A total of 150 adults (64 males; 54 females, aged 18-72) participated in the online self-report study which utilised a modified version of the Yale Survey of SIs (YSSI: Volkmar & Klin, 1996 and the Depression, Anxiety and Stress Scale-21 (Lovibond & Lovibond, 1995). Combined qualitative and quantitative analyses were undertaken. There was partial support for the research hypotheses and additional factors influencing the relationship between SIs and depression and anxiety were identified. The findings contribute to a better understanding of SIs, including their importance for individuals with ASD and the implications of restricting engagement with SIs.
Overview

Research into the ‘restricted interests’ (also known as ‘special interests’) of individuals with autism spectrum disorders (ASD) has been limited. Although the presence of SIs is not required for a diagnosis of Autistic disorder or Asperger syndrome (AS), the pursuit of SIs is a listed criterion under both the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV; APA, 2000) and International Classification of Diseases-10 (ICD-10; WHO, 2004). Over the past century, SIs have been termed ‘odd all absorbing interests’ (Gillberg, 1991), ‘obsessions’ (Myles & Simpson, 2003), ‘circumscribed interests’ (Attwood, 2003), ‘circumscribed topics’ (Klin et al., 2000), and ‘fixations’ (Frith, 1991). The expression ‘special interests’ (Winter-Messiers, 2007) will be adopted in this thesis to indicate a definitional distinction from the obsessions present in obsessive-compulsive disorders.

ASD is not a formal diagnostic category, but a descriptive term used widely in both clinical practice and professional literature to refer to the three disorders classified within the pervasive developmental disorders (PDD) category of the DSM-IV (Autistic disorder, AS and pervasive developmental disorder, not otherwise specified [PDD-NOS]). In this thesis, the term ‘low functioning autism’ is used to describe cases of Autistic disorder with intellectual disability. Also, individuals with Autistic disorder without intellectual disability are referred to as having ‘high functioning autism’ (HFA), although HFA is not a formal diagnostic category. AS is also considered to be on the higher functioning end of the autism spectrum, therefore the term ‘AS/HFA’ is sometimes used for the sake of brevity. Also ‘high functioning ASDs’ is used interchangeably with AS/HFA to emphasise the current shift in focus to a more dimensional approach in ASD classification.
SI research is important for a number of reasons. First, the pursuit of SIs is a dominant characteristic seen in both children and adults with AS/HFA (Klin et al., 2000). Second, SI research is thought to contribute to the discussion concerning whether AS should be retained as a distinct diagnostic group or be subsumed into Autistic disorder and described in terms of severity level (APA, 2010). Further, research and clinical accounts indicate that the intense pursuit of SIs might be mediated by levels of stress, anxiety and depression in individuals with AS/HFA (Attwood, 2006; Bashe & Kirby, 2001). Despite the high prevalence of anxiety and depression in the ASD population, the link between SIs, anxiety and depression has not been investigated. Also, there has been little attention directed towards the subjective experiences of SI pursuit by individuals with AS/HFA. These lines of enquiry may inform ASD theory and have important practical implications for wellbeing in individuals with high functioning ASDs. Therefore, the introductory chapters of this thesis provide a critical review of SI literature and use findings to develop the research questions for the current investigation.

Chapter 1 commences with a review of current diagnostic criteria and prevalence data for AS/HFA, followed by a discussion of issues relating to differential diagnosis between AS and HFA. It also includes a review of the current state of knowledge regarding SIs. This material has informed the development of the SI questionnaire used in the current study. In Chapter 2, the available literature on theories regarding the presence of SIs in AS/HFA is reviewed. Due to the relative lack of theory regarding SIs, this discussion is informed by the cognitive theories of repetitive motor stereotypies observed in autism, which are believed to share several functional parallels with special interest pursuit. In Chapter 3, information regarding the prevalence and presentation of depression and anxiety in the ASD population will
be presented, followed by an examination of available information regarding the potential association between SIs and anxiety and depression. Chapter 4 presents a detailed exploration of the methodological issues common in ASD research and includes discussion of how these will be addressed in the current study, particularly through the use of a newly developed SIs questionnaire. The SIs questionnaire was specifically designed to inform the principal research questions of this study.

The overall objective of this study is threefold: 1) to examine the characteristic features of SIs in an adult population, 2) to investigate whether there is a relationship between engagement in SIs and levels of anxiety and depression in individuals with AS/HFA, and 3) to explore the subjective experiences of individuals who pursue SIs. The methodology for addressing these lines of questioning is reviewed in Chapter 5. A combined qualitative/quantitative approach is utilised in this study as this is believed to address issues of reliability and validity. The results of the qualitative and quantitative analyses are presented in Chapter 6 and discussed in Chapter 7 in the context of available theory. Subsequently, implications for individuals with AS/HFA and directions for future research are discussed.
Special Interests and Emotional Health in Autism Spectrum Disorders

Although the presence of SIs is currently featured as a diagnostic criterion for both AS and autistic disorder under the DSM-IV-TR (APA, 2000) and ICD-10 (WHO, 2004), empirical investigation of this phenomenon has been relatively limited. This chapter commences with an overview of the history and background of AS, including a discussion of issues relating to differential diagnosis between AS and Autistic Disorder without intellectual disability (HFA). To date, research findings have been equivocal and a consensus on whether AS constitutes a separate diagnostic condition has not yet been reached. However, one of the proposed changes in the upcoming fifth edition of the DSM is to remove AS as a distinct disorder category and subsume it under a more general category of Autistic Disorder. In this chapter it is suggested that the findings from SI research may inform future diagnostic approaches. This chapter also includes critical review of SI literature including research findings regarding the content of SIs, process or method of engagement with SIs, development of SIs across the lifespan and current understanding regarding the impact of SIs on the AS/HFA individual and their family.

1.1 Initial Definitions of AS

The characteristics of AS were initially identified and described in 1926 by Sucharewa (cited in Tantam, 1991), and subsequently translated by Wolff (1996). Her description of six male children was very similar to those subsequently described by Hans Asperger in 1944. Asperger’s (1944) group comprised of four children who demonstrated social peculiarities, the presence of average or higher than average intelligence and idiosyncratic interests (Frith, 1991). Asperger coined the term “autistic psychopathy”, and described it as an inherited personality variant which mainly affects boys (Frith, 1991).
At a similar time (approximately one year earlier), Leo Kanner an Austrian-American psychiatrist also published a report on a group of children exhibiting similar behavioural characteristics (Ghaziuddin, 2005). There are several consistencies in the descriptions provided by both Asperger and Kanner. Both used the term ‘autism’ to describe a state of social detachment and both observed shared characteristics between their clients’ and their clients’ relatives. However in later publications, Asperger insisted that there were clear differences between the autism that Kanner described and ‘autistic psychopathy’, now referred to as AS. These differences related to language ability, motor skill and learning ability (Lyons & Fitzgerald, 2005). In Kanner’s descriptions, for instance, three of the eleven children observed did not speak, while the other four children did not use language to communicate with others. In contrast, Asperger (Frith, 1991) observed that his patients could speak at great length on their specific area of interest. He emphasised that although the children’s language was unusually sophisticated, their speech was often long winded, pedantic and carried only literal meanings. Another key area of difference was that Kanner described children who demonstrated clear cognitive deficits (Ghaziuddin, 2005a), while patients with Asperger syndrome were either at or above normal intelligence (Frith, 1991). Motor abilities are another area of distinction between the two accounts. Kanner did not consider delay in motor development to be a core deficit, while Asperger believed this was primary and reported his patients to be clumsy, uncoordinated and to have unusual posture and gait.

While Asperger was aware of the social and learning difficulties of the children he observed, he also appreciated the positive characteristics of the children he studied, especially their unique thinking style and SIs (Frith, 1991). With regards
to this latter characteristic, Asperger described the children as having a particular interest in natural sciences, technology and astronomy or noted them to be gifted with numbers.

1.2 Current Definitions and Diagnostic Criteria for AS

Currently, AS is conceptualised as a neuro-developmental disorder and a unique subtype of the ASDs, along with autism, PDD-NOS, disintegrative disorder and Rett syndrome (APA, 2000). Diagnostic criteria for AS, as specified by the DSM-IV-TR (APA, 2000), includes impairment in social interactions manifesting in at least two of the following: a marked impairment in nonverbal behaviour, such as eye contact, facial expression, body postures and gestures used to regulate social interaction; a failure to develop peer relationships appropriate to developmental level; a lack of spontaneous seeking to share enjoyment, interests, or achievements with others; and a lack of social and/or emotional reciprocity.

A diagnosis of AS also requires the absence of clinically significant language delay. That is, children should be able to use single words by the age of two and can employ communicative phrases by the age of three (APA, 2000). Nevertheless, many individuals with AS seem to have a very literal understanding of language and a speech style that is unusually pedantic and aposodic, that is, lacking rhythm, emphasis, and intonation (McPartland & Klin, 2006). A diagnosis of AS also requires the absence of a clinically significant delay in cognitive development and functioning, or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction) and curiosity about the environment in childhood (APA, 2000). Disturbance must also cause a clinically significant impairment in social, occupational, or in other important areas of functioning. It is
also specified that the symptoms do not better represent another specific PDD or schizophrenia (APA, 2000).

DSM-IV-TR criteria for AS include the presence of restrictive, repetitive and stereotyped patterns of behaviour (APA, 2000). A diagnosis of AS is made if an individual demonstrates at least one of the four primary subgroups of repetitive behaviour: stereotyped motor movements (e.g., rocking, hand flapping), preoccupation with non-functional objects or parts of objects (e.g. repeatedly spinning the wheels of a toy car) and restricted patterns of interest (APA, 2000). Thus a diagnosis of AS may be made if individuals demonstrate other forms of repetitive behaviour, other than SI pursuit.

1.3 Differential Diagnosis: AS/HFA

Since the introduction of AS in the ICD-10 and DSM-IV-TR, there has been considerable debate regarding the legitimacy of separate diagnostic conditions for AS and HFA. While some authors argue that AS and high-functioning autism are separate ASD sub-types, others view AS and HFA as indistinguishable conditions. Proponents of this latter view highlight that while the DSM-IV and ICD-10 specify normal cognitive functioning for a diagnosis for AS, normal cognitive functioning can also be demonstrated in autistic disorder (APA, 2000; World Health Organisation, 2007). Further, there is marked disagreement regarding whether early language development differentiates between AS and HFA (Eisenmajer et al., 1998; Mayes, Calhoun & Crites, 2001). Specifically, language delay is not a required criterion for autistic disorder. Also children with HFA who develop fluent language have similar trajectories to children with AS, with language deficits and delay in preschool aged children with HFA disappearing by early adolescence, thus eliminating
group differences between HFA and AS (Eisenmajer et al., 1998; Ozonoff, South, & Miller, 2000).

Neuropsychological research has also been conducted to investigate possible differences between AS and HFA. Comparisons between the cognitive profiles of children with AS and HFA have produced equivocal results. Specifically, while some studies have failed to find between-group differences in performance in the intellectual, visual-spatial, motor and executive functions of individuals with AS and HFA (Ehlers et al., 1999; Howlin, 2003; Miller and Ozonoff, 2000), other studies have reported group differences in these functions (e.g. Klin, Volkmar, Sparrow, Cicchetti, & Rourke, 1995). Howlin (2003) conducted a review of symptomatology in 42 adult cases of AS and 34 cases of HFA using the Autism Diagnostic Interview – Revised (ADI-R; Lord, Rutter, & LeCouteur, 1994). There was no consistent evidence of group differences in social, emotional and psychiatric problems, motor clumsiness, neuropsychological profile and current symptomatology (Howlin, 2003).

In contrast, other studies have reported group differences on tasks measuring verbal ability, with AS groups demonstrating better performance compared to HFA groups, even when matched on full scale IQ (Klin et al., 1995; Ozonoff, Rogers, & Pennington, 1991; Szatmari, Tuff, Finlayson, & Bartolucci, 1990). However, these studies included ‘modified’ ICD-10 and DSM-IV-TR criteria for AS, in that participants were not required to have demonstrated an absence of delays in language or motor development. While this was justified on the basis that there were few AS cases being diagnosed according to ICD-10 and DSM-IV criteria, interpretation and comparison of results must be made with caution. Further caution is necessitated on the basis that the diagnosis of AS is likely biased towards high verbal ability. Lastly, some authors argue that the lack of evidence for distinct aetiology between AS and
HFA suggest that they are conceptually the same. This is supported by evidence that HFA and Asperger syndrome co-occur in the same families. Supporters of this view maintain that the biological determination of AS and HFA are similar even if the manifestation of the disorder is different (Bolton et al., 1994; Chakrabarti & Fombonne, 2001; Frith, 1991; Frith, 2004; Ghaziuddin, 2005; Volkmar, Klin, & Pauls, 1998).

These issues have a number of implications for clinical practice. For instance, there are practical limitations to using early language development to differentiate between AS and HFA. Retrospective report regarding early language development is more difficult and unreliable, though the average age of diagnosis is becoming lower (Shattuck et al., 2009). Another factor that complicates AS diagnosis, and hence limits the utility of separate diagnosis, is related to the 'precedence' rule set out under the DSM-IV. This rule specifies that a diagnosis of autistic disorder should be given if an individual meets criteria for both autistic disorder and AS. To illustrate problems associated with DSM-IV criteria for AS, Miller and Ozonoff (1997) published a study reporting on Hans Asperger's original work. According to current DSM-IV criteria, all four of the children in Asperger’s report met criteria for autistic disorder, rather than AS (Miller & Ozonoff). These findings are consistent with the results of other studies (e.g., Eisenmajor et al., 1996; Ghaziuddin et al., 1992; Szatmari, Archer, Fisman, Streiner, & Wilson, 1995; Wing, 2005) and have led many researchers to argue that rules relating to 'precedence' make diagnosing AS virtually impossible (Mayes et al. 2001). In contrast, other researchers, such as Ghaziuddin (2008) have found that differential diagnosis of AS versus HFA is possible with current ICD-DSM criteria. Nevertheless despite the difficulties in distinguishing autistic disorder without cognitive impairment and AS,
interventions provided for individuals with either disorder generally do not differ (Szatmari et al., 2000; Howlin, 2003).

The current prevailing view is that AS is located on the ‘milder’ end of the autism spectrum. As stated previously, one of the proposed changes in the DSM-V (expected to be published in 2013) is that the diagnostic category of Asperger syndrome is to be subsumed by autistic disorder (APA, 2010). Using this classification, individuals’ varying levels of ability and impairment would be described dimensionally. The proposed removal of AS from the DSM-V is a controversial recommendation and consensus has not yet been reached. Several researchers and clinicians have suggested that it would be premature to rule out differential diagnosis between AS and HFA (e.g., Ghaziuddin, 2010; Rinehart, Bradshaw, Brereton & Shaw, 2002). The community response to this change has also been mixed, with many preferring the diagnostic label of Asperger syndrome on the basis that it is perceived to carry less negative stigma compared to autistic disorder (Kamin, 2010).

There is still an opportunity to investigate potential differences between individuals with AS and HFA and inform future diagnostic approaches. Attempts to differentially classify distinguish between AS and HFA might be better achieved by examining differences in clinical presentation (Matson & Wilkinson, 2008; Ozonoff et al. 2000). It has been reported, for example, that children with AS are more likely to have a SI (Kerbeshian, Burd & Fisher, 1990; Ozonoff et al. 2000) than children with HFA. In contrast individuals with HFA appear more likely to demonstrate a greater insistence on sameness (i.e. resistance to change in one’s environment and routine) in comparison to individuals with AS (Kerbeshian et al., 1990). Given that one of the greatest difficulties inherent in autism research relates to the vast
variability in symptom expression in different ASD subtypes, obtaining further information about potential differences in specific symptom categories may enable researchers to establish more effective subtypes of ASD. The pursuit of SIs is one such symptom category that may enhance understanding of differential presentations.

1.4 Repetitive behaviours, SIs of Individuals with AS/HFA

Within the subset of repetitive behaviours listed in the DSM-IV diagnostic criteria, some researchers have distinguished between ‘lower level’ stereotypies, such as repetitive motor movements, and cognitively based ‘higher level’ stereotypies, such as SIs (Turner, 1997, 1999). Motor stereotypies are commonly observed in association with a range of disorders such as obsessive compulsive disorder (OCD), Fragile-X syndrome, Rett syndrome, Tourette’s syndrome, Parkinson’s disease, and schizophrenia, developmental and intellectual disabilities, and ASDs (Turner, 1999). However higher-level behaviours such as SIs are predominantly pursued by individuals on the autism spectrum who do not have an intellectual disability (Turner, 1999).

The Autism Diagnostic Interview (ADI; Lord et al., 1989) provides a detailed description of autism and defines a SI as a pursuit that differs from ordinary hobbies in its intensity and in its circumscribed nature. For instance, although the interest may involve a high level of expertise, it is believed to remain unusually focused and does not develop into a broader context of knowledge. Also, the SI is thought to have a non-social quality (i.e., it is not genuinely shared with others and/or is not socially interesting; Lord et al., 1989). Also, while some topics of interest are socially and age-appropriate, such as a child’s interest in dinosaurs other SIs may be unusual (e.g., collecting spark plugs, or remembering engine serial numbers). In contrast to individuals who are on the lower end of the autism spectrum, it is less
common for individuals with AS/HFA to engage in repetitive motor mannerisms or to be preoccupied with parts of objects or non-functional routines or rituals (South, Ozonoff, & McMahon, 2005).

Research findings from studies investigating the function of SIs indicate that SIs are related to temporary, although marked improvements in the social, communicative and motor behaviour of children with AS/HFA (Boyd, Conroy, Mancil, Nakao, & Alter, 2007; Charlop & Haymes, 1998; Vismara & Lyons, 2007; Winter-Messiers, 2007). For instance, Winter-Messiers (2007) noted dramatic improvements in the speech patterns of children with AS/HFA when the topic of conversation was shifted to their SI. Other associated changes included heightened enthusiasm, indicated through increases in affect and animation, as well as significant improvements in vocabulary, word order and syntax. Improvements in body language (i.e., increased eye contact and expressive gestures and a decrease in distractibility, self stimulation and movement) and levels of perseverance and patience with their fine motor skills have also been observed when individuals engage with their SIs (Winter-Messiers, 2007). In addition, children with AS/HFA often display increased sensitivity to their tactile, auditory and olfactory senses making everyday situations, such as having a bath, extremely uncomfortable. However children have been observed to withstand stimuli they would otherwise find extremely aversive (e.g., glue, clay, bright lights and noises of video games) whilst they are engaged with their SI (Winter-Messiers). These findings provide some evidence regarding the significance of SIs to children with AS/HFA, however not much is known regarding the potential benefits of SI pursuit to adults with AS/HFA.
1.4.1 Repetitive Behaviours in AS/HFA and Obsessive-Compulsive Symptoms

A high proportion of children and adults with OCD have been reported to demonstrate repetitive behaviours consistent with autistic symptomatology (Bejerot, 2007; Bejerot, Nylander, Lindstrom, 2001; Ivarsson & Melin, 2008). Similarly, obsessive compulsive traits have also been observed in children, as well as family members of children with autism (Ryaskin, 2004; Wilcox et al., 2003). Children with autism who scored high on a scale of repetitive behaviours, for example, were significantly more likely to have parents with OCD, than children with autism who were lower on repetitive behaviour scores (Hollander et al., 2003a). However findings based on neuropharmacology and neurochemistry research (Hollander et al., 2003b) indicate differences between these disorders. Specifically, while increased oxytocins levels in the brain have been found to be associated with greater repetitive behaviours in OCD (Hollander et al. 2003b), oxytocins administration has been associated with a decrease in repetitive behaviours in ASDs (Leckman et al, 1994; Swedo et al, 1992). Also, similar frequencies of OCD symptoms have also been observed in both ASD and OCD groups (Russell, Mataix-Cols, Anson, & Murphy, 2005). However in Russell et al.'s (2005) study, ritual and somatic obsessions were found to be more common in the OCD group compared to the ASD group. Also, although up to 50% of the ASD group reported moderate or higher levels of interference from their OCD symptoms, the OCD group scored significantly higher than the ASD group on severity rating scales (Russell et al., 2005).

Similarities have also been drawn between the compulsive traits in OCD and the restricted/repetitive behaviours and SIs of individuals with ASD (Lewis & Bodfish, 1998). However research findings indicate that whilst there are some similarities, there are also notable differences (Ruta, Mugno, D’Arrigo, Vitiell &
Mazzone, 2010; Tantam, 2000). In Ruta et al. (2010) higher frequencies of obsessive and compulsive symptoms were reported in children and adolescents with AS compared to typically developing children. However, these were only significant for some compulsive behaviours, including ‘saving/hoarding’, ‘repeating’ and ‘ordering’ behaviours. Also, when compared to an OCD group, the ASD group demonstrated significantly less ‘contamination’, ‘aggression’ and ‘checking’ behaviours.

Another possible shared feature of AS/HFA and OCD relates to the function of repetitive behaviours/pursuit of SIs and compulsions. Specifically, individuals with OCD engage in compulsive behaviours to alleviate subjective feelings of distress associated with their obsessive thoughts. Likewise, there is some indication that repetitive behaviours and pursuit of SIs in ASD serve to regulate levels of sensory arousal and anxiety. However individuals with AS/HFA may engage with their SIs for a number of reasons and have been reported to enjoy their SIs (Attwood, 2006; Bashe & Kirby, 2001) and demonstrate improvements across fine/gross motor and communicative domains whilst engaging with their SIs (Winter-Messiers, 2007). In OCD however, individuals engage in compulsions only as a means to lower their distress levels (Ivarsson & Melin, 2008). Further, engaging in compulsions is often time-consuming, and cause individuals with OCD significant emotional and financial distress. In the current study, the potential link between SI pursuit and levels of anxiety are investigated in addition to the potential impact of SI pursuit on functioning. This line of questioning is considered important to inform discussion regarding shared and non-shared aspects of OCD and AS/HFA (Ozonoff & Jensen, 1999).
1.5 Previous SI Research

The earliest account of SIs was provided by Asperger (1944, cited in Ghaziuddin et al. 1992) and included descriptions involving intense pursuit of facts and information regarding particular topics of interest. The next known description of SIs was provided by Robinson and Vitale (1954). In this account, three children with AS characteristics were described as having a wide range of SIs, including topics relating to chemistry, plants, corporate finance, nuclear fission, local transportation systems and astronomy. Kanner (1954, cited in Tantam, 1991) later commented on the similarities between the group of children observed by Robinson and Vitale, and the children he observed a decade prior. Kanner also added, however, that the children described by Robinson and Vitale were not as socially impaired/withdrawn, attempted to connect with other people using their SIs and overall where more reminiscent of the more able children studied by Asperger.

Another qualitative study involving the SIs of a 13 year old boy was conducted by Kerbeshian and Burd (1986). The researchers identified pinball machines as the SI topic and noted the thorough and ‘obsessive’ way in which the boy drew pictures and designs of pinball machines. In a follow up study five years later, it became evident that this individual’s SI had developed from pinball machines to an interest in computers. Although this initial study provided little empirical data, it attracted research attention and raised questions about whether SIs develop progressively with age. This remains an area requiring further investigation.

In more recent studies, 37% to 95% of children diagnosed with AS/HFA have been found to pursue SIs (Kerbeshian, Burd, & Fisher, 1990; Klin, Danovitch, Merz, & Volkmar, 2007; Szatmari, Bartolucci & Bremner, 1989; Tantam, 1991). Estimates for the pursuit of SIs by adults with AS/HFA are unclear, although in a
survey conducted by the Organization for Autism Spectrum Information & Support – a support organisation made up of parents and professionals (OASIS; Bashe, & Kirby, 2001), 99% of adolescents and adults with AS were reported to pursue a SI. This is consistent with results from the only available empirical study conducted with adults (Mercier, Mottron, & Belleville, 2000). In this study all six adults with AS demonstrated engagement with SIs. However to date, these findings were not replicated with a larger population of adults with higher functioning ASDs.

1.5.1 Content of SIs

Baron-Cohen and Wheelwright (1999) conducted a study into the content of SIs in 92 children with AS and autism. Using parent surveys, the researchers identified 15 categories of SIs including: physics, biology, mathematics, taxonomy, psychology, language, attachments to specific objects, crafts, food-related activities, people and memorisation of facts, sports or games, sensory phenomena and television or video. Overall, the findings of the study supported the prediction that children with ASD would display significantly more SIs in the domain of ‘folk physics’ rather than ‘folk psychology’. Folk physics refers to an understanding of the rules and variables that govern a physical-causal system (e.g., inanimate objects such as machines), while folk psychology refers the understanding of the social world, such as the understanding that people have the capacity for “self-propulsion, goal-directedness, emotional expression, and perception” (Baron-Cohen & Wheelwright, 1999, p. 5). This finding is consistent with the qualitative impairment that individuals with ASD exhibit in their social interactions (APA, 2000).

‘Obsessions’, as they were termed in Baron-Cohen & Wheelwright’s (1999) study were also reported in the control group which consistent of 33 children with Tourette’s syndrome. However differences were reported in the nature of interests
between children with ASD and Tourette’s. Specifically, children with Tourette’s syndrome were more likely to have interests relating to involuntary touching and vocalising, while children with ASD demonstrated more interests relating to taxonomy and physics.

In another study conducted by the National Autistic Society (NAS, 2002) the role of Thomas the Tank Engine™ in the lives of individuals with autism and AS (age range 2 to 21) was explored. Eighty-one parents were surveyed, with the results revealing that 57% of children with autistic disorder and AS associated with Thomas the Tank engine before any other children’s character (NAS, 2000). In addition, nearly a third of parents reported that their children had an obsessive relationship with Thomas. ASD children’s preference for Thomas was considered to be partly related to their difficulties with understanding facial expressions of some other children’s characters. In contrast, ‘Thomas the Tank engine’ included characters that demonstrated exaggerated and easy to understand facial expressions and fixed background and scenery. This was thought to be important for children with autism and AS who are often easily distracted by unimportant stimuli and detail in sound and movement. Additionally, other factors thought to explain children’s preference for ‘Thomas’ characters include the predictability of the characters in the story and the suitability of Thomas for activities of identification, listing and collecting which are often sought out by the child with autism/AS (NAS, 2002). Although this study was conducted predominantly with young children and included individuals with low functioning autism, it is not known to what extent SIs pursued by adults with high functioning ASDs include similar features of predictability, preference for identification, listing and collecting.
In another study, Winter-Messiers (2007) conducted interviews with AS children to investigate the nature of their SIs. Participants in this study included 2 females and 21 males, aged between 7 and 21 years. An advantage of this study was that findings were corroborated with surveys from 18 parents. This study identified 22 SI areas, which they categorised into eight themes: transportation, music, animals, sports, video games, motion pictures, woodworking, and art. A similar study by South et al. (2005) reported the SIs of 19 children with AS and 21 children with HFA, aged between 10 to 19 years (mean age was 14.9). Using the Yale SIs Interview (YSII; South, Klin & Ozonoff, 1999), various SI areas were identified including, physics, video games, the internet, gadgets, power heroes and dinosaurs. The results of both South et al. (2005) and Winter-Messiers were consistent with Baron-Cohen and Wheelwright’s (1999) prediction that the SIs of individuals with AS are predominately topics that are non-social and non-emotional in nature.

The only study using an adult sample is that conducted by Mercier et al. (2000), who examined the SIs of four men, aged between 22 and 52 years, and two women aged between 19 and 21 years. In this study, SIs were placed in three categories: collections (i.e., books, dolls, videos, postcards, stamps, coins, tools); music (i.e., listening to or playing music in an exclusive and repetitive way); and knowledge and activities relating to a specific area of interest (e.g., sport statistics). In total, participants reported having 27 SIs, although the content of these interests were not clearly delineated in the study. Nevertheless, it is interesting that the adults interviewed by Mercier et al. (2000) engaged in more SIs than the children in Winter-Messiers (2007) and South et al.’s (2005) studies. Whether this is because the primary SI areas of the adults were not identified, or whether there is an actual increase in the number of SIs across the lifespan is unclear.
1.5.2 Limitations of Studies

A notable limitation of South et al. (2005), Winter-Messiers (2007) and Baron-Cohen and Wheelwright’s (1999) study is related to the inconsistent classification of SI content. The absence of a shared classification system makes it difficult to compare results and draw any firm conclusions. In light of the limited literature and pre-dominantly under-developed theory of SIs, the observed inconsistency across research studies is unsurprising. Furthermore, these studies did not consider the potential importance of the method of engagement with SIs. The method or process of engagement refers to either the way in which individuals seek information regarding their SI, or the activities/behaviours they adopt when engaging with their SI. Process information might be useful when identifying the true nature of the SI topic. For instance, if an individual has a SI in trains, art work and computers, enquiring about the process of engagement might reveal that the individual enjoys memorising facts regarding all these topics. Hence, the process of memorising might be conceptualised as a SI in itself. Finally, a limitation relevant in particular to the studies undertaken by South et al (2005) and Mercier et al. (2000) is the small sample size. It is proposed that larger samples might be necessary to reveal distinct categories of SIs.

