PSYCHOTROPIC MEDICATION USE AND AUTISM SPECTRUM DISORDERS:
CAREGIVER AND INDIVIDUAL PERSPECTIVES

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Abstract

People with Autism Spectrum Disorders (ASD) are at increased risk of having challenging behaviours and comorbid mental disorders. Pharmacological interventions for these are common; however, the use of medication in this population is controversial and its efficacy remains unclear. The experience and perspectives of individuals with ASD and their caregivers regarding the effectiveness of pharmacological interventions have been largely neglected in the literature. Consequently, the present study aimed to explore the use of psychotropic medications to manage maladaptive emotions and behaviours from the perspectives of self-reporting adults with an ASD and caregivers of dependent children and adults with an ASD within an Australian context. An anonymous questionnaire (online or paper version) was completed by 245 caregivers of people with an ASD and 63 individuals with an ASD. Results were presented on the extent and types of medications prescribed; the reasons provided for use and the perspectives of individuals with ASD and caregivers regarding therapeutic outcomes. Medication use was examined with respect to comorbid mental health conditions, challenging behaviours and sleep difficulties and practice issues were also discussed. Individual and caregiver perspectives provided insights that are important to ongoing debate about psychotropic medication use among people with ASD.
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<th>Full Form</th>
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<tbody>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorders</td>
</tr>
<tr>
<td>APA</td>
<td>American Psychological Association</td>
</tr>
<tr>
<td>AFDA</td>
<td>American Food and Drug Administration</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behaviour Therapy</td>
</tr>
<tr>
<td>CNS</td>
<td>Central Nervous System</td>
</tr>
<tr>
<td>DSM-IV-TR</td>
<td><em>Diagnostic and Statistical Manual of Mental Disorders</em> fourth edition-text revised</td>
</tr>
<tr>
<td>DSM-V</td>
<td><em>Diagnostic and Statistical Manual for Mental Disorders</em>, fifth edition</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
</tr>
<tr>
<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
</tr>
<tr>
<td>PDD–NOS</td>
<td>Pervasive Developmental Disorder–Not Specified</td>
</tr>
<tr>
<td>PRN</td>
<td><em>pro re rata</em> – ‘as required’</td>
</tr>
<tr>
<td>REM</td>
<td>Rapid Eye Movement</td>
</tr>
<tr>
<td>SSRI</td>
<td>Selective Serotonin Reuptake Inhibitors</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
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Thesis Overview

Autism Spectrum Disorders (ASD) are a group of neurodevelopmental disorders that affect individuals in the core domains of behaviour, social communication, and social interaction (APA, 2013). Due to the pervasive nature of these disorders, a comprehensive body of research has explored the impact of ASD on individuals and their caregivers. It has been established that individuals with an ASD are at increased risk of developing comorbid mental or psychiatric disorders, sleep difficulties, and challenging behaviours (Bradley & Bolton, 2006; Brylewski & Duggan, 2004; Matson & Nebel-Shwalm, 2007). This has added an increased complexity to understanding ASD and has made treating this population problematic.

The medical conceptualisation and treatment of ASD has been widely applied to address comorbid problems in people with an ASD (Holden & Glisten, 2009). Despite this, the use of psychotropic medications for people with an ASD has been surrounded by controversy (Antonacci, Manuel & Davis, 2008; Brylewski & Duggan, 1999; Gralton, James & Lindsey, 1998). More specifically, concerns have been raised regarding the use of psychotropic medication in the management of ASD-related challenging behaviours (Antonacci et al., 2008; de Bruin, Ferdinand, Meester, de Nijs & Verheij, 2007). Both positive (e.g., decreased anxiety) and negative outcomes (e.g., weight gain) have been identified as a consequence of pharmacological interventions for people with an ASD (e.g., Jesner, Aref-Adib & Coren, 2009). The equivocal nature of these findings
suggests a need for further analysis into what is known about the current practice and therapeutic outcomes regarding the use of psychotropic medication in people with an ASD.

Despite the controversy surrounding the use of pharmacological interventions for people with ASD, psychotropic medication continues to be a widely used treatment option in this population (Liptak, Stuart & Auinger, 2006). For example, only risperidone (an anti-psychotic medication) has been approved for treating severe behavioural disturbance in children and adolescents with an ASD (Victorian Government, 2009); however, researchers have identified that many other medications have been prescribed to address maladaptive emotions and behaviours associated with ASD (e.g., Lakhan & Jaggar-Johnson, 2007). This highlights a significant disparity between research and clinical practice.

The prevalence of the use of psychotropic medication among people with ASD has been explored in countries such as the Unites States of America (USA) and Iran (e.g., Aman et al., 2005; Esbensen et al., 2009; Memari et al., 2012), yet few studies have been undertaken in Australia (e.g., McGillivray & McCabe, 2005; Webber, Chan & McVilly, 2010. Further, previous research has primarily focused on individuals who have resided in state-based accommodation, and have examined this as part of larger intellectual disability research (e.g., McGillivray & McCabe, 2005; Webber et al., 2010). This means that there has been little exploration of psychotropic medication use in individuals with ASD who reside in home-based care within the community. Moreover, there has been little exploration of the perspectives of the individuals with an ASD or their caregivers.
regarding psychotropic medication. A need was therefore identified, for an
Australian study of community-based individuals with an ASD and their
caregivers to explore their perspectives regarding the use of psychotropic
medications.

This thesis conducted an audit of the use of psychotropic medication in
individuals with ASD, where the primary intent of the medication was to assist
with the management of emotions or behaviours associated with the ASD. The
aim of the thesis was to provide an overview of the nature, extent, reasons for and
outcomes related to the use of psychotropic medication in a community-based
ASD Australian population. Specifically, the primary purpose was to examine the
use of psychotropic medication in children and dependent adults with an ASD as
reported by their caregivers (Study 1), and from self-reporting adults with an ASD
(Study 2). A further exploratory aim was to investigate the narrative perspectives
of individuals with an ASD (Study 3a) and their caregivers (Study 3b) on the use
of psychotropic medication.

A description of psychotropic medication use in children and dependent
adults, with their caregiver serving as an informant, was provided in Study 1. In
Study 2, psychotropic medication use in independent adults who were self-
reporting on their own circumstances was examined. Both studies commence with
a detailed description of the participants. Given that Study 1 involved reports
from caregivers and Study 2 involved self-reports from independent adults with
an ASD, a comparison between the two groups was deemed inappropriate
because the studies capture two different populations. Independent adults are
likely able to make their own decisions and are active participants in the decision to use psychotropic medication. Whereas children and dependent adults caregivers were likely acting on the person’s behalf and making the decision to use psychotropic medication on behalf of the child/dependent adult. Study 3 presents a qualitative analysis of both caregivers and individuals perspectives of psychotropic medication use. This third study is presented in two parts: Study 3a focused on the insights and perceptions of caregivers into psychotropic medication use, whereas Study 3b focused on the insights and perceptions of self-reporting adults with an ASD.

The thesis comprises 11 chapters. A review of the literature is presented in the first three chapters. Chapter 1 explores the links between ASD, challenging behaviour, comorbid mental health conditions and sleep difficulties. In Chapter 2, the use of psychotropic medication among individuals with an ASD is reviewed. In Chapter 3, the relationships between psychotropic medication use and challenging behaviours, comorbid mental health conditions and sleep difficulties are systematically explored. The rationale for the study is presented in Chapter 4 and the methodology and data analysis is provided in Chapter 5. Chapter 6 reports the findings of Study 1, with the discussion presented as Chapter 7. The results and discussion for Study 2 are presented in Chapters 8 and 9, and the qualitative results and discussion of Study 3 are presented in Chapter 10. Finally, in Chapter 11, the three studies are drawn together and overall reflections from the thesis are provided.
Please note, this thesis is an applied study and the data utilised is largely an audit of psychotropic medication use in an Australian population, however, this is examined with reference to the available literature and it adds to what is known by including the perspectives of the individuals themselves. The thesis offers a unique perspective by including qualitative data on individual and caregivers thoughts surrounding medication for the purpose of behavioural or emotional alteration.
Chapter 1: Autism Spectrum Disorders

There have been recent changes to diagnosing Autism Spectrum Disorder (ASD) in the Diagnostic and Statistical Manual for Mental Disorders, fifth edition (DSM-V), which was released in mid-2013 (American Psychiatric Association, APA, 2013). The changes consolidated autistic disorder, Asperger’s disorder, pervasive developmental disorder–not otherwise specified (PDD–NOS), and childhood disintegrative disorder under one diagnosis, ASD (APA, 2013). The consolidation was designed to represent an ASD continuum from mild to severe, rather than individual disorders. The new diagnosis has an indicator of severity and describes an individual’s overall developmental state, in terms of motor, cognitive and social communication (APA, 2013). The aim of the new category is to assist clinicians to diagnose individuals more accurately and ultimately to provide consistency across clinicians and settings for diagnostic labels. Since the studies within this thesis were completed prior to the release of DSM-V, the ASD definitions applied throughout this thesis are consistent with the Diagnostic and Statistical Manual of Mental Disorders fourth edition- text revised (DSM-IV-TR) diagnostic criteria (APA, 2000).

ASD refers to a grouping of people who have been diagnosed with autistic disorder, Asperger’s disorder and PDD–NOS. These diagnoses can significantly affect a person over their lifespan (Fombonne, 2003a, 2003b). ASDs are characterised by significant impairment in social interactions and communication,
and are accompanied by restricted patterns of behaviour, interest and activity (Fombonne, 2008). The characteristics of ASD represent a spectrum of abilities; therefore, each individual with the condition is uniquely affected (Happé & Frith, 2006).

For a child or adult to receive a diagnosis of an ASD within Australia, it is considered best practice for the individual to receive an inter-disciplinary assessment prior to diagnosis (O'Reily, 2013). This includes detailed assessments conducted by a psychologist, developmental paediatrician, speech pathologist and occupational therapist (Hillman & Snyder, 2007).

1.1 Autistic Disorder

The DSM-IV-TR (APA, 2000) specifies that a person with autistic disorder displays impairments in social interaction, which may include: impairment in the utilisation of non-verbal behaviours (e.g., eye contact); failure to acquire developmentally appropriate peer relationships; difficulty with social and emotional reciprocity; and/or an absence of spontaneous engagement with others in the sharing of interests, achievements or enjoyment (APA, 2000). The individual must also display impairments in their communication, which may present as: significant impairment in the individual’s ability to commence or maintain a conversation; spoken language involving stereotyped and repetitive use of words; an absence of spontaneous imaginative play or social imitative play; delayed or absent spoken language without compensatory attempts at
communication (e.g., gesture) (APA, 2000). For an individual to be diagnosed with an autistic disorder, delays or abnormal functioning in the aforementioned areas need to be present prior to three years of age (APA, 2000).

1.2 Asperger’s Disorder

Similarly to individuals with autistic disorder, an individual who is diagnosed with Asperger’s disorder must have a delay in social impairment, together with restricted, repetitive and stereotyped patterns of interests, behaviour and activities (APA, 2000). In contrast to autistic disorder, people with Asperger’s disorder do not display clinically significant delays in the acquisition of language (APA, 2000). Their use of language is often associated with deficits in pragmatics, pitch, stress and rhythm of speech (Ghaziuddin, 2005). Individuals with Asperger’s disorder also do not display clinically significant delays in cognitive development (APA, 2000).

1.3 Pervasive Developmental Delay—Not Otherwise Specified

A PDD-NOS is diagnosed when an individual experiences severe and pervasive impairments in the development of social interaction, along with associated verbal and non-verbal communication deficits or the occurrence of repetitive stereotyped behaviours or interests (APA, 2000). This diagnosis is used for presentations that do not fully meet the criteria for autistic disorder due to a later age of onset, different symptomatology or the absence of impairment in all three areas of communication, social interaction and behaviour (APA, 2000).
1.4 Prevalence of Autism Spectrum Disorders

Recent international research suggests that the prevalence of ASD within a community is approximately 60 in 10,000 (Fombonne, 2005). However, Australian research suggests that the prevalence may be slightly lower; with between 10 to 50 people in 10,000 diagnosed with an ASD (Icasiano, Hewson, Machet, Cooper & Marshall, 2004). These prevalence rates were recently supported by Williams et al. (2008), who found between 12 to 36 per 10,000 people were diagnosed with an ASD, based on their analysis of children aged up to 16 years, known to have an ASD in Australia.

In a meta-analysis conducted earlier this year to explore the specific prevalence of autistic disorder and Asperger’s disorder, French, Bertone, Hyde and Fombonne, (2013) reported significant variability in rates. However, the majority of studies consistently estimated higher rates of autistic disorder than Asperger’s disorder. The authors highlighted an apparent discrepancy amongst the studies as to whether high functioning ASD was included as Asperger's disorder, or whether this was regarded as a diagnosis of autistic disorder. French et al. suggested this definition issue may have contributed to the differing prevalence rates between autistic and Asperger’s disorder.

Lower prevalence rates of ASD were found in a meta-analysis of 42 studies, published between 1966 and 2003, conducted by Williams, Higgins and Brayne (2006). Williams and colleagues established a prevalence estimate of 7.1 per 10,000 for autistic disorder, and 20.0 per 10,000 for ASD. The review
established that more recent studies (post year 2000) demonstrated higher prevalence rates of ASD compared with earlier studies (Williams et al., 2006).

Research conducted in Australia over the past two decades supports this proposition, and indicates that the prevalence of ASD has increased two-fold during this period (Birnbrauer, Bradly, Brigg et al., 1988; Glasson, 2002; Williams, Macdermott, Ridley, Glassons & Ray, 2008). Several suggestions have been proposed to explain this increase in ASD (Williams et al., 2008). First, the diagnostic criteria have changed over time, resulting in more people meeting the diagnostic requirements than previously. Second, it is plausible that the development of the diagnostic criteria for Asperger’s disorder has resulted in the inclusion of individuals who were previously not recognised. Finally, an increase in the awareness of the disorder may be resulting in greater rates of diagnosis (Bryson & Smith, 1998). Regardless, it is important that research continues to explore the effect of this disorder on individuals and their caregivers due to the large number of people who are affected.

1.5 Aetiology of Autism Spectrum Disorders.

ASDs are pervasive and affect individual’s daily functioning in a myriad of ways. Many theories exist as to the aetiology of ASD and the rising occurrence of this disorder. What is accepted in the literature is that ASDs have a neurobiological basis and that they are pervasive (O'Reilly & Benison, 2013). While there is a large body of research suggesting that ASD has a genetic component (see Rutter, 2005), a common causative factor remains elusive. Most cases are considered idiopathic (arising from unknown causes; Marshall, 2013).
Moreover, it appears there may be multiple explanations for the development of ASD, with recent research suggesting differing causes for those who experience a regressive form as opposed to those with who exhibit symptomatology from birth (O'Reilly & Benison, 2013).

1.5.1 Gender.

ASDs are diagnosed more predominantly in males than females, with ratio estimates of 4:1 (Fombonne, 2003; Holtmann, Bölte & Poustka, 2007; Morgan, et al., 2002). However, inconsistent findings have been demonstrated with regard to the gender breakdown of autistic disorder, Asperger’s disorder and PDD-NOS (Holtmann et al., 2007). Most studies suggest that more males are affected by autistic disorder than females—at a rate of 2:1—with rates being higher in Asperger’s disorder, 6:1 (Fombonne, 2003a). While a consensus exists that ASD affects more males than females, recent research has investigated the differences in core symptoms between males and females (Holtmann et al. 2007; Westman, Andersson, Gillberg & Miniscalo, 2013). Holtman and colleagues (2007) explored the different presentations of 23 males and 23 females with an ASD. No significant differences were identified in the symptoms of repetitive and stereotyped behaviour, communication or social interactions; however, parents reported greater impairment in females on social, attention and thought domains (Holtman et al., 2007). Holtman et al. suggested this may be a consequence of different societal expectations for females in terms of communication, rather than true differences in this specific area of ASD psychopathology.
1.5.2 Autism spectrum disorder and intellectual disability.

People with an ASD also often are diagnosed with an intellectual disability. Fombonne, Simmons, Ford, Meltzer and Goodman (2003) found that 44 per cent of people with an ASD had a co-occurring intellectual disability. An Australian study by Icasiano et al. (2004) similarly found that of 131 children diagnosed with an ASD, 47 per cent had an intellectual disability (as measured by an IQ of less than 70). It is important to note that this co-occurrence varies within the type of ASD. For instance, people who are diagnosed with Asperger’s disorder rarely meet the criteria for intellectual disability (O'Reily, 2013). In contrast, intellectual disability is commonly found in individuals with autistic disorder, with 70–75 per cent having an associated intellectual disability (Deb & Prasad, 1994; Fombonne, 2003b; Morgan et al., 2002). The results from this collective group of studies indicate that intellectual disability and ASD often co-exist.

In summary, ASDs are a group of disorders that predominate in males, with speculation that there may be perceived differences in symptomatology between males and females. Intellectual disabilities are highly comorbid with ASD, in particular the subtype of autistic disorder.

1.5.3 Autism spectrum disorders and challenging behaviours.

In addition to the core symptoms of ASD, individuals with an ASD commonly exhibit a range of “challenging” behaviours, a term that is often used interchangeably with ‘behaviours of concern’, ‘problematic behaviours’, and ‘difficult behaviours’, replacing previous terms such as ‘abnormal’, ‘aberrant’,
‘disordered’, ‘disturbed’ and ‘retarded’ behaviours (Brylewski & Duggan, 2004). Challenging behaviours have been defined by Emerson (1995) as “culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities (p7)”. Brylewski and Duggan (2004) reported that challenging behaviours in people with ASD are behaviours that are difficult to manage, may be harmful to people or property, may limit a person’s access to the community, and affect their life and caregivers in a negative manner.

It is important to note that the concept of what constitutes a challenging behaviour can differ depending on the context in which it occurs – that is the individual, family, culture or socio-political norms relevant to the individual (Hanbury, 2007). For example, a person with an ASD who uses coarse language may be deemed to have a challenging behaviour in China, but not in Australia.

Behavioural presentations in those with an ASD vary widely and are largely heterogeneous (Kim & Lord, 2013). Kim and Lord suggested this variability is influenced by a number of individual factors (e.g., developmental trajectories, communication skills, cognitive ability, gender & adaptive skills) and external factors (e.g., living environment, level of support & socio-economic status). While not all individuals with an ASD will have challenging behaviours, these behaviours can be of greater concern to individuals and their caregivers than the core diagnostic symptoms of ASD (Pearson et al., 2006).
The available literature on challenging behaviour has not yet established a consensus on the categories of behaviours most commonly displayed by individuals with an ASD. For the purpose of this thesis, five domains of challenging behaviours will be referred to: (1) aggressive, (2) self-injurious/stereotyped, (3) emotion-related, (4) impulse control, and (5) other disruptive behaviours. Aggressive behaviours are the most commonly researched behaviours reported in the literature (Matson, Stipes, Fodstad & Fitzgerald, 2011; Matson & Nebel-Schwalm, 2007). Aggressive behaviours include physical antisocial acts, such as hitting, kicking, biting or destroying objects. Research has suggested these behaviours occur across the whole spectrum of ASD, regardless of severity or comorbid intellectual disability (Matson et al., 2011).

The second category of challenging behaviours involves self-injurious/stereotyped behaviours. These behaviours often occur in a rhythmical and repetitive manner (Matson et al., 2011); for example, hand biting, skin pinching, head banging, compulsive touching, hand flapping and other ritualistic behaviours (Brereton & Tonge, 2002). Self-injurious behaviours can result in tissue damage in the form of lacerations, contusions or abrasions and often can cause significant lifelong injuries to an individual (Taylor et al., 2011).

In contrast to aggressive and self-injurious challenging behaviours, which both involve physical acts, emotion-related behavioural concerns are more covert and refer to a difficulty expressing emotions appropriately. For example, people with an ASD often experience problems communicating feelings of anger,
sadness, stress or irritability. The final two categories of challenging behaviours include impulse control difficulties and other disruptive behaviours.

Impulse control behaviours refer to difficulties concentrating on tasks or behaviours that are characterised by poor judgment (McDougle, Posey & Stigler, 2006). For instance, people with an ASD may walk across a road without checking it is safe to do so, or may find it difficult to follow instructions. The fifth challenging behaviour category, described as ‘other disruptive behaviours’, includes a variety of behaviours that are not captured by the other four categories. Behaviours in this category include spitting, tantrums, crying, agitation, and manipulation (Tonge, Brereton, Gray & Einfeld, 1999).

Individuals with ASD will often display more than one type of challenging behaviour, with some individuals experiencing a range of behaviours across differing circumstances (Matson & Rivet, 2008b). These inter-related behaviours often compromise the wellbeing of the person with an ASD by serving as a barrier to participation in education, employment, social interactions and community integration (Koegal, Koegal, & Dunlap, 1996; Matson & Rivet, 2008). While a lack of consensus exists on the specific categories of challenging behaviours, these behaviours of concern are receiving increasing attention in the ASD literature due to their association with negative outcomes (Matson et al., 2011).

1.5.4 Prevalence of challenging behaviour.

Prevalence estimates of challenging behaviour among people with an ASD vary significantly, with rates ranging from five to 50 per cent (e.g., Emerson et
al., 2001; Kerth, Progar & Morales, 2009; Murphy, Macdonald, Hall & Oliver, 2000; Myers & Johnson, 2007). This variation in prevalence rates may be a result of several methodological issues. First, challenging behaviour has been interpreted broadly in the literature; consequently, different studies have used different criteria to define the term. Second, certain types of challenging behaviour, such as aggression, have been studied more frequently than other challenging behaviours (Carr & Owen-DeSchryver, 2007). It is likely that this category of behaviour has been more highly researched due to its seriousness, and the greater implications they have for the community and caregivers (Carr & Owen-DeSchryver, 2007). Third, ASD is a broad term used to define individuals with varying levels of impairment, with or without intellectual disabilities; as such, it is likely that the rates of challenging behaviour among this population will vary accordingly. Finally, prevalence rates of challenging behaviour in people with ASD may reflect the rate at which people are referred to intervention services, rather than the actual rates of occurrence within the community.

Challenging behaviours in individuals with an ASD are commonly associated with intellectual disability (Kozlowki, Matson & Sipes, 2012). Accordingly, this relationship has received substantial attention within the research literature. It has been established that individuals with both an ASD and intellectual disability more frequently display challenging behaviours than those with an intellectual disability only (Matson & Rivet, 2008a). It is proposed that the association between challenging behaviour and intellectual disability is due to
the frequency and intensity of such behaviours—in particular self-injurious behaviours—increasing with impairment of cognitive functioning (Lennox, 2007).

It has been suggested that people with both an ASD and intellectual disability are at increased risk of exhibiting challenging behaviour (Matson & Nebel-Schwalm, 2007; McClintock, Hall & Oliver, 2003); specifically stereotypy and self-injurious behaviours (Baghdadli, Pascal, Grisi & Aussilloux, 2003; Baghdadli et al., 2008). Moreover, challenging behaviours have been found to persist throughout adulthood. A study by Matson and Rivet (2008a) investigated the rates of challenging behaviour in 161 adults with an ASD and intellectual disability, compared with 159 adults with an intellectual disability only, who resided in residential care facilities. The findings indicated that people with both ASD and an intellectual disability had more frequent challenging behaviour across the four domains measured (aggression/destruction, stereotypy, self-injurious behaviour and disruptive behaviour). Further, the study found that individuals with a diagnosis of intellectual disability and ASD were more likely to have a co-occurrence of challenging behaviour across the four domains, compared to people with an intellectual disability only.

A further study by Matson and Rivet (2008b) focused on the relationship between severity of ASD traits and the frequency and type of challenging behaviour in 298 adults with severe intellectual disabilities. The findings indicated that people with ASD and intellectual disability engaged in a range of challenging behaviour, including: harm to others, self-injury and other disruptive
behaviours. In addition, the results suggested that severe core traits of ASD were associated with a higher likelihood of challenging behaviour. Matson and Rivet (2008b) also investigated the role of communication and adaptive behaviours in the presentation of challenging behaviour. Findings indicated that the core symptoms of ASD were related to disruptive and self-injurious behaviour beyond what might be expected from their adaptive skills and communication. Despite Matson and Rivet’s results, a significant limitation of their study was that all participants permanently resided at the same residential facility. Consequently, it is uncertain whether these findings are generalisable to other groups of people with an ASD in different settings.

One of the most extensive studies on challenging behaviour was conducted by Murphy et al. (2005). This longitudinal study investigated skills (self-care, motor, visual-spatial, language and communication), social impairments and challenging behaviour in 166 children with an ASD and/or intellectual disability residing in home-based care, using the Schedule of Handicaps Behaviour Skills (Wing, 1996; Wing & Gould, 1978). Twelve years after initial measurement, 141 of the original participants were re-assessed.

Findings indicated that abnormal behaviours (e.g., self-injury, repetitive movements, aggressiveness and hyperactivity) reduced with increasing age.

**1.5.5 Aetiology of challenging behaviour.**

Currently, there is no direct causal link between challenging behaviour and ASD (Hanbury, 2007). However, various theoretical models have been used to explain this relationship. One such model, commonly accepted to explain the
reasons why a person with ASD displays challenging behaviours, is the ‘biopsychosocial’ model (Campbell & Rohrbaugh, 2013; Engel, 1980; Ingham, Clarke & James, 2008). This model posits that an individual’s behaviour is influenced by a dynamic combination of biological, social and psychological factors (Campbell & Rohrbaugh, 2013). This model suggests that formulation of behaviours needs to take into consideration all factors in order to provide a holistic understanding of the reasons for the behaviour. This model views behaviours as a symptom, shifting focus to the influences that may have produced it, rather than on the behaviour itself.

Biological influences of challenging behaviour may include factors such as genetics, neurobiological influences, neurological abnormalities, pain and physical illness (Boucher, 2009). It has been noted that those with an ASD may be more predisposed to neurological comorbidities associated with challenging behaviours, such as intellectual disability and epilepsy (Bonora et al., 2006; Boucher, 2009; Taylor, Oliver & Murphy, 2011;). Moreover, those with behavioural problems are more likely to have different neurobiology to those without (Boucher, 2009; Taylor et al., 2011).

Social factors also assist in explaining the development and perpetuation of challenging behaviours. This component of the biopsychosocial model involves the environment (including the people) within which the ASD individual resides (Boucher, 2009). For example, an individual with an ASD may have limited capacity to clearly communicate their wants and needs. Consequently, if the context does not support this individual’s communication deficit,
inappropriate behaviours may develop and be reinforced (Aylott, 2001; Chiang, 2008; Jensen, McConachie & Pierson, 2001; McConachie & Diggle, 2007). As a result, social factors play an important role in understanding challenging behaviour.

A psychological explanation of challenging behaviour among people with an ASD may be the result of deficits in cognitive functioning (Boucher, 2009). An individual may lack adaptive behaviour skills, which places them at risk of demonstrating behaviours deemed challenging. Individuals with an ASD are characterised by an impairment in social interactions, which places them at risk of behaviours that may be deemed socially inappropriate and thus challenging. While, it is important to consider the three distinct elements of the model, the interactions of these factors and how this may impact the presentation of challenging behaviours is paramount to this model.

An alternate model to understanding challenging behaviour is Durand and Carr’s (1985) social communicative theory of behaviours. This model posits that individuals use some behaviours as nonverbal forms of communication. According to this theory, when individuals are provided with a means to communicate their needs and wants (replacement behaviours), difficult behaviours are less likely to be exhibited. Carr and Durand’s model has served as the precursor for functional behavioural analysis, which is central to understanding the reason why an individual engages in particular behaviours (Webber, Ramcharan & McLean, 2010). It focuses on antecedents to the behaviour, the behaviour itself, and the consequence of the behaviour. Moreover,
it views the behaviour as possibly an adaptive response to a maladaptive environment (Webber et al., 2010). Thus, functional analysis can assist in identifying salient factors involved in explaining an individual’s challenging behaviour.

In summary, challenging behaviours are common among individuals with an ASD. These behaviours significantly impact functioning and ability to engage in activities in individuals with ASDs. While challenging behaviours may pose an issue for the individual’s safety and wellbeing, these behaviours may serve a purpose for that individual and as such, an examination of their function is paramount.

1.6 Comorbid Mental Health Conditions

While it is evident that a large proportion of people with ASD display challenging behaviours, it has been suggested that these behaviours may, at least partly, be the result of a comorbid psychiatric condition (e.g., Brylewski & Duggan, 2004). According to Matson & Nebel-Schwalm (2007), individuals with an ASD are at significant risk of experiencing a comorbid mental health condition, defined as the presence of two or more forms of psychopathology occurring in the same person simultaneously. Psychiatric conditions commonly comorbid with ASD include mood disorders (e.g., depression); anxiety disorders (e.g., generalised anxiety); attention disorders (e.g., attention deficit and hyperactivity disorder (ADHD)) and psychotic illnesses (e.g., schizophrenia).
Although a significant overlap in symptoms is acknowledged (Brylewski & Duggan), the recognition of challenging behaviour in individuals with an ASD often implies the absence of a formal comorbid psychiatric condition. Comorbid mental health conditions can be missed in assessments and assumed to be ‘challenging behaviour’ rather than symptomatic of the mental illness. Moreover, the ability to diagnose comorbid psychiatric conditions in a person with an ASD is often complicated by inter-related pathology that requires a highly skilled clinician (Brylewski & Duggan, 2004).

1.6.1 Prevalence of comorbid mental health conditions.

The prevalence of comorbid psychiatric disorders among individuals with ASD varies considerably, with estimates ranging from 11 to 70 per cent (e.g., Bradley & Bolton, 2006; Lunegard, Hallerback & Gillberg, 2011; Moseley et al., 2011; Skokauskas & Gallaher, 2012). For example Morgan, Roy and Chance (2003) reported that 65 per cent of adults with an ASD met the diagnostic criteria for at least one other psychiatric condition (e.g., anxiety disorder), whereas Moseley and colleagues (2011) identified a 42 per cent rate of comorbidity in 84 adolescents and young adults with autistic disorder. The differences in estimates between these studies may be attributed to the differences in samples; as the later study had a large percentage of participants in the later study (79%) with a concurrent intellectual disability or alternatively in the differing assessment processes.

In an investigation of the rates of episodic psychiatric disorders in adolescents with intellectual disabilities, with and without autism, Bradley and
Bolton (2006) reported that significantly more individuals with ASD and intellectual disability experienced comorbid mental health conditions (most commonly depression) than those with an intellectual disability alone. This was assessed via semi-structured interview, however the study failed to account for behavioural difficulties and whether these were impacting diagnoses. This highlights the association between enhanced risk of a comorbid mental health condition and ASD.

Despite the large variation in prevalence estimates of comorbid mental health conditions, it is clear that people with an ASD are more likely to experience a comorbid mental health condition. Moseley and colleagues (2011) indicated that the prevalence of comorbid mental health conditions is approximately four times that of the general population. As such, it is important to explore what mental health conditions are more prevalent in the ASD population.

1.6.2 Mood disorders.

Mood disorders, including major depressive disorder and bipolar affective disorder, are debilitating episodic illnesses (Matson & Nebel-Schwalm, 2007). Major depression is defined as a negative mood state usually accompanied by diminished energy, interest or pleasure in daily activities, lessened feelings of self-worth or ability to concentrate (APA, 2000). It is the most commonly diagnosed psychological disturbance, affecting approximately one in five people at some point in their life (Lefton & Brannon, 2003). It has been suggested that people with an ASD have higher rates of depression than the general population (Ghaziuddin & Greden, 1998; Ghaziuddin & Tsai, 1991; Stewart, Barnard,
Psychotropic Medication and ASD

Pearson, Hasan & O'Brien, 2006). For instance, on the basis of a semi-structured interview, Ghaziuddin and Greden (1998) reported that 37 per cent of adolescents and young adults with Asperger’s disorder met the diagnostic criteria for major depression. However, this finding was based on an inpatient sample who had severe psychopathology and it is thus unknown the extent to which they may generalise to a community based population.

Similar results were found in an earlier study by Wing (1981), which indicated that 30 per cent of adults with Asperger’s disorder also experience symptoms consistent with major depression. A more recent study by Lugnegard and colleagues (2011) found that up to 70 per cent of adults with Asperger’s disorder had experienced at least one major depressive episode. These studies have highlighted the high incidence of depression among individuals with an ASD, particularly Asperger’s disorder.

In contrast, there has been limited examination of the prevalence of depression among people with both an ASD and an intellectual disability. It has been suggested that the presence of depression manifests itself differently among this subgroup (Matson & Nebel-Schwalm, 2007). For instance, people with an intellectual disability may display depressive-like symptoms through unwillingness to participate in activities, social withdrawal, and possibly vegetative states (Ghaziuddin, Ghaziuddin & Greden, 2002; Shu, 2009). Further, a person’s ASD characteristics may disguise or alter how depression presents. In particular, people with an ASD commonly have difficulty recognising and expressing emotions; as such, they may display depression through increased
obsessive compulsive behaviours, increased social withdrawal, irritability or change in the character of obsessions (Ghaziuddin, 2005). Consequently, people with an ASD and an intellectual disability may have a greater likelihood of experiencing depression, due to a combination of their symptoms resulting from each condition.

Although there has been considerable research into the prevalence between ASD and depression, little is currently known about the prevalence of bipolar affective disorder within the ASD population. One recent study identified two individuals with bipolar affective disorder when screening 36 people with autism and intellectual disability for psychiatric disorders (Bradley & Bolton, 2006). Another study by Morgan et al. (2003) screened 164 individuals with ASD to examine comorbid psychiatric conditions. The findings identified that 16 individuals (11%) in their study had a comorbid diagnosis of bipolar disorder. This may suggest a higher relative comorbidity of bipolar disorder in those with an ASD compared to those without an ASD.

### 1.6.3 Anxiety disorders.

In contrast to the widespread acceptance that depression is highly comorbid with ASD, there is considerable debate as to whether anxiety is a comorbid condition or is an inherent element of ASD (Matson & Nebel-Schwalm, 2007). That is, whether trait based anxiety is part of the disorder. Anxiety is characterised by symptoms of physical tension and feelings of fear or apprehension about the future that impair an individual’s functioning (Barlow & Durand, 2005). As people with ASDs experience a restricted range of interests
and a general dislike for change, it is often accepted that these individuals may experience higher levels of trait based anxiety as a part of their condition (Cath, Ran, Smit, van Balkom & Comijs, 2008). As a result, there is a potential for under-diagnosing anxiety disorders, or state based anxiety, among people with ASD who may consequently fail to receive adequate treatment for anxiety problems (Cath et al., 2008).

The diagnosis of anxiety disorders in people with ASD is further complicated by the possibility that they may present with different signs and symptoms, in comparison to neurotypical people (Matson & Nebel-Schwalm, 2007). For example, Brereton and Tonge (2002) suggested that the signs of anxiety in children with ASD include: school refusal; pervasive worry and fearfulness; restlessness and irritability; timidity, shyness and withdrawal; associated headache and stomach pains; restless sleep and nightmares; poor concentration and distractibility; and reliving stressful events in repetitive play. This diversity in presentation demonstrates the difficulties that professionals face when assessing and treating people with ASD and comorbid anxiety.

Due to the lack of consensus in the literature regarding the relationship between ASD and anxiety, it is not surprising that previous prevalence studies have produced substantial variation in results, ranging from 5 to 84 per cent (e.g., Bellini, 2004; Muris, Steerneman, Merckelbach, Holdrinet & Meesters, 1998). Despite a lack of consensus in this area, most studies suggest that rates of anxiety
in those with an ASD are significantly higher than the general population, or when compared to others with disabilities (e.g., Bradley et al., 2004; Evans et al., 2005; Melfsen et al., 2006).

### 1.6.4 Attention deficit hyperactivity disorder.

One of the most common psychiatric conditions diagnosed concurrently with ASD has been ADHD (e.g., Eisenmajer et al., 1996; Frazier et al., 2001; Goldstein & Schebach, 2004). Goldstein and Schebach (2004) indicated that ADHD was the most prevalent disorder comorbid with ASD, with prevalence rates estimated between 17 to 83 per cent (Eisenmajer et al., 1996; Frazier et al., 2001; Goldstein & Schebach, 2004). There is nonetheless much debate surrounding whether ADHD is a separate disorder in people with ASD. For example, hyperactivity and impulsivity are regularly displayed by people with ASD, thus making differential diagnosis difficult (Kadesjö & Gillberg, 2001). Ghaziuddin (2002) suggests that in circumstances where the severity of symptoms affects a person’s life, ADHD may be diagnosed and become the focus of treatment rather than the ASD. However, a diagnosis of ADHD has not been possible to make in the context of an ASD, because the DSM-IV-TR stipulates that ADHD should not be diagnosed with a PDD (APA, 2000). Consequently, researchers have found it difficult to ascertain an accurate prevalence rate of ADHD among people with an ASD. However, the DSM-V has removed this specifier; as such it is likely there will be a change in the availability of prevalence rates of ADHD in ASD (APA, 2013).
1.6.5 Psychotic disorders.

ASDs were historically viewed as childhood onset schizophrenia (APA, 2000). As knowledge about ASD increased, these two conditions became separate entities, with ASD classified as a PDD and schizophrenia as a psychotic disorder (APA, 2000). It has been acknowledged in previous research that the intense preoccupations and interests exhibited by people with an ASD may superficially resemble psychotic features (Trevarthen, Aitken, Papoudi & Robarts, 1996). Abnell and Hare’s (2005) investigated the phenomenology of delusional beliefs in 46 adults with Asperger’s disorder. The findings indicated that those with Asperger’s disorder tended to report higher levels of delusional beliefs than the general population. However this study did not have a matched control group and participants self-selected and were thus were more likely to have an interested in delusional beliefs.

In addition to delusional beliefs, idiosyncratic speech may be misconstrued as a response to perceptual disturbances (Trevarthen et al., 1996). Although there is potential for misdiagnosis due to the perceived symptom overlap, researchers who specialise in this field have reported that psychotic disorders are not commonly comorbid with ASD (Lunegard et al., 2011; Matson & Nebel-Schwalm, 2007).

1.6.6 Aetiology of comorbid mental health conditions.

The biopsychosocial model has been a useful template to explain the development of comorbid psychiatric conditions in people with an ASD (Ford,
Goodman, & Meltzer, 2004; Gadow et al., 2008; Gurung, 2006; Hill, 2002). Bradley & Bolton (2006) posit that consideration of biological (e.g., genetics) and psychosocial factors (e.g., psychological impact of ASD, coping strategies, social supports) and life-span issues need to be considered when understanding the onset of mental health disorders in this population.

