

**The Presentation and Diagnosis  
of Autism Spectrum Disorder in Adulthood**

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## Summary

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder. Currently, ASD is conceptualised within the Diagnostic and Statistical Manual of Mental Disorders (5<sup>th</sup> ed.; DSM-5; American Psychiatric Association [APA], 2013) as a single disorder with two domains of impairment, Domain A: social communication and social interaction and, Domain B: restricted, repetitive patterns of behaviour, interests or activities. Although symptoms first manifest in childhood, increasing numbers of individuals with ASD are presenting for diagnosis in adulthood (Jensen, Steinhausen, & Lauritsen, 2014). Relatively little is known about the presentation of ASD in adulthood and therefore there is much uncertainty about best practice assessment of adults with suspected ASD. In this thesis I sought to understand the presentation of ASD in adulthood and to develop a comprehensive assessment tool specifically designed to assist with identifying adults with suspected ASD.

In Study 1, Chapter 2, I sought to clarify the presentation of the DSM-5 criteria for ASD among adults. Adults with ASD ( $N = 83$ ), their caregivers or spouses ( $N = 21$ ), and clinicians ( $N = 22$ ), responded to a questionnaire about the manner in which the diagnostic criteria manifest in adulthood. The majority of participants reported that each of the seven DSM-5 diagnostic criteria except Criterion B1 presented frequently in adulthood. Impairments characteristic of the Domain A but not Domain B criteria interfered with everyday life for the majority of adults with ASD.

In Study 2, Chapter 3, I sought to identify specific behaviours that might present frequently and differentiate adults with ASD from adults without ASD, for each DSM-5 criterion. 45 adults with ASD and 48 typically developing adults completed three questionnaires: the Autism Spectrum Quotient (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001); the Ritvo Autism-Asperger's Diagnostic Scale - Revised (Ritvo et al., 2011) and the Social Communication Questionnaire (Berument, Rutter, Lord, Pickles, &

Bailey, 1999). Behaviours were indexed by items from these questionnaires and coded by a clinical psychologist and provisional psychologist according to the DSM-5 criterion they best reflected. The frequency with which these behaviours were endorsed by adults with ASD and their ability to differentiate between adults with or without ASD (i.e. diagnostic sensitivity) were then examined. Relatively few frequently presenting and diagnostically sensitive behaviours consistent with each criterion were identified in the assessment tools, particularly for Criterion B1.

In Study 3, Chapter 4, the presentation of Domain B impairments was explored further among a sample of adults with ASD ( $N = 39$ ). These adults described a number of manifestations of Domain B that had received limited attention within the DSM-5 and/or recommended assessment tools including repetitive behaviour such as tapping and tensing muscles. Most adults with ASD presented with multiple repetitive behaviours, routines, rituals and/or sensory differences. However, few behaviours characteristic of Criterion B1 or B4 were frequently reported by adults with ASD. Nonetheless, for the individuals for whom behaviours characteristic of Domain B did manifest, most behaviours presented regularly.

Given improved understanding of the presentation of the DSM-5 criteria in adulthood, a comprehensive assessment tool specifically designed to assist with identifying ASD as it presents in adulthood was developed in Study 4, Chapter 5. This measure, the Autism Detection in Adult Populations Tool (ADAPT), comprised a battery of role-plays, vignettes, questionnaires and an interview. The components assessed each of the DSM-5 diagnostic criteria and were evaluated among a sample of 33 adults with ASD and 32 typically developing adults. The ADAPT showed promise in this initial study, its DSM-5 algorithm had adequate sensitivity (81.8%) and specificity (100%).

## Declaration

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

Signed.....

Date.....

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*This thesis is dedicated to all the people no longer here to see this journey completed  
but who I know would have been very proud.*

## **Chapter 1: General Introduction**

Autism spectrum disorder (ASD) is a lifelong condition. Relatively little is known about the manner in which it presents in adulthood. Therefore there is much uncertainty about best practice assessment of persons with suspected ASD during this period of life. The scarcity of research about adult presentation, absence of a gold standard diagnostic protocol, and lack of practical, rigorously validated assessment tools has contributed to this uncertainty. This thesis thus sought to assist with adult ASD diagnoses by clarifying the nature of symptom presentation in adulthood and by developing a comprehensive assessment tool specifically designed for adults.

### **Conceptualising ASD**

ASD is characterised by impairments in two domains: social communication and social interaction and, restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association [APA], 2013). The symptoms that now characterise these domains were first described by Leo Kanner (1943) and Hans Asperger (1944) and led to the development of formal diagnostic criteria now described within the International Classification of Diseases (10th ed.; ICD-10, World Health Organization, 1992) and, the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; APA, 2013; Asperger & Frith, 1991). The DSM-5 is the primary classification system for ASD in many countries including Australia, and as such was the conceptualisation of autism used in this thesis.

The conceptualisation of autism within the DSM has been continually updated to reflect changes in the understanding of the disorder and its presentation across the lifespan. Autism was first introduced to the third edition of the diagnostic manual (DSM-III; APA, 1980) as infantile autism; a single disorder presenting in early childhood and characterised by unusual social approach, speech abnormalities, insistence on sameness, unusual interests and

a preoccupation with objects. The subsequent development of the DSM-III-R (APA, 1987) led to greater diversity in presentations as only a subset of symptoms were required to fulfil diagnostic criteria. In addition, these revisions formally recognised the belief at the time that autism represented a triad of impairments in social interaction, communication, activities and interests. With the introduction of the DSM-IV (APA, 1994) and DSM-IV-TR (APA, 2000), the conceptualisation of autism was further expanded to encompass a range of disorders under the umbrella term of Pervasive Developmental Disorders: autistic disorder, Asperger's disorder, pervasive developmental disorder not-otherwise specified, Rett's disorder and childhood disintegrative disorder; some of which could present among individuals with typical language development for the first time.

Currently, autism is conceptualised within the DSM-5 (APA, 2013) as a single disorder; ASD<sup>1</sup>, with two domains of impairment, Domain A: social communication and social interaction and, Domain B: restricted, repetitive patterns of behaviour, interests or activities. These latest revisions acknowledge the sensory responses associated with ASD (i.e. hyper- or hypo-reactivity to sensory stimuli), and were intended to reduce the diversity of symptom presentations given that fewer symptom combinations now satisfy diagnostic criteria. Further, the DSM-5 criteria recognise that ASD symptoms must present in childhood but may not be formally recognised until later in life (APA, 2013). Thus, the conceptualisation of autism within the DSM has evolved over time to reflect improved understanding of symptom presentation and the possibility of ASD diagnoses being made in adulthood.

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<sup>1</sup> Rett's disorder was removed from the pervasive developmental disorders and the remaining disorders described in the DSM-IV-TR were then subsumed into a single disorder: ASD.

## Adult Diagnoses

Increasing numbers of individuals with ASD are presenting for diagnosis in adulthood (Jensen et al., 2014).<sup>2</sup> It is understood that this demographic may seek a diagnostic assessment for a number of reasons. First, a diagnosis may be sought when an adult supports their child through an ASD diagnostic assessment and recognises similar symptoms in themselves (APA, 2013). Second, adults may present to mental health professionals for the management of comorbid psychiatric disorders, at which time the features of ASD may be identified, prompting further assessment (Jensen et al., 2014; Takara & Kondo, 2014; Tantam, 2000). Third, when social demands increase and previous support systems are challenged by stressors such as a change in employment or the breakdown of a relationship, adults may experience greater difficulty managing symptoms and therefore present for assessment (DSM-5; APA, 2013; Jensen et al., 2014; Mandy & Lai, 2016; Tantam, 2000). Fourth, some adults with ASD are only now being recognised due to a lack of understanding of ASD in adulthood and/or the preclusion of diagnoses for individuals with milder symptoms prior to the relatively recent introduction of Asperger's disorder (DSM-IV; APA, 1994). Therefore, there are many reasons that may cause someone to seek a diagnosis as an adult, that in conjunction with an increased understanding of ASD may account for the influx of people presenting for diagnosis in adulthood.

Receiving a diagnosis in adulthood presents a number of benefits to these individuals. The majority of late diagnosed individuals view their diagnosis of ASD as both positive and valuable (Jones, Goddard, Hill, Henry, & Crane, 2014). In particular, adults cite that being diagnosed has assisted them in understanding the underlying reasons for their impairments, allowed them to access services and supports and, to gain a sense of belonging as they become involved with the wider community of people with ASD (Punshon, Skirrow, &

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<sup>2</sup> Throughout this thesis, adults are defined as persons 18 years of age or older.

Murphy, 2009). Thus an ASD diagnosis may have value, even when recognition arises later in life.

### **Diagnostic Complications in Adulthood**

**Uncertainty about the presentation of ASD in adulthood.** Despite their value, late diagnoses present a number of challenges to the individuals seeking or providing these diagnostic assessments. As people age, diagnoses can become blurred by varying environmental experiences. Indeed, it has been argued that some ASD symptoms arise purely due to task demands exceeding the individual's current skills or resources (Mandy & Lai, 2016). For example, Brewer and Young (2015) note that when one's level of social understanding is not commensurate with the complexities of social interactions in adulthood, this social naivety may contribute to vulnerability to exploitation for some adults with ASD. Developmental changes in an individual's capacity and task demands may therefore alter the presentation of ASD across the lifespan and thus differential diagnoses can become very complex. Identifying the core features of the disorder and how they may alter with age is therefore critical.

The DSM-5 now recognises that an individual's social demands and coping or masking behaviours may contribute to changes in symptom expression across the lifespan (APA, 2013), however, the DSM-5 provides few accounts of how such developmental changes may manifest. This is particularly difficult when the behaviour presented reflects behaviours that may only be observed in childhood, for example, "sharing imaginative play" and "lining up toys" - it is not clear how these behaviours are expressed in adulthood (APA, 2013, p. 50). The DSM-5 criteria (APA, 2013) do not differentiate between symptoms presenting in childhood and symptoms presenting only in adulthood. This is understandable given that adults with ASD were not included within the DSM-5 field trials used to develop the most recent revisions to diagnostic criteria (Clarke et al., 2013; Narrow et al., 2013;

Regier et al., 2013).

Despite the limited information about ASD in adulthood within the DSM-5, a number of symptoms common to children and adults have been identified within the broader literature. These symptoms which appear stable across the lifespan, include difficulties responding to other people, having a limited range of facial expressions and impaired social reciprocity (Seltzer et al., 2003; Shattuck et al., 2007). Other symptoms that have been commonly reported in adulthood include difficulty forming friendships and romantic relationships (Allison, Auyeung, & Baron-Cohen, 2012; Bishop & Seltzer, 2012); and enhanced attention to detail (Allison et al., 2012; Bishop & Seltzer, 2012). However, few behaviours that present frequently and discriminate between adults with or without ASD have been identified. In particular, the diagnostic value of responses to olfactory sensations (Tavassoli & Baron-Cohen, 2012; Tavassoli et al., 2014) and difficulties multi-tasking in adulthood are contentious (Allison et al., 2012; Altgassen, Koban, & Kliegel, 2012; Bishop & Seltzer, 2012).

Further, much of the aforementioned research about ASD symptom presentation features pooled samples of adolescents and adults and/or individuals with or without intellectual disability. How representative these behaviours are of ASD as it presents in adulthood, and particularly, as it presents among late diagnosed adults who rarely present with comorbid intellectual disability (Geurts & Jansen, 2012) remains unclear. The presentation of ASD among adults without comorbid intellectual disability is thus the focus of this thesis.

**Absence of a gold standard diagnostic protocol.** Due to the scarcity of research about the presentation of ASD or the validation of assessment tools among adults, at this time, there is no gold standard protocol for adult ASD assessments. Using the research available, a working group from the National Institute for Health and Clinical Excellence

([NICE], 2012a) developed what is currently the most comprehensive guideline for adult ASD diagnosis and intervention. This guideline highlights the value of having trained health professionals conduct such assessments, using information from other informants to evaluate early development, and the need to assess current core symptoms, behavioural difficulties, activities of daily living and mental wellbeing.

In Australia, diagnostic practice reflects several of the recommendations within the NICE (2012a) guideline with assessments typically being performed by a psychologist, paediatrician or speech pathologist who has undergone specific training to be recognised as qualified diagnostician (Australian Psychological Society, 2016; Taylor et al., 2016). Where possible, information about the individual's early development and current functioning is also collected from other informants such as parents, teachers, and spouses and, the individual seeking the assessment. In addition, clinicians may also conduct behavioural observations within an educational, work, home and/or clinic setting to assess current core symptoms and use structured questionnaires, interviews and observation tools to assist them. The assessment of daily living competencies and mental wellbeing may also occur as part of the assessment but its value in guiding the diagnostic conclusion is not clear.

Beyond general methodologies for assessing adults with ASD, the NICE (2012a) guideline provides some insight about best practice ASD assessment in this period of life. Consistent with the practice of clinicians around the world (Ashwood, Buitelaar, Murphy, Spooren, & Charman, 2015), the most widely used assessment tools for persons with suspected ASD among Australian clinicians appear to be the Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord et al., 2000) and the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994; Taylor et al., 2016). A number of diagnostic tools are recommended for use with adults with suspected ASD within the NICE (2012a) guideline including the ADOS-G and ADI-R. The recommended tools can be

divided into three categories: measures that collect information through self-reports, reports from other persons or behavioural observation.

***Information gathered through self-report.*** Measures that use self-reporting to gather information recommended within the NICE (2012a) guideline are unique in that they were specifically intended for adult use. These questionnaires draw upon the insight of individuals with suspected ASD into the presence and/or course of ASD related behaviours. These self-report tools include the Adult Asperger Assessment (AAA; Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005) and the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R; Ritvo et al., 2011).

***Information gathered from other reporters.*** Assessment tools that source information from the reports of others allow evidence about early development to be gathered. Thus, the presence of symptoms in early childhood can be confirmed, providing a valuable picture of what ASD looks like in the earlier years. In particular, structured interviews administered by clinicians to caregivers such as the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994) and the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI; Gillberg, Gillberg, Rastam, & Wentz, 2001), have been recommended for consideration within the NICE (2012a) guideline. Unlike their self-report counterparts, however, these tools were not designed specifically with adults in mind.

***Information gathered through behavioural observation.*** Finally, behavioural observation measures may also be used to assist with adult diagnoses. Comprising interviews and activities designed to elicit ASD symptoms, these tools provide a snapshot of current presentation and use clinicians' judgements (Lord, Rutter, DiLavore, & Risi, 2009). In particular, the clinician led Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord et al., 2000) which is a behavioural observation tool, is listed within the NICE (2012a) diagnostic protocol. Consistent with the recommended tools for gathering information from

other informants, the ADOS-G was originally intended for children.

While the NICE (2012a) guideline provides some insight into current understanding of best practice assessment of adults with suspected ASD, its diagnostic protocol is not supported by strong empirical evidence. Indeed, the NICE (2012a) Guideline Development Group reported that many of the validity studies available to inform judgements about the suitability of the assessment tools had high risk of methodological bias. Consequently, the Guideline Development Group did not identify any gold standard assessment tools for adults with ASD. Instead, they reported that the aforementioned diagnostic tools had “reasonable psychometric properties...[and were] potentially of value” for adult assessments (NICE, 2012a, p. 135). Further, the Guideline Development Group suggested clinicians consider one additional tool, the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing, Leekam, Libby, Gould, & Larcombe, 2002), despite finding no psychometric data for its use among adults at the time of writing. The absence of quality empirical evidence to support the NICE (2012a) diagnostic protocol does not negate its value as it does provide the first comprehensive framework for the assessment of adults. Nonetheless, it is clear that a rigorous, gold standard diagnostic protocol for adults with suspected ASD is lacking.

**Limitations to the suitability of available diagnostic tools.** Though a range of tools is recommended to assist with adult ASD diagnoses, such tools vary in their suitability. In particular, psychometric limitations, pre-requisites for use, age-inappropriate activities and inconsistencies with the DSM-5 conceptualisation of ASD can render these tools unsuitable. Collectively, these factors contribute to the complexities of adult ASD diagnoses.

**Psychometric issues.** Of particular interest are the psychometric properties of the recommended assessment tools within the NICE (2012a) guideline, among adults without comorbid intellectual disability. Despite being endorsed for use with this demographic, few studies are available to provide support for the use of any of the aforementioned tools among

adults without comorbid intellectual disability. Reports of the psychometric performance of the ASDI are exclusively pooled across adolescents and adults within the published literature (Cederlund, Hagberg, & Gillberg, 2010; Gillberg, Gillberg, Rastam, et al., 2001). Further, the studies that evaluate the DISCO among adults combine their reports across adolescent and adult samples (Brugha et al., 2012) or, fail to report specificity among adults with ASD without intellectual disability (Carrington et al., 2014; Kent et al., 2013).

Similarly, information about the potential specificity of the AAA is limited to reports about the psychometric properties of the Autism Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, et al., 2001) and the Empathy Quotient (EQ; Baron-Cohen & Wheelwright, 2004) which partially contribute to this tool's diagnostic algorithm (Baron-Cohen et al., 2005).<sup>3</sup> These data provide little support for the AAA, with psychometric properties rarely being reported for the EQ (Lepage, Lortie, Taschereau-Dumouchel, & Théoret, 2009) while the sensitivity (26% - 95%) and specificity (26% - 95%) of the AQ varies widely (Ashwood et al., 2016; Bishop & Seltzer, 2012; Kanai et al., 2010; Lepage et al., 2009; Woodbury - Smith et al., 2005). Thus the validity of the ASDI, DISCO and AAA, for adults without intellectual disability remains uncertain.

The psychometric performance of ADI-R, ADOS-G and RAADS-R are the only tools that appear to have been evaluated explicitly among adults without comorbid intellectual disability. However, it appears there is only one study in the published literature to have evaluated the ADOS-G specifically among adults without comorbid intellectual disability. This study reports poor sensitivity (61%) when using the standard cut-off score (Bastiaansen et al., 2011). In contrast, both the ADI-R (Howlin, Moss, Savage, & Rutter, 2013; Lai, Lombardo, Pasco, Ruigrok, Wheelwright, Sadek, Chakrabarti, MRC AIMS Consortium, et al., 2011; Nygren et al., 2009) and RAADS-R (Andersen et al., 2011; Ritvo et al., 2011)

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<sup>3</sup> The AAA comprises an algorithm based on items from the AQ, EQ and a series of prerequisites to exclude language delay, intellectual disabilities etc.

perform with consistently high sensitivity and specificity among adults without comorbid intellectual disability. Thus although a range of assessment tools is recommended for adult diagnoses, only the ADI-R and the RAADS-R can be used with a certain degree of confidence as to their validity with this population.

***Pre-requisites.*** All assessment tools require access to individuals who can accurately reflect upon the impairments of the adult with ASD. Some adults with ASD find questions posed as part of the recommended assessment tools difficult to interpret (Holmes, 2011; NICE, 2012b). For example, the use of double negatives in items within the AQ can be confusing (Bishop & Seltzer, 2012), while symptoms manifesting in the manner described by the AQ and RAADS-R, but not with the frequency, severity or course across the lifespan specified can be challenging to rate (Holmes, 2011; NICE, 2012b). Difficulty knowing how best to respond to items within the recommended self-report tools can limit their suitability for some adults with ASD.

Given the time elapsed since early childhood for adults presenting with suspected ASD, information gained through retrospective reports about early development from childhood caregivers, may likewise be limited in detail and accuracy (Tadevosyan-Leyfer, 2003). Further, caregivers who can report about early childhood may be inaccessible for some adults (Pijnacker, Hagoort, Buitelaar, Teunisse, & Geurts, 2009) and so clinicians must rely upon information from the adult themselves or extended family, friends or significant others (Tantam, 2012). Such information, where available, may be more imprecise. These factors may thus limit the suitability of tools such as the ADI-R and DISCO.

Likewise, the administration and interpretation of the recommended assessment tools present a number of requirements for clinicians. Tools such as the ADI-R, DISCO and ADOS-G require specialist training to ensure accuracy and thus are only available to some clinicians (Lord et al., 2000, 1994; Wing et al., 2002). Indeed, in Australia, there appears to

be no organisations providing DISCO training, perhaps explaining its reportedly limited use (Taylor et al., 2016). Further, the ADI-R and DISCO can take several hours to administer (Lord et al., 1994; Wing et al., 2002) and may be impractical for clinicians in private practice who have a median of two 90-minute sessions to assess symptoms and discuss the diagnostic outcome (Taylor et al., 2016).

*Age inappropriate items.* Further, excepting self-report measures, none of the recommended assessment tools were specifically intended for adults. Despite adaptation for adults, the activities used within these tools are often age-inappropriate. In particular, the use of children's storybooks within the ADOS-G may be condescending and some individuals appear particularly uncomfortable participating in tasks such as those requiring them to mime brushing their teeth (Holmes, 2011). Hence using recommended assessment tools originally intended for children can be inappropriate.

*Inconsistencies with the DSM-5.* In addition, each tool discussed within the NICE (2012a) guideline was designed prior to the introduction of the DSM-5 criteria for ASD. Some of these tools such as the RAADS-R, ADI-R, ADOS-G and DISCO have been retrospectively coded so that DSM-5 compliant behaviours may be identified within the pre-existing item framework (Carrington et al., 2014; Eriksson, Andersen, & Bejerot, 2013; Huerta, Bishop, Duncan, Hus, & Lord, 2012a). However, given the timing of their development, the ADI-R and ADOS-G in particular provide few items assessing the sensory symptoms that were only recently introduced to the criteria (DSM-5; APA, 2013). Further, the classification algorithms of the recommended tools are not consistent with the combination of symptoms required to support a diagnosis of ASD according to the DSM-5. The notable exception is the recently revised algorithm of the DISCO (Carrington et al., 2014). However, many of the remaining tools, including the self-report RAADS-R and AQ use the extent rather than type of symptoms reported to determine diagnostic classification.

Further, while the social and repetitive behaviour subscales within the ADOS-G (Hus & Lord, 2014) and ADI-R (Lord et al., 1994) capture Domain A and Domain B, it is possible to receive a classification of ASD using these tools but not meet the combination of criteria within these domains to support a diagnosis of ASD as defined by the DSM-5. Thus, using available diagnostic tools to support a diagnosis of ASD as defined by the DSM-5 is complex.

### **Thesis Objectives**

It is clear that there is much uncertainty about the presentation and assessment of ASD in adulthood as reflected in the limited studies available about this period of life, the lack of a rigorous diagnostic protocol or appropriate, validated assessment tools. These limitations create difficulties for clinicians given the lack of resources within the literature to support and inform their clinical judgements. Hence, conducting adult diagnoses remains a complex process. Given the increasing numbers of adults presenting for an ASD diagnoses, the manifestation of ASD in adulthood requires further scrutiny and more practical comprehensive assessment tools for adults are required. As such, clarifying the presentation and assessment of ASD in adulthood among persons without intellectual disability and developing a more suitable diagnostic tool for this demographic was the purpose of this thesis.