1.5.3 Method of Engagement with SIs

Within the context of challenges discussed in section 1.5.2, research by Klin et al., (2007) and South et al., (2005) attempted to explore not only the content of children’s SIs, but also the process of engagement with SIs. In their study, South et al. reported on the different processes children used with their SI area. Reading about a topic of interest was identified as the most common process used by children with AS (47%). Other identified behaviours included collecting related items (20%),
watching TV/videos (27%), rote memorisation of facts (7%), and playing video games (7%). Research conducted by Klin et al. (2007) also adopted this method of analysis. In this study, eight categories of behaviour were reported including: 1) the collection of facts of a specific interest area using verbal memory and learning (e.g., lyrics of Broadway musicals); 2) the collection of facts or participation in activities relating to a topic using visual memory (e.g., designing highways out of blocks, drawing); 3) engagement in activities to seek sensory stimulation (e.g., smashing light bulbs on the floor, sensing textures); 4) memorisation of numerical facts, mathematical procedures or interest in abstract shapes (e.g., interest in geometric forms, prime numbers); 5) classifying/ordering information: learning classification systems, or otherwise classifying information (e.g., classifying reptiles according to traits); 6) dates and time: interest in calendars, dates of birth, time concepts (time keeping devices, memorising birthdays); 7) hoarding: collection of objects; and 8) fascination with letters and numbers. An advantage of the classification system used by South et al. (2005) and Klin et al. (2007) is that it not only ensured that a child’s SI could be scored in several categories, but also made it more possible to identify the true nature of a SI. For instance, an interest in a historical figure may simply be related to an interest in memorising large amounts of information, without any real understanding of the significance of that person in history.

Furthermore, in an additional attempt to identify true SIs, Klin et al. (2007) excluded behaviours which they believed to be secondary interests. Behaviours (i.e. playing computer games) were excluded if parents were not able to provide additional information which would reveal their child’s true SI. In this study, verbal memorisation and learning were the most predominant processes through which SIs were expressed. Other categories, such as hoarding of items occurred in significantly
lower frequencies. Another major finding of Klin et al.'s (2007) study was that the use of verbal memorisation and learning were as likely to occur alone or with other classes of behaviours, but that other classes of behaviours such as hoarding and sensory stimulation were unlikely to occur without some form of verbal memorisation or learning. The authors in this study suggested that although typically developing children also exhibit behaviours relating to learning via verbal memory, children with ASD dissociate verbal learning from other types of learning and do not integrate information learned through verbal memory into other social activities such as play with other children (Klin et al. 2007). Although verbally learned and memorised information are an important aspect of obtaining knowledge about others (e.g., factual information such as gender, age, and address), not all knowledge can be deduced to this level and other forms of learning are thus required. Consideration of process factors is thought to yield a better understanding of higher-functioning ASDs in general, as well as the learning processes used by individuals to adapt to the demands of everyday life (Klin et al. 2007). In addition, further information regarding the process of engagement with SIs may be integral to comprehending how individuals with ASDs construct knowledge and understanding.

In the current study, there is an attempt to see the extent to which Klin et al.'s (2007) results are replicated using a self-report measure in an adult population. Systematic research into the learning processes of adults with AS/HFA will inform understanding of higher-functioning ASDs. As investigation into SIs is relatively new, inclusion of broader response categories including exploration of various SI topics is warranted to ensure minimal omissions in data collection and analysis.
1.5.4 Perceived Impact of SIs on Self

The study conducted by Winter-Messiers (2007) also reported a strong association between the participants’ self-image and their SIs. Participants reported that they felt more positively about themselves when they were involved in activities related to their SIs and that they enjoyed having increased self confidence and control over their knowledge. This was also demonstrated in some of the younger children with higher functioning ASDs in the study conducted by the NAS (2002). Parents of these children reported that Thomas the Tank Engine and other TV characters acted as a ‘gateway’ to learning, primarily around numbers, colours and language and through the stories, helped children understand basic feelings (NAS, 2002). For instance one parent commented that her five year old son with AS “learned his colours and numbers through Thomas and grew in confidence when he was correct” (NAS, 2002, p. 4). The positive impact of SIs was also highlighted in Mercier et al. (2000). Five out of six adult participants identified SIs to be a source of pleasure and wellbeing, pride and identity, and/or a creative way to spare time, relax or to avoid boredom.

Winter-Messier (2007) also highlighted an association between SIs and social behaviour. For instance, some participants in this study used their SI as a social bridge to assist them in their interactions with peers. This process was termed the ‘masking of SIs’, whereby individuals with AS do not disclose their primary SI topic to peers. The author described seven male participants who initially identified video games as their SI, however, on further interviewing revealed an alternative true SI. It became evident that the children using this process played video games to better fit in with peers because their true SI was rejected. Although limited by small sample size, these research findings indicate the significance of SIs and suggest the need for
further research regarding SIs and particularly the consequences (both positive and negative) of pursuing a SI.

1.5.5 Impact of SIs on Others

Research findings indicate that although SIs are an integral part of the lives of individuals with AS, they often have a significant negative effect on family members (Mercier et al., 2000; Winter-Messiers, 2007). According to Winter-Messiers (2007), a predominant concern for parents of AS children was that their SIs was unacceptable, either because they believed them to be socially inappropriate, or felt that the time and energy invested in the SIs was excessive. Costs associated with the SI were also found to be problematic with parents reporting that they spend anywhere between $100 and $5,000 annually on expenses for SI related clothing, personal items, toys or objects, books, software, supplies, classes, outings and overnight trips. However 14 of the 18 parents also stated that their children’s SI had a positive impact on their families and listed experiencing positive feelings such as humour, fascination, pleasure and enthusiasm (Winter-Messiers, 2007).

Consistent with the results of Winter-Messiers, all relatives in Mercier et al.’s (2000) study identified similar positive and negative feelings towards their adult relatives’ engagement in SIs. Additionally, three of the six participants with AS in Mercier et al.’s (2000) study reported that their pursuit of SIs was invasive and disruptive to their inter-personal relationships and family’s social and occupational functioning. One of the aims of the current study is to explore whether similar findings are replicated with a larger sample of adults with HFA/AS. It is hoped that this research will better inform understanding around the personal experiences and perceptions of adults with ASD.
1.5.6 SIs across the Lifespan

SI literature mainly focuses on the presence and pursuit of SIs by children with ASDs. One of the aims of Mercier et al.'s (2000) study with adults was to investigate the evolution of SIs across the lifespan. The results of this study indicated that over time, participants either: 1) maintained the same SI and found strategies to adapt their SI to meet the demands of their social environment; 2) learned to suppress, or reduce SIs; or 3) diversified their SIs. Development of SIs via one of these three methods was reported to occur as a result of active involvement by the AS/HFA adult. These findings have not been replicated by a study utilising a larger sample. This research might inform understanding around AS/HFA individuals’ ability to regulate their level of engagement with SIs and ability adapt to environmental demands.

In Mercier et al. (2000), parents of adults with AS/HFA were also identified as playing a major role in influencing the individual to adopt the strategies of suppressing/reducing and diversifying SIs. It was reported that individuals who restrict or diversify their interests are better socially integrated than individuals who attempt to adapt to their environment (e.g., by hiding it from others). These findings seem to support Tantam’s (1991) prediction that restricting the time spent on SIs is an important factor in the improvement of social behaviour in individuals with high functioning ASD. However, these findings contradict findings of previous studies which demonstrate the significance of SIs to the self-esteem and overall well-being of individuals with AS/HFA (Mercier, 2000; South et al., 2005; Winter-Messiers, 2007).

South et al. (2005) reported that over time, the SI category demonstrated gradual increases in mean impairment to individual, family and social functioning.
This is in contrast to their findings for other repetitive behaviour patterns (i.e., motor movements, object use and rigid routines) which demonstrated statistically significant decreases in impairment over time. South et al. (2005) also suggested that impairments relating to SIs do not improve with age as much as symptoms relating to communicative and social domains, reported in other studies (e.g., Fecteau, Mottron, Berthiaume, & Burack, 2003). As impairment data were obtained through parent interviews, an alternative possibility may be that SIs become more apparent to relatives over time, due to observed gains in social and communicative areas (South et al., 2005). The significance of SIs and the benefits and consequences of maintaining/restricting or eliminating SIs will be investigated in the current study with a larger sample of adults with HFA/AS. The results may inform current recommendations/practices around managing SI engagement.

1.6 Chapter Conclusion

Although repetitive behaviours are observed in individuals with other psychopathology such as OCD, the nature of SIs is thought to be unique to AS/HFA. SI research may also inform discussion regarding differential diagnosis between AS and HFA. Although improved methods of conceptualising and analysing SIs have emerged in recent years, strategic and standardised research regarding this phenomenon has been limited. The limitations of the empirical literature might be partially explained by the lack of robust theory in relation to SIs and other repetitive, restrictive patterns of behaviour in ASD. The next chapter provides a review of available cognitive theories regarding SIs.
Chapter Two: Theories of Repetitive Behaviour/Special Interests in ASD

There are no cognitive theories that directly explain the occurrence and function of SIs in AS. However the available literature indicates that the pursuit of SIs in AS/HFA share several parallels with the stereotypic repetitive behaviours commonly seen in autism. For this reason, this chapter will present a discussion on the cognitive theories of repetitive behaviours in autism spectrum disorders in general, and will discuss the applicability of these theories to explain the pursuit of SIs by individuals with AS. It is suggested that SI research may help to strengthen cognitive theories of SIs and ASDs in general.

2.1 Repetitive Behaviours/SIs as Operant Responses or Function of Homeostasis

One theory suggests that stereotypic repetitive behaviours are operant responses that are maintained by their sensory consequences (Lovaas, Newsom, & Hickman, 1987). Specifically according to this theory, repetitive motor movements provide auditory, perceptual, or tactile stimulation to individuals with autism. Evidence to support this theory is derived from studies which have shown successful elimination of repetitive behaviours by masking the sensory consequences of their behaviour (e.g., providing earphones to mask the auditory stimulation of repetitive vocalisations; Mason & Newsom, 1990; Singh, Landrum, Ellis, & Donatelli, 1993). However there are some limitations to this theory. First, although repetitive behaviour may serve as a reinforcer, it does not guarantee that the behaviour is actually caused by its sensory consequences. Furthermore, as for many of the repetitive behaviours in autism, researchers are still unclear as to what the reinforcing sensory consequences may be (Turner, 1999). For example, even if repetitive vocalisations are reinforcing, the exact sensory consequence of that behaviour is not well understood. It also follows, that although this theory may account for the
presence of repetitive motor behaviours in AS and HFA, it is not particularly well suited to explain higher level repetitive behaviours such as the presence of SIs. A related theory which is better able to conceptualise the pursuit of both repetitive behaviours and SIs in ASD is the homeostasis theory.

The homeostasis interpretation, within a neuropsychological framework, posits that there is an optimum level of stimulation which contributes to feelings of stability and equilibrium. Within this framework, repetitive behaviour is believed to compensate for under- or overstimulating environments (Baron et al., 2006). The under-arousal hypothesis predicts that self-stimulation through repetitive motor movements regulate extremely low levels of arousal in individuals with autism. Specifically it is thought that repetitive motor stereotypes compensate for the deficiency in the individuals hyposensitive (i.e., under stimulated) central nervous system. Some studies have demonstrated a functional relationship between repetitive motor stereotypes and under-stimulation of the central nervous system (e.g., Lovaas, Bravaccio, & Falco, 1987). The earliest proponents of the over-arousal hypothesis (Hutt & Hutt, 1965, 1970; Hutt, Hutt, Lee, & Ounsted, 1964) hypothesized that the non-specific activity of the ascending reticular system (i.e., the part of the brain which is thought to be responsible for arousal and motivation) is chronically high in autism. Repetitive motor movements in ASD are thought to regulate this activity by blocking arousing stimuli in the environment.

The preference and insistence on sameness in ASD is predicted by the over-arousal interpretation. Specifically, it is hypothesised that novel situations which have been found to be particularly anxiety provoking are avoided where possible by individuals with ASD (Baron. Findings of research studies testing this theory are equivocal. For example, the autonomic nervous system responses in individuals with
ASDs have been measured and have shown changes in heart rate that either precede or are preceded by engagement in repetitive motor movements (Sroufe, Struecher, & Strutzer, 1973; Willemsen-Swinkels, Buitellar, Dekkar, & van Engeland, 1998).

Another prediction of the over-arousal hypothesis is that situations that are associated with higher levels of anxiety will result in increased repetitive behaviours, and conversely situations that are associated with low levels of anxiety will result in less repetitive behaviours. In support of this notion, Hutt and Hutt (1965) reported higher levels of repetitive motor behaviour in children who had autism and a learning disability when a box of unfamiliar toys and a passive adult were introduced into an empty room, compared to when the same children were seated in a relatively empty room. These findings were interpreted as evidence that the children engaged in repetitive motor stereotypies as a means to block further sensory input relating to the anxiety provoking situation and hence to achieve homeostasis. Similarly, researchers who have investigated the role of sensory response have reported reduced stereotyped movements when children with autism are exposed to ‘attractive’ sensory stimuli compared to ‘aversive’ sensory stimuli (Gal et al., 2002). Similar findings were reported by Gabriels et al. (2008), who reported a significant difference in the frequency and severity of repetitive behaviours in 70 children and adolescents with ASD, with individuals exposed to aversive sensory stimuli demonstrating more frequent and severe repetitive behaviours. Furthermore, these results were stable after the effects of age and IQ were accounted for. The homeostasis theory also predicts that engaging in repetitive behaviour decreases levels of arousal in individuals with autism; however this has not been directly investigated. Some preliminary evidence which tentatively supports this theory was reported in a study by Legendre, Trudel, and Dufresne (1992) who examined the
cortisol levels in typically developing children. In this study, typically developing children who engaged in repetitive behaviour were found to be less distressed and in a lower state of physiological arousal (as depicted by lower levels of cortisol secretion) in comparison to children who engaged in less stereotypic behaviour.

The theory of homeostasis also offers an explanation of the function of higher-level repetitive behaviours (i.e., SIs) of individuals with AS. In the study by Winter-Messiers (2007), participants reported that they learned to focus on their SI area, either mentally or by active participation, in order to cope with stressful and highly arousing situations. Clinical accounts also support a homeostasis framework of SIs, although there is a strong emphasis on the “repetitive and restrictive” nature of a SI (Attwood, cited in Baron-Cohen et al., 2006, p. 363) and the impact of this on stress management. A homeostasis theory would predict that individuals demonstrate more engagement with their SIs as a function of stress. This linear relationship between anxiety, stress and SI engagement has received some clinical support (e.g., Attwood, 2006; Bashe & Kirby, 2001) but research has not been conducted with a larger scale AS population and with validated measures of anxiety and stress.

2.2 Repetitive behaviours/SIs as a Result of Weak Central Coherence

‘Central coherence’ refers to an information processing style, specifically to the tendency to process information in its context, so that higher level meaning is achieved (see Happé, 1999). Weak central coherence results in a preference for local rather than global processing, resulting in an enhanced capacity to recall smaller details. For example, weak central coherence is noted in situations where individuals with autism pay special attention to superficial features of objects or sensations that are not normally of interest to most people (e.g., repeatedly spinning the wheels of a
toy car). Findings in relation to central coherence in individuals with AS/HFA are equivocal. Joliffe & Baron-Cohen (1999) presented some evidence for the presence of weak central coherence in AS. They reported that individuals with HFA and AS performed significantly worse when they were required to pronounce words in a context which had a more rare interpretation, for example “there was a big *tear* in her dress” (correctly pronounced as *tear* in the first case, and *tier* as the second) (Joliffe & Baron-Cohen, 1999, p. 155). In contrast, participants responded normally when the context of a sentence entailed a more common interpretation, for example, “there was a big *tear* in her eye” (Joliffe & Baron-Cohen, 1999, p. 155). This failure to take into account the context is consistent with weak central coherence theory and replicates the findings of previous research (e.g., Frith & Snowling, 1983; Happe’, 1997). Other evidence for this theory comes from findings of studies which demonstrate the superior performance of individuals with AS and HFA on cognitive tasks such as the Embedded Figures test (Joliffe & Baron-Cohen, 1997; Shah & Frith, 1983), and the Block Design test (Shah & Frith, 1983), where resisting gestalt (i.e., resisting visual recognition of whole forms and figures and concentrating on smaller details) is beneficial. Turner (1999) reported that the weak central coherence theory also offered an explanation for the pursuit of narrow and specialised interests in AS, in particular, the insistence on sameness; the unusual interest topics, and the intense way in which they are pursued (Turner, 1999. Opponents of the central coherence view of autism and AS, such as Baron-Cohen (2003), argue that individuals with AS actually have a very strong central coherence and suggest that their ability to analyse, construct or predict law-governed systems (i.e., their systemising skills), actually require them to be able to integrate information about
their SIs. Evidence for intact central coherence in ASD is reported in studies by Caron, Mottron, Bertiaume and Dawson (2006) and Garner and Hamilton (2001).

Additionally, a recent study by South, Ozonoff, and McMahon (2007) employed tests such as the Embedded Figures Test (Witkin, Oltman, Raskin & Karp, 1971) and the Gestalt Closure (Kaufman and Kaufman, 1983) task to measure central coherence in individuals with high functioning ASDs. The results of this study did not provide support for hypothesized associations between central coherence and repetitive behaviours (including SIs). Furthermore weak central coherence theory also offers only limited explanation for the pursuit of SIs by preschool and elementary school aged children in Klin et al.’s (2007) study. Specifically, although the theory explains the de-contextualised nature of the interests reported in this study, (e.g., use of rote memorisation), it does not account for the predominantly verbal nature by which children attained knowledge about their SI. It also does not account for the reason that children with AS are so captivated and passionate about their SI area.

Overall, in relation to SI research, the weak central coherence theory predicts that individuals who pursue a SI, use predominantly local information processing methods, and do not achieve higher-level understanding of their interest area. Research with children has produced equivocal results, though further research is necessitated to examine the learning processes of individuals with ASD, and how this informs ASD theory.

2.3 Repetitive Behaviour as the Result of Impaired Mentalising Ability

Another theory of autism and the brain-behaviour relationship is the theory of mind (ToM) deficit hypothesis. This theory proposes that individuals on the autism spectrum have difficulty understanding and predicting the thoughts, emotions and
behaviours of other people, and because of this, have difficulties with communicating and socialising (Baron-Cohen & Swettenham, 1997; Baron-Cohen, Tager-Flusberg, & Cohen, 2000). Research assessing theory of mind in higher functioning ASD individuals has produced equivocal results. Some research using first-order theory of mind tasks have indicated intact mentalising ability in adults with AS/HFA (e.g., Bowler, 1992) while others have reported theory of mind deficits (Beaumont, Newcombe, 2006; Kleinman, Marciano, & Ault, 2001).

Although the theory-of-mind hypothesis is not commonly thought to account for the non-social features of AS, such as repetitive behaviours and SIs (Turner, 1999), some researchers (e.g., Baron-Cohen, 1989) propose that SIs in AS and HFA develop as a result of not understanding the emotions and behaviours of other individuals. More specifically, it is suggested that repetitive behaviours serve to reduce anxiety relating to impairment in understanding the mental states of others (Baron-Cohen, 1989). This account predicts that levels of repetitive behaviour are at their highest when individuals are faced with novel or unpredictable social situations. However, research findings have produced mixed results, with some authors reporting lower levels of stereotypical behaviour when AS/HFA individuals are faced with increased interpersonal demands and stress, including periods of social interaction with unfamiliar people (Charlop, Schreibman, Mason, & Vesey, 1983; Dadds, Schwartz, Adams & Rose, 1988). Turner (1999) also adds that the secondary nature of the theory of mind explanation is consistent with the pervasive and enduring nature of repetitive behaviour in ASD. Mercier et al. (2000) also reported findings which they believed contradicted the association between poor mentalising ability and pursuit of SIs, by demonstrating that people with AS/HFA are capable of self-restricting or eliminating their pursuit of SIs based on the needs of other people.
However, the individuals in Mercier et al.’s study reported restricting or discontinuing their pursuit of SIs only after persistent and overt disapproval from family members. It is likely that similarly to individuals from the general population, the AS/HFA individuals’ decision to alter engagement with their SIs is based on a wide variety of reasons, rather than purely relating to mentalising ability. For example, an individuals’ decision to alter their pursuit of their SIs may be related to their heightened capacity for emotional empathy. According to the empathy imbalance hypothesis, whilst individuals with ASD have a significant cognitive empathy deficit (mentalising ability), they have a heightened capacity for basic emotional empathy (Smith, 2009). Emotional empathy is defined as the emotional response in an individual that arises from, and parallels, the emotional state of another individual (Smith, 2009). One of the key indicators for emotional empathy is the individuals’ awareness that another person is the source of their own affective state (De Vignemont & Singer, 2006).

Although it appears that a theory of mind hypothesis is better suited to the social aspects of ASD, some researchers (e.g., Carruthers, 1996) suggest that a lack of social understanding may leave the individual with no other option but to develop interests around non-social topics. Autobiographical accounts of individuals with AS and HFA are consistent with this theory and indicate that individuals feel that, unlike the social world, routines and rituals provide them with a level of predictability and comfort (Attwood, 2006). According to the ToM account, it would be predicted that individuals would pursue their SI in order to limit their exposure to the emotions of others, which could be experienced as confusing and aversive.
2.4 Repetitive Behaviour as a Symptom of Executive Dysfunction

The executive dysfunction theory of ASD posits that repetitive behaviours in autism/AS are secondary to a deficit in executive function (Hill, 2004). ‘Executive function’ refers to a set of functions used to regulate other cognitive abilities and behaviours including planning, working memory, inhibition, shifting set, and initiation and monitoring action (Hill, 2004). Executive functions are thought to be mediated by the frontal lobes, and impairment in this area is believed to explain the social and non-social characteristics underlying the condition. Proponents of this theory claim that repetitive behaviours such as the refusal or reluctance to engage in non-routine activities and perseverance of a SI are explained by a deficit in executive function (Hill, 2004; Hughes, Russel & Robins, 1994).

There has also been debate about the explanatory power of the executive dysfunction account of autism and the theory of mind account, specifically in relation to social impairment. A few positions have emerged regarding this debate: 1) that the development of executive functions allow the development of an individual’s theory of mind; 2) there are no systems that process mental states, and hence performance on theory of mind tasks can be deduced to executive function ability, and 3) the capacity to develop mental states is required for the development of executive function (Caruthers, 1996; Ozonoff et al., 1991; Perner & Lang, 2000). It appears that there is a complex relationship between executive function and theory of mind. Ozonoff et al. (1991) reported that difficulties on theory of mind tests can be at least in part attributed to deficits in executive function. Although several tests are not ‘pure’ tests of theory-of-mind, due to the inclusion of executive function components, correlations between the two constructs has been reported even when theory of mind tasks have a low executive component (Perner & Lang, 2000).
Interaction between theory of mind and executive function may also be related to the anatomical proximity of the brain regions that mediate these cognitive processes (Hill et al., 2004). The relationship between theory of mind and executive function is also derived from studies in which moderate to severe impairment in the executive and attentional functions of individuals with ASD have been reported (e.g., Hughes et al., 1994; Nyden, Gillberg, Hjelmquist, & Heiman, 1991; Ozonoff et al., 1991). Also, behaviour and perseveration can be explained to some extent by deficits found in the domain of attentional set-shifting (Hughes et al., 1994).

Other deficits in planning, abstract problem solving and multitasking have been reported (Hill & Bird, 2006), although overall findings are equivocal. This may well reflect the variation in participant characteristics and the tasks utilised. For instance, in Hughes et al. (1994) participants ranged from individuals with moderate learning disabilities to those classified as high functioning. While Hughes et al. (1994) contended that executive dysfunction had to be shown as universal to autism to have any explanatory value, there are considerable difficulties with this methodology, one of which is related to the heterogeneity of ability across the autism spectrum. Although there are very few studies employed with individuals with normal intelligence, mixed results are also seen for individuals who are on the higher functioning end of the spectrum, with some studies indicating normal executive function (e.g., Hill & Russell, 2002) and others demonstrating deficits in executive function (e.g., South, Ozonoff & McMahon, 2007). In South et al. (2007), significant correlations were reported between Wisconsin Card Sort Test perseverations and general repetitive behaviour scores of individuals with higher-functioning ASD. However, this relationship was not observed for SIs and thus did
not provide support for the theory that SIs in AS/HFA are a result of impairment in executive dysfunction.

Executive functions are also impaired in individuals with other conditions including those with acquired damage to the frontal lobe of the brain, as well as those with Attention Deficit Hyperactive Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Tourette’s syndrome, phenylketonuria, and schizophrenia (Ozonoff & Jensen, 1999, Sergeant, Guerts, & Oosterlaan, 2002). A significant counter argument to the theory that repetitive behaviours are secondary to deficits in executive functions comes from the finding that repetitive behaviours are not prevalent in patients with frontal lobe damage, with schizophrenia (Elliot & Sahakian, 1995), or with ADHD (Chelune, Ferguson, Koon, & Dickey, 1986 cited in Baron Cohen, 1999). Furthermore, the executive dysfunction account does not explain why the repetitive behaviours of individuals with AS and autism are different to the neurotic obsessions seen in OCD (Baron-Cohen, 1999). Baron-Cohen (2009) also adds that the executive dysfunction theory has difficulty explaining the ‘systems’ that are commonly intrinsic to the SIs of individuals with AS/HFA. This is further discussed next in section 2.5.

2.5 Empathising – Systemizing (E-S) Theory, Extreme Male Brain (EMB) theory and Repetitive Behaviour

A complementary theory to the ToM account, known as the E-S theory, was put forward (Baron Cohen, 2002) to explain both the empathising and systemizing abilities of individuals with ASDs. According to the extreme male brain theory of autism, males have a higher systemizing ability, but lower empathising ability than females. Systemizing is defined as the ability to analyse or construct systems (Baron-Cohen, 2009). Some systems include: collectible systems (e.g.,
distinguishing between different stamps, stones; mechanical systems (e.g., computer); numerical systems (e.g., train timetable); abstract systems (e.g., syntax of a language); natural systems (e.g., weather patterns); social systems (hierarchy within corporate businesses); and motoric systems (e.g., bouncing on a trampoline).

According to the E-S theory, it is the discrepancy between individuals' empathising and systemizing ability that determines the likelihood of an ASD diagnosis. Evidence to support intact or strong systemizing, comes from family studies linking parents (especially fathers and grandfathers) of children with ASD to employment related to engineering, physics or mathematics at a rate higher than in families of typically developing children (Baron-Cohen et al., 1998). Additionally, children with AS have been shown to perform particularly well on tests of physics in comparison to others who are similar or older in age. Studies that have used the Systemizing Quotient (SQ) have also indicated that children with HFA or AS score higher on SQ tests than children from the general population (Baron-Cohen et al., 1998).

Although evidence for the theory is still relatively limited, it provides a novel way to examine SIs compared to ToM, weak central coherence or executive function deficit theories. Intact or above average systemizing abilities in AS/HFA can explain the pursuit of SIs, and also according to Baron-Cohen (2009), the characteristic resistance to change or need for sameness (as it is easier to systemise when everything remains constant). Further, while the weak central coherence theory predicts that people with AS/HFA can never achieve an understanding of the whole system, the E-S theory predicts that over time an individual may understand the whole system (Baron-Cohen, 2009). The desire to incorporate new pieces of information to develop a contextual understanding of a topic could also explain the
intense way in which interests are pursued. If there is evidence to suggest that individuals strive to understand their SI within its broader context, this would be somewhat in contrast to the DSM-IV criteria for SIs “encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus” (APA, 2002, p.70).

2.6 Chapter Conclusion

It is suggested that the individual theories reviewed in this chapter cannot account for the wide variation of repetitive behaviours seen in autism spectrum disorders (Turner, 1999). It follows that certain theories may be better suited to explaining specific classes of repetitive behaviour. For example, while repetitive motor movements seen in lower-functioning autism may be best explained by an operant account, a homeostasis or empathising-systemising account may better explain the occurrence of SIs in ASD, although this has not been subject to empirical investigation. The next chapter will address the possibility that SIs provide a method for regulating anxiety and/or depression in ASD. An understanding of this interaction may be relevant to a better theoretical conceptualisation of the function of SIs in ASD.
Chapter Three: Depression and Anxiety in ASD

Clinical accounts and research findings strongly suggest that individuals with ASD are at increased risk of developing anxiety and depression compared to individuals from the general population (Attwood, 2005; Bellini, 2004; Gillot, Furniss, & Walter, 2001; Gillot & Standen, 2007; Lainhart, 1999; Leyfer et al., 2006; Meyer, Mundy, Vaughan Van Hecke, & Durocher, 2006; Reaven, 2009). This chapter provides a review of this research and a discussion on the diagnostic difficulties inherent in distinguishing symptoms of mood and anxiety disorders from ASD characteristics. Thereafter, preliminary findings which indicate a potential relationship between repetitive behaviours/special interests in ASDs and levels of anxiety and depression will be presented. As there is limited research specifically in relation to SIs, much of the discussion will focus on the association between restrictive, repetitive behaviours and anxiety/depression.