Moreover, the different components of the biopsychosocial model (biological, psychological and social) have been identified in people with ASD that act as risk or protective factors in the development of a comorbid psychiatric condition. A study by Gadow and colleagues (2008) investigated the potential risk and protective factors associated with psychiatric comorbid conditions in 238 children (aged 6 to 12 years), with a diagnosis of ASD. The use of medication, a family history of mental illness, prenatal pregnancy complications, and medical conditions were identified as the most significant risk factors for current psychiatric symptomatology among children with ASD. Protective factors included the individual child’s characteristics, and higher levels of social functioning at school. Gadow et al. (2008) concluded their findings supported the biopsychosocial model of psychopathology in children with an ASD.

1.6.7 Comorbid mental health conditions and challenging behaviour.

While the biopsychosocial model has been used to explain the development of both psychiatric comorbidities and challenging behaviour in people with ASD (Ford et al., 2004), the relationship between challenging behaviour and comorbid psychiatric conditions remains unclear. A collection of studies over the past ten years has reported differing opinions regarding ASD-
related comorbid conditions and challenging behaviours (e.g., Holden & Gitlesen, 2003, 2009; Ross & Oliver, 2002). One approach to explaining challenging behaviour among individuals with an ASD has involved interpreting these behaviours as symptoms of psychiatric illnesses (Holden & Gitlesen, 2003, 2009). Holden and Gitlesen (2009) investigated the association between psychiatric symptoms and challenging behaviour of people with ASD from the perspective of caregivers. The results suggested a significant positive relationship between psychiatric symptom severity and levels of challenging behaviour. According to Ross & Oliver (2002), symptoms such as self-injury, can be interpreted as a consequence of a psychiatric illness (e.g., depression), when in fact the self-injury could have been a risk factor for depression (Ross & Oliver, 2002). That is, individuals who self-harm may experience greater isolation from their community, rejection from their peers, and be less able to participate in activities; consequently developing depression (Holden & Gitlesen, 2009). Although these studies all acknowledge that a relationship exists between psychiatric conditions and challenging behaviour among people with an ASD, there is a lack of consensus regarding how these factors relate to each other. Consequently, future research that seeks to clarify the relationship between comorbid mental health conditions and challenging behaviour among people with an ASD is warranted.

In summary, ASD is a pervasive neurodevelopmental disorder with no single accepted causative factor. Current theories suggest a multitude of factors that influence diagnosis. It is accepted that people with an ASD are at increased risk of experiencing a concomitant psychiatric condition. Given the wide range in
prevalence figures for comorbidity and the difficulties associated with differential diagnosis among this population, it is important that future research continues to explore how these problems are expressed among people with ASD. Research is also needed to clarify the relationship between mental health conditions and challenging behaviour in people with an ASD.

1.6.8 **Sleep difficulties and autism spectrum disorders.**

Another factor commonly associated with mental health difficulties and challenging behaviours in those with an ASD is persistent sleep difficulties. Individuals of all ages with an ASD report higher sleep difficulties than those who are developing typically (e.g., Barlow & Durand, 2005; Polimeni, Richdale & Francis, 2005; Richdale, 2001). Polimeni et al. (2005) found that children with autistic disorder and Asperger’s disorder were more likely to experience sleep disturbance than typically developing children. Sleep problems have been estimated to occur in up to two thirds of children with an ASD (Richdale, 2001). Both subjective and objective data have demonstrated that children with ASD have difficulty falling asleep or maintaining sleep (Polimeni et al., 2005). In addition, sleep problems in children with an ASD have been found to affect a child’s daily functioning, including increased challenging behaviours, drowsiness and increased learning difficulties (Paavonen et al., 2003).

A study by Goldman, Richdale, Clemons and Malow (2012) examined parental sleep concerns in ASD across childhood and adolescents (aged 3 to 18). Sleep problems were evident across all age groups However, factors contributing to sleep disturbance varied across the age groups, with younger children
experiencing difficulty with anxiety, parasomnias, night waking and higher levels of bedtime resistance. In contrast, older children and adolescents were observed to have increased difficulty with delayed sleep onset, shorter sleep duration and daytime drowsiness.

Sleep difficulties in children with an ASD have been found to cause significant distress to both the caregiver and the child (Doo & Wing, 2000; Polimeni et al., 2005). In parents of children with ASD, stress levels are higher in those whose child has sleep difficulties (Doo & Wing, 2000). Children with an ASD who are regarded as having a regular sleep routine have been found as happier, calmer and less irritable (Gordon, 2000). These findings highlight the importance of sleep when it comes to influencing the child and caregiver’s functioning.

A study by Taylor, Schreck and Mulick (2012) examined sleep disturbance as a correlate to cognitive and adaptive behaviour in children with an ASD. Findings suggested that children who slept fewer hours per night had lower verbal skills, adaptive functioning, daily living skills, socialisation skills, motor development and overall intelligence (Taylor et al., 2012). In addition, children who slept fewer hours at night, with more night awakenings, were found to have increased communication problems. This may suggest that sleep quality is likely to be closely related to overall functioning in a child with ASD.

Moreover, sleep difficulties have been found to persist through adolescence, with adolescents more likely to have difficulty with delayed sleep onset, shorter sleep duration and daytime sleepiness (Goldman et al., 2011).
Studies have also suggested that adults with Asperger’s disorder are more likely to report subjective sleep difficulties than their neurotypical counterparts (Tani et al., 2004).

1.6.9 Aetiology of sleep difficulties.

Various studies have attempted to explain the higher incidence of poor sleep in those with an ASD. Theories regarding the development of sleep difficulties include hyperarousal, anxiety, poor social understanding, brain pathology and inadequate regulation of melatonin (Richdale, 1999; Wright, Sims, Smart, Alwazeer, Alderson-Day et al., 2011). The theory of inadequate melatonin regulation has received increasing attention in the literature (Brzezinski et al., 2005; Leu, Beyderman, Botzolakis, Surdyka, Wang & Malow, 2011; Melke et al., 2008). Melatonin is a naturally occurring chemical, which is most known for its function of regulating circadian and seasonal rhythms (Leu et al., 2011). Children with autism who have sleep disturbances have decreased melatonin levels, compared to matched controls (Brzezinski et al., 2005, Melke et al., 2008). Leading researchers in this area currently postulate that abnormalities in melatonin metabolism partly explain higher rates of sleep disturbance in those with an ASD (e.g., Tordjman et al., 2005).

In summary, both children and adults with an ASD report more sleep difficulties than their neurotypical counterparts. Sleep difficulties are associated with poorer academic function and increased behavioural difficulties. Consequently, sleep difficulties are a key variable to consider when assessing individuals with an ASD.
Currently in Australia, there are standardised multidisciplinary approaches to the diagnosis of ASD (O’Reily & Wicks, 2013). A variety of health professionals have expertise in ASD, including general practitioners, paediatricians, neurologists, psychologists, occupational therapists and speech pathologists and thus may be involved in the diagnostic process (O’Reily & Wicks, 2013). Although protocols for the assessment and diagnosis of ASD have been developed, a uniform approach to intervention and treatment of this disorder has not yet been established (O’Reily & Wicks, 2013).
Chapter 2: Autism Spectrum Disorders and Intervention

Approaches

There are a myriad of intervention approaches available for individuals with ASD and their caregivers to consider. Two of the most common include the medical approach, whereby pharmacology (medication) is used to treat associated symptoms of ASD (Erikson, Stigler, Posey & McDougle, 2007); and the psychosocial approach, where a wide range of services and strategies are employed to change behaviour and increase skills for the individual and their caregivers (Harris, 2007). The primary aim of these treatment approaches is to maximise the person’s functional capacity, such that they have an improved quality of life and are able to meet their ultimate developmental potential (Myers & Johnson, 2007).

The medical model of intervention is applied to most mental health conditions and disabilities in Australia, including ASD (McDougle et al., 2006). When a diagnosis is made, a medical practitioner will commonly consider prescribing medication to alleviate any distressing symptoms of the disorder (McDougle et al., 2006). While the medical model of intervention is often applied to ASD, there is currently no medication that targets the core components (McPheeters et al., 2011; O’Reily & Wicks, 2013; Williamson et al., 2012). Despite this, pharmacological treatments are still widely used as a form of intervention for those with an ASD, principally targeting the behavioural and mental health symptoms/comorbidities associated with the disorder.
Psychosocial interventions provide an alternative to pharmacology for the treatment of behavioural and psychiatric symptoms associated with ASD. While medication benefits some people with an ASD, there is growing evidence that psychosocial approaches are equally beneficial and improve the quality of life in people with an ASD (Krebs-Seida et al., 2009). Psychosocial interventions, such as programmes to promote communication and adaptive behaviours require careful assessment and analysis of factors that predict, maintain and interact with problem behaviours and psychiatric symptoms (Carr, et al., 1999; Schwartz, Boulware, McBride & Sandall, 2001). These psychological approaches are accepted best practice and form the foundation for early intervention programmes for ASD within Australia (O'Reily & Wicks, 2013).

The behavioural approach is a further psychosocial intervention has been successfully implemented in the treatment, education and management of individuals with ASD (Brereton & Tonge, 2002). Most recently, this has involved the positive approach which focuses on understanding the meanings and purposes of behaviour from the individual with ASD’s point of view, rather than on extinguishing unwanted behaviours. For example, operant conditioning has been shown to be efficacious in increasing desirable behaviours in individuals with ASD by pairing a positive reinforcement with a desired behaviour (Zachor et al., 2006).

Although psychosocial interventions have been found to improve the quality of life of individuals with an ASD (Rogers & Ozonoff, 2006), there are some important limitations to this therapeutic approach. For instance,
psychosocial interventions are often difficult to access and require a significant amount of time and often financial investment by the individual and/or their caregivers. As a result, many people with an ASD may be precluded from access to psychosocial resources. Conversely, pharmacological options are often less expensive for individuals and their caregivers, are more readily available and require less time investment, compared to psychosocial interventions. Further, in some cases, individuals with ASD have distressing symptoms that do not readily respond to psychosocial interventions and a pharmacological approach is considered necessary (O'Reily & Wicks, 2013).

**Autism Spectrum Disorders and Psychotropic Medications**

Psychotropic medications refer to psychiatric medications prescribed for the purpose of altering emotions and behaviours of a person with an ASD (Weeden et al., 2011). The use of psychotropic medication for people with disabilities has been controversial, and has been much debated in the literature. Lipman (1970) was an early researcher to comment on this, indicating that rates of prescribing psychotropic medications in this population were unusually high. While the prescription of medication to people with disabilities has continued, the research surrounding its efficacy in this population has remained equivocal. It has been suggested there is an association between the presence of ASD and the prescribing of psychotropic medication (e.g., Aman et al., 2002, 2003, 2005; Gralton et al., 1998; Webber, McVilly & Chan, 2011).
Most of the research conducted in this area has addressed the use of psychotropic medications in the treatment of challenging behaviours and comorbid psychiatric conditions in people with intellectual disabilities (e.g., Brylewski & Duggan, 2004; McGillivray & McCabe, 2004). However, there is now a growing body of literature exploring the use of psychotropic medications in individuals with ASD (e.g., Aman et al., 2002, 2003, 2005; Esbensen Greenberg, Seltzer & Aman, 2009; Mandell et al., 2008; McPheeters, 2011). While no medications are known to treat the core elements of ASD (Mandell et al., 2008), they are often prescribed to address challenging behaviours commonly associated with the disorder (e.g., aggression & self-injurious behaviour), sleep difficulties or comorbid conditions (e.g., ADHD, depression, anxiety; Hollander, Phillips & Yeh, 2003; McDougle et al., 2000; Volkmar, Lord, Bailey, Schultz & Klin, 2004).

2.1.1 Prevalence of psychotropic medications.

Psychotropic medication is a common form of intervention in those with an ASD (Aman et al., 2002, Esbensen, Greenberg, Seltzer & Aman, 2009; Schubart, Camacho & Leslie, 2013). Attempts have been made over the previous two decades to establish the prevalence rates of psychotropic medication among ASD populations. Studies have found varying results, with estimates ranging from 30 to 81 per cent (Aman et al., 2005; Esbensen et al., 2009, Green et al., 2006; Mandell et al., 2008; Martin Seahill, Klin & Volkmar, 1999; Memarie et al., 2012; Mire, Nowell, Kibiszyn & Goin-Kochel, 2013; Oswald & Sonenklar, 2007; Rosenberg, Mandell, Farmer, Law, Marvin & Law, 2010; Schubart et al., 2013; Whitwer & Lecavalier, 2005 ).
An influential American study by Aman, Van Bourgondien, Wolford and Saphare (1995) explored participants with mild to severe forms of an ASD and found that 31 per cent were taking psychotropic medication, 11.5% anti-epileptic medication; five per cent were taking other over the counter autism supplements. Aman et al. (1995) reported that 39 per cent of participants were taking both psychotropic medication and anti-epileptic medication. In addition, the study found that increasing age and living out of home were associated with greater use of psychotropic medications.

A previous study by Aman, Lam and Collier-Crespin (2003) investigated the level of reported psychotropic medication in 417 families registered with the Autism Society of Ohio, America. The findings indicated that 46 per cent of participants (age range two to 46) were taking psychotropic medication. Similar to Aman et al.’s (1995) earlier study, greater age, and living outside of the family home were related to increased medication use. In addition, those who were male, had an intellectual disability, and had a more severe form of autism were more likely to be taking psychotropic medication (Aman et al., 2003). One important limitation of Aman et al.’s (1995, 2003) studies was they did not collate classes of medication, or the reasons for medication use. Further, these studies most likely included professionals responding on behalf of families, thus limiting their applicability to the wider community.

Recent studies have begun to investigate the use of psychotropic medication among people with an ASD in more detail (e.g., Mandell et al., 2008;
Rosenberg, et al., 2010). A large-scale American study of 5,181 children with an ASD, who were registered on an internet- research database, found that 35 per cent were currently taking at least one psychotropic medication (Rosenberg et al., 2010). The most common medications were stimulants, neuroleptics and/or antidepressants. In another large-scale American study (n = 60,641) of the use of psychotropic medication among Medicaid enrolled children with an ASD (aged 4 to 21 years) a much higher percentage of psychotropic medication use was found (Mandell et al., 2008). Specifically, 56 per cent of respondents reported taking at least one psychotropic medication. Mandell and colleagues (2008) also found the presence of autistic disorder, intellectual disability, and increasing age positively correlated with psychotropic medication use. Moreover, the findings suggested that psychotropic medication use was unexpectedly common among young children with an ASD (18% of 0 to 2 year olds, and 32% of 3 to 5 year olds). These startling findings influenced the authors to conclude that ‘there is an urgent need to assess the risks, benefits and costs of medication use’ (Mandell et al., 2008, p. 441). The data used in this study was collected from Medicaid (a health programme for low income families in the United States of America (USA) and as such, no information on symptoms or severity of ASD or comorbid conditions was available.

An international internet study of parent reported treatments for ASD indicated that 52 per cent of parents reported using medication as a form of treatment for their child with an ASD (Green et al., 2006). The authors found parental reporting of higher levels of ASD impairment was associated with
increased medication use, as was increasing age. Medication use, according to any further demographic variables beyond, age, sex and severity of impairment, was not examined. Thus, the number of participants with comorbid intellectual disability is unknown.

A study of psychotropic medication use in those with an ASD who do not have an associated intellectual disability (e.g., IQ of greater than 70) was undertaken by Martin et al., (1999). The findings revealed that 55 per cent of participants were taking at least one psychotropic medication, with 23 per cent taking two, and six per cent taking three or four psychotropic medications. This was similar to the findings of Mandell et al. (2008) and Green et al (2006), mentioned above, incorporating those with an intellectual disability. The most commonly observed psychotropic medication in the sample was anti-depressants (32%), followed by stimulants (20%). Therefore, it appears that psychotropic medications were widely used in individuals with an ASD with and without a comorbid intellectual disability.

While most research on the prevalence of psychotropic medication use has been conducted in America, the highest noted prevalence of psychotropic medication use (81% of 345 children and adolescents attending ASD specific schools) was reported in an Iranian study (Memari et al., 2012). Anti-psychotic medications were the most commonly reported (57.4%), with a small number of individuals taking anti-depressants (8.7%). This study found no relationship between demographic variables (e.g., age & gender) and medication use. While
this study provided useful information, it did not differentiate between medications prescribed for epilepsy or other medical conditions. Moreover, it did not provide any information surrounding the reason for prescription, representing an important limitation of the findings.

Longitudinal research indicates that the prevalence rate of psychotropic medication use is increasing (Aman et al., 2005; Esbensen et al., 2009; Schubart et al., 2013). A study by Aman and colleagues (2005) investigated patterns in psychotropic medication across an eight year period in Ohio and North Carolina, USA. The findings indicated there was a significant increase in the use of anti-depressants, anti-psychotics and stimulants with greater age, degree of impairment, and accommodation setting being associated with several classes of medications. A further longitudinal study conducted by Esbensen et al. (2009) examined psychotropic and non-psychotropic medication use among 286 adolescents and young adults with an ASD (mean age = 21.1). The rates of psychotropic medication use increased from 57 to 64 per cent over a four year period, with those who commenced psychotropic medications likely to continue taking them. While these studies provided some important initial findings on the use of medication by those with an ASD, there was limited information regarding the differences between those who had an intellectual disability and those with comorbid conditions. Moreover, the majority of research conducted on the prevalence of psychotropic medication use has occurred in America, with limited research elsewhere. It is currently unknown if the trends noted above can be
applied to an Australian sample, or whether there are differences in the use of psychotropic medications across cultures.

A significant limitation of the research available to date is that the primary purpose of medication is often not explicitly stated. It is therefore, difficult to determine whether reported high levels of psychotropic medication use is for the treatment of co-morbid medical conditions such as epilepsy, or for emotions or behaviours. For example, sodium valproate may be used to primarily manage epilepsy or be used to stabilise mood.

In summary, psychotropic medication use appears to be a common intervention for individuals with an ASD. Research has primarily been conducted in the USA thus limiting its generalisability to Australia, with differing demographic variables being identified as relation to psychotropic medication use. Further research on the prevalence and characteristics of psychotropic medication use, as well as on those individuals who are prescribed it, is needed. This is particularly the case with respect to Australians with an ASD, since there is currently limited local data on the use of psychotropic medication in this population.

2.1.2 Issues related to psychotropic medications.

Despite the high prevalence of psychotropic medication use among individuals with ASD, a number of concerns have been highlighted around its use in this population. These include, but are not limited to, off-label prescription, side effects, a failure to reduce or review medication once commenced, and the
cost-effectiveness of such interventions (Witwer & Lecavalier, 2005). Several professional organisations and a host of researchers have provided comment on these important issues.

There has been extensive research over the past five decades into the short and long term, positive and negative impact of medication. This work well is well explored by Whitaker (2005), Ross and Read (2004), Weinman, Read & Aderhold (2009). In particular, these authors present a case that the long term health outcomes of anti-psychotics needs to be carefully considered when making the decision to use these medications.

Currently, the American Food and Drug Administration (AFDA) have only approved two medications to treat symptoms associated with ASD: these medications include risperidone and aripiprazole (both anti-psychotic medications) (Williamson & Martin, 2010). In Australia, only risperidone is currently approved for the treatment of associated behavioural disturbances in people with ASD (Australian Government, 2007). According to the Pharmaceutical Benefits Scheme (PBS) advisory committee (Australian Government, 2007), risperidone should be prescribed under the supervision of a paediatrician or psychiatrist for people with ASD. Despite this direct PBS recommendation, research indicates that a number of medications are often used in an ‘off-label’ capacity for a condition or age group, which has not been approved by the PBS (Williamson & Martin, 2010).
Off-label prescription of psychotropic medications to individuals with an ASD appears to be increasingly common (e.g., Williams, Woods, Stevenson, Davis, Radmacher & Smith, 2012). These psychotropic medications include various anti-depressants, stimulants, anti-psychotics, and anti-convulsants (Aman et al., 2003; Oswald & Sonenklar, 2007; Rosenberg et al., 2010). They are commonly given to treat comorbid symptoms of ASD, such as irritability, aggression, self-injurious behaviours, attention deficits, anxiety or obsessive compulsive behaviours (Esbensen et al., 2009; Valdovinos, Caruso, Roberts, Kim, & Kennedy, 2005; Witwer & Lecavalier, 2005). This is particularly concerning given the lack of randomised controlled trials or meta-analyses ascertaining the effectiveness of these medications in this population.

Both on-label and off-label psychotropic medications have been associated with adverse side effects and with some, the negative impacts for individuals are substantial (Williams et al., 2012). Noted adverse effects in people with ASD include weight gain, rashes, nausea, elevated blood sugar levels, suicidal ideation, sleep disturbance, sedation, increased salivation and tardive dyskinesia (Williams et al., 2012). The array of potential negative consequences arising from psychotropic medication use in people with ASD has prompted an increasing volume of research into outcomes.

Valdovinos et al. (2005) investigated the incidence of medical and behavioural symptoms that could result as side effects of psychotropic medications in 30 adults with intellectual disabilities. Participants were selected on the basis that they were receiving psychotropic medication through a
psychopharmacological review panel. Each participant reported having at least one side effect, with the majority affecting behaviour (e.g., increased aggression), mood or sleep (Valdovinos et al., 2005). Further, when side effects were reported by participants, a change in medication was likely to occur; yet in most cases, the change involved an increase in the psychotropic regime. One important limitation of Valdovinos et al.’s study is the retrospective nature of data collection and the challenge often associated with accurate reporting of side effects. It is unclear what result these side effects have on the wellbeing and quality of life of people with ASD.

Despite concerns being raised about the side effects of psychotropic medication on children and adults with an ASD, it appears that once an individual commences medication, it is likely to continue being prescribed (Esbensen et al., 2009). Some studies have investigated the impact of withdrawal from medications to address concerns regarding side effects and to determine an accurate prevalence of psychiatric comorbidity (e.g., Branford 1994, 1996). Branford (1994) investigated the withdrawal of anti-psychotic medication in 198 people with intellectual disabilities. Of the 198 people reviewed, 123 were deemed suitable to have their medication reduced or withdrawn. Findings indicated that twelve months after the initial reduction in dose, 25 per cent remained free of anti-psychotic drugs and 32 per cent had a dose reduction. Although 42 per cent of individuals suffered from deteriorating behaviour after dose reduction or complete withdrawal, this study suggested that significant numbers of individuals with an intellectual disability might be unnecessarily medicated.
In a further linked study, Branford (1996) reported on the factors associated with the outcome (successful, unsuccessful) of withdrawing anti-psychotic medication. A history of epilepsy, a lower initial dose and the prescription of thioridazine were associated with successful withdrawal from anti-psychotic medication. Minimal psychopathology, low levels of hyperactivity, aggression and stereotypy all significantly related to successful withdrawal from medication. A significant relationship was identified between autism symptoms and poor withdrawal from medication. However, caution is needed when interpreting this result, as further investigation of behaviours and traits of autism have not supported this finding (Branford, 1996). Nonetheless, the association between ASD and poor withdrawal from medication suggests the importance of further research to examine its use in this population and factors related to its use.

Recently, the cost-effectiveness of psychotropic medication has also come under scrutiny with some estimating that ASD-related therapeutics have an approximate global market value of $2.2 to $3.5 billion dollars (King & Bostic, 2006). An analysis of the cost-effectiveness of treating challenging behaviour in 86 people with intellectual disabilities was conducted by Romeo and colleagues (2006). A randomised controlled trial was used to compare the cost-effectiveness of risperidone, haloperidol and a placebo from a societal perspective (unpaid caregiver inputs and service effects) using a double-blind trial with outcomes being measured in terms of aggression and quality of life. After 26 weeks, individuals allocated to the placebo group had the lowest costs compared to the haloperidol and risperidone groups. Quality of life was found to be highest among
people receiving risperidone, with the lowest found among the haloperidol group. In contrast, aggression rates were highest among individuals in the risperidone group and lowest for people receiving haloperidol. However, a large proportion of participants (25%) were lost to follow-up data collection. This affected the overall power of the study to draw meaningful conclusions. While this study explored the quality of life of people with an intellectual disability, the generalisability of these results to people with ASD are currently unknown.

In summary, despite the high prevalence of psychotropic medication in individuals with an ASD, there are many concerns around its use. In particular, many of these medications are being prescribed off-label without a significant evidence base for their use. Moreover, the use of these medications, particularly anti-psychotics are associated with concerning side effects, and the cost-effectiveness of this intervention has been questioned. At this time, relatively little is known about the use of psychotropic medication among people with ASD in Australia. Further research is thus warranted to ascertain the current use of psychotropic medications in Australians with ASD.
Chapter 3: Psychotropic Medication, Mental Health, Challenging Behaviour, and Sleep Difficulties

Despite an increasing body of research attempting to establish prevalence rates of psychotropic medication in people with an ASD, there has been less focus on the reasons for prescription. Psychotropic medication recommendations in the ASD population are typically based on open-label trials, extrapolation from studies and expert opinions (Myers & Johnson, 2007). However, in clinical practice, people with an ASD are often prescribed medications for comorbid problems, with limited evidence to support effectiveness in this population. This chapter examines the relationship between psychotropic medication use and challenging behaviours, comorbid mental health conditions and sleep difficulties. These problems are likely to account for a large proportion of the use of psychotropic medication among people with ASD. Given the limited research examining psychotropic medication use, according to these variables for people with ASD, the following section includes research conducted on people with other types of disabilities, such as intellectual disability.

3.1 Mental Health and Psychotropic Medication

An extensive body of research exists suggesting that psychotropic medications are an effective treatment for many mental health conditions. Limited research has investigated the relationship between comorbid mental health conditions and the use of medication in people with ASD. Estimates of the prevalence of comorbid psychiatric conditions among those taking psychotropic
medication vary widely, from 60 to 100 per cent (e.g., Mandell et al., 2008; Memari et al., 2012; Morgan et al., 2003). For example, a study by Morgan and colleagues (2003) investigated the prevalence rates of psychiatric illnesses and use of medication in 164 adults with an ASD and intellectual disability. Results indicated that 35 per cent of individuals had a comorbid psychiatric illness, all of whom were on some form of psychotropic medication. Not surprisingly, Morgan et al. found that anti-depressants were the most common medication administered for the treatment of depression. In addition, of the 52 per cent of the sample treated with anti-psychotics, a large proportion (40%) had no identified comorbid mental health condition. A strength of Morgan et al.’s study was the heterogeneous nature of the sample, which made the results more representative for this complex population. Conversely, Morgan et al. only examined participants who were in full-time residential care, and only included individuals who had both an ASD and an intellectual disability. As such, the prevalence of medication use among individuals without an intellectual disability, across different residential settings was not established in this study.

Two recent studies have explored the relationship between comorbid mental health conditions and psychotropic medication use in children with an ASD (Mandell et al., 2008; Memari et al., 2012). Memari and colleagues (2012) found a significant relationship between psychiatric comorbidity and use of psychotropic medications, with 91 per cent of all people with a comorbid mental health condition taking medication. Participants with a psychiatric comorbidity were most likely to be taking anti-psychotics (67%). The study did not find a
significant relationship between psychiatric comorbidity and higher levels of medication use. Despite these findings, the study failed to conduct more detailed analyses on specific comorbid conditions and did not include children with more severe forms of ASD, thus limiting generalisability.

While research has started to examine the relationship between comorbid mental health conditions and psychotropic medication use among individuals with an ASD, further research is needed, given the high prevalence of psychotropic drug use in this population. Moreover, it would be beneficial to have data on comorbid mental health conditions and medication use in adults with an ASD who are living independently, as well as children of varying levels of impairment. Currently no such research exists on these ASD sub-groups.

### 3.2 Challenging Behaviour and Psychotropic Medication

While psychotropic medication for the treatment of comorbid mental health conditions is accepted as a standard level of care (Barlow & Durand, 2004), the use of medication to manage challenging behaviours is more controversial, particularly in individuals with an ASD. Research examining the benefits of such medication has yielded conflicting findings, and vigorous debate surrounds the efficacy of this treatment approach in those with an ASD (e.g., Dove et al., 2012; Siegel & Beaulieu, 2012; Webber et al., 2010; Weeden et al., 2011).

In the state of Victoria, Australia, psychotropic medication used for the primary purpose of restricting a person’s behaviour is seen as a form of ‘chemical restraint’ (Victorian Government, 2007). This method of intervention is only
permitted within specialised disability service settings if it is necessary ‘to prevent
the person from causing physical harm to themselves or other person’, or ‘to
prevent the person from destroying property where to do so could involve the risk
of harm to themselves or any other person’ (Victorian Government, 2007, p 142).
At the outset, disability service providers employing restrictive interventions must
apply to the Office of the Senior Practitioner for approval and must provide
ongoing monthly reports of any restrictive intervention employed. In addition,
any restraints must be the least restrictive form of intervention in the given
circumstances (Victorian Government, 2007). Further, no individual is permitted
to be subject to restraint unless the restraint is specified in that person’s individual
management plan, or is in an emergency situation (Victorian Government, 2007).
For example, a person may be administered prescribed medication on a daily
basis to reduce the likelihood of them engaging in self-injurious behaviour (e.g.,
head banging). Such practice has been widely referred to as a form of ‘chemical
restraint’ (Aman, Van Bourgondien, Wolford & Sarphare, 1995; Branford,
Collacott & Thorp, 1995; McGillivray & McCabe, 2006).

Chemical restraint is defined under the Disability Act (2006) as any form
of medication given primarily for the purpose of behavioural control, but does not
include the use of chemical substances specifically prescribed for the treatment of
a psychiatric condition or physical illness (Victorian Government, 2009). Under
this definition, these circumstances are not required to be reported to the Office of
the Senior Practitioner, although it has been acknowledged there may be cases
where medication is used for both treatment and restraint (Victorian Government,
2009). However, no data is available on how many people receive medication as a sole treatment. In addition, the numbers of people with disabilities who receive medication for treatment or restraint purposes, and who do not receive services through registered disability service providers, are unknown. Similarly, it is unknown how many individuals do not receive medication administered by staff while receiving such services and thus are not reported.

An analysis of the 2007–2008 data collected by the Office of the Senior Practitioner on chemical restraint found that those with an ASD were over-represented compared to the relative proportions of these people in registered disability services (Webber et al., 2010). It was reported that those subject to restrictive interventions were more likely to be young males with multiple disabilities, mainly autism. Similarly, the broader intellectual disability literature has identified that an ASD diagnosis is a risk factor for proportionally higher psychotropic medication use (e.g., Gralton et al., 1998; Robertson et al., 2005).

Gralton and colleagues (1998) investigated the use of anti-psychotic medication and psychiatric diagnosis in children with an intellectual disability. The study was a 12-year longitudinal follow up that reviewed the relationship between anti-psychotic drug use and diagnosis. Case notes of 235 people with an intellectual disability were examined to extract information about the type and duration of medication prescribed, behavioural and psychiatric symptoms, and any comorbid mental health conditions. Findings revealed that children with challenging behaviours were significantly more likely to receive anti-psychotic medication (Gralton et al., 1998). Further, the more types of challenging
behaviour displayed, the more likely they were to receive anti-psychotic medication. The single factor that differentiated those children with challenging behaviours who received anti-psychotic medication from those who did not, was a diagnosis of ASD. However, this study did not further explore the link between ASD and anti-psychotic medication. Consequently, it was unclear whether ASD was associated with more significant challenging behaviour, or that ASD results in the challenging behaviour, having a larger impact on caregivers’ management abilities. A further limitation of their study was that it failed to examine the use of other psychotropic medication, including hypnotics and anxiolytics. It is therefore unclear whether these medications also had a significant relationship with an ASD diagnosis.

Robertson and colleagues (2005) conducted a further study investigating comorbid conditions and the use of psychotropic medication in 500 people with intellectual disabilities. One of their important findings showed a significant relationship between ASD diagnosis and the use of psychotropic medication. This suggested that people with an ASD and intellectual disability may be more likely to be prescribed psychotropic medication than people with only an intellectual disability. Robertson et al. highlighted that these results should be interpreted tentatively, due to several methodological limitations, such as sole reliance on self-report data for analyses. With this in mind, Robertson et al.’s study provides additional preliminary evidence that having an ASD may increase the likelihood of being treated with psychotropic medications. While more research focusing on intellectual disability has identified ASD as a risk factor for psychotropic
medication use for managing challenging behaviour, there has also been some research specifically investigating the relationship between ASD, challenging behaviour and psychotropic medication use.

Challenging behaviours have been identified as a predictor of medication use in adults with ASD. A study by Tsakanikos, Costello, Holt, Sturmey and Bouras (2007) investigated behaviour management problems as predictors of psychotropic medication in 66 adults with autistic disorder and an intellectual disability, compared to 99 matched controls in age, gender, level of intellectual disability. It was found that adults with autism had higher rates of behaviour problems and more frequent use of anti-psychotic medications than the control group. Tsakanikos et al. reported that the generalisability of the findings was limited because other client factors were not included in the analyses, such as housing, services and carer attitudes. These factors may also affect the relationship between challenging behaviours and medication use; consequently, further research needs to examine these factors among people with ASD.

A systematic review of medical treatments for children aged 12 years and under was conducted by McPheeters and colleagues (2011). The review identified 18 studies examining medical interventions, 10 being randomised controlled trials. Findings only indicated evidence to support the benefits of anti-psychotic medications (risperidone and aripiprazole) for challenging and repetitive behaviours in children with an ASD. McPheeters et al. also found these medications had significant adverse effects, leaving the authors to conclude that ‘although many children with ASD are currently treated with medical
interventions, strikingly little evidence exists to support clear benefit for most medications’ (McPheeters et al., 2011, p. 1,318).

Siegel and Beaulieu (2012) conducted a more recent review and synthesis of psychotropic medications in children aged 0 to 18 years with ASD. Thirty-three randomised controlled studies were identified, with the authors noting that the quality and distribution of studies had improved over the last 10 years. The review stated that the only medications to have established evidence were the following anti-psychotics: aripiprazole for the treatment of irritability, hyperactivity and stereotypy; haloperidol for behavioural symptoms; and risperidone for irritability and hyperactivity. Siegel and Beaulieu suggested that none of the other medications had sufficient evidence. The review noted the trials had taken place across heterogeneous samples, making it difficult to determine the ‘true effect’ of the medications. In addition, 70 per cent of the trials emphasised positive results and minimised adverse effects, suggesting a positive results publication bias (Siegel & Beaulieu, 2012).

A further systematic review examined psychotropic medication as a form of treatment for adolescents and young adults (aged 13 to 30) with an ASD (Dove et al., 2012). Of the eight studies identified, five were randomised controlled trials. The findings indicated there was currently insufficient evidence to determine the effectiveness of psychotropic medication in this population. However, there was some indication that risperidone assisted in the reduction of challenging behaviours. Dove et al. recommended an urgent need for further
studies investigating psychotropic medication use in adolescents and young adults with an ASD to inform clinical practice.

The growing controversy surrounding the use of medication in individuals with ASD has generated separate Cochrane reviews on the use of risperidone, aripiprazole, and anti-depressant selective serotonin reuptake inhibitors (SSRIs). A Cochrane review by Jesner et al. (2009) specifically investigated the efficacy and safety of risperidone (also known as risperdal) in individuals with an ASD. The review analysed all randomised controlled trials of risperidone versus a placebo in individuals with an ASD. The studies included in the review were required to have a standardised outcome measure that was clearly administered to treatment and control groups. Only three studies were found that met the review criteria. The review identified some evidence that supported the benefits of using risperidone in treating irritability, repetition, and social withdrawal. However, the authors suggested that adverse side effects associated with use (in particular, weight gain) should be considered when evaluating the advantages and disadvantages, prior to prescribing this medication.

Another Cochrane review has been conducted into the safety and efficacy of aripiprazole in individuals with an ASD (Ching & Pringsheim, 2012). Two randomised controlled trials were identified, each with similar methodology and occurring over eight weeks. The authors suggested there was some evidence to support the benefit of aripiprazole in treating irritability and hyperactivity in children and adolescents with an ASD. Several side effects were also found: most notably weight gain, sedation, excessive saliva and tremors. The authors
concluded there was a need for further research investigating the efficacy of psychotropic medications among individuals with ASD, as well as the long term effects on these individuals.

A third Cochrane review examined the efficacy of anti-depressant SSRIs in those with an ASD (Williams, Brignell, Randall, Silove & Hazell, 2013). Nine randomised controlled trials were identified, examining the outcome of four different SSRIs. The review noted that many studies had different components of outcome measures, which meant these studies were unsuitable for meta-analysis. The review found no evidence suggesting SSRIs were beneficial to children with an ASD, in terms of addressing challenging behaviours; with some evidence indicating its use potentially may cause harm (Williams et al., 2013). There was a small amount of evidence in the review suggesting that SSRIs may be beneficial to adults with an ASD to treat comorbid depression (Williams et al., 2013). It was concluded that caution should be taken when prescribing these medications to this population.

While there are a range of medications that may be prescribed to individuals with ASD, it is important to note that similar medications are commonly prescribed to individuals, regardless of the reason (challenging behaviour or psychiatric illness) for prescription (Holden & Glisten, 2009). Although the use of pharmacology to manage behaviour or treat a psychiatrically comorbid condition may be warranted on some occasions (McGillivray & McCabe, 2004), it is important that research continues to explore the reasons for
the use and efficacy of the pharmacological intervention of the targeted symptoms.

In summary, psychotropic medication is a commonly used management strategy for challenging behaviours in those with ASD. There is some sparse evidence to suggest that aripiprazole and risperidone may be beneficial in reducing irritability and hyperactivity in those with an ASD. However, there are significant limitation to the research base, including largely heterogeneous groups, limited longitudinal data collection, a variety of different outcome measures. In addition, there is currently limited support for other classes of medications.

3.3 Sleep and Psychotropic Medication

Psychotropic medications have been used to treat comorbid sleep problems among people with an ASD; however, there has been limited research evaluating the best methods to address sleep problems in this population (Bramble & Feehan, 2005; Myers & Johnson, 2007). One recent open-label trial investigated the effects of donepezil for rapid eye movement (REM) sleep problems in five children (aged 2 to 6 years) with an ASD (Buckley, Sassower, Rodriguez, Jennison, Wignert, Buckley, Thurm, Sato & Swedo, 2011). Findings suggested that REM sleep as a percentage of total sleep time improved and REM latency decreased significantly. Although these results provided a positive case study analysis for the use of donepezil in treating five young children with a specific sleep problem, no strong conclusions could be made from such a study.
The majority of studies evaluating treatments for sleep problems in people with an ASD have involved the use of melatonin (e.g., Guenole, Godbout, Nicolas, Franco, Clasutrat & Balyete, 2011). This may be due to the availability of studies showing positive results from the use of melatonin in treating sleep disorders in typically developing children (Smits et al., 2001, 2003). As Melatonin is naturally produced in the brain, arguably there are less ethical objections to its use in children.