**Chapter 2, Study 1.** Adults with ASD were not included within the initial validation samples used to develop the DSM-5 diagnostic criteria for ASD (APA; 2013; Clarke et al., 2013; Regier et al., 2013). Further, only one study by Wilson et al. (2013) has specifically examined whether adults meet each of these criteria, albeit based on current and/or historically presenting symptoms. Thus uncertainty remains about the DSM-5 criteria as they present in adulthood. Study 1, Chapter 2, sought to address this uncertainty. Specifically, the reports of adults with ASD, their parents, spouses and clinicians about the frequency,

regularity, interference with daily functioning and qualitative manner in which DSM-5 impairments presented was examined. To my knowledge, Study 1 provides the first accounts of the frequency and severity of each individual DSM-5 criterion and demonstrated the varying picture of ASD with age among adults without intellectual disability.

**Chapter 3, Study 2.** For diagnostic purposes, clinicians require an understanding of the specific behaviours that capture each of the diagnostic criteria, that is, the behaviours that differentiate individuals with ASD from individuals without and frequently present. Identifying the behaviours of diagnostic relevance in adulthood, particularly among adults without intellectual disability using the limited available literature is difficult. Indeed, the frequency with which specific behaviours characteristic of each DSM-5 criterion present among adults with ASD without comorbid intellectual disability does not appear to have been previously studied. The purpose of Chapter 3, Study 2, was thus to identify behaviours of diagnostic relevance in adulthood for each DSM-5 diagnostic criterion. A clinical psychologist and provisional psychologist coded items from three assessment tools, the AQ, RAADS-R and SCQ, which describe a range of behaviours characteristic of ASD, according to the DSM-5 criterion they best reflected. These items were then used to index behaviours that were frequently presenting and diagnostically sensitive in effectively differentiating adult participants with ASD from adult participants without ASD.

**Chapter 4, Study 3.** Given lack of clarity about the presentation of Domain B in adulthood within the literature and earlier chapters, Chapter 4, Study 3, sought to explore the frequency, severity and manifestation of each Domain B criterion among a sample of adults with ASD. Adults with ASD were invited to respond about the type, qualitative manner, and regularity of specific behaviours characteristic of Domain B using a questionnaire. To my knowledge, Study 3 provides the first accounts of the manifestation of Domain B in adulthood among a large sample of adults with ASD without intellectual disability.

**Chapter 5, Study 4.** As discussed in the present chapter, the recommended assessment tools for adult diagnoses have a number of limitations to their validity and practicality. Chapter 5, Study 4, thus sought to develop a diagnostic tool informed by findings about the presentation of ASD in adulthood in this thesis. This measure, the Autism Detection in Adult Populations Tool (ADAPT), comprises a battery of items that draw upon the strengths of behavioural observation, self-reporting and clinician led interviews to provide a comprehensive assessment of each DSM-5 criterion as it presents in adulthood. Specifically, the ADAPT comprises behavioural observation activities such as filmed vignettes and role plays, a self-report questionnaire, and a clinician led interview. Items from these activities inform the DSM-5 diagnostic algorithm that classifies whether impairments are present across the combination of criteria required to support an ASD diagnosis. In Study 4, the psychometric properties of the ADAPT were evaluated among a sample of adults with or without ASD.

### **Summary**

Increasing numbers of individuals with ASD are presenting for diagnosis in adulthood (Jensen et al., 2014). Nonetheless, understanding of ASD in this period of life is relatively limited due to limited research about ASD in adulthood. Available studies offer little insight into the presentation of symptoms in this period of life. Further, the most comprehensive guideline for the best practice assessment of adults with ASD (NICE; 2012) lacks an empirically rigorous diagnostic protocol. Indeed, the tools recommended within this protocol to assist with adult diagnosis have a number of limitations due to their poor psychometric performance and/or impracticality for use with adults.

In conducting the research presented in this thesis I had two aims. First, I sought to clarify the presentation of ASD among adults without intellectual disability who most frequently seek diagnosis later in life (Geurts & Jansen, 2012). Second, I aimed to develop a

diagnostic tool to assist in assessing these adults, informed by my improved understanding of ASD in this period of life. In Studies 1, 2 and 3 I thus examine how ASD presents in adulthood, clarifying the frequency, severity and manifestation of the DSM-5 criteria and behaviours of diagnostic relevance. In my final study, I use this information to develop the ADAPT, a comprehensive battery of tests designed to assist in classifying whether an adult meets the DSM-5 criteria for ASD. This tool is the first to be specifically developed to assess the DSM-5 criteria as they present in adulthood.

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## Chapter 2: The Presentation of the DSM-5 Criteria in Adulthood

It is understood that behaviour characteristic of ASD may change in its frequency, severity and manifestation across the lifespan. How such changes affect the presentation of ASD in adulthood remains uncertain. The purpose of this chapter is to clarify and understand the presentation of the DSM-5 criteria in adulthood. Of particular interest is the frequency and severity of these criteria.

### The DSM-5 Criteria

The DSM-5 (APA, 2013) defines ASD as a lifelong developmental disorder comprising impairments in two domains. Domain A captures impairments in social communication and social interaction while Domain B reflects restricted, repetitive patterns of behaviour, interests, or activities. The diagnostic criteria that describe Domain A and B are summarised in Table 1.

Table 1  
*Overview of the DSM-5 Criteria for ASD<sup>a</sup>*

Domain A
Criterion A1: difficulties initiating, maintaining and responding to social conversations.
Criterion A2: challenges using and understanding nonverbal cues and pairing them with verbal communication.
Criterion A3: problems with the formation and maintenance of social relationships. Extends to difficulties understanding relationships and social norms in various settings.
Domain B
Criterion B1: repetitive speech, motor behaviour and object use.
Criterion B2: insistence on sameness and the need for routines and rituals.
Criterion B3: interests unusual in their content and/or strength
Criterion B4: heightened or dulled responses to sensory stimuli.

<sup>a</sup> American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Arlington, VA: Author.

It is understood that changes in symptom presentation may be part of the natural development of the disorder with presentation and change being influenced by variables such as age (APA, 2013). A number of behaviours, particularly within Domain B,

appear to improve or present less frequently with increasing age (Howlin et al., 2013; Hus & Lord, 2014). These behaviours include the repetitive use of objects, stereotypical behaviour, unusual interests, ritualistic behaviour and visual sensation seeking (Chowdhury, Benson, & Hillier, 2010; Esbensen, Seltzer, Lam, & Bodfish, 2009; Leekam, Nieto, Libby, Wing, & Gould, 2007; Seltzer et al., 2003). Qualitatively, symptoms may also differ across the lifespan, manifesting in different forms in adulthood. For example, the DSM-5 manual notes that Criterion A2 typically manifests as the absence of one or more nonverbal cues in childhood, but in adulthood may be seen in the use of unconventional or stilted non-verbal cues (APA, 2013).

### **Current Understanding about ASD Symptoms Presenting in Adulthood**

Though the DSM-5 (APA, 2013) acknowledges some changes in symptomatology that may occur across the lifespan, both the manual and broader literature provide limited information about how these changes may affect the frequency, severity and qualitative manifestation of the behaviours thought to reflect ASD in adulthood. Understanding these aspects of symptom presentation is necessary to ensure that adults with ASD can be identified for diagnostic purposes. Examining the frequency, severity, and qualitative manifestation of the DSM-5 criteria in adulthood among persons without comorbid intellectual disability is thus the focus of this chapter.

**Frequency.** Throughout this thesis, frequency is defined as the proportion of adults with ASD presenting with symptoms in this period of life. General consensus within the developmental disability literature is that symptoms characteristic of these conditions should be identifiable among at least 70% of individuals who experience ASD. While this percentage is arbitrary, it was drawn from current guidelines (Glascoe, 2005; NICE; 2012a). for the frequency with which behaviours suitable for screening purposes should present among persons with developmental disabilities such as ASD. This threshold of 70% is thus used as a starting point for evaluating whether diagnostic

criteria present with adequate frequency to be considered salient in adulthood. Less frequently presenting symptoms may also have diagnostic value if they are specific to ASD. Other chapters thus discuss less frequently presenting behaviours that may also assist with diagnosis given their specificity to ASD.

The DSM-5 manual and broader literature provide little information about the frequency with which the DSM-5 diagnostic criteria present among adults with ASD (APA, 2013). The manual notes that most adults will experience difficulties forming reciprocal relationships indicative of Criterion A3, while few adults engage in the repetitive behaviours characteristic of Criterion B1, particularly in public (APA, 2013). The incidence with which any criterion manifests is not however, explicitly specified.

Accounts of the frequency with which the DSM-5 criteria present in adulthood, are likewise limited within the broader literature by small samples ( $N = 19$  Howlin, Mawhood, & Rutter, 2000; Mawhood, Howlin, & Rutter, 2000;  $N = 11$ ; Whitehouse, Watt, Line, & Bishop, 2009), the inclusion of individuals with comorbid intellectual disability (Seltzer et al., 2003; Woodman, Smith, Greenberg, & Mailick, 2015) and/or, pooled responses from children, adolescents and adults (Georgiades, Papageorgiou, & Anagnostou, 2010). While these studies provide some insight about the frequency with which impairments may present among adults with ASD, it is unclear how representative these findings are of persons diagnosed as adults who do not have an intellectual disability (Geurts & Jansen, 2012).

At this time, to the best of my knowledge, only one study examining behaviour consistent with Domain A and B specifically among adults without intellectual disability is available. This study by Howlin et al. (2013), examined the proportions of adults meeting diagnostic thresholds on the Reciprocal Social Interaction (RSI) and Restricted Repetitive Stereotyped Behaviour (RRBI) subscales of the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994). Given that these subscales

include behaviour consistent with DSM-5 Domains A and B respectively (Huerta, Bishop, Duncan, Hus, & Lord, 2012b), this study thus offers some insight into the frequency with which these overall domains may present in adulthood.

Howlin et al. (2013) studied whether impairments consistent with the aforementioned subscales had presented in childhood and/or adulthood among a large sample of adults with ASD ( $N = 60$ ). Although the authors reported that most adults with ASD presented with behaviours consistent with Domains A and B, only behaviours from the RSI subscale which captures Domain A presented with adequate frequency (70%). Further, the frequency with which the Domain B RRBI threshold was met was significantly higher in childhood (98%) than in adulthood (62%).

While the study by Howlin et al. (2013) offers potential insight into the overall frequency of Domain A and B impairments in adulthood, only one study by Wilson et al. (2013) has examined how frequently each of the DSM-5 criteria present among a sample of adults. Wilson et al. (2013) investigated the presence of impairments consistent with these criteria across the lifespan among 58 adults with ASD, including two adults with comorbid intellectual disability. According to clinicians, each of the DSM-5 Domain A criteria had presented among at least 70% of the sample. However, none of the Domain B criteria presented with adequate frequency. Indeed, Criterion B4 was met by less than a third of the adults with ASD. Thus again it appears that Domain B may not be particularly salient.

Though the study by Wilson et al. (2013) provides some insight into the frequency with which impairments consistent with the DSM-5 criteria can be identified among adults, their study design limits the conclusions that can be drawn. These authors were not specifically interested in the presentation of the diagnostic criteria in adulthood. Consequently, when symptoms characteristic of the criteria did not present in adulthood, experimenters used historically presenting symptoms to verify whether

criteria were met. The data reported do not distinguish between participants who met criteria historically or specifically in adulthood. Therefore, uncertainty remains about the frequency with which each DSM-5 criterion presents in adulthood. In examining symptom frequency, the aim of the present chapter was thus to extend the work of Wilson et al. (2013) by examining the frequency with which the DSM-5 criteria have been met in adulthood.

**Symptom severity.** It is understood that the severity with which ASD impairments present in adulthood may also differ relative to childhood and adolescence (APA, 2013). Nonetheless, the DSM-5 manual and broader literature provide limited information about symptom severity among adults. Indeed, the manual does not provide any age-specific guidance regarding symptom severity. Instead, three levels of symptom severity for Domain A and B are outlined. Level 1 reflects impairments that are conspicuous and/or interfere in specific settings. Level 2 outlines obvious impairments that present regularly and interfere in various settings. Finally, Level 3 captures impairments that present so regularly they create significant difficulties in all aspects of life. The DSM-5 thus operationalises symptom severity as the degree to which impairments present regularly and/or interfere with daily life. This definition of symptom severity is thus adopted throughout this thesis.

Within the broader literature, information about symptom severity is limited. Few studies explicitly assess how overall impairments in Domain A or B affect adaptive functioning in adulthood. A number of small qualitative studies suggest that lack of social awareness, all-consuming interests and hyper-reactive responses to sensory stimuli may interfere with relationships and employment (Hurlbutt & Chalmers, 2002; Mercier, Mottron, & Belleville, 2000; Robledo, Donnellan, & Strandt-Conroy, 2012). Further, accounts from clinicians, caregivers and adults with ASD highlight a general pattern of decreasing impairments across the lifespan (Hus & Lord, 2014; Lai,

Lombardo, Pasco, Ruigrok, Wheelwright, Sadek, Chakrabarti, Baron-Cohen, et al., 2011; Seltzer et al., 2003). In particular, Criterion B1: repetitive behaviour appears to markedly improve with increasing age (Howlin et al., 2013; Seltzer et al., 2003).

Beyond the aforementioned small qualitative studies and general trends, little information is forthcoming about symptom severity in adulthood as operationalised by behaviours that interfere with everyday life. Further, only one study has systemically considered the other aspect of symptom severity defined by the DSM-5: how regularly impairments present, and only among typically developing adults (Barrett et al., 2015). Understanding how the severity of impairments consistent with each DSM-5 criterion may differ from earlier life, and how they affect adults at present would assist in using the DSM-5 severity ratings to evaluate the impact of Domain A and B impairments among adults. The aim of this chapter is therefore to examine whether behaviour consistent with any particular criterion is viewed as more severe in adulthood than in earlier life and, which criteria appear to affect adults most and the regularity of their presentation.

**Manifestation.** Just as the frequency and severity of the diagnostic criteria may change across the lifespan, so too may the qualitative manifestation of these criteria. The DSM-5 manual provides a series of ‘descriptors’ for each diagnostic criterion. These descriptors describe a range of behaviour that captures how each criterion may manifest. For example, descriptors for Criterion A1 in the manual include “abnormal social approach and failure of normal back-and-forth conversation” (DSM-5, APA, 2013, p.50). Information about the manifestation of these diagnostic criteria in adulthood is however limited within the DSM-5 and broader literature. In its descriptions of diagnostic features and the development and course of ASD, the manual provides few examples of behaviours presenting in adulthood. The examples available are summarised in Table 2. You will see that few examples are available for each

criterion, particularly for the Domain B criteria. Further, while Criterion B3 interests in childhood are usually maladaptive, in adulthood they may be functional and adaptive, thus questioning the impact they have on daily life, and therefore their severity.

Table 2

*Manifestations of the DSM-5 criteria in adulthood<sup>a</sup>*

A1	<ul style="list-style-type: none"> <li>• Difficulty following and entering conversation</li> <li>• Difficulty judging appropriate topics of conversation</li> </ul>
A2	<ul style="list-style-type: none"> <li>• Body language is unusual</li> <li>• Trouble integrating nonverbal and verbal communication</li> </ul>
A3	<ul style="list-style-type: none"> <li>• Difficulty understanding social etiquette in different contexts</li> <li>• Difficulty understanding metaphorical language</li> <li>• Prefers the company of younger or older persons</li> <li>• Relationships may not reflect give and take</li> </ul>
B1	<ul style="list-style-type: none"> <li>• Repetitive behaviour may only present in private</li> </ul>
B3	<ul style="list-style-type: none"> <li>• Interests may be functional and adaptive, resulting in positive mood and/or work and study opportunities.</li> </ul>

<sup>a</sup> American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Arlington, VA: Author.

The overall lack of guidance regarding how the DSM-5 criteria manifest in adulthood within the manual might be expected given the limited research in this area. Indeed, no adults with ASD were included within the initial validation samples used to develop these criteria (Clarke et al., 2013; Regier et al., 2013). Thus one must examine the broader literature to find information about symptom manifestation in adulthood.

Studies exploring symptom trajectories across the lifespan provide useful information about behaviour characteristic of ASD in childhood that appears to present in the same manner in adulthood (Piven, Harper, Palmer, & Arndt, 1995; Seltzer et al., 2003). Further, a few studies validating the use of self-report tools intended specifically for adults, provide information about frequently presenting and discriminatory behaviours in this period of life (Allison et al., 2012; Bishop & Seltzer, 2012; Eriksson et al., 2013). Case studies and the aforementioned qualitative studies likewise provide some accounts of symptoms presenting in adulthood according to clinicians and adults with ASD (Bankier, Lenz, Gutierrez, Bach, & Katschnig, 1999; Hurlbutt & Chalmers,

2002; Mercier et al., 2000; Robledo et al., 2012; Smith & Sharp, 2013; D. Tantam, 2000).

Nonetheless, this body of research is again limited by samples predominantly featuring adults with intellectual disability (Bishop & Seltzer, 2012; Piven et al., 1995; Seltzer et al., 2003; Woodman et al., 2015), small sample sizes (Hurlbutt & Chalmers, 2002; Mercier et al., 2000; Robledo et al., 2012; Smith & Sharp, 2013) or, data pooled across adolescents and adults (Allison et al., 2012). Given age and comorbid intellectual disability is known to affect symptom presentations (APA, 2013; Seltzer et al., 2003; Woodman et al., 2015), whether the manifestations reported in the aforementioned literature are representative of adults seeking diagnosis is uncertain. As a result of our lack of understanding about the presentation of ASD in adulthood specifically, applying the DSM-5 diagnostic criteria to adults with suspected ASD can be difficult for clinicians.

### **Summary**

While it is understood that changes in the frequency, severity and manifestation of symptoms may occur across the lifespan, the effect on the presentation of the DSM-5 criteria in adulthood remains unclear. Primarily, there is uncertainty regarding the frequency, severity and manifestation of each DSM-5 criterion in this period of life. Such uncertainty has implications for clinicians performing ASD assessments, providing them with little guidance in applying the DSM-5 criteria to adults presenting for diagnoses. The present chapter thus assesses the frequency and severity of the DSM-5 criteria in adulthood and provides preliminary accounts of their manifestation.

## Method

### Participants

**Adults with ASD.** Participants with ASD ( $N = 114$ ) were recruited through social media advertisements<sup>4</sup> and a research database.<sup>5</sup> Individuals who completed less than 80% of the assessment measures ( $n = 33$ ) were excluded from further analyses. The final sample thus comprised 81 individuals who reported a formal diagnosis of ASD by a trained health professional. The diagnoses of the final sample included: Asperger's disorder ( $n = 63$ ), ASD ( $n = 8$ ), autistic disorder ( $n = 5$ ) or, PDD-NOS ( $n = 5$ ). The majority of participants were diagnosed in adulthood (75.9%) and reported other disorders such as anxiety and depression (57.8%) but not intellectual disability. Note that the number of females with ASD sampled is disproportionate to the number of males. Further participant demographics are described in Table 3 for each of the three participant groups.

Table 3  
*Participant Demographics*

	<i>n</i>	Gender (M:F)	Age <i>M (SD)</i>	Age at diagnosis <i>M (SD)</i>
Adults with ASD	83	28:55	35.6 (9.92)	29.04 (13.59)
Significant others	21	11:11	50.19 (12.99)	-
Clinicians	22	4:15	43.05 (13.62)	-

**Significant others.** Each participant with ASD was given a web link to the study that could be shared with their parents, caregivers or spouse, hereafter referred to as significant others, if they chose to do so. Each significant other ( $N = 23$ ), created an

<sup>4</sup> Adverts were posted on the Australasian Society for Autism Research social media accounts and my professional Twitter account 'followed' by adults with ASD, clinicians and ASD organisations.

<sup>5</sup> The research database comprised individuals diagnosed with ASD by a health professional trained in ASD assessments and eligible for services with the state autism organisation.

identification code based on the initials and birth date of the adult with ASD they were reporting about so that their data could later be matched. One significant other completed less than 80% of the assessment measures and was therefore removed from further analyses ( $n = 1$ ). One adult with ASD invited both parents to participate; their ratings were therefore combined and treated as one response. The final sample ( $N = 22$ ) thus comprised ten parents/caregivers and eleven spouses reporting about different adults with ASD.

**Clinicians.** Psychologists and psychiatrists, hereafter referred to as clinicians, with self-reported experience working with adults with ASD were also recruited through social media advertisements<sup>6</sup> or email mail-outs ( $n = 29$ ). Individuals who completed less than 80% of the assessment measures were again removed from further analyses ( $n = 10$ ). The final sample ( $N = 19$ ) comprised 16 psychologists and three psychiatrists who had on average, twelve years of experience working with adults with ASD ( $SD = 11.22$ ). The majority of adults with ASD the clinicians worked with had reportedly been diagnosed with a comorbid psychiatric disorder (89.5%), typically anxiety or depression, but not intellectual disability. Note that these clinicians were not reporting about the aforementioned adults with ASD, instead they were reporting about the adults with ASD that they encountered collectively in their clinical work.

### **Questionnaires**

Each of the three questionnaires used in this study comprises a series of multiple choice ratings and written extended response items. Each questionnaire differs subtly in wording and items depending on its intended participant group: adults with ASD, significant others or, clinicians. The general composition of the questionnaires is described below. A copy of each questionnaire is included in Appendix A.

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<sup>6</sup> Adverts were posted on my professional Twitter account. Adverts were also emailed to clinicians on the state register for ASD practitioners and clinicians worldwide who indicated they worked with adults with ASD.

**Background information.** Each questionnaire includes items to verify the respondent's participant group. As such, participants with self-reported ASD are asked to describe the type of ASD diagnosis they have received and the age at which they were diagnosed. Significant others are asked about the context in which they know the person with ASD and the type and timing of this person's diagnosis. Finally, clinicians are asked to identify their profession, years of experience and the most common diagnostic subtypes of the individuals with ASD with whom they work.

Further, the questionnaires invite participants with ASD to report their age and sex so that these factors may be considered when evaluating the frequency and severity with which the DSM-5 criteria present in adulthood. Likewise the questionnaires invite each participant group to respond about comorbid disorders so that any individuals with intellectual disability may be excluded from further analyses.

**Frequency.** One of the aims of the present chapter was to assess the frequency with which the DSM-5 criteria present in adulthood, that is, the proportions of adults with ASD meeting each criterion. To assess symptom frequency, each questionnaire presents respondents with the description of each DSM-5 criterion from the manual (APA, 2013), reworded to reduce jargon for the adults with ASD and significant others. For example, Criterion A3 is reworded as "challenges forming relationships, maintaining relationships (friendships or intimate relationships) or observing social rules." The questionnaire then invites adults with ASD and significant others to rate how often each criterion affects them or the adult with ASD about whom they are completing the questionnaire. Clinicians are instead invited to respond about the group of adults with ASD with whom they work. Participants use a Likert Scale with five anchors to make these ratings: never, rarely, sometimes, often or always.