3.1 Depression in Individuals with ASDs

Reported prevalence estimates of depression in ASDs vary widely, ranging from 4% to 38% (Lainhart, 1999). This variability is likely related to differences in study methodology, including sample size, the period of study, the age of individuals, inclusion and exclusion criteria, and sampling methods (Stewart, Barnard, Pearson, Hasan, & O’Brien, 2006). Nevertheless, overwhelming research evidence and clinical accounts indicate a high clinical presence of depression in this population (Ghaziuddin & Zafar, 2008; Tantam, 1991). This appears to be a level that is significantly greater than that in the general population (Ghaziuddin, Weidmer-Mikhail, & Ghaziddiin, 1998; Kim et al., 2000; Wing, 1981). Currently, most available research is based on children and adolescents and there is a lack of literature relating to depression in adults with ASD.
Investigations into the aetiology of depression and other mood-related psychopathology in people with ASD have revealed a number of influential factors. Similar to neuro-typical individuals, external factors are considered to influence the development of depression in individuals with ASDs. However, Tantam (2000) suggested that individuals' with ASD are also at risk due to their increased likelihood of experiencing adverse life effects, including family tension or breakdown, relationship difficulties, victimization, awareness of difference, and over-sensitivity to slight. Environmental demands, and particularly those associated with educational settings, are also thought to impact on the development of depression and other psychopathology (Baron et al., 2006). It is also possible that the executive function problems experienced by individuals with ASD may be experienced as problematic as they try to cope with the demands of every-day life (Baron et al., 2006; Twachtman-Cullen, 2006). Lastly, high rates of comorbidity may be related to shared underlying neurobiology by both ASD and mood/anxiety (e.g., in limbic and frontal systems; Shultz, Romanski, & Tsatsanis, 2000).

There is some evidence to suggest that depression does not present equally across the autism spectrum. Individuals who are higher-functioning are diagnosed with depression at a higher rate than individuals with lower-functioning ASD (Ghaziuddin, 2005). Two explanations have been offered for this phenomenon. First, the overrepresentation in individuals with AS/HFA may be related to difficulties with identifying and diagnosing depression (and other mental health disorders) in individuals who are lower functioning and non-verbal. There are inherent problems with employing diagnostic interviewing or individual self-report scales to individuals who are on the lower-functioning end of the spectrum (Tsai, 1996). Alternatively, it has been proposed that higher functioning individuals may
be more likely to be aware of their social differences, potentially leading to low self-esteem, loneliness or feelings of rejection and therefore at a higher risk of developing depression (Vickerstaff, Heriot, Wong, Lope & Doessetor, 2007). Both explanations are supported to some extent by available research data. For example, although individuals with AS/HFA are more cognitively able than those with lower functioning autism, there is little evidence to suggest that they are able to make and sustain friendships of better quality (Howlin, 2003; Whitehouse, Durkin, Jaquet & Zlatas, 2009). For example, Whitehouse et al. (2009), examined the quality of friendships, motivation for developing friendships, feelings of loneliness and depressive symptomatology of 35 adolescents with AS and matched controls. Their findings showed that adolescents with AS rated the overall quality of their ‘best’ friendship significantly poorer than the comparison group. These adolescent-ratings were found to be consistent with their caregiver’s perception of the same friendship. In the same study, adolescents with AS also reported significantly higher levels of loneliness when compared to typically developing adolescents. Further, loneliness in this study was predicted by the quality of the friendship, but also predictive of depressive symptoms in the AS group. Overall the findings indicated that for the AS individuals in this study, not only were peer relationships rated as poor but that this contributed to feelings of loneliness and depressive symptoms (Whitehouse et al. 2009).

Additional research into the significance of self-perceived social competence has indicated that individuals who attributed social failure to their own ability, demonstrated higher depression symptomatology, compared to individuals who attributed social failure to external factors such as chance or luck (Capps, Sigman & Yirmiya, 1995; Vickerstaff et al., 2007). It appeared from the findings that autistic
children with lower IQ were more likely to attribute social failure to external factors, while those with higher IQ (those with AS/HFA) tended to attribute social failure to deficits in social competence (Vickerstaff et al., 2007). Findings also indicated that age is predictive of self-perceived social competence, with older children demonstrating greater awareness of their social difficulties. In relation to depressive symptoms, Vickerstaff et al. (2007) found that individuals with higher IQ demonstrated more depressive symptoms, compared to individuals with lower IQ. Although the generalisability of the findings is compromised by a small sample size (N = 22), these findings are consistent with research conducted with typically developing (Chan, 1997; Dalley, Bolocofsky, & Karlin, 1994; Hymel, Rubin, Rowden, & Le Mare, 1990; Jacobsen et al., 1983); learning disabled (Haager & Vaughn, 1995); and intellectually disabled populations (Benson & Ivins, 1992; Reiss & Rohahn, 1993). Overall these research findings suggest that individuals who are higher functioning are more likely to be aware of their social deficits and are thus at increased risk for developing depressive symptoms. These results indicate a strong need for further research into the psychological functioning of higher functioning ASD adults.

Despite the variability in research methodology, a number of depression markers have emerged. Steward et al. (2006) reviewed 27 research reports relating to the presentation of depression in ASD. The most frequently reported indicator for depression within the ASD population was depressed mood (Steward et al., 2006). Other indicators of depression included loss of interest in activities, sleep and appetite disturbance and dysregulated speech (Steward et al., 2006). However other depressive symptoms typically reported by individuals in the general population, such as feelings of worthlessness, guilt, diminished ability to concentrate, or thoughts
of suicide were not identified for individuals with ASD. One of the limitations of the studies reported in Stewart et al. (2006) is that most of the identified features of depression were reported by relatives of individuals with ASD, rather than the individuals themselves. This may mean that internalising symptoms of depression, commonly reported in the general population (e.g., feelings of guilt and worthlessness) were not identified with individuals with ASD. This is because third-party informants are less likely to be aware of any internalising, as opposed to externalising symptoms of depressed individuals with ASD. This is consistent with other findings (Achenbach et al., 1987; Hodges, Gordon, & Lennon, 1990; Hurtig et al., 2009; Kolko & Kazdin, 1993; Yeh & Weisz, 2001). For example in their study Hurtig et al. (2009) found poor inter-rater agreement between parents and adolescents with ASD, with parents reporting significantly more observable symptoms such as withdrawn behaviour and social problems, compared to adolescents who reported more internalising problems (i.e., depression/anxiety).

Further, other evidence suggests high rates of suicidal thoughts and attempted or completed suicide amongst the ASD population (Gillberg, 2002; Ghaziuddin, 2005; Shtayermman, 2008; Wolff & Chick, 1980). For example, Shtayermman (2008) reported that in a study of 10 adolescent and young adults, fifty percent demonstrated clinically significant suicidal ideation. Also, twenty percent of the sample met diagnostic criteria for major depressive disorder. In another study, Wolff & Chick (1980) identified 5 out of 22 people with AS who attempted suicide by the time of early adult life. Although sample sizes are small in these studies, preliminary suggest that suicidal ideation/attempts may be more frequent than previously assumed. The high incidence of suicidal ideation in depressed individuals with AS/HFA is consistent with data obtained from depressed individuals from the
general population (Pompili, Di Cosimo, Innamorati, Leste, Tatarelli, & Martelletti, 2009; Rihmer, 2007). Overall, research findings indicate the importance of including ASD individual’s subjective experiences of affective disorders.

To date there are no validated measures (either self-report or third-party informant) specifically designed for the assessment of depression in individuals with ASD. Thus, scales designed for the general population or for individuals with intellectual and learning disabilities have been utilised with individuals with ASD. Three of the most widely used scales to assess the severity of depression include the Hamilton Depression Rating Scale (Hamilton, 1960), the Beck Depression Inventory (BDI; Beck et al., 1961), and the Depression Anxiety and Stress Scale (DASS; Lovibond & Lovibond’s, 1995). These self-report scales have been reported to be suitable for high-functioning individuals on the spectrum (Barnhill, 2001; Cederlund, Hagberg & Gillberg, 2010; Lang, Regester, Lauderdale, Ashbaugh & Haring, 2010; Tani et al., 2003). In Hamilton & McGillivray (2008), inter-correlations between the BDI and the DASS measures on depression were .86 (significant at the .01 level) suggesting intact inter-method reliability between these measures.

3.2 Anxiety in ASD

Across research studies, the reported prevalence rate for anxiety disorders in ASD ranges from 11% to 84% (White, Oswald, Ollendick, & Scahill, 2009). Variation is these estimates can be explained by the lack of large scale epidemiological studies, variations in measurement techniques and the extent of psychiatric comorbidity in the samples (Matson & Nebel-Schwalb, 2007). Despite differences in reported rates, it is well-acknowledged that individuals with ASD are at a particular disadvantage when it comes to managing stress and anxiety (Baron-Cohen et al., 2006). This disadvantage is related to the physiological vulnerabilities
of individuals with ASD, particularly within the sensory, cognitive and social-cognitive domains of functioning. One line of opinion is that individuals with ASD have impaired ability to cognitively appraise anxiety provoking situations (e.g., Gillott & Standen, 2007; Groden, Baron, and Groden, 2006). For example, Groden et al. (2006) specify that individuals incorrectly perceive non-threatening environmental situations as threatening. Some situations that are thought to be particularly anxiety provoking for many individuals with ASDs include verbal communication with others (e.g., taking turns when speaking, beginning and ending appropriately and maintaining a topic of interest to the listener); understanding and responding to non-verbal communication (e.g., facial expressions and gestures); and increased sensitivity to sensory factors, such as hypersensitivity to specific aromas and tactile experiences.

The most common sensitivity is reported for auditory experiences, such as those that are loud or unexpected (Attwood, 2006). Also, several authors believe that the most common events that precipitate stress in individuals with ASD are situations involving change or surprise (Attwood, 2006; Russell & Sofronoff, 2005). Several of the issues outlined above can be explained by known deficits in executive function and theory of mind. Specifically, deficits in executive function are thought to contribute to difficulties with self regulation including impulsivity, distractibility and inflexibility (Groden et al., 2006). Deficits in theory of mind lead to difficulties with understanding and predicting the behaviour of others. This in turn, makes it difficult for individuals with ASD to know how to modify their own behaviour in order to adapt to a situation, thus increasing their susceptibility to stress and anxiety (Frith, 1991).
Individuals with ASD may also be more susceptible to stress and anxiety due to deficits in their ability to modulate their arousal to novel social and sensory stimuli (Dawson, 1991; Dawson & Lewy, 1989). Evidence to support this theory has been reported in research with individuals with ASD (Cohen & Johnson, 1977; Kootz & Cohen, 1981; Kootz, Marinelli & Cohen, 1982). In these studies, individuals with ASD were found to be more likely to have high arousal levels as indicated by sympathetic reactivity (e.g., increased heart rate, respiration and papillary dilation) in response to changes in the environment, than typically developing individuals. These results are consistent with the findings of Stern, Ray, & Quiqley, (2001) who investigated attention responses to environmental stimuli and autonomic arousal. In Stern et al. (2001), individuals with ASD were reported activate an adaptive strategy termed the ‘defensive attention response’ in order to block environmental stimuli perceived as threatening.

Research findings also indicate that individuals with higher functioning ASDs have higher levels of anxiety compared to individuals who are lower functioning and non-verbal (Ghaziuddin, 2005), though most evidence is based on studies of children and adolescents with AS/HFA, and adults with intellectual disability (Bellini, 2004; Kim et al., 2000; Gillott & Standen, 2007; Hofvander, Ossowski, Lundstrom, & Anckarsater, 2009; Hurtig et al., 2009). In one of these studies, Hurtig et al. (2009) utilised multiple informants to assess the presentation of psychiatric symptoms in 43 adolescents with AS/HFA. The results indicated significantly higher levels of psychiatric symptomatology including anxiety and depression, in AS/HFA adolescents than in typically developing adolescents (Hurtig et al., 2009). Furthermore, the high overall mean scores between the adolescent-rated (YSR) and parent-rated measures (CBCL) suggested good agreement between parents and
adolescents, specifically on externalising symptoms. However lower agreement was reported on the internalising problem scale and anxious/depressed scale, suggesting that parents may be less aware of the internal emotions of their adolescent child. Overall, the results of this study support previous research conducted with adolescent AS/HFA populations (Belini, 2004; Green et al., 2000).

Currently, there is a paucity of anxiety research conducted with AS/HFA adults. In Tani et al. (2004) anxiety disorders were diagnosed in 65% of AS individuals with comorbid sleep disturbances. However, the results of this study may not be generalisable to AS/HFA adults without sleep disturbances. In another study, levels of anxiety in adults with low functioning ASD (those with intellectual disability) and non-ASD adults with intellectually disability were examined. Results suggested that anxiety levels were significant higher in individuals with autism and intellectual disability compared to those with intellectual disability only, indicating that individuals with autism have unique challenges (Gillot & Standen, 2007). ASD adults in this study were found to be more sensitive to stress relating to change, anticipation, sensory stimuli and unpleasant events (Gillot & Standen, 2007).

Overall, further research utilising a larger sample of adults is warranted, particularly in light of the high comorbidity of ASDs and affective disorders (e.g., Meyer et al., 2009). This is particularly important given that some ASD characteristics such as social withdrawal and abnormal speech patterns may be confused for symptoms of depression or anxiety (e.g., fatigue or psychomotor agitation; Stewart et al., 2006). Further, anxiety may lead to an increase in AS characteristics such as stereotypical behaviours (Willemsen-Swinkels et al., 1998) or treatment of conditions such as anxiety and depression may sometimes reduce the apparent severity of AS (Tantam, 2000). The overlap in ASD and anxiety symptom
expression contributes to difficulties with differential diagnosis and may contribute to misdiagnosis in this population (Stewart et al., 2006). Thus anxiety and depression research within the ASD population, specifically with higher functioning individuals is considered crucial and may help contribute to a better understanding of unique symptom categories for both mood related disorders and AS characteristics. Research with adults with high functioning ASDs is particularly important given the limited amount of information regarding the presentation of anxiety in this population.

3.3 The Role of Sls in Anxiety and Depression

Some authors suggest that when individuals with ASDs are depressed, these clinical features are accompanied by an increase in repetitive or ritualistic behaviours, or Sls in higher-functioning ASDs (Attwood, 2005; Ghaziuddin, 2005). In his clinical account, Ghaziuddin also suggested that the content of Sls may also be affected by depression, with Sls taking on a more depressive theme. In relation to depressed individuals with AS, some clinicians/researchers (e.g., Attwood; Gillberg, 1985) are of the opinion that depressed individuals with AS become less preoccupied with their SI area. Although Gillberg’s (1985) study comprised only of a single case, and is thus limited in its generalisability to the AS population, an interesting paradox would be raised if this theory were correct. Specifically, due to the overlap in AS characteristics and symptoms of depression and anxiety discussed in the previous section, a decrease in the engagement of Sls (either in frequency or duration) is likely to be viewed by clinicians, researchers and relatives/peers as an improvement in AS symptomatology, rather than as a characteristic of depression (Stewart et al., 2006). If so, it is possible that depression in the AS population is vastly underrepresented.
No other study has examined the relationship between SIs and depression and anxiety.

ASD behaviours including repetitive behaviours or length of time spent pursuing SIs may increase due to other stressful events unrelated to depression, including change in routine, or physical or mental illness (Stewart et al., 2006). Also, some authors have suggested a relationship between anxiety and repetitive behaviours and/or the pursuit of SIs (Gillot & Standen, 2007). Research conducted with autistic children with intellectual disability demonstrates a link between stereotypical and repetitive behaviours (such as rocking, echolalia, hand flapping), repetitive questioning and anxiety, indicating that these behaviours may be regulating anxiety and stress (Howlin, 1998).

Likewise there is some suggestion that SI pursuit by individuals with AS/HFA provides a similar function to motor stereotypies in autism and assist in regulating anxiety levels. In a study by Kim et al., (2000) the prevalence of anxiety and mood-related problems in a group of 9 to 14 year old children with autistic disorder and AS were investigated. A prediction of this study was that children who exhibited greater repetitive behaviours at the time of diagnosis would demonstrate more anxiety symptoms 6 years later, in comparison to children with less repetitive behaviour, however this hypothesis was not supported. A possible explanation for the findings is that repetitive behaviours may be reflective of current, rather than future anxiety and/or mood related problems. Furthermore, Kim et al. (2000) employed the ADI to measure the repetitive behaviours of the participants. However the ADI does not include a measure of SIs, which are a fundamental category in the class of repetitive behaviours exhibited in AS and, compared to repetitive motor behaviours, may be more reflective of the anxiety experienced by this higher-
functioning population. Bashe & Kirby (2001) suggest that the level of preoccupation with a SI activity is directly related to the degree of anxiety individuals with AS are experiencing. Attwood (2006) also suggests that higher levels of anxiety increase the intensity and frequency of thinking of and/or engaging in SI activities (Attwood, 2006). Although this theory is supported by anecdotal evidence, (see Attwood, 2006), it has not been directly tested in research. This provides a further rationale for the current investigation which sets out to examine the association between levels of anxiety and SI engagement.

3.4 Summary and Concluding Remarks

Research findings indicate that depression and anxiety are the two most common conditions affecting individuals with ASD. However there is insufficient information regarding the presentation of depression and anxiety in adult populations, as most of the research to date has been conducted with children, adolescents and adults with intellectual disabilities. Further, due to the concerns regarding the validity of self-report scales in the ASD population, several researchers have utilised information from third-parties. This has contributed to bias in the collection of predominantly externalising, compared to internalising symptoms of depression in this population.

Research into the mental health of ASD individuals is important for a number of reasons. For example, there are current difficulties with distinguishing between ASD characteristics and symptoms of anxiety and depression. Additionally, preliminary results suggest that ASD characteristics may affect the expression of depressive symptoms. There have been some suggestions regarding a potential relationship between repetitive behaviours/SIs and affective disorders, including one line of research which suggests that these behaviours serve to regulate levels of
depression/anxiety. To date, the relationship between SIs and levels of depression and anxiety has not been investigated. Possible implications include using SIs as a tool for the early detection of depression in the ASD population. In light of the increasing number of adults who have an ASD, there is a need to investigate comorbidity in this population. This identified need provided a key rationale for the development of the present study and it was with this aim that the present study was undertaken. The next chapter will discuss the methodological issues that need to be considered in ASD research and reviews the measures being taken in the current study to address these issues.
Chapter Four: Methodological Issues in ASD Research and the Development of a New SI Questionnaire

This chapter will address the methodological issues that commonly arise in ASD research. Specifically issues that relate to the aims of the current study will be discussed, including 1) issues relating to differential diagnosis between AS and HFA and the impact this may have on participant selection and 2) levels of insight across different ASD populations and the implications this may have for research utilising self-report methods. Specific issues relating to the validity of self-report versus parent-report measures in assessing the internal emotional states of individuals with AS/HFA and the utility and limitations of research investigating the subjective experiences of individuals with AS/HFA, including their perceptions of others’ experiences will be delineated. Thereafter attempts made to address these methodological issues as they apply to the current study will be discussed. Also in this section, it is suggested that adults with high functioning ASD have sufficient insight to complete self-report measures of mood and anxiety.

4.1 AS/HFA

Uncertainty regarding the diagnostic conceptualisation of AS and HFA have contributed to the methodological limitations present in some ASD research. In research studies where the primary aim is to investigate differences between AS and HFA, this limitation is related to the use of specific grouping criteria. In ASD research, grouping criteria is typically informed by three primary methods of diagnosis. In the first method, psychologists (who may or may not be directly involved with the research) diagnose individuals according to DSM-IV (APA, 2000) or ICD-10 (WHO; 2004) criteria. Additionally, psychometric assessments that have been developed to specifically measure autism (e.g. ADI-R, Le Couteur, Lord,
Rutter, 2003) may be used to group participants according to the presence of specific ASD traits. A third approach in determining groups is the use of participant self-report (of AS or autistic disorder diagnosis). All three approaches are limited by their reliance on current DSM-IV and ICD-10 criteria, which if applied strictly would lead to most individuals being identified with HFA rather than AS (Klin et al., 2005). Additionally, as discussed in Chapter One, there is the risk of producing tautological research if differences between AS and HFA groups reflect original grouping criteria rather than true group differences. An additional concern regarding self-report methods relates to the possibility that participants are reporting their own self-diagnosis of either AS or HFA rather than a formal diagnosis made by an experienced mental health professional. This is especially problematic given the presence of misinformation in popular media, or availability of online ‘ASD diagnosis’ measures which have little to no psychometric validity. Although all three methods of determining grouping criteria are flawed in some way, compared to research utilising observation or psychometric assessments, the advantages of using self-report need to be rigorously defended against these stated limitations.

One advantage of relying exclusively on participant reports of diagnostic status is related to the availability and use of specific data collection methodology. Survey methods, in particular online questionnaires, are one example. First, survey methods enable the collection of large amounts of data, often from participants of a broad range of ages, ethnicities and socio-economic backgrounds. A second advantage relating to surveys (and especially online surveys) which utilise participant report of ASD diagnosis, is that they are often suited to the needs of autistic individuals who may not otherwise be able to contribute to research studies, (e.g., due to their difficulties with social interaction). Secondly, it has been indicated
in past research that some individuals with ASD 'mask' the true nature of their SI from their peers (Winter Messiers et al., 2007). Online methods provide individuals with anonymity and therefore increase the likelihood that individuals will reveal the true nature of their SI, therefore resulting in more valid data. Lastly, the use of clinical observation and psychometric assessments are costly and time consuming. In comparison, online research studies offer a time and cost effective method of accessing populations. Despite these advantages, a number of measures need to be taken to minimise the methodological issues that can arise. First, research utilising participant report of diagnosis should seek to identify participants that report self-diagnosis versus those who report diagnosis by a professional. Second, the potential impact of self-diagnosis should be verified by conducting analyses with and without the group of participants who report self-diagnosis. Third, interpretations regarding differentiation between the ASD subtypes should be made with caution when this type of methodology is used. In the following section, other common concerns regarding the use of self-report in ASD are reviewed and the implications for the current study are discussed.

4.2 Self-Report in ASD Populations

Self report measures of psychiatric symptoms in ASD have been used across a variety of studies (Barnhill, 2001; Cederlund et al., 2010; Chalfant, Rapee & Carroll, 2007; Lang et al., 2010; Tani et al., 2003; White et al., 2009). Despite this, there are some concerns regarding the use of self-report in this population. One such concern is related to whether individuals with ASD have sufficient insight and self-awareness to identify and describe their mental states. Although ToM deficits are reported with the ASD population (see Tager-Flusberg, 2007), most research relating to ToM has focused on the ability to understand the mental state of others. There has
been some suggestion, however, that individuals with ASD also lack awareness of their own mental states, including their own emotions (Frith & Happe’, 1999). While the results of early ToM research indicated ToM deficits across all ASD children (Happe, 1994; Holroyd & Baron-Cohen, 1993; Kleinman, Marciano, & Ault, 2001), there is growing evidence to suggest that individuals who are on the higher-functioning end of the spectrum are able to identify both their own and others’ thoughts, however results are equivocal (e.g., Johnson, Filliter & Murphy, 2009).

The primary method of investigation regarding self-awareness in individuals with ASD includes comparisons between self and parent ratings on a number of measures with both ASD and control populations. While online research has focused on the ASD individuals’ insight into their autistic traits, other research has been conducted in relation to awareness of their mood and other psychiatric symptoms. In studies utilising this approach, high agreement between self and parent ratings are considered to indicate intact self-awareness in individuals with ASD. In Johnson et al. (2009) self versus parent ratings on the Autism Quotient (AQ; Baron-Cohen et al. 2001); the Empathy Quotient (EQ; Baron-Cohen and Wheelwright, 2004) and the Systemising Quotient (SQ; Baron-Cohen, Richler, Bisarya, Gurunathan, & Wheelwright, 2003) were examined. The AQ measures the degree to which individuals’ display traits associated with ASD; the EQ evaluates the extent to which individuals’ can understand the intentions and predict the behaviours of other people and experience emotions as a result of comprehending the emotions of others (Baron-Cohen and Wheelwright, 2004), while the SQ measures individuals’ interest in constructing or analysing systems. Findings from Johnson et al. (2009)’s study indicated significant differences between self and parent ratings on the AQ and EQ, with children and adolescents reporting fewer autistic traits and less social
difficulties than their parents. These findings are consistent with the results of previous research with children (Green et al. 2000; Koning & Magill-Evans, 2001; Knott et al. 2006). However in Johnson et al. (2009) significant differences between the ASD and control groups on the SQ were not reported. This finding suggests that self-awareness may not be impaired across all ASD traits and behaviours. More specifically, it suggests that individuals with ASD may be aware of their tendency to be particularly interested in how systems work (e.g., how a machine works). This has implications for the current investigation which aims to explore individuals’ interests and the impact on themselves of their pursuit of interests.

One distinct limitation of Johnson et al.’s (2009), findings is the possibility that discrepancies between parent and self-reports may not be entirely related to poor self awareness in the child or adolescent. The researchers acknowledge this possibility. However, they suggest that consistency between parent and self reports on the SQ indicates that discrepancies reported in other measures were not the result of under-reporting by adolescents or over-reporting by parents. To date, ratings on the AQ, SQ and EQ from other sources, such as a teacher or peer, have not been utilised. Further, all these studies (Green et al. 2000; Johnson et al., Koning & Magill-Evans, 2001; Knott et al. 2006) focused on insight into symptoms and traits of autism, rather than insight into their affective mood and mental states. While research with children overwhelmingly indicates at least some deficits in their insight into their ASD traits and symptoms, there is some evidence that individuals with higher functioning ASDs are aware of their mental states/mood.

In Meyer et al., (2006), the social information and attribution processing of 31 children with AS and 33 typically developing children were examined. Results demonstrated several indicators of intact self-awareness in children with AS. First,
consistency was observed between children’s reports of social anxiety and parents’ reports of impaired social competence. Second, children’s reported awareness of their social difficulties was related to their performance on social information processing measures. Third, children’s self-reported emotional difficulties were systematically associated with their social information processing difficulties. These results are consistent with the findings of previous research with children (Bauminger & Kasari, 1999; Bowler, 1992; Buitelaar, van der Wees, Swaab-Barneveld & van der Gaag, 1999; Dahlgren, Sandberg & Jelmquist, 2003; Dyck, Ferguson, & Shochet, 2001). These findings are also consistent with suggestions that individuals with higher functioning ASDs are more likely to have depression and anxiety and that this may be associated with their greater self-perception and in particular, their awareness of their difficulties (e.g., Vickerstaff et al., 2007).

Few studies examine levels of self-awareness in adults with higher functioning ASDs. In one study that attempted to compare the responses of adults with AS and the responses of their parents on the Autism Spectrum Quotient (AQ; Baron-Cohen et al. 2001), the results indicated slight inconsistencies, with parents reporting more autistic traits than the adult participants themselves. Although not subject to analysis, a mean difference score of 2.8 points suggests that the responses of adults with AS and their parents do not differ significantly from one another. There appear to be no other studies that compare the reports of adult individuals with AS/HFA and their parents. This is partially related to the practical limitations of recruiting parents of adult individuals with ASD to participate in research.

Physiological measures have also been utilised to assess level of self-awareness in HFA and AS samples. For example in Lopata et al. (2008), HFA and AS children’s levels of cortisol and self-reported stress as reported by the Subjective
Units of Distress Scale (SUDS). Overall the findings indicated that the self-report of children with HFA and AS may have validity when they report moderate to high levels of distress, but not for lower levels of reported distress. This is in contrast to previous studies where physiological measures did not correlate significantly with self-reports (Jansen et al., 2000; Shalom et al. 2006). Shalom et al. (2006) for example, presented pleasant, unpleasant and neutral images to children with higher functioning ASDs as well as a control sample of typically developing children. The physiological responses were measured and examined against the self-reports of participants. The results suggested that both the ASD and control groups had similar physiological responses to the stimuli, but different self-reports. Although there may be other interpretations for these results, one suggestion was that children with ASD have difficulty identifying and describing their own emotions. The difference in findings reported by these studies may also be explained by differences in the self-report measures used, the stressor or differences in study populations.

Psychological measures have also been used to assess levels of self-awareness in the high functioning ASD population. A study by Hill, Berthoz and Frith (2004) investigated self-awareness by assessing the emotion processing abilities in 27 HFA adults. A self-report questionnaire, the Toronto Alexithymia Scale (TAS-20; Bagby et al., 1994), was used to assess three components of emotion processing: difficulty identifying feelings, difficulty describing feelings, and externally oriented thinking. The results of this study indicated greater emotion processing difficulties in adults with HFA, compared to controls. Difficulties were specifically related to identifying and describing their feelings. These results were maintained once the impact of depression on emotion processing difficulties was controlled. The authors also found that adults commonly demonstrated concrete thought patterns and focused
on external events rather than on their own inner experiences (Hill et al. 2004). Despite this finding, the authors concluded that high functioning ASD were capable of reporting their own emotional processes as indicated by their responses on the TAS-20 and BDI (Beck et al. 1988), and spontaneous reporting to interviewers. Additionally, in relation to the TAS-20, some items are negatively keyed, requiring high scorers (participants with indicated emotion processing deficits) to understand questions and switch responses from one question to the next. Further, although participants were encouraged to telephone the researchers for clarification about the research, only two participants phoned to ask whether questions on the BDI concerned the preceding week, and no questions were asked about the meaning of items on either the BDI or the TAS-20. Consistent findings were reported in a follow up study by Berthoz and Hill (2005).