There have been three open-label trials of melatonin in individuals with an ASD published to date. A study of 25 children with autistic disorder who had sleep difficulties indicated that controlled-release melatonin improved sleep and improvements were maintained at one and two year follow ups (Giannotti, Cortesi, Cerquiglini & Bernabei, 2006). A second study of 15 children and adolescents with Asperger’s disorder found a significant improvement in sleep latency during treatment with melatonin; however, these improvements weren’t maintained at follow-up (Paavonen et al., 2003). The most recent trial examined melatonin in 24 children with ASD over a 14-week intervention period. Again, melatonin was found to be effective in improving latent sleep length (Malow, Adkins, McGrew, Wang, Goldman, Fawkes & Burnett, 2012). Despite these preliminary results supporting the use of melatonin for sleep difficulties, each study had the limitations based on study design of open-label trials. The true efficacy of melatonin is thus currently unclear.

Wright et al. (2010) conducted a randomised controlled crossover trial investigating the effectiveness of melatonin versus a placebo in 22 children with
an ASD, with severe sleep problems who had not responded to behaviour management strategies. The findings indicated that melatonin significantly improved sleep latency and total sleep time compared to the placebo, but not the number of night awakenings. Despite these promising findings, the long term safety of this medication is unknown and needs to be formally addressed, given that children may receive this treatment for several years or even indefinitely (Guenole & Baleyte, 2011). A systematic review of the use of melatonin in individuals with an ASD found that while there was a small amount of literature supporting the benefits of melatonin to treat sleep disturbances, these conclusions were preliminary and not yet approved by professional medical institutions (Guenole et al., 2011). Further research is required to determine the prevalence of melatonin prescriptions and to determine its effectiveness in assisting sleep difficulties.

In summary, there is a small amount of research suggesting that melatonin use may be beneficial in assisting selected sleep difficulties in those with an ASD. The long term outcomes of this treatment modality are largely unknown. Further, there is a gap in the knowledge regarding the perspectives of individuals with ASD and caregivers about the effectiveness of this medication.

### 3.4 Experiences of Individuals and Caregivers

A considerable amount of research has focused on the views and experiences of individuals and caregivers regarding ASD (e.g., Gray, 2003; Hastings & Brown, 2002; Myers & Johnson, 2007). However, to date there has
been little investigation into the views and experiences of medication as a form of intervention from the perspective of recipients with ASD and their caregivers.

The limited research that does exist within this domain has primarily addressed caregivers’ views of compliance with medication prescription (Moore & Symons, 2009; Morton-Cooper, 2004). From a medical approach, adherence with medication should be a straightforward process. This seemingly simple step fails to take into account other factors that may influence an individual’s (or a caregiver’s) decision to take or administer medication (Morton-Cooper, 2004). These factors could include knowledge or understanding of the medication, potential side effects, the ability of the medication to adequately treat people with an ASD, and the individual’s choice to accept or decline taking the medication (Morton-Cooper, 2004).

In a study by Moore and Symons (2009), the adherence of caregivers of children with ASD in accurately administering medication regimes was investigated. Two hundred and twenty parents were surveyed regarding the implementation of pharmacological treatments to children living in home-based care environments. The study identified two significant predictors of adherence to medication regimes: a diagnosis of autistic disorder over Asperger’s disorder, and the caregiver being married. While this provides information as to caregivers’ administrative adherence, ASD individuals’ adherence with medication regimes and their perspectives on this has yet to be investigated.

A further consideration is the extent to which individuals with ASD and their caregivers understand and agree with the decision to use pharmacological
Psychotropic Medication and ASD

interventions. It is currently unclear whether people with ASD and their caregivers make an informed choice about the use of medication for challenging behaviour and comorbid psychiatric conditions, or whether they are fully informed about alternative psychosocial intervention options. Further, as a consequence of their disability, people with ASD may be vulnerable to the decisions made by those around them regarding medication use (Schall, 2002). While caregivers may report an increase in challenging behaviour or symptoms of comorbid mental illness, it is also plausible that this may indicate the caregiver is frustrated or not coping (Schall, 2002). Consequently, an increase in a person’s medication may occur when the caregiver simply requires more support services (Schall, 2002). Given that a large proportion of people with an ASD receive psychotropic intervention for challenging behaviour, comorbid mental illness and sleep difficulties, it is of particular importance that the perspectives of the individuals concerned are researched and understood. To date, research has failed to explore both the individuals with ASD and their caregivers’ perspectives of why pharmacological interventions have been selected, and their attitudes towards this treatment approach.

In summary, there is a paucity of research into the experiences of medication use from the perspective of caregivers and individuals with ASD. Further, there has been little exploration of ASD-affected people’s understanding of the reasons they receive medication and whether their views concord with those of their caregiver.
Chapter 4: The Present Research

Given that there is relatively little research into the use of psychotropic medications in people with an ASD within Australia, further research is warranted. The majority of studies conducted in Australia have focused on individuals who access state funded accommodation services (Webber, McVilly, Stevenson & Chan, 2010), with limited research exploring the use of pharmacology in individuals with an ASD residing independently or in family based care. This research seeks to broaden the knowledge base available of psychotropic medication use by including individuals who reside independently, or with caregivers. Caregivers of children and dependent adults have been included to provide information on this population. The terms ‘caregivers’ and ‘informants’ are used interchangeably to refer to those reporting on behalf of children and dependent adults.

In addition, there has been little exploration of issues related to the use of pharmacology from the perspective of people with ASD and the caregivers of children and dependent adults with ASD. Specifically, there is a paucity of research into the understanding of people with ASDs, and their caregivers, regarding the reasons they receive medication, their experiences with medication, and the attitudes they have regarding medication. These gaps in the research literature signal a need for further exploration of the medication experiences of people with ASD and their caregivers.
The current series of studies will provide pivotal information regarding the use of medication in a broad sample of people with an ASD in Australia. Findings will promote a greater understanding of prescribing practices in this population. This research may ultimately provide individuals, caregivers and practitioners with the information to enable informed choices regarding the use of medication (and possible psychosocial alternatives) in the treatment of psychiatric conditions and challenging behaviour.

4.1 Aims and Hypotheses

The principal goal of this thesis is to better understand psychotropic medication use in people with an ASD in Australia, from the perspectives of individuals and caregivers. This will be examined through three studies. The first study explores psychotropic medication use in children and dependent adults with an ASD, with their caregivers serving as informants. The second study explores psychotropic medication use in self-reporting adults with an ASD. The third study is a qualitative study of caregivers’ (3a) and individual’s (3b) perspectives of psychotropic medication use.

4.1.1 Study 1: Aim and hypotheses.

The overall aim of Study 1 was to provide a detailed description and analysis of the use of psychotropic medication in children and dependent adults with an ASD in Australia. With consideration given to three key variables: challenging behaviour, comorbid psychiatric conditions and sleep difficulties. In addition, Study 1 aimed to contribute understanding to overall knowledge of psychotropic medication use in this through ascertaining the perspectives of
caregivers regarding the use of psychotropic medication in children and dependent adults with an ASD. On the basis of the current literature, the following hypotheses\(^1\) were explored:

a. Male children/dependent adults are more likely to be in receipt of psychotropic medication than their female counterparts.

b. Psychotropic medication use will increase with age in children/dependent adults.

c. Children/dependent adults reported as having challenging behaviours are more likely to be in receipt of psychotropic medication than those without challenging behaviours.

d. Children/dependent adults with comorbid mental health conditions are more likely to be in receipt of psychotropic medication than those without.

e. Children/dependent adults with reported sleep difficulties are more likely to be in receipt of psychotropic medication than those without.

Study 1 aimed to examine informants’ attitudes and perspectives on the use of psychotropic medication for the reduction of ‘challenging behaviour’, for the treatment of comorbid psychiatric conditions or sleep difficulties in children and dependent adults with an ASD. Given the lack of research exploring this, key questions were postulated, rather than specific hypotheses. Given the literature to date, the following key questions were asked from the caregivers perspectives:

\(^1\) Although these hypotheses are akin to audit standards and are largely self-evident, a decision was made to include them in this way in order to enhance the systematic examination of findings
a. What are the reasons for psychotropic medication use in a child/dependent adult?

b. To what extent do caregivers perceive psychotropic medication as helpful for the child/dependent adult with an ASD?

c. Do caregivers view psychotropic medication as a form of restraint?

d. What are caregivers’ attitudes towards the administration of psychotropic medication to people with ASD?

### 4.1.2 Study 2: Aim and hypotheses

The aim of Study 2 was to examine the use of psychotropic medication to manage emotions or behaviours associated with an ASD from the perspective of adults with an ASD. The study aims to explore those who currently use medication, who have previously used it and who have never used it. This study will explore the differences variability in the extent of medication use, in addition to examining factors associated with medication use; in particular challenging behaviours, comorbid mental health conditions and sleep difficulties. On the basis of the current literature, the following hypotheses were posed:

a. Males are more likely to be in receipt of psychotropic medication than females.

b. Psychotropic medication use will decrease with age.

---

2 Although these hypotheses are akin to audit standards and are largely self-evident, a decision was made to include them in this way in order to enhance the systematic examination of findings.
c. Individuals with comorbid mental health conditions are more likely to be prescribed psychotropic medications than those without.

d. Individuals who reported challenging behaviour are more likely to be prescribed psychotropic medications than those without.

e. Individuals with reported sleep difficulties are more likely to report psychotropic medication use than those without.

A second aim was to examine the perspective of adults with an ASD regarding medication as an option for reducing challenging behaviour, or for the treatment of comorbid psychiatric conditions. Based on the literature the following key questions were asked:

a. Is psychotropic medication perceived as helpful by adults with an ASD?

b. Do adults with an ASD view psychotropic medication as a form of restraint?

c. What do adults with an ASD state as their reason for using psychotropic medication?

d. What are the attitudes of adults with an ASD towards the administration of psychotropic medication to people with ASD?

4.1.3 Study 3: Aims.

The primary goal of the last study was to explore caregivers’ and individuals’ attitudes and perspectives towards the use of psychotropic medication in an ASD population, through qualitative methodology. This approach aimed to
allow participants to provide personal perspectives in relaying their thoughts about psychotropic medication use. There were three main objectives: 1) to provide further insight into the topics covered; 2) to capture the viewpoints of informants and individuals and generate common themes; and 3) to inform future practice in this area.
Chapter 5: Method

5.1 Participants

A total sample of 308 individuals (240 males, 58 females) with an ASD, aged between three and 74 years of age (M = 18.13, SD = 14.75) participated in these studies. This sample comprised two groups of participants across three studies. Table 5.1 below presents the demographic material for each study.

Table 5.1

<table>
<thead>
<tr>
<th>Study</th>
<th>No of. Participant</th>
<th>Males</th>
<th>Age Range</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>245</td>
<td>198</td>
<td>3-69</td>
<td>12.91</td>
<td>9.65</td>
</tr>
<tr>
<td>2</td>
<td>63</td>
<td>42</td>
<td>18-74</td>
<td>38.44</td>
<td>13.57</td>
</tr>
<tr>
<td>3a</td>
<td>173</td>
<td>138</td>
<td>3-45</td>
<td>10.17</td>
<td>9.45</td>
</tr>
<tr>
<td>3b</td>
<td>46</td>
<td>30</td>
<td>18-63</td>
<td>37.85</td>
<td>14.23</td>
</tr>
</tbody>
</table>

Studies 1 and 3a included 245 children and dependent persons survey information (240 online, 5 paper versions) was provided by parents/caregivers who acted as informants on behalf of the child/dependent adult. Studies 2 and 3b included 63 adults (42 males, 21 females) with an ASD who independently completed an anonymous questionnaire (54 online, 10 paper versions).

5.2 Materials

Two questionnaires were developed for this study. The first was designed for completion by caregivers of a child/dependent adult with an ASD; the second was designed for completion by adults with an ASD. The first part of the questionnaire was designed to collect information regarding characteristics of the
individual with an ASD, and their use of psychotropic medication. Topics included the extent of any sleep problems, any past or current use of medications, the reasons for and effect of, any such use. For these topics, caregiver informants were asked to provide information with respect to the person with an ASD. In addition, attitudes towards medication were sought from participants with an ASD; informants were asked to report their own attitudes. A ‘free text area’ was included throughout the questionnaire for respondents to provide comments about any medications prescribed to treat emotions or behaviours associated with ASDs, or to provide feedback about the survey. The questionnaire took approximately 20 minutes to complete for both self-reporting adults with an ASD and informant caregivers.

5.2.1 Demographic information.

Demographic information was collected on participants with an ASD, including age, country of residence, and postcode. Respondents were also asked to confirm that they, or the person they cared for, had a diagnosis of an ASD and to indicate: the subtype of ASD (i.e. Autistic disorder, Asperger's disorder, PDD), the type of professional who diagnosed the disorder (no supporting documentation required), the age of the individual at diagnosis, the extent to which autism affected their functioning, the presence of any associated intellectual disability, and the presence of any communication impairment or any other medical conditions (e.g., epilepsy or diabetes).
5.2.2 Mental health and challenging behaviour.

Participants were asked to report whether they (or in the case of the informant, the person they cared for) experienced any mental ill health. If so, they were asked to indicate whether this, or these, had been formally diagnosed (yes/no), by which type of professional, or if they believed a diagnosis should have been made (yes/no). Participants were also asked to indicate (yes/no/sometimes) if they (or in the case of the informant, the person they cared for) had difficulty managing their behaviour (e.g., obsessions, anger, self-stimulation, impulse control). If yes, respondents with an ASD were asked to describe the behaviour they found difficult to manage, how often it presented, what management strategies they used and who assisted in developing these strategies. Caregiver informants were asked if they had difficulty managing the behaviours of the person with an ASD. If yes, they were asked to describe the behaviours that were difficult to manage, how often they presented, what management strategies they used and who assisted in developing these strategies.

5.2.3 Extent of medication use.

Participants were required to report if they (or in the case of the informant, the person they cared for) currently took and/or have previously taken medication to assist with emotions and behaviours associated with their ASD. If they indicated yes, they were then asked to complete a series of questions about each medication. The range of items relating to medication use, the response format, and extent of opportunity for other responses and/or comments can be found in Appendix A).
5.3 Sleep Characteristics

5.3.1 Self-reporting adults with an Autism spectrum disorder.

Four items from the Insomnia Severity Index (ISI; Morin, 1993) were administered to participants who reported they had difficulties with sleep. Self-reporting adults with an ASD were asked to report how severe their sleep problems were, across three domains (difficulty falling asleep, difficulty staying asleep and problem waking too early), as well as to report overall sleep satisfaction on a five point Likert scale (1 = none to 5 = very severe). Total possible scores ranged from four to 20, with higher scores representing more severe levels of insomnia. Participants were further required to report if they used medication to assist with sleep. The ISI is an established measure with sound psychometric properties. It has been found to have acceptable internal consistency ($\alpha = .90 -.91$), convergent validity and acceptable correlations between individual items and overall scores ($r = .73, r = .71$) in both clinical and community samples (Morin et al., 2011). This current study found the items a relatively reliable measure of sleep difficulties (self-report $\alpha = .67$).

5.3.2 Caregivers of children/dependent adults with an Autism Spectrum Disorder.

Four items from the ISI (ISI; Morin, 1993) were administered to informant participants, who reported the person they cared for had sleep difficulties. Informants were asked to report how severe they perceived the sleep problems were, across three domains (difficulty falling asleep, difficulty staying asleep and problem waking too early), as well as reporting their overall satisfaction with the
child’s/dependent adult’s sleep on a five point Likert scale (1 = none to 5 = very severe). Total possible scores ranged from four to 20, with higher scores representing more severe levels of insomnia. Informants were further required to report if the person they cared for used medication to assist with sleep (informants $\alpha = .71$).

5.4 Attitudes Towards Medication

5.4.1 Self-Reporting adults with an Autism Spectrum Disorder.

The Drug Attitude Inventory (DAI 30; Hogan, Awad & Eastwood, 1983) was administered to participants with an ASD who currently took medication or had previously taken medication. This 30-item self-report inventory focuses on attitudes towards medication use, as well as values concerning illness and health. The DAI-30 has primarily been used for people with schizophrenia to determine factors that may affect medication compliance.

The DAI-30 has been found to have excellent internal consistency ($\alpha = .93$; Hogan, Awad & Eastwood, 1983); high test-retest reliability ($r = .82$; Awad, 1993); and a high correlation with medication compliance and treatment outcome in people with schizophrenia and depression (Brook, van Hout, Nieuwenhuyse & Heerdink, 2003; Gervin et al., 1999; Hogan et al., 1983; Pae et al., 2004; Rossi, Arduini, Stratta & Pallanti, 2000; Kampman et al., 2000; Sajatovic, Davies & Hroud, 2004).

In addition, a shortened version of the DAI was administered to individuals with an ASD who had never taken medication to manage emotions and behaviours associated with the disorder. This version removed all items.
relating to how medication affected the individual and reflected only attitudes towards medication use. The adapted version of this questionnaire was found to have acceptable internal consistency (self-report $\alpha = .82$).

### 5.4.2 Caregivers of people with an Autism Spectrum Disorder.

The DAI-30 was adapted for completion by parents/caregivers. This questionnaire was shortened to 16 items, focusing on understanding the informants’ values around medication and how they think medication affects the person they cared for. This adapted version of the DAI was found to have acceptable internal consistency ($\alpha = .87$).

In addition, a shortened version of the DAI was administered to caregivers who reported that the person they cared for had never taken medication to manage emotions and behaviours associated with ASD. This version removed all items relating to how medication affected the child/dependent adult and reflected only values relating to medication use. The adapted version of this questionnaire was found to have acceptable consistency ($\alpha = .72$).

The entire questionnaire is available to any interested reader by contacting the author or her supervisor, Associate Professor Jane McGillivray, contact details in Appendix C.

### 5.5 Procedure

Ethics approval for this study was obtained from the Human Research Ethics Committee at Deakin University. Participants were required to have a minimum age of 18 years, and to either have an ASD or be the caregiver of a child/dependent adult with an ASD. The individuals who took part in this study
were recruited from five sources over a 12 month period. First, through advertisements of the study in ASD and disability services newsletters; second, via announcements about the study and distribution of flyers to support groups for people with an ASD; third, via direct emails to caregivers who had self-identified through a research website as wanting to participate in research that focused on people with an ASD; fourth, posting brief information and/or the flyer about the project on ASD specific webpages and Facebook groups; fifth, advertisements were placed on search engines (e.g., Google), where the advertisement was displayed when key words were searched. For instance, if the words ‘autism and medication’ were entered into the search engine, a brief advertisement of the study may have appeared in the corner of the browser. Advertisements provided researchers contact details for further information or to access a paper copy of the questionnaire and/or directed potential volunteers to the webpage for access to the questionnaire. The advertisement (Appendix B) provided brief information about requirements for participation.

The proportion of participants sourced from each recruitment method is unknown, as participation was anonymous. However, a large proportion of participants specified their location as Victoria, and any overseas participants were not included. The majority of participants (95.1%) elected to complete the online version of the questionnaire. Respondents were invited to email the researchers separately if they wished to receive a copy of group findings. Participation was voluntary and anonymous, and no financial or other inducements were offered. A Plain Language Statement was provided, which
contained information regarding informed consent (Appendix C). Participants were told that they could withdraw from the study at any time up until the questionnaire was submitted. Once the questionnaire was submitted, participants were not able to be identified; thus it was not possible to withdraw post-submission. In the event of any stress associated with completion of the survey, participants were encouraged to seek assistance from their local ASD association, crisis support service or attend their local general practitioner for support if necessary.
Chapter 6: Results Study 1

This study involved a detailed description and analysis of 245 children and dependent adults with an ASD whose caregivers acted as informants. The caregivers will be referred to as ‘informants’ throughout this section of the results. A power analysis was conducted using the G-Power 3.1 Program (Faul, Erdfelder, Buchner & Lang, 2009), with anticipated moderate effect sizes. The power analysis indicated that the study required approximately 110 participants, and therefore was deemed to have sufficient power for analysis. Non-parametric approaches to analysis was taken as the data was not normally distributed.

In the first section of this chapter, the demographic details of the sample are presented, including the frequencies of children and dependent adults according to age, gender, communication ability, intellectual ability, type of ASD and source of information. In the second section of this chapter, the characteristics of the children and dependent adults who are currently using psychotropic medication to assist the management of behaviours and emotions concomitant with the disorder are explored and compared with those who previously used medication, and those who have never used medication. The number and types of drugs are described for those who are prescribed medication. Further, the perspectives of informants regarding the use of psychotropic medication in the management of mental health, undesirable emotions and behaviours in the person with an ASD are reported. This is followed by a description and analysis of any relationship with psychotropic medication use in those who reported challenging
behaviour, those who reported comorbid mental health conditions, and finally, those who reported sleep problems.

6.1 Overview of the Sample of Children and Dependent Adults with an ASD

6.1.1 Sample characteristics.

The 245 children and dependent adults with an ASD (80.8% males) who were subject to report in this study ranged in age from three to 69 years, with a mean age of 12.92 years ($SD = 9.56$, Median = 10, Mode = 10). A Chi-Square Test for Independence determined that age and gender of this sample were not significantly related ($\chi^2 (N = 245, df = 4) = 4.27, p = .37, phi = .13$). As shown in Table 6.1.1, the majority were males aged between three and 11 years, with no females over 30 years; only 13.9% of the sample were aged 19 years or over. Three age groups were consequently determined for comparison: children (those aged 3 to 11 years), teenagers (those aged 12 to 18 years) and adults (19 + years).

Table 6.1.1

*Frequency and Percentage of Age Distribution by Gender (N = 245)*

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 to 11</td>
<td>112</td>
<td>56.6</td>
<td>28</td>
<td>59.6</td>
<td>140</td>
<td>57.1</td>
</tr>
<tr>
<td>12 to 18</td>
<td>55</td>
<td>27.8</td>
<td>16</td>
<td>34.0</td>
<td>71</td>
<td>29.0</td>
</tr>
<tr>
<td>19 to 29</td>
<td>16</td>
<td>8.1</td>
<td>3</td>
<td>6.4</td>
<td>19</td>
<td>7.8</td>
</tr>
<tr>
<td>30 to 55</td>
<td>13</td>
<td>6.6</td>
<td>-</td>
<td>-</td>
<td>13</td>
<td>5.3</td>
</tr>
<tr>
<td>56 to 69</td>
<td>2</td>
<td>1.0</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Total</td>
<td>198</td>
<td>100.0</td>
<td>47</td>
<td>100.0</td>
<td>245</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Most informants were parents of children and dependent adults with ASD. A small proportion of other caregivers completed the survey, including foster carers, siblings and partners. As shown in Table 6.1.2, the majority of informants were mothers who resided with the child or dependent person with an ASD. A small proportion of informants did not live with the child/dependent person with an ASD (2.9%), or only did so occasionally (2.5%).

Table 6.1.2

*Informant Relationship to Dependent Person with ASD and Living Status (N=245)*

<table>
<thead>
<tr>
<th>Informant relationship to person with ASD</th>
<th>Resides with informant</th>
<th>Does not reside with informant</th>
<th>Occasionally resides with informant</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Mother</td>
<td>204</td>
<td>87.9</td>
<td>3</td>
<td>42.9</td>
</tr>
<tr>
<td>Father</td>
<td>14</td>
<td>6.0</td>
<td>2</td>
<td>28.6</td>
</tr>
<tr>
<td>Other</td>
<td>14</td>
<td>6.0</td>
<td>2</td>
<td>28.6</td>
</tr>
<tr>
<td>Total</td>
<td>232</td>
<td>100.0</td>
<td>7</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Informants for dependent adults were asked if they thought the individual with an ASD would also complete the survey, with most indicating ‘no’ (94.0%); a small percentage indicated ‘yes’ (1.7%) or unsure (4.3%).
Table 6.1.3

*Frequency and Percentage of ASD Type and Severity of Impairment (N = 245)*

<table>
<thead>
<tr>
<th>Severity of impairment</th>
<th>Autistic disorder</th>
<th>Asperger’s disorder</th>
<th>PDD–NOS</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Mild</td>
<td>17</td>
<td>26.1</td>
<td>37</td>
<td>30.8</td>
</tr>
<tr>
<td>Moderate</td>
<td>59</td>
<td>63.6</td>
<td>76</td>
<td>63.3</td>
</tr>
<tr>
<td>Severe</td>
<td>34</td>
<td>20.3</td>
<td>7</td>
<td>5.8</td>
</tr>
<tr>
<td>Total</td>
<td>110</td>
<td>100.0</td>
<td>120</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 6.1.3 shows the frequency and percentage of participants according to ASD type and ratings of severity of impairment. According to informants, the majority of dependent children and adults with an ASD had received a diagnosis of Asperger’s disorder and autistic disorder, with a small proportion being diagnosed with PDD–NOS. A Chi-Square Test of Independence determined a significant relationship between ASD subtype and severity ($\chi^2 (n = 244, df = 4) = 27.76, p < .001$). More people were found to be in the mild level of impairment range with Asperger’s disorder, and a greater number of participants who had autistic disorder were in the severe level of impairment category.

Frequency of intellectual disability in the sample according to ASD diagnosis is presented in Table 6.1.4. Most children and dependent adults were diagnosed with Asperger’s disorder without intellectual disability. Of those with a reported intellectual disability, the significant majority were diagnosed with a moderate intellectual disability and autistic disorder ($\chi^2 (n = 243, df = 2) = 64.62, p < .001, phi = .52$).
Table 6.1.4

Frequency of Intellectual Disability According to ASD Diagnosis (n = 243)

<table>
<thead>
<tr>
<th>Intellectual Disability</th>
<th>Asperger’s disorder Freq.</th>
<th>Asperger’s disorder %</th>
<th>Autistic disorder Freq.</th>
<th>Autistic disorder %</th>
<th>PDD–NOS Freq.</th>
<th>PDD–NOS %</th>
<th>Total.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>13</td>
<td>11.0</td>
<td>25</td>
<td>22.5</td>
<td>5</td>
<td>35.7</td>
<td>43</td>
</tr>
<tr>
<td>Moderate</td>
<td>3</td>
<td>2.6</td>
<td>28</td>
<td>25.2</td>
<td>3</td>
<td>21.4</td>
<td>34</td>
</tr>
<tr>
<td>Severe</td>
<td>-</td>
<td>-</td>
<td>18</td>
<td>16.2</td>
<td>1</td>
<td>7.1</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>13.6</td>
<td>71</td>
<td>63.0</td>
<td>9</td>
<td>64.3</td>
<td>96</td>
</tr>
<tr>
<td>No</td>
<td>102</td>
<td>86.4</td>
<td>40</td>
<td>36.0</td>
<td>5</td>
<td>35.7</td>
<td>147</td>
</tr>
<tr>
<td>Total</td>
<td>120</td>
<td>100.0</td>
<td>111</td>
<td>100.0</td>
<td>14</td>
<td>100.0</td>
<td>243</td>
</tr>
</tbody>
</table>

In summary, significant relationships were identified between type of ASD and severity of impairment; those with Autistic disorder were more likely to be reported as having a severe impairment, along with an intellectual disability.

6.2 Use of Psychotropic Medication

This section presents a comparison of children and dependent adults with an ASD who were currently prescribed psychotropic medication, with those who had previously taken medication and those who had never done so. Medication use is described according to demographic variables, as well as the reasons for use and caregiver views on its effectiveness, whether it was restrictive, and overall attitudes regarding use.

6.2.1 Psychotropic medication.

Of the 245 child/dependent adult participants, 149 (60.8%) were reported to be currently taking medication to assist with emotions or behaviours. A further 16 (6.6%) had used medication in the past to assist with emotions and
behaviours, but were not currently using medication, and 81 (33.0%) had never used medication for this purpose. This group of 81 will be referred to as non-users. Results for each group of participants are provided in Table 6.2.1.1.

Table 6.2.1.1

Demographic Details According to Medication Status (N = 245)

<table>
<thead>
<tr>
<th>Total</th>
<th>Male</th>
<th>Female</th>
<th>Age</th>
<th>No. of challenging behaviours</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 198</td>
<td>n = 47</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Non-user</td>
<td>81</td>
<td>61</td>
<td>20</td>
<td>11.79</td>
</tr>
<tr>
<td>Previous user</td>
<td>15</td>
<td>13</td>
<td>3</td>
<td>12.60</td>
</tr>
<tr>
<td>Current user</td>
<td>149</td>
<td>124</td>
<td>24</td>
<td>13.55</td>
</tr>
</tbody>
</table>

Chi-Square Tests of Independence were conducted to determine whether medication status (non-user, previous user, current user) related to gender, type of ASD diagnosis, level of impairment or communication ability. The results indicated no significant relationships between medication status and gender (p =.29), ASD diagnosis (p =.26), level of impairment (p =.26) or intellectual ability (p =.62).

Informants indicated that the child/dependent adult with an ASD used between 0 and 5 different psychotropic medications. A total of 241 medications, with an average of 1.65 medications (SD =.88, Median =1, Mode =1) per person, were reported for the 149 individuals currently prescribed psychotropic medication. Routine use of medication was reported for 143 individuals, and pro re nata (PRN; ‘as required’) medication was reported for six individuals. A further seven informants (and thus 13 overall) indicated that the person they cared
for used both routine and PRN medication. Of note, 17 informants (7%) reported
use of complementary and alternative medications (e.g., St Johns Wort, fish oil)
to assist the child/dependent adult with their emotions or behaviours. This
medication use was excluded from the analyses, as the focus of the study was on
prescribed psychotropic medication, however it is plausible the use of these
medications may have affected responses in terms of perceived effectiveness.
Medications that were reported for primary treatment of diagnosed medical
conditions were also excluded from the analysis (e.g., sodium valproate for
epilepsy, diabex for diabetes). Where informants reported medication was used
for a dual purpose (e.g., behavioural control and epilepsy), the medication use
was included in the analysis.

The reported psychotropic medications were coded according to their
primary MIMS classifications (MIMS online, 2012): anti-depressant, anti-
psychotic, anti-anxiety, anti-convulsant, hypnotic sedatives, central nervous
system stimulants (CNS stimulants), or other. The coding of each medication
according to type can be found in Appendix D. Table 6.2.1.2 presents the
frequencies of psychotropic medication reported. As can be seen, risperidone was
the most commonly reported medication, followed by methylphenidate and
fluoxetine.
Table 6.2.1.2

*Frequency of Medications Reported by Name and Type (n of medication = 241)*

<table>
<thead>
<tr>
<th>Type of Medication</th>
<th>Name of Medication</th>
<th>Number of Children/Dependent Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anti-depressant</td>
<td>Fluoxetine</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>Fluvoxamine</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Escitalopram</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Sertraline</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Talohexal</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Duloxetine</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Venlafaxine</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Amitriptyline</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Desvenlafaxine</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>60</strong></td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>Risperidone</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td>Olanzapine</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Queitiapine</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Haloperidol</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Lithium</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Pericyazine</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Ziprasidone</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>69</strong></td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>Methylphenidate</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Atomoxetine</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>43</strong></td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>Sodium Valproate</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Carbamazepine</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Lamotrigine</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Clonazapam</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>14</strong></td>
</tr>
<tr>
<td>Hypnotic Sedative</td>
<td>Melatonin</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Dexamphetamine</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Chloral Hydrate</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>22</strong></td>
</tr>
<tr>
<td>Anti-Anxiety</td>
<td>Diazepam</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>Other</td>
<td>Clonidine</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Depo Provera</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Benzhexol</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>21</strong></td>
</tr>
</tbody>
</table>
6.2.2 Psychotropic medication and gender.

In this section, the reported use of psychotropic medications taken by children and dependent adults to manage emotions and behaviours associated with an ASD are examined according to age and gender. Frequencies related to the concurrent use of medications are also presented, to determine the extent of polypharmacy (multiple medications) among the sample.

The frequencies and percentages of medication use according to gender are illustrated in Table 6.2.2.1. The majority of female and male children/dependent adults took one medication. A small number of male children/dependent adults (1.6%) were reported to be taking five medications to manage emotions and behaviours associated with the disorder. The mean number of medications used by male and female children and dependent adults was 1.61 and 1.83, respectively.

Table 6.2.2.1

*Number and Percentage of Medication in Current Users used Routinely by Gender (n = 125)*

<table>
<thead>
<tr>
<th>No. of Medications</th>
<th>Male</th>
<th></th>
<th>Female</th>
<th></th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>1</td>
<td>68</td>
<td>54.4</td>
<td>13</td>
<td>54.2</td>
<td>81</td>
<td>54.4</td>
</tr>
<tr>
<td>2</td>
<td>43</td>
<td>34.4</td>
<td>5</td>
<td>20.8</td>
<td>48</td>
<td>32.2</td>
</tr>
<tr>
<td>3</td>
<td>10</td>
<td>8.0</td>
<td>3</td>
<td>12.5</td>
<td>13</td>
<td>8.7</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>1.6</td>
<td>3</td>
<td>12.5</td>
<td>5</td>
<td>3.4</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>1.6</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Mean No. of Medication</td>
<td>1.61</td>
<td></td>
<td>1.83</td>
<td></td>
<td>1.65</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>125</td>
<td>100.0</td>
<td>24</td>
<td>100.0</td>
<td>149</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Further analyses revealed that 68 (45.6%) of children/dependent adults who were taking psychotropic medication were prescribed two or more medications, with seven (4.6%) being prescribed four or more medications to manage emotions or behaviours associated with an ASD. A Mann-Whitney U Test revealed no significant difference in the number of medications prescribed for males ($Md = 1, n = 125$) and females ($Md = 1, n = 24$), $U = 1396$, $z = -0.60$, $p = 0.55$, $r = 0.05$.

As shown in Table 6.2.2.2, of the children/dependent adults who were described as currently taking medication, the majority (42.3%) were reported to be taking one or more anti-depressant medications, with 40.9% taking anti-psychotic drugs. The most commonly reported medication types were the same for males and females (anti-depressant and anti-psychotic medication). A smaller proportion of males (11.2%) were taking anti-convulsant drugs; however, no females were reported as taking these.
Table 6.2.2.2

*Gender Comparison According to Type and Number of Medications (n = 149)*

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>No. of Medications</th>
<th>Male (n = 125)</th>
<th>Female (n = 24)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq</td>
<td>%</td>
<td>Freq</td>
<td>%</td>
</tr>
<tr>
<td>Anti-depressant</td>
<td>1</td>
<td>49</td>
<td>39.2</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>3</td>
<td>2.4</td>
<td>3</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>1</td>
<td>49</td>
<td>39.2</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>3</td>
<td>2.4</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>1</td>
<td>2</td>
<td>1.6</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
<td>1.6</td>
<td>-</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>1</td>
<td>12</td>
<td>9.6</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
<td>1.6</td>
<td>-</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>1</td>
<td>17</td>
<td>13.6</td>
<td>5</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>1</td>
<td>32</td>
<td>25.6</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
<td>1.6</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>16</td>
<td>12.8</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Total medications</td>
<td>197</td>
<td></td>
<td>44</td>
<td></td>
</tr>
</tbody>
</table>

6.2.3 Psychotropic medication and age.

Table 6.2.3.1 presents results of medication status (current user, previous user, non-users) across age groups (3–11 years, 12–18 years, 19–69 years). Most participants in each age group were reported as currently taking medication (55.7% of 3–11 yrs; 69.0% of 12–18 yrs; 64.7% of 19–69 yrs). There was no significant relationship between medication status and age group, $\chi^2 (N = 245, df = 4) = 6.13, p = .19.$
Table 6.2.3.1

*Medication Status According to Age Group (N = 243)*

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Current user</th>
<th>Previous user</th>
<th>Non-user</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>3 to 11</td>
<td>78</td>
<td>55.7</td>
<td>7</td>
<td>5.0</td>
</tr>
<tr>
<td>12 to 18</td>
<td>49</td>
<td>69.0</td>
<td>5</td>
<td>7.0</td>
</tr>
<tr>
<td>19 to 69</td>
<td>22</td>
<td>64.7</td>
<td>3</td>
<td>8.8</td>
</tr>
<tr>
<td>Total</td>
<td>149</td>
<td>15</td>
<td>81</td>
<td>81</td>
</tr>
</tbody>
</table>

Table 6.2.3.2 presents the frequencies and percentages of medication use according to age group. The majority of participants in the three to 11 year old and the 12 to 18 year old groups were reported to be taking one medication, whereas the majority of participants in the 19 to 69 years age group were reported to be taking two medications. Children aged three to 11 years used a mean number of 1.44 medications, with those aged 12 to 18 using 1.84 medications on average. Those above 19 years old were taking a mean number of 2.00 medications. A Kruskal-Wallis Test revealed a significant difference in the number of medications between the three age groups, with more medications being prescribed in the 19 to 60 year old group ($\chi^2 (N = 245, df = 2) = 11.04, p = .003$).
Table 6.2.3.2

*Frequency and Percentage of Medications used Routinely by Age Group (N = 245)*

<table>
<thead>
<tr>
<th>No. of Medications</th>
<th>3 to 11 years</th>
<th>12 to 18 years</th>
<th>19 to 69 years</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>1</td>
<td>51</td>
<td>65.4</td>
<td>23</td>
<td>46.9</td>
</tr>
<tr>
<td>2</td>
<td>22</td>
<td>45.8</td>
<td>17</td>
<td>34.7</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>5.1</td>
<td>4</td>
<td>8.2</td>
</tr>
<tr>
<td>4</td>
<td>-</td>
<td>-</td>
<td>4</td>
<td>8.2</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>1.3</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Mean No. of Medication</td>
<td>1.44</td>
<td>1.84</td>
<td>2.00</td>
<td></td>
</tr>
</tbody>
</table>

Table 6.2.3.4 indicates the frequency of children and dependent adults using at least one of the five medication types according to age group. The most frequently reported medication type in the three to 11 year old group was anti-psychotic medication. In contrast, anti-depressant medication was most commonly reported for 12 to 18 year olds and those aged over 19 years.

Table 6.2.3.4

*Type of Psychotropic Medication by Age Group (n = 149)*

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>3 to 11 years</th>
<th>12 to 18 years</th>
<th>19 to 69 years</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Anti-depressant</td>
<td>23</td>
<td>29.5</td>
<td>23</td>
<td>46.9</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>32</td>
<td>41.0</td>
<td>20</td>
<td>40.8</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>22</td>
<td>28.2</td>
<td>19</td>
<td>38.2</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>3</td>
<td>3.8</td>
<td>6</td>
<td>12.2</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>14</td>
<td>17.9</td>
<td>6</td>
<td>12.2</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>1</td>
<td>1.3</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>15.4</td>
<td>8</td>
<td>16.3</td>
</tr>
</tbody>
</table>
6.2.4 Reasons for psychotropic medication use.