The DSM-5 manual provides no explicit guidelines for evaluating whether the manifestation, number, regularity or severity of impairments reported suggest that a

given criterion is met. Indeed, it is acknowledged that impairments in this period of life may not present with marked regularity or severity (APA, 2013). In the absence of explicit guidelines, impairments consistent with criteria that adults with ASD reportedly experience at least ‘sometimes’ were considered present for the purposes of this study.

**Severity.** The severity of the DSM-5 criteria was also investigated in the present study as indexed by their interference with everyday life and, the regularity with which these impairments presented. First, to capture impediments with everyday functioning the questionnaire invites participants with ASD and their significant others to describe what about having ASD as an adult affects these adults most. Further, the questionnaire invites participants to describe whether any aspects of having ASD are harder to manage now in adulthood, than in childhood and adolescence.

Second, to assess the regularity of impairments, the questionnaire invites participants to rate how often the DSM-5 criteria present in adulthood using the aforementioned Likert scale. Given that no definitions are provided in the manual about how often behaviours must present to be deemed conspicuous and therefore severe as defined by the DSM-5, regularly presenting behaviour is defined as that which presents ‘often’ or ‘always.’ This threshold was chosen based on existing assessment tools that regard impairments as more severe the more consistently they present (c.f. ADI-R; Le Couteur, Lord, & Rutter, 2003; ADOS-G; Lord et al., 2009).

**Manifestation.** Whether manifestations of the DSM-5 criteria could be identified from the reports of adults with ASD, significant others and clinicians was also investigated. In addition to the aforementioned descriptive items designed to capture symptom frequency and severity, other items were included to gather qualitative accounts of the manifestation of ASD in this period of life. Specifically the questionnaires for significant others and adults with ASD required these participants to describe the aspects of having ASD in adulthood that appeared to affect the people

around them most to provide information about a broader range of contexts in which impairments may present. Further, clinicians were invited to describe the features of ASD they deemed most characteristic of adulthood. Finally all participants were invited to describe the strengths of adults with ASD. The rationale for this item was that it might assist in capturing qualitative accounts of Criterion B3 likely to be overlooked in the aforementioned symptom severity items, given that these interests tend to be adaptive in adulthood (APA, 2013; Mercier et al., 2000).

### **Procedure**

Adults with ASD, their significant others and clinicians independently completed the appropriate questionnaire online using Survey Monkey. Clinical judgement was used to code the responses to each of the descriptive questions according to the DSM-5 diagnostic criterion that they captured.<sup>7</sup> Behaviours attributed to ASD but not reflecting a specific DSM-5 criterion or domain for example problems in the workplace, were coded as ‘non-DSM-5 impairments.’

## **Results**

### **Frequency**

The proportion of adults with ASD meeting the DSM-5 criteria, that is, presenting with impairments consistent with each criterion at least sometimes, is shown in Table 4. Each Domain A diagnostic criterion reportedly presented with adequate frequency (i.e. among at least 70% of the sample according to adults with ASD, significant others and clinicians). Results varied for the Domain B diagnostic criteria. While Criteria B2, B3 and B4 presented with adequate frequency across rater groups, Criterion B1 only achieved adequate frequency according to the reports of adults with ASD, not clinicians or significant others.

Whether reports differed across the rater groups was considered. Mean point-

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<sup>7</sup> My clinical experience comprised a three-month placement assisting with DSM-5 diagnostic assessments under the supervision of a clinical psychologist and , throughout the course of my research independently conducting numerous diagnostic interviews with adults with ASD.

by-point agreement between adults with ASD and their significant others as to whether criteria were met was adequate ( $n = 21$ ;  $M = 88.84\%$ ,  $SD = 16.05$ ). Chi-squares tests of independence were used to determine whether the proportions of adults with ASD, clinicians and significant others reporting that criteria presented, significantly differed. Alpha levels for significance were set to .01 for all analyses due to multiple comparisons. Fisher's exact tests were used when cells fell below expected counts.

While clinicians were reporting about different groups of adults with ASD to the adults with ASD and significant others, none of the participant groups significantly differed from each other in their perceptions of the frequency with which criteria were met by adults with ASD. The effects of variables such as sex and age were also considered. The proportions of individuals reporting that each criterion was present did not significantly differ between males and females or between individuals diagnosed in adulthood or earlier.

Table 4.

*The Frequency with which the DSM-5 Criteria Present Among Adults with ASD*

	Present sample						Wilson et al. sample <sup>8</sup>
	ASD ( $N = 81$ )		Significant others ( $N = 22$ )		Clinicians ( $N = 19$ )		Clinicians ( $N = 113$ )
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	%
A1	77	95.06	21	95.45	19	100	94.7
A2	70	87.5	21	95.45	18	94.74	80.5
A3	80	98.77	22	100	18	94.74	93.8
B1	62	76.54	14	63.64	12	63.16	54.9
B2	76	93.83	22	100	19	100	57.5
B3	75	94.94	21	95.45	18	94.74	66.4
B4	77	95.06	20	90.91	19	100	18.6

<sup>8</sup> See Wilson, C. E., Gillan, N., Spain, D., Robertson, D., Roberts, G., Murphy, C. M., ... Murphy, D. G. M. (2013). Comparison of ICD-10R, DSM-IV-TR and DSM-5 in an adult autism spectrum disorder diagnostic clinic. *Journal of Autism and Developmental Disorders*, 43(11), 2515–2525. doi:10.1007/s10803-013-1799-6.

**Comparisons with Wilson et al. (2013).** As shown in Table 4, only Criterion B1 consistently presented with inadequate frequency in the present study. This differs from data reported by Wilson et al. (2013) who found that no Domain B criteria presented with adequate frequency. Whether the frequency with which the Domain B criteria were met significantly differed across the two studies was examined using two sample Z-tests for proportions. Compared to the Wilson et al. (2013) sample, a significantly greater proportion of adults with ASD in the present study, reported that Criteria B1 ( $z = 3.1, p = .002$ ), B2, ( $z = 5.6, p < .001$ ), B3 ( $z = 4.7, p < .001$ ) and B4 ( $z = 10.5, p < .001$ ) presented in adulthood. Similarly, a significantly greater proportion of significant others in the present study reported Criteria B2 ( $z = 3.7, p < .001$ ), B3 ( $z = 2.7, p = .007$ ) and B4 ( $z = 7.1, < .001$ ) presented. Finally, a significantly greater proportion of clinicians in the present study reported that Criteria B2 ( $z = 3.6, p = .001$ ) and B4 ( $z = 3.6, p = .001$ ) presented in adulthood than did Wilson et al. (2013)

The reasons why these results differed from Wilson et al. (2013) were investigated. In the present study I regarded criteria satisfied when they presented at least ‘sometimes.’ Whether raising this threshold to ‘often or always’ affected the data and reduced the discrepancies between the two studies was considered. The proportion of adults with ASD meeting criteria using this new threshold is shown in Table 5. Overall, the majority of participants reported that each DSM-5 criterion was met with adequate frequency among adults with ASD. However, Criteria A2 and B1 consistently failed to present with adequate frequency when using this higher threshold.

Table 5  
*The Frequency with which the DSM-5 Criteria Present Among Adults with ASD when Raising the Threshold for Meeting Diagnostic Criteria*

	ASD (N = 81)		Significant others (N = 22)		Clinicians (N = 19)	
	n	%	n	%	n	%
A1	58	71.60	11	50	18	94.74
A2	49	61.25	15	68.18	13	68.42
A3	63	77.78	18	81.82	18	94.74
B1	41	50.62	9	40.91	12	63.16
B2	61	75.31	19	86.36	15	78.95
B3	63	79.75	19	86.36	12	63.16
B4	68	83.95	19	86.36	10	52.63

Two sample Z-tests were used to compare reports of the proportions of adults with ASD meeting DSM-5 criteria in the present study and that by Wilson et al. (2013). Specifically, the proportions of adults with ASD meeting the Domain B and A2 criteria across the two studies when using the adjusted threshold was examined. Of the Domain B criteria, significant differences were only observed between the two studies for Criterion B4. A significantly greater proportion of adults met Criterion B4 in the present study according to adults with ASD ( $z = 9, p < .001$ ), significant others ( $z = 6.4, p < .001$ ) and clinicians ( $z = 3.2, p = .001$ ). Further, significantly greater proportions of the clinicians in the Wilson et al. (2013) study than the adults with ASD in the present study reported that individuals met Criterion A2 ( $z = 3, p = .003$ ).

**Individuals satisfying DSM-5 diagnostic criteria.** Whether the threshold used to judge criteria as present in adulthood adversely affected diagnostic outcomes was also considered. The number of individuals presenting with three Domain A criteria and at least two of the four Domain B criteria according to each threshold is shown in Table 6. Adults with ASD reportedly met the minimum number of criteria required to satisfy each domain and an overall diagnosis of ASD with adequate frequency when using the lower, more inclusive threshold. Only Domain B was met

with adequate frequency when using the higher threshold that required behaviour to present often or always to satisfy each criterion.

Table 6

*% of Adults with ASD Meeting Domain A or B Requirements for Diagnosis According to each Threshold for Judging Criteria as Present*

	Low threshold			High threshold		
	Domain A	Domain B	Both domains	Domain A	Domain B	Both domains
Adults with ASD	83.75%	98.77%	82.5%	42.5%	87.65%	37.5%
Significant Others	95.45%	95.45%	95.45%	40.91%	95.45%	40.91%
Clinicians	94.74%	100	94.74%	68.42%	73.68%	47.37%

*Note.* The low threshold required symptoms to present at least sometimes. The high threshold required symptoms to present often or always

### Severity

**The regularity of symptoms.** Symptom severity was also examined, first as indexed by the regularity with which symptoms presented.<sup>9</sup> Most DSM-5 criteria presented regularly for the majority of adults with ASD. Chi-squares tests of independence were used to examine the regularity with which the criteria presented in adulthood across the three participant groups. Perceptions differed between adults with ASD and clinicians regarding the regularity with which Criterion B4 presented with moderate effect  $\chi^2(1, N = 100), = 17.38, p = .002$ , Cramer's  $V = .42$ . Specifically, greater proportions of adults with ASD than clinicians reported that Criterion B4 'always' presented. Clinicians and significant others also differed in their perceptions of Criterion A1 with a strong effect  $\chi^2(1, N = 100), = 11.47, p = .004$ , Cramer's  $V = .53$ . A significantly greater proportion of clinicians reported that Criterion A1 always presented than did significant others. The regularity of criteria is displayed in Table 7.

<sup>9</sup> Recall that regularly presenting symptoms are defined as those presenting often or always for the majority of adults with ASD.

Table 7

*% of Participants Reporting the Regularity with Which each DSM-5 Criterion Presents Among Adults with ASD*

	Never			Rarely			Sometimes			Often			Always		
	ASD	SO	Clinicians	ASD	SO	Clinicians	ASD	SO	Clinicians	ASD	SO	Clinicians	ASD	SO	Clinicians
A1	0	0	0	4.9	4.5	0	23.5	45.5	5.3	44.4	31.8	36.8	27.2	18.2	57.9
A2	2.5	0	0	10	4.5	5.3	26.3	27.3	26.3	38.8	40.9	31.6	22.5	27.3	36.8
A3	0	0	0	1.2	0	5.3	21	18.2	0	33.3	40.9	47.4	44.4	40.9	47.4
B1	3.7	13.6	5.3	19.8	22.7	31.6	25.9	22.7	31.6	34.6	31.8	31.6	16	9.1	0
B2	1.2	0	0	4.9	0	0	18.5	13.6	21.1	46.9	50	68.4	28.4	36.4	10.5
B3	0	4.5	0	5.1	0	5.3	15.2	9.1	31.6	34.2	45.5	47.4	45.6	40.9	15.8
B4	1.2	4.5	0	3.7	4.5	0	11.1	4.5	47.5	37	45.5	42.1	46.9	40.9	10.5

*Note.* ASD = Adults with ASD ( $N = 81$ ), SO = Significant others ( $N = 22$ ), Clinicians ( $N = 19$ )

The effects of variables such as sex and age at diagnosis on the regularity of symptoms were considered using chi-squares tests of independence. The proportion of adults with ASD reporting that they presented with each DSM-5 criterion regularly did not significantly differ according to sex or whether diagnosed before 18 years of age. Whether the average age of adults who regularly presented with a given criterion differed was also examined using t-tests. A large effect was observed for the relationship between age and the regularity of Criterion B2. Specifically, adults with ASD who reported that they regularly experienced B2 related symptoms were older on average ( $M = 37.21, SD = 9.19$ ) than adults who did not present with these impairments regularly ( $M = 29.65, SD = 9.72$ )  $t(79) = -3.15, p = .002$ , Cohen's  $d = .80$ .

**Impairments interfering with everyday life.** Symptom severity as operationalised as impairments interfering with everyday life was also examined. Reports from adults with ASD and significant others about the aspects of having ASD in adulthood that affected these adults most, were coded according to the DSM-5 criteria they reflected. As shown in Table 8, according to the majority of participants, Domain A impairments affected adults with ASD most. While Domain A impairments were more widely endorsed, the proportions of individuals reporting Domain A or B impairments did not significantly differ ( $z = 2.4, p = .02$ ). Within Domain A, impairments arising from Criterion A3 were most commonly reported. With Domain B, Criterion B4 impairments were the most widely reported. The effects of variables such as sex and age at diagnosis were also considered using chi-squares tests of independence for each diagnostic criterion implicated. The proportions of adults with ASD nominating the criteria that affected them most did not significantly differ according to sex or whether diagnosed in adulthood.

Table 8

*% of Participants Nominating Impairments Causing them Most Difficulty*

Impairment type	Adults with ASD ( <i>N</i> = 81)		Significant others <sup>a</sup> ( <i>N</i> = 18)		How impairments interfere
	<i>n</i>	(%)	<i>n</i>	(%)	
Domain A	48	59.26	12	63.67	
A1	17	20.99	4	22.22	Social isolation; regarded as distant by peers; poor communication skills lead to avoidance
A2	3	3.70	2	11.11	Difficulty using nonverbal cues to read between the lines creates problems navigating politics in the workplace
A3	33	40.74	8	44.44	Commits social faux pas especially when social scripts unavailable; limited friendships; social isolation.
Domain B	24	29.63	5	27.78	
B1	1	1.23	0	0	Has a monotonous tone of voice
B2	6	7.41	2	11.11	Avoids taking chances; cannot manage change
B3	0	0	0	0	-
B4	17	20.99	3	16.67	Sensory hyper-sensitivities are difficult to manage in public spaces; can interfere with socialising; cause emotional distress
Any domain	62	76.54	15	83.33	

*Note.* The *n*'s do not amount to the total number of individuals reporting DSM-5 impairments because some participants with ASD (*n* = 30; 37.5%) and significant others (*n* = 9; 31.58%) reported more than one impairment

<sup>a</sup> The responses of the two parents reporting about the same adult with ASD were amalgamated.

Interestingly, almost half the adults with ASD ( $n = 38$ ; 46.91%) and the majority of significant others ( $n = 10$ ; 55.56%) noted adults with ASD were affected most by impairments that did not reflect the DSM-5 criteria. These sources of impairments hereafter referred to as ‘non-DSM-5 impairments,’ included difficulties managing emotional distress, obtaining employment and performing activities of daily living. Table 9 provides further detail about these non-DSM-5 impairments and, the frequency with which they manifested according to the adults with ASD and significant others who noted them.

Table 9

*% of Adults Reporting Difficulty Managing Impairments Attributed to their ASD but not Consistent with the DSM-5 Criteria*

Non-DSM-5 Impairment Subtypes	Adults with ASD ( $N = 38$ )		Significant others ( $N = 10$ )	
	$n$	(%)	$n$	(%)
Emotional distress e.g. fear, stress and anxiety	11	28.95	2	20
Difficulties finding and maintaining employment	9	23.68	3	30
Trouble managing in the absence of appropriate services and accommodations	8	21.05	0	0
Problems performing activities of daily living e.g., budgeting, chores, hygiene and driving	6	15.79	2	20
Executive function difficulties with organisation, memory and attention	6	15.79	3	30

How impairments that interfered with everyday life changed across the lifespan was also explored. Adults with ASD and significant others reported aspects of having ASD in adulthood that were harder to manage in this period of life than in childhood and/or adolescence. As shown in Table 10, only a minority of adults with ASD reported that impairments arising from any DSM-5 criterion or domain were harder to manage in adulthood. However, the majority of significant others reported that Domain

A caused greater impairments in adulthood than in childhood and/or adolescence. The overall proportions of individuals indicating that Domain A or B impairments were more severe in adulthood did not significantly differ ( $z = 1.1, p = .26$ ).

The effects of variables such as sex and age at diagnosis were also considered using chi-squares tests of independence for each diagnostic criterion. The proportions of adults with ASD reporting that impairments consistent with the DSM-5 criteria were more difficult to manage in adulthood did not significantly differ according to sex or whether they were diagnosed in adulthood. Neither did t-tests show that the mean age of adults reporting whether one or more DSM-5 criteria were harder to manage in this period of life significantly differed.

Table 10

*% of Participants Reporting DSM-5 or Non-DSM-5 Impairments that are Harder to Manage in Adulthood Relative to Childhood and/or Adolescence*

	Adults with ASD ( <i>N</i> = 75)		Significant others ( <i>N</i> = 17)		Examples
	<i>n</i>	(%)	<i>n</i>	(%)	
Domain A	23	30.67	9	52.94	
A1	5	6.67	1	5.88	Greater difficulty forming sentences; problems encouraging other people to speak with them; meeting higher social expectations for conversation
A2	2	2.67	1	5.88	Greater difficulty understanding and using facial expression; more marked difficulties interpreting nonverbal cues
A3	18	24	8	47.06	Difficulty meeting higher standards for social etiquette in adulthood, especially at work; being more aware of mistakes; pronounced difficulties developing and maintaining friendships or romantic relationships
Domain B	8	10.67	1	5.88	
B1	2	2.67	0	0	Engaging in repetitive motor behaviour with greater regularity; some repetitive motor behaviours such as thumb sucking being less socially acceptable
B2	2	2.67	0	0	Increased difficulty making choices or multitasking; problems with activities of daily living due to lack of structure in day-to-day activities.
B3	0	0	0	0	-
B4	3	4	1	5.88	Hyper-sensitivity prevents some individuals from being in certain environments which can be detrimental to social relationships.
Domain A and/or B	28	37.33	10	58.82	

Participants also reported greater difficulty managing non-DSM-5 impairments in adulthood than in childhood and adolescence. The majority of adults with ASD ( $n = 43$ ; 57.33%) and significant others ( $n = 12$ ; 70.59%) noted these more severe impairments. Table 11 provides further detail about the frequency with which subtypes of these impairments were nominated as being harder to manage in adulthood than earlier life. The most commonly reported non-DSM-5 impairments were greater difficulties managing more demanding societal expectations.

Table 11

*% of Impairments Attributed to ASD but not Consistent with the DSM-5 Criteria that were Harder to Manage in Adulthood Relative to Childhood and/or Adolescence*

Non-DSM-5 Impairment Subtypes	Adults with ASD ( $N = 43$ )		Significant others ( $N = 12$ )	
	$n$	(%)	$n$	(%)
Meeting societal expectations, e.g. parenting, household management, employment, independence	24	55.81	5	41.67
Limited recognition of ASD in adulthood and lack of accommodations	11	25.58	2	16.67
Managing emotional distress, e.g. anxiety, anger, depression and fatigue	10	23.26	4	33.33

### **Manifestation**

Finally, the qualitative manifestation of each DSM-5 criterion in adulthood was examined. As discussed previously, the DSM-5 provides some examples of behaviours that characterise each domain, referred to as descriptors. Whether the qualitative responses of adults with ASD, significant others and clinicians within this study could be used to provide further examples of how these descriptors manifest in adulthood was evaluated. Table 12 displays the examples of each descriptor provided about an adult with ASD (from the amalgamated reports of adults with ASD and their significant others where available) or, the group of adults with ASD with whom clinicians worked.<sup>10</sup>

<sup>10</sup> Descriptors are italicised (see DSM-5; APA, 2013, p.50)

Table 12

*The Number of Reports of each DSM-5 Descriptor for Adults with ASD (N = 87)*

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A1	<ul style="list-style-type: none"> <li>▪ <i>Failure of normal back-and-forth conversation</i> Presents as difficulty initiating and/or maintaining conversations including social chit-chat, group settings and difficulty relating to others when communicating (<math>n = 20</math>)</li> <li>▪ <i>Failure to initiate or respond to social interactions</i> Manifests as misunderstanding or being misunderstood in conversation (<math>n = 6</math>) or, a preference for being alone (<math>n = 2</math>)</li> <li>▪ <i>Reduced sharing of interests, emotions, or affect</i> (<math>n = 0</math>)</li> <li>▪ <i>Abnormal social approach</i> (<math>n = 0</math>)</li> </ul>
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A2	<ul style="list-style-type: none"> <li>▪ <i>Deficits in understanding and use of nonverbal cues</i> As seen in difficulties recognising, interpreting and/or using nonverbal cues e.g. facial expression and body language and difficulty gauging others' emotions, motives and meaning. May contribute to perspective taking difficulties (<math>n = 21</math>).</li> <li>▪ <i>Abnormalities in eye contact and body language</i> May manifest as difficulty using nonverbal cues, e.g. unusual posture and gestures or limited, staring or avoidant eye-contact (<math>n = 5</math>)</li> <li>▪ <i>Poorly integrated verbal and nonverbal communication</i> Presents as poor integration of eye contact (<math>n = 1</math>)</li> <li>▪ <i>Total lack of facial expressions and nonverbal communication</i> (<math>n = 0</math>)</li> </ul>
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A3	<ul style="list-style-type: none"> <li>▪ <i>Difficulties developing, maintaining and understanding relationships</i> Manifests as difficulty forming and/or maintaining social relationships may not understand how to do this or how to classify how well they know someone (<math>n = 33</math>)</li> <li>▪ <i>Difficulties adjusting behaviour to suit various social contexts</i> Presents as problems understanding and observing social norms including difficulty judging socially appropriate behaviour. May create difficulty in work settings (<math>n = 24</math>)</li> <li>▪ <i>Absence of interest in peers</i> (<math>n = 0</math>)</li> <li>▪ <i>Difficulties sharing imaginative play, imagination or pretence</i> (<math>n = 0</math>)</li> </ul>
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B1	<ul style="list-style-type: none"> <li>▪ <i>Stereotyped or repetitive speech</i> Repetitious and/or unusual speech including pedantic phrasing, difficulties with verbal expression, e.g. atypical grammar, speech patterns and monosyllabic speech (<math>n = 6</math>)</li> <li>▪ <i>Stereotyped or repetitive motor movements</i> Repetitious hand and motor behaviour including poor motor skills (<math>n = 5</math>)</li> <li>▪ <i>Stereotyped use of objects</i> (<math>n = 0</math>)</li> </ul>
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- B2 ■ *Inflexible adherence to routines or ritualised patterns of verbal or nonverbal behaviour*  
 Need for routines, rituals. Tendency for black and white thinking ( $n = 15$ )
- *Insistence on sameness*
  - Presents as difficulty managing change, dislike for spontaneity and difficulty multi-tasking ( $n = 6$ )
- 
- B3 ■ *Highly restricted, fixated interests that are abnormal in intensity or focus*  
 Such interests may either interfere or assist in the maintenance of relationships and finding employment. Typically these interests are intense e.g. time consuming, notable expertise and/or talent, but not unusual including:
1. Creative pursuits: crafts, music, writing, art and cooking ( $n = 19$ );
  2. STEM related interests: engineering, maths, scientific research, and IT ( $n = 12$ );
  3. Humanities based interests: history, learning foreign languages ( $n = 3$ )
  4. Motherhood ( $n = 1$ )
  5. Autism ( $n = 1$ )
  6. Animals ( $n = 1$ )
- *Preoccupation with unusual objects* ( $n = 0$ )
- 
- B4 ■ *Hyper- or hypo-reactivity to sensory input*  
 Sensitivity to auditory, olfactory, gustatory or visual stimuli may create ‘sensory overload,’ emotional distress and impede employment or social functioning ( $n = 24$ ).
- *Unusual interest in sensory aspects of the environment* ( $n = 0$ )
- 

*Note.*  $n$ 's reflects one adult with ASD or one group of clients reported by a clinician observing the behaviour across their qualitative responses.