Finally, evidence for self-awareness also comes from studies utilising self-report and assessing response to treatment or convergence with known anxiety/mood diagnoses. For example, CBT has been utilised with high functioning ASD samples and has been shown to lead to improvements in mood and anxiety symptoms in children (Chalfant et al., 2007) and adolescent/young adult samples (Lang et al., 2010; Russell, Mataix-Cols, Anson, Murphy, 2009). As CBT requires some level of self-awareness in order to identify automatic thoughts and feelings, the results of these studies would indicate sufficient levels of insight/self-awareness. Convergence between known anxiety/mood diagnoses and self-report measures of emotional functioning have been demonstrated in AS samples (e.g., Cederlund et al. 2010). In Cederlund, levels of depression in 100 adolescent and young adult males were examined using the BDI (Beck et al. 1961). The results of this study indicated that almost all individuals who were clinically diagnosed with depression were identified
by the BDI (Cederlund et al., 2010). The results provide support for the use of self-report in the current study which utilizes an adult AS/HFA population.

4.3 Mentalising Ability and Reporting on Others Experiences

As stated previously, theory of mind deficits suggest that individuals with ASD are not able to accurately reflect on the emotions of others. Despite some research suggesting advanced theory of mind abilities in high functioning ASDs (Bowler, 1992; Ozonoff, Pennington, & Rogers, 1991), the measures employed in this study produce ceiling effects when used with participants over the age of 6 years, thus is not able to demonstrate whether older people with ASD have age appropriate theory of mind abilities. Baron-Cohen, Jolliffe, Mortimore, & Robertson (1997) reported on the performance of HFA and AS adults on an adult test of theory of mind ability as well as a task requiring participants to understand mental state terms and match them to 25 photographs of the eye region (of both males and females) that reflect different mental states. Consistent with the findings of Happe’ (1994), Baron-Cohen et al., (1997) reported that adults with AS or HFA had impaired theory of mind. This is consistent with subsequent findings of Rutherford, Baron-Cohen and Wheelwright (2002) who additionally also included an auditory task with the Eyes Task.

4.4 Summary

Self-report provides a measure of subjective experience that cannot be ascertained through any other means. It is commonly used for both research purposes and assessment in clinical practice within the general population. Despite this, much of ASD research is based on data derived from proxy reports, such as those obtained from parents of individuals with ASD. Part of the reluctance to utilise self-report in ASD research is related to concerns regarding deficits in insight,
specifically the ability to identify and express autistic traits or internal emotional states (Gillott et al., 2001; Groden et al., 2006). It appears that individuals with ASD have more difficulty with identifying and describing affective states compared to individuals from the general population. However, there is evidence that children, adolescents and adults with high functioning ASDs are able to comprehend and respond to self-report questionnaires requiring introspection into thoughts and emotions. High levels of convergence between self-report, and a known mood/anxiety diagnosis have also been found, as well as improvements in anxiety/mood related symptoms in individuals who have participated in interventions that require ability to introspect.

In light of the advantages of self-report and issues associated with obtaining third party reports, the use of self-report is considered appropriate for adults with AS/HFA. Also, research findings indicate that individuals with AS/HFA have a specific deficit in making social inferences (Rutherford et al., 2002). Despite this, the use of self-report data to explore the subjective experiences of adults with AS/HFA and specifically, how they perceive others' thoughts and feelings in regard to their SI pursuit is appropriate and worthwhile. Also as discussed in this chapter, there is evidence to suggest that individuals are more aware of their systemising abilities, than interested in knowing how systems (rather than people) operate. Thus the current study utilises a self-report questionnaire to investigate the SIs of adults with AS/HFA. As there were no existing self-report SI questionnaires for the ASD population, a SI survey was developed on the basis of available literature and current measures of SIs. These are reviewed in the next section.
4.5 Existing SI Measures and the Current Survey

There have been some attempts to develop a measure of SIs. These attempts can be categorised as either qualitative interviews or questionnaires that primarily employ a multi-dimensional format. Measures that have been used to investigate the pursuit of SIs by children, adolescents and adults with AS/HFA include the Yale Survey of Special Interests (YSSI: Volkmar & Klin, 1996) and the Cambridge University Obsessions Questionnaire (CUOQ: Baron-Cohen & Wheelwright, 1999). The YSSI is a semi-structured questionnaire, designed to be completed by family members of individuals with AS or HFA. The survey was designed to gain an understanding of the SIs of individuals with AS/HFA and it includes questions for different periods of development (i.e., Preschool Age [ages 2-6], elementary school age [7-12], adolescence [13-18] and adulthood [19+]). The survey consists of a mixture of short-answer and 3-point likert scale questions which range from “sometimes (less than 25% of the time), to “quite a bit (between 25 to 75% of the time, to “almost always (more than 75% of the time”. Questions relating to the content of SIs and the process of engagement with SIs are included. For example, in relation to SIs pursued between the ages of 2 and 6, parents/carers are asked to provide “examples of the things the preschooler knew or did involving this topic”.

A strength of both the YSII and the CUOQ (Baron-Cohen & Wheelwright, 1999), was that they ensured that all SIs could be accounted for. However a further strength of the YSII was that information obtained regarding the content of SIs was obtained by utilising an open ended question, as opposed to the forced-response categories in the CUOQ. This addition minimised the possibility for research bias.

Another strength of the YSSI, and in contrast to the CUOQ, is the opportunity to obtain information regarding the nature rather than simply the content
of SIs. Specifically, information regarding whether children read, memorise, categorise or collect objects relating to their special interests is sought. This ensures a better understanding of how individuals with ASD construct knowledge and understanding. Furthermore this process is better able to identify the true nature of a SI. For instance, an interest in a historical figure may simply be related to a general interest in memorising large amounts of information rather than an interest in learning about the significance of that person in history (Klin et al., 2007). In the current study, the process or method of engagement with a SI was explored by utilising the same questionnaire item as the YSSII ‘provide examples of the things you know or do regarding your SI topic’ though an additional item not included in the YSSII enabled participants to also endorse relevant categories regarding their method of engagement with their SI (i.e., reading, memorising, talking, categorising or collecting). This enabled consistency to be measured across the responses from the two questionnaire items relating to the process of SI engagement. Information regarding reliability/validity of the YSSII is limited. In Klin et al. (2007) however, topics of interest were coded by two independent individuals. Across the four age groups, kappa was calculated to range from .81 to 1. Level of agreement between the coders ranged from .93 to 1. The overall kappa score was .85, with 94.66% agreement between the coders.

A significant limitation arising from the YSSII (Klin & Volkmar, 1996) is related to the use of a 3-point likert scale. Compared to a 5-point scale, a 2-point likert scale has limited numerical distribution and thus elicits less statistical information. Furthermore, although the authors of the YSSII clearly acknowledge the non-equal distances between the response categories by defining them, (i.e., quite a bit - between 25 to 75% of the time, sometimes - less than 25% of the time and
almost always - more than 75% of the time, this ordinal-level of measurement limits the type of statistical analyses that can be achieved with the resulting data. Klin & Volkmar (1996) however treated their data as interval level data and subjected their data to parametric analyses. Although this practice is sometimes utilised in psychological research, it remains controversial and is not recommended (Jamieson, 2004). The YSII was also used in a study by Klin et al. (2007). In relation to the analysis of the YSSI, the researchers calculated total interference scores by assigning a numerical value of 0 (no interference) to 3 (high interference) for each of the interference questions on the YSSI. Thus parents who responded ‘less than 25% of the time’ to a particular question were rated 0 on the interference scale. This method has the potential to underestimate the frequency of engagement in SIs and the impact on the individual, family and peers.

4.6 Measuring Depression and Anxiety

Currently, there are no scales specifically designed to measure depression, anxiety in the ASD population. In the present study, the DASS-21 (Lovibond & Lovibond, 1995) was used as a self-report measure to investigate levels of anxiety and depression. The DASS is one of the most commonly used instruments and has been used to investigate the prevalence of depression in various population studies (Bados, Balaguer, & Saldaña, 2007; Henry & Crawford, 2007). One of the reasons why the DASS-21 was selected over other screening tools was because several of the items in the DASS-21 are concrete and do not require great introspection (e.g., requires information about the physical symptoms of depression and anxiety). Further, the DAS-21 similarly to other self-report measures of psychiatric functioning requires individuals to select a response from a list of items rather than
generate and report their own thoughts, feelings and experiences. This may be easier for participants to complete.

4.7 Research Questions/ Hypotheses for the Current Study

The over-arching goal of the current study is to expand on the current understanding of SIs in adults with ASD. In order to achieve this, the following hypotheses were utilised. Where there is insufficient literature regarding SIs, exploratory questions rather than hypotheses were used.

4.7.1 Characteristics of SIs of Adults with AS/HFA

1. What are the various SIs of adults with AS/HFA and do individuals report significantly more special interests in some topic domains compared to others?

2. To what extent do the results support different cognitive theories of SIs? (i.e., homeostasis theory, theory of mind, empathising-systemising theory of SIs)

3. How much time do adults with AS/HFA spend pursuing their SI on any given day?

4. Are there significant differences in the SIs/intensity of SI pursuit between individuals with AS and HFA?

Specifically, the following hypotheses were used in the current study:

1. Adults with AS/HFA will have significantly more SIs that are non-people oriented or ‘non-social’ in nature, than ‘social’ SIs. Further, it is hypothesised that adults in the current study will demonstrate significantly more SIs within the domain of folk physics compared to folk psychology, in accordance with Baron-Cohen & Wheelwright’s (1999) empathising-systemising theory.

2. Adults with AS/HFA will use significantly more verbal processes when pursuing their SI, compared to non-verbal processes.
3. Adults with AS/HFA will report using multiple learning processes e.g. verbal, and visual, rather than focusing on one aspect of their SI.

4.7.2 Depression/Anxiety and SIs:

The following hypotheses were used to investigate the relationship between anxiety and depression and SI engagement:

1. Higher levels of anxiety and stress are predicted to be associated with higher levels of SI engagement e.g. more time spent pursuing SIs.
2. Hypothesis: Higher levels of depression are predicted to be associated with lower levels of SI engagement.

4.7.3 Subjective Experience and Purpose/Impact of SIs:

Three additional exploratory questions were posed to investigate the subjective experiences of individuals with AS/HFA:

1. In what way do SIs change and develop from childhood to adulthood;
2. What are the participants’ perceptions of the impact and purpose of SIs?
3. What are the participant’s perceptions on the impact of their SI pursuit on family/peers?

The method for the current investigation is presented in the next section.
Chapter Five: Research Method

5.1 Participants

A total of 150 participants (64 males and 86 females) with AS/HFA were recruited to participate in this study through advertisement placed on several autism/Asperger related websites located in Australia (see Appendix G), the United Kingdom, Canada and the United States of America. Ages of participants ranged from 18 to 72 ($M = 32.3$, $SD = 11.82$). The sample is comprised of individuals from various countries, with the majority residing within the United States, the United Kingdom and Australia (see Appendix D). Most participants reported a diagnosis of AS rather than HFA (See Table 1).

Table 1

| Diagnosis (AS or HFA) of Male and Female Participants |
|---------------------------------|----------|----------|----------|
| Diagnosis | Males | Females | Total |
| AS | 54 | 82 | 136 |
| HFA | 10 | 4 | 14 |

Participants reported various sources for their diagnosis of either AS or HFA (see Table 2). The majority of participants reported a confirmed diagnosis by a mental healthcare provider. Overall, 26 participants (8 male, 18 female) reported self-diagnosis.

Table 2

<table>
<thead>
<tr>
<th>Source of AS/HFA Diagnosis</th>
<th>Number of participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practitioner</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Mental healthcare provider</td>
<td>112</td>
<td>75</td>
</tr>
<tr>
<td>Self-diagnosed</td>
<td>26</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>146</td>
<td>97</td>
</tr>
</tbody>
</table>

Note: Four people did not respond to this item
Table 3 details participant study/work/volunteer status. Over half the participants in the sample (53.5%) were employed at the time the questionnaire was completed.

Table 3

**Participant Study/Employment Status**

<table>
<thead>
<tr>
<th>Status</th>
<th>Number of Participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed for Wages</td>
<td>55</td>
<td>36.7</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>25</td>
<td>16.7</td>
</tr>
<tr>
<td>Out of work for more than 1 year</td>
<td>36</td>
<td>24</td>
</tr>
<tr>
<td>Out of work for less than 1 year</td>
<td>19</td>
<td>12.7</td>
</tr>
<tr>
<td>A homemaker</td>
<td>7</td>
<td>4.7</td>
</tr>
<tr>
<td>Retired</td>
<td>5</td>
<td>3.3</td>
</tr>
<tr>
<td>Volunteer</td>
<td>44</td>
<td>29.3</td>
</tr>
<tr>
<td>Currently at a TAFE/university</td>
<td>43</td>
<td>28.7</td>
</tr>
</tbody>
</table>

Note that some participants reported multiple categories and as such N totals higher than 150.

5.2 Measures

5.2.1 *Demographic questions*. The initial section of the SI questionnaire (SIQ); refer to Appendix C) consists of questions aimed at identifying demographic information relating to the participant: age; gender; diagnosis (AS or HFA), country of residence, ethnicity, marital status, employment and volunteer status, education status and highest level of education achieved. Information relating to any area of study, employment, or volunteer work was also obtained to examine whether participants pursued study or employment relating to their special interest topic. Information regarding source of diagnosis was also requested, with response options: ‘I was diagnosed by a general practitioner’, ‘I was diagnosed by a mental health care professional (psychologist, psychiatrist)’, ‘I am self-diagnosed’ and ‘Other’.
5.2.2 SIs measure. The SIQ was used as a self-report measure of SIs and was based on a modified version of the Yale SIs Interview (YSSI: Klin & Volmar, 1996). Participants were asked whether they have a topic of interest for which they have an extensive level of knowledge and understanding. The question was developed in a way to avoid labelling the interest area as a ‘special’ or ‘restricted’ interest or ‘obsession’. SIs were distinguished from ‘hobbies’ or typical ‘interests’ in accordance with current DSM-IV (APA, 2000) criteria. Specifically, interests that were not unusual in either their intensity or focus were not categorised as a special interest. Consisting of 43 questions, the SIQ was developed to obtain information relating to the characteristic features of SIs including the content of SIs, method of engagement with SIs, the intensity of the SI (as measured by the average total number of hours spent pursuing a SI in a day), evolution of SIs across time and impact of SIs on the AS/HFA individual and others. Items on the online questionnaire were structured so that participants did not need to answer questions that did not relate to them, as identified by their responses to previous questions. Therefore, time required to complete the questionnaire was minimised as much as possible to increase response rate.

Method of engagement with SIs was analysed in two ways. First, participants were provided with a list of processes and were required to select the processes that they used whilst engaging with their SIs. Participants were able to select more than one process per SI. A second question within the questionnaire required participants to provide qualitative information regarding the things they ‘know or do involving their SI’. The question was framed in this way to ensure processes of any type could be recorded. Thus, data collection was as broad and as neutral as possible, whilst allowing for consistency across the two different methods to be obtained.
Participants were provided the opportunity to describe the processes for three SIs thereby also allowing for consistency of process across different SI areas to be assessed. The data was analysed both in terms of frequency and percentage of responses and the number and percentage of participants who mentioned each process once. Participant indicated ‘process’ responses were combined with researcher identified themes (via dummy coding of qualitative information), therefore increasing the number of possible themes. This allowed a type of ‘inter-rater’ reliability to be assessed for variables indicated initially by respondents. The Kappa Measurement of Agreement value was .59 which represents moderate to good agreement between respondent identified and researcher identified ‘processes’.

Information regarding ‘frequency’ of SI pursuit in the past week was obtained more specifically to address the primary research question regarding the potential relationship between levels of SI engagement and levels of depression, anxiety and stress as measured by the DASS-21 (which is based on participants’ affective states across the last week). A five-point likert scale was utilised in the current measure. Response categories included ‘less than 1 hour a day’, ‘1-3 hours a day’, ‘3-6 hours a day’, ‘more than 6 hours a day’ and ‘did not spend time on my special interest every day’.

One other main research question in the current study was to explore the participants’ subjective perceptions of the impact of special interest pursuit on themselves and family members/peers. In the SIQ both multidimensional and open-ended questions are utilised to explore the positive and negative impact of the special interest on participants’, their family members and peers. For example, some questions were designed to directly measure the function of SIs during stressful periods or during times when individuals feel “sad or down”. Although the
information obtained will not be corroborated with reports from family members or peers, the purpose of these items is to obtain information about the participants subjective experience (e.g., perceived impact of SI pursuit on self and family/peers).

5.2.3 Depression, Anxiety and Stress Scale 21 (DASS 21; Lovibond & Lovibond, 1995). The Depression Anxiety Stress Scales 21 (DASS-21) is a reliable and valid method of assessing features of depression, anxiety and stress. The DASS-21 has been used to assess levels of depression and anxiety in the AS population (e.g., Schreiner & Malcolm, 2008). It consists of three 7-item self-report scales that measure depression, anxiety and stress respectively. These consist of statements used by the participant to describe the extent to which each state has been experienced ‘over the past week’. All 21 items are scored on a 4-point severity scale which range from ‘did not apply to me at all’ to ‘applied to me very much, or most of the time’. The DASS-21 is a short form of Lovibond and Lovibond’s (1995) 42-item self-report measure. It has a number of advantages relative to the 42-item version. For example, the DASS-21 has fewer items to administer, thus making it more efficient for research purposes and more suitable for individuals who have difficulties with retaining attention. The DASS-21 also omits items from the full length DASS which have previously been identified as problematic. These include anxiety item 9, and stress item 44 (both which double-load) and anxiety item 30 (which does not load strongly on any factor) (Antony, Bieling, Cox, Enns, & Swinson, 1998; Crawford & Henry, 2003). This has resulted in less inter-factor correlations and a cleaner latent structure in the DASS-21.

Factor analytic studies have demonstrated that the DASS-21 has a three-factor structure and distinguishes well between features of depression, physical arousal, and psychological tension and agitation. The DASS-21 has also been shown
to indicate very good internal consistency, convergent validity, and good
discriminative validity (Antony et al., 1998; Gloster et al., 2008). There is no
absolute criterion for the reliability of a psychological instrument. As a rule of
thumb, Anastasi (1990) has suggested that Cronbach’s alpha should be at least .85 if
an instrument is to be used to draw inferences regarding an individual. Based on
this, the reliabilities of the DASS-21 Anxiety, Depression, Stress, and Total scales
are adequate (Cronbach’s alpha was .88 for the Depression scale, .82 for the Anxiety
scale, .90 for the Stress scale, and .93 for the Total scale). The DASS-42 has been
validated against formal measures of psychological distress, including the Beck
Anxiety Inventory (BAI) and the BDI. The DASS anxiety scale correlated .81 with
the BAI and the DASS depression scale correlated .74 with the BDI. In comparison
to the BAI and BDI, the DASS-42 demonstrated greater separation between factor
loadings (Lovibond & Lovibond, 1995).

5.3 Procedure

Ethics approval for the current study was obtained from the Deakin
University Human Research Ethics Committee (see Appendix A). Advertisements
located across a number of ASD specific websites were utilised to attract individuals
interested in participating in an online study of SIs and mood/emotion. The
advertisements included a Deakin University URL link which directed potential
participants to the plain language statement (Appendix C) and the questionnaire. The
online questionnaire was kept open for 8 months. The plain language statement
described the purpose of the study, duration, general content of the questionnaire and
included exemplar questions. The confidential and anonymous nature of
participation was made explicit to individuals. Participants were also informed that
their completion of the online questionnaire would be taken to indicate consent. Participants were not paid for their involvement in the study.

5.4 Analytical Method

5.4.1 Statistical Analysis. The AMOS statistical program (version 17.0) was used to analyse the data. Exploratory factor analysis was used to screen the data for missing values, homogeneity, normality, linearity, outliers, multi-collinearity and singularity. Data was cleaned as per procedures outlined in Tabachnick and Fidell (1996). It was established that missing data were completely random throughout the data set and constituted less than 4% of the values. Expectation maximization (EM) method was used to estimate missing values (Tabachnick and Fidell, 1996). The data was also screened for skewness, kurtosis, and outliers. DASS depression and anxiety scores were noted to be slightly non-normal, however due to the large sample size (and thus the application of the central limit theorem), this was not believed to be a concern. This practice is supported by the results of studies which have a range of non-normal distributions and which indicate that Type 1 error rates deviate slightly from their nominal values, though typically in a conservative direction (Clinch & Keselman, 1982; Sawilowsky & Blair, 1992; Tan, 1982). Mixed model analysis of variance (ANOVA) and chi-square analyses were conducted where necessary. Separate analysis without the group of HFA and self-diagnosed participants were conducted to examine the potential unique contribution of these groups. However the results reported are derived from the entire sample, unless otherwise specified.

5.4.2 Qualitative Analysis. Qualitative analysis was conducted prior to quantitative analysis to limit bias during thematic analysis. Grounded theory was used as the basis for the qualitative analysis of the data derived from the current study. Core theoretical concepts were identified through the process of thematic
analysis. This is in contrast to other qualitative analytic methods such as content analysis, which is often criticised for relying exclusively on frequency outcomes of particular words or phrases and hence removing meaning from the data’s context (Marks & Yardley, 2004). Thematic analysis permits the researcher to combine analysis of the frequency of codes together with analysis of their meaning in context and has been reported to include the advantages of the subtlety and complexity of true qualitative analysis (Braun & Clarke, 2006).

For the current study, a close reading of the transcripts was conducted to gain an initial sense of the issues arising from the data. After reading each participant response, the researcher made a journal entry including the identification number of each of the participants and their reported SIs. Responses to key research questions were also summarised and included in the document as well as any thoughts or ideas provoked by participant responses. Responses/researcher thoughts were then typed into an Excel processor document, resulting in 35 pages of single spaced text which increased familiarity and intimacy with the data. Responses on the questionnaire were read on more than one occasion to search for regularly recurring phases and counterintuitive statements (Miles & Hubermann, 1994). If a response was not clear, the participant responses to other questions in the survey were examined to add to the wealth of information being obtained.

Electronic versions of the questionnaire responses were imported into NVivo (Richards, 2002), a software program designed for computer assisted coding. This software provides an efficient method of organising, retrieving and verifying data and assists with examination of complex relationship in the data. The software also provided a means to search the frequency of particular words or phrases relevant to the research questions. This enabled emerging themes and patterns of data to be
explored and tested. As emerging patterns were identified from the data set, text passages containing references to particular themes were coded. Single segments of text were sometimes allocated multiple codes. These codes were developed from the study’s original research questions and from the available empirical and anecdotal literature. Also, counter-evidence data – data that contradicted the main school of thought was noted.

Following the initial coding process, patterns within the data set were analysed to compile more compact and meaningful groupings of codes. Codes were re-visited several times to assess whether they were appropriate reflections of the data. This resulted in the development of fine codes which were evaluated to identify patterns, complex relationships and possible explanations in the data. This process was continued until no new themes emerged from the data and theoretical saturation was reached (Strauss & Corbin, 1990). Consideration was also given to potential hierarchies in the data and networks were designed to provide a graphical display of the data.

5.5 Methodological Issues

5.5.1 Use of Self-Report In the Current Sample. As discussed in Chapter Four, there is some indication that individuals on the higher functioning end of the ASD demonstrate better levels of insight and self-awareness (Johnson et al. 2009). The adult participants who have completed this study are assumed to have sufficient insight and self-awareness to accurately reflect their subjective experiences. There are a few reasons for this assumption. First, the recruitment process and content of the questionnaire indirectly select for participants who have a reasonable level of cognitive ability. Specifically, in order to access the online questionnaire, participants were required to use the internet and subsequently follow instructions
from advertisements located on an ASD related website. Additionally, the study required participants to answer open and closed-questions relating to their ASD and emotional state over the previous two weeks. These responses were later analysed by the researcher. As research findings suggest that adults with AS/HFA are able to comprehend items across a variety of self-report measures (Johnson et al., 2009), in the current study, adults were considered to have the ability to comprehend the requirements of the questionnaire items.

The use of self-report was also considered appropriate due to the nature of the main line of research relating to SIs. There is evidence to suggest that individuals may be better able to respond to questions relating to their special interest, due to their significant role. This evidence comes from studies conducted with children that have found that when children discuss their SIs they demonstrate temporary improvements across a range of behaviours including eye contact, speech, gross and fine motor skills. As there are still some concerns regarding the presence of impaired insight, questionnaire items that are pertinent to the primary research question, such as those relating to frequency of engagement with a special interest do not require interpretation of events, and are thus less likely to be influenced by cognitive bias. For example, response categories regarding frequency of engagement with SIs include likert scales (e.g., almost always: more than 75% of the time)’.

In relation to the participants main diagnosis, individuals were asked to identify whether they had a diagnosis of AS or HFA. Although HFA is a descriptive term rather than a diagnosis, it was thought to be better understood than the term autism without cognitive impairment/ intellectual disability.

5.5.2 Use of Qualitative Methods. The choice of qualitative methods in this study poses methodological issues that need to be addressed. Traditional,
quantitatively-oriented criteria specify the need for internal and external validity, reliability and objectivity (Bannister, Burman, Parker, Taylor, & Tindall, 1994). The evaluation of qualitative research is conducted through the use of criteria proposed by Lincoln and Guba (1985), including credibility, transferability, dependability and confirmability. Credibility refers to whether the information presented by the participant is adequately reflected in the research findings. This study utilised numerous techniques to ensure that the meaning conveyed by participants was not lost (frequency outcomes of particular words/phrases, use of qualitative analysis program and traditional methods, correlation matrices using qualitative data. Issues relating to transferability are dependent on the provision of sufficient, rich information and the judgement of the reader as to the applicability of the findings to another setting (Lincoln & Guba, 1985). In the current study, issues relating to transferability were addressed through the description of the research context and recognition of participant characteristics.

Dependability and confirmability relate to the reliability and objectivity of qualitative research paradigms (Golafshani, 2003). Dependability and confirmability is dependent on the richness of information gathered and the quality of analysis (Patton, 1990). The current study, applied triangulation principles, which is the use of different research methodologies to assess the dependability and confirmability of qualitative research findings (Patton, 1990). Specifically, the quantitative measures were employed in this study to verify the credibility of the qualitative findings. Further, data was analysed numerous times for consistency of interpretation and employed an active search for information that contradicted prior observations.
Chapter Six: Results

In this chapter, the data forming the basis for the current study are presented. The focus of analysis was threefold. Initially, findings relating to the various characteristics of SIs are presented, including information regarding the content of SIs, intensity of SI pursuit (time spent on SIs) and the process of engagement with SIs. Changes in the content and nature of SIs according to participant reports of childhood SIs through to current SIs are also reported. Subsequently the results of the qualitative and quantitative investigation regarding the frequency of SI engagement and levels of anxiety, depression and stress will be presented. Thereafter, the results of qualitative data relating to participant’s subjective experiences of their SIs are reviewed including their views on the positive and negative impact of their SI pursuit on themselves and family/peers.

6.1 Characteristics of SIs

Overall, 128 participants (85% of the total sample) reported having a SI. This was consistent, when ‘self-diagnosed’ participants ($n = 26$) were not included in the analysis (87%). Participants who did not report having a SI were excluded from analysis, unless otherwise indicated. The number of males and females with and without a SI are shown in Table 4.

Table 4

<table>
<thead>
<tr>
<th>Participants ($N=150$)</th>
<th>SIs</th>
<th>No SIs</th>
<th>Total $n$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>55</td>
<td>9</td>
<td>64</td>
</tr>
<tr>
<td>Female</td>
<td>73</td>
<td>13</td>
<td>86</td>
</tr>
</tbody>
</table>

Most participants ($n = 115$, 90%) engaged with their SI on a daily basis.

Table 5 shows the frequency of engagement with SIs, reported by participants per
day over the last week (prior to completing questionnaire). Out of these participants, most \( n = 43, 33.6\% \) spent between 1-2 hours at any one time on their SI, while 21.9\% \( n = 28 \) spent between 5-6 hours at any one time. There was no effect of gender on SI engagement \( F (1, 106) = 1.19, p > .05 \).

Table 5

*Frequency of Engagement with SIs Reported Over the Last Week*

<table>
<thead>
<tr>
<th>Frequency of SI engagement</th>
<th>No. of Participants ( (N = 150) )</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not engage with SI daily</td>
<td>13</td>
<td>10.2</td>
</tr>
<tr>
<td>Less than 1 hour per day</td>
<td>7</td>
<td>5.5</td>
</tr>
<tr>
<td>Between 1-3 hours per day</td>
<td>28</td>
<td>21.9</td>
</tr>
<tr>
<td>Between 3-6 hours per day</td>
<td>35</td>
<td>27.3</td>
</tr>
<tr>
<td>More than 6 hours per day</td>
<td>45</td>
<td>35.2</td>
</tr>
</tbody>
</table>

Participants described a total of 324 SIs. A complete list of the characteristics of SIs and the number of times they were reported are provided in Appendix E. The responses of participants indicated a wide range of SIs. While some participants were specific in the way they reported their SIs e.g., Japanese Mahjong, others reported more general interests e.g., Japanese culture. The content of SIs fell into 11 main categories (See Figure 2). The large number of reported SIs necessitated the use of categories. Topics were assigned to various categories or ‘general themes’, in line with the process used in Winter-Messiers (2007). In the current study, topics relating to natural science included astronomy, biology, chemistry, earth sciences (e.g., climate research, geology, geography, mineralogy) and physics. Natural sciences form the basis for applied sciences such as engineering. SIs that fell within the field of social sciences related to: anthropology,
archaeology, economics, history, linguistics, political science, international studies. Formal sciences included: mathematics, theoretical computer science and statistics.