The majority of the sample (75.4%) stated that medication was prescribed for a single purpose. The reasons for medication use were coded into the categories of mental health conditions, challenging behaviour, sleep difficulties and other. Table 6.2.4.1 presents the frequencies of reasons for each medication reported. The most commonly reported primary purpose was a mental health condition (103 participants, 42.7%) and challenging behaviour (85 participants, 35.3%). Sleep difficulties were reported as the primary reason by 19.5% (45 participants). The other category (6 participants, 2.5%) included stress, as well as prescription of medication to assist with the side effects of another medication.

The primary reason provided by informants for psychotropic medication use was further analysed by type of medication (see Table 6.2.4.1). The majority of informants reported that anti-depressant and CNS stimulants were used primarily for a mental health condition, whereas anti-psychotic and anti-convulsant drugs were predominantly reported for the management of challenging behaviours. Hypnotic sedatives were most commonly used for management of sleep disturbance.
Table 6.2.4.1

Frequency of Primary Reason for Medication Use According to Medication Type in Current Users (n = 149)

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>Freq. Mental Health</th>
<th>Challenging Behaviour</th>
<th>Sleep Disturbance</th>
<th>Other</th>
<th>No Reason Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anti-depressant</td>
<td>66</td>
<td>48</td>
<td>9</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>69</td>
<td>19</td>
<td>45</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>41</td>
<td>27</td>
<td>14</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>12</td>
<td>3</td>
<td>8</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>22</td>
<td>4</td>
<td>1</td>
<td>17</td>
<td>-</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>21</td>
<td>-</td>
<td>8</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>233</td>
<td>103</td>
<td>85</td>
<td>37</td>
<td>6</td>
</tr>
</tbody>
</table>

6.2.5 Restraint.

The majority of informants reported they did not believe their medication was a form of restraint (69.9%), with less than one third (27.1%) indicating that the medication was restrictive; a small proportion were not specific (3%).

Responses are presented below in Table 6.2.5.1, according to medication type.

Table 6.2.5.1

Frequency and Percentage of Informants Indicating Medication as Restraint by Medication Type (n of medication = 233)

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>N</th>
<th>Yes</th>
<th>No</th>
<th>Unspecified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anti-depressant</td>
<td>66</td>
<td>15</td>
<td>49</td>
<td>2</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>69</td>
<td>26</td>
<td>40</td>
<td>3</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>41</td>
<td>7</td>
<td>34</td>
<td>-</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>12</td>
<td>6</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>22</td>
<td>1</td>
<td>21</td>
<td>-</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>2</td>
<td>2</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>21</td>
<td>6</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>233</td>
<td>63</td>
<td>165</td>
<td>7</td>
</tr>
</tbody>
</table>
A Chi-Square Test of Independence revealed a significant relationship between the reason for medication use and views on restraint ($p<.001$), with more informants reporting they did not believe the medication was restrictive, in those who reported medication use for sleep disturbance (see Table 6.2.5.2).

Table 6.2.5.2

| Reason for Medication Use According to Belief about Restraint (n = 236) |
|-----------------|----------------|----------------|-----------------|-----------------|-----------------|-----------------|
|                  | n   | Mental Health | Challenging Behaviour | Sleep Disturbance | Other | No Reason Provided |
| Restrictive      | 64  | 29            | 27                | -                | 1     | -                |
| Not Restrictive  | 165 | 73            | 54                | 35               | 1     | 2                |
| Unspecified      | 7   | 1             | 3                 | 2                | 1     | -                |
| Total            | 236 | 103           | 85                | 45               | 6     | 3                |

6.2.6 Perceived helpfulness of psychotropic medication.

Informants were asked to report whether they felt the medication assisted them to manage the behaviours or emotions of the person with an ASD. Informants were also asked whether they believed the medication helped the child or dependent adult to manage their own emotions and behaviours. The vast majority (89.9%) of informants indicated that the medication assisted them to manage the behaviours or emotions in the person with an ASD. Similarly, a large number of informants (88.8%) also reported they felt that medication assisted the person they cared for, while a smaller percentage remained undecided (8.8%), and a small number (2.4%) stated they did not believe the medication helped the person they cared for. Perceived helpfulness was examined according to reason for medication use, as well as according to type of medication (see Table 6.2.6.).
Table 6.2.6

*Frequency of Primary Reason for Medication Use According to Medication Type (n = 149)*

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>n</th>
<th>Mental Health</th>
<th>Challenging Behaviour</th>
<th>Sleep Disturbance</th>
<th>Other</th>
<th>No Reason Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anti-depressant</td>
<td>66</td>
<td>48</td>
<td>9</td>
<td>10</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>69</td>
<td>19</td>
<td>45</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>41</td>
<td>27</td>
<td>14</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>12</td>
<td>3</td>
<td>8</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>22</td>
<td>4</td>
<td>1</td>
<td>19</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>21</td>
<td>-</td>
<td>8</td>
<td>15</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>103</td>
<td>85</td>
<td>45</td>
<td>6</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Informants were further requested to report on a 10-point Likert scale how satisfied they were with the child/dependent adult taking the medication, from 0 (totally dislike) to 10 (totally like) \( (M = 7.69, SD = 2.88) \). Kruskall-Wallis Tests established no significant relationship in satisfaction according to the reported reason for medication use, \( (p = .058) \), and no significant relationship in satisfaction according to type of medication, \( (p = .68) \).

**6.2.7 Caregiver attitudes towards psychotropic medication.**

Table 6.2.7.1 presents overall frequencies of responses (by informants who reported that the child/dependent adult was currently taking psychotropic medication) to each item of the modified DAI scale. The most strongly endorsed items (94.6%) were, ‘For the person I care for, the good things about medication outweigh the bad’ as well as the item, ‘Medications make the person I care for more relaxed’ (93.2%). The least endorsed item (10.7%) overall was, ‘The person I care for only needs to take medication when they feel ill’. The majority of
participants endorsed the items, ‘By staying on medication I can prevent the person I care for having difficult behaviour’ (72.3%). Almost half of the sample endorsed the item ‘Taking medications will do no harm to the person I care for.’

Table 6.2.7.1

Frequency of Informant Responses on the Modified DAI (n = 149)

<table>
<thead>
<tr>
<th>Item</th>
<th>True Freq.</th>
<th>True %</th>
<th>False Freq.</th>
<th>False %</th>
</tr>
</thead>
<tbody>
<tr>
<td>For the person I care for, the good things about medication outweigh the bad</td>
<td>140</td>
<td>94.6</td>
<td>7</td>
<td>4.7</td>
</tr>
<tr>
<td>Medications make the person I care for more relaxed</td>
<td>137</td>
<td>93.2</td>
<td>9</td>
<td>6.8</td>
</tr>
<tr>
<td>The person I care for is more relaxed on medication</td>
<td>135</td>
<td>91.2</td>
<td>11</td>
<td>7.4</td>
</tr>
<tr>
<td>The person I care for is happier on medication</td>
<td>131</td>
<td>88.5</td>
<td>15</td>
<td>10.1</td>
</tr>
<tr>
<td>The person I care for gets along better with people when on medication</td>
<td>125</td>
<td>85.1</td>
<td>21</td>
<td>14.2</td>
</tr>
<tr>
<td>The person I care for is on medication to control their behaviour</td>
<td>111</td>
<td>75.0</td>
<td>34</td>
<td>23.0</td>
</tr>
<tr>
<td>By staying on medication I can prevent the person I care for having difficult behaviour</td>
<td>107</td>
<td>72.3</td>
<td>37</td>
<td>25.0</td>
</tr>
<tr>
<td>The person I care for should keep taking medication even when they are well</td>
<td>105</td>
<td>70.9</td>
<td>39</td>
<td>26.4</td>
</tr>
<tr>
<td>It is up to the doctor to decide when the person I care for should stop taking their medication</td>
<td>86</td>
<td>58.1</td>
<td>60</td>
<td>40.5</td>
</tr>
<tr>
<td>Taking medications will do no harm to the person I care for</td>
<td>71</td>
<td>48.0</td>
<td>64</td>
<td>43.2</td>
</tr>
<tr>
<td>The person I care for experiences unpleasant effects of medication</td>
<td>34</td>
<td>23.0</td>
<td>112</td>
<td>75.7</td>
</tr>
<tr>
<td>Medications make the person I care for tired and sluggish</td>
<td>26</td>
<td>17.6</td>
<td>120</td>
<td>81.8</td>
</tr>
<tr>
<td>The person I care for is only on medication because of pressure from other people</td>
<td>19</td>
<td>12.8</td>
<td>128</td>
<td>86.5</td>
</tr>
<tr>
<td>Medications are slow acting poisons</td>
<td>13</td>
<td>8.8</td>
<td>129</td>
<td>87.2</td>
</tr>
<tr>
<td>The person I care for is no different on or off medication</td>
<td>8</td>
<td>5.4</td>
<td>138</td>
<td>93.2</td>
</tr>
<tr>
<td>The person I care for only needs to take medication when they feel ill</td>
<td>5</td>
<td>3.4</td>
<td>139</td>
<td>93.9</td>
</tr>
</tbody>
</table>

In summary, psychotropic medication was reported being administered to 60.8% of children and dependent adults with an ASD. A key finding included that
the age group significantly related to the number of prescribed medications, with those aged over 19 years more likely to receive multiple medications. Informants predominantly viewed medication as helping the child or dependent adult, and did not view the medication as a form of restraint.

6.3 Challenging Behaviour and Psychotropic Medication

Following an overview of the nature and extent of any challenging behaviours, and with respect to demographic variables, this section of the study examines any relationships between challenging behaviours and psychotropic medication status (current use, previous use and non-users). Finally, differences among those who currently take psychotropic medication and have challenging behaviour are examined.

All informants were required to report whether the child/dependent adult with an ASD had behaviours that they or the individual with ASD found challenging (yes, no, sometimes). The majority of informants (57.6%) reported the person with an ASD regularly had difficulty with their behaviour, with almost a third reported sometimes having difficulty (30.2%); only a small proportion reported no difficulties (12.2%). The number of reported challenging behaviours ranged from 0 to 10 ($M = 2.91, SD = 2.01$), and the majority of the sample (87.5%) reported that the child/dependent adult with an ASD had difficulty with at least one challenging behaviour. Table 6.3.1.1 presents the numbers of behaviours reported. A Mann-Whitney U Test revealed no significant difference in the number of challenging behaviours reported by males ($Md = 3, n = 198$) and females ($Md = 3, n = 47$), $U = 4594, z = -.14, p = .89, r = .009$. 

96
Table 6.3.1.1

**Numbers of Challenging Behaviour Reported by Informants (N = 245)**

<table>
<thead>
<tr>
<th>No. of Behaviours</th>
<th>Males ( n = 198 )</th>
<th>Females ( n = 47 )</th>
<th>Total Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
</tr>
<tr>
<td>0</td>
<td>27</td>
<td>13.6</td>
<td>3</td>
</tr>
<tr>
<td>1</td>
<td>25</td>
<td>12.6</td>
<td>9</td>
</tr>
<tr>
<td>2</td>
<td>34</td>
<td>17.2</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>38</td>
<td>19.2</td>
<td>15</td>
</tr>
<tr>
<td>4</td>
<td>39</td>
<td>19.7</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>13</td>
<td>6.6</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>13</td>
<td>6.6</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>7</td>
<td>3.5</td>
<td>1</td>
</tr>
<tr>
<td>8</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>1.0</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Mean No. Of Behaviours</td>
<td>2.91</td>
<td>2.95</td>
</tr>
<tr>
<td>Total</td>
<td>198</td>
<td>100.0</td>
<td>47</td>
</tr>
</tbody>
</table>

Table 6.3.1.2 presents informants’ reports of the presence of challenging behaviour (regular, sometimes, no), according to age group. Similar rates of behaviours across age groups were reported by informants. Chi-Square Tests of Independence demonstrated no significant relationships between the presence of challenging behaviour and gender \( (p = .39) \), cognitive ability \( (p = .31) \), age group \( (p = .92) \), ASD diagnosis \( (p = .63) \), or level of impairment \( (p = .20) \).
Table 6.3.1.2

**Difficulty Managing Behaviour by Age Group**

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Yes</th>
<th>%</th>
<th>Sometimes</th>
<th></th>
<th>%</th>
<th>No</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 to 11</td>
<td>85</td>
<td>60.7</td>
<td>40</td>
<td>28.6</td>
<td>15</td>
<td>10.7</td>
<td>140</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>12 to 18</td>
<td>38</td>
<td>53.5</td>
<td>25</td>
<td>35.2</td>
<td>8</td>
<td>11.3</td>
<td>71</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>19 to 29</td>
<td>10</td>
<td>52.6</td>
<td>4</td>
<td>21.1</td>
<td>5</td>
<td>26.3</td>
<td>19</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>30 to 55</td>
<td>7</td>
<td>53.8</td>
<td>4</td>
<td>30.8</td>
<td>2</td>
<td>15.4</td>
<td>11</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>56 to 69</td>
<td>1</td>
<td>50.0</td>
<td>1</td>
<td>50.0</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

*Note: Freq. = Frequency*

Informant responses to ‘Describe the behaviour you have difficulty managing’ were coded into five categories of behaviours: aggressive, stereotyped/self-injurious, emotion-related, impulse control or other disruptive behaviours.

Aggressive behaviours included verbal and physical aggression towards other people, as well as property destruction. Stereotyped/self-injurious behaviours included repetitive routines, obsessions and self-harming behaviours (e.g., biting self, hitting head). Emotion-related behaviours of concern included reports of anxiety, depression and psychosis. Other disruptive behaviours included absconding and smearing faeces. Difficulty with impulse control was coded as its own category, due to a large number of informants reporting this behaviour. The majority of informants reported that the dependent child/adult had difficulty with at least one aggressive behaviour (59.0%), with a large number also reporting difficulty with at least one other disruptive behaviour (56.6%), and emotion-related behaviour (51.4%).
Chi-Square Tests (with Yates Continuity Correction reported as required (to prevent overestimation of statistical significance for small samples)) were conducted to determine if the type of challenging behaviour related to demographic variables (age gender, ASD diagnosis, intellectual disability, level of impairment). Bonferroni adjustments (Tabachnik & Fidell, 2007) were made to safeguard against type-one error, reducing the significance level to \( p < .001 \). As illustrated in Table 6.3.1.3, a significant relationship was found between reporting stereotyped/self-injurious behaviour and level of impairment, with more children and dependent adults who reported stereotyped/self-injurious behaviour also reporting a severe level of impairment. While not significant, there was a trend for a relationship between emotion-related behaviours and ASD diagnosis, with more children/dependent adults with Asperger’s disorder reporting emotion-related behaviours. Similarly, there was a trend for relationships between stereotyped/self-injurious behaviour and gender, with boys more likely to exhibit stereotyped behaviours; ASD diagnosis, those with autistic disorder were more likely to report stereotyped/self-injurious behaviours; and those with an intellectual disability were more likely to have stereotyped/self-injurious behaviours.
### Table 6.3.1.4

**Relationship between Type of Challenging Behaviour and Demographics (N = 245)**

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>df</th>
<th>χ²</th>
<th>p</th>
<th>phi</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aggression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>1.28</td>
<td>.20</td>
<td>-.08</td>
</tr>
<tr>
<td>Age group</td>
<td>2</td>
<td>0.84</td>
<td>.66</td>
<td>.06</td>
</tr>
<tr>
<td>ASD diagnosis</td>
<td>2</td>
<td>0.63</td>
<td>.73</td>
<td>.05</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>0.47</td>
<td>.49</td>
<td>.04</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>3.24</td>
<td>.20</td>
<td>.12</td>
</tr>
<tr>
<td><strong>Emotion-Related</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>2.25</td>
<td>.13</td>
<td>.11</td>
</tr>
<tr>
<td>Age group</td>
<td>2</td>
<td>2.35</td>
<td>.31</td>
<td>.10</td>
</tr>
<tr>
<td>ASD diagnosis</td>
<td>2</td>
<td>6.35</td>
<td>.04</td>
<td>.16</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>2.32</td>
<td>.13</td>
<td>.11</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>2.96</td>
<td>.23</td>
<td>.11</td>
</tr>
<tr>
<td><strong>Stereotyped/Self-injurious</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>5.27</td>
<td>.02</td>
<td>.16</td>
</tr>
<tr>
<td>Age group</td>
<td>2</td>
<td>2.42</td>
<td>.30</td>
<td>.10</td>
</tr>
<tr>
<td>ASD diagnosis</td>
<td>2</td>
<td>7.71</td>
<td>.02</td>
<td>.18</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>4.19</td>
<td>.04</td>
<td>.14</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>17.43</td>
<td>.00***</td>
<td>.27</td>
</tr>
<tr>
<td><strong>Impulse Control Difficulty</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>0.10</td>
<td>.76</td>
<td>-.03</td>
</tr>
<tr>
<td>Age group</td>
<td>2</td>
<td>5.11</td>
<td>.07</td>
<td>.14</td>
</tr>
<tr>
<td>ASD diagnosis</td>
<td>2</td>
<td>1.28</td>
<td>.53</td>
<td>.07</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>0.00</td>
<td>.83</td>
<td>.01</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>1.19</td>
<td>.55</td>
<td>.07</td>
</tr>
<tr>
<td><strong>Other Disruptive</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>1.70</td>
<td>.19</td>
<td>-.08</td>
</tr>
<tr>
<td>Age group</td>
<td>2</td>
<td>5.52</td>
<td>.06</td>
<td>.15</td>
</tr>
<tr>
<td>ASD diagnosis</td>
<td>2</td>
<td>5.57</td>
<td>.06</td>
<td>.15</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>1.17</td>
<td>.23</td>
<td>-.08</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>2.19</td>
<td>.33</td>
<td>.10</td>
</tr>
</tbody>
</table>

*Note: *** significant at p < .001*

The relationship between medication status (current user, previous user, non-users) and difficulty managing behaviour was examined. A Chi-Square Test indicated a significant relationship between medication status and presence of challenging behaviour, $\chi^2 (n = 245, df = 2) = 27.60, p < .001$, Cramer’s $V = .24$. Findings indicated that those who reported the child/dependent adult had
challenging behaviour, or sometimes had challenging behaviour, were more likely to report current medication use than those who did not.

A Kruskal-Wallis Test was conducted to determine if there were significant differences between the numbers of challenging behaviour across the three medication status groups (current user, previous user, non-user). A significant difference between the number of challenging behaviours was observed across the three groups, $\chi^2 (n = 245, df = 2) = 8.40, p = .015$. This indicated a greater number of reported challenging behaviours among those who used medication, compared to those who did not.

A Mann-Whitney U Test was conducted to determine if the presence of challenging behaviours related to the number of reported medications. A significant difference in the mean number of medications was found between those who reported challenging behaviours (Md = 1, $n = 215$) and those who did not. (Md = 0, $n = 30$), $U = 2326, z = -2.617, p < .009, r = .17$. That is, those with reported challenging behaviours were more likely to take one or more medications.

Informants were requested to report specifically whether the child/dependent adult experienced aggression and/or impulse difficulties. Chi-Square Tests of Independence were conducted to examine if aggression or impulse control related to medication status. A Bonferonni correction (Tabachnik & Fidell, 2007) was used; thus the alpha level was adjusted to $p = .025$. Aggression was not found to relate significantly to medication status, $\chi^2 (n = 245, df = 2) = 5.23, p = .073, \phi = .15$. Impulse control difficulties were found to relate
significantly to medication status $\chi^2 (n = 245, df = 2) = 7.55, p = .023, \phi = .18$. That is, according to informants, children and dependent adults who were currently using medication were more likely to experience impulse control difficulties than expected by chance.

The frequency and percentage of children and dependent adults using each type of medication was examined according to the type of challenging behaviour (see Table 6.3.1.5.). Individuals who reported multiple challenging behaviours were allocated to more than one category of behaviour. Those children and dependent adults who reported using at least one anti-depressant medication were most commonly reported as experiencing emotion-related behavioural difficulties (59.1%). Alternatively, those taking at least one anti-psychotic medication were reported to experience at least one type of aggressive behaviour (53.6%). Individuals who were taking CNS stimulants were most likely to have other disruptive behaviours reported (58.5%), while those on hypnotic sedatives and anti-convulsants were most commonly reported to experience aggressive behaviour.
Table 6.3.1.5

*Frequency of Type of Challenging Behaviour According to Medication Type (n of medication =236)*

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>n</th>
<th>Aggression</th>
<th>Emotion-Related</th>
<th>Stereotyped Self-injury</th>
<th>Other Disruptive</th>
<th>Impulse Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anti-depressant</td>
<td>66</td>
<td>33</td>
<td>39</td>
<td>27</td>
<td>32</td>
<td>17</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>69</td>
<td>37</td>
<td>29</td>
<td>31</td>
<td>29</td>
<td>17</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>41</td>
<td>23</td>
<td>17</td>
<td>13</td>
<td>24</td>
<td>22</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>12</td>
<td>9</td>
<td>6</td>
<td>6</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>22</td>
<td>13</td>
<td>9</td>
<td>6</td>
<td>22</td>
<td>10</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>22</td>
<td>1</td>
</tr>
</tbody>
</table>

In summary, the majority of children and dependent adults were reported to exhibit at least one challenging behaviour. The presence of challenging behaviours was found to relate to the use of psychotropic medication; those with challenging behaviours were more likely to report current use and number of types of medication. Those who were taking anti-psychotic drugs had more reports of aggressive-type behaviours, whereas those on anti-depressants had more reports of emotion-related behaviours.

### 6.4 Mental Health and Psychotropic Medication

The relationship between comorbid mental health conditions and psychotropic medication is examined in this section of the study. First, data on comorbid mental health conditions across the sample is presented and explored, with respect to demographic variables. The relationship between medication status (current user, previous user, and non-users) and comorbid mental health
conditions is then presented, followed by any differences between those currently taking psychotropic medications with comorbid mental health, with those who did not have a diagnosis.

Informants were requested to report whether the person with an ASD currently experienced any mental health difficulties, and if so, had they received a formal diagnosis for this condition. Approximately two thirds (66.5%) indicated that the child/dependent adult with an ASD had at least one diagnosed mental health condition. The type of mental health conditions are presented in Table 6.4.1.1. Children and dependent adults with an ASD were most commonly reported to have a diagnosed anxiety disorder. A large proportion of informants also reported that the child/dependent adult experienced attention deficit disorder (ADD) or ADHD and depression, with a smaller number reporting obsessive compulsive disorder (OCD), oppositional defiance disorder (ODD) or bipolar disorder.

Table 6.4.1.1

*Mental Health Conditions Present in Sample as Reported by Informants (N = 245)*

<table>
<thead>
<tr>
<th>Mental Health Condition</th>
<th>Presence of Condition</th>
<th>Formally Diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>185</td>
<td>64.5</td>
</tr>
<tr>
<td>ADHD</td>
<td>69</td>
<td>28.2</td>
</tr>
<tr>
<td>Depression</td>
<td>53</td>
<td>21.6</td>
</tr>
<tr>
<td>OCD</td>
<td>7</td>
<td>2.9</td>
</tr>
<tr>
<td>ODD</td>
<td>7</td>
<td>2.9</td>
</tr>
<tr>
<td>Bipolar</td>
<td>3</td>
<td>1.2</td>
</tr>
</tbody>
</table>

*Note:* ADHD = Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder, OCD = Obsessive Compulsive Disorder, ODD = Oppositional Defiance Disorder
Of note, a quarter of the sample (24.5%) reported two formal mental health diagnoses, and a small number (7.5%) stated the child/dependent adult had received three or more such diagnoses. Specifically, 15.5% of informants indicated the child/dependent adult had a formal diagnosis of depression and anxiety, 13.8% of all participants indicated a diagnosis of anxiety and ADHD, with a further 4.5% indicating a diagnosis of depression and ADHD.

Chi-Square Tests of Independence were conducted to determine if the presence of a diagnosed mental health condition related to age group, gender, ASD diagnosis or level of impairment. Findings indicated that the presence of a mental health condition (formally diagnosed) did not significantly relate to age group ($p = .30$), gender ($p = .35$), or level of impairment ($p = .26$). A significant relationship was found between the presence of a mental health condition and ASD diagnosis, $\chi^2 (N = 245, df = 2) = 10.85, p = .004, \phi = .21$. That is, higher numbers of children and dependent adults were found to report a comorbid mental health condition than expected by chance.

Table 6.4.1.2 presents the Chi-Square results (Yates Continuity Correction reported as required) for the type of mental health condition and demographic characteristics. Bonferroni adjustments (Tabachnik & Fidell, 2007) were conducted to safeguard against type-one error, reducing the significance level to $p < .01$. As can be seen in Table 6.4.1.2, significant relationships were found between anxiety and age group, with younger age being associated with diagnosis; depression and age group, with those aged 19 years and over more
likely to be diagnosed with depression; and between depression and type of ASD, with more children and dependent adults with a diagnosis of Asperger’s disorder being diagnosed with depression.

Table 6.4.1.2

*Relationship between Diagnosed Mental Health Conditions and Demographics (N = 245)*

<table>
<thead>
<tr>
<th></th>
<th>Df</th>
<th>$\chi^2$</th>
<th>p</th>
<th>phi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety (n =127)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>2.20</td>
<td>.14</td>
<td>.11</td>
</tr>
<tr>
<td>Age group</td>
<td>4</td>
<td>11.16</td>
<td>.00**</td>
<td>.21</td>
</tr>
<tr>
<td>Type of ASD</td>
<td>2</td>
<td>7.02</td>
<td>.03</td>
<td>.17</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>0.65</td>
<td>.42</td>
<td>-.06</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>6.32</td>
<td>.04</td>
<td>.16</td>
</tr>
<tr>
<td>Depression (n = 39)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>1.05</td>
<td>.30</td>
<td>-.08</td>
</tr>
<tr>
<td>Age group</td>
<td>4</td>
<td>41.36</td>
<td>.00***</td>
<td>.41</td>
</tr>
<tr>
<td>Type of ASD</td>
<td>2</td>
<td>12.41</td>
<td>.00**</td>
<td>.23</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>3.99</td>
<td>.05</td>
<td>-.14</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>6.14</td>
<td>.05</td>
<td>.16</td>
</tr>
<tr>
<td>ADHD (n = 60)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>1.75</td>
<td>.19</td>
<td>-.09</td>
</tr>
<tr>
<td>Age group</td>
<td>4</td>
<td>2.33</td>
<td>.32</td>
<td>.10</td>
</tr>
<tr>
<td>Type of ASD</td>
<td>2</td>
<td>2.80</td>
<td>.25</td>
<td>.11</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>0.01</td>
<td>.99</td>
<td>.01</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>1</td>
<td>0.94</td>
<td>.63</td>
<td>.06</td>
</tr>
</tbody>
</table>

*Note:* *** significant at $p < .001$, ** significant at $p < .01$

The relationship between medication status (current user, previous user, non-user) and comorbid mental health diagnosis was examined. A Chi-Square Test of Independence indicated a significant association between medication status and the presence of a diagnosed mental health condition, $\chi^2 (n = 245, df = 2) = 37.32, p < .001, phi = .39$. This indicated that children/dependent adults who were reported as having a formally diagnosed comorbid mental health condition were more likely to be currently taking medication.
Further Chi-Square analyses (Yates Continuity Correction) were conducted to determine if there was a significant relationship between medication status with the three most commonly reported mental health diagnoses (anxiety, ADHD, depression). Bonferonni adjustments (Tabachnik & Fidell, 2007) were conducted, reducing the significance levels to \( p < .017 \). As shown in Table 6.4.1.3, medication status related significantly to a diagnosis of anxiety and ADHD, but not to a diagnosis of depression. This indicates that people with a reported formal diagnosis of anxiety and/or ADHD were more likely to be taking medication than those without these diagnoses.

Table 6.4.1.3
The Relationship between Medication Status and Comorbid Depression, Anxiety and ADHD

<table>
<thead>
<tr>
<th></th>
<th>( Df )</th>
<th>( \chi^2 )</th>
<th>( p )</th>
<th>( \phi )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>2</td>
<td>10.06</td>
<td>.01**</td>
<td>.20</td>
</tr>
<tr>
<td>Depression</td>
<td>2</td>
<td>4.59</td>
<td>.10</td>
<td>.14</td>
</tr>
<tr>
<td>ADHD</td>
<td>2</td>
<td>28.29</td>
<td>.00***</td>
<td>.34</td>
</tr>
</tbody>
</table>

\textit{Note:} *** significant at \( p < .001 \), ** significant at \( p < .01 \)

A Mann-Whitney U Test was conducted to determine if there was a significant difference in the mean number of medications prescribed to those who had a mental health diagnosis and those who did not. A significant difference was found in the number of medications prescribed for those who had mental health diagnoses (\( Md = 0, n = 82 \)) and those who did not (\( Md = 1, n = 163 \)), \( U = 5389, z = -6.25, p < .001, r = .40 \). That is, those with a comorbid mental health diagnosis were prescribed more medication than those without such a diagnosis.
Additional Mann-Whitney U tests were conducted to determine if there was a significant difference in the number of medications prescribed for children and dependent adults for whom there was a reported formal diagnosis of depression, anxiety or ADHD, compared to those without these diagnoses. Bonferroni adjustments (Tabachnik & Fidell, 2007) were made, reducing the significance level to \( p < .017 \). A significant difference was found in the number of medications prescribed for those who reported a diagnosis of anxiety (\( Md = 1, n = 130 \)) and those who did not (\( Md = 0, n = 115 \)), \( U = 5238, z = -4.27, p < .001, r = .27 \), as well as in those who reported a diagnosis of ADHD. A significant difference was not observed in the number of medications prescribed for those who reported a diagnosis of depression (\( Md = 1, n = 41 \)) and those who did not (\( Md = 1, n = 204 \)) \( U = 3262, z = -2.34, p = .019, r = .15 \). Significant differences were also observed in the number of medications prescribed for those with a reported diagnosis of ADHD (\( Md = 1.5, n = 60 \)) and those without (\( Md = 1, n = 185 \)), \( U = 3205, z = -5.19, p < .001, r = .33 \). These results indicated that children and dependent adults who had a diagnosis of anxiety or ADHD were more likely to report taking medication.

In summary, a large proportion of children and dependent adults with ASD were reported to have at least one comorbid mental health condition. Current use of psychotropic medication was found to relate to the presence of a comorbid mental health condition. Most particularly, those who reported a diagnosis of anxiety were more likely to be taking a greater number of psychotropic medications than those without anxiety.
6.5 Sleep and Psychotropic Medication

This final section of Study 1 focuses on the relationship between psychotropic medication use and sleep. Data for sleep difficulties across the sample is presented, as well as any relationships between sleep difficulties and demographic variables. This is followed by an examination of any relationships between medication status (current user, previous user, non-users) and sleep difficulties. Finally, differences in sleep are explored in those who were currently taking psychotropic medication.

6.5.1 Sleep and psychotropic medication.

The majority of informants (69.8%) reported that the child/dependent adult experienced some difficulty with sleep, with 31.2% indicating the person had been formally diagnosed with a sleep disorder. Chi-Square Tests (Yates Continuity Correction) were conducted to determine if sleep difficulties related to gender, age group, type of ASD or intellectual disability. Bonferroni adjustments (Tabachnik & Fidell, 2007) were conducted, reducing the significance level to $p < .013$. As displayed in Table 6.5.1.1, no significant relationships were observed between sleep difficulties and demographic variables.

Table 6.5.1.1

<table>
<thead>
<tr>
<th>Characteristics (N = 245)</th>
<th>$Df$</th>
<th>$\chi^2$</th>
<th>$p$</th>
<th>$\phi$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>2</td>
<td>0.36</td>
<td>.48</td>
<td>-.05</td>
</tr>
<tr>
<td>Age group</td>
<td>4</td>
<td>1.29</td>
<td>.86</td>
<td>.07</td>
</tr>
<tr>
<td>Type of ASD</td>
<td>2</td>
<td>3.35</td>
<td>.19</td>
<td>-.12</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>1</td>
<td>1.48</td>
<td>.22</td>
<td>.09</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>8.52</td>
<td>.01</td>
<td>.19</td>
</tr>
</tbody>
</table>
Informants who reported the child/dependent adult with an ASD experienced sleep difficulties were requested to rate whether these difficulties occurred in the domains of falling asleep, staying asleep, or early wakening over the previous two weeks. Of the total children/dependent adults in the study, 19.2% of the sample indicated sleep difficulty in at least one domain, with 20.0% indicating sleep difficulties in two domains, and 31.2% of the sample indicating difficulty in all three domains. The majority of informants who reported their child/dependent adult had sleep difficulties reported that the child/dependent adult experienced difficulty falling asleep (83.0%), with the majority (85.3%) indicating they had experienced moderate levels of difficulties across the three domains. Table 6.5.1.2 illustrates the range of reported sleep difficulties according to severity.

Table 6.5.1.2

Sleep Difficulties in Dependent Children/Adults According to Severity as Reported by Informants (n of those reporting sleep difficulties = 177)

<table>
<thead>
<tr>
<th>Sleep Difficulty</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very Severe</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
</tr>
<tr>
<td>Falling asleep</td>
<td>42</td>
<td>23.7</td>
<td>59</td>
<td>33.3</td>
<td>34</td>
</tr>
<tr>
<td>Staying asleep</td>
<td>49</td>
<td>27.6</td>
<td>44</td>
<td>24.9</td>
<td>19</td>
</tr>
<tr>
<td>Waking too early</td>
<td>33</td>
<td>18.6</td>
<td>48</td>
<td>27.0</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>72</td>
<td>151</td>
<td>92</td>
<td>29</td>
</tr>
</tbody>
</table>
6.5.2 Mental health and sleep.

A Chi-Square Test (Yates Continuity Correction) revealed that diagnosis of a mental health condition was significantly related to overall reported sleep difficulties, $\chi^2 (N = 245, df = 1) = 6.63, p = .01$. Further Chi-Square Tests (Yates Correction Continuity) were conducted to determine if there was a significant association between sleep difficulties and diagnosis of anxiety, depression or ADHD (see Table 6.5.2.1). Bonferroni adjustments (Tabachnik & Fidell, 2007) reduced the significance level to $p < .017$. A significant relationship was found between reported sleep problems in children and dependent adults, and diagnosis of an anxiety disorder. The findings indicated that children and dependent adults with an ASD who were reported to have sleep difficulties were also more likely to have a reported diagnosis of anxiety, than those who did not have sleep difficulties.

Table 6.5.2.1

<table>
<thead>
<tr>
<th>Condition</th>
<th>df</th>
<th>$\chi^2$</th>
<th>$p$</th>
<th>phi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>1</td>
<td>12.67</td>
<td>&lt;.001***</td>
<td>-.24</td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>4.80</td>
<td>.028</td>
<td>-.15</td>
</tr>
<tr>
<td>ADHD</td>
<td>1</td>
<td>0.00</td>
<td>1.00</td>
<td>-.00</td>
</tr>
</tbody>
</table>

Note: *** significant at $p < .001$
6.5.3 Psychotropic medication for sleep.

Sixty-nine informants reported that their child/dependent adult took medication to assist specifically with sleep difficulties. Fifty-nine male participants (47.2%) and 10 female participants (41.6%) were reported to take medication to assist with sleep. The medications reported as being taken by children and dependent adults can be seen in Table 6.5.3.1. The majority (47.8%) were prescribed melatonin to assist with sleep difficulties, followed closely by clonidine. A small number reported taking amitriptyline, and quetiapine for sleep purposes. Other medications reported to assist with sleep included paracetamol, valerian, fluvoxamine, clobazam, ziprasadone, and diazepam.

Table 6.5.3.1

<table>
<thead>
<tr>
<th>Medications</th>
<th>Male Freq.</th>
<th>Male %</th>
<th>Female Freq.</th>
<th>Female %</th>
<th>Total Freq.</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melatonin</td>
<td>27</td>
<td>45.9</td>
<td>6</td>
<td>60.0</td>
<td>33</td>
<td>47.8</td>
</tr>
<tr>
<td>Clonidine</td>
<td>22</td>
<td>37.3</td>
<td>3</td>
<td>30.0</td>
<td>25</td>
<td>36.3</td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>3</td>
<td>5.1</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>4.3</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>1</td>
<td>1.4</td>
<td>1</td>
<td>10.0</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>10.3</td>
<td>-</td>
<td>-</td>
<td>6</td>
<td>8.7</td>
</tr>
<tr>
<td>Total</td>
<td>59</td>
<td>100.0</td>
<td>10</td>
<td>100.0</td>
<td>69</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Note: Freq. = Frequency

A Chi-Square Test was conducted to determine if gender related to the use of medication to assist with sleep. No significant difference was found, $\chi^2 (n = 63, df = 2) = .51, p = .47, \phi = -.13$.

A further Chi-Square Test examined the relationship between overall reported sleep difficulties and medication status (current user, previous user, non-user). A significant relationship was found, with those currently using medication
more likely to have informant-reported sleep difficulties than those without $\chi^2 (n = 245, df = 2) = 8.10, p = .017, phi = .18$. A Mann-Whitney U Test was conducted to determine if the presence of sleep difficulties related to the number of psychotropic medications that a child/dependent adult was taking. A significant difference in the mean number of medications was found between those with reported sleep difficulties ($Md = 1, n = 171$) and those without ($Md = 0, n = 74$), $U = 4988, z = -2.78, p = .005, r = .18$. The children/dependent adults with reported sleep difficulties were thus more likely to be taking a higher number of psychotropic medications than those without reported sleep difficulties.

In summary, it was found that most children and dependent adults were reported to have difficulties with sleep. Sleep difficulties were more commonly observed in those with a reported diagnosis of anxiety. In addition, those with reported sleep difficulties were more likely to be currently using psychotropic medication, and a greater number of medications, than those without sleep difficulties.
Chapter 7: Study 1 Discussion

The purpose of Study 1 was to gain a comprehensive understanding of the use of psychotropic medication in an Australian sample of children and dependent adults with an ASD, from the perspective of caregivers. Psychotropic medication use according to gender, age, ASD diagnosis and intellectual disability was examined, with a particular focus on those who reported challenging behaviours, comorbid mental health conditions and sleep difficulties. There is now a considerable amount of international literature on psychotropic medication use in people with disabilities (e.g., Brylewski & Duggan, 2004; McGillivray & McCabe, 2004), including some specifically focused on people with ASD (e.g., Aman et al., 2003, 2005; Jesner et al., 2007; Morgan et al., 2003). However, these studies predominantly involve administrative or clinical samples and there is less knowledge about community-based individuals and relatively little understanding from the caregivers’ perspectives. This study is an attempt to address this gap.