As shown in Table 12, the number of DSM-5 descriptors for which participants provided qualitative examples of their manifestation in adulthood, varied. For most criteria, examples were not consistently reported for every descriptor. Examples of how the Criterion A3 descriptor “difficulties developing, maintaining and understanding relationships” (DSM-5; APA, 2013, p. 50) manifested in adulthood were most commonly reported, but only by a third of the sample ( $n = 33$ ; 37.93%).

### **Discussion**

The DSM-5 (APA, 2013) states that the frequency, severity and manifestation of ASD symptoms may change across the lifespan but provides limited guidance as to how these changes may present. The purpose of this chapter was therefore to improve our understanding about the expression of the DSM-5 criteria in adulthood. To this end, I

collected accounts about the frequency, severity and manifestation of the DSM-5 criteria from adults with ASD, significant others and clinicians.

### **Sample Characteristics**

It is important to acknowledge a number of peculiarities about the sample of adults with ASD studied. First, most adults with ASD were diagnosed in adulthood. Late diagnoses arise for a number of reasons, including but not limited to the relatively recent recognition of milder forms of ASD within diagnostic criteria (DSM-IV; APA, 1994). Arguably, individuals with ASD diagnosed in adulthood may differ in their presentation from individuals diagnosed in childhood and/or adolescence. While late diagnosis was unrelated to the frequency or severity of symptoms in the present sample, a more comprehensive study of these aspects of symptom presentation between late diagnosed and earlier diagnosed individuals is needed.

Second, the sample within the present study is unusual in that it has a distinct female bias in contrast to the over-representation of males among individuals diagnosed with ASD reported in the literature (Russell, Rodgers, Ukoumunne, & Ford, 2013; Windham et al., 2010). This selection bias is likely attributable to the study advert being shared by the Autistic Women's Network on Twitter which has a large following of females with ASD. While the sex ratio of the sample in the present study may be unusual, it provided an opportunity to examine sex differences in presentation. Information about sex differences in the broader literature is conflicting, with varying reports of the presence or absence of such differences in symptom presentation across studies of children (Hiller, Young, & Weber, 2014; Reinhardt, Wetherby, Schatschneider, & Lord, 2014) and adults with ASD (Happé et al., 2016; Lai, Lombardo, Pasco, Ruigrok, Wheelwright, Sadek, Chakrabarti, Baron-Cohen, et al., 2011). Interestingly, no differences were observed in the frequency or severity with which the DSM-5 criteria presented among males or females in the present study.

Whether these findings can be replicated in a further sample of adults with ASD warrants consideration to assist in clarifying conflicting reports of sex differences in the broader literature.

Finally, the present sample is unusual in that the majority of participants participated online. This presented some difficulties in verifying diagnoses. These adults were asked to describe the nature and timing of their diagnoses and these descriptions were evaluated against the responses of their significant others where possible. Further, the qualitative responses of adults with self-reported ASD were examined to confirm that they provided sufficient accounts of their ASD symptomatology to support their self-reported diagnoses. Replicating the trends reported in the present study in samples where diagnoses were verified further would assist in increasing confidence in the veracity of findings.

### **The DSM-5 Criteria in Adulthood**

**Symptom frequency.** This study provides the first account of the frequency with which the DSM-5 criteria present in adulthood. As expected, each Domain A and B criterion presented with adequate frequency (i.e. among at least 70% of the sample, according to adults with ASD, significant others and clinicians). The notable exception was Criterion B1. Only accounts from adults with ASD suggested that it presented with adequate frequency. The frequency of Criterion B1 in adulthood thus requires investigation.

The frequency with which criteria were met in the present study also differed from the reports of clinicians in the Wilson et al. (2013) study for each Domain B criterion. Specifically, the proportion of adults meeting these criteria in the Wilson et al. (2013) sample was significantly smaller than the present sample. One possible explanation for these discrepancies is that the threshold that was chosen for determining the presence of each criterion in this study, was lower than that used by Wilson et al

(2013). Indeed, when raising this threshold and considering criteria present only when manifesting ‘often’ or ‘always’ in adulthood, discrepancies between these studies persisted only for Criterion B4.

Interestingly, when raising the aforementioned threshold adverse impacts were reported for the Domain A criteria. Using this threshold, Criterion A2 presented significantly less often in the present study than in that by Wilson et al. (2013) and, with inadequate frequency. Consequently, less than half the adults with ASD satisfied the minimum number of criteria to meet a DSM-5 diagnosis of ASD based on their current presentation according to each participant group.

The DSM-5 allows ASD diagnostic criteria to be met according to currently or historically presenting impairments (APA, 2013) noting that Domain B may be met when related symptoms manifest only in childhood. Whether Domain A may likewise be satisfied by historically presenting symptoms is unclear however. Thus, the diagnostic implications of many individuals with ASD failing to present with Criterion A2 impairments in adulthood are likewise uncertain. Guidance about the use of childhood symptoms to justify a DSM-5 diagnosis of ASD in adulthood is needed.

Various studies have noted that children, adolescents and adults previously diagnosed under DSM-IV-TR or ICD-10 are less likely to be identified as having ASD as defined by the DSM-5 if all three Domain A criteria must be met, even when using historically presenting symptoms to satisfy criteria (Wilson et al., 2013; Young & Rodi, 2014). Collectively, the broader literature and the present study thus suggest that re-evaluating the importance of symptom regularity when determining whether criteria are met in adulthood or, reconsidering how many Domain A criteria are required to consider a diagnosis of ASD, may be necessary.

Interestingly, there were no marked discrepancies in the frequency with which adults with ASD, the significant others and clinicians observed each DSM-5 criterion in

adulthood. It is important to acknowledge that the clinicians were reporting about different groups of adults with ASD to the significant others and adults with ASD describing adult presentation. However, this lack of discrepancy between raters' perceptions provides some preliminary support that most adults with ASD may not be impaired in perceiving the extent of their symptoms, potentially challenging hypotheses in the broader literature that these adults lack the insight to reflect on their symptoms accurately (Johnson, Filliter, & Murphy, 2009).

**Symptom severity.** The present chapter also sought to improve understanding about symptom severity in adulthood as indexed by the regularity with which symptoms presented and how they interfered with everyday functioning. No symptom domain or criterion clearly emerged as harder to manage in adulthood or as causing greater difficulty more than any other. However, the majority of adults with ASD reported that impairments consistent with Domain A affected them most. Particularly salient were Criterion A3 difficulties observing social norms which led to problems in the workplace. Thus the findings of the present study provide information about how Domain A may present in adulthood and interfere with functioning.

Less than a third of the sample reported that Domain B impairments affected daily functioning in adulthood. Symptom severity in this domain may thus be better indexed by the regularity with which such behaviours present. This methodology shows promise given that Criteria B2, B3 and B4 symptoms reportedly presented regularly among most adults with ASD. Further research is needed to confirm whether these particular findings generalise beyond the present study and if any specific behaviours characteristic of the criteria present with marked regularity. This is one of the aims of Study 3.

In addition to impairments interfering with functioning linked to the DSM-5 criteria, almost half the participants nominated impairments that were attributed to

having ASD but that did not reflect a specific DSM-5 diagnostic criterion. For the majority of adults with ASD, these ‘non-DSM-5 impairments’ included difficulties managing symptoms while meeting the increasing demands of employment, financial independence and household responsibilities. Some individuals also reported managing emotional distress arising from their impairments. Many of these non-DSM-5 impairments reflect areas of difficulty reported among adults with ASD in the broader literature. For example, it has previously been noted that comorbid mood disorders are common among adults with ASD (Elst, Pick, Biscaldi, Fangmeier, & Riedel, 2013) and that problems accessing relevant supports and poor adaptive functioning may also occur (Farley et al., 2009; Howlin et al., 2013).

The aforementioned non-DSM-5 impairments may have clinical relevance, appearing to capture the concept of “clinically significant impairment” described within the diagnostic manual (DSM-5; APA, 2013). Specifically, clinically significant impairments are defined as ASD related impairments that create difficulty in various areas of functioning. Thus the non-DSM-5 impairments presented in this study offer additional avenues to consider when evaluating the clinical significance of impairments when assessing adults with suspected ASD. In addition, these non-DSM-5 impairments provide further support for assessing the emotional wellbeing and adaptive functioning of adults with ASD presenting for diagnosis as recommended by the NICE (2012a) guideline, so that appropriate intervention and supports may be provided.

**Symptom manifestation.** The secondary aim of the present study was to examine whether the descriptive accounts of symptoms provided by participants might inform our understanding of how the descriptors for each DSM-5 diagnostic criterion manifest in this period of life. Few participants provided examples of how more than one descriptor manifested for any criterion in adulthood. Further, no commonly presenting descriptors emerged. Indeed, in some instances none of the behaviours

described matched some of the descriptors outlined within the DSM-5 for some criteria. These findings imply that the presentation of each DSM-5 criterion in adulthood may be diverse, with the expression of each criterion varying widely among adults with ASD.

### **Summary**

The present study provides information about the frequency, severity and manifestation of the DSM-5 criteria in adulthood. As expected most adults with ASD presented with each DSM-5 diagnostic criterion in adulthood. However when symptoms had to occur regularly to be considered present, many adults failed to meet Criterion A2 and therefore satisfied insufficient criteria to consider a diagnosis of ASD as operationalised by the DSM-5. Accounts of symptom severity suggested that clinicians should examine interference with everyday functioning when rating the severity of Domain A impairments. In contrast, when rating the severity of Domain B, considering the regularity with which impairments presented appeared most useful. Reports of the manifestation of both Domain A and B behaviours in adulthood highlighted diversity in the expression of each criterion. Thus considering a range of behaviour when assessing adults with ASD is important.

Given the infrequency with which some criteria appear to present in adulthood, it is important to identify behaviours that may best assist in effectively identifying these criteria. Clarifying specific behaviours characteristic of each of the diagnostic criteria that may be of diagnostic relevance in adulthood thus has value. In the proceeding chapters, individual behaviours that present frequently and differentiate adults with ASD from adults without ASD for each DSM-5 diagnostic criterion will be investigated (see Study 2). Further, the manifestation and regularity of Domain B behaviours in adulthood will be explored (see Study 3).

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### **Chapter 3: The Behaviours of Diagnostic Relevance in Adulthood**

The presentation of behaviours characteristic of Domain A or B, can, for some individuals with ASD, be identified in early infancy (Young, Brewer, & Pattison, 2003). However, adults may also seek diagnoses. Little is known about the presentation or best practice assessment of ASD in adulthood. While Study 1 provided insight into the overall frequency, severity and manifestation of the DSM-5 criteria, little is known about the specific behaviours that best capture these criteria as they present in adulthood. To address this uncertainty, the present chapter sought to clarify the behaviours of diagnostic relevance to each DSM-5 criterion in this period of life.

#### **Diagnostic Relevance**

Given that the presentation of ASD may change across the lifespan it is important to understand the profile of impairments characteristic of this disorder in each period of life. Behaviours characteristic of ASD, hereafter referred to as behaviours of diagnostic relevance, present both frequently and with diagnostic sensitivity. Study 1 offers valuable insights into the frequency with which the DSM-5 diagnostic criteria present in adulthood. However, the frequency of the individual behaviours that capture these criteria and the diagnostic sensitivity of these behaviours in differentiating adults with ASD from adults without ASD, remain unclear. Therefore, addressing uncertainty about behaviours of diagnostic relevance is critical to improving our understanding of ASD as it presents in adulthood.

As discussed in Study 1, it is understood that ASD impairments should present with a frequency of 70% among persons with the disorder to be considered useful for diagnostic purposes (Glascoe, 2005; NICE, 2012a). Guidelines are also available for identifying diagnostically sensitive behaviour that effectively differentiates adults with ASD from adults without ASD. Specifically, other authors have used effect sizes to identify these behaviours (Allison et al., 2012), regarding behaviour differentiating with

at least moderate effect (effect size  $\geq .3$ ), as diagnostically sensitive. Thus in the present chapter, these guidelines will be followed to identify diagnostically relevant behaviour presenting with adequate frequency and diagnostic sensitivity.

### **Behaviours of Diagnostic Relevance in the Literature**

Information about specific behaviours presenting among adults with ASD is available (c.f. Allison et al., 2012; Bishop & Seltzer, 2012; Eriksson et al., 2013). Nonetheless, reports about the frequency with which these behaviours present and their diagnostic sensitivity are limited. Difficulties thus arise in clarifying whether the behaviours reported as manifesting in adulthood are of diagnostic relevance. The select few behaviours of diagnostic relevance that may be identified within the available literature are presented in this chapter.

Much of the information about behaviours presenting in adulthood comes from studies evaluating emotion recognition or theory of mind. These studies highlight problems recognising emotion, consistent with Criterion A2 (Golan, Baron-Cohen, & Hill, 2006; Rump, Giovannelli, Minshew, & Strauss, 2009; Shamay-Tsoory, 2007; Sucksmith, Allison, Baron-Cohen, Chakrabarti, & Hoekstra, 2013); difficulty predicting other people's thoughts and judging social etiquette, characteristic of Criterion A3 (Dziobek et al., 2006; Golan, Baron-Cohen, Hill, & Rutherford, 2007; Zalla, Sav, Stopin, Ahade, & Leboyer, 2009) and, hyper-reactivity to auditory stimuli, representative of Criterion B4 (Kujala et al., 2007; Teresa Tavassoli et al., 2014). Nonetheless, these studies rarely report effect size or frequency so only one behaviour of diagnostic relevance may be identified within this body of literature: difficulty judging social etiquette (Zalla et al., 2009).

Similarly, qualitative studies and studies of symptom change also offer accounts of behaviour manifesting in adulthood, but little information about its diagnostic relevance. Small qualitative studies of adults with ASD describe specific behaviours

consistent with Criterion B3 or B4 such as interest in computers and unusually high pain tolerance (Mercier et al., 2000; Robledo et al., 2012; Smith & Sharp, 2013). Studies evaluating changes in the frequency of specific symptoms across the lifespan suggest that difficulty forming friendships characteristic of Criterion A3 frequently presents in adulthood (Seltzer et al., 2003; Woodman et al., 2015). Nonetheless, none of these studies report suitable statistics to judge whether the frequency and/or diagnostic sensitivity of these behaviours are appropriate.

Validity studies represent perhaps the best source of information about the behaviours of diagnostic relevance in adulthood. These studies have evaluated items from the Ritvo Autism Asperger Diagnostic Scale-14 (RAADS-14; Eriksson et al., 2013) and the Autism Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, et al., 2001). These measures contain items from two of the recommended assessment tools for adults (NICE, 2012a): the Adult Asperger Assessment (AAA; Baron-Cohen et al., 2005) which comprises the AQ and the Empathy Quotient (EQ; Baron-Cohen & Wheelwright, 2004) and, the 80 item Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R; Ritvo et al., 2011).

The RAADS-14 validity study by Eriksson et al. (2013) outlines fourteen items from the RAADS-R deemed most sensitive in differentiating adults with ASD from adults without ASD. The authors coded items from this abridged version of the RAADS-R by the consensus of clinicians according to the DSM-5 criterion they best reflected. Behaviours capturing the diagnostic criteria are thus described among these items. These behaviours include Criterion A2 problems judging other people's expectations and Criterion B4 hyper-reactivity to texture. No behaviour characteristic of Criterion B1 was reported among the items used to develop the RAADS-14 (Eriksson et al., 2013). Effect sizes to determine diagnostic sensitivity were also omitted and the frequency with which these behaviours manifest in adulthood was not

reported. Therefore, while the behaviours outlined by Eriksson et al. (2013) offer some insight into adult presentation, without further information about the frequency and sensitivity of these behaviours, their diagnostic relevance remains unclear.

In contrast, the AQ validity studies by Allison et al. (2012) and Bishop and Seltzer (2012) explicitly report the frequency and/or effect sizes of items describing individual behaviours characteristic of ASD. Though these authors pool data across adolescents and adults (Allison et al., 2012) or individuals with or without intellectual disability (Bishop & Seltzer, 2012), these individuals form the minority of either sample (personal communication; Allison, 2012). At present, in the absence of other studies, the AQ validity studies are therefore the best means of identifying behaviours of diagnostic relevance for adults with ASD without comorbid intellectual disability.

### **Behaviours of Diagnostic Relevance Identifiable in Validity Studies**

In Table 13, I present the behaviours of diagnostic relevance in adulthood that may be identified within the AQ validity studies (Allison et al., 2012; Bishop & Seltzer, 2012). You will notice that no behaviours of diagnostic relevance were identified for Criterion B1 or Criterion A2. This is perhaps unsurprising given that these criteria reportedly present with inadequate frequency in adulthood (see Study 1). However, it should be noted that the AQ does not assess any behaviour that captures the repetitive motor behaviour, speech or object use characteristic of Criterion B1.

Table 13  
*Diagnostically Relevant Behaviour Identified from the AQ Validity Studies<sup>11</sup>*

Item	Criterion A1 <sup>12</sup>
39	Misjudging when to talk or listen
Criterion A3	
22	Problems developing friendships
45	Difficulty engaging in perspective taking
Criterion B2	
23	Notices patterns
25	Need for routine
46	Dislikes novelty
Criterion B3	
4	Interests that are all-consuming
6	Interest in numbers
41	Interest in keeping lists of facts
Criterion B4	
5	Hypo-reactivity to faint noises

Little diagnostically relevant behaviour emerges from the AQ validity studies for any diagnostic criterion. The paucity of behaviours that may be identified as diagnostically relevant within this body of research primarily occurs due to conflicting results between the two studies (Allison et al., 2012; Bishop & Seltzer, 2012). Specifically, there is little consensus about whether behaviours present with adequate frequency. Indeed, when examining whether reports from the two studies place each of the 50 AQ items above or below the threshold for adequate frequency (70%), agreement is reached for only 24 of the 50 items. Thus in the absence of additional accounts about the frequency with which adults with ASD endorse the behaviours assessed in the AQ, the diagnostic relevance of these behaviours remains unclear.

Insufficient coverage of some criteria may also contribute to the scarcity of behaviours of diagnostic relevance that may be identified. In addition to failure to evaluate Criterion B1, the AQ contains relatively few items that capture Criteria A2

<sup>11</sup> Allison et al., 2012; Bishop & Seltzer, 2012.

<sup>12</sup> Items from the AQ were used to index behaviours. Following the procedure used by Eriksson et al., (2013) to classify the RAADS-14 items according to the DSM-5 criteria, the AQ items were coded according to the criterion they best represented by a provisional psychologist and clinical psychologist.

or B4. The three AQ items that assess Criterion A2 evaluate understanding of nonverbal communication and present with adequate diagnostic sensitivity but not frequency. Impairments in the expression of nonverbal communication also characteristic of this criterion are overlooked and thus their diagnostic relevance requires further investigation. The one item in the AQ which captures Criterion B4 by assessing hyper-reactivity to auditory stimuli, appeared to be diagnostically relevant (Allison et al., 2012; Bishop & Seltzer, 2012). However, whether responses to stimuli from other sensory domains may also be relevant for adult diagnoses remains unclear and warrants further consideration given the frequency with which Criterion B4 reportedly presents in adulthood and the range of hyper- or hypo-reactive responses to other sensory domains reported in Study 1.

### **Future Directions**

Uncertainty about behaviour of diagnostic relevance in adulthood continues due to having few accounts of the frequency and sensitivity of specific behaviours presenting in this period of life for each diagnostic criterion. What is needed is an examination of the frequency and sensitivity of the same behaviours assessed within the AQ and RAADS-14 in an additional sample of adults with ASD to reconcile conflicting findings (Allison et al., 2012; Bishop & Seltzer, 2012) and to provide information about these properties for the behaviours for which it is lacking (Eriksson et al., 2013). Further, given the limited coverage of behaviours consistent with some DSM-5 criteria across these tools, the frequency and sensitivity of a broader range of behaviour requires evaluation.

While using the recommended assessment tools for adults with ASD would appear the most logical approach to assessing the diagnostic relevance of a broader range of behaviour characteristic of the DSM-5, their suitability is limited for this purpose. Of particular interest is identifying diagnostically relevant behaviour

consistent with Criteria A2, B1 and B4. The complete version of the RAADS-R, rather than the RAADS-14 discussed by Eriksson et al. (2013), assesses additional behaviour characteristic of these criteria. Nevertheless, given that Eriksson et al. (2013) regarded none of these additional items as particularly discriminatory, it appears unwise to rely solely on the RAADS-R.