New categories were created if the SI topic could not be categorised under an existing theme. For example, gardening or the ‘Great Pacific Garbage Patch’ was not believed to fit under the theme of biology, so a new category 'environment' was created. The ‘miscellaneous’ category included interests that could not be classified under existing categories, and were reported infrequently (in less than 3 occasions) and thus did not warrant creation of a new category. SIs were most frequently reported within the domain of social sciences (see Figure 1).

*Figure 1.* Frequency of various SI domains.
Figure 2. SI categories.
6.1.2 Application to Baron-Cohen and Wheelwright’s model. In order to investigate distribution of SIs in social and non-social domains, Baron-Cohen and Wheelwright’s (1999) framework of analysis was adapted and applied to the experiences of participants in this study. Table 6 shows the distribution of SI content frequencies according to Baron-Cohen and Wheelwright’s (1999) SI ‘core domains’ including ‘folk physics’, which refers to understanding inanimate objects or systems and ‘folk psychology’, which refers to social understanding. ‘Folk mathematics’, ‘folk biology’ and ‘language’ are also primary cognitive domains identified by Baron-Cohen and Wheelwright.

Table 6.

*Frequencies of SIs across Cognitive Domains*

<table>
<thead>
<tr>
<th>SI Content</th>
<th>Physics</th>
<th>Mathematics</th>
<th>Biology</th>
<th>Psychology</th>
<th>Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>a (117)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Topic A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(48)</td>
<td>20</td>
<td>4</td>
<td>16</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Topic B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(42)</td>
<td>11</td>
<td>4</td>
<td>16</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Topic C</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(27)</td>
<td>8</td>
<td>2</td>
<td>12</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

*Note* Participants were each able to list up to three SIs and these correspond to SI Topics A, B and C as seen in Table 6.

*a Not all SIs were able to be categorised according to Baron-Cohen & Wheelwright’s (1999) core domains.

Results indicated fewer (total) reported SIs in the domain of folk psychology than folk physics (see Table 6). To test the significance of this difference, a Fisher’s exact test was used. However, in order to meet one of the key assumptions of this test (that each participant contributes data to only one cell), frequencies within
separate SI topics e.g. Topic A, Topic B and Topic C were used rather than total SIs. Thus, results indicated significantly fewer SIs in the domain of folk psychology than folk physics ($p < .0001$) within Topic A, Topic B ($p < .05$), and Topic C ($p < .0001$).

Also in the current study, folk biology rather than folk physics was reported most frequently in Topic A SIs ($p < .0001$), Topic B SIs ($p < .0001$), and Topic C SIs ($p < .0001$). Second, the frequency of reported SIs within the domain of folk psychology was identical to the frequency of SIs reported within the domain of folk mathematics. An attempt was made to see whether SIs could be classified according to Baron-Cohen and Wheelwright's (1999) 'other areas of everyday life'. The categories included: Attachments (to a specific object); crafts; everyday life; facts; food; people; sports or games; TV/audio, sensory phenomena. The results indicated that while several SIs fit into these categories, 207 SIs could not be classified (Figure 1 includes all categories). The most frequently reported category of interests relating to 'social sciences' could not be categorised into any of Baron-Cohen and Wheelwright's (1999) core domains. For example, social sciences could not be classified under 'folk physics' which refers to knowledge of how the physical world of objects works, or under 'folk psychology' which refers to the knowledge of the social world.

6.1.2 Social SIs. Analysis of the content of SIs revealed that social SI were reported significantly less than SI that were not people oriented ($p < .0001$). The following cases represent SI that were identified as 'social' in nature:

Check facebook pages several times a day, remember a lot about them
and analyse from these memories, write stories (some novels)

involving them. P (21)
I will sit for hours on end and observe the ways that people interact with each other, the ways they move, the places they go, what they buy, etc. I am keen on figuring out social dynamics as I have little subjective bias. P (43)

The participants’ responses indicate their interest in gaining an understanding of social relationships, self-awareness and desire for social relationships. For several other participants, the nature of interests was not immediately identified from the title they provided for their SI topic. In these cases, the classification made was informed by the analysis of their responses to other questions. For example, in the following case, the participant identified their SI as relating to ‘psychology’, and was initially coded as a social interest. However upon examining the individuals’ description of their engagement, the SI topic was re-classified as non-social:

I attempt to find correlations between the hypothesis proposed by E.O. Wilson, Richard Dawkins, Helen Fisher, etc and the behavior I see NT’s exhibiting during social interactions. (P 31)

Only two individuals reported an interest in law enforcement, criminality, and weaponry and none of the SI reported were ‘anti-social’ or violent in nature. These interests were categorised under ‘miscellaneous’ (see Figure 2) due to the fact that they were reported fewer than 3 times. These interests were reported by male participants only.

6.1.3 SI Content and Gender. Fisher’s Exact Probability Test was used to analyse group differences according to SI content. Females were more likely than males to report SIs relating to animals ($p < .05$) and SIs relating to health topics ($p < .05$). No other differences were significant, despite a trend for females to report
more SIs within the domain of natural sciences and less SIs within the domain of applied sciences than males (see Figure 3).

![Bar chart showing frequency of science SIs within reported by males and females.]

*Figure 3.* Frequency of science SIs within reported by males and females.

**6.2 Retrospective SI data.** Participants were asked to report on any SIs they had when they were younger. Overall, 10.5% of participants (*n* = 16) reported consistent SI topics over the course of their life (under 5 years of age to current). Of these, SIs relating to art were the most frequently reported (*n* = 4). Other topics included sport, music, transport and science. SI categories also broadened substantially in adolescence, with a greater focus on subjects relating to humanities, science topics and health. Also compared to SIs acquired in childhood, there was greater consistency between SIs acquired in adolescence and participants’ current interests (*n* = 30, 19.7%). Only one participant reported a current SI she engaged in since childhood relating to children’s television shows ‘Sesame Street’ and ‘Muppets’, which was now age-inappropriate and all encompassing (high frequency of engagement and no other reported interests). Some gender differences emerged from the retrospective data. Specifically, only male participants (*n* = 7) reported a transport related SI in the under 5 category, while more females reported an animal
related SI in the 6-12 year old range \((n = 19)\) compared to males \((n = 2)\). Additionally only females reported social SIs before the age of 18 years. No other differences between males and females emerged from the retrospective data. A total of 34 (28\%) of participants reported spending up to 50\% of all their time on their SI when they were under the age of 5. Between the ages of 6 to 12 years and 13 to 18 years, 37 (33.3\%) and 30 (26\%) participants respectively reported spending up to 50\% of their time on their SIs.

6.3 Differences in SI Content/Process in AS and HFA

Overall, 10 of the 11 participants with HFA reported a SI, whilst 118 out of 139 participants with AS reported having a SI. The small sample size of HFA participants precluded statistical analysis of the data. Although qualitative analysis was also limited due to the differences in group size, the available data did not present any observable differences between the content or method of engagement with SIs reported by adults with HFA and AS.

6.4 Process of Engagement with SIs

Responses were analysed according to the process by which participants engaged with their SIs. Results are presented according to participant responses on the qualitative and quantitative analysis, and combined participant and researcher identified themes. Table 7 shows the frequency/percentage of individuals who endorsed different processes or methods of engagement with their SI. Reading about SI was the most frequently employed method of engaging with a SI. In the ‘other’ category, participants reported various methods of engagement such as ‘thinking or fantasizing’ about the SI topic, ‘watching’, ‘listening’, ‘experiencing’ the SI (e.g., video game, bike riding), ‘classifying information’, or ‘creating’ (e.g., art work).
Processes under the ‘other’ category were better identified using qualitative measures (see Table 8).

Table 7

*Frequency (%) of Participants (with a SI) Endorsing Different Processes*

<table>
<thead>
<tr>
<th>Process</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Read about SI</td>
<td>114 (89)</td>
</tr>
<tr>
<td>Memorise verbal information about SI</td>
<td>81 (63)</td>
</tr>
<tr>
<td>Talk about SI</td>
<td>98 (77)</td>
</tr>
<tr>
<td>Categorise/classify information</td>
<td>81 (63)</td>
</tr>
<tr>
<td>Collect</td>
<td>69 (54)</td>
</tr>
<tr>
<td>Other</td>
<td>59 (46)</td>
</tr>
</tbody>
</table>

*Note: Percentages total greater than 100% due to the fact that participants could identify multiple processes.*

Table 8 presents the processes identified from the qualitative data which demonstrated that reading was again the most prevalent theme (89.8%). Additionally, 21.9% of participants who reported having a SI, reported pursuing their SI through visual learning, that is, they engaged in behaviours or activities involving visual memory. Visual learning did not include activities that potentially included a component of verbal learning, e.g. watching television, which was included as a distinct category. Additionally, 57 (38%) of participants reported ‘experiencing’ their SI. Experiential processes include kinaesthetic or tactile learning. See Appendix F for a full list of experience sub-themes.
Table 8

**Process of Engagement Employed by Participants with a SI**

<table>
<thead>
<tr>
<th>Process of Engagement</th>
<th>No. of times endorsed (%)</th>
<th>No. of Participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading</td>
<td>160 (41.0)</td>
<td>115 (89.8)</td>
</tr>
<tr>
<td>Visual learning</td>
<td>35 (8.8)</td>
<td>28 (21.9)</td>
</tr>
<tr>
<td>Create</td>
<td>46 (11.5)</td>
<td>35 (27.3)</td>
</tr>
<tr>
<td>Watch</td>
<td>24 (6.0)</td>
<td>20 (15.6)</td>
</tr>
<tr>
<td>Rote memory</td>
<td>22 (5.5)</td>
<td>12 (9.4)</td>
</tr>
<tr>
<td>Collect</td>
<td>33 (8.2)</td>
<td>24 (18.8)</td>
</tr>
<tr>
<td>Communicate</td>
<td>11 (2.7)</td>
<td>16 (12.5)</td>
</tr>
<tr>
<td>Experience (total)</td>
<td>72 (1.8)</td>
<td>57 (44.5)</td>
</tr>
<tr>
<td>Write</td>
<td>15 (3.8)</td>
<td>11 (8.6)</td>
</tr>
<tr>
<td>Categorising/Classifying</td>
<td>42 (10.7)</td>
<td>20 (15.6)</td>
</tr>
</tbody>
</table>

*Note: Percentages total greater than 100% due to the fact that participants could identify multiple processes*

Using the qualitative data, the frequency of participants coded as using ‘reading’ to engage in their SI was consistent with the result obtained when they were asked to endorse items from a predetermined list (see Table 7). However, other processes are under-represented by the qualitative data, (e.g., only 12 people spontaneously reported memorising verbal information in the qualitative section of the questionnaire, whilst 81 participants had previously endorsed the item). Overall reliability, as measured by kappa, was assessed for processes analysed by quantitative and qualitative methods (reading, communicating, collecting, categorising/classifying). For most variables, kappa ranged from .5 to .98, indicating moderate to very good agreement across both quantitative and qualitative strategies (reading = .98; collecting = .5, categorising/classifying = .6, all with a significance of $p < .0001$). Only the process communicating produced very low agreement (kappa = .12, $p < .01$).
As a further measure, qualitative and quantitative data were combined to obtain a thorough picture of the processes used by participants. To do this, participants' indicated responses on the quantitative items on the questionnaire and information obtained from the subjective responses of participants were combined. Due to the difficulties with requiring participants to identify visual learning processes that did not include a verbal learning component, visual learning processes were not included in the quantitative section of the survey. The result of this combined qualitative/quantitative approach is demonstrated in Figure 4 which displays the frequencies of participants using different processes of engagement with their SI.

![Bar Chart]

**Figure 4.** Frequency of participants using various learning processes.

As can be seen in Figure 4, processes involving 'verbal learning', such as reading, communicating, memorising, categorising and classifying information were
more frequently reported than processes involving visual learning. Most participants employed verbal and non-verbal learning processes in combination (see Table 9). Six participants reported ‘reading’ without pursuing their interests in a different way. As expected, participants reported reading alongside other verbal learning processes such as memorising and writing. Results also indicated that visual learning processes (watching) and kinaesthetic processes (e.g. collecting) also mostly occur in combination with reading, rather than in isolation.

Table 9

Frequency and Percentage of Participants Using Reading Processes with Other Methods of Engagement with SIs.

<table>
<thead>
<tr>
<th>Process</th>
<th>Use ‘reading’ processes (%)</th>
<th>Do not use ‘reading’ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Create</td>
<td>28 (90.3)</td>
<td>3 (9.7)</td>
</tr>
<tr>
<td>Watch</td>
<td>25 (92.6)</td>
<td>2 (7.4)</td>
</tr>
<tr>
<td>Visual Learning</td>
<td>24 (85.7)</td>
<td>4 (14.2)</td>
</tr>
<tr>
<td>Collect</td>
<td>65 (91.5)</td>
<td>6 (8.5)</td>
</tr>
<tr>
<td>Communicate</td>
<td>93 (93.0)</td>
<td>7 (7.0)</td>
</tr>
<tr>
<td>Experience (total)</td>
<td>60 (88.2)</td>
<td>8 (9.1)</td>
</tr>
<tr>
<td>Write</td>
<td>19 (100.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Categorise/Classify</td>
<td>76 (93.9)</td>
<td>5 (6.2)</td>
</tr>
<tr>
<td>Memorise</td>
<td>80 (97.6)</td>
<td>2 (2.4)</td>
</tr>
</tbody>
</table>

Additionally, participants who pursued their SI visually (n = 28) also commonly reported using other verbal learning processes such as ‘memorising’ (n = 20, 71%) and communicating’ (n = 23, 85.2%). However the inverse relationship was not true. Specifically, SIs involving verbal learning (e.g., communicating, categorising/ classifying information) were more likely to occur in the absence of visual activities. Participant responses were analysed to assess consistency of
processes used across different SI areas. As participants were required to list up to three SI areas, consistency was identified as relating to the same process for at least two SI topics. The results of the qualitative analysis indicated that 68 (53\%) participants who pursued a SI area, employed consistent processes across their SI areas. Out of these, 58 (80.5\%) consistently used reading for more than one SI.

6.5 Restricted vs. Broadened Processes

Two main types of process were identified: processes that were restricted in nature, and processes that were broadened to include various creative methods of engagement. Restricted SIs were identified if they involved minimal processes or ‘lower order’ processes (e.g., collection of objects/attachment to objects without the use of other processes, collection of facts without the intention to broader understanding of the topic). However participants who were interested in broadening their overall understanding of their topic and who pursued their SI in different ways were identified as utilising ‘broadened processes’. Participants who indicated that they were employed within their SI field were classified as having non-restricted SIs. Also processes that involved the sharing of knowledge (e.g., writing a book), indicated SIs that were non-restricted in nature.

Most SIs involved processes that were non-restricted in nature ($n = 263$, 87\%), while some processes ($n = 39$, 13\%) were restricted (e.g., collecting objects without using other processes, or collecting facts for no wider purpose). The restricted nature of these participants’ engagement was often consistent across different SIs. A Fisher’s Exact Test of Probability was performed to examine the proportion of participants who pursued their interests in a broadened compared to a restricted manner. The results indicated significance at the $p < .001$ level. Additionally, apart from a minority of participants who report interests/activities in
order to achieve sensory stimulation/inhibition \( n = 2 \), an over-arching theme related to \textit{knowledge or information acquisition}. Specifically, it became apparent that regardless of the process participants used to engage with their SI, the overall aim was often to acquire further understanding of their particular interest area. It was also indicated from the analysis that individuals pursue a number of different SIs at any one time, and attempt to exhaust information for a particular topic before moving on to a new SI.

\textbf{6.6 The Depression, Anxiety and Stress Characteristics of the Current Sample}

The following sections report the results relating to the depression, anxiety and stress characteristics of the sample. As there was no significant difference in the DASS scores of participants with and without a SIs \( p < .05 \), all participants were included in the analysis unless otherwise specified.

\textbf{6.6.1 Depression and anxiety data.} Participants were asked to report official diagnosis of anxiety and depression (see Table 10). A diagnosis of either anxiety or depression, or comorbid anxiety and depression was reported by 74% of participants.

\begin{table}[h]
\centering
\begin{tabular}{ll}
\hline
Diagnosis & Frequency (%) \\
\hline
Neither Anxiety nor Depression & 38 (25.3) \\
Depression & 30 (20.0) \\
Anxiety & 15 (10.0) \\
Depression and Anxiety & 66 (44.0) \\
Total & \textsuperscript{*}149 (99.3) \\
\hline
\end{tabular}
\caption{Frequency (%) of Participants Diagnosed with Depression and/or Anxiety}
\end{table}

\textsuperscript{*}One participant did not provide a response.

\textbf{6.6.1.1 DASS results.} Table 11 shows mean scores on each of the DASS subscales for the each group. The overall mean for participants without a diagnosis of depression is significantly lower than the mean score for participants with a
diagnosis of depression or comorbid depression and anxiety $F(1,133) = 10.27, p < .01$. Also, the mean score is significantly lower for participants without a reported a diagnosis of anxiety compared to participants with a diagnosis of anxiety or comorbid anxiety and depression $F(1,118) = 5.87, p < .05$.

Table 11

*Mean (Standard Deviation) of DASS Depression and Anxiety Scores for All*

<table>
<thead>
<tr>
<th>DASS</th>
<th>Participants ($N = 150$)</th>
<th>Dx Depression ($n = 30$)</th>
<th>Dx Anxiety ($n = 15$)</th>
<th>Dx Dep/Anx ($n = 66$)</th>
<th>No Dx ($n = 38$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>10.26 (8.9)</td>
<td>6.93 (4.6)</td>
<td>10.27 (9.2)</td>
<td>13.02 (9.9)</td>
<td>8.08 (8.2)</td>
</tr>
<tr>
<td>Depression</td>
<td>14.30 (11.9)</td>
<td>15.01 (9.2)</td>
<td>7.07 (7.7)</td>
<td>18.09 (12.5)</td>
<td>10 (11.5)</td>
</tr>
<tr>
<td>Stress</td>
<td>18.93 (10.9)</td>
<td>16.6 (8.3)</td>
<td>20.4 (10.6)</td>
<td>21.82 (11.2)</td>
<td>15.16 (11.0)</td>
</tr>
</tbody>
</table>

### 6.6.1.2 Participants with a diagnosis of depression and/or anxiety.

There are five severity ratings for the DASS (Lovibond & Lovibond, 1995) including ‘Normal’, ‘Mild’, ‘Moderate’, ‘Severe’ and ‘Extremely Severe’. In the current study, the mean DASS scores for the entire sample fell within the ‘Moderate’ range for Depression, Anxiety and Stress. The average DASS score for participants with a diagnosis of Depression and/or Anxiety did not differ significantly from the total mean, and was also within the ‘Moderate’ range. In fact, 50 (45%) of participants who reported a diagnosis of Depression and/or Anxiety scored within the Normal range on the DASS anxiety scale and 38 (34.2%) scored within the Normal range on the DASS depression scale. Twenty six percent of participants scored above the
Severe range on the DASS anxiety scale, whilst 20 (31%) of participants scored above the Severe range on the DASS depression scale.

6.6.1.3 Medication effects. A total of 45 participants (30%) reported the use of medication in the treatment of anxiety and/or depression. There were no significant differences in DASS scores between participants who reported using medication for the treatment of symptoms of anxiety and depression and participants who were not using medication ($p > .1$). Similarly medication effects were not found when only participants with a diagnosis of anxiety and/or depression were included in the analysis.

6.6.14 Gender, DASS data, depression/anxiety diagnosis. For the current sample ($N = 150$), Levene’s Test for Equality of Variances indicated equal variances for scores on the DASS depression and anxiety scale, but not for DASS stress scores. An independent samples t-test was conducted to compare depression, anxiety and stress scores for males and females. Results indicated that females scored significantly higher on DASS stress scores when un-equal variances were taken into consideration ($M = 20.6, SD = 11.54$) than males ($M = 16.5, SD = 9.57$), $t (148) = -2.38, p < .05$. Despite reaching statistical significance, the actual difference in mean scores between the groups was quite small (eta squared = .035). There were no significant difference in depression scores for males ($M = 13.97, SD = 12.76$) and females ($M = 14.44, SD = 11.2$), $t (148) = -.68, p = .15$ and anxiety scores for males ($M = 10.06, SD = 9.07$) and females ($M = 10.3, SD = 8.76$), $t (148) = .159, p = .54$. Group differences between males and females did not change significantly when only participants with a SI were used in the analysis, $t (148) = -2.45, p < .05$. However in the current study, females were significantly more likely to have a diagnosis of anxiety and/or depression compared to males, $t (148) = -2.58, p < .05$. 
6.6.1.5 AS/HFA. Independent Samples t-test was conducted to compare differences on DASS scores between participants who reported a diagnosis of AS, and participants who reported a diagnosis of HFA. The results indicated no significant differences between these groups on anxiety, \( t(148) = -0.07, p = .95 \), or stress, \( t(148) = -0.55, p = .59 \) or depression.

6.7 DASS Data and SIs

Although there was a trend for participants without a SI to score higher on the DASS than participants with a SI (see Table 12), significant between-group differences were not obtained (Depression: \( t(148) = -1.26, p = .21 \); Anxiety: \( t(148) = -7.44, p = .58 \); Stress: \( t(148) = -0.15, p = .88 \)).

Table 12

*Means (SD) of DASS Scores for Participants With and Without SIs.*

<table>
<thead>
<tr>
<th>SI</th>
<th>DASS Depression ( M \ (SD) )</th>
<th>DASS Anxiety ( M \ (SD) )</th>
<th>DASS Stress ( M \ (SD) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>With SI</td>
<td>13.73 (11.64)</td>
<td>9.98 (8.70)</td>
<td>18.8 (11.11)</td>
</tr>
<tr>
<td>Without SI</td>
<td>17.18 (12.89)</td>
<td>11.50 (9.87)</td>
<td>19.18 (9.81)</td>
</tr>
</tbody>
</table>

The main effects of SI frequency group on DASS scores were not significant (depression: \( F(4, .49) = .74 \); anxiety: \( F(4, 1.12) = .35 \); stress: \( F(4, .57) = .68 \)), despite a trend for participants in the highest frequency group (more than 6 hrs per day) to score higher on the DASS than participants in the lower frequency groups (see Figure 5). With depression scores, there was also a trend for participants who did not engage in their SIs everyday to demonstrate higher DASS depression scores than those who engaged with their SIs to some extent (up to 6 hours).
Figure 5. Mean DASS scores across varying levels of SI engagement.

However this was not consistent when only participants with a diagnosis of depression and/or anxiety were included in the analysis (see Figure 6). Participants who demonstrated more SI engagement also scored higher on the DASS anxiety scale though this trend did not reach significance, despite being stronger when only participants with a diagnosis of anxiety and/or depression were included. When only participants with a diagnosis of anxiety and/or depression were included in the analysis, there was a (non-significant) trend for higher DASS anxiety scores across higher levels of SI engagement.
Figure 6. Mean DASS scores, SI engagement levels of participants with a diagnosis of anxiety and/or depression.

6.8 Factors Relating to Increases and Decreases in SI Engagement

6.8.1 Analysis 1. To investigate whether perceived stress, anxiety or low mood have an impact on the frequency and duration of engagement using qualitative processes, participants were asked two questions:

1. "Were there times that you increased your engagement in your SI topic? If yes, why do you believed this happened?"

2. "Where there times that you decreased your engagement in your SI topic? If yes, why do you believed this happened?"

6.8.1.1 Increase in SI engagement. This next section interprets the data obtained for question 1 (why increased engagement). Ninety-two of the 128 participants with a SI responded to this item. Major over-arching themes that
emerged from analysis of this data included the impact of negative experiences, such as low mood and stress, boredom, social isolation and loneliness, on increased SI engagement. Another theme included the impact of positive experiences such as the availability of time and resources, employment and study opportunities within a SI field, interpersonal factors, inspiration and new information about a SI, on increased SI engagement. Several participants reported increased engagement with their SI in times of stress and most reported that engaging in SIs helped them to overcome stressful or difficult experiences. Social isolation, loneliness, not ‘fitting in’ with peers and overall feeling ‘rejected’ by society were some of the factors contributing to an increase in pursuit of SIs.

In contrast, 34% of participants reported an increase in their SI engagement as a result of positive experiences. Opportunities such as the availability of time, and financial resources were reported to be associated with increased time spent pursuing SIs. Employment and study opportunities were also reported as positive experiences that led to natural increases in SI engagement. For some individuals, finding other people who shared a similar interest also led to an increase in time spent on the SI. Another theme that emerged from the analysis was the role of inspiration, new SIs, or un-explored information. Several participants reported that new SIs signified a steep learning curve and opportunity to learn vast amounts of information. Table 13 includes factors relating to increases in the amount of time spent on SIs as perceived by the participants.
Table 13

Factors Relating to Increases in SI Engagement.

<table>
<thead>
<tr>
<th>Factors relating to Increases in SI engagement</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low mood/ depression</td>
<td>5 (4.7)</td>
</tr>
<tr>
<td>Anxiety/stress</td>
<td>19 (17.8)</td>
</tr>
<tr>
<td>Both low mood and anxiety/stress</td>
<td>12 (11.2)</td>
</tr>
<tr>
<td>Boredom</td>
<td>9 (8.4)</td>
</tr>
<tr>
<td>Loneliness/social isolation</td>
<td>9 (8.4)</td>
</tr>
<tr>
<td>Opportunity: Availability of time</td>
<td>19 (17.8)</td>
</tr>
<tr>
<td>Employment/study</td>
<td>9 (8.4)</td>
</tr>
<tr>
<td>Inspiration/new information/New SI</td>
<td>17 (15.9)</td>
</tr>
<tr>
<td>Interpersonal factors</td>
<td>6 (5.6)</td>
</tr>
</tbody>
</table>

6.8.1.2 Decrease in SI engagement. Exploration for the reasons why participants spend less time with their SI revealed a number of themes (see Table 14). These themes included negative experiences, such as loss of employment/study (where SI was used), time restriction/other responsibilities, low mood or depression and stress. Participants reported that their role as a parent, partner or employee (in a non-SI related field) greatly restricted the amount of time and hence opportunity to engage with their SIs. Another major theme related to the impact of depression on participants’ loss of interest in their SI and hence reduction in their engagement with their SI. The excerpts below demonstrate the impact of clinical depression on SI engagement:

I was taking a supplement that both made me clinically depressed and made me uninterested in my obsessions. (P 20)

Reason for decrease in SI engagement) Depression, just wanting to die. (P 149)
Interpersonal factors emerged as a major contributing factor to the decrease in time spent on SI. Several sub-themes were revealed, such as lack of interest shown by others, and (others) restriction of time spent on SI. Some of these inter-personal factors were associated with themes of loss and indicate the likely presence of depressive symptoms, for example:

I lost interest in writing and many other things when I broke up with my first long term girlfriend at 19 years old. (P 8)

One participant reported a notable decrease in the time they spent on SIs when there was less ‘un-explored’ information about the topic area. Additionally for some participants positive experiences, such as satisfaction with interpersonal relationships and employment led to decreases in SI engagement.

Table 14

Factors Relating to Less SI Engagement.

<table>
<thead>
<tr>
<th>Factors Relating to Decreases in SI engagement</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>14 (17.9)</td>
</tr>
<tr>
<td>Satisfaction with social relationships</td>
<td>10 (13)</td>
</tr>
<tr>
<td>Other life satisfaction: e.g. employment</td>
<td>4 (5.1)</td>
</tr>
<tr>
<td>Lack of new information about SI</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td>Social factors: socialising</td>
<td>4 (5.1)</td>
</tr>
<tr>
<td>Social factors: peer/familial pressure</td>
<td>9 (1.2)</td>
</tr>
<tr>
<td>Stress</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td>Lack of time availability/responsibilities</td>
<td>35 (44.9)</td>
</tr>
</tbody>
</table>

Themes relating to positive experiences included, positive mood factors, satisfaction with interpersonal relationships and employment/study. Some participants reported engaging with their SIs far less when they were in a positive mood, or felt higher life satisfaction. For some participants, engaging in SIs less
frequently or with less intensity is associated with “living more”, or “getting more out of life”. One participant explains this:

I actually lived more & studied less when i was well (all round) ... I still enjoyed my topics 'but with real life' & my head out of the fog. (P 106)

Positive interpersonal relationships were deemed to decrease the time, energy and interest spent on their SI. For some participants, this was specifically related to intimate relationships, and several spoke of the impact of new romantic relationships on decreased SI engagement:

Definitely, particularly when in a new relationship (and falling in love!) (P 4)

When I'm happy, typically at the start of a new relationship. (P 131)

Made friends with people, finally had a relationship. (P 10)

The extracts above suggest it is the satisfaction, and hence improved mood relating to being in an intimate relationship that had an impact on their decreased engagement with SIs. Finally, for others satisfaction with employment or study contributed to less engagement with SIs. Participants made it clear that it wasn’t only related to having less time, but also finding their employment interesting and enjoyable.