While previous research has examined the use of psychotropic medications in Australians with disabilities (e.g., McGillivray & McCabe, 2004; Webber et al., 2010), the first study is now quite dated; in both studies, samples were drawn from administratively collected data on individuals who resided in or accessed state funded accommodation or other services. Further, both the cohorts included all disability types, who were reported on the basis of medication used for behaviour management. In contrast, Study 1 attempted to capture evidence for psychotropic medication use in children and dependent adults, who are primarily living in family based care in Australia, were likely to have been overlooked by previous research, and who had an
ASD. By increasing knowledge of psychotropic medication use in children and dependent adults with an ASD in this population, the capacity to tailor clinical and research investigations to meet the needs of these individuals and their caregivers will be improved.

In this chapter, the findings of Study 1 are systematically explored and discussed in the context of previous research. The characteristics of psychotropic medication use are discussed in the context of the sample. Consideration is then given to caregivers’ views on medication and the difference in psychotropic medication use among those who have a comorbid mental illness, challenging behaviour and sleep problems. The discussion includes acknowledgement of the limitations of this research, recommendations for future research, as well as suggestions for clinical practice.

7.1 Sample Characteristics

Since there is a dearth of Australian research exploring psychotropic medication use in children/dependent adults with an ASD, it was imperative to provide an accurate description of the sample in terms of demographic characteristics. The sample of individuals with an ASD, subject to informant report, was comprised of similar proportions of individuals diagnosed with autistic and Asperger’s disorder, with few diagnosed with PDD–NOS. Specifically, there were slightly more reports on individuals with Asperger’s disorder than autistic disorder, a pattern that is inconsistent with previous research, indicating a higher rate of autistic disorder compared to those with Asperger’s disorder (e.g., Fombonne et al., 2006, Williams et al., 2008; Lazoff et
al., 2010). A recent meta-analysis by French and colleagues (2013) concluded that epidemiological data comparing rates of Asperger’s disorder and autistic disorder were questionable, due to the recent use of the term ‘high functioning ASD’, and issues surrounding the diagnosis of Asperger’s disorder as separate from this (French et al., 2013). It is therefore plausible that the rates of autistic disorder to Asperger’s disorder observed in this study reflect this trend. The lower level of participants with PDD–NOS observed in this study is consistent with previous research, suggesting this disorder has a lower prevalence rate than autistic disorder and Asperger’s disorder (Fombonne et al., 2005; Williams, 2005).

The gender comparison of participants in this study was observed at a rate of four males per one female. This finding is consistent with previous research suggesting a 4:1 ratio of male to females diagnosed with an ASD (Holtmann, Bölte & Poustka, 2007; Fombonne, 2005; Morgan et al., 2002), and thus appear representative. Of note, the study did not include any female participants over the age of 30. This may be due to the historical nature of ASD being considered more prevalent among males (Baron-Cohen, Lombardo, Auyeung, Ashwin, Chakrabarti et al., 2011). It is therefore possible that the findings discussed below may not be representative of trends in adult females diagnosed with an ASD and the generalisability of results beyond this subgroup are thus limited.

The focus of this study was on capturing data from individuals who resided in home-based care situations. Consistent with this aim, the overwhelming majority of caregivers who provided data for this study resided full time with the child/dependent adult, on behalf of whom they completed the questionnaire. The
A high rate of comorbid intellectual disability was evident in those who had a diagnosis of autistic disorder, with a relatively low level of comorbid intellectual disability in those with Asperger’s disorder. This finding is consistent with previous research showing similar rates of comorbidities between autistic disorder and intellectual disability (Deb & Prasad, 1994; Fombonne, 2003b; Morgan et al., 2002). This finding has likely been to have been confounded on the basis of what psychometric instruments were used to diagnose intellectual disability. That is, those with an intellectual disability may have been more likely to have lower expressive language capacity and therefore more likely to have received a diagnosis of autism as opposed to Asperger’s disorder. This situation is likely to be rectified by the consolidation of the three disorders and the new criteria of the DSM-V (APA, 2014).

7.2 Prevalence

Although limited by the self-selecting nature of the sample, the data obtained provides some indication of medication use extent in community-based children and dependent adults with ASD. The majority of children and dependent adults with an ASD, who were subject to report, were taking at least one
psychotropic medication. The rate of psychotropic medication use observed in this study was comparable to that in America (Aman et al., 2002, 2005); however it was less than the rate recently observed in Iran (Memari et al., 2012). This may be a result of differences in prescriptions across developing as opposed to developed countries, or different sampling procedures.

Only a small proportion of children/dependent adults in this study were reported as having previously used psychotropic medication. Again, this may reflect a sampling bias (e.g., carers of people who have previously taken medication may be less inclined to participate in a study on medication). Alternatively, this may reflect a situation whereby individuals who receive psychotropic medication predominantly stay medicated over time. In a longitudinal study, Esbensen and colleagues (2009) reported an increase in the number of adolescent and adults with ASD taking psychotropic medication over time, as well as an increase in the number of medications they were taking. This may be a result of prescribers/caregivers having more concerns (medical and ethical) about prescription of psychotropic medication to younger children, given a lack of data on effectiveness and long term side effects in children. The findings also concur with those of Esbensen et al. (2009) and who concluded that once an adolescent/adult commenced psychotropic medication, it was highly unlikely the medication would be discontinued.

In the current study, the most commonly reported type of medication was anti-depressants, followed closely by anti-psychotics. Previous research has identified an increase in the use of anti-depressants in people with ASD (Aman et
al., 2005; Esbensen et al., 2009) and an increasing trend to treat anxiety symptoms in this population with SSRIs. There are suggestions that anti-depressants reduce ‘autistic behaviour’ (Aman et al., 1999; Esbensen et al., 2009). This is consistent with the low use of anti-anxiety medication observed in this study, despite a large majority of participants having a diagnosed anxiety disorder. This is consistent with the use of anti-depressants to treat anxiety disorders in the general population (Barlow & Durand, 2005). In addition, common anxiolytics, such as benzodiazepine, are recognized as having an addictive potential and so are unlikely to be used to treat pervasive anxiety (Barlow & Durand, 2005). It thus appears unlikely that these medications would be prescribed to young children in other than an isolated situation.

Children and dependent adults were commonly reported to take anti-psychotic medication. This finding is consistent with previous research in which increasing levels of anti-psychotic use (particularly atypical anti-psychotics) in this population, when compared to other psychotropic medications, are reported (Aman, 2002; Aman et al., 2005; Esbensen, 2009). The findings are consistent with other research indicating these medications are used to treat irritability and challenging behaviours in individuals with an ASD (Aman & Madrid, 1999; Esbensen et al., 2009; McDougle et al., 2000).

In this study, the most commonly reported psychotropic medication was Risperidone, which is on the PBS in Australia, as a recognised treatment for severe behavioural disturbance in children and adolescents with autism (Australian Government, 2007). A Cochrane Review, conducted by Jesner et al
(2009), identified some benefits of using Risperidone in treating irritability, repetition and social withdrawal in people with an ASD. However, it is also noteworthy that the authors cautioned a decision to use this medication demanded consideration of the balance between the advantages and disadvantages, particularly the adverse side effects associated with its use (e.g., weight gain). Given the high level of participants reporting taking anti-psychotic medication, there is a clear need for further randomised controlled trials into the effectiveness of different anti-psychotic drugs, as well as longitudinal studies focusing on any long term side effects in this population.

CNS stimulants were the next most commonly reported psychotropic medication in this study. Over a quarter of those reported as taking medication were taking a CNS stimulant, with the majority indicating methylphenidate. This appeared to be higher than reported in previous studies (e.g., Esbensen et al., 2009) and may reflect different diagnostic trends, related to the high number of participants diagnosed with comorbid ADHD, or to the predominantly younger age of this current sample. The use of stimulant medication among those with ASD appears controversial; with research indicating that stimulants are not as effective in individuals with ASD compared to those in the general population (Aman, 1996; Aman & Langworthy, 2000) and with it being hypothesised that stimulants may exacerbate anxiety in those with an ASD. However, three recent studies have indicated positive effects on ADHD symptoms from administration of a non-stimulant, atomoxetine, and with claims that adverse events were no worse in children with ASD than neurotypical children (Aman et al., 2008).
Despite the conflicting evidence, many Australian children and dependent adults with an ASD appear to be using CNS stimulants. This finding highlights a need for further examination of the evidence base to support CNS stimulant use in this population.

In the present study, a large number of children and dependent adults were reported as receiving more than one different psychotropic medication; either from the same type of medication (e.g., anti-psychotics) or from different types (e.g., anti-psychotic and anti-depressant). The rates of polypharmacy were higher than those reported in previous research in Ohio, USA (Aman et al., 2003). This may reflect a general trend for increasing rates of prescribing psychotropic medications to individuals with ASD (Aman et al., 2005; Esbensen et al., 2009).

It may also be explained by the trend for the ongoing use of medication once initiated, with additional medications added to address further symptoms and behaviours as they arise (Aman et al., 2005; Esbensen et al., 2009). The need for further education concerning the benefits of each type of medication, as well as examination of the interactions between medications prior to their prescription is clearly needed to determine if it results in increased side effect profiles or reduced tolerances (Williamson & Martin, 2012).

No relationship was found between psychotropic medication use and levels of cognitive impairment or severity of ASD in the present study. This is inconsistent with previous research, which indicated that more severe ASD impairment and cognitive impairment were related to increased rates of psychotropic medication use (Aman, Lam & Collier-Crespin, 2003; Aman, Lam
& Bourdegion, 2005). Although this may result from differing sampling procedures (community versus clinical populations), it may also reflect a difference in patterns of prescribing across countries, or may indicate a change in prescription trends. Regardless, it was evident that in this Australian community sample, more severe impairment and/or more impaired cognitive functioning did not make it more likely that children/dependent adults would be prescribed psychotropic medication. More sophisticated measures of impairment would be required to determine this, which was beyond the scope of this study. In addition to gaining some understanding of the characteristics and extent of psychotropic medication use among this population, it was important to explore the role of gender and age in medication use.

7.3 Gender and Age

The hypothesis that males would be more likely to be receiving psychotropic medication than females was not supported by the current study. Males and females were reported as equally likely to be taking psychotropic medication. This supports similar research conducted by Memari et al. (2012), whereby no differences in psychotropic drug use were identified according to gender. However, these findings contrast with previous research by Aman et al. (2002, 2005), who suggested that males were more likely to take psychotropic medication than females. The lack of gender distinction in the current study may be a result of the small number of female participants; alternatively, it may reflect different prescribing practices in Australia, or be a consequence of changes in prescription or diagnostic trends. It is possible, for example, that increases in
recognising girls with ASD is resulting in more of those with concomitant mental health issues being identified: such that females and males are equally likely to be prescribed medications. While the mean number of medications taken by male and females was similar, it was important to note the trend for a slightly higher number of medications being reported in female participants. This highlights the need for further examination of psychotropic medication prescription patterns regarding females.

Although trends in the type of psychotropic medication appeared to be similar across genders, with anti-depressant and anti-psychotic medication being the most commonly prescribed medications for both females and males, it is noteworthy that only males took anti-convulsant medication (except for the stated treatment of epilepsy). This differs from research by Memari and colleagues (2012) who found that more females than males were prescribed anti-convulsants in Iran. However, Memari et al.’s findings included the use of anti-convulsants used primarily for epilepsy. The findings of the present study may therefore reflect the exclusion of those who used this medication for treating epilepsy. However, it is also plausible that prescription practices differ across countries.

In addition to examining the relationship between gender and medication use, the relationship between age and medication use was explored in Study 1. On the basis of the literature (e.g., Aman et al., 2003, 2005), it was hypothesised that the use of psychotropic medication would increase with age. This was examined by comparing current medication status and the extent of use in those who were
currently in receipt of medication. The hypothesis was partially supported, with a higher number of psychotropic medications associated with increasing age.

However, the findings did not indicate any difference in the age of those who currently used, had previously used or had never used. The relationship between age and the number of medications could be explained thus: once psychotropic medication was commenced it was accepted as an ongoing treatment modality and more medications were added, rather than removed or changed (Esbensen et al., 2009). Alternatively, the relationship may be due to increased difficulty in managing a person with an ASD as they developed in size and strength, possibly increasing risks to self and others. This highlights the importance of regularly reviewing the rationale for each medication as the person ages.

Prior research has established differences in types of psychotropic medication prescribed across age groups (Memari et al., 2012). In the present study, children aged three to 11 were most commonly prescribed anti-psychotics, whereas those aged 12 to 18 years and <19 years were most commonly prescribed anti-depressant medications. This indicates prescribing differences in Australia according to age. This may be a result of the PBS introduction in 2008 of risperidone as a treatment modality for behaviours in those with an ASD (Australian Government, 2008); older children may have already commenced alternative medication prior to this change. However, this may also reflect differences in prescription practices across age groups by different professionals. The results indicated that a growing number of children were being prescribed
anti-psychotic medication in Australia. It is unclear at what age these children commence psychotropic medication, and the effect this may have on their development is not known. The high level of psychotropic medication use (57%) in children aged three to 11 is a concerning finding, given there are no randomised controlled trials evaluating medication in children with ASD who are this young. Given the adverse side effects that have been identified and the possibility that the effect these may have (specifically on children), there is a need for careful consideration prior to deciding to use medication in children and adolescents (Jesner et al., 2009). The present findings highlight the need for prospective follow up by prescribers of established metabolic and physical parameters to determine if the medications are adversely affecting the child.

7.4 Attitudes and Perceptions of Caregivers

A key aim of this study was to explore caregivers’ perceptions of why their child/dependent adult was taking psychotropic medication, and their attitudes towards its use. The predominant reason stated for medication was the existence of a comorbid mental health condition (42.7%), followed closely by the presence of challenging behaviour (35.3%). This suggests that a considerable proportion of children and dependent adults with ASD in Australia, primarily residing in the care of their parents, receive psychotropic medication for the primary purpose of behavioural management (according to their carers). However, the two categories (behaviour management and mental health) are not mutually exclusive and the findings may reflect the understanding of the caregiver of these terms or alternatively the capacity of the mental health clinician to
accurately diagnose a mental health condition in this population. This can be particularly difficult with children/dependent adults with a co-morbid intellectual disability. Further, large numbers of this population were reported to have a diagnosed comorbid mental health condition that was being treated with psychotropic medication.

Although the debate regarding the use of these drugs for children and adults with ASD continues, their use appears widespread. As previously stated, this highlights a significant need for further controlled evaluations of these medications in children and dependent adults. Moreover, ongoing education is required for caregivers surrounding the various interventions available and their potential side effects and relative efficacy.

In addition to determining the reasons for psychotropic medication use, another aim of this study was to explore how caregivers perceived medication in terms of managing ‘challenging behaviour’, or the treatment of comorbid psychiatric conditions in children and dependent adults with an ASD. The overwhelming majority of caregivers reported they felt the medication was both helpful for themselves, in managing their child’s emotions or behaviours, as well as helpful to the person for whom they cared. The majority of caregivers endorsed the items ‘Medications make the person I care for more relaxed’, and ‘The person I care for is happier on medication’. Despite this overall positive view expressed by caregivers, the literature remains conflicted over the helpfulness of psychotropic medication in those with an ASD: many argue there is little clinical evidence of efficacy in treating core symptoms of ASD (e.g., Antonacci, Manuel...
& Davis, 2008; Brylewski & Duggan, 1999; Gralton, James & Lindsey, 1998). Of course, the current findings may reflect the sampling methodology, whereby perhaps those caregivers with more positive views are more interested in participating in the research; or it may result from a tendency for caregivers to validate their use of medication. However, it could also reflect a situation whereby the medications are effective in the management of challenging behaviours or concomitant symptoms of mental ill health. There is clearly a need for further controlled research to explore the equivocal findings regarding clinical benefits, against those largely positive views expressed by caregivers.

As previously mentioned, concerns have been raised about the side effects of psychotropic medication on individuals with an ASD (e.g., Jesner et al., 2007; Valdovinos et al., 2005). For example, Jesner et al. cautioned that the adverse side effects associated with Risperidone use (in particular, weight gain) should be considered when evaluating the advantages and disadvantages, prior to deciding to use this medication. Nonetheless, the large majority of caregivers in this study endorsed the item ‘For the person I care for, the good things about medication outweigh the bad.’ It is unclear whether the side effects are truly minimal in comparison to the benefits of the medication. The impact of negative side effects may be negated by caregivers in light of the perceived gains for the individual, or in terms of the caregiver’s capacity to care for them.

Approximately half the caregivers endorsed the item ‘I feel it is up to the doctor to decide when the person I care for should stop taking their medication.’ This indicated deferred decision making to the prescribing professional highlights
the need for medical professionals to undertake frequent reviews of the purpose and effectiveness of medication, in consultation with caregivers.

Medication that is primarily given for the purpose of ‘behavioural control’ in a person with a disability is widely regarded in the literature as restrictive (e.g., Finn & Sturmey, 2009; Palley, 2006; Victorian Government, 2009). In the present study, most of the caregivers did not believe that the medication their child/dependent adult took restricted behaviour. This was consistent for all types of medications. Similarly, when analysed according to the reason for medication use, the majority of caregivers reported they did not perceive the medication as restrictive for the child/dependent adult. Despite this view, the large majority of caregivers endorsed the following: ‘The person I care for is on medication to control their behaviour.’ Therefore, there appears to be a disparity between caregiver perceptions and what the literature considers as restrictive. This may reflect different population samples (residential, community, institutional). This potentially highlights the need for caregiver education and discussion around medication use, and what constitutes restrictive practices. In addition to establishing the attitudes and perceptions of caregivers regarding the use of psychotropic medication, it was important to determine if gender or age related to medication use.

7.5 Challenging Behaviour and Psychotropic Medication

Another important aim of Study 1 was to explore the relationship between the presence of challenging behaviours and the use of psychotropic medication. According to the caregiver respondents, approximately half of the children and
dependent adults exhibited some form of challenging behaviour. This was consistent with previous estimates of challenging behaviour in those with an ASD (e.g., Emerson, et al., 2001; Kerth, Progar & Morales, 2009; Murphy, Macdonald, Hall & Oliver, 2000; Myers & Johnson, 2007).

It was hypothesised that individuals demonstrating challenging behaviours were more likely to be prescribed medications than those without challenging behaviours. This hypothesis was supported, with psychotropic medication use associated with the presence of challenging behaviours. In addition, those who were currently taking medication had a higher number of reported challenging behaviours, compared with those who had previously used or had never used medications. These findings are consistent with previous research demonstrating a link between psychotropic medication use and the presence of challenging behaviour in those with an ASD (Witwer & Lecavalier, 2005). This is likely because children/dependent adults with challenging behaviour are by definition more difficult to manage; as such, their caregivers may have sought assistance from medical professionals.

Interestingly, while aggressive behaviours were the most commonly reported type of challenging behaviour in the current sample, those who currently used psychotropic medication were not more likely to report aggressive behaviours than those who had never used or had previously used medication.

While aggressive behaviours were not found to relate to overall psychotropic medication status, it was found that those who were currently taking anti-psychotic medication were more likely to exhibit aggressive behaviours than
those who were not. This finding was consistent with research investigating those with an intellectual disability, which found that patients exhibiting aggressive behaviours were more likely to be taking anti-psychotic medications (Allington-Smith, 2006; McGillivray & McCabe, 2005). Individuals with aggressive behaviour were therefore not necessarily more likely to be taking medication than those without; however, if they were prescribed medication they were likely to be prescribed an anti-psychotic.

In addition, those who were reported with impulse control difficulties were more likely to be currently taking psychotropics medication. Impulse control difficulties are not considered a core symptom of ASD; however they are commonly associated in those with the disorder (Kadesjo & Gillberg, 2011; Nazeer, 2011). Therefore, children/dependent adults who express impulse control difficulties may be more likely prescribed medication for these difficulties, given the evidence base supporting its effectiveness (Nazeer, 2011). This suggests that clinical interventions tailored to prevent or minimise psychotropic medication use may benefit from focusing on improving impulse control difficulties in children and dependent adults with an ASD with consideration to the effect size each produces.

The findings discussed in this section, on the use of psychotropic medication in association with challenging behaviour, indicate that challenging behaviours were highly prevalent in this sample. Moreover, those who had challenging behaviours were more likely to be taking psychotropic medication. As such, thorough clinical assessments appear to be warranted when caregivers
present with their dependent child/adult for medication. This would assist in identifying the type of behaviours, and whether or not these stem from a comorbid condition. It appeared that some caregivers identified emotion-related difficulties as challenging behaviours; as such, it is important when conducting assessments that consideration is given to the presence of a mental illness in children/dependent adults with an ASD. The findings further illustrated the importance of education for caregivers around the difference between challenging behaviours and mental illness. This may enable caregivers to respond appropriately to different presentations and reframe the behaviour.

7.6 Comorbid Mental Health Conditions and Psychotropic Medication

An additional aim of Study 1 was to examine the level of comorbid mental health conditions among children and dependent adults with ASD, and to explore its relationship with psychotropic medication use. The majority of children/dependent adults were reported to have at least one comorbid mental health condition. This was higher than findings in previous research, focusing on adults with an ASD and an associated intellectual disability (Morgan et al. 2003), and those examining children and adolescents with an ASD (Ghazziuddin, Weidmer-Mikhail & Ghazziuddin, 1998). This finding may result from caregivers reporting conditions that have been diagnosed over a lifespan, not understanding diagnosis or increasing rates of the recognition of comorbid conditions in children and dependent adults with an ASD. Alternatively it may be harder to elicit the information required to make a diagnosis with confidence in those with a co-
morbid intellectual disability than in the current sample population. Regardless, the findings suggest a high level of reported comorbid conditions; as such, tailoring interventions (both medical and psychosocial) specifically for those with an ASD may prove beneficial. This is especially important, given that the presence of psychiatric symptoms predicts social and academic functioning (Gadow et al, 2008).

The most commonly reported diagnosed comorbid mental health condition in the children and dependent adults involved in Study 1 was anxiety. Much debate has centred around whether anxiety is a symptom of ASD or is a separate comorbid condition (Matson & Nebel-Schwam, 2007). Nevertheless, many caregivers reported that their child/dependent adult had been diagnosed with an anxiety disorder. In this study, it was not possible to confirm the validity of the informant reports of a diagnosis. Their response may be based on acknowledgement of anxiety by professionals, either as a component of the ASD, or as a separate comorbid condition. This finding highlights the importance of clinical interventions targeting anxiety in this population. Clinically, the need for tailored intervention is likely to be similar regardless of whether an anxiety disorder is considered separate to, or a component of, the ASD.

The study also found a high prevalence of reported ADHD, which was somewhat surprising, given the DSM-IV-TR (APA, 2000) stipulation that ADHD should not be diagnosed during the course of a PDD (this has since been addressed by the DSM-V (APA, 2014)). Despite this stipulation, ADHD has been identified as one of the most commonly diagnosed comorbid conditions.
Hyperactivity and impulsivity are regularly displayed by people with ASD (Kadesjö & Gillberg, 2001), although much debate has surfaced in the literature surrounding whether impulsivity and hyperactivity are core symptoms of ASD or separate disorders (Kadesjo & Gillberg, 2011; Nazeer, 2011). Similarly, in the current study there appears to be a disparity between diagnostic criteria and diagnostic practice, in terms of comorbid ADHD in children and dependent adults with an ASD.

Compared to previous research (e.g., Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998) examining depression rates in adolescents and adults with Asperger's disorder, lower rates of diagnosed depression were reported in this sample. This may reflect differences between the samples. In particular, previous research focused on psychopathology in adolescents and young adults, whereas the present study incorporated a large number of children. Further, the current sample was community-based, rather than clinical. The discrepancy may also arise from the high number of participants with an ASD and intellectual disability in the current sample. Depression may be more difficult to diagnose in this population, due to differential symptom presentation (Matson & Nebel-Schwalm, 2007). Collectively, the findings indicated a high level of reported diagnosis of comorbid conditions in children and dependent adults with an ASD. Comorbid mental health conditions are clearly relevant to examining rates of psychotropic medication.
Consistent with previous research (e.g., Mandell et al., 2008; Memari et al., 2012; Morgan et al., 2003), children and dependent adults with a comorbid mental illness were more likely to be taking psychotropic medication than those without a diagnosis. Once a comorbid diagnosis was made, it appeared likely it would be treated pharmacologically. Specifically, those who were reported to have a diagnosis of anxiety or ADHD were more likely to be taking psychotropic medication (as well as a higher number of such medications) than those who did not have these diagnoses. However, a diagnosis of depression was not found to be related to psychotropic medication use. This may be attributed to the smaller number of participants (15.9%) having a diagnosis of depression. Conversely, it may reflect that those with depression were less likely to be treated with medication. Regardless, the finding was somewhat surprising, given the high level of anti-depressant medication use reported in this study. It is possible that medication is more likely to be sought and/or prescribed for ADHD and anxiety, due to the overt nature of the symptoms (Nazeer, 2011). In contrast, symptoms of depression (e.g., withdrawal, apathy) may be less apparent or challenging, resulting in less help-seeking among caregivers and/or less prescription by medical practitioners.

### 7.7 Sleep and Psychotropic Medication

Consistent with previous research (Richdale, 2001; Polimeni et al., 2005), the majority of children/dependent adults with an ASD were reported to experience sleep difficulties. The most commonly reported sleep difficulty was related to falling asleep, which was similar to that estimated in the literature.
(Polimeni et al., 2005). In addition, it was found that one third of the sample with sleep difficulties had a diagnosed sleep disorder, as reported by their caregivers. The level of sleep disturbance observed in this sample is particularly pertinent, as sleep difficulties persist across the lifespan, and thus are likely to influence these individuals for many years (Goldman, Richdale, Clemons & Malow, 2012). Sleep difficulties have been associated with intensified symptoms of autism, higher levels of psychiatric comorbidities, and higher levels of challenging behaviour (Goldman et al, 2012; Malow et al., 2012; Schreck, Mulick & Smith, 2004; Taylor et al., 2012).

A higher prevalence of comorbid mental health conditions was also found among those with sleep difficulties. In particular, children and dependent adults with an ASD who had a comorbid diagnosis of anxiety were more likely to have sleep difficulties reported than those without. This link is consistent with previous suggestions that sleep difficulties in those with an ASD are related to increased anxiety (Paavonene et al., 2003; Richdale, 1999). These findings highlight sleep disturbance and anxiety as significant issues in this population that warrant consideration when individuals with ASD present for treatment.

Further, previous research has established that those with an ASD who have sleep difficulties are more likely to exhibit challenging behaviour and comorbid mental illnesses (Goldman et al, 2012; Malow et al., 2006; Schreck et al., 2004; Taylor et al., 2012). On the basis that challenging behaviour and comorbid mental illness are considered predictors for the use of psychotropic medication (Matson & Nebel-Shwalm, 2007; Morgan et al., 2003), it was
hypothesised that individuals with sleep difficulties would be more likely to be taking psychotropic medication, as well as a higher number of medications. This was supported, with those who reported sleep difficulties more likely to be taking psychotropic medication, and a higher number of medications than those without sleep difficulties.

Approximately a third of those who reported sleep difficulties were taking a specific psychotropic medication for sleep, with the majority also reporting melatonin use. This is consistent with recent research in which melatonin has been found to be effective in improving sleep in children with an ASD, particularly sleep onset (Leu et al., 2011; Wright et al., 2011). Intervention for sleep difficulties in children and dependent adults with an ASD commonly appears to be pharmacologically based and may have contributed to the level of polypharmacy observed in this sample.

7.8 Limitations and Directions for Future Research

This study has provided an analysis of psychotropic medication in a community-based sample of children and dependent adults with an ASD from the perspective of caregivers. The findings must be viewed in light of several limitations. Foremost is the possibility that the sample may not be representative due to ascertainment bias. There are a number of factors that could have contributed to this possibility. First, respondents who elect to participate in an online survey would be more likely, for example, to be caregivers of individuals with ASD who are administered psychotropic drugs. Second, they may also be more likely to have a particular interest in, or strong views about, the topic. Third,
due to the significant skew in the age distribution of children and dependent adults towards younger people (≤18 years), it is likely that a large proportion of people with an ASD (>18) were not captured in this study. Although a positive feature of this study was its focus on individuals living in the community who may not have been included in previous studies, the methodology also means that older individuals with more severe impairment who reside in government run accommodation are unlikely to be included. It is not known if prescribing patterns differ in this population.

In addition, the study utilised predominantly online methods for recruitment and completion of the questionnaire. This allowed for the anonymous collection of sensitive information across a broad population of children and dependent adults with an ASD and their caregiver’s, however, it also limited the generalisability of the study. Considering participants required computer and internet access in order to complete the questionnaire, this suggests that the current study may have recruited caregiver’s with higher education levels and socio-economic status than those who did not have access to computers or the internet. While a paper version of the questionnaire was available it was not readily accessed. It would be beneficial for further studies to clarify the association between education level and socio-economic status when investigating caregiver perspectives.

The reliability of some of the findings may also be limited as the data provided by caregivers may not be accurate. No supporting documentation was requested in relation to diagnosis of ASD, comorbid mental health conditions,
psychotropic medication, sleep difficulties or challenging behaviours. While the focus of this study was on obtaining caregivers' viewpoints, it is important to acknowledge that caregivers’ perspectives do not always reflect those of the individuals they are reporting for (Hope et al., 1999). It is suggested that future research would be strengthened by including data from multiple sources to cross-reference the accuracy of caregiver reporting and from exploring and comparing individual and caregiver viewpoints surrounding psychotropic medication use to determine if there are differences in views and attitudes.

In addition, there were few caregivers who reported that their child/dependent adult had previously taken psychotropic medication. This may simply be because there are relatively few of these as noted in previous research (Esbensen et al., 2009). Alternatively, it may be because these individuals did not feel the study related to them and therefore chose not to participate. Further investigation of those who have previously used psychotropic medication and discontinued it would be valuable. This would allow for exploration of why this group ceased using medication and more extensive analysis of the differences between this group and those who continue with medication.

A further limitation of the study was that caregivers' were reporting the behaviours of the child or dependent adult with ASD that they found personally challenging. The interpretation of behaviour as 'challenging' is subjective, and thus possibly dependent on individual views as well as other factors, such as their parental efficacy, level of stress and mental state (Gray, 2003). The conclusions that can be drawn with relation to challenging behaviour are therefore limited to
subjective caregiver accounts. On the other hand, gaining personal caregiver experiences of challenging behaviour added valuable information to the literature. It would be of benefit to examine psychotropic medication use and challenging behaviours where an objective measure of behaviour was included such as the developmental behaviour checklist (Einfeld & Tonge, 1995).

It is important to note that the majority of caregivers indicated that they used a range of different interventions (e.g., positive behaviour support, social stories, speech therapy, communication aids) in addition to psychotropic medication for behavioural management. This study's primary focus was on the use of psychotropic medication as a treatment rather than as a component of a treatment approach. There has been recent research indicating the benefits of psychotropic medication in combination with behaviour management programs when compared to medication alone in children with an ASD (Arnold et al., 2012). Consequently, the findings of the present study need to be viewed in the context that there were likely to have been other interventions that impacted caregivers’ perspectives. It was beyond the scope of this study to compare those who used additional interventions as well as medication. Future research would benefit from exploring further the different treatment approaches caregivers use in addition to medication to assist in determining the perceived helpfulness of the different approaches.

It was not possible in the present study to examine and compare the level of psychotropic medication use in terms of dosage. This was made particularly difficult by the manner in which the information was collated, but also levels can
be highly variable based on individual characteristics (e.g., height, weight). It would be helpful for future research to be able to compare and examine the different levels of psychotropic medication and caregivers perceptions of the effectiveness.

It is possible that the findings relating to the DAI (Hogan & Awad, 1983) have some level of bias as the inventory was explicitly designed to help to increase compliance with psychotropic medication. It is likely that caregivers had viewpoints and attitudes that were not captured by the DAI. Consequently future research may benefit from exploring attitudes from a qualitative perspective, thus not limiting the scope of caregivers responses with relation to psychotropic medication use.

The findings from Study 1 have been conducted with the current DSM-IV-TR (APA, 2000) criteria for ASD. As previously mentioned the proposed changes to DSM-V (due for release in 2013) would possibly alter the diagnosis of some participants in this study. Thus it is possible that some participants would not continue to meet the criteria for ASD. While the complexities of such changes are not able to be addressed in this Study (see Gensler, 2012; Kurita, 2012; Mandy, Charman & Skuse, 2012), it may impact the future generalisability of the findings to those who meet the new criteria. Despite the limitations of the study, it provided important information into the extent and characteristic prevalence of psychotropic medication use among a sample of community-based children and dependent adults with ASD in Australia.
7.9 Implications and Conclusions

Study 1 has demonstrated the high prevalence of psychotropic medication use among a sample of children and dependent adults living with carers in the Australian community. The rate of reported psychotropic medication use suggests that psychotropic medication prescription is common practice among professionals treating children and dependent adults with ASD. This study provides further support for the suggestion that while there is evidence supporting the efficacy of some psychotropic medications in the management of emotions, behaviours and comorbid conditions occurring with ASD, others are being prescribed with minimal research support (Aman et al., 2003). This is of particular concern as it highlights the need for randomised controlled trials to determine the efficacy and appropriateness of the specific medications prescribed in this population and the importance of including caregivers in these studies. These trials need to not only focus on adolescents, but also include younger children, as it has been established in this study that psychotropic medication is being prescribed in Australia to young children with ASD. In addition, longitudinal research needs to be conducted to determine not only the long term outcomes of medication use in children and dependent adults, but also how likely it is that medication is ceased as a form of intervention.

Despite the controversy surrounding the effectiveness of psychotropic medication in reducing challenging behaviours, this study demonstrates that caregivers perceive psychotropic medication as helpful to them in managing their child/dependent adult’s difficult behaviour or emotions. Further examination of
these perceptions needs to occur in order to determine the reasons for the disparity between caregivers’ perspectives and other sources of data. It is unclear from the current findings whether this relates to caregivers need to justify the use of psychotropic medication, a possible placebo effect, the focus of change not being identified or that it is actually effective for what prescribers are targeting.

It was demonstrated that caregivers did not perceive psychotropic medications as restrictive, despite some using them as a way to manage challenging behaviours. This suggests a disparity between caregivers’ perceptions and current policy and practices within Australia (Victorian Government, 2009). For example, in the state of Victoria, medication that is prescribed to a child/adult who accesses disability funded care, with the primary intent of behavioural control is considered restrictive and reportable under the Disability Act (Victorian Government, 2009). This suggests that further work needs to occur in order to bring parental perceptions in line with current policies and what is considered best practice.

In this study, the majority of children and dependent adults were reported as being administered psychotropic medication. It was also the case that the majority of these children and dependent adults were reported to have been diagnosed with a comorbid mental health condition. It is plausible, even likely that these two factors relate to each other. It is possible, for example, that those with an ASD had a significantly higher level of comorbid conditions for which treatment with psychotropic medication is considered an appropriate option.
Alternatively, diagnosis with a mental health condition (such as ADHD) may be sought and provided in order to enable access to pharmacological treatment.

In conclusion, the use of psychotropic medication was common among children and dependent adults with ASD whose caregivers participated in an online questionnaire. Anti-depressants and anti-psychotics were the most commonly reported type of medications in use, with challenging behaviour, comorbid mental health conditions and sleep difficulties all relating to medication use. Overall, psychotropic medications were viewed positively and were perceived by caregivers as helpful to the child/dependent adult. This study contributes new knowledge regarding the extent and nature of psychotropic medication use among children and dependent adults with ASD residing in home-based care in Australia. In particular, it highlights key variables relating to the administration of psychotropic medication, including the reasons for use and the extent to which it is perceived as helpful.
Chapter 8: Results Study 2

This study involved a detailed description and analysis of self-reported data from a sample of 63 adults with an ASD. A power analysis was conducted using the G-Power 3.1 program (Faul, Erdfelder, Buchner, & Lang, 2009) with anticipated moderate effect sizes. The power analysis indicated that the study required approximately 111 participants, the study does not therefore, have sufficient power and the results need to be interpreted with caution. Non-parametric approaches to data analysis was taken as the data was not normally distributed.

In the first section of this chapter, the demographic details of the sample are presented including: age, gender, communication ability, intellectual ability and type of ASD. The focus of the second section of this chapter is on any differences between participants who reported current use of psychotropic medication to assist with the management of maladaptive behaviours and emotions arising in association with their ASD, participants who had previously taken psychotropic medication, and those who had never taken psychotropic medication. It presents their perspectives and attitudes towards psychotropic medication and their views on its effectiveness. This section then details information relating to the number and types of medications prescribed, as well as an examination of any differences in reported mental health concerns, sleep difficulties and challenging behaviour across the samples.
8.1 Overview of Sample of Adults with ASD

8.1.1 Participant characteristics.

The 63 adults with ASD (66.6% males) all resided in Australia and ranged in age from 18 to 69 years, with a mean age of 38.44 years ($SD = 13.58$, Median $= 37$, Mode $= 39$). See Table 8.1.1 for a distribution of ages. A Chi-Square Test for Independence was conducted to determine if the relationship between age and gender differed from expectations. Age and gender were not found to be significantly related ($\chi^2 (n = 63, df = 5) = 5.56, p = .06, \phi = .30$). The majority of participants were aged between 30 to 55 years old, with no females aged over 56 years. The majority of participants reported residing in their own home (87.2%), with a small percentage indicating that they were living with some support (12.8%).

Table 8.1.1

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Male Freq.</th>
<th>Male %</th>
<th>Female Freq.</th>
<th>Female %</th>
<th>Total Freq.</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 to 29</td>
<td>14</td>
<td>33.3</td>
<td>5</td>
<td>23.8</td>
<td>21</td>
<td>30.2</td>
</tr>
<tr>
<td>30 to 55</td>
<td>21</td>
<td>50.0</td>
<td>16</td>
<td>72.2</td>
<td>37</td>
<td>58.7</td>
</tr>
<tr>
<td>56 to 69</td>
<td>7</td>
<td>16.7</td>
<td>-</td>
<td>-</td>
<td>7</td>
<td>11.1</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>100.0</td>
<td>21</td>
<td>100.0</td>
<td>63</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 8.1.2 presents the frequency and percentage of participants according to ASD type and reported severity of impairment. The majority of participants reported being diagnosed with Asperger’s disorder (84%), with few
reporting a diagnosis of PDD-NOS (Pervasive Developmental Disorder - Not Otherwise Specified). Most participants reported their levels of impairment in the mild to moderate range.