None of the other assessment tools recommended for use with adults (NICE, 2011) provide a suitable means of evaluating behaviours consistent with these criteria. While the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994) and the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al., 2002) assess a number of behaviours characteristic of each of these criteria, it is particularly difficult to access adults' parents in order to use these tools and thus they are likely to be ill-suited (Pijnacker et al., 2009).<sup>13</sup> Indeed, less than a third of the adults with ASD from Study 1 who were willing to recruit a significant other to report about them, were able to do so. While behavioural observation tools such as the ADOS-G may be more practical, it is understood that they should not be relied upon for eliciting information about Domain B behaviour (Hus & Lord, 2014). Further, the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI; Gillberg, Gillberg, Råstam, & Wentz, 2001) contains just two items that assess the same facet of Criterion B1, stereotypical speech and, one Criterion B4 item that assesses vestibular disturbances, (i.e. difficulties with gait). Therefore, the ASDI also offers little additional insight into the behaviour of diagnostic relevance for the purposes of this chapter.

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<sup>13</sup> A version of this tool that may be administered with adults with ASD was recently developed (Carrington et al., 2014). This updated version of the DISCO and information about its psychometric performance were not available at the time of conducting the study within the present chapter.

The recommended assessment tools are inadequate in providing an index of Criteria A2, B1 and B4 in adults and as such considering other ASD assessment tools may be more prudent. One such tool, the Social Communication Questionnaire (SCQ; Berument et al., 1999) assesses a range of Criterion B1 behaviours including stereotypical speech, object use and repetitive motor behaviour. Further, it contains items that assess sensory responses characteristic of ASD across several sensory domains and numerous behaviours consistent with Criterion A2 such as difficulty conveying information through gestures and restricted facial expressions. While the SCQ is intended to be used by caregivers, it has been modified for self-reporting for adults with ASD and performs with appropriate sensitivity (75%) when used in this form (Holmes, 2011). The SCQ thus appears to have value in providing information about a broader range of Criteria A2, B1 and B4 behaviour presenting in adulthood.

### **Summary**

While symptoms consistent with ASD first manifest in childhood some individuals are not diagnosed until adulthood. Given that the presentation of ASD may change across the lifespan it is important to understand the behaviours of diagnostic relevance in adulthood. Due to the limited and at times conflicting literature available, identifying specific behaviours that present frequently and differentiate adults with ASD from adults without ASD is difficult. The aim of the present chapter is to clarify the behaviours of diagnostic relevance. I will examine the frequency and diagnostic sensitivity of specific behaviours that present among a further sample of adults with ASD using the AQ, RAADS-R and SCQ. Given the inadequate frequency with which some criteria (e.g. Criteria A2 and B1) reportedly present in adulthood, whether considering diagnostically sensitive behaviours alone offers potential impairments to consider for adult assessments will be evaluated.

## Method

### Participants

Adults who were typically developing (TD;  $N = 58$ ; 20 females, 28 males) and adults diagnosed with ASD ( $N = 45$ ; 14 females; 31 males) were recruited from university students, the general community and a research database of adults with ASD.<sup>14</sup> Inclusion within the control group (TD) required a self-reported absence of ASD corroborated by scores below the ASD diagnostic cut-off score on at least two of the three self-report measures completed. The diagnostic status of participants within the ASD group was confirmed by eligibility for services with the local autism organisation that required a diagnostic assessment conducted by two health professionals with ASD diagnostic training.

The adults with ASD were diagnosed prior to the introduction of DSM-5 with Asperger's disorder ( $n = 44$ ) or autistic disorder ( $n = 1$ ). A subset of these individuals' data ( $n = 26$ ) was collected for a previous study (Holmes, 2011). Ten individuals, who were recruited for the control group and who had not been diagnosed with ASD, met the diagnostic cut-off score on two or three of the self-report measures. These individuals were thus excluded from the study leaving a total of 48 typically developing adults.

Participant characteristics were explored to determine whether variables other than diagnosis may contribute to any differences in the symptomatology reported. No significant mean differences were found in performance on the Wechsler Adult Intelligence Scale (WAIS-IV; Wechsler, 2008) Verbal Comprehension Index  $t(72) = .407, p = .685$ , Perceptual Reasoning Index  $t(88) = -.324, p = .747$  or Full-Scale IQ  $t(83) = -.431, p = .667$  between the groups, nor did the proportions of men and women significantly differ between groups  $\chi^2(1, N = 93), = 1.116, p = .291$ . Similarly, neither

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<sup>14</sup> The research database comprised individuals diagnosed with ASD by a health professional trained in ASD assessments and eligible for services with the state autism organisation. They were originally recruited to the database via targeted mail-outs and consented to be informed about potential research participation opportunities.

the age nor FSIQ correlated with total scores on any of the ASD assessment measures. Neither did mean scores on any of the measures significantly differ between males or females for individuals with or without ASD. The demographic details of the participants are shown in Table 14.

Table 14  
*Participant Characteristics*

	ASD ( <i>N</i> = 45)		TD ( <i>N</i> = 48)	
	<i>M</i> ( <i>SD</i> )	Range	<i>M</i> ( <i>SD</i> )	Range
Age (years)	33.24 (12.51)	18 - 61	24.72 (9.15)	18 - 59
VCI	104.43 (14.38)	74 - 130	103.39 (8.7)	83 - 122
PRI	102.09 (15.56)	71 - 127	103.04 (12.19)	71 - 123
FSIQ	104.17 (9.74)	80 - 124	104.32 (14.69)	72 - 132

The control group were younger than participants with ASD on average  $t(90) = 3.742, p = .000, d = .78$  and age was weakly positively correlated with total scores for the AQ ( $r = .36, p = .000$ ) and RAADS-R ( $r = .28, p = .01$ ). To identify if age rather than diagnostic status was driving the symptoms reported, hierarchical multiple linear regression analyses were conducted with total AQ or RAADS-R scores as the dependent variable. Diagnostic status was entered at stage one and two. The hierarchical multiple regressions demonstrated that diagnostic status explained 66.2% of the variance in AQ total scores  $F(1,90) = 176.16, p = .000$ , and 58.6% of the variance in RAADS-R total scores  $F(1,86) = 121.97, p = .000$ . However, age did not explain additional variation in AQ ( $R^2$  change = .005,  $F(2,89) = 1.25, p = .266$ ) or RAADS-R total scores ( $R^2$  change = .001,  $F(2,85) = 60.41, p = .741$ ). The relationship between age and total scores appears spurious, thus it appears that behaviours discriminating between the two groups can be attributed to the presence or absence of ASD rather than age differences.

## Measures

Individuals diagnosed in adulthood typically do not present with intellectual disability. Therefore, the fourth edition of the Wechsler Adult Intelligence Scale (WAIS-IV; Wechsler, 2008) was used to confirm that each participant had at least average IQ. Short forms of the WAIS-IV perform with appropriate reliability and validity (Sattler & Ryan, 2009). Thus to reduce administration time, five subtests from the WAIS-IV were selected so that Full Scale IQ could be pro-rated: Comprehension, Similarities, Vocabulary, Block Design and Matrix Reasoning. Participants' intellectual functioning was in the average range or higher for the Verbal Comprehension, Perceptual Reasoning and Full Scale IQ indices as reported previously in Table 14.

Items from three self-report measures: the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R), the Autism-Spectrum Quotient (AQ) and the Modified Social Communication Questionnaire (M-SCQ) were used to index the frequently presenting and diagnostically sensitive behaviours thought to be associated with the social communication and social interaction impairments and restricted, repetitive patterns of behaviour, interests or activities of ASD in adulthood. The RAADS-R and AQ were selected for this purpose to reconcile conflicting findings about the diagnostic relevance of behaviour arising from other studies reporting about these measures (Allison et al., 2012; Bishop & Seltzer, 2012; Eriksson et al., 2013). The M-SCQ was created for the purposes of this study to supplement these measures given its broader coverage of Criteria A2, B1 and B4 symptoms, for which particularly few behaviours of diagnostic relevance had been identified in the literature or were not adequately assessed by the RAADS-R and AQ. A copy of each questionnaire may be found in Appendix B.

**Self-Report measures.** The 80-item Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R: Ritvo et al., 2011), evaluates the presence and longevity of ASD symptomatology across the lifespan for four subscales: social relatedness, circumscribed interests, language and sensory motor (Ritvo et al., 2011). Total possible scores range from 0 to 140. Higher scores reflect more numerous restricted, repetitive behaviours and social and communication difficulties and scores of 65 or greater support an ASD diagnosis. Items are typically rated according to whether the behaviour is present across the lifespan, only in childhood, only in adulthood or, never. Due to interest in adult presentation, the RAADS-R was used to examine current functioning only. Thus the behaviours described in the items were coded as present when they occurred in adulthood or throughout an individual's life but absent when they had never occurred or only when younger.

Evaluations of psychometric properties were guided by recommendations by Glascoe (2005) for screening for developmental disorders where sensitivity is ideally 70%, specificity, 80% and, internal consistency is ideally at an alpha level of .8 or higher (Cicchetti et al., 2010).<sup>15</sup> The RAADS-R performed with appropriate sensitivity (92.89%) but inadequate specificity (70.21%) in the present study. Its internal consistency was appropriate for the total scale ( $\alpha = .96$ ), but varied somewhat for each subscale (language  $\alpha = .59$ ; circumscribed interests  $\alpha = .85$ ; sensory motor  $\alpha = .85$ ; social relatedness  $\alpha = .93$ ).

The 50-item Autism Spectrum Quotient (AQ: Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) was used to assesses social skill, attention switching, attention to detail, communication and, imagination, evaluated by statements regarding one's behaviour, experiences and partialities. Participants rate these statements according to

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<sup>15</sup> The use of Cronbach's alpha has recently been contested in the literature with authors disputing that it adequately captures reliability or internal consistency (c.f. Sijtsma, 2009). Given that studies examining test validity among persons with ASD in the broader literature commonly report Cronbach's alpha, it has likewise been reported in this study.

whether they definitely or slightly agree or disagree with them. Total possible scores on this measure range from 0 to 50, higher scores signify more ASD traits and individuals who score 32 or above likely have ASD. Due to interest in adult presentation, item 40 that refers to childhood difficulties with imagination was removed when examining the behaviours of diagnostic relevance in adulthood.

For the present study, the AQ performed with appropriate specificity (100%) and sensitivity when using the cut-off score of 26 (84.44%) recommended by Woodbury-Smith et al. (2005) rather than 32 (60%) from the original validation sample. Internal consistency was adequate for the total scale ( $\alpha = .93$ ) but weaker overall for the subscales (attention to detail  $\alpha = .67$ , imagination  $\alpha = .74$ , attention switching  $\alpha = .77$ , communication  $\alpha = .83$  and social skill  $\alpha = .86$ ).

The SCQ requires participants to rate whether they have experienced the communication, social and restricted, repetitive and stereotyped behaviours typical of ASD within the last three months (Berument et al., 1999; Rutter, Bailey, & Lord, 2010). The 40-item 'Current' version of the Social Communication Questionnaire (SCQ: Rutter, Bailey, Berument, Lord, & Pickles, 2003) was modified to create a self-report format version of this tool, in a similar manner to previous research using the 'Lifetime' SCQ (Holmes, 2011). The modified self-report SCQ or M-SCQ is consistent with the traditional version of the SCQ excepting changes to pronouns to allow for self-reporting and the adaptation of three items to increase their appropriateness for adults. Specifically, item 34 was revised to assess individuals' participation and mimicry of pointing, waving, dancing, cheering or chanting rather than actions in children's games; item 39 was adapted to assess the ability to understand whether someone is serious or joking rather than pretend play; and, item 40 adjusted to reflect participation in cooperative ball games instead of hide-and-seek.

Possible scores on this measure range from 0 to 39, higher scores imply more impairment and scores of 15 or more support an ASD diagnosis (Berument et al., 1999; Rutter et al., 2010). The M-SCQ performed with inadequate sensitivity (42.11%) but perfect specificity in the present study. The internal consistency of the total scale was appropriate ( $\alpha = .81$ ), however the internal consistency of the subscales was inadequate (communication  $\alpha = .34$ , reciprocal social interaction  $\alpha = .75$ , restricted, repetitive and stereotyped patterns of behaviour  $\alpha = .78$ ).

**DSM-5 coding.** Each item across the aforementioned assessment tools was categorised according to the DSM-5 criteria. For a subset of items from the RAADS-R, DSM-5 classification were already available (Eriksson et al., 2013), and subsequently used. For the remaining items, a clinical psychologist and the author (a provisional psychologist), independently used their clinical judgement to classify the remaining items according to the DSM-5 criterion they best reflected. This approach is consistent with that of other authors who have coded items from existing assessment tools according to the DSM-5 criteria (Eriksson et al., 2013; Huerta et al., 2012a).

Given that each of the assessment tools preceded the development of the DSM-5 and the items sometimes reflected multiple criteria, the two raters did not always agree on the item classification. In these instances, an educational and developmental psychologist independently coded the items and the coding chosen by the majority of raters was then used. In cases in which each of the three clinicians coded the items differently ( $n = 15$ ; 9.68%), the coding chosen by the clinician with the most experience with ASD diagnoses was used.<sup>16</sup> The proportion of items capturing each diagnostic criterion across the tools is shown in Table 15. You will notice that the M-SCQ does contain more items specific to Criteria A2 and B1 than the AQ or RAADS-R. Further, the one item that assessed Criterion B4 in this measure covers hyper-reactivity to

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<sup>16</sup> The DSM-5 coding of each item is also shown in Appendix B.

sensory stimuli across four sensory domains. Participant characteristics across the assessment tools are shown in Table 16.

Table 15

*Items Reflecting DSM-5 Criteria Across the RAADS-R, AQ and M-SCQ*

	RAADS-R	AQ	M-SCQ	Total
	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>
Domain A	50	28	29	107
A1	17	9	13	38
A2	7	3	10	20
A3	26	16	6	49
Domain B	30	21	11	62
B1	7	0	6	13
B2	4	9	1	14
B3	6	11	3	20
B4	13	1	1	15
Total	80	49	40	169

Table 16

*Mean Scores from the RAADS-R, AQ and M-SCQ*

	ASD ( <i>N</i> = 45)			Controls ( <i>N</i> = 48)		
	M	SD	Range	M	SD	Range
RAADS-R	130.2	40.19	33 - 227	52.34	25.72	11 - 116
AQ	32.65	7.97	14 - 45	14.05	5.38	3 - 24
M-SCQ	14.53	6.46	5 - 31	7.76	3.32	3 - 14

### Procedure

First, participants were administered the Similarities, Vocabulary, Comprehension, Block Design and Matrix Reasoning subtests of the WAIS-IV according to standard procedure. Participants were then given the self-report RAADS-R, AQ and M-SCQ measures to complete in a counterbalanced order, advised not to dwell on their answers and to ask the administrator should any questions arise.

## Results

To identify behaviours of diagnostic relevance for adults with ASD, the frequency and diagnostic sensitivity of symptoms assessed using the RAADS-R, AQ and M-SCQ were examined. Of particular interest were behaviours presenting with high frequency among adults with ASD that effectively differentiated these adults from adults without ASD. As defined previously, items endorsed by at least 70% of adults with ASD were considered sufficiently frequent. Chi-square tests of independence were used to examine the proportions of adults with or without ASD endorsing items. The criterion for appropriate sensitivity was behaviours differentiating between the two diagnostic groups with moderate effect (i.e.  $\phi \geq .3$ ), adopted from Allison et al. (2012). Fisher's exact tests were used when cells fell below expected counts. Due to multiple comparisons, alpha levels for significance were set to .01.

### **The Behaviours of Diagnostic Relevance Identified Within the Present Study**

As expected, a greater proportion of adults with ASD than without ASD, endorsed a range of symptomatic behaviours from the AQ, RAADS-R and M-SCQ overall. Table 17 displays the number of behaviours that were frequently presenting and/or diagnostically sensitive among adults with ASD for each domain and criterion. Few of the Domain B behaviours assessed across each tool were frequently presenting, diagnostically sensitive or diagnostically relevant. Domain A behaviours were similarly under-represented though a range of diagnostically sensitive Domain A behaviours were identified across the AQ and RAADS-R. The specific behaviours presenting with appropriate frequency and sensitivity and thus considered diagnostically relevant are reported in Table 18.

Table 17

% of Frequently Presenting and/or Sensitive Behaviours for each DSM-5 Criterion

<sup>a</sup> Behaviours both frequently presenting and diagnostically sensitive.

	RAADS-R						AQ						M-SCQ					
	Frequently presenting		Diagnostically Sensitive		Diagnostically relevant <sup>a</sup>		Frequently presenting		Diagnostically Sensitive		Diagnostically relevant		Frequently presenting		Diagnostically Sensitive		Diagnostically relevant	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Domain	9	18	34	68	8	16	9	31.03	25	83.33	11	40.74	2	6.9	8	27.59	1	3.45
A																		
A1	2		14		2		5		8		4		1		4		0	
A2	2		6		2		1		3		1		0		2		0	
A3	5		14		4		3		14		6		1		2		1	
Domain	3	10	19	63.33	1	3.33	10	50	11	55	9	42.86	1	9.09	1	9.09	0	0
B																		
B1	0		2		0		-		-		-		1		0		0	
B2	0		4		0		4		5		4		0		0		0	
B3	2		4		1		5		5		4		0		1		0	
B4	1		9		0		1		1		1		0		0		0	
Total	12	15	53	66.25	9	11.25	19	38	36	72	20	40	3	7.5	9	22.5	1	2.5

Table 18  
*Behaviours of Diagnostic Relevance*

Criterion	Item	Behaviour	$\phi$	Frequency
A1	AQ 38	I am good at social chit-chat	0.60	71.1
	AQ 10	In a social group, I can easily keep track of several different people's conversations	0.55	75.6
	RAADS-R 5	I often don't know how to act in social situations	0.51	81
	AQ 26	I frequently find that I don't know how to keep a conversation going	0.51	77.8
	RAADS-R 78	People tell me that I give too much detail.	0.43	70.7
	AQ 39	People often tell me that I keep going on and on about the same thing	0.38	71.1
A2	AQ 36	I find it easy to work out what someone is thinking or feeling just by looking at their face	0.69	73.3
	RAADS-R 76	It is difficult to figure out what other people expect of me	0.58	87.5
	RAADS-R 44	I cannot tell if someone is interested or bored with what I am saying.	0.42	71.4
A3	AQ 11	I find social situations easy	0.66	86.7
	RAADS-R 22	I have to "act normal" to please other people and make them like me	0.54	70
	AQ 15	I find myself drawn more strongly to people than things	0.40	75.6
	AQ 42	I find it difficult to imagine what it would be like to be someone else	0.57	82.2
	AQ 45	I find it difficult to work out people's intentions	0.55	80
	M-SCQ 39	Do you ever find it difficult to work out whether someone is being serious or just pretending?	0.57	84.2
	AQ 13	I would rather go to a library than a party	0.48	71.1
	AQ 22	I find it hard to make new friends	0.42	75.6
	RAADS-R 23	Meeting new people is usually easy for me	0.48	71.4
	RAADS-R 17	Others consider me odd or different.	0.64	83.3
	RAADS-R 12	Sometimes I offend others by saying what I am thinking, even if I don't mean to.	0.36	76.2

Criterion	Item	Behaviour	$\phi$	Frequency
B2	AQ 32	I find it easy to do more than one thing at once	0.53	73.3
	AQ 23	I notice patterns in things all the time	0.40	84.4
	AQ 2	I prefer to do things the same way over and over again	0.37	84.4
	AQ 46	New situations make me anxious.	0.32	86.7
B3	AQ 41	I like to collect information about categories of things	0.61	84.1
	AQ 4	I frequently get so absorbed in one thing that I lose sight of other things	0.42	95.6
	RAADS-R 9	I focus on details rather than the overall idea.	0.39	85.7
	AQ 6	I usually notice car number plates or similar strings of information	0.35	77.8
	AQ 16	I tend to have very strong interests which I get upset about if I can't pursue	0.34	86.7
B4	AQ 5	I often notice small sounds when others do not	0.39	91.1

## Updating Current Understanding About Behaviours of Diagnostic Relevance

As discussed previously, uncertainty about the diagnostic relevance of a number of behaviours associated with ASD exists because of conflicting reports about the frequency with which they present in the literature. The consistency with which Allison et al. (2012), Bishop et al. (2012) and the present study reported whether behaviour presented among at least 70% of adults with ASD was thus examined. Item by item agreement was poor across the studies, ranging from 48.98% between Allison et al. (2013) and Bishop and Seltzer (2012) to 69.39% between the present study and that by Allison et al (2013). Appendix B outlines which studies reported whether each item met the threshold for adequate frequency.

Nonetheless, when examining data from all three samples, trends were observed that clarified the frequency of some behaviour. With the addition of data from the present sample, a number of behaviours ( $n = 21$ ) emerged that had not previously been identified as diagnostically relevant but now met this criterion. Most of these behaviours ( $n = 11$ ) were those from the AQ for which the appropriateness of their frequency had previously varied between studies (Allison et al., 2012; Bishop & Seltzer, 2012). Further, some behaviours from the RAADS-14 ( $n = 3$ ) thought to have had potential diagnostic relevance emerged as both sensitive and frequent in the present study. In addition, a number of other behaviours from the RAADS-R and M-SCQ ( $n = 7$ ), were newly identified as diagnostically relevant in the present study. These behaviours are shown in Table 19. You will notice that many behaviours of diagnostic relevance to Domain A have been identified including difficulty maintaining conversations, interpreting facial expressions and observing appropriate social etiquette. Domain B behaviours were less forthcoming. No Criterion B1 behaviour was identified as being of diagnostic relevance while for Criterion B4 these behaviours were limited to auditory hypo-reactivity.

Table 19  
*Revised Understanding of Behaviour of Diagnostic Relevance in Adulthood*

Item	Criterion A1
AQ 10	Difficulty keeping track of conversations
AQ 26	Difficulty maintaining a conversation
AQ 38	Difficulty making small talk
AQ 39	Misjudging when to talk or listen
AQ 46	Dislikes social interactions
RAADS-R 5	Problems understanding social etiquette
RAADS-R 78	Conversational style is overly detailed
Criterion A2	
AQ 36	Difficulty using facial expression to gauge thoughts or feelings
RAADS-R 76	Difficulty judging what other people expect
RAADS-R 44	Problems judging when others are bored
Criterion A3	
AQ 11	Social situations are difficult to navigate
AQ 13	Preference for solitary pursuits over social engagements
AQ 15	Disinterest in people
AQ 22	Problems developing friendships
AQ 42	Difficulty with perspective taking
AQ 45	Difficulty judging other people's motives
RAADS-R 12	Inadvertently makes offensive comments
RAADS-R 17	Does not follow social norms
RAADS-R 22	Social behaviour is learned and effortful, not intuitive
RAADS-R 23	Difficulty making acquaintance with someone
M-SCQ 39	Difficulty judging when someone is serious or pretending
Item	Criterion B2
AQ 2	Insistence on sameness when performing tasks
AQ 23	Notices patterns
AQ 32	Difficulty multi-tasking
AQ 46	Dislikes novelty
Item	Criterion B3
AQ 4	All-consuming interests
AQ 6	Interest in numbers
AQ 16	Distressed when interrupted from interests
AQ 41	Interest in keeping lists of facts
RAADS-R 9	Interested in details
Item	Criterion B4
AQ 5	Hypo-reactivity to faint noises

Given that Criterion B1 and to a lesser extent Criterion A2 reportedly present with low frequency in adulthood (see Study 1) additional behaviours that met the criteria for diagnostic sensitivity but not frequency were considered. Further, given the limited accounts of frequently presenting Criterion B4 behaviours in the present study, examples of diagnostically sensitive hyper- or hypo-reactivity to sensory stimuli were also identified. These behaviours are displayed in Table 20 and include a greater diversity of Criterion A2 behaviours such as impairments in the expression of nonverbal cues. Diagnostically sensitive Criterion B1 behaviour remained limited to stereotyped speech however, a plethora of diagnostically sensitive Criterion B4 behaviours were identified.