6.8.2 Analysis 2. Participants were also asked directly about their experience of SIs when they feel more anxious or stressed and when they are low in mood. Overall, 44.9% of participants’ reported spending more time on their SI when they were stressed or anxious, compared to 17.2% who reported spending less time with their SI (see Table 15).
Table 15

Intensity of Engagement with SIs when Stressed/Anxious

<table>
<thead>
<tr>
<th>Level of Engagement</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Far Less</td>
<td>12 (8.0)</td>
</tr>
<tr>
<td>Less</td>
<td>14 (9.3)</td>
</tr>
<tr>
<td>More or less the same</td>
<td>22 (14.7)</td>
</tr>
<tr>
<td>More</td>
<td>28 (18.7)</td>
</tr>
<tr>
<td>Far More</td>
<td>36 (24.0)</td>
</tr>
<tr>
<td>Unsure</td>
<td>15 (10.0)</td>
</tr>
<tr>
<td>Total</td>
<td>127 (100.0)</td>
</tr>
</tbody>
</table>

*Note: One person did not respond.*

When asked about their level of engagement in SIs when feeling sad or 'down', 14.7% of the sample reported not being interested at all in their SI, while 29.3% indicated being interested in their SI ‘to some extent’. However 31% reported no change in their level of engagement with SIs in association with low mood and some participants (16.3%) indicated an increase in their level of engagement in their SI at these times.

6.9 Subjective perceptions of the sample. One of the overall aims of the current study was to analyse the role of SIs in the lives of individuals with AS/HFA. Thus, participants were asked about the impact of SIs on themselves, and the impact participants believe SIs had on their family and friends. The following section presents the interpretation and discussion of discourse relevant to these issues.

6.9.1 Impact of SIs on self. Only a minority of participants ($n = 29$) reported the negative impacts of SI pursuit on themselves. Issues related to responsibilities/time management. Specifically, some participants commented on the encompassing nature of their SIs and difficulties with managing time in relation to interests and other responsibilities:
I definitely calm down when I am relaxing, but then I get mad at myself for having wasted so much time on something that I know is not as important as my responsibilities. It is one of the biggest problems I have. (P 1).

Additionally, the isolating effects of pursuing a SI were reported by some participants. Specifically, participants reported that this related to their difficulties communicating with others on topics unrelated to their SI and disagreements with others about the time spent on the SI compared to other activities with family members and peers.

Table 16

Positive Impacts of SI Pursuit As Reported by Participants

<table>
<thead>
<tr>
<th>Positive Impact of SI</th>
<th>Frequency (%) Reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion regulation</td>
<td>33 (24.5)</td>
</tr>
<tr>
<td>Social benefits</td>
<td>17 (12.6)</td>
</tr>
<tr>
<td>Employment</td>
<td>10 (13.5)</td>
</tr>
<tr>
<td>Life-satisfaction</td>
<td>23 (17.0)</td>
</tr>
<tr>
<td>Positive sense of self</td>
<td>26 (19.3)</td>
</tr>
<tr>
<td>Acute</td>
<td>4  (2.9)</td>
</tr>
</tbody>
</table>

*Note: Statistical analyses of the themes were not possible due to the fact that participants provided multiple responses per survey item.*

As can be seen in Table 16, the most frequently reported positive impact of SI pursuit, related to emotion regulation. Specifically, participants reported the way in which SIs helped to regulate their feelings of stress and low mood. For many, SI pursuit provided an opportunity to escape the issues in their social relationships. The participant below talks about using SIS as a preventative measure against depression. For this individual, SIs provides opportunities to engage with the social world, though he suggests that stress can interfere with this process:
I have a really high need for cognition; so things get a lot worse when I’m stressed and can’t put out the cognitive effort I need to learn those new things. It’s no wonder I get depressed when I get stressed out—the stress keeps me from concentrating and learning as well, and that stops me from doing the things I love so much, automatically resulting in depression. In fact, over the years I’ve discovered that losing interest in SIs is a red flag for depression. I hate being depressed and I never want to have another episode, so I make sure to make time for my SI every day—at least four hours, more if I can—because that’s how I stay sane and engaged with the world. (P 55)

Several participants reported the social benefits of their SI, including being able to connect and socialise with individuals with similar interests and having a topic to discuss when meeting people for the first time. This is consistent with quantitative information provided by participants, which indicate that on a likert scale, 53 participants reported using their SI ‘sometimes’ and 53 ‘quite a bit’ to help them socialise with others, compared to 22 participants who reported ‘never’ using their SI to socialise. Several participants identified SIS as improving their sense of self and reflected on positive feelings associated with success and being respected by family members, peers and colleagues, as a result of their knowledge and use of SIS. Participants’ sense of self was found to be uniquely tied to their engagement with SIS, rather than social relationships and interactions. The following extract provides a good illustration of this:

It allows me a sense of self. As stated above, others may derive a sense of self from a variety of areas in their lives from career through to social relations and exchanges. For me, a complete sense of self is only EVER accessed during SIs times. That is when I am most fused and most ‘alive.’ I do not derive enjoyment from social get togethers with other women. I derive enjoyment
and emotional, mental and spiritual completeness when I am painting and
drawing by myself. (P 82)

In a related theme, participants also reflected on the benefits of SIS on their
overall satisfaction with life, and positive feelings akin to euphoria:

My obsessions are my main passion in life and my main source of joy.
Exploring the topic I'm obsessed with gives me a feeling much like the feeling
people get at the beginning of a new romantic relationship. (P 20)

Some participants identified particularly strong feelings about their SI. The
following comments exemplify the significance of SIs in the lives of individuals with
AS/HFA and the role SIs may have in assisting participants to cope during negative
life experiences.

I believe that music is partially the reason why I have not attempted to take
my own life. It has been a calming experience when I have been going
through some really tough times in my life, for example not fitting into
groups. (P 17)

6.9.2 Impact of SIs on family/peers. The present study revealed a number of
themes relating to the impact of AS/HFA individuals’ SIs on family members and
peers. The responses of participants indicated both positive and negative impact on
family and peers. Themes of positive impact related to the individuals knowledge
about the SI topic and the perceived usefulness of this transfer of information to
family members and peers. Some participants described that the positive impact
related to their family member’s pleasure in seeing them engage and succeed within
their SI area. Other emerging themes included family members or peers improved
understanding of the AS/HFA individual, enjoyment either relating to or appreciation
of the AS/HFA individuals’ particular skills. Some participants spoke of the positive
impact their SIs had on improving their connection with relatives and peers and the financial or material benefits to their family and/or peers.

My father has a mutual interest in and knowledge of popular music, so that's a really cool topic to talk about. (P 63)

Other participants did not refer to the impact of SIs on others, and instead described the positive impact their SI on themselves. For example:

I'm in better shape. I have a plan for my career. I have a backup plan for my career. (P 44)

A very positive impact has been based around go-kan-ryu karate, and since introducing me to the martial art, I have been able to express myself freely more often with friends, family and new people. (P 89)

Sixteen participants did not perceive their SIs to have any positive impact on their family members or peers. Participants were also asked to report their perception of negative impacts that their SI had on family members/peers. Major themes included awareness regarding the impact on lines of communication with family members/peers. Several participants reported being aware that people became disinterested in hearing them talk about their SI. Others reported awareness of the loneliness experienced by their relatives/peers, as a result of the amount of time/effort/focus participants invest into SI. Others reported awareness that their family members/peers were concerned about the negative impact on participants’ health or general wellbeing as a result of intense SI pursuit. Twelve participants did not report any perceived negative impacts to family/peers. This minority may indicate no negative interference effects to others or may indicate a lack awareness of the impact. Alternatively it may be that some of these individuals have relatively low levels of social interaction.
6.9.3 **Restriction of SIs – self.** The data presented in this section reflects on explanations provided by participants for restricting their engagement with their SI. There was a focus on intentional restriction of SI. Overall, 41.4% of the sample \( n = 53 \) reported restricting their engagement with SI to some extent. However over half the sample did not report trying to restrict their SIs. The reasons provided by participants relate to the perceived positive impact of SIs on overall levels of life satisfaction.

The extent to which SI were restricted and the way in which they were restricted varied amongst participants. For some individuals restriction involved reducing conversations based on the SI topic, whilst for others it involved a reduction in overall time spent on the SI topic. Factors contributing to the self-restriction of SI pursuit are reported in Table 17.

Table 17

*Factors Contributing to Self-Restriction of SI Engagement*

<table>
<thead>
<tr>
<th>Reasons for restricting SI engagement</th>
<th>Frequency reported ( (N = 150) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family responsibilities/socialise with peers</td>
<td>14</td>
</tr>
<tr>
<td>Social difficulties</td>
<td>8</td>
</tr>
<tr>
<td>Employment/study</td>
<td>15</td>
</tr>
<tr>
<td>Financial</td>
<td>1</td>
</tr>
<tr>
<td>Acute interference effects</td>
<td>4</td>
</tr>
<tr>
<td>Un-disclosed</td>
<td>11</td>
</tr>
</tbody>
</table>

As highlighted in Table 17, a number of participants restricted their engagement with SIs when they became aware of the negative impact SIs had on other people and on their relationships with loved ones. Several participants also
identified that they restricted the time spent on their SIs to socialise with peers.
While the majority of participants indicated that the desire to socialise resulted in a
reduction in time spent on SIs, some participants reported their sense of pressure to
socialise with family/peers. Participants reported restricting either their SI pursuit or
talking about their SI with others, as a result of bullying during adolescence (social
difficulties). Four participants reflected on needing to restrict their pursuit of
interests when they felt that it was having a detrimental impact on their health or
overall quality of life. The following extract provides an example of this:

Yes, when I realise that my behaviour is having a negative impact on my life,
and causing problems. For example one time I was obsessively playing a
particular computer game, I was only getting out of bed to play, and would not
leave the computer except to go to the toilet or get food from the fridge. Then
I would go to bed only to do the same thing the following day. For more than
a week I didn't leave the house. I knew that I had to break the pattern as other
aspects of my life (study, relationships etc) were getting damaged. (P 4)

For another participant, their SI relating to nutrition began to take on a more
‘obsessive’ role and had negative consequences for her health:

I developed an eating disorder as I became obsessed with counting calories,
weighing food and weighing myself 5/6 times a day. I tried to stop this as I
knew it was bad for my physical health. (P 55)

The comments made by five participants indicated that efforts to reduce the
time spent on the SI topic were frequently unsuccessful. Overall 73 participants
reported that they did not restrict their engagement with their SIs. Many of these
participants did not elaborate on their response other than to say that they did not
attempt to restrict their level of SI engagement. Participants who did elaborate
reported that they either did not consider their level of SI engagement to be
problematic, or that the positive impact of their SI was too important to consider
restricting their SI engagement. One participant commented that while they were
able to restrict their SI engagement in the short-term, the intensity of their
engagement would often become more severe in the long-term:

Temporarily, it was good (restricting SI), as I focused more on my friendships,
but in the long run it meant I had all that fascination saved up and ended up
hoiling up in my flat for a few weeks just rereading and rereading them. (P 95)

6.9.4 Restriction of SIs – others. A total of 62% of participants (n = 80) also
reflected on times when other people restricted the AS/HFA individual’s engagement
with a SI. Several participants reported that restrictions were not placed on them by
other people. Emerging themes overlapped significantly with previously reported
themes relating to the impact on family members/peers. Specifically several
participants reported the perceived impact on social relationships as leading to
restriction placed by others. These were generally by parents, partners, teachers and
in some cases, a peer. However the data also revealed several new themes. Many of
themes were related to participants’ experiences during childhood and adolescence.

Themes relating to the restriction of SIs by others during this time included
parents/teacher’s concerns regarding social development and school work. Two
participants commented on restrictions placed by an employer as a result of work
related responsibilities. The way in which other individuals restricted the AS/HFA
individual’s engagement with the SI varied. Some participants reported being
requested not to talk about the SI topic (or to reduce the time spent talking about the
SI), others reported being ignored. Most participants were restricted from physically
engaging in a topic e.g., reading, writing, playing with a computer game. The extent
of the restriction also varied, with some participants reporting total restriction and
others reporting time limitations. Many participants reported that a family member
tried to re-direct their attention to other areas. Reporting on their own subjective experience, none of the participants spoke of parents/teachers who attempted to gradually broaden the AS/HFA individual’s interest area.

6.9.5 Impact of Restriction. Restriction of participant’s SIs, were perceived as a negative experience by the majority of participants whose SI engagement had been restricted to some extent. This was observed by individuals when they tried to restrict their engagement with SIs themselves, though the interference was greater when others’ restricted their interests. Several participants reported experiencing poor self-image as a result of other’s restriction of their SIs or identified reduced coping as a negative consequence of restricted SIs, resulting in increased anxiety, depression or low mood. The negative impact is described by one participant in the following extract:

Forced decrease by parents - led to substance abuse. Having to ‘fit in with others,’ is another pressure - all lead to a loss of sense of self. Often our sense [sic] of self is acutely defined by our SIs. They give our lives meaning. Others derive meaning from social relations. We derive meaning and sense of self from engagement with our SIs. It is important this is fully understood by the neurotypical [sic] world. For me personally, life without SI is like a dull and bland exercise - a kind of colourless [sic] groundhog day that has little appeal. All experiences - from nature through to looking at things are viewed [sic] through the prism of my SIs. (P 82)

Other negative impacts related to the long-term impact on potential academic and occupational success. Positive consequences as a result of their reduced engagement with SIs were also identified, including within the area of education/employment, improved social relationships, mental health and opportunity to broaden interests, though these were only reported for participants who reported
partial restriction e.g., restricting time spent engaging with SIs rather than complete restriction.
Chapter Seven: Discussion, Clinical Implications and Direction for Future Research

Although the pursuit of SIs are reported by up to 95% of the ASD population (Tantam, 1991), little is known specifically about the characteristics and function of SIs. Much of the literature is focused on the presence and pursuit of SIs within the child ASD population, while only one previous study has been conducted with adults (Mercier et al., 2000). Although Mercier et al.’s (2000) study provided some insight into the nature of SIs pursued by adults, the small sample size \(n = 6\) precluded the findings generalisability. Past research has also revealed some of the learning processes used during SI pursuit. Specifically, children with AS/HFA have been found to engage with their SI using predominantly verbal methods. To date, there has been no indication of whether adults with AS/HFA demonstrate similar learning processes.

These gaps in knowledge provided the rationale for the current study. Following an overview of the prevalence and characteristics of reported SIs, the explanatory power of various theories including weak central coherence theory, ToM, empathising-systemising and homeostasis theory for the occurrence and pursuit of SIs will be discussed. This discussion will be followed by consideration of the impact of SI pursuit on emotional health and wellbeing and conclude with consideration of limitations, recommendations for future research and clinical implications.

7.1 Prevalence and Characteristics of SIs

7.1.1 Prevalence and frequency of engagement. Overall, 85% of the sample of 150 adults with AS/HFA reported pursuing a SIs, with 90% of these individuals reporting that they engaged with their SI on a daily basis and 35% reporting that they
do so for more than 6 hours per day. The prevalence rate of SIs pursuit is consistent with past research conducted with children (Kerbeshian, Burd, & Fisher, 1990; Klin, Danovitch, Merz, & Volkmar, 2007; Szatmari, Bartolucci & Bremner, 1989; Tantam, 1991). However, the finding that 15% of the sample did not report SIs is in contrast to case studies of adults, in which rates of 100% have been indicated (Mercier et al., 2000). These previous studies, however, are limited by a small sample size that may not be representative of the prevalence in the wider ASD community.

7.1.2 Content of SIs. Overall, the participants in the current sample described a total of 324 SIs which fell into the following 11 broad categories: health topics, sciences, humanities, environment, transport related interests, animals, arts, films/movies, games, social interests and miscellaneous interests (interests that did not fit under the previously mentioned categories). SIs within the field of social sciences were the most frequently reported. Past research with children did not indicate a predominant interest in social sciences (Klin et al., 2006; Winter-Messiers, 2007), although this is likely related to the age of participants. Predictably, the adults in the current study demonstrated interests that were more sophisticated than those of the children studied by Klin et al. (2006) and Winter-Messiers (2007), most of whom reported age-appropriate, though restricted SIs. It is unclear why SIs were reported most frequently within the domain of social sciences. One possible explanation may be related to the underlying aim of SI pursuit which was identified in the current study as relating to information/knowledge acquisition. Specifically, it may be that topics within the social sciences offer a variety of ‘facts’ and information arising from the different theoretical/philosophical perspectives, compared to, for example ‘computers’ which may have a more defined array of information.
Although computers weren't the least frequently reported SI topic, the low reporting of computer related SIs also warrant some discussion. Computers are a frequently cited as a predominant interest area for individuals with AS/HFA in popular media (e.g., Mayor, 2008). However the current findings are consistent with past research (Klin et al., 2006; Winter-Messiers, 2007). The misconception about computer related SIs may have arisen because individuals with ASD utilise their computers for extensive periods, though not because computers constitute a SI per se, but because they provide an avenue for the individual to undertake research regarding their actual SI. It is likely that the estimates obtained in the current study regarding SIs in computing is valid, as ASD individuals with an interest in computers may be more likely to participate in an online study (however results were not believed to be biased because of the low number of computer related SIs).

Furthermore, in the current study, 'collecting' was also identified as one of the least common of reported SIs. This is in contrast to clinical accounts (Attwood, 2006), the findings of Mercier et al. (2000), where 'collections' were identified as a main category of interest for adults with AS, while 17.4% of children in the study undertaken by Klin et al. (2006) were reported to engage in 'hoarding'. The current findings may reflect developmental changes from interests involving the acquisition of 'objects', to interests with an emphasis on the acquisition of 'knowledge'.

7.1.3 Development of SIs. Another line of exploration in the current study, relates to whether there are developmental differences in the content of SIs. Participant reports of childhood SIs were consistent with the SI topics previously identified in Winter-Messiers (2007) study of children. Overall, participants reported having fewer SIs when they were children, with the prevalence of SIs peaking during adolescence. Although the number of retrospectively reported SIs may reflect a
difficulty with recall, it may well reflect a real increase in SIs across development. Participants also reported that they had spent the most time engaging with their SIs during adolescence. As social relationships are a focus in adolescence, individuals with ASD may well utilise SIs during this time as a way of coping with their social differences and difficulties (Ghaziuddin et al., 1998; Tantam, 1991). Other contributing factors for increased SI engagement during adolescence may relate to increased autonomy and access to resources.

According to Mercier et al. (2000), SIs may follow a certain sequence that involves successive transformations of the same interest over time. This is reflected in the current study whereby, the majority of participants reported a change from childhood to adolescence SIs that reflected an overall increase in complexity. However, some participants reported that SIs remained constant through childhood to adolescence and almost a quarter demonstrated similar interests from adolescence to adulthood, although these interests were frequently not the primary SI at the time of report. This is consistent with the current finding that individuals commonly demonstrate less engagement with a single SI topic over time, in association with the decline in the availability of novel information regarding the SI. Another finding relating to participants’ childhood SIs related to gender differences in content. Specifically, female participants reported significantly more SIs relating to animals and social interests during childhood compared to males. This is consistent with findings relating to women’s current SIs, which are explored further in the next section.

7.1.4 Social Interests. Consistent with previous research (Baron-Cohen & Wheelwright, 1999; Klin et al., 2007; Mercier et al., 2000; South et al., 2005; Winter-Messiers, 2007), only a minority of participants in the current study, reported
SIs that were ‘social’ in nature. The qualitative nature of ‘social’ interests ‘identified in the current study is markedly different than that reported previously. It has been indicated from past research that an interest in ‘people’ mainly revolved around learning rote facts and trivia (Baron-Cohen et al., 2003; Klin et al., 2007). However in the current study, reported social interests often related to interests in others’ thoughts, feelings and social behaviours. The difference in the findings of this study and those of others may be explained by the nature of the current investigation (breadth of research and qualitative nature) and/or may be related to participant characteristics. It is possible, for example, that the nearly equal distribution of males and females in this study may partly explain the current findings. Although females predominantly reported non-people oriented SIs, they were also found to be significantly more likely to report social interests compared to male participants (current interests and interests acquired in childhood and adolescence). Several of the current social SIs reported by females related to pregnancy, childbirth and childcare. Although these topics were not identified as ‘unusual’ in content, individuals engaged with their SI in light of the methods of engagement employed. Also, due to the current difficulties with identifying ASD in females, examining the unique interests of women was thought to be particularly important. The pursuit of child-care related SIs may be explained by current socially defined gender roles. Specifically, within the general population, women are reported to have more responsibility with household tasks including the care of children, compared to males (e.g. Biernat & Wortman, 1991). The results regarding female social SIs is also consistent with the reported association in the current study between familial responsibility and decreased time spent on SIs.
Further, cultural expectations, differing socialisation of girls compared to males, and greater social support may lead women with ASD to develop less ‘typical’ SIs. The extent to which males can invest in their SIs is also impacted by the availability of time and the presence of family and employment responsibility. However women with ASD have been described as having unique challenges as a result of their ASD diagnosis and socially prescribed gender roles (Faherty, 2002).

Additionally for mothers with ASD, SIs relating to parenting may reflect an effort to improve difficulties they may have in understanding and meeting their children’s emotional needs. The finding that females with ASD demonstrate more social SIs compared to males is also consistent with anecdotal reports in which females are reported to be more adept at camouflaging their social difficulties (Attwood, 2006). Attwood has found within his clinical practice that more females compared to males, observe socially skilled individuals in social situations and copy their mannerisms and persona. Although this may have a significant protective role for girls and women with ASD, it also contributes to the difficulty in identifying ASD in this population.

7.2 Process of engagement with SIs

In the current study, there was an attempt to explore how adults with ASD use their SIs to construct knowledge and understanding. Also, analysis of the method of engagement with SIs was considered important to elucidate the characteristics of SI engagement that may not be evident from the highly variable content of SIs. In Klin et al.’s (2006) previous study with AS/HFA children, the pursuit of SIs most frequently involved verbal learning processes. This finding was replicated in the current adult sample, with participants reporting reading as the most common method of engagement with SIs and only a minority using auditory
learning. Interestingly, over half the sample employed consistent engagement processes across their SI areas, suggesting that these processes may provide a method for characterising SIs.

The participants in the current study were able to identify multiple methods of engagement with their SI. As expected, most participants utilised a number of processes of engagement. This is consistent with suggestions from Klin et al., (2006) that the processes used by higher functioning individuals with ASD are different to individuals with autism and cognitive impairment. The latter more commonly engage in activities that require specific skills (e.g., drawing, rote memorisation of seemingly unrelated bits of information, calculation or other numerical procedures). Furthermore, in the current study, learning that involved visual or kinaesthetic approaches was rarely reported in isolation and was more likely to occur in association with verbal learning processes. However, the opposite was also true. That is, verbal learning processes were more likely reported as being utilised in isolation, rather than in association with non-verbal processes of learning. These results replicate the findings of Klin et al.’s (2006) study with children and may indicate that learning processes in individuals with ASD remain relatively constant throughout development.

Although cognitive profiles were not examined in the current study, the results might be indicative of strong verbal processing abilities as evidenced by the predominant use of verbal learning processes. This is consistent with previous findings indicating higher verbal IQ (VIQ) compared to performance IQ (PIQ) in AS and HFA samples (Cichetti, Klin, Rourke, Sparrow & Volkmar, 1995; Rourke, 1995; Williams, Goldstein, Kojkowski & Minshew, 2008). While higher VIQ compared to PIQ has been associated with AS, the opposite pattern has been attributed to HFA
(Rourke, 1995). However the results from other studies (e.g., Majjova & Prior, 2000; Ozonoff et al., 2000) have failed to distinguish AS from HFA on the basis of cognitive testing. Further, some researchers have reported superior fluid (non-verbal) intelligence in children with AS (Hayashi, Igarashi, Kashima, & Kato, 2008) and HFA (Chen, Planche & Lemonnier, 2010) compared to control groups. Chen et al. (2010) suggest that one reason for the discrepancies in findings is that standard intelligence scales such as the WISC-III (Wechsler, 1991) and WAIS-R (Wechsler, 1981 used in Cichetti et al., 1995) underestimate non-verbal intelligence in individuals with AS/HFA. The variability in research findings may be related to the age of participants. Specifically, changes in cognitive style and abilities have been noted with increasing age in typically developed populations (e.g., Karp, Oltman, Raskin & Witkin, 1971) and individuals with autism (e.g. Joseph, Lord & Tager-Flusberg, 2002). Specifically, participants of Cichetti et al. (1995) were adults while those in Chen et al. (2001) and Hayashi et al., (2008) comprised of children and adolescents. For example, in Joseph et al. (2002), the VIQ-PIQ discrepancy commonly seen in younger children with AS/HFA was found to lessen substantially with age, with older individuals demonstrating higher VIQ. However heterogeneity in the cognitive profiles of individuals with AS/HFA are widely observed, with Joseph et al. (2002) noting that while 28% of their sample exhibited higher verbal to nonverbal scores, a further 34% demonstrated higher nonverbal to verbal scores. The findings from the current study also clearly indicate that verbal processes of learning were not preferred by all participants who were in the higher-functioning end of the autism spectrum.

Finally, equivocal results reported in the literature may relate to sample characteristics. For example, in the current study, exploration of preferred cognitive
styles or learning processes was limited to AS/HFA individuals who pursued a SI. Similarly, Cichetti et al. (1995) utilised stringent criteria and required the pursuit of SIs for a diagnosis of AS. Thus the methods adopted by the current study and Cichetti et al. (1995) might select for participants who have particularly well developed verbal skills, as the development of SIs may be mediated by verbal skills. Thus conclusions in relation to cognitive styles in individuals with autism must be drawn with caution. Nevertheless, the current findings contribute to the body of literature regarding preferred cognitive styles of individuals who are on the higher-functioning end of the autism spectrum.

7.3 Theoretical Explanations of SIs

The extent to which the current findings provide support for various ASD theories including weak central coherence theory, ToM, empathising-systemising theory and extreme male brain theory are discussed in this section. The applicability of homeostasis theory is discussed within the context of current findings relating to depression and anxiety (see section 7.5).

7.3.1 Weak central coherence theory. The weak central coherence theory offers limited explanation for the pursuit of the SIs identified in the current study. The main conjecture of this theory is that individuals with ASD have stronger local processing abilities (detail-focused processing) and difficulties with understanding contextual information. In the current study, participants demonstrated an initial preference for learning the details about their SI topic. If the initial preference to acquire smaller details of information is understood within the context of neuropsychological differences, a weak central coherence theory may account for the development of SIs in the ASD population. Also, a preference for learning details may explain another phenomenon identified in the present study: participants
reported replacing their primary SI when they acquired sufficient knowledge about the topic. However the complex nature by which most participants engaged with their SI was fully borne out of the data. More specifically, the major theme that emerged from the data related to knowledge acquisition and in particular participants' desire to broaden their understanding of their interest area. Additionally, significantly more participants engaged in broadened rather than restricted processes of engagement in order to acquire information about their SI. That is, most participants employed numerous processes to engage with their SI (rather than collection of objects/facts) in order to obtain a greater understanding regarding their topic. Participants also often applied their understanding in various ways that demonstrated creativity or that lead to functional benefits e.g., financial, social, educational.

Turner (1999, p 843) proposed that the weak central coherence theory offers an explanation of the “the obtuse topics that may become features of circumscribed interests, and the narrow and rote fashion with which these interests are pursued”. However in the current study, individuals often demonstrated interests that were not unusual in nature, and although a small number of participants pursued their interests in a repetitive, restrictive manner (e.g., re-reading same series of books, acquiring facts regarding car engine numbers), the findings indicate that individuals with AS/HFA typically do not use rote methods of learning and often strive to attain the context of their interest. The current findings are also inconsistent with previous suggestions (e.g., Joliffe & Baron-Cohen, 1999) that individuals with AS/HFA are inefficient in creating contextually meaningful associations between linguistic information in either short-term or long-term memory (local coherence). In order to achieve an in-depth understanding of their interests, most participants in the current
study would need to obtain, manipulate and remember large and often complex pieces of information.

Overall, although individuals have an initial preference for detail-focused information processing, the weak central coherence theory does not account for the wide range of processes used by AS/HFA participants, the predominant use of verbal processes of learning and the desire to understand their topic in terms of broader detail. Although not directly measured via neuropsychological measures, the qualitative findings of the current study are supportive of the viewpoint that individuals with higher functioning ASDs overwhelmingly have strong central coherence, as evidenced by their ability to integrate information about their SIs and utilise their SIs in ways that are functional. Nevertheless there is variability in cognitive abilities of individuals across all populations, and likewise superior central coherence is not thought to be present amongst all individuals with high functioning ASDs.