Table 8.1.2

*Frequency and Percentage of ASD and Severity of Impairment (N = 63)*

<table>
<thead>
<tr>
<th></th>
<th>Autistic Disorder</th>
<th>Asperger’s Disorder</th>
<th>PDD-NOS</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Mild</td>
<td>6</td>
<td>75.0</td>
<td>25</td>
<td>47.2</td>
</tr>
<tr>
<td>Moderate</td>
<td>2</td>
<td>25.0</td>
<td>23</td>
<td>42.4</td>
</tr>
<tr>
<td>Severe</td>
<td>-</td>
<td>-</td>
<td>5</td>
<td>9.4</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>100.0</td>
<td>53</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Frequencies relating to intellectual ability and communication ability of the sample are presented in Table 8.1.3. Most individuals reported no intellectual disability (90.5%), with 33 per cent of these participants reporting above average communication ability.

Table 8.1.3

*Frequency of Intellectual Disability and Communication Ability (N = 63)*

<table>
<thead>
<tr>
<th>Communication Ability</th>
<th>Below average</th>
<th>Average</th>
<th>Above average</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>No ID</td>
<td>8</td>
<td>72.7</td>
<td>30</td>
<td>90.9</td>
</tr>
<tr>
<td>ID</td>
<td>3</td>
<td>27.3</td>
<td>3</td>
<td>9.1</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>100.0</td>
<td>33</td>
<td>100.0</td>
</tr>
</tbody>
</table>

*Note: ID = Intellectual Disability*
8.2 Use of Psychotropic Medication

This section describes the participants who reported currently taking medication, in comparison to those who had previously taken medication and those who had never taken medication. Medication use is presented according to demographic variables, as well as reasons for use, perceived helpfulness of the medication, views on whether the medication is seen as restrictive and general attitudes pertaining to the use of psychotropic medication.

8.2.1 Psychotropic medication.

The 63 adults with ASD (66.6% males) all resided in Australia and ranged in age from 18 to 69 years, with a mean age of 38.44 years ($SD = 13.58$, $Median = 37$, $Mode = 39$). See Table 8.1.1 for a distribution of ages. A Chi-Square Test for Independence was conducted to determine if the relationship between age and gender differed from expectations. Age and gender were not found to be significantly related ($\chi^2 (n = 63, df = 5) = 5.56, p = .06, phi = .30$). The majority of participants were aged between 30 to 55 years old, with no females aged over 56 years. The majority of participants reported residing in their own home (87.2%), with a small percentage indicating that they were living with some support (12.8%).
Chi-Square Tests of Independence were conducted to determine if medication use related to gender, type of ASD diagnosis, levels of impairment or communication ability. The results indicated no significant relationship between medication status and gender ($p = .84$), ASD diagnosis ($p = .98$), level of impairment ($p = .093$), communication ability ($p = .69$), age ($p = .55$) or intellectual ability ($p = .52$).

A total count of 33 participants reported using psychotropic medication, with nine taking two or more medications ($M = 1.39$, $SD = .73$, Median = 1, Mode =1). Nine participants (14.2%) were taking two or more medications, with four (6.3%) using three medications. Table 2.1.2 displays the number of medications according to gender.

Of the 33 people reporting medication use, 30 reported routine use, and three reported only PRN use. A further seven individuals (thus, 10 overall) reported they also used PRN medication to assist with managing their emotions or behaviours. Of note, 10 participants (16% of the total sample) reported using complementary and alternative medications (e.g., St Johns Wort, fish oil) to assist with their emotions or behaviours. This medication use was excluded from
analyses, due to the study’s focus on psychotropic medication. The reported
medications were coded according to their primary MIMS classifications (MIMS
online, 2012): anti-depressant, anti-psychotic, anti-anxiety, anti-convulsant,
hypnotic sedatives, CNS stimulant or other. If there were two classifications
listed, the first listed classification was used. The coding of each medication
according to type can be found in Appendix E.

8.2.2 Psychotropic medication and gender.

In this section, the number of psychotropic medications routinely taken by
individuals was examined according to the participant’s gender. The majority of
male and female participants reported taking one such psychotropic medication
(see Table 8.2.2.1). A Mann-Whitney U test revealed no significant difference in
the number of medications prescribed for males ($Md = 1, n = 42$) and females ($Md
= 1, n = 21$), $U = 438$, $z = -.42$, $p = .96$, $r = .05$.

Table 8.2.2.1

<table>
<thead>
<tr>
<th>Number of Medications</th>
<th>Male</th>
<th></th>
<th>Female</th>
<th></th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>1</td>
<td>16</td>
<td>72.7</td>
<td>8</td>
<td>78.7</td>
<td>24</td>
<td>38.1</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>18.2</td>
<td>1</td>
<td>9.0</td>
<td>5</td>
<td>7.9</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>9.0</td>
<td>2</td>
<td>18.2</td>
<td>4</td>
<td>6.3</td>
</tr>
<tr>
<td>Mean no. Medication</td>
<td>1.36</td>
<td></td>
<td>1.45</td>
<td></td>
<td>1.39</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>100.0</td>
<td>11</td>
<td>100.0</td>
<td>33</td>
<td>100.0</td>
</tr>
</tbody>
</table>
As shown in Table 8.2.2.2, of the 33 individuals who reported taking medication, the majority (60.6%) reported taking one or more anti-depressant medications. Anti-psychotic and anti-anxiety medications were the next most commonly reported. The overall pattern of medication use appeared to be similar in males and females, with the exception that females indicated greater use of anti-convulsants and no use of hypnotic sedatives or CNS stimulants.

Table 8.2.2.2

<table>
<thead>
<tr>
<th>Type of Medication</th>
<th>No. of Med.</th>
<th>Male (n = 22)</th>
<th>Female (n = 11)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Anti-depressant</td>
<td>1</td>
<td>11 50.0</td>
<td>7</td>
<td>50.0</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1 4.5</td>
<td>1</td>
<td>9.5</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>1</td>
<td>4 18.2</td>
<td>2</td>
<td>18.2</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>1</td>
<td>6 15.8</td>
<td>1</td>
<td>9.1</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>-</td>
<td>1</td>
<td>5.6</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>1</td>
<td>3 13.6</td>
<td>2</td>
<td>18.2</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>1</td>
<td>2 4.5</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>1</td>
<td>2 4.5</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2 9.1</td>
<td>1</td>
<td>9.1</td>
</tr>
<tr>
<td>Total</td>
<td>31</td>
<td>14 66.2</td>
<td>46</td>
<td>82.4</td>
</tr>
</tbody>
</table>

*Note: Med = Medications*

8.2.3 Psychotropic medication and age.

The extent of medication use and number of medications was examined by participant age group (18 to 29 years, 30 to 55 years, or 56 and older; see Table 8.2.3.1). The sample of 63 participants comprised 30.2% of individuals who were aged between 18 and 29, 58.7% who were between 30 and 55 years, and 11.1% who
were 56 years or over. Across all age groups, a substantial proportion of participants reported current use of medication.

Table 8.2.3.1

_Medication Use According to Age (N = 63)_

<table>
<thead>
<tr>
<th>Medication use</th>
<th>N</th>
<th>18 - 29 yrs</th>
<th>30 - 55 yrs</th>
<th>56+ yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Never</td>
<td>22</td>
<td>6</td>
<td>13</td>
<td>35.2</td>
</tr>
<tr>
<td>Previous</td>
<td>8</td>
<td>2</td>
<td>6</td>
<td>16.2</td>
</tr>
<tr>
<td>Current</td>
<td>33</td>
<td>11</td>
<td>18</td>
<td>48.6</td>
</tr>
<tr>
<td>Total</td>
<td>63</td>
<td>19</td>
<td>37</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 8.2.3.2 displays the number and mean number of medications routinely administered according to age group. Individuals aged 30 to 55 years used the highest mean number of medications \((M = 1.55)\), with those aged 18 to 29 years using the lowest \((M =1.18)\).

Table 8.2.3.2

_Number and Percentage of Medication Used Routinely by Age Group (n = 33)_

<table>
<thead>
<tr>
<th>Number of Medications</th>
<th>18-29 yrs</th>
<th>30-55</th>
<th>56+ yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
</tr>
<tr>
<td>1</td>
<td>10</td>
<td>90.9</td>
<td>11</td>
</tr>
<tr>
<td>2</td>
<td>-</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>9.1</td>
<td>3</td>
</tr>
<tr>
<td>Mean No. of Medications</td>
<td>1.18</td>
<td>1.55</td>
<td>1.22</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>18</td>
<td>4</td>
</tr>
</tbody>
</table>
Table 8.2.3.3 displays the frequency of individuals using the five medication types according to age group. The most frequently reported medication type across 18 to 29 year olds and 30 to 55 year olds was anti-depressant medication.

Table 8.2.3.3

<table>
<thead>
<tr>
<th>Type of medication</th>
<th>18-29 yrs</th>
<th>30-55 yrs</th>
<th>56+ yrs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Anti-depressant</td>
<td>7</td>
<td>58.4</td>
<td>14</td>
<td>50.0</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>2</td>
<td>16.7</td>
<td>4</td>
<td>14.3</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>1</td>
<td>8.3</td>
<td>5</td>
<td>17.8</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>1</td>
<td>8.3</td>
<td>4</td>
<td>14.3</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>1</td>
<td>8.3</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>3.6</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
<td>100.0</td>
<td>28</td>
<td>100.0</td>
</tr>
</tbody>
</table>

8.2.4 Reasons for psychotropic medication use.

In this section, the reasons provided by participants for medication use were examined, according to medication type (see Appendix E for a full list of primary and secondary reasons provided for prescription). The majority of this adult sample (66.6%) provided a single reason for each medication, with the remainder providing two reasons. The most commonly reported primary reasons for medication were anxiety (30.7%) and depression (28.4%). Smaller numbers reported that medication was used for sleep disturbance (17.6%), mood
stabilisation (13.3%) and obsessional thoughts (5.6%). Responses coded as ‘other’ (4.4%) included use for agitation, and on the basis of a past history of codeine abuse.

The primary reason for medication was further examined according to the type of medication (see Table 8.2.4.1). Of note, the five participants who reported anti-convulsant medication use reported their primary reason for using this medication was for mood stabilisation.

Table 8.2.4.1

*Primary Reason for Medication Use According to Medication Type (no. of medication = 46)*

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>n</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Mood stabilisation</th>
<th>Sleep disturbance</th>
<th>Obsession thoughts</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anti-depressant</td>
<td>23</td>
<td>12</td>
<td>7</td>
<td>-</td>
<td>3</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>6</td>
<td>-</td>
<td>5</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>8</td>
<td>-</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>1</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Participants were asked whether they viewed the medication they were taking as a form of restraint. The majority (87.8%) responded that they did not believe the medication was restrictive, with a smaller number (12.2%) indicating
it was. This trend appeared consistent across medication types (see Table 8.2.4.2). Anti-depressant medication was viewed as restrictive by the largest proportion of respondents (26.1%).

Table 8.2.4.2

*Frequency of Participants Indicating Medication as Restraint by Type (n of medication = 46)*

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>N</th>
<th>Restrictive</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-depressant</td>
<td>23</td>
<td>6</td>
<td>26.1</td>
<td>17</td>
<td>73.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>8</td>
<td>1</td>
<td>12.5</td>
<td>7</td>
<td>87.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>100.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>4</td>
<td>100.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>100.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>6</td>
<td>1</td>
<td>14.3</td>
<td>5</td>
<td>85.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>1</td>
<td>33.3</td>
<td>2</td>
<td>66.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>9</td>
<td>100.0</td>
<td>37</td>
<td>100.0</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The responses provided by adults with ASD to the question ‘Do you believe this medication is a form of restraint?’ was further analysed according to the reasons for medication use (see Table 8.2.4.3), with evidence of some endorsement across reasons.

Table 8.2.4.3

*Reason for Medication According to Belief about Restraint (n of medication = 46)*

<table>
<thead>
<tr>
<th>n</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Mood stabilisation</th>
<th>Sleep disturbance</th>
<th>Obsessions</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restrictive</td>
<td>9</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Not restrictive</td>
<td>37</td>
<td>10</td>
<td>11</td>
<td>5</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>13</td>
<td>14</td>
<td>6</td>
<td>8</td>
<td>3</td>
</tr>
</tbody>
</table>
8.2.5 Perceived helpfulness of psychotropic medication.

Participants were asked to report the extent to which they found each medication helpful in assisting them to manage difficult emotions or behaviours, on a four point Likert scale from (1) not at all to (4) a lot (see Table 8.2.5.1). Most adults reported that medication helped a ‘moderate amount’ or ‘a lot.’ All recipients of anti-convulsant medication rated the medication as helping ‘a moderate amount’ or ‘a lot.’ Those taking anti-depressants and anti-psychotic medication most commonly indicated the helpfulness of the medication was ‘a lot.’

Participants were further requested to report on a 10 point Likert scale how satisfied they were with the medication from 0 (totally dislike) to 10 (totally like) ($M = 6.52, SD = 2.95$). The majority of participants rated the medication positively.

Table 8.2.5.1

Perceived Helpfulness of Medication According to Type of Medication in Managing Difficult Emotions & Behaviours ($n$ of medication = 46)

<table>
<thead>
<tr>
<th>Type of Medication</th>
<th>Not at all</th>
<th>A little bit</th>
<th>A moderate amount</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anti-depressant</td>
<td>1</td>
<td>2</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>-</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>CNS stimulant</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anti-convulsant</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Hypnotic sedative</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>-</td>
<td>2</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>8</td>
<td>14</td>
<td>22</td>
</tr>
</tbody>
</table>
8.2.6 Attitudes towards psychotropic medication.

A further aim was to examine the views of adults with an ASD towards medication use in participants who reported current medication use. Table 8.2.6.1 presents the overall frequencies of responses by participants to each item of the DAI (Hogan et al., 1998; participants that did not provide a response were omitted from the table). The most strongly endorsed item overall was ‘I take medications of my own free will.’ The least endorsed items were, ‘I can’t relax on medication’ and ‘I would rather be ill than take medication.’ Twenty participants (60.6%) indicated they disagreed with the statement ‘Taking medications will do me no harm’, with 14 (42.4%) participants indicating that ‘Medications make me feel tired and sluggish’, and ten participants (30.3%) endorsing the item ‘I am given medication to control behaviour that other people (not myself) don’t like.’
Table 8.2.6.1

*Frequency of Participant Responses on the DAI-30 (n = 33)*

<table>
<thead>
<tr>
<th>Item</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>I take medications of my own free choice</td>
<td>31 (93.9%)</td>
<td>2 (6.1%)</td>
</tr>
<tr>
<td>For me the good things about medication outweigh the bad</td>
<td>30 (90.9%)</td>
<td>3 (9.1%)</td>
</tr>
<tr>
<td>Even when I am not in hospital I need medication regularly</td>
<td>27 (81.8%)</td>
<td>6 (18.2%)</td>
</tr>
<tr>
<td>I am happier and feel better when I am taking medications</td>
<td>26 (78.8%)</td>
<td>7 (21.2%)</td>
</tr>
<tr>
<td>I should keep taking medication even if I feel well</td>
<td>26 (78.7%)</td>
<td>7 (21.2%)</td>
</tr>
<tr>
<td>I am in better control of myself when taking medication</td>
<td>25 (75.8%)</td>
<td>8 (24.2%)</td>
</tr>
<tr>
<td>Medications make me feel more relaxed</td>
<td>24 (72.7%)</td>
<td>8 (24.2%)</td>
</tr>
<tr>
<td>I get along better with people when I am on medication</td>
<td>24 (72.7%)</td>
<td>8 (24.2%)</td>
</tr>
<tr>
<td>Taking medication will prevent me from having a breakdown</td>
<td>22 (66.7%)</td>
<td>10 (30.3%)</td>
</tr>
<tr>
<td>By staying on medication I can prevent myself getting sick</td>
<td>22 (66.7%)</td>
<td>10 (30.3%)</td>
</tr>
<tr>
<td>My thoughts are clearer on medication</td>
<td>22 (66.7%)</td>
<td>11 (34.8%)</td>
</tr>
<tr>
<td>I feel more normal on medication</td>
<td>21 (63.6%)</td>
<td>13 (36.4%)</td>
</tr>
<tr>
<td>It is up to the doctor to decide when I should stop taking medication</td>
<td>20 (60.6%)</td>
<td>12 (36.4%)</td>
</tr>
<tr>
<td>I am more aware of what I am doing of what is going on around me when I am on medication</td>
<td>19 (57.6%)</td>
<td>14 (42.4%)</td>
</tr>
<tr>
<td>It is unnatural for my mind and body to be controlled by medication</td>
<td>15 (45.5%)</td>
<td>17 (54.5%)</td>
</tr>
<tr>
<td>Medications make me feel tired and sluggish</td>
<td>14 (42.4%)</td>
<td>19 (57.6%)</td>
</tr>
<tr>
<td>Taking medications will do me no harm</td>
<td>12 (36.4%)</td>
<td>20 (63.6%)</td>
</tr>
<tr>
<td>The unpleasant effects of medication are always present</td>
<td>12 (36.4%)</td>
<td>20 (63.6%)</td>
</tr>
<tr>
<td>I am given medication to control behaviour that other people (not myself) don’t like</td>
<td>10 (30.3%)</td>
<td>23 (69.7%)</td>
</tr>
<tr>
<td>I feel strange, doped up on medication</td>
<td>9 (27.3%)</td>
<td>24 (72.7%)</td>
</tr>
<tr>
<td>I know better than the doctors when to stop taking medication</td>
<td>8 (24.2%)</td>
<td>25 (75.8%)</td>
</tr>
<tr>
<td>I don’t need to take medication once I feel better</td>
<td>7 (21.2%)</td>
<td>26 (78.8%)</td>
</tr>
<tr>
<td>Things that I could do easily are much more difficult when I am on medication</td>
<td>7 (21.2%)</td>
<td>25 (75.8%)</td>
</tr>
<tr>
<td>Medications are slow acting poisons</td>
<td>6 (18.2%)</td>
<td>25 (81.8%)</td>
</tr>
<tr>
<td>I can’t concentrate on anything when I am taking medication</td>
<td>5 (15.2%)</td>
<td>28 (84.8%)</td>
</tr>
<tr>
<td>I am no different on or off medication</td>
<td>5 (15.2%)</td>
<td>28 (84.8%)</td>
</tr>
<tr>
<td>I take medication only when I feel ill</td>
<td>3 (9.1%)</td>
<td>30 (90.9%)</td>
</tr>
<tr>
<td>If I take medication, it's only because of pressure from other people</td>
<td>2 (6.1%)</td>
<td>31 (93.9%)</td>
</tr>
<tr>
<td>I can’t relax on medication</td>
<td>1 (3.0%)</td>
<td>32 (97.0%)</td>
</tr>
<tr>
<td>I would rather be ill than take medication</td>
<td>1 (3.0%)</td>
<td>32 (97.0%)</td>
</tr>
</tbody>
</table>
8.3 Challenging Behaviour and Psychotropic Medication

This section of the study examines the relationship between self-reported challenging behaviour and psychotropic medication. Firstly, the data for challenging behaviour across the whole sample of adult respondents is described and the relationship between demographic variables and challenging behaviour is explored. Then, the relationship between challenging behaviour and medication status (current users, previous users, and non-users) is examined. The differences between individuals with challenging behaviour who currently take psychotropic medication and those who do not are then explored.

In response to a question about difficulties in managing their behaviours, the majority of total adult respondents (79.4%) reported at least sometimes having difficulty, with 20.6% reporting regular difficulties. The number of reported challenging behaviours ranged from zero to seven (see Table 8.3.1) ($M = 2.39$, $SD = 1.85$), with the majority of participants (79.4%) indicating at least one challenging behaviour. A Mann-Whitney U test revealed no significant difference in the mean number of challenging behaviours reported by males ($Md = 2$, $n = 42$) and females ($Md = 2$, $n = 21$), $U = 412.0$, $z = -.43$, $p = .67$, $r = .058$. 
Table 8.3.1

*Frequency and Percentage of Challenging Behaviour (N = 63)*

<table>
<thead>
<tr>
<th>No. of Behaviours</th>
<th>Males n = 42</th>
<th>Females n = 21</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
</tr>
<tr>
<td>0</td>
<td>9</td>
<td>21.4</td>
<td>4</td>
</tr>
<tr>
<td>1</td>
<td>7</td>
<td>16.7</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>9</td>
<td>21.4</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>14.3</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>14.3</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>4.8</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>4.8</td>
<td>2</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>2.4</td>
<td>1</td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>2.29</td>
<td></td>
<td>2.48</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>42</td>
<td>100.0</td>
<td>21</td>
</tr>
</tbody>
</table>

Participant responses to ‘describe any behaviours you have difficulty managing’ were coded into four categories of behaviours: aggressive, stereotyped/self-injurious, emotion-related or other disruptive behaviours.

Aggressive behaviours included verbal and physical aggression towards other people, as well as property destruction. Stereotyped/self-injurious behaviours included repetitive routines, obsessions and self-harming behaviours (e.g. cutting, hurting oneself). Emotion-related behaviours included anxiety, depression and psychosis. Other disruptive behaviours included sleep and social difficulties.

Table 8.3.2 displays the frequency and percentage of individuals reporting one or more of these categories of behaviours. The majority (74.0%) identified at least one emotion-related challenging behaviour, with many (60.0%) also indicating they experienced difficulty with stereotyped/self-injurious behaviour. Chi-Square Tests for Independence indicated that the overall presence of challenging behaviour did not significantly relate to the type of ASD diagnosis ($p$
= .34), gender (p = 1.00), level of impairment (p = .47), cognitive ability (p = .58), age group (p = .22), communication ability (p = .20) or the reported presence of a mental health condition (p = .31). Chi-Square Tests of Independence examined whether the type of challenging behaviour related to gender. No significant differences were observed between the type of behaviour reported and gender.

Table 8.3.2

*Frequency of Participants Reporting Types of Challenging Behaviour (n = 50)*

<table>
<thead>
<tr>
<th>Type of Behaviour</th>
<th>Number of Behaviours</th>
<th></th>
<th>Total Sample</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
</tr>
<tr>
<td>Aggression</td>
<td>16</td>
<td>32.0</td>
<td>3</td>
<td>6.0</td>
<td>19</td>
</tr>
<tr>
<td>Emotion-related</td>
<td>20</td>
<td>40.0</td>
<td>17</td>
<td>34.0</td>
<td>37</td>
</tr>
<tr>
<td>Stereotyped/Self-injurious</td>
<td>16</td>
<td>32.0</td>
<td>14</td>
<td>28.0</td>
<td>30</td>
</tr>
<tr>
<td>Other disruptive</td>
<td>9</td>
<td>16.5</td>
<td>1</td>
<td>2.0</td>
<td>10</td>
</tr>
</tbody>
</table>

The relationship between reported medication use and reported difficulty in managing behaviour was examined. A Chi-Square Test of Independence indicated no significant relationship between medication status and presence of challenging behaviour, \( \chi^2 (n = 63, df = 2) = 5.091, p = .078, \) Cramer’s \( V = .28. \) A Kruskal-Wallis test was conducted to determine if there were significant differences between the numbers of challenging behaviours across the three sample groups. No significant differences were observed (current medication users, \( n = 33 \); previous users, \( n = 8 \); non-users, \( n = 19 \)), \( \chi^2 (n = 63, df = 2) = 2.84, p = .24. \)
Chi-Square Tests of Independence were also conducted to determine if there was a relationship between the type of challenging behaviour and medication status (Bonferroni adjustments reduced the significance level to \( p < .017 \)) (see Table 8.3.3). There were no significant relationships observed between medication status and the type of concerning behaviour.

Table 8.3.3

The Relationship between Medication Status and Specified Type of Behaviour (\( N = 63 \))

<table>
<thead>
<tr>
<th>Challenging Behaviour</th>
<th>( Df )</th>
<th>( \chi^2 )</th>
<th>( p )</th>
<th>Cramer's ( V )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Injurious</td>
<td>2</td>
<td>5.65</td>
<td>.05</td>
<td>.30</td>
</tr>
<tr>
<td>Emotion-Related</td>
<td>2</td>
<td>3.86</td>
<td>.15</td>
<td>.25</td>
</tr>
<tr>
<td>Aggression</td>
<td>2</td>
<td>3.44</td>
<td>.18</td>
<td>.23</td>
</tr>
</tbody>
</table>

Note: *** significant at \( p < .001 \), ** significant at \( p < .01 \), * significant at \( p < .05 \)

A Mann-Whitney U test was conducted to examine if the number of challenging behaviours differed between those who reported taking an anti-depressant and those who did not. No significant difference was found between those who reported taking an anti-depressant (\( Md = 2, n = 20 \)) and those who did not (\( Md = 2, n = 43 \)), \( U = 376, z = -.81, p = .42 \).

8.4 Mental Health and Psychotropic Medication

This section of the study examines the relationship between comorbid mental health conditions and psychotropic medication. The data for comorbid mental health conditions is presented across the whole sample and demographic variables. The relationship between medication status (current use, previous use, and non-users) and comorbid mental health conditions is presented next. Lastly,
the differences between those with comorbid mental health conditions currently taking psychotropic medication are examined.

Participants were requested to report whether they currently experienced any mental health difficulties and if so, whether they had received a formal diagnosis for this condition. The majority of adults reported experiencing at least one mental health difficulty (79.6%), while a significant proportion indicated experiencing two or more mental health conditions (61.6%). Table 8.4.1 displays the mental illnesses, as reported by participants. The majority of adults with an ASD reported difficulty with anxiety. Further, a large proportion of the sample reported experiencing depression, with almost all having been formally diagnosed. A formal diagnosis of both depression and anxiety was reported by 35.6% of the sample. Chi-Square Tests for Independence indicated that the presence of an anxiety disorder (formally diagnosed) did not significantly relate to the type of ASD diagnosis \((p = .84)\), gender \((p = .38)\), level of impairment \((p = .84)\), age group \((p = .55)\) or communication ability \((p = .08)\). Similarly, a formal diagnosis of depression did not significantly relate to the type of ASD diagnosis \((p = .29)\), gender \((p = .93)\), level of impairment \((p = .79)\), age group \((p = .78)\) or communication ability \((p = .66)\). A Chi-Square Test of Independence indicated a significant association between depression and anxiety \(\chi^2 (n = 63, df = 1) = 15.01, p < .001, \phi = .50\); that is those who reported experiencing depression were more likely to report anxiety than those who did not.
Table 8.4.1

<table>
<thead>
<tr>
<th>Mental Health Condition</th>
<th>Presence of Condition</th>
<th>Formally Diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>45</td>
<td>71.4</td>
</tr>
<tr>
<td>Depression</td>
<td>32</td>
<td>52.4</td>
</tr>
<tr>
<td>ADHD</td>
<td>9</td>
<td>14.3</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>4</td>
<td>6.3</td>
</tr>
<tr>
<td>Post-traumatic stress disorder</td>
<td>2</td>
<td>3.2</td>
</tr>
<tr>
<td>Obsessive compulsive disorder</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>Schizoaffective disorder</td>
<td>1</td>
<td>1.6</td>
</tr>
</tbody>
</table>

The relationship between medication status (current user, previous user, or non-user) and comorbid mental health diagnosis was examined. A Chi-Square Test for Independence indicated a significant association between medication status and the presence of a mental health condition, \( \chi^2 \) \( (n = 63, df = 2) = 8.53, p = .014 \), Cramer’s \( V = .39 \). Further Chi-Square analyses were conducted to determine if there was a significant relationship between medication status (current users, past users and non-users), with the two most commonly reported mental health diagnoses (depression & anxiety) (see Table 8.4.2.). Bonferonni adjustments (Tabachnik & Fidell, 2007) were conducted to reduce Type I error, and as such, reduced significance levels for mental health diagnoses to \( p < .017 \). Medication status significantly related to a diagnosis of anxiety, but not depression. Follow-up analyses indicated that those who reported a diagnosis of anxiety were more likely to be currently taking medication.
Table 8.4.2

The relationship between Medication Status (Current User, Previous User, Non-User) and Comorbid Depression and Anxiety

<table>
<thead>
<tr>
<th></th>
<th>df</th>
<th>$\chi^2$</th>
<th>p</th>
<th>phi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>2</td>
<td>9.83</td>
<td>.01**</td>
<td>.40</td>
</tr>
<tr>
<td>Depression</td>
<td>2</td>
<td>5.90</td>
<td>.05</td>
<td>.31</td>
</tr>
</tbody>
</table>

Note: *** significant at p < .017,

A Mann-Whitney U test revealed a significant mean difference in the number of medications prescribed for those with mental health diagnoses ($Md = 1, n = 50$) and those who did not ($Md = 0, n = 13$), $U = 206, z = -2.21, p = .027, r = .28$. That is, those who reported having a mental health diagnosis were more likely to report taking a higher number of medications than those who did not have a diagnosis.

Additional Mann-Whitney U tests were conducted to determine if there was a significant difference between the number of medications prescribed for those who reported a formal diagnosis of depression, anxiety, or both depression and anxiety, and those who did not (Bonferroni adjustments reduced significance to $p < .017$). A significant difference was found in the number of medications prescribed for those who reported a diagnosis of anxiety ($Md = 1, n = 34$) and those who did not ($Md = 0, n = 29$), $U = 318, z = -2.64, p = .008, r = .33$. That is, those who reported a diagnosis of anxiety were more likely to report taking a higher number of medications than those who did not. A significant difference was found in the number of medications prescribed for those who reported a diagnosis of anxiety and depression ($Md = 1, n = 23$) and those who did not ($Md = 1, n = 22$), $U = 197, z = -2.54, p = .011, r = .32$. That is, those who reported a diagnosis of anxiety and depression were more likely to report taking a higher number of medications than those who did not.
0, \( n = 40 \), \( U = 284.5 \), \( z = -2.74 \), \( p = .006 \), \( r = .35 \). However, a significant difference was not observed in the number of medications prescribed for those who reported a diagnosis of depression alone (\( Md = 1 \), \( n = 33 \)) and those who did not (\( Md = 0 \), \( n = 30 \)) \( U = 340 \), \( z = -2.34 \), \( p = .019 \), \( r = .30 \).

### 8.5 Sleep and Psychotropic Medication

The majority of participants (69.8%) reported experiencing some difficulty with sleep; a smaller number of participants (19.0%) indicated they had been formally diagnosed with a sleep disorder. Chi-Square Tests of Independence were conducted to determine if there was a relationship between reporting of sleep difficulties, gender, age group, type of ASD communication ability, or level of impairment. Table 8.5.1 presents the findings. Bonferroni adjustments (Tabachnik & Fidell, 2007) were conducted to safeguard against type-one error, reducing the significance level to \( p < .013 \). Age group related to sleep difficulties, with those aged 18–29 and 30–55 more likely to report sleep difficulties than those aged over 55.

Table 8.5.1.1

**Relationship between Overall Reported Sleep Difficulties and Demographic Characteristics (\( N = 63 \))**

<table>
<thead>
<tr>
<th></th>
<th>( df )</th>
<th>( \chi^2 )</th>
<th>( p )</th>
<th>( \phi )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>1</td>
<td>1.14</td>
<td>.29</td>
<td>-.17</td>
</tr>
<tr>
<td>Age group</td>
<td>2</td>
<td>11.69</td>
<td>.00*</td>
<td>-.43</td>
</tr>
<tr>
<td>Type of ASD</td>
<td>2</td>
<td>1.06</td>
<td>.59</td>
<td>.13</td>
</tr>
<tr>
<td>Communication ability</td>
<td>2</td>
<td>0.06</td>
<td>.97</td>
<td>.03</td>
</tr>
<tr>
<td>Level of impairment</td>
<td>2</td>
<td>0.88</td>
<td>.64</td>
<td>.12</td>
</tr>
</tbody>
</table>

Note: significant at \( p < .013 \)*
Participants were requested to report any specific difficulties they had experienced over the previous two weeks in the domains of falling asleep, staying asleep or early wakening, and to rate these in terms of severity. Table 8.5.1.2 presents the frequency and percentage of participants reporting each sleep difficulty according to severity. Difficulty with falling asleep was reported by 58.7% of the sample, with 57.1% reporting moderate levels of sleep difficulties across the three domains. The majority of participants (69.8%) reported difficulty in at least one sleep domain, with 27.0% indicating difficulties in two domains of sleep, while a smaller percentage of the overall sample (19.0%) reported difficulty in all three domains.

Table 8.5.1.2

Sleep Difficulties Reported by Participants According to Severity (N = 63)

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Minor</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very Severe</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>Falling asleep</td>
<td>15</td>
<td>23.8</td>
<td>12</td>
<td>19.0</td>
<td>7</td>
</tr>
<tr>
<td>Staying asleep</td>
<td>9</td>
<td>14.3</td>
<td>13</td>
<td>20.6</td>
<td>3</td>
</tr>
<tr>
<td>Problem waking too early</td>
<td>8</td>
<td>12.7</td>
<td>11</td>
<td>17.5</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32</strong></td>
<td><strong>36</strong></td>
<td><strong>14</strong></td>
<td><strong>7</strong></td>
<td><strong>-</strong></td>
</tr>
</tbody>
</table>

**8.5.1 Mental health and sleep.**
Chi-Square Tests of Independence (Bonferroni adjustment; \(p < .017\); Tabanack & Fiddell, 2007) were conducted to determine if there was a significant association between those who reported some form of sleep difficulty (from any domain or severity) and diagnosis of anxiety, depression or ADHD. As indicated in Table 8.5.1.3, there was no significant relationship observed with the reduced significance level. However, the relationship between the presence of an anxiety disorder and difficulties with sleep appears to approach significance.

Table 8.5.1.3

<table>
<thead>
<tr>
<th></th>
<th>df</th>
<th>(\chi^2)</th>
<th>(p)</th>
<th>(phi)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>1</td>
<td>4.29</td>
<td>.04</td>
<td>.30</td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>2.29</td>
<td>.13</td>
<td>.23</td>
</tr>
<tr>
<td>ADHD</td>
<td>1</td>
<td>0.31</td>
<td>.57</td>
<td>-.07</td>
</tr>
</tbody>
</table>

*Note: *** significant at \(p < .017\)*

Sixteen participants reported using medication to assist with their sleep difficulties. Participants reported using the following medications to assist with sleep: sertaline, codeine, antihistamines, sodium valproate, fluvoxamine, melatonin, mirtazapine, quetiapine, zolpidem, temazepam and agomelatine. A Chi-Square Test of Independence indicated no significant difference (Yates Continuity Correction) between the gender of those taking medication to assist with sleep and those who were not \(\chi^2 (n = 63, df = 2) = .51, p = .47, phi = -.13\).

A Chi-Square Test of Independence was conducted to determine if there was a relationship between medication status and reporting of overall sleep difficulties.
difficulties. No significant association was found ($\chi^2 (n = 63, df = 2) = 1.37, p = .50, \phi = .15$); that is, those who reported experiencing sleep difficulties were not more likely to be currently taking medication than those without. Neither was any significant relationship found between anti-depressant use and reported sleep difficulties ($\chi^2 (n = 63, df = 2) = .098, p = .75, \phi = -.077$).

The relationship between the three domains of sleep difficulties and anti-depressant use was examined (Bonferroni adjustment; $p < .017$; Tabachnik & Fidell, 2007). Table 8.5.1.4 presents the findings. As can be seen, no significant relationships were found at this reduced significance level.

Table 8.5.1.4

<table>
<thead>
<tr>
<th></th>
<th>Anti-depressant Use (U)</th>
<th>(p)</th>
<th>(Z)</th>
<th>(R)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty falling asleep</td>
<td>362</td>
<td>.29</td>
<td>-1.05</td>
<td>.13</td>
</tr>
<tr>
<td>Difficulty staying asleep</td>
<td>355</td>
<td>.22</td>
<td>-1.24</td>
<td>.16</td>
</tr>
<tr>
<td>Early wakening</td>
<td>301</td>
<td>.03</td>
<td>-2.18</td>
<td>.35</td>
</tr>
</tbody>
</table>

*Note: *significant at \(p < .017\),

In summary, 63 adults independently completed the questionnaire; most had a diagnosis of Asperger’s disorder without an intellectual disability. Over two thirds of the sample reported having one mental health difficulty, with those having mental health difficulties also being more likely to report sleep difficulties. Thirty-three adults reported using medication to assist with management of emotions and behaviours associated with their ASD. The majority reported taking anti-depressant medication, with only a small proportion (20.5%) using multiple
medications. Participants who indicated they had a diagnosed mental health
condition were more likely to be currently taking psychotropic medication.
Further analysis revealed that participants who reported having a diagnosis of
anxiety or anxiety with depression were more likely to report taking psychotropic
medication than those who did not. The majority of participants indicated they did
not believe the medication they were taking was restrictive, and rated the
medication as being helpful.
Chapter 9: Discussion Study 2

The purpose of Study 2 was to gain an understanding of the use of psychotropic medication, from the perspective of an Australian sample of adults with an ASD. Although previous research had captured findings regarding adults residing in state-based accommodation (e.g., Webber et al., 2010), the current study adds to the literature through its focus on medication use in community-based adults with ASD, who are able to self-report. In this chapter, the results of Study 2 are explored and the findings are discussed in the context of previous research. Individuals who reported psychotropic medication use were compared with those who had previously used medication and those who never had; and also according to gender, age, ASD diagnosis and the presence of intellectual disability. The views and experiences of adults were explored, and a particular focus was placed on describing medication use in those who presented with comorbid mental health conditions, challenging behaviour and sleep difficulties. The limitations of the study, recommendations for future research and the clinical implications of the findings are also discussed.

9.1 Description of Sample

The majority of participants indicated they were diagnosed with Asperger’s disorder, lived independently and had communication skills enabling them to articulate their views. This was expected, given that the study aimed to recruit independent adults who were able to provide self-report data on their current medication use. The gender ratio observed in the sample of one female to
three males indicated a higher number of females than the widely accepted one to four ratio (Fombonne, 2003). This may be attributed to a bias in females participating in this study or alternatively may be the result of a higher number of females diagnosed with Asperger’s disorder.

9.2 Extent of Use

The rates of psychotropic medication use observed in the sample of self-reporting adults in this study (52%) was somewhat lower than the rates of 57 to 64 per cent reported in recent international research on adults residing in residential care (Esbensen et al., 2009). However, the rates in this study are well within those identified across the literature (30 to 81%) (Aman et al., 2005; Esbensen, Greenberg, Seltzer & Aman, 2009, Green et al., 2006; Mandell et al., 2008; Memari et al., 2012; Oswald & Sonenklar, 2007; Whitwer & Lecavalier, 2005). Lower rates may have arisen from the community-based nature of the sample, in comparison to the majority of research to date that has been conducted on adults living in residential care settings and who by virtue of this are likely to be more significantly impaired (Esbensen et al., 2009). Alternatively, this relatively lower rate in this study may arise from the small number of participants with a comorbid intellectual disability, given the reported high level of psychotropic drug prescription to people with intellectual disabilities (Aman et al., 2002).