Table 20

*Diagnostically Sensitive but Infrequent Criterion A2, B1 and B4 Behaviours*

Item	Criterion A2
AQ27	Difficulty using nonverbal cues to understand non-literal speech
AQ31	Cannot use facial expressions to judge disinterest
R25	Cannot use nonverbal cues to judge other people's feelings
R28	Nonverbal cues for embarrassment and jealousy are misinterpreted
R39	Misses nonverbal cues that someone is romantically interested
R45	Difficulty reading facial expressions, body language and gestures
S27	Does not engage in reciprocal smiling
S33	Has a narrow range of facial expressions
Criterion B1	
R33	Unusual pacing of speech
R62	Unusual tone of voice
Criterion B4	
R19	Hyper-reactivity to clothing fabrics
R29	Tactile hypersensitivity
R34	Experiences both hyper or hypo-reactivity to the same sensory stimuli
R42	Has to avoid further stimulation when experiencing hyper-reactivity
R46	Experiences both hyper or hypo-reactivity to tactile stimuli
R57	Covers ears when exposed to certain noises
R59	High pain tolerance
R67	A multitude of sensory stimuli provokes feelings of anxiety
R73	Cannot stand offensive sensory stimuli
R74	Dislikes hugs or physical restriction

## Discussion

Given that little is known about the specific behaviours that best capture the DSM-5 criteria as they present in adulthood, this chapter sought to identify behaviours of diagnostic relevance to these criteria. That is, behaviours that present frequently and effectively differentiated adults with ASD from adults who do not have ASD. I thus examined items within a number of assessment tools that captured a broad range of behaviour consistent with the DSM-5 criteria. Findings introduced a number of new behaviours of diagnostic relevance in adulthood.

### **Classifying Behaviour in Assessment Tools According to the DSM-5 Criteria**

In seeking to identify behaviours of diagnostic relevance to each DSM-5 criterion, I first classified behaviours as indexed by items from the three self-report measures according to the DSM-5 criteria. Pre-existing DSM-5 coding was available for a subset of items from the RAADS-R (Eriksson et al., 2013). However, for the remaining items, a coding protocol modelled on the approach used by other authors was adopted (Eriksson et al., 2013; Huerta et al., 2012a). Specifically, clinicians independently rated test items and a third clinician was employed as arbitrator when these ratings did not correspond.

Though this group consensus approach to coding items is perhaps less subject to idiosyncratic differences than ratings by a single clinician, it is still possible some items were wrongly classified. Consequently, some behaviour of diagnostic relevance presented within this study may be misattributed to a given criterion. A lack of consensus about the DSM-5 diagnostic criteria that ASD test items best represent is apparent in the literature. Specifically, some items within diagnostic tools appear to address multiple DSM-5 criteria, with authors reporting particular difficulty differentiating between Criterion B1 or B4 behaviours, and in addition, Criterion A1 or A3 behaviours (Huerta et al., 2012a; Taheri & Perry, 2012). Similarly, the clinicians

coding the items in the present study occasionally disputed which Domain A or B criteria test items most closely represented. Clearly, much work is needed to clarify behavioural distinctions between each of the Domain A and B criteria. This thesis therefore contributes to ongoing discussions about the application of the DSM-5 criteria by presenting proposed coding for a range of ASD behaviour in line with these criteria.

### **Defining Diagnostic Relevance**

Using the aforementioned coding, the present study examined behaviours of diagnostic relevance. In doing so, I considered how best to define these behaviours. I regarded behaviour that presented frequently, that is, among at least 70% of adults with ASD and, which differentiated between adults with or without ASD with moderate effect as a working definition for such behaviour, modelled on guidelines in the literature (Allison et al., 2012; Glascoe, 2005; NICE, 2012a). A greater proportion of behaviours were diagnostically sensitive than frequently presenting in the present study. A similar finding emerged from Study 1, with adults with ASD, significant others and clinicians reporting that adults with ASD engaged in a range of behaviours consistent with each criterion, but identifying no commonly presenting manifestations. Collectively, these findings provide further support for my interpretation of findings in Study 1. Specifically, the behavioural expression of each diagnostic criterion again appears to be diverse in adulthood rather than easily identified by several frequently presenting behaviours. This diversity appears particularly true for Criterion A2, for which little diagnostically relevant behaviour was identified in the present study, largely due to the lack of frequently presenting behaviour.

### **Behaviours of Diagnostic Relevance in Adulthood**

Behaviours of diagnostic relevance assessed using the AQ, RAADS-R and M-SCQ were identified within the present study that likewise performed with appropriate sensitivity and/or frequency in the literature (Allison et al., 2012; Bishop & Seltzer,

2012; Eriksson et al., 2013). Further, a number of behaviours for which diagnostic relevance had previously been uncertain due to conflicting reports of their frequency and/or absent data were identified. In this manner, the present chapter contributes to our understanding of ASD in adulthood by providing accounts of the specific behaviours most useful to target when assessing adults with ASD. Nonetheless, little frequently presenting behaviour was identified among the items from the AQ, RAADS-R and M-SCQ. Consequently, even fewer behaviours of diagnostic relevance were noted. Despite the restricted number of diagnostically relevant manifestations of each criterion, these behaviours provide specific examples of how the DSM-5 criteria are likely to present among most adults with ASD.

**Domain A.** Within Domain A, a number of behaviours of diagnostic relevance were identified. Criterion A1 primarily manifested as impairments in following and maintaining conversations. It appears that a pedantic conversational style may also effectively capture behaviour consistent with this criterion in adulthood.

Several diagnostically relevant behaviours consistent with Criterion A2 were also identified including difficulty reading facial expressions and in particular, using nonverbal cues to judge when someone is disinterested. This finding appears to corroborate reports from Study 1 that when the regularity with which Criterion A2 behaviour presents receives lesser priority, as in the manner in which these behaviours were identified and endorsed in the present study, impairments consistent with this criterion can be identified with adequate frequency.

Finally, a plethora of behaviour of diagnostic relevance to Criterion A3 was presented in this chapter. Of particular note are examples of how difficulty with imagination manifest in adulthood that may be useful for diagnosis, namely, difficulty judging whether someone is pretending or trouble imagining being someone else.

**Domain B.** Decidedly fewer behaviours of diagnostic relevance were identified within Domain B. Indeed, consistent with reports from Study 1 that Criterion B1 presents infrequently in adulthood, only one frequently presenting behaviour, the use of repetitive or unusual phrases (reported in Study 1), was identified for this criterion. Further, only two diagnostically sensitive behaviours characteristic of Criterion B1, atypical pacing and tone of speech, were identified. None of these behaviours were simultaneously frequent and sensitive and so no behaviours of diagnostic relevance were identified for this criterion. Again these findings speak to the merit of prioritising diagnostic sensitivity over frequency. Nonetheless, with so few diagnostically sensitive or frequently presenting behaviours being identified for Criterion B1 across both Studies 1 and 2, these impairments may not be particularly representative of ASD in adulthood, as observed within the DSM-5 (APA, 2013). Nonetheless, given the scarcity of information about how Criterion B1 manifests in adulthood, there is still a need to explore its presentation further so that it may be more accurately assessed and identified among the adults for whom it does present.

In contrast, behaviour of diagnostic relevance was more forthcoming for Criterion B2. First, support was found for behaviours more recently regarded as representative of Criterion B2 insistence on sameness in adulthood (Allison et al., 2012; Baron-Cohen, Wheelwright, Skinner, et al., 2001; Barrett et al., 2015; Bishop & Seltzer, 2012), specifically attention to patterns and difficulty multi-tasking. Exactly how a tendency to notice patterns may manifest in adulthood requires further consideration. At present, it is suspected that adults may notice changes in the appearance or layout of items (Barrett et al., 2015), replication of this finding is needed. Second, reports of Criterion B2 multi-tasking difficulties were reported, lending support to the observations of adults with ASD, significant others and clinicians in Study 1, who also reported these difficulties.

A range of Criterion B3 behaviours was likewise identified. The behaviours reported within the present study extend accounts of interests characteristic of ASD in adulthood reported within Study 1 and the broader literature (Mercier et al., 2000). Specifically, it appears that interests in detail, numbers and factual lists may be added to the interests in the creative arts, science, technology, engineering, and mathematics previously reported. Interestingly, preoccupations with factual information had not been regarded particularly characteristic of ASD by other authors (Jordan & Caldwell-Harris, 2012), albeit among a mixed sample of adults and adolescents. It may be that these particular interests are adult specific, explaining why they manifested with higher frequency and diagnostic sensitivity in the present study.

Finally, behaviours of diagnostic relevance to Criterion B4 remained limited with only one such behaviour, auditory sensitivity being reported. The primary reason for such little behaviour of relevance to this criterion is that so few of the diagnostically sensitive behaviours presented frequently. Prioritising sensitivity over frequency may thus be particularly important when assessing Criterion B4 in adulthood. Indeed, when focusing only on diagnostically sensitive behaviour, many additional behaviours that may be characteristic of this criterion in adulthood emerged. It is also important to note that while the RAADS-R, AQ and M-SCQ collectively cover the auditory, olfactory, tactile, visual and gustatory domains, the vestibular/proprioceptive domain, (i.e. the domain capturing body awareness), is largely neglected. The presentation of this criterion in adulthood thus warrants further attention.

***Implications.*** The paucity of accounts of the presentation of Domain B across Studies 2 and 3 suggest that our understanding of its presentation in this period of life still requires refinement. It may be that some Domain B criteria, particularly Criterion B1 are simply not as salient in adulthood. However, it may also be that current assessment tools are not accurately operationalising the way this behaviour manifests in

adulthood, accounting for the lack of behaviours of diagnostic relevance identified. Additional accounts of how Domain B does manifest in adulthood would assist in clarifying if manifestations of this domain have been overlooked within existing assessment tools. Specifically, future research should consider a more open-ended qualitative approach to examining these symptoms from the perspective of adults with ASD. This approach is thus adopted in subsequent studies.

In addition, some researchers speculate that some adults with ASD may lack insight into the nature of their symptoms (Johnson, Filliter, & Murphy, 2009), perhaps accounting for the reduced incidence of some of the behaviours reported. However, this thesis and the broader literature suggest that having ASD does not preclude accurate self-reporting of symptoms with adequate agreement being reported between the perspectives of these adults and their caregivers throughout this thesis and the broader literature (Ashwood et al., 2016; Baron-Cohen et al., 2001; Wakabayashi et al., 2006; see Study 1). Rather it appears that the format of self-report tools could lead to under-reporting by some individuals with ASD. Specifically, clinicians and adults with ASD report that adults with ASD experience difficulties interpreting rating scales and judging whether their symptoms match the descriptions provided when using available self-report tools (Bishop & Seltzer, 2012; NICE, 2012b). It is thus important to explore further whether Domain B symptoms, particularly Criterion B1 symptoms, may emerge when limitations in the format of self-report tools that may preclude accurate reporting for some individuals are addressed.

### **Summary**

In the present chapter, I aimed to identify behaviours of diagnostic relevance to each DSM-5 diagnostic criterion, presenting in adulthood. A number of these behaviours were identified, many of which reflected the behaviours initially reported by the adults with ASD, significant others and clinicians in Study 1, providing support for

the veracity of these findings. While a number of Domain A behaviours of diagnostic relevance were identified, and promisingly, a number of behaviours for Criterion A2, few behaviours were identified in Domain B. It appeared that in assessing Criteria B1 and B4 in particular, it may be more useful to prioritise diagnostic sensitivity over frequency when selecting behaviours to target for assessment. Whether the scarcity of Domain B behaviours of diagnostic relevance identified may be due to poor operationalisation of these impairments across the tools studied warrants consideration. Overall the findings presented in this chapter highlight that much work is necessary to clarify the presentation of Domain B in adulthood. Study 3 will thus evaluate the manifestation, frequency and severity of specific behaviours associated with each Domain B criterion among adults with ASD.

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## **Chapter 4: The Presentation of Domain B in Adulthood**

To perform adult assessments and recognise ASD effectively, clinicians must understand three aspects of symptom presentation: how behaviours characteristic of each domain typically manifest in adulthood, with what frequency and, their severity (DSM-5; APA, 2013; NICE, 2012a). While earlier chapters and the broader literature provide insight into the presentation of Domain A in adulthood, relatively little information is available about the presentation of Domain B in this period of life. Therefore, the purpose of the present chapter was to explore the qualitative presentation of the behaviours that represent Domain B among adults with ASD, the frequency with which these behaviours present in this demographic and, their severity.

### **Assessing Adults with Suspected ASD**

As discussed in earlier chapters, the presentation of ASD may change across the lifespan (APA, 2013; Howlin, Moss, Savage, & Rutter, 2013; Seltzer et al., 2003). To diagnose these adults effectively, clinicians must first have a clear understanding of symptom manifestation in adulthood. Symptom manifestation describes the specific behaviours that capture how each of the diagnostic criteria within Domains A and B, manifest in this period of life. Second, to determine which behaviours characteristic of ASD in adulthood may be most prudent to target in their assessments, clinicians must also be aware of the frequency with which each symptomatic behaviour presents among adults. Third, the DSM-5 requires that clinicians rate symptom severity. These ratings require familiarity with the nature in which symptoms interfere in daily life and the regularity with which these symptoms present (DSM-5; APA, 2013). Thus understanding the qualitative manifestation, frequency and severity of symptoms in adulthood is essential to conduct adult ASD assessments effectively.

## **Domain A**

Comprehensive accounts of the manifestation, frequency and severity of Domain A in adulthood are available to guide clinicians in their assessments. As outlined in earlier chapters (see Studies 1 and 2) and the broader literature (Allison, Auyeung, & Baron-Cohen, 2012; Bishop & Seltzer, 2012; Eriksson, Andersen, & Bejerot, 2013), a range of behaviours that capture how each of the three Domain A diagnostic criteria manifest in adulthood have been identified. These behaviours include difficulty with social ‘chit-chat,’ interpreting facial expressions and observing social etiquette. Similarly, the frequency with which Domain A behaviours present among adults with ASD is also clear. For example, difficulties navigating social interactions are prevalent among adults with ASD, as reported in earlier chapters and the broader literature (see Studies 1 and 2; Allison et al., 2012). Further, this thesis (see Study 1) and the broader literature (Baldwin & Costley, 2016; Howlin et al., 2013), provide accounts of the severity with which behaviours characteristic of Domain A present in adulthood. For example, Criterion A3 impairments in developing and maintaining relationships and adjusting behaviour to context appear to present regularly, and, are associated with impaired functioning in everyday life. Thus, information about the manifestation, frequency and severity of Domain A in adulthood has received considerable attention in the literature and information is available to assist in assessing this domain in adulthood.

## **Domain B**

In contrast, comprehensive information about the presentation of Domain B behaviours in adulthood is lacking. Information available in the literature about the manifestation, frequency and severity of Domain B in adulthood is typically drawn from small samples (Hurlbutt & Chalmers, 2002; Mercier, Mottron, & Belleville, 2000; Robledo, Donnellan, & Strandt-Conroy, 2012; Smith & Sharp, 2013), samples

including adults with intellectual disability (Bishop & Seltzer, 2012; Woodman, Smith, Greenberg, & Mailick, 2015), data pooled between children, adolescents and adults (Anthony et al., 2013; Georgiades, Papageorgiou, & Anagnostou, 2010; Jordan & Caldwell-Harris, 2012) or, reports of clinical impressions that require more rigorous empirical study (Berney, 2004; Tantam, 2000). Given that both age and IQ may affect symptom presentation (DSM-5; APA, 2013; Bishop & Seltzer, 2012; Esbensen, Seltzer, Lam, & Bodfish, 2009; Woodman et al., 2015), to clarify current conceptualisations of how Domain B presents in adulthood, larger samples of adults with ASD without intellectual disability must be studied. The focus of this chapter is thus the presentation of specific behaviours characteristic of Domain B in adulthood.

**Manifestation.** Though the DSM-5 (APA, 2013) allows for criteria to be satisfied according to historically presenting symptoms, the manual does not specify how many criteria may be met in this manner or whether a diagnosis is still warranted if some criteria or domains no longer cause clinically significant impairments. Thus until such time as clear guidelines are provided for using historically presenting symptoms to support a diagnosis of ASD, it is important to understand how each Domain B diagnostic criterion manifests in adulthood to assist with adult diagnoses.

Accounts of how behaviours consistent with Domain B manifest in adulthood are scarce. As reported in Study 2, assessment tools provide few items that capture behaviour of diagnostic sensitivity consistent with this domain. Further, few descriptions of behaviour consistent with the Domain B diagnostic criteria are available in the broader literature. For example, from the one study that has reported about Criterion B1 among adults without intellectual disability, we can only suggest that adults with ASD have difficulty controlling their speech and may perseverate on certain words, phrases or sounds (Robledo, Donnellan, & Strandt-Conroy, 2012). Accounts of Criterion B2 are likewise incomplete. Routines for sleeping, eating, and leisure

activities and rules for the arrangement of items have been reported (Georgiades, et al., 2010), but no examples of insistence on sameness or verbal rituals in adulthood exist in the literature.

Studies reporting specific manifestations of Criteria B1 and B2 among mixed samples of persons with or without comorbid intellectual disability (Whitehouse, Watt, Line, & Bishop, 2009; Woodman et al., 2015), predominantly report behaviours drawn from the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994). This measure was originally intended to capture ASD as it presents in childhood. Indeed, many of the Criteria B1 and B2 behaviours assessed within the ADI-R are rated according to whether they have ever presented. Therefore, whether the manifestations described in the aforementioned studies specifically apply in adulthood remains unclear (Whitehouse et al., 2009; Woodman et al., 2015).

Preliminary descriptions of Criterion B3 interests are more comprehensive and include collecting, fact gathering, creative pursuits and interests in science, technology, engineering and mathematics (see Studies 2 and 3; Anthony et al., 2013; Georgiades et al., 2010; Hurlbutt & Chalmers, 2002; Jordan & Caldwell-Harris, 2012; Mercier et al., 2000). Nonetheless, questions remain about the manifestation of intense interests in adulthood. It is understood that intense interests may manifest as the pursuit of activities to the detriment of employment or relationships in adulthood (see Study 1; Mercier et al., 2000). However, in childhood, intensity can also be seen in emotional distress when disrupted from these interests (Young, Brewer, & Pattison, 2003). Whether intense interests may also present in this manner in adulthood remains unclear but warrants exploration given that adults with ASD attribute their interests to their emotional wellbeing (Bargiela, Steward, & Mandy, 2016; Mercier et al., 2000).

The manifestation of Criterion B4 in adulthood has received the most attention of the Domain B criteria. Impairments consistent with this criterion are outlined in the

DSM-5 (APA, 2013) as hyper- or hypo-reactivity to sensory stimuli. However, the manual provides little information to operationalise how hyper- or hypo-reactive responses present. Dunn's Sensory Processing Model (Dunn, 1997) provides a framework for understanding how sensory responses may manifest and has been validated among persons with ASD (Winnie Dunn, Myles, & Orr, 2002). Hyper-reactive responses are operationalised as having particular interest in sensory stimuli or feeling distracted or discomforted by these sensations. Hypo-reactive responses are operationalised as being disinterested in sensory stimuli, failure to notice sensations or unusual tolerance for uncomfortable sensations.

It is understood that adults with ASD may present with hyper- or hypo-reactivity to sensory stimuli that they see, hear and/or touch (Leekam, et al., 2007; Robledo, et al., 2012; Smith & Sharp, 2012). Study 2 demonstrated that a range of hyper-reactive sensory responses appear diagnostically sensitive in adulthood including discomfort arising from tactile and auditory sensations. Further, some examples of sensory responses characteristic of ASD in adulthood can be drawn from qualitative studies. Nonetheless, as summarised in Table 21, examples of hyper- and in particular, hypo-reactive responses in the visual, olfactory and gustatory domains are still lacking. In addition, whether sensory information is processed differently between adults with or without ASD in the olfactory domain remains unclear with one study suggesting no differences in hyper- or hypo-reactive responses between these groups of adults (Tavassoli & Baron-Cohen, 2012), in contrast to a qualitative study that suggests hyper-reactivity may arise for persons with ASD (Smith & Sharp, 2013).

Table 21

*Manifestations of Criterion B4 Sensory Responses*

	Sample	Auditory	Visual	Tactile	Olfactory	Gustatory	Vestibular
(Hurlbutt & Chalmers, 2002)	ASD: <i>n</i> = 3	<i>Hyper-reactive:</i> To high pitch noise	n/a	n/a	n/a	n/a	n/a
(Kujala et al., 2007)	ASD: <i>n</i> = 8 Control: <i>n</i> = 10	<i>Hyper-reactive:</i> Faster pitch processing. Greater accuracy judging sound duration and gaps in sound.	n/a	n/a	n/a	n/a	n/a
(Cook, Blakemore, & Press, 2013)	ASD: <i>n</i> = 14 Control: <i>n</i> = 15	n/a	n/a	n/a	n/a	n/a	<i>Hyper-reactivity:</i> Quicker motor movements <i>Hypo-reactivity:</i> Less controlled motor movements.
(Doumas, McKenna, & Murphy, 2015)	ASD: <i>n</i> = 15 Control: <i>n</i> = 15	n/a	n/a	n/a	n/a	n/a	<i>Hyper-reactivity:</i> Over-correction to balance <i>Hypo-reactivity</i> n/a
(Fiene & Brownlow, 2015)	ASD: <i>n</i> = 64 Control: <i>n</i> = 227	n/a	n/a	n/a	n/a	n/a	<i>Hyper-reactivity</i> n/a <i>Hypo-reactivity:</i> Reduced awareness of thirst and fullness.

*Note.* 'n/a' denotes that the sensory domain was not explicitly assessed.