7.3.2 Theory of mind account (ToM) of SIs. According to the ToM account, individuals with ASD have specific mentalising difficulties; that is, difficulties with being able to predict, interpret and respond to other peoples’ emotional states and behaviour. The applicability of ToM in explaining the presence and pursuit of SIs in ASD was also considered. In the current study, SIs were found to occur significantly more in some domains e.g., ‘non-social’ interests, compared to people oriented or ‘social’ interests. This finding is consistent with past research conducted with children (Baron-Cohen & Wheelwright, 1999; South et al., 2005 & Winter-Messiers, 2007) and has implications for the ToM account of SIs. It is indicated in anecdotal and clinical accounts of individuals with ASD that the social world frequently cannot meet the needs of the ASD individual nor be a source of
pleasure that it can be for typically developing individuals. For individuals with ASD, the difficulties experienced in establishing satisfactory social relationships may be partially, if not totally replaced by the pleasure derived from intellectual or creative pursuits. This functional analysis perspective (Iwata et al., 1982) emphasises the social consequences of poor ToM and is supported by the findings of the current study. Additionally in the current study, although individuals with ASD frequently reported a desire to be a part of the social world, they also reported their awareness of their difficulties in establishing and maintaining social relationships and how this contributed to their negative mental state and reliance on their SIs. These findings indicate support for the ToM account of SIs.

Another major theme identified in the current study related to reported decreases in SI engagement in the presence of satisfactory social relationships. Although this does not directly support the ToM hypothesis, it is consistent with the findings of Mercier et al. (2000) and indicates that SIs are sensitive to social factors. The results are consistent with Tantam’s (1991) concept of ‘social gain’ which refers to the gains individuals’ experience as a result of restricting their pursuit of SIs. As ToM abilities have been shown to vary across individuals in the ASD population, further research may include investigating whether time and intensity of SI pursuit can be accounted for by varying ToM abilities.

7.3.3 Empathising-systemising account of SIs. Another cognitive theory presented in the introduction is Baron-Cohen’s emphathising-systemising (E-S) theory of ASD. The E-S theory of ASD has evolved from the concepts of ‘folk’ physics and ‘folk psychology’, (Lawson et al., 2004). Although empathising and systemising abilities have been previously tested using broader measures (Baron-Cohen et al., 2003), the aim of the current study was to investigate the extent to
which E-S theory could explain SI pursuit. Hence in the current study, SIs were classified according to Baron-Cohen’s cognitive core domains ‘folk physics’, ‘folk psychology’, ‘folk mathematics’, ‘language’ ‘folk biology’. Interests that related to folk psychology were thought to be indicative of empathising ability and relate to the knowledge and interest in social phenomenon, whilst interests that related to folk physics, folk mathematics and biology were thought to be indicative of systemising ability.

The findings were partially supportive of Baron-Cohen’s E-S theory which predicts that individuals with ASD have below average empathising abilities and intact or superior systemising abilities. Utilising Baron-Cohen and Wheelwright’s (1999) domains of SIs, a significantly higher proportion of SIs reported in the current study related to ‘folk physics’ (that is, the knowledge and interest in how things work), compared to ‘folk psychology’. This is consistent with the empathising-systemising theory. The extract below provides an example of the benefits of systemising for one participant:

In some ways it (SIs) feels/acts a bit like a drug - it helps me deal with difficult emotions, perhaps like alcohol does for other people. Many situations seem to upset and confuse me. But with computers or numbers I can be in control - I can order them and make sense of them. This is reassuring. I cannot measure people and accurately sort them, but I can measure data and rearrange it however I like. (P 4)

It is important to point out that whilst the E-S theory predicts that significantly more individuals with ASD demonstrate intact or superior systemising abilities, compared to empathising ability, there is still room for individual variation. Goldenfield, Baron-Cohen & Wheelwright (2005) reported that 65% of individuals with an ASD were superior in systemising, thus leaving a large percentage of
individuals who have relatively intact empathising abilities. This is consistent with the current findings. Specifically, in an attempt to further investigate empathising in the current sample, a less stringent criteria for ‘social’ interests than required for ‘folk psychology’ was used (e.g., interest in social activities). The results indicated that only a small percentage of the sample \( n = 16, 12.5\% \) demonstrated social (empathising) interests, thus also providing support for the E-S theory.

Other findings from the current study could not, however, be explained by the E-S theory. For example, some individuals reported the identical number of interests relating to folk psychology as for folk mathematics. Baron-Cohen and Wheelwright (1999) did not make a prediction in regards to the pursuit of interests relating to folk mathematics. However, mathematics may also require ‘systemising’ ability (Baron-Cohen & Wheelwright). The current findings are thus inconsistent with the E-S theory which should predict higher numbers of SIs related to folk mathematics compared to folk psychology. A greater percentage of participants reported interests in folk psychology than reported in previous studies (Baron-Cohen & Wheelwright, 1999; South et al., 2005). Secondly, interests within the social sciences were most commonly reported. However social sciences were not able to be categorised according to Baron-Cohen’s core domains of interests. If Baron-Cohen’s definition of systemising was broadened however, social sciences may be classified as a ‘social system’ which can be analysed and predicted like any other physical system that is separate to folk psychology. Several other SIs, unrelated to the social sciences could also not be categorised utilising Baron-Cohen’s (1999) cognitive domains. These domains thus had limited explanatory power in the current study. One possible explanation for this may relate to the age of participants, as the sample in Baron-Cohen’s original study consisted of children. It is possible (and supported
retrospectively in our study) that children do not demonstrate the depth of complexity in their interests as adults with ASD.

Results regarding gender differences on empathising and systemising ability are not explicitly hypothesised for the ASD population. However if principles of the extreme male brain theory are applied, then typical sex differences in the general population should not be found. The empathising-systemising related findings of the current study are purely based on SI content rather than a systemising specific measure such as the Systemising Quotient (SQ); Baron-Cohen et al., 2003), thus it is more difficult to ascertain whether gender differences exist on systemising. Analysis of the gender distribution on natural/physical science topics was conducted to be consistent with the methodology of previous research which compared gender differences in terms of university degrees (Wheelwright et al., 2006). In Wheelwright et al. (2006) physical sciences were found to be significantly and positively correlated with the SQ and significantly and negatively correlated with the Empathising Quotient. This is consistent with reports that the empathising and systemising abilities are largely independent of each other (Baron-Cohen, 2002). The current findings indicated no significant differences in the ratio of males and females pursuing a natural/physical science related SI. This is consistent with previous findings (Wheelwright et al., 2006) and the EMB theory. However in the current study, significantly higher levels of social SIs (reflecting empathising traits) were reported by females compared to males. This is in contrast to previous findings by Wheelwright et al. (2006) and is inconsistent with the EMB theory. The results need to be interpreted with caution as empathising ability that is independent of SI content was not identified in the current study.
Overall, the E-S theory and specifically Baron-Cohen’s (1999) cognitive domains have some explanatory power for the pursuit of SIs in the current study. However, cognitive domains which have been tested with child ASD populations need to be broadened to incorporate the sophisticated SIs of adults with AS/HFA. For example, it is suggested that SIs relating to social sciences, should be reflective of systemising ability. Future research may include investigation into whether SIs relating to social sciences can be predicted by high scores on the SQ. Using this strategy, it is noteworthy that males and females in the current study had an equal distribution of SIs relating to social sciences, which is consistent with principles of EMB.

7.3.4 Executive function account of SIs. Measures of executive dysfunction were not included in this study. However a discussion of the reported methods of SI engagement informs discussion around the executive function abilities in the ASD population. In the current study, there appeared to be a wide variability in the way in which participants used their SI. Some participants reported trying to divide their time between several responsibilities and their SIs. However, others reported never having had the ability nor inclination, to manage their time effectively and as a consequences spent most, if not all their free time pursuing their SI. Participants also reported activities that required a great deal of planning and organisation ability (e.g., participants involved in advocacy). The variability in participant reports is not surprising given the heterogeneity of ASD. Nevertheless although the results are not conclusive, they suggest that a theory of executive dysfunction offers limited explanation for the pursuit of SIs by individuals with ASD, including the sense of personal satisfaction and enjoyment derived from SI pursuit, and the use of multiple processes whilst engaging with SIs.
7.3.5 SIs and information processing. As stated previously, regardless of the SI topic or the process used, an overarching goal or interest for participants in the current study related to knowledge acquisition. For many participants this meant researching the interest area, focusing on specific details and eventually gaining an in-depth understanding of the SI topic. This ‘systemising’ process involves acquiring enough details to build a coherent story, or gestalt and may allow broader information to be ‘built’ into the story. Information saturation may contribute to some individuals with AS/HFA to be more likely to utilise social processes of engaging with their SI (e.g., advocacy, education), or alternatively abandon the interest topic in favour of a new SI. This finding was fully born out of the current data.

Systemising and attention-to-detail go hand in hand, as small details within a system may have a functional role and hence may be critically important. Attention to detail in autism has been repeatedly demonstrated (Jolliffe & Baron-Cohen, 2001; Fecteau, Mottron, Burack, Iarocci et al. 2003; O’Riordan, Plaisted, Driver et al., 2001; Shah & Frith, 1993). The qualitative examination in the current study revealed participants’ preference for collecting large amounts of detailed information about an area of interest, in order to collate this information and obtain a complex understanding of their topic. Systemising is consistent with this method of knowledge acquisition (rather than chunking general information together, possibly missing out of information and hence rendering the system unpredictable). There are some similarities between the E-S theory and the weak central coherence (WCC) theory (i.e., both these theories stress the importance of detail). However the WCC theory conceptualises detail-processing as an inability to integrate information, whilst the E-S theory sees this quality as a highly purposeful process to understand a
system from the bottom up (Baron-Cohen, 2009). Unlike the WCC theory, E-S theory also predicts that over time, an individual may be able to understand the system as a whole, rather than always focusing on the detail. Future studies may want to explore this further, by having a group of individuals learn and report the findings of the system. This should enable deficits according to WCC or intact/superior performance according to the E-S to become apparent.

7.4 AS and HFA

It has been indicated in past research that SI pursuit may be more prevalent in individuals with AS than in individuals with HFA (Kerbeshian, Burd & Fisher, 1990; Ozonoff et al. 2000). One of the goals of the present study was to investigate whether there were any significant differences in either the characteristics of SIs, or in the intensity of SI pursuit, between AS and HFA individuals. However the small sample size of HFA participants \(n=11\) in the present study, precluded thorough investigation of potential differences between these groups. Nevertheless, the identification of HFA and AS ensured that the research findings were not related to potential characteristics unique to either group.

The low frequency of HFA participants is surprising given the DSM-IV requirement that individuals who meet criteria for both autism and AS are diagnosed with autism (APA, 2000). The differences in AS/HFA participant numbers in the current study may be explained by either differences in rate of participation or some other unknown variable. As the questionnaire was marketed in general ASD rather than AS specific websites, recruitment processes are not likely to have impacted the ratio of AS to HFA participants. Research regarding differences in the cognitive profiles of AS and HFA individuals are equivocal, though there is no indication that individuals with HFA would have found it cognitively more difficult to access the
online questionnaire. The differences in rate of participation between AS and HFA participants also cannot be accounted for by potential differences in rate of self-diagnosis, as only a small percentage of the overall sample reported self-diagnosis.

One possible explanation for why only a limited number of HFA participants were recruited may be related to the focus of the current investigation on SIs. It may be that individuals with HFA were less interested in completing a questionnaire that related to SIs. This may be because 1) they are less likely to pursue a SI than individuals with AS, or 2) other possible motivational factors, such as less perceived gain from completing the survey. It should be noted that although 10 out of 11 participants with HFA pursued a SI, this may not be representative of the HFA population. The available qualitative data was investigated to examine potential differences between AS/HFA, with no differences evident in either the content of SIs, the process of engagement or the impact of SIs to self. Although the results need to be interpreted with caution, it does indicate the possibility that the presentation of SIs of HFA and AS is largely the same. This is consistent with the current move to a more dimensional approach to ASD diagnosis and likely removal of AS as a unique disorder from the upcoming edition of the DSM (DSM-V, 2010).

7.5 Depression/Anxiety and SIs

It has been reported that repetitive motor behaviours regulate distress and sensory over or under-arousal levels in individuals with ‘lower functioning’ ASDs (Buitellar, Dekkar, & van Engeland, 1998; Gabriels et al., 2008; Gal et al., 2002; Hutt and Hutt, 1965; Legendre, Trudel, and Dufresne, 1992; Lovaas, Bravaccio, & Falco, 1987; Sroufe, Struecher, & Strutzer, 1973; Willemsen-Swinkels). It was not clear whether the results relating to motor behaviours in lower functioning individuals extend to the pursuit of SIs in ‘higher functioning’ individuals, although
some of the AS/HFA children in Winter-Messiers (2007) study reported pursuing their SIs to cope with stressful situations. In the present study, it was predicted that if individuals pursue their SIs to regulate their levels of stress and anxiety, than individuals who report high levels of SI engagement would report greater symptoms of stress and anxiety, compared to individuals who report lower levels of SI engagement. A second hypothesis related to the relationship between depression and levels of SI engagement. Loss of interest in activities (anhedonia) is a well known predictor of depression is the general population (DSM-IV; APA, 2000). Less SI engagement has also been reported in clinical accounts and case studies of depressed individuals with ASD (Clarke et al., 1999; Gillberg, 1985). Therefore, in the current study it was predicted that individuals with ASD with more depressive symptoms would report less engagement with their SIs compared to individuals who report fewer depressive symptoms.

In the present study, the expected main effect between DASS depression and anxiety levels and the SI engagement levels was not obtained, although there was a non-significant trend for participants who engaged more with their SIs to score higher on the DASS anxiety scale, with participants who pursue their SI for over 6 hours per day scoring the highest on the DASS anxiety scale. This result was consistent when only participants with a formal diagnosis of anxiety and/or depression were included in the analysis. Further, no significant group differences were identified in levels of anxiety or depression between participants with and without a SI. This may indicate the absence of a relationship between SI pursuit and overall levels of anxiety, depression and stress and/or the presence of unidentified qualitative differences between individuals who have a SI and those who do not have a SI. As is the case in the general population, individual variation in coping
responses and styles should be expected with the ASD population. It may be that individuals who do not have a SI have developed different coping strategies to individuals who have a SI. This process and the presence or absence of SIs may be affected by differences in the empathising-systemising abilities of individuals with AS/HFA, or in the extent to which individuals employ a detail-focused information processing approach. The absence of a finding is not likely to be related to the use of the DASS measure. Specifically in the current study, participants who reported a diagnosis of anxiety and or depression scored higher on the DASS anxiety and depression scales. This result would indicate that the DASS is an effective measure of negative emotional states of individuals with high functioning ASDs. It also supports the notion that individuals with higher-functioning ASDs have sufficient insight to report on their mental states.

Results were mixed when participants were asked directly about the impact of stress, anxiety and depression on their level of SI engagement. Specifically, although nearly half the sample reported engaging more frequently with their SI when they were stressed or anxious, 18% noted no change in their level of SI engagement and 17% indicated lower levels of SI engagement when they were feeling stressed or anxious. The results relating to the relationship between low mood and SI engagement were also mixed, with approximately half the sample reporting either unchanged, or greater interest in their SI when they were feeling ‘sad or down’. Due to the use of the term ‘sad’ or ‘down’ the results may be reflective of the relationship between SI engagement and sub-clinical levels of depression (e.g., low mood). In fact, this is consistent with the results of the qualitative analysis which indicated that negative experiences resulting in lowered mood often increased SI engagement, while clinical levels of depression resulted in less time spent on SIs. Overall results
relating to the DASS scores are consistent with the literature on anxiety and depression in the ASD population and indicate higher levels of depression, anxiety and stress than levels typical in the general population (Bellini, 2004; Brereton, Howlin, 2000; Gillot, Furniss, & Walter, 2001; Gillot & Standen, 2007; Lainhart, 1999).

The lack of a significant linear association between SI engagement and depression, anxiety and stress was not surprising given the results from the qualitative analysis. Specifically, a number of factors were found to be contributing to either increases or decreases in SI engagement. As expected, when participants were asked about factors that influenced an increase in their SI engagement, anxiety and stress was reported the most frequently. However there was evidence to suggest that both negative and positive ‘experiences’ had an impact on SI pursuit (see Figure 7). Positive experiences that resulted in increased SI pursuit included the availability of time and resources, employment and study opportunities within a SI field, interpersonal factors, inspiration and new information about a SI. Other negative experiences that resulted in increased SI pursuit included social isolation or loneliness, boredom and ‘sensory overload’. Overall, participants who reported using SIs to cope with negative stressors, including loneliness/social isolation accounted for 42.1% of the sample. Participants were also asked to explain factors that influenced the decrease of their SI engagement. As expected, low mood was also reported to decrease SI engagement, although the most frequently reported factor related to the lack of availability of time due to responsibilities (e.g., employment, family). Themes relating to negative experiences included loss of employment, study (involving SI), time restriction/other responsibilities while
positive experiences included satisfaction with interpersonal relationships and employment led to decreases in SI engagement (see Figure 8).

Figure 7. Factors contributing to increases in SI engagement.

Anxiety was predicted to be a major factor in contributing to increased SI engagement. The findings supported this prediction, with only one participant reporting that anxiety contributed to less engagement in their SI. For this individual, they reported being too anxious to be able to focus on their SI. The influence of positive and negative experiences on SI engagement may explain the mixed quantitative findings. Specifically, even if anxiety leads to significantly higher levels of SI engagement, the influence of positive experiences may be negating this relationship. The relationship between anxiety, stress and depression and the mediating effect of other factors, as supported by the results of the qualitative study, is illustrated in Figure 9.
Figure 8. Factors contributing to decreases in SI engagement.
For example, participants who reported feeling generally low or stressed, reported greater engagement with their SIs compared to participants who reported high levels of depression (clinical impairment indicated in their responses). The homeostasis account for repetitive behaviours in ASD (Tantam, 1991) can offer some explanation for these results. Participants indicated that their SI topic was a source of comfort and relaxation when feeling low, stressed or anxious and further, that SIs were not able to provide this function once a certain threshold of anxiety/depression was met. Support for this interpretation comes from clinical and research evidence from the general population, where anhedonia is a well known symptom for clinical depression (APA, 2000). There was also some support for the under-arousal theory of homeostasis. According to the under-arousal theory of homeostasis, individuals who require further stimulation should demonstrate higher levels of SI engagement. For example, boredom and need for intellectual stimulation were frequently expressed as reasons for increases in SI engagement.

Another theme that emerged from the qualitative data related to the association between level of social interaction and level of engagement with a SI. That is, individuals who reported satisfaction in their social relationships reported less interest in their SIs. Likewise, individuals frequently identified pursuing their SI to a greater extent when they felt isolated and lonely. These responses may be expected with typically developing individuals, although the social and communicative difficulties of individuals with ASD, and the resulting stress and anxiety that these difficulties can cause, may be creating a sense of dependence on SIs. The availability of social opportunities, employment and education also result in a decrease in SI engagement. The results from the study suggest that the decrease in SI engagement is related to less available time to engage in interests, rather than a
reflection of improved mental health. Supporting evidence for this includes the fact that participants reported that having less time directly influenced the extent to which they engaged with their SI. Additionally, SIs were found to be uniquely connected to personal satisfaction. The relationship between these different factors and SI engagement is illustrated in Figure 9.

![Diagram of relationships between factors affecting SI engagement]

**Figure 9.** Mediating effects of various factors on SI engagement

### 7.6 Impact of SIs on Self and Others

One of the primary reasons for utilising self-report in the current study was to obtain participants’ subjective experiences of SI pursuit. Overall, the results replicate the findings of past studies conducted with children (Winter-Messiers, 2007) and adults (Mercier et al. 2000). All participants in the present study who reported having a SI described the positive impact of their SIs on themselves and others, while some were able to also identify negative aspects of SI pursuit. The most commonly reported benefit of SI pursuit related to emotion regulation. Specifically individuals reported that engaging in SIs helped them cope with negative
situations that led to feelings of anxiety and low mood. Other themes that were fully born out of the current data related to the intrinsic relationship between SIs and individuals sense of identity, life and personal satisfaction. This positive impact is highlighted by one participant:

The special interests are what bring me joy and happiness. They are the things I prize most in life, after my family and best friend. When I’m talking about or engaging in one of my special interests I cannot be happier. They also earn me respect with people, because people admire my memory for facts, passion, and dedication. Also, the special interests are my most obvious AS symptom, and since they are so wonderful, it makes me view AS in a very positive light. Even though AS causes lots of problems, I would NEVER give up my AS, because I cannot imagine how neurotypicals live without the joy associated with special interests. (P 49)

Participants also perceived that SIs provided an avenue to socially connect with their relatives and peers, provided financial assistance and assistance through the provision of useful information relevant to the non-ASD relative/friend. Additionally, participants in the current study report seeking and establishing friendships with other individuals with an ASD who share a similar interest to their own. Overall although SIs are commonly assumed to have a non-social quality (i.e., are not genuinely shared with others and/or are not socially interesting; Lord et al., 1989), the current findings indicate that SIs often provide an avenue of communication with others. Overall, the results replicate the findings of past studies conducted with children (Winter-Messiers, 2007) and adults (Mercier et al. 2000).

When asked about the positive impact of SIs on others, some participants reported on the ultimate benefits to themselves rather than on others. This could be
interpreted in two ways. First, it may be suggested that these participants could not identify potential positive factors from the perspective of their family members or peers. Alternatively, it could indicate that participants believe that the positive impact on themselves (the individual with AS/HFA) ultimately has a positive indirect impact on family members/peers. The latter interpretation is plausible in light of the fact that it might be similarly difficult for typically developing individuals to discuss the benefits of their sub-clinical hobbies or interests for their relatives or peers.

Some participants also described what they perceived were the negative impacts of their SIs on themselves and others. The negative impact on themselves included the isolating effects of intense SI pursuit and difficulties associated with effectively allocating time for SIs and family/friends or other responsibilities such as employment. Most participants were also able to articulate the impact of SI pursuit on family members/peers. The responses demonstrated an acute awareness that most people in their lives were, at the very least, disinterested and at most overwhelmed by the ASD individuals ‘endless’ desire to talk about their SI. Individuals reported that they found it difficult to know what other topics to talk about with family or peers, or found it difficult to not talk about their SI. Participants were often highly aware that this often contributed to difficulties in their social interactions and relationships. Individuals were also aware that family and friends were often concerned about the amount of time their ASD relatives spent on their SI and the impact that this may have on their general well-being.

Although the findings suggest that the current sample has some insight into the concerns of family/peers, conclusions regarding their mentalising ability cannot be confidently drawn. It is highly likely that, over time, individuals have developed an understanding into the social appropriateness of different behaviours (e.g., giving
monologues about their SI result in adverse reactions by others). Several participants also commented that they were informed explicitly by others that their level of engagement with SIs or discussions around SIs were not appreciated or approved of. Also it is likely that some of the negative effects reported by participants are more reflective of their social and communicative difficulties rather than a result of their SI pursuit. Nevertheless the current findings inform knowledge about AS/HFA individuals’ perception of the impact on others and identify some of the ways in which families cope and benefit from the individuals engagement with their SI topic.

7.7 Restricting SI pursuit

As a result of their self-awareness regarding the negative impact of their SI pursuit on themselves and others, nearly half the sample reported restricting their level of SI engagement at some point in their life. For some individuals this involved limiting their conversations regarding their SIs to certain individuals, for others it involved elimination of all engagement with a SI, while others attempted to gradually reduce the amount of time they spent on their SI topic. Not all participants were successful in being able to restrict their level of engagement, with some participants reporting more intense engagement with SIs following a period of restriction. The main findings indicate that 1) AS/HFA individuals have locus of control in relation to their SI engagement and 2) SIs are to an extent, influenced by social pressure. That is, individuals have the capacity to decrease the amount of time they spend on them and adapt their interests to meet the demands of their environment. These results replicate the findings of Klinc et al.’s (2006) case studies with 6 adults with AS/HFA.

Individuals also reported on the restrictions placed on them by others (typically parents and teachers) during childhood and adolescence. Restrictions
ranged from total elimination to providing the ASD individual opportunities to engage with different topics and activities. Participants, who were completely restricted from engaging with their SI, reported the negative impact to their emotional health, life satisfaction and sense of identity. However other participants saw the benefits of their parents and teachers placing some limits on their SI engagement and reported the positive implications for their relationships, educational and vocational outcomes.

7.8 Limitations of the Present Study and Directions for Future Research

The results obtained in this study provide an original contribution to understanding of SIs in a large sample of adults with ASDs. Previously, SIs have been studied with children or with very small samples of adult participants. However this study is not without limitations and these need to be discussed.

First, the study is not experimental in nature and did not attempt to investigate changes in anxiety and depression in individuals with ASD prior and subsequent to SI engagement. Hence the current results do not indicate whether individuals who typically pursue a SI would score even higher on anxiety if they did not engage with their SI. Second, another limitation relates to participant characteristics. Due to the online nature of the study, participants’ diagnosis or SIs could not be confirmed by the researcher, thus interpretations drawn regarding differences between AS and HFA individuals is limited.

The third issue relates to the fact that there were significantly more females \( n = 86 \) than males \( n = 64 \) in the sample (when the reverse is true in terms of prevalence in ASD). Current estimates indicate that the male to female ratio in high functioning ASDs is around 2.7: 1 (Baron-Cohen, Hockstra, Knickmeyer & Wheelwright, 2006; Klin et al., 1995). This may raise some questions regarding the
sampling methods in the study. However none of the internet sites utilised for marketing of the questionnaire were gender specific (see Appendix G). Further, all participants in the current study were identified regardless of whether or not they pursued. One possible reason for the high number of female participants in this study may be related to the nature of the study itself. Specifically, although males and females were identified to be equally likely to pursue a SI, it may be that individuals with SIs were more likely to drawn to participate in a study of this nature. Thus, it may be that ASD females in the general population are either more likely to pursue a SI or communicate about their SI. Research conducted within clinical settings may be able to identify further demographic/SI information regarding potential participants.

Fourth, although all available qualitative information regarding SIs were analysed, there remained some inherent difficulties with quantifying and drawing a line between SIs in autism and the sometimes very intense and/or restricted interests of typically developing individuals. For this reason, future studies may warrant inclusion of a comparison group of typically developing adults who pursue intense/restricted interests. However, this approach may be problematic, particularly in relation to whether the SIs of individuals with ASD and the intense interests of typically developing individuals are comparable.

Finally, 15% of participants in the current study did not pursue a SI. The reasons for this and the characteristics that may be unique to these individuals were not explored. However prevalence rates for SI pursuit are consistent with those reported by previous studies (e.g., Klin et al., 2007). Future studies could investigate qualitatively, whether these individuals ever had a SI and if so, the factors influencing SI extinction. In addition, methods of coping in ASD individuals who do
not report areas of SI require investigation. For example, it might be that these individuals do not pursue SIs because SIs for them do not provide the same functional benefits they do for others. Alternatively, there may be differences in ToM abilities, social skills or overall life satisfaction between individuals with and without SIs that determine the origin and pursuit of SIs.

7.9 Clinical Implications

The findings of the current study indicate that whilst the content of SIs may not assist in the clinical diagnosis of ASD, the amount of time and resources invested into SIs, and the processes used whilst pursuing SIs may indicate the need for further ASD assessment. Specifically, although the majority of participants in the current study reported non-social interests, topics were highly variable in content, and were rarely considered to be unusual in their own right. However, individuals spent a large amount of their available time on their SI, and often preferred it to other activities. Further, individuals demonstrated a consistent preference for detail focused processing of information. These characteristics may be helpful when screening individuals for ASD.

One of the main findings in this study related to the pleasure associated with SI pursuit. The personal satisfaction derived from engaging with SIs is believed to be one of the defining characteristics of AS and help to differentiate AS from other conditions such as OCD where the obsession and compulsions often cause severe emotional distress. Further in OCD, individuals engage in compulsions only in an attempt to alleviate subjective feelings of distress associated with their obsessive thoughts. The current findings indicate that although individuals with AS may utilise SIs as a coping strategy, there are several positive factors that contribute to the development and maintenance of SIs. Overall, from a therapeutic perspective,
clinicians should be mindful of the positive role of SIs for individuals with ASD, whilst assessing the level of interference of SI pursuit and the presence of possible comorbid OCD symptoms using a rating scale such as the Yale–Brown Obsessive–Compulsive Scale (Y–BOCS; Goodman et al, 1989).

Questions relating to the intensity of SI pursuit may be included when screening ASD individuals for anxiety or depression. Individuals suspected to have anxiety or depression, may be questioned about the circumstances under which they typically engage with SIs, and whether there has been a change in relation to the number of hours spent engaging with a SI. This line of questioning may also provide important clinical information in relation to changes in mood. Also, assessment of the intensity of SI pursuit is essential to determining whether an element of restriction or diversification of SIs would be helpful. It is also important to note that for some individuals, SIs may provide an avenue to socialise with others with similar interests, while for other individuals intense engagement with SIs may limit their opportunities to socialise and build social relationships. In the current study, SIs were found to be not only a source of coping for many individuals with ASD, but they also commonly tied uniquely to their self-esteem and identity. On this basis, it is therefore proposed that complete restriction or eradication of an individuals’ engagement with their SI is likely not conducive to their emotional health and overall well-being. Further, it is proposed that greater awareness and education regarding SIs need to be established with carers and in schools. Although SIs are sometimes used as reinforcers in therapy and in classrooms to assist children improve their self-help skills, social, communication or academic functioning, there is no consensus regarding the management and use of SIs. Professionals working with adults may
also need to be mindful of participants SIs when assisting them with educational or employment options.