In this study, most participants reported current use, with only a small proportion reporting previous use. This is in keeping with findings from longitudinal research in those with an ASD and co-morbid intellectual disability.
indicating that those who commence taking medication are unlikely to cease its use (e.g., Esbensen et al., 2009; Aman et al., 2005). It would be beneficial for future researchers to undertake a more in depth exploration of those who previously used psychotropic medication, the reasons for discontinuation and their views on medication. This would enable greater understanding of the variables that influence cessation.

The findings did not support any relationship between the use of psychotropic medication and type of ASD. This result may simply reflect the high number of participants with Asperger’s disorder in the sample.

9.3 Gender and Age

A further aim of this study was to examine differences in the use of psychotropic medication across age and gender. The findings are in contrast with previous research on those with an ASD and an intellectual disability, which found that males were more likely to receive psychotropic medication (Aman et al., 2003). It is plausible that there may be no differences in the use of medication according to gender in self-reporting adults with ASD in Australia. However, these findings may also reflect a bias in the population who participated in this study. Overall, the type of medication use appeared to be similar across males and females, with anti-depressant medication being the most commonly taken psychotropic medication for both. However, more females reported using anti-convulsants, none used hypnotic sedatives or CNS stimulants. Given the small number of overall participants reporting taking these medication types, it is impossible to know whether this is a result of a pattern in differences in
prescription or a sampling error (due to the small sample size). A larger study investigating the use of medication in this population is clearly warranted.

In addition to gender, age has been established in the literature as a variable relating to psychotropic medication use (e.g., Aman et al., 2003; Aman et al., 2005). In this study, however, age did not appear to affect either mean number or type of medication, irrespective of whether participants were previous, current or non-medication users. This contrasts with previous research on adults with intellectual disability, in which those who were younger appeared to receive higher levels of medication (Aman et al., 2003, 2005; Esbensen et al., 2009 McGillivray & McCabe, 2004). The differences in findings may be attributed to an older mean age in the present study, or alternatively the higher proportion of participants in those with ASD without an intellectual disability. Further exploration of the relationship between psychotropic medication and age is indicated to address this question.

9.4 Attitudes and Perceptions

An additional key aim of this study was to explore the perspectives of self-reporting adults with an ASD on psychotropic medication as an option for reducing challenging behaviour or for the treatment of comorbid psychiatric conditions. This was explored in terms of the reason for medication use, perceived helpfulness, overall satisfaction with the medication and the extent to which they perceived the medication as restrictive.

The most commonly reported reason for medication use was depression, followed by anxiety and mood stabilisation. These apparent emotional difficulties
are likely symptomatic of a mental illness. In contrast, only a small number of participants reported that medication was used to assist with the management of behaviours and stereotypies. In addition, it was found that anti-depressants were most commonly reported for treatment of anxiety and depression. This indicates that while many participants reported having difficulty with challenging behaviours (see Section 9.6), this was not the reported primary reason for using psychotropic medication. There could be a myriad of reasons why challenging behaviours were not reported as the primary reason; for example, the person may not feel that they have challenging behaviours, self-reporting adults may feel the need to justify their decision to use medication in the survey; alternatively they may have wanted to avoid the viewpoint that medication was used as a form of restraint. Conversely, practitioners may be prescribing medication based on comorbid mental health conditions.

A possible explanation for why participants indicated mental health as the primary reason for taking medication is to avoid the perception of medication as a form of restraint. The study explicitly explored whether participants believed the psychotropic medication they were taking was restrictive. There have been significant questions raised in the literature as to the appropriateness of psychotropic medication for the management of behaviours, or the treatment of symptoms co-occurring with ASD (Aman et al., 2005; Matson et al., 2011; Webber et al., 2010). Consistent across types of medications, most participants did not view their psychotropic medication use as restrictive. For example, the majority of participants endorsed the item, ‘I take medications of my own free
will.’ This perception that medication was not restrictive may be a result of the large number of participants reporting primary use for mental health purposes.

This explanation is consistent with literature and legislation endorsing the view that psychotropic medication use is not restrictive if it is used for the treatment of a comorbid mental health condition (Victorian Government, 2009; Webber et al., 2010). It is also possible these adults view themselves as being empowered in their decision making around medication use, and as such do not view it as restrictive.

Research investigating the perspectives of adults with an ASD on the use of psychotropic medication is limited. In this study, most adults perceived psychotropic medication as helpful, with a trend for those taking anti-psychotics and anti-depressants to indicate these as particularly helpful. In addition, it was found that adults had a positive attitude towards taking their medication, with findings indicating that the majority accepted their medication. The overwhelming proportion of participants acknowledged, ‘For me the good things about medication outweigh the bad’ and ‘I am happier and feel better when I am taking medications.’ This indicates that in this sample of adults with ASD, the use of psychotropic medication was a predominantly positive experience. Given the above statement, this suggests there is a partial role for the use of psychotropic medication in this population.

The findings of this study indicated that participants were concerned about the side effects of medications. A large number of participants indicated that medications ‘make me feel tired and sluggish’ and that medications ‘do harm.’
This corresponds with a body of research indicating the presence of concerning side effects from many medications (e.g., Valdovinos et al., 2005, Williams et al., 2012).

9.5 Mental Health and Psychotropic Medication Use

A further goal of the study was to examine whether mental health difficulties related to the use of psychotropic medication. Most participants (79.6%) reported experiencing at least one comorbid mental illness. This finding was higher than expected, as previous research has reported that 42 per cent of adolescents and adults with an ASD had a comorbid mental illness (Mosley et al., 2011). This difference may be accounted for by the robust approach to diagnosis used in the Mosley et al. study, including the use of semi-structured clinical interviews and specific measures of psychopathology, compared to the self-report data collected in the present study. Additionally, this may be explained by the differences in the samples used, with those in Mosley’s study being largely dependent on others for support and having a comorbid intellectual disability (79%). It was also likely that those participating in this study reported a diagnosis received some time ago; one that may no longer be accurate. This may be due to an incorrect initial diagnosis, the illness abating or successful treatment. The practitioners who were diagnosing may have had difficulty distinguishing between ASD symptoms and comorbid conditions (Heidgerken et al., 2005).

While it is difficult to determine the exact rate of comorbid psychiatric conditions in those with an ASD, the present study supports the consistently higher reported rates of comorbid mental health conditions in those with an ASD
when compared to the general population (Mosley et al., 2011; Morgan et al., 2003). These comorbid conditions are reflected in higher levels of distress in these individuals; consequently, there is a need for adequate diagnosis and treatment.

The most commonly diagnosed comorbid mental health condition was anxiety, followed by depression and ADHD. Those with a diagnosis of depression were also more likely to have a diagnosis of anxiety. The prevalence of anxiety and depressive disorders observed in this study appears to be significantly greater than the prevalence reported by neurotypical adults (e.g., Goldney, Eckert, Hawthorne & Taylor, 2010; Hollingworth, Burgess & Whiteford, 2010). There has been much debate in the literature about whether anxiety is a central component of ASD or is a separate condition (Gillott & Standen, 2007; Matson & Nebel-Shawalm, 2007). In this study, a high number of individuals reported diagnosis of an anxiety condition. One of the reasons for this high level of comorbidity may be the difficulty with differential diagnosis in this population. This suggests a need for clearer guidelines in determining when anxiety becomes pathological in those with an ASD and delineating the crossover of anxiety with sensory issues (Heidgerken et al., 2005).

The hypothesis that individuals with comorbid mental health conditions were more likely to be prescribed psychotropic medications was supported, both in terms of current use and higher number of medications. The finding that current use was associated with comorbid mental health conditions was consistent with previous research on children and adults with an ASD (Mandell et al., 2008;
Memari et al., 2013; Morgan et al., 2003). Moreover, the findings were consistent with Morgan and colleagues’ findings demonstrating that those who were using medication were more likely to report a diagnosis of anxiety, or anxiety and depression, but not depression alone (Morgan et al., 2003). The present study’s findings indicate a difference in medication prescription among those who reported anxiety, as opposed to depression alone. This result may have occurred, as those with anxiety tend to experience higher levels of cognitive and somatic arousal, and thus make their symptoms more overt to medical practitioners (Harvey, 2002). In contrast, those with depression are more likely to be withdrawn, and may not seek help in the same way (Barlow & Durand, 2005).

Increasing research attention has been focused on the relationship between ASD and comorbid mental illnesses. This body of literature has reported a large variation in the estimates of comorbid conditions ranging from 40 to 70 per cent (Lugnegard, Hallerback & Gillberg, 2011; Simonoff et al., 2008; Tsakanikos, Underwood, Kravariti, Bouras & McCarthy, 2011). These findings, along with the present study, suggest that comorbid mental health conditions are common in this population. They are common in comparison with the neurotypical population and those with other disabilities (Mosley et al., 2011). Given the high level of medication use reported in this population, there is a need for practitioners to conduct thorough assessments to explore differential diagnosis among this population and for non-pharmacological interventions targeting comorbidity to be developed and trialled in adults with ASD. This would allow greater choice when selecting interventions for the treatment of comorbid mental health conditions.
Moreover, preventative health programmes may benefit this population, focusing on early identification and management of emotions, particularly anxiety and depression.

## 9.6 Challenging Behaviour and Psychotropic Medication

The findings of this study indicate that most of the participants had difficulty managing their behaviour ‘some’ or ‘all of the time’. Of those reporting difficulties with behaviour, they most commonly reported difficulty with emotion-related and stereotyped/self-injurious behaviours. Those reporting difficulties with emotions and the presence of stereotyped/self-injurious behaviours believed these presented as challenging behaviours. It has been previously suggested that both difficulty with emotions and stereotyped/self-injurious behaviours can be symptoms of mental illness (Matson & Nebel-Shwalm, 2007). This poses a diagnostic dilemma related to aetiology as it may not be possible to always establish the primary cause of each difficulty in this population. However, participants perceived these behaviours as challenging, and therefore it is important to consider these difficulties when working with individuals with an ASD.

It was hypothesised that those who reported psychotropic medication use would be more likely to report difficulties with challenging behaviour (in terms of its both presence and number of behaviours). However, the findings did not support this hypothesis, instead indicating no difference in those reporting challenging behaviours and their medication status (current use, previous use, non-user), or in the mean number of behaviours reported by each group. In
addition, no relationship was found between medication status and the type of challenging behaviour reported. This was inconsistent with previous suggestions that those who exhibit challenging behaviour were more likely to receive psychotropic medication (Matson & Hess, 2011). This may be the result of medical professionals deeming these adults as having the capacity to engage in alternative interventions (e.g., CBT or social skills training). Alternatively, they may be self-selecting other forms of intervention (counselling, sensory skills training).

9.7 Sleep and Psychotropic Medication Use

The majority of the adult participants with ASD reported having sleep difficulties; a proportion of these reported they had been diagnosed with a sleep disorder. This is consistent with previous research suggesting that adults with Asperger’s disorder were more likely to report subjective sleep difficulties than neurotypical adults (Tani et al., 2004). However, sleep difficulties were not reported by any of the participants aged over 55 in the current study. The most likely reason for this appears to be the relatively small number of participants in this age group, given the large body of research indicating that sleep difficulties generally become more prevalent in older age (e.g., Foley, Ancoli-Israel, Britz & Walsh, 2004). Alternatively, sleep difficulties may abate in this population as they age. Given there is very little research exploring sleep in adults with an ASD in this age group, it is suggested that future research examine the sleep patterns of older individuals with an ASD.
The relationship between mental health diagnosis and sleep difficulties in those with ASD was further explored in this study. The findings indicated no significant relationships between the presence of depression, anxiety or ADHD and sleep difficulties. However, the relationship between anxiety and sleep difficulties did approach significance. This finding provided support for the suggestion by Tani and colleagues (2005) that anxiety may relate to sleep difficulties in this population. It is plausible that people with an ASD experience higher levels of cognitive and somatic arousal, thus making sleep a more difficult task to attain and maintain (Tani et al., 2005).

A large variety of medications for sleep was reported, with no one medication being more prominent than another. The hypothesis that individuals who reported overall sleep difficulties were more likely to report using psychotropic medication was not supported in the current study. Given the high level of sleep difficulties observed in this study, further investigation of sleep patterns in independent adults with an ASD appears warranted. Moreover, it would be beneficial to investigate if this population have similar patterns of melatonin deficiency to those observed in children (Brzezinski et al., 2005, Melke et al., 2008).

9.8 Limitations of the Findings

First and foremost, this study was deemed to have insufficient power; therefore, the findings need to be interpreted with caution. The study should be viewed as exploratory, highlighting where future research could be directed. A more comprehensive analysis with a larger sample would allow future research to
make more significant contributions to the literature. As was the case with Study 1, it is possible that individuals who hold strong views and perceptions about the use of psychotropic medication were more likely to participate in this study, and consequently a sampling bias may be present.

The focus of this study was on those adults who were able to self-report and who primarily lived independently in the community. The design of the questionnaire required them to be able to read and write, and to have adequate English proficiency. It is therefore likely that individuals with more significant difficulties who may be residing independently, as well as those with limited communication skills, were excluded from the study. It is suggested that future research attempts to replicate the study with participants with a variety of needs, to increase the generalisability of the findings.

The recruitment of only a small number of participants who had previously used medication was a notable limitation; as such, it restricted the level of analysis undertaken. This group was likely to provide key information as to whether they ceased medication because it was ineffective, was no longer needed or assisted them such that they no longer required it. It would have been beneficial to conduct more extensive comparisons between those who currently used medication with those who have previously used medication; consequently, this should be a consideration for future research.

It must be acknowledged that the Drug Attitude Inventory provided a limited viewpoint of individuals with relation to psychotropic medication. Other the viewpoints and processes included in the questionnaire are likely to be
identified. Moreover, the measure is designed explicitly to help to increase compliance with psychotropic medication which may have impacted findings. Further research would benefit from adopting a qualitative methodology to overcome problem and provide further information relating to individuals attitudes and views.

A significant additional limitation was that the study relied upon on the accuracy of self-report. It is plausible that this study captured some participants who may not meet ASD criteria. Participants may also have had deficits in knowledge concerning the topics covered (e.g. psychotropic medication, challenging behaviour, mental health conditions), and as such inadvertently provided inaccurate information. Moreover, this study did not include objective measures of challenging behaviours or mental health. Future research investigating psychotropic medication use would benefit from including a variety of assessment measures to confirm ASD diagnosis, intellectual ability, mental health conditions and challenging behaviours, to further strengthen the findings.

A final limitation of this study was the inability to comprehensively analyse and compare the dose of medications. This is a particularly difficult measure to obtain via online self-report. Future research may benefit from collecting information on dosage, as well as demographics associated with dosage of medication, for example weight, height and age, and comparing individual and informants’ perspectives across therapeutic ranges. In summary, although the
study was limited by a number of methodological considerations, it provides useful information surrounding psychotropic medication use in independent adults with an ASD in Australia.

9.9 Implications and Conclusions

This study has demonstrated that self-reporting adults with an ASD in Australia appear to be using psychotropic medication mainly for assistance with comorbid mental health difficulties, especially anxiety. The high prevalence of comorbid mental health conditions, and medication use to assist with these difficulties, has implications for those who provide care and support for this population. In particular, it emphasises the need for thorough mental health assessments and the possibility that medication may benefit those individuals with comorbidities. Moreover, it indicates the need for randomised controlled studies examining the benefit of psychotropic medications in the treatment of comorbid mental health conditions, most notably anxiety and depression, in this population.

In this study, the extent of anxiety in independent adults with ASD was substantial; a need for future research to explore the role of anxiety is indicated. The relationship between anxiety and the use of psychotropic medication was apparent. It is apparent from the observed prevalence, as well as the relationship it had with sleep and depression, that anxiety appears to have a significant influence on those with an ASD. Further exploration of these relationships would allow greater understanding of not only comorbid mental health conditions, but also provide further insight into psychotropic medication use. In addition, it would be
beneficial to compare the effectiveness of psychotropic medication with other
treatment options in this population (e.g., mindfulness, behavioural activation).

The findings indicate that many individuals with ASD find psychotropic
medication useful. Most do not view it as restrictive. Given the mixed views
about the helpfulness of psychotropic medication in people with an ASD, the
findings of this study provide a novel insight from the perspectives of those who
take the medications. It is central that these views are considered when
determining the effectiveness of medications in those with an ASD.

It is important that the findings and implications of the present study are
interpreted with caution, due to the current changing diagnostic criteria
surrounding ASD (e.g., APA, 2013). Some of the self-reporting adults with
Asperger’s disorder included in this study may not meet the new criteria for an
ASD. To what extent this would affect the findings remains unclear; however, it
emphasises the need for further research to establish the prevalence and rationale
for psychotropic medication use across the new diagnostic categories.

This study contributes to the understanding of psychotropic medication
use in self-reporting adults with an ASD. It provides a unique insight into the
views self-reporting adults on the benefits of medication, and how medication use
relates to mental health, challenging behaviours and sleep difficulties alongside
ASD.
Chapter 10: Study 3 Qualitative Analyses

A search of available literature on psychotropic medication use in people with ASD highlights a dearth of narrative accounts from caregivers and individuals with an ASD. Quantitative analysis provides important data. However, it does not allow for the individual insights that can be captured from those who observe and experience the impact of psychotropic medication use on a daily basis. Qualitative research enables this to occur and focuses on the subjective experience of caregivers and independent adults, and the meaning of their responses (Storey, 2007).

The third study of this thesis sought to enhance the quantitative data reported in Studies 1 and 2, by providing ‘free text’ areas for participants to provide greater details and personal perspectives in their response to questions. The goal of this study was to gain further understanding into the perceptions and viewpoints of caregivers and independent adults surrounding psychotropic medication use in people with an ASD, through narrative accounts. The intention of including the qualitative data was to complement the quantitative results, provide insight into the topics covered, capture a sense of (all) participants’ perspectives, and to inform future practice in this area. The qualitative data is presented as Study 3 in this thesis, and is comprised of two components: Study 3a and Study 3b. Study 3a examines the views and perspectives of caregivers regarding the use of psychotropic medication to manage undesirable emotions and behaviours associated with ASD. Obtaining an understanding of caregivers’
views is imperative since they generally make decisions around the use of psychotropic medication in their child/dependent adult. Study 3b focuses on the views and perspectives of independent adults with an ASD.

This chapter commences with an overview of the methodological approach used to analyse the qualitative data, followed by Study 3a results and discussion and Study 3b results and discussion. The limitations from both studies are then discussed, followed by an overall reflection on the findings.

10.1 Methodological Approach

Free text areas were provided in the questionnaire for participants to respond with their views on the reasons for use, the effectiveness of use, and their overall attitudes towards the use of psychotropic medication in the management of undesirable behaviours and emotions in people with ASD.

10.1.1 Participants

Of the 245 caregivers who completed Study 1, 173 provided additional comments that pertained to psychotropic medication use in people with an ASD to manage undesirable emotions or behaviours. These caregivers were providing care for a child/dependent adult with an ASD, who ranged in age from three to 45 years.

Of the 63 independent adults who completed Study 2, 46 provided comments that pertained to psychotropic medication use to manage undesirable emotions or behaviours associated with ASD. The age range of these participants was between 18 and 63 years.
10.1.2 Data analysis

A thematic analysis, as described by Braun and Clarke (2006), was used to explore the perspectives of both caregiver informants and individuals (independent adults) with an ASD, regarding the use of psychotropic medication to manage undesirable emotions and behaviours associated with ASD. A thematic analysis was selected as it is not theoretically bound, and is adaptable to the nature of the data provided, in response to open ended questions (Braun & Clarke, 2006). It allowed the researchers to organise and describe the data, as well as interpret its meanings. All data was analysed together, so as to not limit the analysis by the specific questions asked. The transcripts were initially read by the researchers to enable familiarity with the content. Key themes were then identified and meanings were generated. Statements were independently coded on the basis of their key concepts by two independent people, with inter-rater reliability found to be acceptable (caregivers $r = .80$; independent adults; $r = .83$). These results exceeded the suggested minimum reliability value ($r = .75$; e.g., Boyatzis, 1998; King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009). The meanings were then collated and grouped together according to clusters, with subthemes then identified. The thematic analysis revealed a number of emergent themes, with illustrative quotations available from caregivers and independent adults. The reported quotations include whether the person was the caregiver for a child/dependent adult who currently used psychotropic medication (Med), who previously used psychotropic medication (PMed) or who had never used such medication (NMed).
10.2 Results Study 3a

The following section presents the findings from an analysis of responses provided by informant caregivers, with regard to their experiences and views on using psychotropic medication to manage undesirable emotions and behaviours associated with an ASD. Findings are presented according to five linked themes: caregiver identity; emotional responses to the use of psychotropic medication; fear of side effects, the value of psychotropic medication and the burden of caregiving. Underlying these themes were two key subthemes: defensive responses and a pervasive sense of desperation.

10.2.1 Caregiver identity.

It was evident from the analysis that the caregiver identity of informants intertwined heavily with their view on the role of medication. The decision to administer psychotropic medication to their child/dependent adult appeared to be influenced by their individual identity and beliefs about their perceived role as a parent/caregiver. Some caregivers felt that medication was not warranted, or that they would not administer psychotropic medication because it conflicted with their perceived role to protect and nurture their child/dependent adult. Among those caregivers who administered psychotropic medication to their child/dependent adult with an ASD, many disclosed they struggled with this decision because children ‘should not’ take psychotropic medication. It appeared these caregivers had difficulty integrating this decision with their sense of who they were as a parent, their overall belief systems, and how they thought others perceived their decision:
I did not wish for my son to be prescribed any type of medication, but when you have a ten year old telling you he wants to kill himself it is terrifying. It still wasn’t until the Zoloft was prescribed for his tactile defensiveness that I finally succumbed. It seemed like a much more acceptable reason for medication than anxiety or depression. (CMed)

A dominant theme was caregivers’ perceptions of how psychotropic medication use related to their ‘duty’ to their child within their care-giving role.

The perception of ‘duty’ varied considerably. Some respondents emphasised a ‘duty’ to medicate to protect their child from harm at an emotional, social or behavioural level. Others conveyed a sense that they were failing in their ‘duty’ to protect and nurture their child, through resorting to using this type of medication. These caregivers viewed the use of psychotropic medication negatively, and as different from medications that were for prescribed for regular health ailments (e.g., cold and flu). This view appeared to be the basis for many respondents questioning their ability to parent, whether their decision to medicate was in the best interests of the child, whether it was doing harm to the child, and whether they were meeting their parental duty.

The complexity of the decision to use medication was evident. Many caregivers discussed the factors that affected their decision, which included individual factors, availability of informal and formal supports, level of interventions, and individual family situations. Caregivers stated that consideration of these factors needed to be balanced in deciding to medicate or
not. In addition, caregivers stated they felt the decision was a personal one, and that it should be made on the basis of each individual and their circumstances:

*ASD and the choice to use medication is a very personal decision for each situation. I believe it should be used as a last option and should be used alongside therapeutic services, help from medical professionals and behavioural services.* (NMed)

**10.2.2 Emotional responses to the use of psychotropic medication.**

Many caregivers expressed significant guilt regarding the need to use psychotropic medication for their child/dependent adult with an ASD. Guilt was expressed in terms of how their child/dependent adult affected relationships with partners, with other children, between siblings, within the family, and also the family’s relationship with the outside community. This was observed to be a consideration when deciding whether to use medication:

*Having a family member with autism impacts the whole family and means that we all live an autistic life.* (CMed)

It was evident that caregivers experienced complex emotional responses to the decision, and many felt their decision had been questioned by family, friends and other professionals. Many disclosed they believed it was a personal failure that their child/dependent adult required medication to assist with their behaviours and emotions, and expressed guilt relating to this. They also queried whether it related to their own coping and parenting abilities, rather than something within the child:
I hate that he needs them [medication] that they may have long term side effects and that I have failed to care for him without exposing him to the risks of those side effects. I hate that he is learning that when you have a problem, you pop a pill. I hate being on the divide of the parental line and it’s the side that no one wants to be on and that some people would never cross. I hate that I have had to cross the line. (CMed)

The feelings of guilt that many caregivers expressed appeared to be closely linked to a sense of desperation in their situation as a caregiver. A number of caregivers stated they felt totally consumed by their role as a caregiver of a child/dependent adult with an ASD, and that this role had become their identity. Some caregivers expressed concern about their capacity to continue caring for their child/dependent adult, with some stating they did not feel they could continue this role. Many caregivers specifically commented that without medication, they could no longer continue to care for the dependent adult/child with ASD. Many cited that despite tireless efforts, it was difficult to gain assistance from support services, and that even when they gained access, outcome successes were limited. These experiences led to the decision to resort to using psychotropic medication.

It was also evident that many caregivers felt a sense of desperation around the level of challenging behaviour displayed by the child/dependent adult for whom they cared. For example, a number of caregivers commented they felt that they had no choice but to use medication, otherwise the child/dependent adult would be required to be physically restrained, due to assaultive or self-harming
behaviour. Some caregivers reported that protecting the safety of their other children was essential, and that without medication they may not have been able to care for the child/dependent adult at home, due to the risk of harm to their other children:

*Medication is better than my child being physically restrained by people who do not understand his situation.* (CMed)

A small number of caregivers specifically described their anxiety regarding the effort to maintain the safety of the child/dependent adult, or other family members. Many reported they felt desperate about the need to stop a specific behaviour, and acknowledged the use of medication for restraint of behaviour:

*A 3 year old that throws dining room chairs across the room requires restraint for the safety of himself and those around him.* (CMed)

Many caregivers identified the pressure they felt regarding the decision to use medication to manage the child/dependent adult’s ASD symptoms, as well as a form of ‘restraint’. Pressure to use psychotropic medication was cited from a number of sources including schools, family members and professionals. School was consistently cited as a reason for ‘restraining’ their child, with other services also cited, including respite and care support agencies:

*I was continually badgered to try my son on medication by his school and I chose not to continue with it. I was subjected to negative responses and attitudes.* (PMed)
In contrast, other identified pressures came from the impact of negative community views on the decision to administer psychotropic medication, particularly in children. Specific comments on the role of the media in influencing how the public perceived medication use for children with an ASD were also provided:

*There is a great community pressure to avoid medication almost at all cost. Add to this the pressure to avoid any sort of medication for children and you have a dangerous pressure to avoid medication when it may be of great benefit to an individual.* (CMed)

This quote highlights the role of outside influences in decision-making by caregivers about medication use. It was apparent that caregivers perceived significant social pressure around the decision to use medication. This emphasizes the importance of the availability of clear and accurate information and support to assist families in decision making about medication use.

**10.2.3 Fear of side effects.**

It was evident through informant responses that significant concerns were present regarding the side effects of medication use in the ASD population. Caregivers reported that many children/dependent adults experienced weight gain associated with medication, ranging from four to 20 kilograms. Caregivers were concerned about the long term health effects of this weight gain. In addition, four caregivers reported that the child/dependent adult experienced tics or involuntary movements associated with the medication. Two caregivers reported their child experienced stunted growth, while other side effects reported by caregivers
included increased aggression, increased obsessional behaviours, headaches, stomach cramps and reduced cognitive functioning:

_He quite often had fast heart rate which distressed him and was getting extremely hot, he had trouble urinating and one eyelid began to droop after being on it for 6 weeks._ (PMed)

Many caregivers expressed concern regarding the long term outcomes of psychotropic medication use on children, and the effect of medication on the developing brain. Several stated they were aware that medications were prescribed ‘off-label’ to children, and some noted the lack of randomised controlled studies evaluating the long term effects of psychotropic prescriptions on this population. It was apparent that caregivers struggled with their level of responsibility in allowing a child/dependent adult to be medicated, when research was yet to extensively evaluate the evidence base for psychotropic medication in children, and the long term outcomes of this on the developing brain:

_Our research shows that these medications in kids this young are not properly researched and can have very dangerous side effects._ (NMed)

### 10.2.4 Value of psychotropic medication.

Despite the clearly negative themes identified, the value of medication in providing caregivers of children/dependent adults with improved quality of life was evident. Improvements in quality of life were reported, not only for caregivers themselves, but for the family unit as a whole. Many caregivers
reported improved sleep, reduced stress and lower levels of conflict in the house. In turn, this allowed them to care for the child/dependent adult to the best of their ability:

*It has changed my life. He goes to sleep and stays asleep with rarely a problem. I feel like I can cope.* (CMed)

In regards to the impact of medication on the family, caregivers commented on specific improvements in the relationship between siblings. Specifically, siblings were reported to have a reduction in exposure to aggressive outbursts by the child/dependent adult with ASD, which ultimately improved the lives of siblings:

*I tried for many years to avoid having any medication prescribed to my son, preferring to use natural remedies and supplements. I now think the whole family would have benefited if my son had been on melatonin sooner as his sleep difficulties caused a lot of additional stress to everyone in the family, particularly his sisters.* (CMed)

In addition to the reported value of medication to quality of life, caregivers noted significant positive changes in the child/dependent adult. For example, many caregivers reported that the child/dependent adult learnt new skills following the commencement of medication, with a few reporting that the child/dependent adult began to speak. In addition, some caregivers reported advancements in reading ability, with one respondent reporting that their child commenced writing:
He is now a different child, he started speaking 10 days after beginning medication and is now sleeping better, generally happier, more engaged and relaxed and now shows affection. (CMed)

...I truly believe it gives my son a better quality of life. (CMed)

Medication was also identified as being particularly useful in reducing aggression in children and dependent adults, such as hitting, kicking and biting. Many caregivers reported that lower rates of aggressive behaviour meant that the child/dependent adult was more readily able to access the community, which improved overall family functioning:

When not medicated he can smash windows, destroy a room in 5 minutes.
We see kicking biting, punching etc...On medication thought processes seem to be slowed right down, so intervention can actually occur when he is heightened. This is not possible un-medicating. (CMed)

Caregivers also noted improvements in attention and the concentration levels of children and dependent adults with an ASD, following the commencement of medication. The majority stated this allowed the person to participate more fully in school and home life, with some also noting improved social interactions:

Both of us (parents) and his teachers at school have remarked that he has settled and is able to focus better for longer periods since being on medication. (CMed)
A further theme that emerged was the reduction of anxiety. Anxiety was identified as particularly debilitating, and often interfered with the child/young person’s ability to participate in life:

*My daughter had so many fears that the anxiety was debilitating and she was too afraid to do just about anything... Now she can do just about anything.* (CMed)

Another theme that was evident was the benefit of medication in improving the child/dependent adults’ sleep patterns. Medication was noted to assist in falling asleep, staying asleep and reducing early wakening. Caregivers commented that with additional sleep, the child/dependent adults were often observed as calmer, happier and less anxious:

*Before he was prescribed Risperidome at the age of three his sleeping patterns were all over the place sleeping at 2, 3, 4 am etc., and waking up afternoon but within two weeks of taking this he went into a proper routine. He is also a lot calmer... a lot less hyperactive.* (CMed)

Many caregivers also reported they felt that medication reduced obsessional, ritualistic behaviours in the child/dependent adult. Caregivers reported that this often allowed for people to more fully participate in activities, as they were not so focused on rituals:

*It calms her down and reduces the repetitive behaviours which would get her so worked up. She was able to attend her school social without problems, something she would never have achieved prior.* (CMed)
10.2.5 Caregiver burden.

The burden of care giving appeared to be an influence in the decision of caregivers to use medication to assist the child/dependent adult with an ASD. Many caregivers spoke about the difficulties of being a carer, and that they often felt as if they could not cope without medication:

*Caring for someone with ASD is really wearing and I feel quite drained a lot of the time. The possibility of me working full time is really beyond what I could cope with and therefore we are financial disadvantaged due this disorder. So far medications have been a godsend for my daughter.*

(CMed)

Although the focus of this study was on the use of medications in managing emotions and behaviours associated with an ASD, many caregivers took the opportunity to provide general comments about the difficulty of caring for a child/dependent adult with an ASD. In particular, how ‘isolating’ being a caregiver could be and that often it was ‘a thankless job’. Many spoke of feeling as though they were alone in caring for the child/dependent adult, and that decisions pertaining to their child were theirs alone, as opposed to being shared with professionals and family members. Several caregivers felt excluded from the community as a result of their child/dependent adults’ behaviours, level of difficulties or lack of acceptance. A few caregivers commented that it takes a ‘community to raise a child with an ASD’; however, it was apparent this support was not widely available. Isolation from family, friends and community played a significant role in how respondents perceived their role and value as a caregiver.
Many felt that if they were a ‘better’ caregiver, this would not have resulted in social isolation. Others articulated the view that isolation stemmed from the negative judgment of their parenting made by the community:

*To care for someone with an ASD can be extremely challenging with family friends and the community to quick to judge and condemn...the toll on relationships is especially hard. (CMed)*

An additional theme related to the perception of informants that their caregiving ability was criticised by people who ought to be supporting them in their caring duties, including schools, teachers, psychologists and other professionals. A number of caregivers reported they felt dismissed by professionals, and that they were not treated as an expert in the child/dependent adult’s life. It was evident that this lack of respect affected their overall trust of professionals, in particular if they suggested medication:

*For people to understand they need to walk a mile in our shoes. This is especially when it comes to professionals who won’t listen and think they know your child better than their family does. (CMed)*

Caregivers reported that the lack of community acceptance and understanding of people with an ASD was a significant issue. This often resulted in the child/dependent adult being isolated from their community, family and friends. Also apparent was the view that medication was often used as a way to assist the individual with ASD to conform to societal norms and expectations regarding behaviour.
10.3 Subthemes Study 3a

Underlying the aforementioned themes, a subtheme of defensiveness was evident in the responses from caregivers surrounding the decision to use psychotropic medication for their child/dependent adult. Numerous caregivers provided multiple justifications as to why they had decided to use psychotropic medication. It appeared many felt the need to validate and explain the rationale for their decision. In particular, this defensiveness appeared to arise from a perception that using psychotropic medication in children and dependent adults was ‘bad’, and only permissible if they had a diagnosed mental health condition.

It was further identified that the defensiveness appeared to stem from a perception that psychotropic medication use had arisen from personal failure as a caregiver. This sense of failure appeared to originate from a feeling of continually being judged by people within their support systems, by professionals and by society at large, regarding the decision to administer psychotropic medication to their child/dependent adult.

An additional identified subtheme was a pervasive sense of desperation in caregivers, which served as the basis for psychotropic medication use. It appeared they were experiencing burnout, and were at a loss as to how to improve the life of the child/dependent adult for whom they cared. Medication provided the only option. It was apparent that caregivers did not feel well supported and there were suggestions that improved access to support may curb the need for medication. To summarise, society was also seen as partly responsible for the need to use psychotropic medication in children/dependent adults with an ASD.
10.4 Discussion Study 3a

The aim of Study 3a was to gain insight into the perceptions of caregivers about psychotropic medication use in children/dependent adults with an ASD. Caregivers play a pivotal role in whether their child/dependent adult with an ASD takes psychotropic medication. Their perspectives are thus highly valuable in understanding psychotropic medication use in this population. Caregivers’ experiences give them unique firsthand knowledge of the effectiveness of psychotropic medication in managing undesirable emotions and behaviours associated with ASD.

Results from the qualitative analysis of free text areas draw attention to a level of complexity surrounding decisions to use psychotropic medication, to assist in the management of undesirable emotions or behaviours in a child/dependent adult. It was clearly evident that caregivers endeavoured to act in the best interests of the child/dependent adult, and that the decision to use psychotropic medication affected them considerably. It was also apparent from the analysis that caregivers’ experiences were individual and differed; thus, responses varied significantly.

Caregiver identity was found to be deeply intertwined with the decision to use psychotropic medication in the management of their child/dependent adult. Caregivers were conflicted about their caregiving ‘duty’ to their child. The caregivers’ identities appeared affected by their parental efficacy, meaning the ability to manage their child/dependent adult with an ASD. In turn, this appeared to affect a caregiver’s decision to use medication. Previous research has found
that parental efficacy is a significant predictor of parental stress (Hassall et al., 2005; Hastings & Brown, 2002). Further, it has been shown to have a negative correlation with challenging behaviour in children with ASD (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Given that higher levels of challenging behaviour have been found associated with psychotropic medication use, it is plausible that parental efficacy is also likely to affect medication use. This highlights the importance of including parental efficacy as a variable when examining psychotropic medication use in this population.

Little research has explored the attitudes of caregivers regarding psychotropic medication use. This study found that caregivers commonly experienced a significant negative emotional response to psychotropic medication use in those for whom they cared. Close reading of the transcripts underscored an overwhelming sense of guilt in caregivers, around the decision to use psychotropic medication in the management of their child/dependent adult. It was clear that while caregivers gave a lot of themselves in their caring capacity, they nonetheless felt they needed to give more, or that it was a personal failure that their child/dependent adult needed psychotropic medication. This guilt was intertwined with their identity, and they appeared to question their competency as a ‘care’ giver. It appeared they sought validation from health professionals, who were offering medication, that it was not their personal failure. The findings therefore indicate that the emotional responses of caregivers are important to consider in the context of psychotropic medication use in ASD.
Caregivers also reported feeling significant pressure from outside sources around decisions pertaining to psychotropic medication use. This was articulated as feeling both ‘pressure to medicate’ and ‘pressure to make decisions’ they did not feel skilled to make. This supports findings by Valentine (2010) that parents of children with ASD often feel obliged to make decisions about their child’s treatment, for which they feel ill-equipped. Valentine (2010) concluded that it was important to consider that some parents may feel disempowered in regards to treatment options, while others were able to be more active participants. This indicates the importance of further exploring the effect of caregiver confidence in making decisions regarding psychotropic medication. In addition, it appears important that caregivers are provided not only with all available information regarding medication, enabling them to make an informed choice, but time with a health professional to clarify and discuss it as a treatment option. Caregivers need to be empowered not only to make decisions around their child’s health needs, but also to assert their beliefs about what is best for their child to outside sources.

The side effects of psychotropic medication were another central concern for caregivers. Consistent with previous research (Valdovinos et al., 2005), many reported that the child/dependent adult experienced side effects. In addition, caregivers held significant concerns regarding the long term outcomes of using these types of medications, in particular on the child’s developing brain. The randomised controlled trials that have been conducted for many of these medications have used adult participants, and there is insufficient long term data available, particularly for a child population (Jesner et al., 2007). For example,
risperidone has been trialled in children aged five to 17 years for a six month period, and while common side effects were identified (e.g., weight gain, sedation, liver problems), the long term outcomes of these side effects for children/dependent adults remaining on this medication are not clear (McCracken et al., 2002). Therefore, caregivers’ acknowledgement of fear regarding not knowing the long term outcomes of psychotropic medication use in children appears warranted. Further research is urgently required to explore the long term effects of these medications, to provide caregivers accurate information prior to placing their child on these medications long term.