	Sample	Auditory	Visual	Tactile	Olfactory	Gustatory	Vestibular
(Robledo et al., 2012)	ASD: <i>n</i> = 5	<i>Hyper-reactive:</i> Sound is painful, prompts fear or anger <i>Hypo-reactive:</i> n/r	<i>Hyper-reactive:</i> Bright and colourful stimuli are pleasant. Bright stimuli, strobe and fluorescent lighting may be painful. <i>Hypo-reactive:</i> n/r	<i>Hyper-reactive:</i> Dislikes being touched, certain clothing fabrics <i>Hypo-reactive:</i> Seeks out deep pressure.	n/a	n/a	<i>Hyper-reactive:</i> n/r <i>Hypo-reactive:</i> High pain tolerance. Difficulty controlling movements. Difficulty with spatial reasoning.
(Smith & Sharp, 2013)	ASD: <i>n</i> = 9	<i>Hyper-reactive:</i> Sounds feel louder, notices faint sounds. Sounds prompt anger or distress. <i>Hypo-reactive:</i> Difficulty processing multiple sounds. Enjoys loud music.	<i>Hyper-reactive:</i> Lights seem brighter, sunlight is overpowering. Fascinated by visual stimuli e.g. traffic lights, detail. <i>Hypo-reactive:</i> n/a	<i>Hyper-reactive:</i> Seeks out soft sensations. Cannot tolerate hugs. <i>Hypo-reactive:</i> Seeks out deep pressure e.g. squeezing, uses weighted objects	<i>Hyper-reactive:</i> Notices scents others do not. Good memory for smells <i>Hypo-reactive:</i> n/a	<i>Hyper-reactive:</i> Prefers bland food. Can taste individual ingredients. <i>Hypo-reactive:</i> n/a	<i>Hyper-reactive:</i> Other people's movement are overwhelming. <i>Hypo-reactive:</i> Enjoys rocking.
(Baldwin & Costley, 2016)	ASD: <i>n</i> = 82	<i>Hyper-reactive:</i> Noise provokes 'melt-downs.'	n/a	n/a	n/a	n/a	n/a

*Note.* 'n/r' denotes sensory responses were assessed but not reported; 'n/a' denotes that the sensory domain was not explicitly assessed.

In Table 21 you will notice few samples of more than 15 adults with ASD. This is also true of much of the literature exploring the remaining Domain B criteria. Indeed, as discussed previously, the literature about the manifestation of each Domain B criterion in adulthood requires replication given the small sample sizes and samples of mixed age and intellectual ability. Some of this research has also used measures originally intended for use with children and may thus overlook symptoms presenting in a qualitatively different manner in adulthood. Inviting adults with ASD to freely report the manner in which symptoms present as in the small qualitative studies available (Mercier et al., 2000; Robledo et al., 2012; Smith & Sharp, 2013), may thus assist in identifying any manifestations of Domain B symptoms in adulthood overlooked within the existing literature. This chapter thus aims to explore whether Domain B behaviours identified within the existing literature and/or any additional manifestations emerge in a sample of adults with ASD without intellectual disability.

### **Frequency**

Similarly, our understanding of the frequency with which behaviours characteristic of Domain B present in adulthood is limited. Information about the overall frequency of the four Domain B criteria is available within this thesis (see Study 1) and the published literature (DSM-5; APA, American Psychiatric Association, 2013; Wilson et al., 2013).<sup>17</sup> Specifically, it is understood that Criterion B1 presents infrequently in adulthood in contrast to Criteria B2 and B3. However, the frequency with which Criterion B4 sensory responses presents in adulthood remains unclear with Study 1 reporting adequate frequency but few frequently presenting behaviours capturing these responses being identified in Study 2.

Information about the frequency with which specific behaviours consistent with Domain B present in adulthood is uncertain for several criteria. It is understood that

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<sup>17</sup> Recall that frequency refers to the proportions of adults with ASD who present with impairments.

Criterion B1 repetitive motor mannerisms, object use and speech are reported less often among adults with ASD without comorbid intellectual disability than adults with intellectual disability (Esbensen et al., 2009; Woodman et al., 2015). In addition, it has been demonstrated that Criterion B4 sensitivities to bright lights, shiny things and manipulating objects in front of the eyes become less prevalent with increasing age (Leekam, et al., 2007). However, the proportions of individuals with ASD endorsing specific behaviours characteristic of any Domain B criterion has predominantly been reported among samples largely comprised of adults with intellectual disability in the literature (Bishop & Seltzer, 2012; Woodman et al., 2015). Whether these findings are representative of the broader population of adults with ASD is thus unclear.

Much of this research has also identified only a narrow range of frequently presenting behaviours characteristic of Domain B in (Allison et al., 2012; Bishop & Seltzer, 2012; Woodman et al., 2015; see Study 2). Further these studies have relied upon assessment tools such as the Autism Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R; Ritvo et al., 2011), the Modified Social Communication Questionnaire (M-SCQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999) and the ADI-R (Lord et al., 1994) which do not address some manifestations of Domain B. For example, though the RAADS-R and M-SCQ both assess repetitive motor behaviour, they do not assess these behaviours individually, instead a range of these behaviours is grouped in each item assessing Criterion B1. Therefore, the frequency with which specific types of repetitive behaviours present in adulthood remains unclear. The same is true for many of the items that capture Criterion B4 behaviours across the aforementioned tools. Further, vestibular sensory responses, that is, hyper- or hypo-reactive responses to proprioceptive stimuli such as temperature, spatial awareness and motor control receive little attention within these measures. Therefore, to clarify the

frequency with which behaviour characteristic of Domain B presents in adulthood, the present chapter will consider the frequency of individual behaviours overlooked in the aforementioned assessment tools among a sample of adults with ASD without intellectual disability.

In addition, while it is clear that a range of Domain A behaviours present frequently and thus many adults with ASD may present with more than one type of behaviour characteristic of these criteria, whether this holds true for the Domain B criteria is unclear. The quantity of impairments presenting within any Domain B criterion has received little attention in the literature. It is important to consider the quantity of these behaviours presenting in adulthood given that this has proven useful for differential diagnoses in childhood (Harrop et al., 2013) and some typically developing adults present with isolated behaviours that capture the DSM-5 criteria such as insistence on sameness (Allison et al., 2012; Barrett et al., 2015; Bishop & Seltzer, 2012). This chapter will thus also consider the quantity of behaviour consistent with each criterion presenting in adulthood for each individual.

### **Severity**

The severity ratings within the DSM-5 manual capture the degree to which symptoms interfere with functioning, are conspicuous or persist across contexts. Study 1 explored how Domain B symptoms interfered with functioning. Reportedly, Domain B behaviour rarely interfered in adulthood more so than it did in childhood and/or adolescence. Further, only a minority of adults were most affected by Domain B behaviours in adulthood. For example, difficulty multi-tasking arose from Criterion B2 insistence on sameness while managing Criterion B4 sensory hyper-reactivity was particularly difficult in public spaces in adulthood. Thus information about the manner in which Domain B symptoms interfere with daily functioning in adulthood is available.

In contrast, relatively little is known about the other aspects of symptom severity for Domain B operationalised in the DSM-5, that is, how conspicuous or persistent symptomatic behaviours are in adulthood. Arguably, behaviours that are conspicuous and persistent across contexts are those that present with greater regularity. Thus considering how often behaviour occurs among the adults for whom they manifest may be useful in rating the severity of Domain B in adulthood.

Study 1 offered some preliminary insights into the severity of Domain B by considering how often the DSM-5 criteria presented in adulthood for the individuals for whom these impairments presented. Reportedly, every Domain B criterion exception Criterion B1 presented regularly (i.e. often or always) in this period of life. Nevertheless, two aspects of symptom regularity in Domain B remain unclear. First, how often Criterion B4 presented in adulthood was contested in Study 1. Specifically, clinicians reported that this criterion presented less often than did adults with ASD or their significant others. Second, how often specific behaviours characteristic of each Domain B criteria present in adulthood is also uncertain. Only one study has examined the regularity with which these individual behaviours present in adulthood among persons without intellectual disability (Barrett et al., 2015) and none has considered an ASD sample. The present chapter thus seeks to clarify the regularity with which specific behaviours indicative of each diagnostic criterion present among adults with intellectual disability.

### **Summary**

To identify and diagnose adults with suspected ASD, a clinician must have a thorough understanding of the qualitative manifestation of each domain, the frequency with which behaviours characteristic of these domains present in adulthood and the severity of their presentation. While reports within the published literature and earlier chapters within this thesis offer insight into these properties for Domain A, information

about the presentation of Domain B in adulthood is less comprehensive. Available studies have typically considered small samples of adults with ASD, have pooled the responses of children, adolescents and adults and/or provide little information about the manifestation, frequency or severity of specific behaviours characteristic of this domain. Thus, it is difficult to draw precise conclusions about the presentation of Domain B in adulthood. Therefore the present study seeks to contribute to our understanding of Domain B in adulthood by exploring the qualitative manifestation, frequency and severity of these impairments among a large sample of adults with ASD without intellectual disability.

## Method

### Participants

Adults with ASD ( $N = 43$ ) were recruited through social media advertisements and from a research database.<sup>18</sup> The majority of adults with ASD were recruited via social media and participated externally ( $n = 30$ ) while a subset completed the study at the university ( $n = 13$ ). This latter group and one external participant contributed to the study previously described in Chapter 2 (Study 1). To verify the diagnostic status of individuals recruited via social media who self-reported a diagnosis of ASD, AQ scores were considered. Individuals scoring below the diagnostic cut-off score of 26 for the AQ recommended by Woodbury-Smith (2005) ( $n = 1$ ) or responding to less than 80% of study items were removed from further analyses ( $n = 3$ ).

The characteristics of the final sample ( $N = 39$ ; 16 males, 22 females) are reported in Table 22. Most participants were diagnosed in adulthood with Asperger's disorder ( $n = 34$ ); the remainder being diagnosed with ASD ( $n = 4$ ) or autistic disorder ( $n = 1$ ). A few external participants were self-diagnosed ( $n = 3$ ) but were retained in the

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<sup>18</sup> Individuals from the database were diagnosed with ASD by a health professional trained in ASD assessments and had at least average IQ according to WASI-II or WAIS-IV assessments. These individuals were invited to join the database to be informed about potential research participation opportunities via mail-outs.

final sample because their AQ scores fell within acceptable limits. Half the participants ( $n = 20$ ; 51.28%) had been diagnosed with other disorders including depressive disorders ( $n = 6$ ); anxiety disorders ( $n = 5$ ); ADHD ( $n = 4$ ); personality disorders ( $n = 2$ ); PTSD ( $n = 2$ ); schizoaffective disorder ( $n = 1$ ) and learning disorders ( $n = 1$ ), but not intellectual disability, in addition to ASD.

Table 22  
*Participant Demographics (N = 39)*

	<i>M(SD)</i>	Range
Age (years)	36.58 (9.71)	18 - 57
Age at diagnosis (years)	31.86 (11.72)	10 - 57
AQ score	39.38 (5.62)	27 - 49

## Measures

**The Autism Spectrum Quotient.** The 50-item Autism Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) was used to verify the self-reported diagnoses of adults with ASD recruited online. This self-report questionnaire assesses attention switching, attention to detail, communication and imagination. Participants use this questionnaire to rate whether they definitely or slightly agree or disagree with a range of statements about their behaviour, experiences and partialities. Total scores range from 0 to 50, higher scores signify more ASD traits and individuals who score 32 or above likely have ASD. Given the variable sensitivity of the AQ ([21%] Bishop & Seltzer, 2012; [90%] Wouters & Spek, 2011), the cut-off score of 26 recommended by Woodbury-Smith et al. (2005) was used.

**Restricted, repetitive patterns of behaviour, interests or activities questionnaire.** There is a measure specifically designed to assess each of the Domain B criteria in adulthood, the Repetitive Behaviours Questionnaire-2 (RBQ-2A; Barrett et al., 2015). However, at the time of conducting this study, this measure had not yet been

developed or reported and so another measure was created to assess Domain B for the purposes of this study.

***Test development.*** Specifically, to address the manifestation, frequency and severity of Domain B presentation in adulthood, a self-report questionnaire was developed. Self-reporting was deemed the most appropriate approach to assessing Domain B for the present study given interest in the perspectives of adults with ASD. Nonetheless, this demographic report difficulty interpreting whether the symptoms they experience are the same as described in self-report tools, particularly when their symptoms do not present with the regularity or impediments to adaptive functioning described in these tools (Holmes, 2011). To ease problems interpreting whether symptoms are characteristic of ASD, the self-report questionnaire thus provides specific examples of symptoms e.g. spinning, rocking and flapping. The severity with which these behaviours present is then considered separately.

The behaviours targeted within this measure for each of the four Domain B diagnostic criteria are drawn from the DSM-5 manual (APA, 2013), the reports of adults with ASD, clinicians and significant others from earlier chapters and, existing assessment tools that assess aspects of Domain B. These tools include the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994); Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord et al., 2000); Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001) and the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R; Ritvo et al., 2011). Hyper-reactive responses to sensory stimuli operationalised as distraction, discomfort or interest; and, hypo-reactive responses operationalised as indifference, high tolerance or disinterest as in Dunn's Sensory Processing Model (Dunn, 1997) are assessed in the questionnaire. This model reflects the unique sensory responses of persons with ASD (Winnie Dunn et al., 2002).

While behaviours that appeared diagnostically relevant in adulthood from earlier chapters are primarily targeted for assessment within the questionnaire, additional behaviours are included to capture those not previously assessed in Study 2. For example, specific types of Criterion B1 repetitive motor behaviour and a broader range of Criterion B4 hyper- and hypo-reactive responses to vestibular stimuli are included. An overview of the questionnaire is provided below. The complete questionnaire may be found in Appendix C.

***Qualitative probes.*** The restricted, repetitive patterns of behaviour, interests or activities questionnaire comprises items intended to produce qualitative accounts of symptomatology. Specifically, respondents are presented with descriptions of behaviour characteristic of the four Domain B criteria drawn from the aforementioned sources and invited to describe any related additional symptomatology they may experience or, to elaborate about how and when these symptoms manifest for them. For example, respondents describe any additional Criterion B1 repetitive behaviour they engage that may not be explicitly operationalised within the questionnaire. Further, to clarify the manifestation of Criterion B3 intense interests in adulthood, respondents report about the effects of being disrupted from pursuing these interests.

***Quantitative probes.*** The questionnaire also assesses quantitative aspects of symptom presentation. First, symptom severity is assessed. Respondents rate the regularity with which behaviours described in the questionnaire present in adulthood. For behaviours characteristic of Criteria B1, B2 and B3, these ratings are made using a six anchor Likert scale (i.e. less than once a month, once a month, two to three times a month, once a week, two to three times a week, daily). A different rating scale is used to assess the regularity with which behaviours characteristic of Criterion B4 present in adulthood. Specifically, to clarify discrepancies between the perceptions of clinicians, adults with ASD and significant others about the regularity of these symptoms reported

in Study 1 respondents are presented with the six anchor Likert scale from Study 1. This scale requires participants to rate how often hyper- or hypo-reactive sensory responses in each domain create difficulties in their daily lives (i.e. never, rarely, sometimes, frequently, almost always). This same Likert scale is used to report the regularity with which continuity errors are noticed, a manifestation of Criterion B2 insistence on sameness, given that participants may not be routinely exposed to such errors.

The DSM-5 manual (APA, 2013) acknowledges that regularly presenting behaviours are considered more severe, noting that conspicuous symptoms presenting across contexts are indicative of more marked impairments. However, how often behaviours must present to be seen as ‘severe’ is not operationalised within the manual. In the present study, regularly presenting behaviour is thus defined as that which presents at least multiple times a week or more, or as behaviour that presents often or almost always.<sup>19</sup> These thresholds were chosen based on existing assessment tools that regard impairments as more severe the more consistently they present (ADI-R; Le Couteur, Lord, & Rutter, 2003; ADOS-G; Lord, Rutter, DiLavore, & Risi, 2009).

The questionnaire developed also provides a means of assessing symptom frequency. Frequency is defined as the proportion of adults with ASD that present with behaviour characteristic of ASD. Behaviours presenting at least once a month or at least sometimes are considered ‘present in adulthood.’ The ideal threshold for frequency discussed in earlier chapters (see studies 1 and 2) is used to evaluate frequency in the present chapter (i.e. behaviours that present among at least 70% of the sample). While it may be that a more conservative threshold is required to identify behaviour of potential diagnostic relevance, particularly for Criterion B1, this threshold is used as a starting point in evaluating frequency for the sake of consistency with

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<sup>19</sup> Consistent with Study 1.

earlier chapters.

***Qualitative data analysis.*** Respondents' qualitative accounts were examined using the "conventional content analysis" approach described by Hsieh and Shannon (Hsieh & Shannon, 2005). Specifically, the author coded the behaviours described by participants into groups using the terminology most commonly provided by participants. For example, when asked to describe any additional hand, finger or motor mannerisms that they might engage in, many participants noted rubbing or scratching at their skin. Thus any responses that used these terms or, that matched the way these terms has been described by these participants, i.e. as including "scraping" or "picking," were then coded together as rubbing or scratching behaviours.

At times this approach yielded more than ten unique codes for responses to a given item, with several codes being endorsed by only one or two participants. In these cases, additional summary codes were created to provide a general framework that would make assessing these behaviours more practical for clinicians. These summary codes were drawn from behavioural definitions described in the literature or the context in which the behaviour occurred. For example, when describing their main routine, participants reported a wide variety of behaviours such as eating, dressing and bathing routines that yielded numerous codings. A summary code 'activities of daily living routines' was therefore created based on the match between these behaviours and the definition of these activities in the literature (Weaver, 2015). Other low incidence codes emerged from this item about routines including checking websites, reading and swimming. All of these activities reportedly occurred at the end of the working day and were thus given the additional summary code of 'end of day routines.'

## **Procedure**

Participants completed the restricted, repetitive patterns of behaviour, interests or activities questionnaire. Participants recruited online then completed the AQ to

verify their self-reported ASD diagnoses. Questionnaires were administered via Qualtrics.

## Results

### Criterion B1

**Manifestation.** The manner in which repetitive behaviours presented among the adults with ASD is described in Table 23. Of note, one participant who did not engage in any of the repetitive behaviour operationalised within the questionnaire identified two additional types of repetitive behaviour when invited to describe additional manifestations that had been overlooked. Indeed, almost half the participants reported additional manifestations of Criterion B1 ( $n = 18$ ; 46.15%) beyond those operationalised in the questionnaire. These additional behaviours included rubbing or scratching at objects or one's skin; twirling or waving items; mouthing objects or one's thumbs, hands, nails or hair; tapping objects or one's body and, tensing muscles.

Table 23  
*Adults Presenting with Criterion B1 Behaviours*

<i>N</i>	Behaviours operationalised in the questionnaire	<i>n</i>	%
38	Knee jiggling	31	81.58
37	Hand wringing or twisting	22	59.46
37	Finger flicking	22	59.46
38	Rocking	22	57.89
35	Bouncing	17	48.57
36	Flapping	17	47.22
35	Spinning	13	37.11
<i>N</i>	Additional manifestations	<i>n</i>	%
39	Rubbing or scratching at objects or one's skin	9	23.07
39	Twirling or waving items	4	10.26
39	Mouthing objects or one's thumbs, hands, nails or hair	3	7.69
39	Tensing their muscles	3	7.69
39	Tapping objects or one's body	3	7.69

**Frequency.** As shown in Table 23, the majority of the repetitive behaviours described presented among few adults with ASD. The more commonly presenting behaviours were knee jiggling, hand wringing or twisting, finger flicking and, rocking.

However, only knee jiggling met the criterion for appropriate frequency (70%). Most adults with ASD presented with multiple repetitive behaviours ( $n = 35$ ; 89.74%,  $M = 4.25$ ,  $SD = 2.26$ ). T-tests were used to examine whether sex or timing of diagnosis affected the number of repetitive behaviours reported. Throughout this chapter alpha levels for significance were set to .01 to adjust for multiple comparisons. The average number of repetitive behaviours endorsed did not significantly differ between males ( $M = 3.25$ ,  $SD = 2.01$ ) or females ( $M = 4.77$ ,  $SD = 2.18$ ;  $t(36) = 2.19$ ,  $p = .035$ ) or, according to whether the individual had been diagnosed before 18 years of age ( $M = 3.33$ ,  $SD = 1.51$ ) or later ( $M = 4.45$ ,  $SD = 2.26$ ;  $t(35) = -1.55$ ,  $p = .256$ ).

**Severity.** The severity of symptoms as indexed by the regularity with which they presented was also investigated. Most repetitive behaviours operationalised in the questionnaire presented regularly, (i.e. at least multiple times a week), for the individuals for whom they did manifest. Indeed, only spinning presented regularly for less than half the individuals who manifested this behaviour, as summarised in Table 24.

Table 24

*The Regularity with Which Criterion B1 Behaviours Present Among Adults with ASD (N = 38)*

Behaviours operationalised in the questionnaire	Less than once	Monthly	2-3 times a	Weekly	2-3 times a	Daily
	a month (n)	(n)	month (n)	(n)	week (n)	(n)
Knee jiggling	7	2	4	2	6	17
Hand wringing or twisting	15	1	1	1	7	12
Finger flicking	15	3	2	2	4	11
Rocking	16	3	5	1	5	8
Bouncing	18	3	2	3	4	5
Flapping	19	2	4	2	1	8
Spinning	21	2	4	3	2	2
	Less than once	Monthly	2-3 times a	Weekly	2-3 times a	Daily
Additional manifestations	a month (n)	(n)	month (n)	(n)	week (n)	(n)
Rubbing /scratching at objects or skin	0	0	0	0	0	9
Twirling or waving items	0	0	0	0	1	3
Mouthing objects, hands or hair	0	0	0	0	1	3
Tensing muscles	0	0	0	0	0	3
Tapping objects or one's body	0	0	0	0	1	1

## Criterion B2

**Manifestation.** Adults with ASD reported insistence on sameness behaviours when reading books or watching films or TV shows. Specifically, they noticed continuity errors such as factual errors, plot inconsistencies, changes in the appearance or layout of characters or settings or, grammatical errors. Participants also reported ordering behaviour, verbal rituals and routines for daily living activities such as eating, bathing and dressing. Their main routines or rituals are summarised in Table 25. Note that the *n*'s reported for each category exceed the number of individuals describing these primary routines and rituals because some participants engaged in multiple behaviours.