Overall the current study has made an original contribution to the current state of knowledge regarding SIs, particularly within the adult ASD population. SIs may present unique challenges to individuals with ASD and their families/peers, however the findings of this study overall indicate the importance of SIs in the assessment and promotion of mental health and wellbeing in adults with ASD.
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MEMORANDUM

TO: Dr David Hamilton
School of Psychology,
Burwood
cc: Melis Kantarcioğlu

FROM: Deakin University Human Research Ethics Committee (DU-HREC)

DATE: 15 June 2009

SUBJECT: Project: EC 56-2009 (Please quote this project number in future communication.)

The development and characterization of special interests in adults with Asperger syndrome

The application for this project was considered at the DU-HREC meeting held on 11 May 2009.

Approval has been given for Melis Kantarcioğlu (Aday, under the supervision of Dr David Hamilton, School of Psychology, to undertake this project for a period of three years from 15 June 2009.

The approval given by the Deakin University Human Research Ethics Committee is Given only for the project and for the period as stated in the approval. It is your responsibility to contact the Executive Officer immediately should any of the following occur:

- Serious or unexpected adverse effects on the participants
- Any proposed changes in the protocol, including extensions of time.
- Any events which might affect the continuing ethical acceptability of the project.
- The project is discontinued before the expected date of completion.
- Modifications are requested by other HREC’s.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project. DU-HREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Signature Redacted by Library

Vicky Bates, Secretary
On behalf of DU-HREC
Appendix B

Plain Language Statement

DEAKIN UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE
PLAIN LANGUAGE STATEMENT

My name is Melis Kantarcioğlu, I am a postgraduate student conducting a research project under the supervision of Dr David Hamilton, a Senior lecturer in the School of Psychology at Deakin University. The findings from this study will be written up as a thesis, counting towards a Doctor of Clinical Psychology degree.

I would like to invite you to participate in a research project which aims to investigate the occurrence, role and development of special interests in people with Asperger syndrome or high functioning autism. Also despite a high incidence of depression and anxiety in people with Asperger syndrome or high functioning autism, little research has been conducted with individuals to see how they experience and react to stressful events.

If you agree to participate in this study, you will be asked to complete the following on-line questionnaire. It is estimated to take between 30 to 45 minutes to complete. I require information from individuals who have Asperger syndrome, or high functioning autism who do not have an intellectual disability and who are over 18 years of age. Your consent will be indicated by electronically submitting your responses to the anonymous questionnaire following completion of the questions.

In this questionnaire, you will be asked to explain your special interest topic, and the circumstances under which you tend to pursue them. The following are examples of the questions you will be asked to respond:

*EG. 1. Please list and explain the topics that you have a particular interest/fascination with.*

*EG. 2 On average, how much of your free time do you spend on your special interest topic?*

*EG. 3 Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers.*

*I couldn’t seem to get any enjoyment out of the things I did: 0 1 2 3*
Possible Benefits
Possible benefits include gaining a better understanding of the characteristics and development of your special interest topic. However we cannot guarantee or promise that you will receive any benefits from this project.

Possible Risks
There are no expected risks with this research study, however sometimes thinking and talking about your thoughts and feelings can make you feel sad or stressed. If this happens to you, please contact an autism support service in your local area. One way in which you can find their contact details is through an internet search engine, e.g. www.google.com and typing in “autism support service” and the name of your state and country i.e. New South Wales, Australia.

Please remember also that you are under no obligation to complete the questionnaire.

Privacy, Confidentiality and Disclosure of Information
All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. To maintain confidentiality no names will be allocated to the questionnaires that are completed.

Storage of the data collected will adhere to the University regulations and kept in secure storage for 6 years. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report, as only aggregated data will be reported.

Participation is Voluntary
Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. However due to the anonymous nature of this questionnaire, individual results are not able to be retracted once the questionnaire is submitted.

Ethical Guidelines
This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethics aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University.

Queries/results?
If you have any queries or would like to be informed of the aggregate research finding, please contact David Hamilton on (03) 9244 6139 or david.hamilton@deakin.edu.au.
What if I have a complaint?

Should you have any concern about the conduct of this research project DUHREC-HMNBS 35/07, please contact the Deakin University Ethics Subcommittee – Health Medicine Nursing & Behavioural Sciences at the following address:
Professor Caryl Nowson
Chair – Deakin University Ethics Subcommittee-HMNBS
221 Burwood Highway
Burwood VIC 3125
Tel: +61-3-9251-7174  Fax: +61-3-9244-6019  Email: hmnbs.research@deakin.edu.au

Thank you.
Appendix C

Special Interest Questionnaire

SECTION A

Age:

Sex:

Country of residence:

Ethnicity:

Marital status:
- Married
- Divorced
- Widowed
- Separated
- Never been married
- A member of an unmarried couple

Employment status

Are you currently:
- Employed for wages
- Self-employed
- Out of work for more than 1 year
- Out of work for less than 1 year
- A homemaker
- A student
- Retired

What is your occupation:

How many hours of paid employment do you complete a week:

What is your estimated annual income?

What is your highest level of education?

What is your current diagnosis?
• Asperger Syndrome
  Autistic Disorder (High Functioning)

**Tick the box which applies to you.**

• I was diagnosed by a general practitioner (doctor).
• I was diagnosed by a mental health care professional (psychologist, psychiatrist)
• I am self-diagnosed
• Other? Please explain.

**Have you ever been diagnosed with having depression or anxiety?**

• Depression
• Anxiety
• Depression and Anxiety
• Neither Anxiety or Depression

**When were you diagnosed with anxiety/depression?**

**What, if any medication do you use?**

**Do you have a topic or topics of interest for which you have an extensive level of knowledge and understanding?**

• YES
• NO

If you answered yes to this question, please answer Section B below.

**SECTION B**

Please list and explain the topics that you have a particular interest or fascination with.

**Topic A:**

Examples of the things you know or do involving this topic:

**Topic B:**

Examples of the things you know or do involving this topic:

**Topic C:**
Examples of the things you know or do involving this topic:

**Do you have any extraordinary skills (memory feats, drawing abilities, or calendar calculation etc)?**

- YES
- NO

If Yes, please name the skills you have as an adult. Describe as briefly but as specifically as possible the kind of things you can do. These may be things that either you or others have noticed.

Skill A

Skill B

**Do you have a strong attachment to a particular item (e.g. an article of clothing etc)**

Yes  No

If YES, please specify

Please answer the questions below, in relation to the past week

Please tick the box that is most appropriate for you

*In total* I spent less than **1 hour a day** on activities involving my special interest topic

*In total* I spent around **1-3 hours a day** on activities involving my special interest topic

*In total* I spent around **3-6 hours a day** on activities involving my special interest topic.

*In total* I spent more than **6 hours a day** on activities involving my special interest topic.

I did not spend time on my special interest topic every day. Please clarify.
On each occasion that you spend time on your special interest topic, approximately how long is this for?

Less than 1 hour:

Between 1 – 2 hours:

Between 3-4 hours:

Between 5-6 hours:

* How many hours did you spend on your special interest topic during paid employment?

On average, how much of your free time do you spend on your special interest topic?

I spent some of my free time on my special interest topic (less than 25% of the time)

I spent quite a bit of my free time on my special interest topic (25% to 50% of my free time).

I spent a lot of my free time on my special interest topic (50% - 75% of my free time)

I spent most of my free time on my special interest topic (more than 75% of the time)

Please answer the questions below, in relation to the past 6 months

Please tick the box that is most appropriate for you

On average I spent less than 1 hour a day on activities involving my special interest topic

On average I spent between 1-3 hours a day on activities involving my special interest topic.

On average I spent between 3-6 hours a day on activities involving my special interest topic.

On average I spent more than 6 hours a day on activities involving my special interest topic.
How many hours did you spend on your special interest during paid employment?

* On average, how much of your free time did you spend on your special interest topic?
I spent some of my free time on my special interest topic (less than 25% of the time)

I spent quite a bit of my free time on my special interest topic (25% to 50% of my free time).

I spent a lot of my free time on my special interest topic (50% - 75% of my free time).

I spent most of my free time on my special interest topic (more than 75% of the time).

In what way do you spend time on your special interest topic/s? (please tick appropriate box(es):

I read about my topic of interest.

I memorise information about my topic of interest.

I talk about my topic of interest.

I categorise/classify information about my topic of interest

I collect objects relating to my special interest.

Other? Please specify

How much of your interactions and conversations with your family are related to your topic of special interest/s?

Some of my interactions and conversations with my family are related to my special interest topic (less than 25% of the time)

Quite a bit of my interactions and conversations with my family are related to my special interest topic (25% to 50% of the time).

A lot of my interactions and conversations with my family are related to my special interest topic (50% to 75% of the time).
Most of my interactions and conversations with my family are related to my special interest topic (more than 75% of the time).

How much of your interactions and conversations with your peers/friends are related to your topic of special interest/s?

Some of my interactions and conversations with my peers/friends are related to my special interest topic (less than 25% of the time).

Quite a bit of my interactions and conversations with my peers/friends are related to my special interest topic (25% to 50% of the time).

A lot of my interactions and conversations with my peers/friends are related to my special interest topic (50% to 75% of the time).

Most of my interactions and conversations with my peers/friends are related to my special interest topic (more than 75% of the time).

How much of your interaction and conversation with other adults (such as when meeting new people) is related to your topic of special interest/s?

Some of my interactions and conversations with other adults are related to my special interest topic (less than 25% of the time).

Quite a bit of my interactions and conversations with other adults are related to my special interest topic (25% to 50% of the time).

A lot of my interactions and conversations with other adults are related to my special interest topic (50% to 75% of the time).

Most of my interactions and conversations with other adults are related to my special interest topic (more than 75% of the time).

Functions

To what extent have you used your special interest to help you interact with other people?

Never
Sometimes
Quite a bit
Was there a positive impact of your special interest on your family/peers? Please explain.

Was there a negative impact of your special interest on your family/peers? Please explain.

To the best of your ability, please list the special interest topics you have been involved in during different periods in your life. You may leave sections blank for questions you are not able to answer.

5 years and under

Special Interest topic:

How often did you engage in this topic?

- Sometimes (less than 25% of the time)
- Quite a bit (between 25-50% of the time)
- A lot (between 50%-75% of the time)
- Almost always (More than 75% of the time)

On each occasion that you spent time on your special interest topic, approximately how long was this for?

- Less than 1 hour:
- Between 1 – 2 hours:
- Between 3-4 hours:
- Between 5-6 hours:

In what way did you spend time on your special interest topic/s? (please tick appropriate box(es):

- I read about my topic of interest.
- I memorised information about my topic of interest.
- I talked about my topic of interest.
- I categorised/classified information about my topic of interest
- I collected objects relating to my special interest.

Other? Please specify
6 to 12 years

Special Interest Topic

How often did you engage in this topic?

Sometimes (less than 25% of the time)
Quite a bit (between 25-50% of the time)
A lot (between 50%-75% of the time)
Almost always (More than 75% of the time)

On each occasion that you spent time on your special interest topic, approximately how long was this for?

Less than 1 hour:
Between 1 – 2 hours:
Between 3-4 hours:
Between 5-6 hours:

In what way did you spend time on your special interest topic/s? (please tick appropriate box(es):

I read about my topic of interest.
I memorised information about my topic of interest.
I talked about my topic of interest.
I categorised/classified information about my topic of interest.
I collected objects relating to my special interest.

Other? Please specify

13 to 18 years

How often did you engage in this topic?

Sometimes (less than 25% of the time)
Quite a bit (between 25-50% of the time)
A lot (between 50%-75% of the time)
Almost always (More than 75% of the time)
On each occasion that you spent time on your special interest topic, approximately how long was this for?

Less than 1 hour:

Between 1 – 2 hours:

Between 3-4 hours:

Between 5-6 hours:

In what way did you spend time on your special interest topic/s? (please tick appropriate box(es)):

I read about my topic of interest.

I memorised information about my topic of interest.

I talked about my topic of interest.

I categorised/classified information about my topic of interest

I collected objects relating to my special interest.

Other? Please specify

18 to current age

How often did you engage in this topic?

Sometimes (less than 25% of the time)

Quite a bit (between 25-50% of the time)

A lot (between 50%-75% of the time)

Almost always (More than 75% of the time)

On each occasion that you spent time on your special interest topic, approximately how long was this for?

Less than 1 hour:

Between 1 – 2 hours:

Between 3-4 hours:

Between 5-6 hours:
In what way did you spend time on your special interest topic/s? (please tick appropriate box(es)):

I read about my topic of interest.

I memorised information about my topic of interest.

I talked about my topic of interest.

I categorised/classified information about my topic of interest

I collected objects relating to my special interest.

Other? Please specify

Were there times that you increased your engagement in your special interest topic?

Yes, No.

If Yes, why do you believe this happened?

Were there times that you decreased your engagement in your special interest topic?

Yes, No.

If Yes, why do you believe this happened?

Were there times that you tried to restrict how much time you spent on your special interest topic? Please provide details

Were there times that others (i.e. parents/relatives/teachers/peers) tried to restrict your engagement in your special interest topic? Please explain.

If Yes, do you believe this affected you in a positive or negative way. Please explain.
FORENSIC

Has there been a time when you got into trouble with the law because of your special interest?

Yes    No

Has this been to have better access to your special interest (either financially or otherwise?)

Yes    No

Please cross the box for the answer that is most true for you.

During the day, to what extent do you engage with your special interest topic when you feel stressed/anxious? Choose one option only.

I engage in my special interest far less often when I feel stressed/anxious

I engage in my special interest less often when I feel stressed/anxious

I engage in my special interest more or less the same when I feel stressed/anxious as when I don’t feel stressed/anxious.

I engage in my special interest more often when I feel stressed/anxious

I engage in my special interest far more often when I feel stressed/anxious

I am unsure.

Comments box?

When you do spend time on your special interest topic, to what extent does this change when you feel stressed/anxious?

I engage in my special interest for far shorter periods of time when I feel stressed/anxious

I engage in my special interest for shorter periods of time when I feel stressed/anxious

I engage in my special interest more or less the same when I feel stressed/anxious or when I don’t feel stressed/anxious.
I engage in my special interest for longer periods of time when I feel stressed/anxious.

I engage in my special interest far longer periods of time when I feel stressed/anxious.

I am unsure.

Comments box?

**To what extent are you less interested in your special interest topic when you are feeling sad or down?**

Not at all interested

Interested to some extent

Interested to the same extent as when I don’t feel depressed

More interested than when I don’t feel depressed

Far more interested than when I don’t feel depressed.

**To what extent does your special interest topic have a positive impact on you?**

A little

Quite a bit

A lot

**Please explain what this positive impact is?**
Appendix D

Demographic Details of the Current Sample

*Participants’ Country of Residence*

<table>
<thead>
<tr>
<th>Country of Origin</th>
<th>Number of Participants</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>48</td>
<td>32</td>
</tr>
<tr>
<td>Australia</td>
<td>29</td>
<td>19</td>
</tr>
<tr>
<td>New Zealand</td>
<td>2</td>
<td>&lt;1</td>
</tr>
<tr>
<td>UK</td>
<td>15</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Canada</td>
<td>10</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Netherlands</td>
<td>4</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Sweden</td>
<td>2</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Wales</td>
<td>2</td>
<td>&lt;1</td>
</tr>
<tr>
<td>France</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Israel</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Germany</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Norway</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Japan</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>India</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Switzerland</td>
<td>1</td>
<td>&lt;1</td>
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</table>

*Marital Status of Participants in Current Sample*

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>32</td>
<td>21</td>
</tr>
<tr>
<td>Divorced</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Never been married</td>
<td>85</td>
<td>57</td>
</tr>
<tr>
<td>A member of an unmarried couple</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>148*</td>
<td>100</td>
</tr>
</tbody>
</table>

*Note. Two participants did not respond to this question.*
### Employment Status of Participants

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed for wages</td>
<td>55</td>
<td>37</td>
</tr>
<tr>
<td>Self-employed</td>
<td>25</td>
<td>17</td>
</tr>
<tr>
<td>Out of work for more than 1 year</td>
<td>36</td>
<td>24</td>
</tr>
<tr>
<td>Out of work for less than 1 year</td>
<td>19</td>
<td>13</td>
</tr>
<tr>
<td>A homemaker</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Retired</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>147*</td>
<td>100</td>
</tr>
</tbody>
</table>

*Note. Three participants did not respond to this question.

### Educational level of Participants

<table>
<thead>
<tr>
<th>Educational Level</th>
<th>Frequency</th>
<th>Percentage (%)</th>
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<tbody>
<tr>
<td>Prior to Secondary School</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Graduation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary School</td>
<td>35</td>
<td>26</td>
</tr>
<tr>
<td>TAFE/technical/vocational school</td>
<td>19</td>
<td>14</td>
</tr>
<tr>
<td>University</td>
<td>76</td>
<td>55</td>
</tr>
<tr>
<td>Total</td>
<td>137*</td>
<td>100</td>
</tr>
</tbody>
</table>

*Note. Thirteen participants did not respond to this question.
Appendix E

Special Interest Topics

<table>
<thead>
<tr>
<th>Topics</th>
<th>Frequency</th>
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</thead>
<tbody>
<tr>
<td>Aircraft</td>
<td>1</td>
</tr>
<tr>
<td>American Politics</td>
<td>1</td>
</tr>
<tr>
<td>Animals</td>
<td>7</td>
</tr>
<tr>
<td>Anthropology</td>
<td>3</td>
</tr>
<tr>
<td>Anti-prostlytizing information</td>
<td>1</td>
</tr>
<tr>
<td>Anorexia</td>
<td>1</td>
</tr>
<tr>
<td>Archery</td>
<td>1</td>
</tr>
<tr>
<td>Architeuthis</td>
<td>1</td>
</tr>
<tr>
<td>Art</td>
<td>15</td>
</tr>
<tr>
<td>Artificial Intelligence</td>
<td>1</td>
</tr>
<tr>
<td>Astrology</td>
<td>2</td>
</tr>
<tr>
<td>Astronomy</td>
<td>2</td>
</tr>
<tr>
<td>Astrophysics</td>
<td>1</td>
</tr>
<tr>
<td>Arthurian Mythology</td>
<td>1</td>
</tr>
<tr>
<td>ASD</td>
<td>17</td>
</tr>
<tr>
<td>Autism</td>
<td>1</td>
</tr>
<tr>
<td>Backpacking / Trek Hiking</td>
<td>1</td>
</tr>
<tr>
<td>Bae Yong Joon</td>
<td>1</td>
</tr>
<tr>
<td>Ballet</td>
<td>1</td>
</tr>
<tr>
<td>Board games/ card games/ RPGs</td>
<td>1</td>
</tr>
<tr>
<td>Brain</td>
<td>1</td>
</tr>
<tr>
<td>Charity</td>
<td>2</td>
</tr>
<tr>
<td>Psychology</td>
<td>1</td>
</tr>
<tr>
<td>Bicycle</td>
<td>1</td>
</tr>
<tr>
<td>Bicycling</td>
<td>2</td>
</tr>
<tr>
<td>Biology, especially Genetics</td>
<td>2</td>
</tr>
<tr>
<td>Books/book authors</td>
<td>4</td>
</tr>
<tr>
<td>British Politics after circa 1900</td>
<td>1</td>
</tr>
<tr>
<td>Cars/Car performance specs</td>
<td>2</td>
</tr>
<tr>
<td>Camera</td>
<td>1</td>
</tr>
<tr>
<td>Cats</td>
<td>2</td>
</tr>
<tr>
<td>Celebrities</td>
<td>1</td>
</tr>
<tr>
<td>Chemistry</td>
<td>1</td>
</tr>
<tr>
<td>Cognition</td>
<td>1</td>
</tr>
<tr>
<td>Coffee</td>
<td>1</td>
</tr>
<tr>
<td>Child care</td>
<td>1</td>
</tr>
<tr>
<td>Child raising</td>
<td>2</td>
</tr>
<tr>
<td>Chess</td>
<td>1</td>
</tr>
<tr>
<td>Civil Rights</td>
<td>1</td>
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</tbody>
</table>
Classical Music 3
Colosseum/Titanic 1
Colours 2
Computers 7
Computer games 7
Counselling 1
Crafting 2
Cultural anthropology 1
Cultural history 1
Dental radiology 1
Disney 2
Doctor Who 1
Dolls Houses 1
Dromedaries 1
Dystopias and totalitarian societies 1
Early 20th Century Men's Clothing 1
Economics 2
Electronic communications 1
Environmental Issues 2
eRecruitment 1
Fashion 1
Films 3
Finances 1
Fire safety 1
Firearms 1
Floral Design 1
Football (soccer) 1
Formula 1 racing 1
Game shows 1
Gardening 2
Gems and minerals 2
Gender 1
Genealogy 2
General Knowledge 2
Genocides 1
Geography 1
GKR karate 1
Government Policy 1
Great Pacific Garbage Patch 1
Handspinning 1
Health 1
High Fire Stoneware 1
Historical cemetery research 1
History 10
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<th>Special Interest</th>
<th>Count</th>
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<tr>
<td>Homoerotic Art</td>
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<tr>
<td>Horology</td>
<td>1</td>
</tr>
<tr>
<td>Horses</td>
<td>3</td>
</tr>
<tr>
<td>Horticulture</td>
<td>1</td>
</tr>
<tr>
<td>House plans and types</td>
<td>1</td>
</tr>
<tr>
<td>How things fit in the natural world</td>
<td>1</td>
</tr>
<tr>
<td>Human species-consciousness</td>
<td>1</td>
</tr>
<tr>
<td>Humanities</td>
<td>2</td>
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<tr>
<td>Inca civilization</td>
<td>1</td>
</tr>
<tr>
<td>Information gathering</td>
<td>1</td>
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<tr>
<td>Intellectual creativity in the highly gifted</td>
<td>1</td>
</tr>
<tr>
<td>Investment</td>
<td>1</td>
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<tr>
<td>Invertebrates - Bugs n Slugs</td>
<td>1</td>
</tr>
<tr>
<td>Japanese Culture</td>
<td>1</td>
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<tr>
<td>Japanese Mahjong (Reach Mahjong)</td>
<td>1</td>
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<tr>
<td>Jewish religion and culture</td>
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<tr>
<td>Languages</td>
<td>5</td>
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<tr>
<td>Lighting and electricity</td>
<td>1</td>
</tr>
<tr>
<td>Literature</td>
<td>1</td>
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<tr>
<td>Law</td>
<td>1</td>
</tr>
<tr>
<td>Library Science</td>
<td>1</td>
</tr>
<tr>
<td>Linguistics</td>
<td>2</td>
</tr>
<tr>
<td>Maps /geography</td>
<td>3</td>
</tr>
<tr>
<td>Marylin Monroe</td>
<td>1</td>
</tr>
<tr>
<td>Massage</td>
<td>1</td>
</tr>
<tr>
<td>Math</td>
<td>4</td>
</tr>
<tr>
<td>Medicine/medical mysteries</td>
<td>3</td>
</tr>
<tr>
<td>Military medals</td>
<td>1</td>
</tr>
<tr>
<td>Models eg Model Rocketry</td>
<td>2</td>
</tr>
<tr>
<td>Motor racing</td>
<td>1</td>
</tr>
<tr>
<td>Movies</td>
<td>5</td>
</tr>
<tr>
<td>Morbid anatomy</td>
<td>1</td>
</tr>
<tr>
<td>Music</td>
<td>14</td>
</tr>
<tr>
<td>Mutated clovers</td>
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</tr>
<tr>
<td>Native plants</td>
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<tr>
<td>Naturopathy</td>
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<tr>
<td>Net Benefitism</td>
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<tr>
<td>Neuro-diversity</td>
<td>1</td>
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<tr>
<td>Neuropsychiatric disorders</td>
<td>1</td>
</tr>
<tr>
<td>North Korea</td>
<td>1</td>
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<tr>
<td>Nutrition, WEight loss</td>
<td>1</td>
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<tr>
<td>ND Health and Diet</td>
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<tr>
<td>Organized crime</td>
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<tr>
<td>Interest</td>
<td>Count</td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>-------</td>
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<tr>
<td>Ornithology</td>
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</tr>
<tr>
<td>Particular group of friends</td>
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<tr>
<td>Philosophy</td>
<td>3</td>
</tr>
<tr>
<td>Photography</td>
<td>3</td>
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<tr>
<td>Physics</td>
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<tr>
<td>Playing the violin</td>
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<tr>
<td>Politics</td>
<td>3</td>
</tr>
<tr>
<td>Pregnancy/Childbirth</td>
<td>1</td>
</tr>
<tr>
<td>Processes</td>
<td>2</td>
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<tr>
<td>Psychology</td>
<td>7</td>
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<tr>
<td>Railways</td>
<td>1</td>
</tr>
<tr>
<td>Random objects e.g. keys</td>
<td>1</td>
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<tr>
<td>Reading</td>
<td>5</td>
</tr>
<tr>
<td>Religion/spirituality</td>
<td>2</td>
</tr>
<tr>
<td>RMS Titanic</td>
<td>1</td>
</tr>
<tr>
<td>Robert Jordan's The Wheel of Time</td>
<td>1</td>
</tr>
<tr>
<td>Rural life</td>
<td>1</td>
</tr>
<tr>
<td>Science</td>
<td>7</td>
</tr>
<tr>
<td>Serial killers</td>
<td>1</td>
</tr>
<tr>
<td>Sexuality</td>
<td>1</td>
</tr>
<tr>
<td>Shamanic practices</td>
<td>2</td>
</tr>
<tr>
<td>Socializing</td>
<td>1</td>
</tr>
<tr>
<td>Sociology</td>
<td>2</td>
</tr>
<tr>
<td>Sociology of childhood</td>
<td>1</td>
</tr>
<tr>
<td>Society</td>
<td>3</td>
</tr>
<tr>
<td>Special Education</td>
<td>1</td>
</tr>
<tr>
<td>Sport</td>
<td>2</td>
</tr>
<tr>
<td>Spreadsheetsing</td>
<td>1</td>
</tr>
<tr>
<td>Stamp collecting</td>
<td>1</td>
</tr>
<tr>
<td>Statistics Data/Election Results/</td>
<td>1</td>
</tr>
<tr>
<td>Technology</td>
<td>1</td>
</tr>
<tr>
<td>Transport</td>
<td>1</td>
</tr>
<tr>
<td>Trivial facts</td>
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</tr>
<tr>
<td>Turkey</td>
<td>1</td>
</tr>
<tr>
<td>TV</td>
<td>1</td>
</tr>
<tr>
<td>Undemocratic corporations</td>
<td>1</td>
</tr>
<tr>
<td>Used car prices</td>
<td>1</td>
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<tr>
<td>Video games</td>
<td>2</td>
</tr>
<tr>
<td>Weather</td>
<td>3</td>
</tr>
<tr>
<td>Website</td>
<td>2</td>
</tr>
<tr>
<td>World's Columbian Exhibition</td>
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<tr>
<td>Writing</td>
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<td><strong>Total</strong></td>
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Appendix F

‘Experience’ or Kinesthetic Methods of Special Interest Engagement

<table>
<thead>
<tr>
<th>Process – Experience</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation</td>
<td>5</td>
</tr>
<tr>
<td>Sport</td>
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</tr>
<tr>
<td>Stimulation</td>
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</tr>
<tr>
<td>Travel</td>
<td>4</td>
</tr>
<tr>
<td>Listening (music)</td>
<td>4</td>
</tr>
<tr>
<td>Game play</td>
<td>7</td>
</tr>
<tr>
<td>Conferences</td>
<td>1</td>
</tr>
<tr>
<td>Sex</td>
<td>1</td>
</tr>
<tr>
<td>Socialising</td>
<td>1</td>
</tr>
<tr>
<td>Music play</td>
<td>4</td>
</tr>
<tr>
<td>Animal training/care</td>
<td>3</td>
</tr>
<tr>
<td>Religion/spirituality</td>
<td>3</td>
</tr>
<tr>
<td>Teach</td>
<td>5</td>
</tr>
<tr>
<td>Fix/use</td>
<td>5</td>
</tr>
<tr>
<td>Own finances</td>
<td>2</td>
</tr>
<tr>
<td>Healthy living</td>
<td>2</td>
</tr>
<tr>
<td>Food</td>
<td>1</td>
</tr>
<tr>
<td>Growing plants</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>57</strong></td>
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Appendix G

ASD Organisations/Websites that Listed the SI Questionnaire

Websites
www.tonyatwood.com.au
http://asplanet.info/forum/index.php?topic=1236.0
http://www.aspergers.ca
http://www.wrongplanet.net

Facebook Groups
Adults with Asperger's Syndrome
‘Asperger Syndrome Research’
Asperger Syndrome Group
Asperger's Syndrome: Raising Awareness
Aspergers Society of Ontario
The Ultimate Asperger Supergroup (for Aspies & Supporters)

Yahoo Groups
http://health.groups.yahoo.com/group/for-and-by-autistics/message/630