Despite the concerns of caregivers around the use of medication, particularly the risk of side effects, the results of this study indicated that psychotropic medication use in a child/dependent adult was also considered valuable by most caregivers. For instance, caregivers indicated significant improvement in many daily functioning tasks, including increased skill levels, reduced challenging behaviours, improved concentration and enhanced sleep patterns. This observation supports previous research suggesting significant benefit to psychotropic medication use in this population (e.g., McCracken et al., 2002), and challenges those studies indicating no difference in a person’s presentation when using psychotropic medication (e.g., Antonacci, Manuel & Davis, 2008; Brylewski & Duggan, 1999; Gralton, James & Lindsey, 1998). Of course, it is not possible to determine the extent that reports of positive outcomes in this analysis accurately reflect the effectiveness of psychotropic medication. It
may also demonstrate a tendency for caregivers to show a positive bias to justify their role in the administration of psychotropic medication to their child or dependent adult with ASD.

It was apparent from the findings that quality of life is a central focus for caregivers. They appeared to be concerned with not only their own quality of life, but that of the child/dependent adult, other members of the family and the family unit. The potential for improved quality of life appeared paramount in the decision to use psychotropic medication. It is widely accepted that caring for a child/dependent adult with an ASD can be stressful for caregivers (e.g., Gray, 2003; Hastings & Brown, 2002) and that they often experience lower levels of quality of life, compared to those who provide care for offspring who are typically developing or who have an intellectual disability (Lee et al., 2008). The relationship between quality of life and psychotropic medication use in those with an ASD and their caregivers has largely been unexplored. However, it is accepted that psychotropic medication would influence a person’s wellbeing (Henderikus, 2004). The findings of this study also suggest that psychotropic medication use resulted in improvements in quality of life for the child/dependent adult, the caregiver and the wider family. As described above, with respect to effectiveness of psychotropic medication, it is not possible to differentiate the true impact of psychotropic medication from potential bias in reporting by caregivers. There is clearly a need for further exploration of the relationship between quality of life and psychotropic medication use.
It was evident that the views of caregivers regarding the use of psychotropic medication were heavily influenced by their perceptions of others views. This raises the question of how society perceives psychotropic medication use, and whether caregiver perceptions of these are accurate. The analysis of caregiver responses indicated they perceived society’s views on the use of psychotropic medication in ASD as largely negative. Limited research to date has explored community attitudes regarding psychotropic medication usage in not only those with an ASD, but also the wider community. This type of information could provide a basis for assisting caregivers in their decision making. Alternatively, it could assist caregivers to challenge their own beliefs and coping with the perceptions of others on using medications to help better care for their children/dependent adults with an ASD.

The findings demonstrated that the psychological burden of caregiving influences the decisions made by caregivers to use psychotropic medication, to assist the child/dependent adult with an ASD. It has been established that higher levels of challenging behaviour, increased aggression and comorbid mental health conditions relate to the level of burden reported by caregivers (e.g., Baker, Blacher, Crnic & Edelbrock, 2002; Dunst, Trivette & Deal, 1988; Feldman et al., 2007; Gray, 2003). Moreover, psychotropic medication use has been shown as higher among those who exhibit challenging behaviour, aggression and comorbid mental health conditions (e.g., Eaves & Ho, 2008; Howlin, Goode, Hutton & Rutter, 2004). It may thus be expected that a relationship between psychotropic medication use and the psychological burden of parenting is reported by
caregivers of children/dependent adults with ASD. In addition, the burden of caregiving appeared to be exacerbated by feeling judged and criticised in their caregiving role. The findings suggested that many caregivers felt particularly criticised or judged by the professionals involved in the care of their offspring. It was highlighted that caregivers perceived a lack of both formal (teachers, doctors, psychologists) and informal (family, friends, community groups) support. Many caregivers provided information that suggested they were barely managing the care of their child/dependent adult; and that without medication, their family would not be able to function. This raises the possibility that if caregivers were provided with higher levels of support, other strategies to manage their child with an ASD (e.g., positive behaviour support, sensory skills training) and greater respite opportunities, there may be less cause for psychotropic medication.

Previous research has identified that caregivers who report low levels of social support and high levels of parental distress perceive higher levels of challenging behaviour in children with ASD (Bromley et al., 2004). Higher levels of challenging behaviour in a person with an ASD were found to increase medication use (Robertson et al., 2005). Levels of social support have also been identified as being associated with parents’ sense of competence and parents’ self-esteem levels (Johnston & Mash, 1989). Therefore, it is plausible that level of support may be a factor in psychotropic medication use. This highlights the need for future research to explore the relationship between support, or lack thereof, on psychotropic medication use and to determine whether the choice to medicate is affected by the caregiver’s level of support.
The findings from this analysis have important implications for those working with caregivers of children/dependent adults with an ASD. The analysis highlighted that although there were common themes identified in responses, there was also individual variability in caregivers’ experiences, and this needs to be considered when working therapeutically with this population. The strong sense of powerlessness that was detected in many of the responses highlights the importance of empowering caregivers with a sense of autonomy over decisions to use psychotropic medication in the management of their offspring. Moreover, caregivers need to be provided with a range of support and options for interventions, such that they feel confident to manage and respond to their child/dependent adult with ASD. Caregiver education regarding options for the management of undesirable emotions and behaviours associated with ASD (with psychotropic medication being one of these) is also likely to be beneficial.

Education needs to incorporate information on the evidence base for the effectiveness of the available options, as well as the risks, including possible side effects. It is imperative that caregivers be viewed as ‘experts’ in the life of their child/dependent adult by professionals. Taking the time to actively listen to caregivers and value their unique knowledge is paramount in enabling them to become active participants in the decision making process, and increase feelings of self-efficacy and empowerment. There is also a clear need for professionals to recognise and validate the complexity of a caregiver’s role in negotiating what is not only in the best interests of the child/dependent adult, but also other members of the family. The quality of life of all family members needs to be considered, as
this factor appeared to play an important role in the decision to use psychotropic medication.

In conclusion, this analysis identified a range of caregiver opinions regarding psychotropic medication use in children and dependent adults with an ASD. The decision to use psychotropic medication appeared to be complex and influenced by individual, familial and systemic factors. The quality of life of not only the child/dependent adult, but also the wider family appeared to be a key consideration in a caregiver’s decision to medicate. The findings provided important evidence as to the views, attitudes and perceptions of caregivers’ towards psychotropic medication use in this population. The clinical implications are broad ranging. It appears particularly important to recognise that each caregiver will present with an individual set of circumstances. Consequently, professionals need to ensure that caregivers are provided with thorough levels of education around the evidence to support use of psychotropic medication in those with an ASD.

10.5 Results Study 3b

The following section provides an exploration of qualitative data provided in response to open ended questions by self-reporting adults with an ASD. Responses relate to views on the reasons for use, the effectiveness of use, and their overall attitudes towards the use of psychotropic medication in the management of undesirable behaviours and emotions in people with ASD. Findings are presented according to six linked themes: lack of community understanding and social isolation; disempowerment; individual identity and
social expectations; lack of other options; mental health; and quality of life. Underlying these themes were two key subthemes: desire for autonomy and lack of services.

10.5.1 Lack of community understanding of ASD and social isolation.

Many participants expressed the view that there was a lack of understanding of people with an ASD within the community, and this influenced their decision to take psychotropic medication. That is, they were more likely to take medication if they did not feel accepted. It was emphasised that participants did not wish to be defined by their ASD diagnosis; rather they wanted to be viewed as individuals. Specifically, they wanted to be provided with the same emotional support or guidance as others, irrespective of their diagnoses. This theme was endorsed by the majority of participants, and appeared to have a pervasive effect across all aspects of their lives, including employment, education, social relationships and health.

The lack of understanding of ASD also affected relationships between participants and health professionals. Concerns were expressed that prescription of psychotropic medication might be used by health professionals as an alternative to other social or psychological supports for people with an ASD. In particular, respondents were of the opinion that health professionals viewed medication as an easier option for emotional and behaviour management, than a therapeutic approach based on addressing the reasons why the feelings or behaviour may be occurring:
Medication ... is an after effect cure. (CMed)

According to some participants, when they had sought assistance from doctors or other professionals, a common response was to automatically increase their medication. There was a clear preference expressed for consultation with professionals who took the time to understand their difficulties:

To a degree I feel as though my psychiatrist ups my medication or prescribes more when I am upset or something sets me into a meltdown and I contact her, the first thing she does is medication to the rescue, why not just listen or be with me? (CMed)

In addition, a number of participants commented on feelings of isolation and loneliness. It was apparent that for many that loneliness played a role in the decision to use medication. Social isolation and a lack of community support for people with an ASD were acknowledged as having a significant effect on their mental health, in particular feelings of anxiety and depression. These feelings led to them seeking professional assistance, which in turn resulted in them accepting a recommendation for medication. A few participants reported their belief that a lack of availability of social supports and friendships were predictors for medication use:

Issues of social isolation and lack of community support are causing people on the Autism Spectrum to be medicated. (NMed)
Moreover, it was apparent that people with ASD sought acceptance and meaningful relationships. The difficulties experienced in these areas often resulted in medication use:

*Medication should be used to help feelings of anxiety and depression only when not caused by other issues such as loneliness, socialisation problems etc. which should be treated by support groups, social groups and help becoming part of the community etc. (PMed)*

**10.5.2 Disempowerment.**

It was evident from comments provided that many participants felt disempowered not only in their decision to use medication, but also more generally in their lives. There was a sense that people with an ASD were heavily influenced by health professionals, and were not active participants in decision making pertaining to their own health. They attributed this lack of perceived power to their ASD diagnosis. In particular, participants reported feeling disempowered around the decision to use or not use medication to assist with the management of their behaviours and emotions. The decision to use medication was viewed as complex and was influenced by a multitude of external factors that participants perceived were beyond their control. Participants emphasised it was not a decision that was
made lightly, but that often people with ASD perceive the use of psychotropic medication as their only available coping strategy:

*I have a love hate relationship with having to take medication. I resent having to take a pill to feel even remotely like I want to remain living.*

(CMed)

10.5.3 Individual identity and social expectations.

The importance of identity presented as another significant theme. Many participants commented that they did not wish to take psychotropic medication if it took away who they were, or was used to make them conform to social norms. Several stated they liked being who they were, and embraced their ASD characteristics. Those who did take medication endeavoured to clarify the reasons behind this decision, with an emphasis on a need to clearly articulate who they were and what they believed:

*I haven’t seen a doctor since my diagnosis so have never discussed medication in relation to having autism. I don’t think medication should be a first point of call or an excuse not to deal with underlying problems and trauma.* (NMed)

A number of responses by participants highlighted the impact of social pressure behind motives for psychotropic medication use. Participants also identified the pressure they felt to conform to society’s norms and values. Many reported they thought that medication was often used in people with an ASD as a form of restricting one’s nature, personality and behaviour. It was further stated
that medications were used as a form of control to assist people with an ASD to conform to social expectations, and reduce behaviours or emotions that others deemed inappropriate. Taking medication solely to inhibit behaviours unacceptable to society was viewed as restraint by some participants. However, this was distinguished from people who chose to take medication to treat specified conditions. In this circumstance, medication use was not viewed as a form of restraint:

*Why else would you be given medication, other than to control you and make you quiet? (PMed)*

Some participants stated that using medication to ‘fit in’ with other’s expectations restricted their nature. Many respondents articulated they would prefer differences to be embraced, rather viewed as something to be eradicated with medication:

*Society expects people to conform to ‘their’ norms and puts pressure on people to take medications in order to fit neatly in the boxes they have created. Yeah I know I am a bit different it is what I am and I don’t feel comfortable being medicated into something that does not feel right. (NMed)*

10.5.4 Lack of other options.

The majority of participants conveyed that the decision to use medication was affected by the lack of availability of other options to address the behavioural and emotional difficulties they experienced. Medication was a commonly
available and subsidised treatment, while alternatives such as counselling, auditory training, emotion skills training, and sensory assistance were often pursued at the expense of the person with an ASD. Essentially, medication was the cheapest option:

_I can't afford the auditory re-training required to fix my problems, drugs are the ambulance at the bottom of the hill for me._ (CMed)

It was also noted that treatment of ASD symptoms with medication was perceived as an easier option. Many participants felt the reason they were prescribed medication was for its quick-fix nature, in lieu of the time and effort required to conduct detailed assessments and interventions:

_Medication is the lazy cheap way to treat disorders. If there was funding for proper assessment and treatment medication would not be needed for most people._ (PMed)

Many participants claimed that medication should not be used as an isolated intervention for the treatment of a mental health condition, nor for the undesirable emotions or behaviours associated with their ASD. A couple of participants commented that medication should only be used within the context of other psychological interventions, including working with a psychologist or counsellor to address the complexity of issues facing a person with an ASD. A few participants also indicated they believed alternative interventions, including sensory-based activities and natural therapies were important aspects of
intervention. These participants believed that medication only provided limited assistance if used in isolation:

*Medication should not be relied upon and be the only therapeutic treatment. Exercise, diet, lifestyle, goals, groups, courses...Everything needs to be considered.* (NMed)

### 10.5.5 Mental health.

Mental health was a dominant theme. It was raised by participants in terms of both their own misdiagnosis, as well as their desire to separate the use of medication for mental health purposes from medication for undesirable emotions or behaviours associated with their ASD. Many participants indicated they had received a number of diagnoses prior to receiving their ASD diagnosis, including depression, OCD, personality disorders, bipolar and anxiety disorders, and that this had negatively affected their mental health. For a number of participants, misdiagnosis had resulted in the prescription of inappropriate medication and a corresponding denial of access to alternative evidence-based interventions for people with an ASD:

*I feel that I was diagnosed too late in life to get the support I deserve.*

*Being misdiagnosed and placed on medication that was not effective caused 2–3 years of harm, emotionally, physically and mentally.* (PMed)

In line with this, participants strongly emphasised the importance of separating psychotropic medication use for co-existing mental health conditions, from medication taken to assist in managing undesirable emotions and/or
behaviours associated with their ASD. Although the use of psychotropic medication for the treatment of mental health conditions was apparently viewed as permissible, its use for the treatment of ASD symptoms was viewed less favourably.

### 10.5.6 Quality of life.

A final theme evident in the responses provided by adults with ASD related to overall quality of life. It was frequently stated that medication was used as a substitute for addressing underlying issues associated with a lowered perceived quality of life. Some participants identified feeling distressed by having to rely on medication to achieve enhanced quality of life, and questioned whether these opportunities could be improved through avenues other than medication. Conversely, a few participants indicated the benefits of medication for improved quality of life for people with an ASD. Specifically, they reported that medication permitted them to engage in activities they would otherwise find overwhelming. These included activities of daily living, social encounters, as well as employment. In addition, medication provided participants with a sense of control over emotions and behaviours:

> Medication is overwhelmingly positive for me, my family and my friends. I can do more and I can join in with more things. (CMed)

### 10.6 Subthemes Study 3b

Underlying the identified primary themes was a strong sense that participants desired autonomy, both in terms of their decision to use psychotropic
medication, but also more generally in their own lives. This desire for an autonomous life appeared intertwined with the disempowerment they experienced because of their diagnosis; but it was also emphasised in terms of their interactions with professionals around psychotropic medication use.

An additional subtheme identified was the lack of available services for adults with an ASD. It was apparent that many participants wished to be further engaged with services. However, services were either not available to assist them, or they specialised in children with an ASD. An undertone of frustration was particularly evident regarding the lack of subsidised options, as many of the evidence-based treatments (e.g., auditory training, sensory work, CBT) were expensive. This raises the question of whether in some cases medication may be prescribed as a coping strategy due to its ready availability in the face of a dearth of alternatives.

10.7 Discussion Study 3b

The aim of Study 3b was to explore the perspectives and beliefs of independent adults with an ASD towards psychotropic medication use. The analysis of the responses indicated that views of psychotropic medication use altered, depending on the reason for usage. For example, it appeared that many individuals with an ASD perceived psychotropic medication negatively if it was used to ameliorate ASD symptoms. This view changed if the person used medication to treat a comorbid mental health difficulty. Similar to the findings from caregivers, the decision by adults with an ASD to use medication appeared complex and entwined with other factors.
Psychotropic medication use was found to be influenced by a lack of community understanding towards individuals with an ASD. The findings specifically indicated that independent adults felt disconnected from their community and that this influenced their wellbeing. This is consistent with previous research demonstrating that independent adults with an ASD experience a profound sense of isolation, a longing for greater intimate relationships and a desire to not only participate, but also contribute to their community (Muller, Schuler & Yates, 2008). This study highlights that social isolation is a contributing factor to psychotropic medication use, and needs to be considered when adults with ASD present to health care services.

It appears that many adults with ASD perceive a lack of understanding from the health care professionals who work with them. This raises the question as to whether professionals have an adequate knowledge base that enables them to work competently with ASD adults. Some previous research has compared ASD knowledge within the health care system (e.g., Heidgerken et al., 2005; Stone, 1986). While primary health care providers and specialists have been show to accurately endorse the DSM-IV-TR criteria for ASD (APA, 2000), in comparison to health professionals working in an ASD specific organisation, they differentially endorsed items relating to prognosis, course and treatment (Heidgerken et al., 2005). Primary health care professionals may well have limited information as to the best interventions available for those with ASD. This highlights the need for further education of these professionals around the evidence base for available interventions.
The findings demonstrate that individuals with an ASD felt disempowered when discussing treatment options with medical professionals. People with disabilities are considered some of the most marginalised individuals in the community, and this status is often associated with having less autonomy (Ward & Stewart, 2008). These results suggest that this lack of autonomy extends to decisions pertaining to medical needs of those with an ASD, specifically psychotropic medication. It emphasises the importance of conducting thorough assessments of those with an ASD. Further, these results suggest that professionals need to take time to explain and clarify the treatment options available to those with an ASD. This illustrates that independent adults with an ASD are seeking to participate more actively in their treatment, and gain further control over their own lives and the interventions they receive.

The results also suggest that many individuals in this study had accepted and embraced their ASD symptoms, and did not wish to take psychotropic medication if it ‘restricted’ their individuality. This view is consistent with the current legislative framework within Victoria, Australia, ‘that restraint only be only be used if it is necessary to prevent the person from causing physical harm to themselves or other person’ or ‘to prevent the person from destroying property where to do so could involve the risk of harm to themselves or any other person’ (Victorian Government, 2007, p142). This poses the dilemma of the rights of the individual over those of others and what happens when these are not aligned. In addition, there is growing evidence suggesting that alternative interventions (e.g., positive behaviours support, social skills training) are equally, if not more
effective, than psychotropic medication in many circumstances and should be used prior to medication (Osgood, 2004). This indicates it is important to consider the rationale for medication use, especially if it is seen as ‘restricting’ a person’s individuality.

It appears that the wide availability of psychotropic medication and the dearth of alternative interventions have a significant role in the decision to use psychotropic medication. Many individuals with an ASD turn to psychotropic medication as a ‘last resort’ option, to cope with mental health difficulties or ASD symptoms. Despite the significant evidence base for alternative treatment modalities (e.g., positive behaviour support for working with an ASD; Hwang & Hughes, 2000), these were clearly difficult for participants to access, many citing cost as the most significant barrier. The autism community at large has acknowledged the need for improved health care services and specialised programmes for adults with an ASD (Autism Ontario, 2008; National Autistic Society, 2006; White, McMorris, Weiss & Lunsky, 2012). The comments made by participants in this study support the view that there is a need for improved access to health and support services for adults with an ASD living in the community.

The analysis of responses further reveals that psychotropic medication use is inextricably linked to mental health. The findings suggest that participants sought to differentiate between using medication for ASD symptoms and comorbid mental health conditions. Previous research has found those with ASD have higher rates of psychopathology than the general population (e.g.,
Ghaziunddin, 2002; Ghaziunddin & Gredden, 1998; Ghaziuddin & Tsai, 1991; Matson & Nebel-Schwalm, 2007). However, this thesis contributes new knowledge by highlighting the distinction made by adults with an ASD concerning psychotropic medication use for a comorbid condition, as opposed to use for symptoms of ASD. This implies that individuals perceive their ASD differently to an associated mental health condition. These individuals felt that psychotropic medication should not be readily prescribed for ASD, but rather be prescribed for a comorbid mental health condition if needed. This raises the key question of how mental illness is perceived as different from ASD among those affected by ASD. Further research is warranted to explore the views around mental health conditions and treatment options among those with an ASD.

There are several anecdotal reports of individuals with an ASD being incorrectly diagnosed with various other mental health conditions (Bradley, Lunsky, Palucka, & Homitidis, 2011; Perlman, 2000). The current findings suggest that misdiagnosis has a profound impact on individuals’ wellbeing, as well as on their subsequent use of psychotropic medication. It is evident that there was a significant negative impact on individuals who were diagnosed with a myriad of alternative mental health conditions prior to receiving their ASD diagnosis. In turn, this meant that individuals felt they were being incorrectly medicated. There is limited research investigating the impact of misdiagnosis on those who subsequently receive an ASD diagnosis. This raises questions as to whether earlier diagnosis and the ready availability of ASD specific intervention
could have circumvented the use of psychotropic medication. Further exploration of the effects of misdiagnosis on independent adults with ASD, and the role they believed this played in psychotropic medication use, is warranted.

It was also apparent from the analysis of comments that quality of life is vital to independent adults with an ASD. Findings demonstrate that many felt they had poor quality of life. While quality of life was important to individuals with an ASD, they nonetheless believed that medication should not be used as a substitute to addressing the underlying issues pertaining to quality of life, such as social inclusion, employment, participation in day-to-day activities. This finding is consistent with previous research from longitudinal studies, which indicated that many adults with an ASD experienced ‘poor’ or ‘very poor’ quality of life in adulthood (Howlin, 2000; Howlin et al., 2004). Adults with an ASD have been found to be highly reliant on others for support, including family, friends and support services (Howlin et al., 2004). Support characteristics, including social support and professional support, have been found as significantly related to better quality of life outcomes in people with high functioning ASD (Renty & Royeers, 2006). This indicates that if medication use allows for greater social interaction and participation with supports, this may ultimately improve the quality of life of independent adults with an ASD.

The implications from this study are broad ranging. While independent adults with ASD appear largely self-sufficient, they require access to support services, in particular multidisciplinary assessments and interventions that are specifically targeted to ASD symptoms, and undesirable emotions and
behaviours. There also appears to be a need for further ASD education for health professionals, particularly regarding the recognition of ASD, interventions and available support services. It is especially important that primary health care providers have accurate and up to date information about approaches that may assist or benefit this group, in the event they present with difficulties. Moreover, there is a need for enhanced availability of these professionals for referral. There is also an identified need to develop better protocols around supporting those diagnosed with ASD later in life. They may still benefit from interventions that are evidence-based in younger individuals with ASD.

In conclusion, the views and experiences of independent adults with an ASD are varied. Many sought to express their concern around the level of medication use themselves, and the lack of alternative options available to them. Many specifically reported a need for increased availability of alternative interventions to assist with undesirable emotions and behaviours associated with ASD. Despite this, there was a clear message that psychotropic medication use to manage comorbid mental health conditions was viewed as important and permissible. The information provided by participants in this study gave unique insights into the views and experiences surrounding psychotropic medication use by those with an ASD.

10.8 Limitations of Study 3a and 3b

It is possible that the respondents who participated in Study 3 held stronger beliefs compared to the respondents who did not participate in this part of the study. As a result, respondents who displayed stronger beliefs may have
encompassed more motivation to document information in the free text areas of the survey. Those who did not have strong beliefs about the use of psychotropic medication may have been less likely to document their responses in the free text areas, and thus their perspectives might not have been heard.

A further limitation of the study was that the scope of the qualitative data was limited to the use of psychotropic medication, rather than incorporating all interventions therefore limiting the breadth of information that may have been extracted during the analysis. In addition, the depth of information provided was limited to the size of the free text areas provided in the open questionnaire on the three key topics. Future research may benefit from conducting face-to-face interviews allowing more in depth questioning and response clarification. This would enable greater understanding of the experiences of both independent adults and caregivers of children/dependent adults in using psychotropic medication to assist with undesirable emotions or behaviours associated with an ASD.

As with most qualitative research, the researchers’ own biases and opinions will have influenced how the data has been perceived and coded. While the data was coded independently, both coders have a significant interest in psychotropic medication use, and by virtue of this will have been more inclined to recognise themes and subthemes fitting with their theoretical perspectives.

10.9 Conclusions

The current study’s qualitative analysis has provided valuable insights into the perspectives of caregivers and independent adults regarding the use of psychotropic medications in an ASD population. The responses indicated that the
decision to use psychotropic medication was complex and multifaceted, and that individual factors needed to be taken into account. The analysis revealed a clear desire for alternative therapeutic options to medication to be more readily available to independent adults, children and dependent adults with an ASD. There was a need for empowerment of both individuals and caregivers, to enable them to make collaborative decisions relating to medication use. There was also a necessity for more education about the evidence base of available interventions.

Quality of life appeared to be a significant motivation to use or not use psychotropic medication. The importance of the wellbeing of the person with an ASD was a dominant theme that emerged, but there was also consideration given to the quality of life of those who supported and cared for them. There is a need for future research to focus explicitly on factors associated with quality of life in people with an ASD and in their caregivers, as well as the role that psychotropic medication use has on these factors.

The new evidence derived from this analysis highlights the need for further exploration of psychotropic medication use from the perspective of caregivers and independent adults. The qualitative data provided here has enhanced understanding of the impact of psychotropic medication use in an ASD population, while also providing insight into the perspectives of self-reporting adults and caregivers of children and dependent adults with an ASD.
Chapter 11: Overall Reflections

This thesis examined the use of psychotropic medication in a community-based ASD sample within Australia. The findings indicated that psychotropic medication use was common among those with an ASD. Many participants reported being prescribed medications for ASD-related conditions that fall outside the use that had been approved by regulatory bodies. For instance, children with an ASD in this Australian sample were being prescribed psychotropic medication, despite the absence of randomised controlled trials to support its use in this age group. These findings are a cause for concern as the health outcomes of long term psychotropic medication use in this population are unknown.

The three studies that comprise this thesis differ in terms of groups (individuals who are self-reporting adults to those who are children and dependent adults), informants (self and parent/carer) and nature of the information provided (quantitative and qualitative). Although these differences limit the direct comparability of findings, it is important to examine commonalities and differences in the findings. An important question raised across the studies is whether individuals and caregivers perceive medication as a form of ‘restraint’ as defined by the Victorian Government. A clear difference was apparent in response to this issue between individuals with ASD and carers/family members. Individuals with an ASD were of the belief that medication should not be used to restrict ‘one’s nature’ whereas a number of caregivers endorsed using medication
for behavioural control. It appeared that many caregivers did not perceive using medication as a form of restraint when given for the primary purpose of managing challenging behaviours.

As the perspectives outlined within this thesis demonstrate, both the clinical and familial decision to use medication in this population is clearly complex and requires careful consideration and collaboration. Caregivers and individuals require education about the available intervention options and current literature, the effectiveness of these interventions, as well as potential side effects. Practitioners need to ensure that they are actively involving caregivers and individuals in the decision making process and empowering them to be able to make the decision in the best interests of the individual. Future investigations into the decision making process of caregivers, individuals and medical practitioners to use psychotropic medications would generate greater understanding, and assist in formulating best practice guidelines and treatment protocols for people with ASD. It is also apparent that there is a need for regular reviewing of the use of medications by both the individual, caregivers and professionals involved.

Individuals with an ASD and their caregivers both reported that quality of life was central to the decision to use psychotropic medication. Participants indicated that medication use resulted in perceived improvements in quality of life. This is an important finding because it provides a rationale as to why medical practitioners prescribe medications to people with an ASD, when they have not yet been scientifically proven to be effective. It is important for practitioners
working with the family focus on quality of life and how this can be achieved for the family. Further research is warranted to examine the relationship between psychotropic medication use and the subjective wellbeing of both individuals and their caregivers.

It was beyond the scope of this thesis to examine concurrent or alternative interventions among people with an ASD, in addition to psychotropic medications. This meant that it was unknown whether other interventions were used in conjunction with psychotropic medication among this sample, and how these may have affected psychotropic medication use or perceptions of its effectiveness. Currently, little is understood about the interactions between psychotropic medications and psychosocial interventions (e.g., Weeden et al., 2011). Therefore, future research that investigates the combination of psychotropic medication use and alternative interventions is essential.

The findings from the studies comprising this thesis highlight a potential disparity in the perceived effectiveness of medication compared with previous studies involving caregivers and individuals. While previous research has reported mixed results on the efficacy of psychotropic medications, the current findings indicated that both individuals and caregivers perceived psychotropic medications as both helpful and effective. Future research needs to explore this discrepancy as our understanding of the true effectiveness of psychotropic medication use in this population is limited by so few controlled studies. Moreover, these studies need to control for other interventions, such as applied behavioural analysis, communication devices, and cognitive behavioural therapy.
The current findings indicated that few participants ceased psychotropic medication use once it had commenced. This was an important issue because these participants also reported several side effects from taking these medications. Despite this, the results suggested that once an individual commenced psychotropic medication, this brings into question the level of review that is occurring with relation to the need for this medication. Consequently, it is suggested that the decision to commence medication should not only occur at the beginning of pharmacological treatment, but should be subject to ongoing reviewed with caregivers and individuals, to assess the continuing need for and both the positive and negative effects of this form of treatment. An increased collaboration between individuals, care-givers, and health professionals (including teachers, social workers, psychologists, occupational therapists, speech pathologists) will likely translate into better informed choices and treatment outcomes. Standardised guidelines regarding the review of psychotropic medication among people with ASD therefore requires further consideration.

11.1.1 Practice Recommendations

The findings of this thesis provide much information to inform clinical practice within those with an ASD. The findings emphasise the need for thorough clinical assessment of individuals with an ASD when presenting to health care services, particularly if the question of medication is raised. These assessments need to give consideration to how co-morbid mental health conditions may present differently in those with an ASD. It is essential that where challenging
behaviours are raised, an in-depth review and functional analysis of the behaviour occurs, to ensure that the intervention options selected are most appropriate and least restrictive for the behaviours.

For all individuals with an ASD it is important that emotional support is made available to them. This can be both formal, in terms of counseling, but also informal through empathic listening, discussing problems and spending time discussing the different options. Long term support needs to be available for individuals and their caregivers.

Individuals need to be viewed as experts in their own lives (Valentine, 2010). Professionals working with those affected by an ASD, need to focus on empowering them to make decisions about their life. There is a role for professionals to provide education to individuals and caregivers around intervention options, with a particular focus on medication. This needs to include information related to its mixed evidence base, efficacy, potential side effects and long term outcomes associated with its use. In particular, it is important that those caring for children are made aware that the long term outcomes of many of these medications are unknown.

One of the most significant approaches that can be offered to individuals and their caregivers involves the enhancement and provision of support. This includes both formal and informal support. Informal supports include those that naturally occur in one’s life, including neighbours, friends, parents, spouses, religious institutions who can provide psychological, emotional and physical support (Myers & Johnson, 2007). There is also a significant role for formal
supports including publicly funded programs such as early intervention, special education, respite services, vocational and residential services, as well as access to specialised health care services. It is important that support strategies focus on ensuring the physical and emotional health of both individuals with ASD and their caregivers. Support can be given through education about ASDs, interventions available, providing training and empowering them to make decisions around interventions and be active participants in the interventions.

This thesis has contributed new knowledge to the field of psychotropic medication use among individuals with ASD in Australia. Since this body of research is still in its infancy, it is important that the administration and effects of psychotropic medication in this population are continually investigated. There is a clear need for collaboration between individuals with an ASD, their caregivers and professionals, to ensure that psychotropic medication is used in an appropriate and transparent manner.
References


Goldstein, S., & Schwebach, A. J. (2004). The comorbidity of pervasive developmental disorder and attention deficit hyperactivity disorder:


were intolerant to risperidone. Human Psychopharmacology and Clinical Experiments, 19, 47–51.


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Appendices

Appendix A

1. What medications do you currently take (Please list all)

<table>
<thead>
<tr>
<th>Medication Name (frequency &amp; dosage)</th>
<th>Primary Reason for Prescription</th>
<th>Secondary Reasons for Prescription</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(The following section will be asked with respect to each reported medication)

2. Who prescribed this medication:
   - GP
   - Psychiatrist
   - Paediatrician
   - Other, please specify, ____________________________

3. Have you been diagnosed with a mental health or behaviour disorder associated with being prescribed this medication?
   - No, proceed to question 12
   - Yes

The condition for which this medication was prescribed is:
Psychotropic Medication and ASD

☐ Anxiety Disorder
☐ Depression
☐ Adjustment Disorder
☐ Bipolar Affective Disorder
☐ Schizophrenia
☐ Behaviour Disorder
☐ Other, please specify, ____________________________

4. Do you feel this medication helps you to manage your mental health or behaviour disorder?
   ☐ Yes
   ☐ No

Please comment further: ___________________________________________
________________________________________________________________

5. Please rate how you feel about taking this medication:

<table>
<thead>
<tr>
<th>Totally Dislike</th>
<th>Neutral</th>
<th>Totally Like</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>9</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

6. Do you believe this medication is a form of restraint?
   ☐ Yes
   ☐ No
Appendix B

Have a Say in the Debate about Medication

Are you an adult with an Autism Spectrum Disorder?

Or

Are you a care-giver of a child or adult with an Autism Spectrum Disorder?

Dr Jane McGillivray and Belinda Minett from Deakin University are conducting a study about the individuals and care-giver’s perspectives of medication to manage behaviour and emotions associated with Autism. There has been lots of debate about the use of medication by people with autism spectrum disorder. However, little is known about the perspectives of people with ASD.

In this study, we want to find out what you think about medication. Do you take it, what do you take and why, how do you feel about it. What you have to say is important to discussions about the best treatment alternatives for managing the conditions associated with ASD. Your answers are anonymous, so you can say what you want.

What will you be asked to do: If you agree to participate in this study, you will be asked to complete an online or paper questionnaire that will take approximately 20 minutes. Your involvement is voluntary and your responses will be anonymous. The link for the online version of the study is [http://www.deakin.edu.au/psychology/research/autismstudy](http://www.deakin.edu.au/psychology/research/autismstudy)

You can request a paper version to be sent to you by contacting Belinda and Jane on the details below. A copy of group findings will be made available to participants upon request.

How to get involved? If you would like to participate, or if you wish to obtain further information about this research please contact Jane McGillivray Ph: 03 9244 6426 or Belinda Minett email: bami@deakin.edu.au
Appendix C

DEAKIN UNIVERSITY

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Participants

Plain Language Statement

Date: 23rd October 2009

Full Project Title: Pharmacology and Autism Spectrum Disorders

Principal Researcher: Associate Professor Jane McGillivray

Student Researcher: Belinda Minett

This Plain Language Statement and Consent Form is three pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project. This Plain Language Statement contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project so that you can make a fully informed decision whether you are going to participate.

Please read this Plain Language Statement carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Plain Language Statement and Consent Form to keep as a record.

2. Purpose and Background

The purpose of this project is to gain an understanding of individuals with autism spectrum disorder and their care-giver’s perspectives of medication.
A total of 400 people will participate in this project.

You are invited to participate in this research project because you or someone you care for has an Autism Spectrum Disorder and is currently taking medication. The results of this research may be used to help researcher Belinda Minett to obtain a Doctor of Psychology (Clinical) degree.

3. **Funding**
This research is not a funded project.

4. **Procedures**
Participation in this project will involve filling out an anonymous questionnaire which will take approximately 20 minutes to complete. No identifying data will be requested as part of the questionnaire and you are free to withdraw at any time.

5. **Possible Benefits**
We cannot guarantee or promise that you will receive any benefits from this project. However, this research will result in an enhanced understanding the use of medication in people with autism spectrum disorders. Further it will provide insight into individuals and care-giver’s perspectives of the use of medication in this population group.

6. **Possible Risks**
There is a possible but unlikely potential for participants to experience a low level of stress and anxiety associated with the questions that are asked of them. However the benefit of gaining a greater understanding of the factors associated with medication use offers a new perspective.
If participants experiences distress while completing the survey they are able to suspend or end their participation in the project. If any distress occurs we suggest contacting your local autism association, crisis support service or medical practitioner for support.

7. **Privacy, Confidentiality and Disclosure of Information**
No individual will be able to be identified who has participated in this study. We plan to present findings as a conference paper and in a peer-reviewed journal, however, only group results will be reported. All data collected will be stored securely at Deakin University for a period of six years from publication.

8. **Results of Project**
A copy of summary results will be forwarded to any interested parties at the completion of the study by contacting us by e-mail bami@deakin.edu.au. You may also access the results through the following website [link].

9. **Participation is Voluntary**
Participation in any research project is voluntary. **If you do not wish to take part you are not obliged to.** If you decide to take part and later change your mind, you are free to withdraw from the project at any stage **until the questionnaire is submitted.** Once the questionnaire is completed and submitted participants will not be able to be identified therefore it is **not possible to withdraw data after submission.**
10. 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.

11. Complaints
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

*Should you have any concern about the conduct of this research project, please contact the Secretary HEAG-H, Dean’s Office, Faculty of Health, Medicine, Nursing and Behavioural Sciences, 221 Burwood Hwy, Burwood, VIC, 3125. Telephone: (03) 9251 7174, Email: hmnbs-research@deakin.edu.au*”

Please quote project number HEAG-H: EC00213

12. Reimbursement for your costs
You will not be paid for your participation in this project.

13. Further Information, Queries or Any Problems
If you require further information or if you have any problems concerning this project, you can contact the principal researcher Associate Professor Jane McGillivray on Tel: 9244 6426 or e-mail jane.mcgillivray@deakin.edu.au.

Or alternatively you may contact the student researcher involved in this project Belinda Minett on email: bami@deakin.edu.au
Appendix D

Table 12.1

*Frequency of medications reported by name and class (n of medication = 241)*

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Class of Medication</th>
<th>Number of Children/Dependent Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amitriptyline</td>
<td>Anti-depressant</td>
<td>2</td>
</tr>
<tr>
<td>Atomoxetine</td>
<td>CNS stimulant</td>
<td>5</td>
</tr>
<tr>
<td>Benzhexol</td>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Carbamazepine</td>
<td>Anti-convulsant</td>
<td>2</td>
</tr>
<tr>
<td>Chlora hydrate</td>
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### Appendix E

**Table 12.2**

*Medsation name, type, primary and secondary reason for prescription for those who currently used medication (n of medication = 46)*

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<tr>
<th>Medication Name</th>
<th>Type of Medication</th>
<th>Reason for Prescription</th>
<th>Secondary Reason For Prescription</th>
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<td>Anxiety</td>
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<td>Anxiety</td>
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<td>Anxiety, panic attacks</td>
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<td>Bi Polar</td>
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