Table 25

*Types of Primary Routines and Rituals Presenting Among Adults with ASD (N = 22)*

Activities of daily living ( <i>n</i> = 14)
<ul style="list-style-type: none"> <li>• Preparing for the day: belongings must be laid out; must check they are in order</li> <li>• Eating: specific foods eaten, at particular times or, in a set order</li> <li>• Bathing: there is an order to washing; washing occurs at a set time</li> <li>• Dressing: there is an order to dressing; certain items are always worn</li> <li>• Taking medication: very specific times; medications are elaborately organised</li> <li>• Cleaning (house, belongings): very specific times; with unusual frequency</li> </ul>
Organisational ( <i>n</i> = 5)
<ul style="list-style-type: none"> <li>• Ordering: Belongings have a certain order or place; repeatedly checks order is correct</li> <li>• Uses schedules, colour-coding or a structured system for daily tasks</li> </ul>
End of day / recreational routines ( <i>n</i> = 4)
<ul style="list-style-type: none"> <li>• Checking websites: in a specific order or particular timing (e.g. when arriving home)</li> <li>• Reading: always reads before bed</li> <li>• Swimming: always done; set number of laps</li> </ul>
Travelling ( <i>n</i> = 2)
<ul style="list-style-type: none"> <li>• Navigation: always follows a specific route when travelling somewhere</li> <li>• Activities: has to listen to music when travelling</li> </ul>
Verbal rituals ( <i>n</i> = 2)
<ul style="list-style-type: none"> <li>• Must repeat self over and over; must count when walking</li> </ul>

**Frequency.** Table 26 summarises the frequency with which the three broad categories of Criterion B2 behaviour presented among the adults with ASD. Only verbal rituals presented with inadequate frequency. You may notice that verbal rituals and ordering behaviour presented more frequently in Table 26, than they did across participants' reports of their main routine or ritual in Table 25. It thus appears that although these behaviours do present in adulthood, adults do not regard them as the primary manifestations of their routine or ritualistic behaviour.

Table 26

*Proportion of Adults with ASD (N = 39) Presenting with Criterion B2 Behaviours*

	<i>n</i>	%
Routines	35	89.74
Ordering behaviour	33	84.62
Insistence on sameness - continuity errors	33	84.62
Verbal rituals	25	64.10

The number of Criterion B2 symptoms presenting among adults with ASD was also considered. The majority of these adults ( $n = 36$ ; 92.31%) presented with multiple categories of Criterion B2 behaviour, i.e. routines, rituals, insistence on sameness and/or ordering behaviour ( $M = 3.10$ ,  $SD = .91$ ). T-tests indicated that the average number of Criterion B2 categories endorsed did not significantly differ between males ( $M = 3$ ,  $SD = 1.15$ ) and females ( $M = 3.14$ ,  $SD = .71$ ;  $t(36) = 3.502$ ,  $p = .655$ ). Neither did the Mean categories endorsed differ according to whether the individual had been diagnosed before 18 years of age ( $M = 2.83$ ,  $SD = 1.17$ ) or later ( $M = 3.23$ ,  $SD = .80$ ;  $t(35) = -1.02$ ,  $p = .317$ ).

**Severity.** The severity of Criterion B2 behaviour as indexed by its regularity was also considered. Each type of Criterion B2 behaviour presented regularly (at least multiple times a week) for most adults with ASD. As shown in Table 27, routines presented with the greatest regularity, occurring on a daily basis for most participants. Given that continuity errors may not always occur on a weekly basis, a different Likert

Scale (i.e. never, rarely, sometimes, frequently, almost always) was used to rate their regularity. Most adults with ASD ( $n = 28$ ; 87.5%) reported that they frequently or almost always noticed these continuity errors.

Table 27  
*The Regularity with Which Criterion B2 Behaviours Present*

	Less than once a month ( <i>n</i> )	Monthly ( <i>n</i> )	2-3 times a month ( <i>n</i> )	Weekly ( <i>n</i> )	2-3 times a week ( <i>n</i> )	Daily ( <i>n</i> )
Routines	1	0	0	2	5	28
Verbal rituals	2	1	3	2	7	12
Ordering	4	2	4	2	6	19
	Never ( <i>n</i> )	Rarely ( <i>n</i> )	Sometimes ( <i>n</i> )	Frequently ( <i>n</i> )	Almost Always ( <i>n</i> )	
Continuity	2	4	5	11	17	

### Criterion B3

**Manifestation.** Adults with ASD described numerous Criterion B3 behaviours. Specifically, they reported collecting things, gathering facts, keeping lists, gaming, social media and fantasy play. When invited to volunteer their primary interests, participants described various pastimes including electronics, Internet searching, data analysis, reading, writing, learning languages, taking care of animals, volunteering, arts and craft, railways and football. Note that only computing based interests, gaming and social media use had been previously operationalised in the questionnaire and as such many more manifestations were reported when freely reporting the nature of their primary interests. The manifestation of intense interests was also explored. Many participants reported experiencing anxiety, sadness or a ‘melt-down’ ( $n = 27$ ; 71.05%) when disrupted from their primary interests. A minority reported feeling that they must return to the activity immediately ( $n = 5$ ; 13.16%).

**Frequency.** As shown in Table 28, only half of the restricted interests operationalised within the questionnaire presented among at least 70% of participants.

In particular, interest in fantasy play, i.e. role-playing games such as Dungeons and Dragons, rarely presented. Further, there was a lack of consistency in the activities on which participants spent most of their time (primary interests).

Table 28

*% of Adults Presenting with Criterion B3 Interests*

Restricted interests operationalised in the questionnaire ( $N = 39$ )	$n$	(%)
Gathering facts	34	87.18
Social media	32	82.05
Keeping lists	32	82.05
Gaming - computer, video and/or board games	26	66.67
Collecting things	21	53.85
Fantasy play	11	28.21
Primary interests volunteered by participants ( $N = 38$ )	$n$	(%)
Computing	12	31.58
The Humanities - reading, writing, learning languages	8	21.05
Gaming - video or pen and paper games	6	15.79
Creative arts - music, craft, visual arts, knitting	6	15.79
Facebook	4	14.29
Sport	4	14.29
Thinking	2	5.26
Animals	1	2.63
Volunteering	1	2.63
Socialising	1	2.63

You will notice that the  $n$ 's reported do not equate to the total sample as all participants reported multiple areas of interests ( $M = 5.13$ ;  $SD = 1.59$ ). T-tests indicated that the average number of interests reported did not significantly differ between males ( $M = 5.13$ ,  $SD = 2.13$ ) or females ( $M = 5.09$ ,  $SD = 1.15$ ;  $t(36) = -.06$ ,  $p = .950$ ) or, according to whether the individual had been diagnosed before 18 years of age ( $M = 5.5$ ,  $SD = 3.02$ ) or later ( $M = 5.10$ ,  $SD = 1.27$ ;  $t(35) = .32$ ,  $p = .760$ ).

**Severity.** As shown in Table 29, only three of the restricted interests described in the questionnaire presented regularly for most participants: social media, gathering facts, and keeping lists. However, as expected, almost all participants regularly engaged in their primary interest/s ( $n = 38$ ; 97.44%).

Table 29

*The Regularity with Which Criterion B3 Interests Present*

Restricted interests operationalised in the questionnaire ( <i>N</i> = 39)	Less than once a month ( <i>n</i> )	Monthly ( <i>n</i> )	2-3 times a month ( <i>n</i> )	Weekly ( <i>n</i> )	2-3 times a week ( <i>n</i> )	Daily ( <i>n</i> )
Social media	1	0	0	0	7	25
Gathering facts	3	0	4	1	10	19
Keeping lists	5	2	3	7	7	13
Gaming <sup>a</sup>	5	1	2	4	3	16
Collecting things	5	4	5	4	1	7
Fantasy play	5	2	1	1	2	5
Primary interests volunteered by participants ( <i>N</i> = 38)	Less than once a month ( <i>n</i> )	Monthly ( <i>n</i> )	2-3 times a month ( <i>n</i> )	Weekly ( <i>n</i> )	2-3 times a week ( <i>n</i> )	Daily ( <i>n</i> )
Computing	0	0	0	0	2	10
The Humanities	0	0	0	0	4	4
Gaming <sup>b</sup>	0	0	0	0	2	4
Creative arts	0	0	0	0	2	4
Facebook	0	0	0	0	0	4
Sport	0	0	0	1	1	2
Thinking	0	0	0	0	0	2
Animals	0	0	0	0	0	1
Volunteering	0	0	0	0	1	0
Socialising	0	0	0	0	1	0
Railways	0	0	0	0	1	0

<sup>a</sup> Computer, video and/or board games. <sup>b</sup> Computer, video and pen and paper games

## Criterion B4

**Manifestation.** Examples of hyper- and hypo-reactive responses to sensory stimuli were provided for every sensory domain, with the exception of hypo-reactive responses to visual sensation where none were reported.<sup>20</sup> These descriptions are shown in Table 30. Predominantly, responses to sensory stimuli manifested as experiencing stimuli as unpleasant, such as feeling deafened by sound or being unable to tolerate certain fabrics. Instances of sensory seeking behaviour including craving weighted blankets were also described. In addition, some adults with ASD reported that they had enhanced awareness of sensations, noticing faint noises or being able to reproduce a complex meal from taste alone. Four individuals reported auditory-visual synaesthesia.

Table 30

*Types of Hyper- and Hypo-Reactive Responses to Sensory Domains in Adulthood*

Auditory ( $N = 33$ )	( $n$ )
<i>Hyper-reactive responses</i>	
• Sounds are unpleasant, e.g. high-pitched, electronic or loud sounds	27
• Clearly hears faint sounds, e.g. electrical hum, water dripping, household noise	12
• Difficulty distinguishing between multiple sounds	4
<i>Hypo-reactive responses</i>	
• Sounds do not register, e.g. speech not heard if there is background noise	1
<hr/>	
Olfactory ( $N = 27$ )	
<i>Hyper-reactive responses</i>	
• Dislikes scents, e.g. food, perfumes, chemicals	24
• Clearly identifies faint scents	3
<i>Hypo-reactive responses</i>	
• May not notice unpleasant smells, e.g. body odour, burning smells	5
<hr/>	
Tactile ( $N = 30$ )	
<i>Hyper-reactive responses</i>	
• Seeks out deep pressure or warm, smooth or soft sensations	18
• Cannot tolerate fabric, clothing tags; food textures, light touch	14
<i>Hypo-reactive responses</i>	
• Cannot register sensations, e.g. may not realise when touching something	1

<sup>20</sup> Recall that Dunn's Sensory Processing Model (Dunn, 1997) operationalises hyper-reactivity as interest, discomfort or distraction arising from sensory stimuli and hypo-reactivity as indifference, high tolerance or disinterest in sensations.

Visual ( $N = 29$ )	( $n$ )
<i>Hyper-reactive responses</i>	
• Unusually aware of visual sensation, e.g. movement, lights, colours	20
• Strong reactions to specific colours or lighting, may be painful, intolerable	12
<hr/>	
Gustatory ( $N = 22$ )	
<i>Hyper-reactive responses</i>	
• Particular flavours are very unpleasant, e.g. sweet, salty, bitter, sour, spicy	16
• Can reproduce a meal or identify specific ingredients without a recipe using taste	5
<i>Hypo-reactive responses</i>	
• May not be at all picky about the taste of food	1
<hr/>	
Vestibular ( $N = 17$ )	
<i>Hyper-reactive responses</i>	
• Motion sickness, vertigo, poor balance/spatial awareness, movement causes pain	12
• Thrill seeker e.g., craves amusement rides and spinning	5
<i>Hypo-reactive responses</i>	
• Does not notice when travelling at high speed	1
• Poor sense of gravity, feels weightless	1
<hr/>	
Pain ( $N = 23$ )	
<i>Hyper-reactive responses</i>	
• Minor ailments (e.g. bites, scratches) feel disproportionately painful; takes longer to recover from pain, may avoid medical procedures for fear of pain	12
<i>Hypo-reactive responses</i>	
• High pain tolerance e.g. does not require pain-relief for body piercings, burns, migraines or child-birth	9
• May be severely injured and not realise, can cause health complications	4
• Deliberately inflicts pain, e.g. self-harms; manipulates joints	3
<hr/>	
<i>Note.</i> $n$ 's reflect % of participants reporting a hyper- or hypo-reactive response to sensory stimuli	

**Frequency.** The majority of adults with ASD ( $n = 27$ ; 69.23%) reported sensory responses consistent with Dunn's (1997) Model in more than one sensory domain ( $M = 2.87$ ,  $SD = 2.09$ ). Hyper-reactive responses to sensory stimuli were reported by most adults ( $n = 20$ , 54.05%), the remaining participants reported a combination of hyper- and hypo-reactive responses ( $n = 17$ ; 43.59%) or, no such responses to sensory stimuli ( $n = 1$ ; 2.56%). Only one individual was hyper and hypo-reactive to stimuli within the same sensory domain.

A number of participants reported being unsure whether they experienced hyper- or hypo-reactive responses to sensory stimuli for one or more sensory domains. Identifying whether reactions to vestibular stimuli ( $n = 11$ ) or one's pain tolerance ( $n = 9$ ) presented in this manner posed the most difficulties. Thus, only reports from individuals who were confident about whether they experienced hyper- or hypo-reactive responses in a given domain were considered further when examining the frequency of Criterion B4 impairments.

As shown in Table 31, hyper- or hypo-reactive responses presented most frequently in the auditory and visual domains. Interestingly, these responses presented among fewer than 70% of adults with ASD across the other sensory domains. Examining the specific types of responses reported in Table 31, a number of hyper-reactive behaviours presented frequently among adults with ASD. These included experiencing discomfort due to auditory, olfactory, gustatory or vestibular stimuli. T-tests showed that the average number of hypo or hyper-reactive responses did not significantly differ according to whether diagnosed before 18 years of age ( $M = 3.23$ ,  $SD = .80$ ) or later ( $M = 3.23$ ,  $SD = .80$ ;  $t(35) = -1.02$ ,  $p = .317$ ) or, whether identifying as male ( $M = 1.88$ ,  $SD = 1.75$ ) or female ( $M = 3.5$ ,  $SD = 2.09$ ;  $t(36) = -2.53$ ,  $p = .02$ ).

Table 31  
% of Adults Experiencing Hyper- or Hypo-reactive Sensory Responses

	<i>N</i>	Hyper-reactivity (%)	Hypo-reactivity (%)	Neither (%)
Auditory	38	86.84	2.63	10.53
Visual	34	82.35	2.94	14.71
Olfactory	35	65.71	14.29	20
Tactile	34	61.77	5.88	32.35
Gustatory	34	61.77	5.88	32.35
Vestibular	27	55.56	11.11	33.33
Pain	30	43.33	40	16.67

**Severity.** Despite hyper- or hypo-reactive responses being reported by most adults, only two sensory domains: visual ( $n = 24$ ; 61.5%) and auditory ( $n = 22$ ; 56.41%), regularly presented difficulty for the majority of adults with ASD as outlined in Table 32. The reports of clinicians about the proportions of adults with ASD regularly experiencing Criterion B4 impairments from Study 1 ( $N = 21$ ; 52.6%) were compared to the adults with ASD in the present study for the least and most regularly presenting sensory domains using z-tests for sample proportions. Reports of the regularity with which the visual domain ( $z = .6, p = .518$ ) and the gustatory domain ( $z = 2, p = .04$ ) presented in the present study and the regularity of overall Criterion B4 impairments reported by the clinicians in Study 1 did not significantly differ.

Table 32.

*Participants (N = 39) Indicating Criterion B4 Hyper- or Hypo-reactive Responses to Sensory Stimuli Created Difficulty*

	Never (%)	Rarely (%)	Sometimes (%)	Frequently (%)	Almost always (%)
Visual	7.69	12.82	17.95	33.33	28.21
Auditory	7.69	7.69	28.21	17.95	38.46
Tactile	10.26	10.26	33.33	23.08	23.08
Pain	7.69	28.21	28.21	12.82	23.08
Vestibular	10.53	31.58	26.32	13.16	18.42
Olfactory	12.82	20.51	35.9	17.95	12.82
Gustatory	15.38	15.38	43.6	12.82	12.82

Participants also described how specific types of hyper or hypo-reactive responses affected them and in doing so provided some insights into how these symptoms interfered with everyday functioning. The difficulties caused by hyper-reactive responses to sensory input predominantly manifested as emotional distress ( $n = 18$ ; 46.15%) such as anger, irritation and feeling overwhelmed or, in pain or illness ( $n = 17$ ; 43.59%). The most frequently cited impairment arising from hypo-reactivity to sensory stimuli was apparent indifference to pain leading to medical complications

when not noticing or appreciating the severity of injuries ( $n = 7$ ; 17.95%). Interestingly, hypo-reactive responses were an asset for some individuals ( $n = 10$ ; 25.64%), allowing them to tolerate pain or providing enjoyment, with many of these individuals finding vestibular sensations such as spinning or going on amusement rides particularly exciting and/or soothing.

## **Discussion**

There is a lack of clarity about the presentation of Domain B symptoms among adults with ASD. This uncertainty adds to the complexity of conducting ASD diagnoses within this demographic. The present study sought to expand current understanding regarding the manifestation, frequency and severity of impairments characteristic of each of the four Domain B criteria as they present in adulthood.

### **Symptom Manifestation**

The present study contributes to current understanding of the manifestation of Domain B among adults with ASD in a number of ways. First, a range of behaviour thought to be characteristic of Domain B in childhood and adolescence (DSM-5; APA, 2013) was confirmed to present in a similar manner in adulthood. For example, Criterion B1 finger flicking and hand wringing or twisting behaviours commonly included within assessment tools intended for children (ADI-R; Le Couteur et al., 2003; ADOS-G; Lord et al., 2000), appeared to present among the majority of adults with ASD. Further, Criterion B2 routines and rituals for sleeping, eating and leisure activities noted by Georgiades et al. (2010) among a mixed sample of children, adolescents and adults were likewise reported among adults in the present sample.

Second, additional information about the qualitative presentation of behaviour characteristic of Domain B specific to adulthood emerged. Participants reported bathing, dressing, cleaning, travelling and organisational routines in addition to the routines identified by Georgiades et al. (2010). Behaviour characteristic of ASD in

adulthood but not assessed within the recommended assessment tools for adults with ASD (NICE, 2012a) was also identified. These behaviours included Criterion B1 repetitive motor mannerisms such as tensing muscles and tapping objects. It should be noted that much of this information was elicited when asking adults to freely report about the nature of their symptoms or any additional manifestations. Thus providing opportunities to freely report the nature of symptoms and including these additional manifestations of Domain B impairments may be particularly valuable when assessing adults with suspected ASD.

Third, the present chapter provides important insight into the manifestation of Criterion B3 in adulthood. Specifically, it was confirmed that when disrupted from interests, adults experience emotional distress, consistent with the presentation of intense interests in childhood (Young et al., 2003). In addition, while it appears that stereotypical manifestations of interests such as fact gathering (Asperger & Frith, 1991) may present in adulthood, a plethora of the interests reported in the present study were not unusual in their content. For example, adults in the present study reported interests in social media and arts and craft. Thus clinicians should be mindful that interests in adulthood may not be unusual in their content, but are likely to provoke distress when disrupted.

### **Symptom Frequency**

Reports of the frequency with which specific Domain B behaviours presented among adults with ASD from the present study likewise contribute to our understanding of the disorder in this period of life. It was common for adults to report multiple behaviours consistent with each Domain B diagnostic criterion, consistent with reports about the presentation of this domain in childhood (Harrop et al., 2013). Few Domain B behaviours met the minimum criterion for appropriate frequency (70%), particularly for Criteria B1 and B4. Further, even for the more frequently presenting criteria, B2

and B3, few specific interests or routines and rituals presented frequently among adults with ASD. This diversity of symptoms in adulthood reiterates reports from Studies 1 and 2 and suggests that much behaviour considered characteristic of ASD does not present frequently among adults. Clinicians should thus consider a broad range of behaviours when evaluating each Domain B criterion in adulthood.

### **Symptom Severity**

**The regularity of symptoms.** The present study likewise offers insights into how best to assess the severity of Domain B impairments in adulthood. Within the DSM-5, symptom severity ratings are made according to the degree that symptoms interfere with functioning, are noticeable or, present across contexts. Arguably the regularity with which symptoms present provides an index of how noticeable or consistently impairments are likely to present. Adults with ASD reported that a range of behaviours characteristic of each Domain B criterion presented regularly (i.e. at least multiple times a week) for most adults with ASD for whom they manifested. For example, Criterion B1 hand wringing or twisting and finger flicking, Criterion B2 routines, Criterion B3 interests and select Criterion B4 hyper- or hypo-reactive sensory responses in the visual or auditory domains, presented with regularity. These findings imply that Domain B impairments are likely to present across contexts and/or be noticeable to the individuals with whom adults with ASD interact. Thus the regularity with which Criteria B2, B3 and B4 symptoms present may be useful to consider when evaluating the severity of Domain B in adulthood.

Accounts of symptom severity as indexed by its regularity likewise provided some clarification about the presentation of Criterion B4 hyper- or hypo-reactive sensory responses in adulthood. As reported in Study 1, adults with ASD and significant others perceived Criterion B4 to manifest with greater regularity among adults with ASD than did clinicians. Interestingly, reports of the regularity with which

specific types of sensory hyper- or hypo-reactivity manifested in the present chapter were comparable to that of clinicians in Study 1. These findings suggest that these sensory responses may present with lesser regularity than first thought.

***Differential diagnosis.*** As noted previously, isolated behaviours similar to that characteristic of Domain B, including Criterion B3 interests, manifest among typically developing individuals (Barrett et al., 2015; Jordan & Caldwell-Harris, 2012). Indeed, many of the primary interests reported by adults with ASD in the present study including writing, learning languages and electronics were not markedly unusual in their content. However, almost every adult with ASD in the present study engaged in his or her primary interests daily, in apparent contrast to typically developing adults in the Barrett et al. (2015) study, the majority of whom did not ‘almost always’ engage in these interests when they had spare time. Likewise, while few adults with ASD in the present study engaged in routines less than once a month, the majority of typically developing adults from the Barrett et al. (2015) study never or rarely engaged in daily routines. These findings reiterate observations that typically developing persons who exhibit symptoms characteristic of ASD, do so with less regularity than people with ASD (DSM-5; APA, 2013; Harrop et al., 2013). The present study suggests that considering the regularity with which interests present may be of value to clinicians when evaluating whether less stereotypical interests presenting in adulthood may be indicative of ASD.

**Symptoms interfering in everyday life.** While symptom severity as indexed by the regularity with which symptoms presented was the primary focus of this chapter, participants’ descriptions of Criteria B3 and B4 behaviour highlighted how some behaviours interfere with everyday functioning. Despite the minority of adults in Study 1 reporting that Domain B impairments caused them most difficulty, the present study demonstrated that specific types of difficulties do present within this domain for most

adults with ASD. Specifically, the disruption of interests and exposure to sensory stimuli can cause significant emotional and physical distress. Thus, clinicians may be able to consider the impact of Criteria B3 and B4 impairments on everyday functioning when evaluating the severity of Domain B.

### **Sample Characteristics**

While the present study offers potential insights into the manifestation, frequency and severity of Domain B in adulthood, the unusual characteristics of the present sample must be considered. First, the majority of participants were diagnosed in adulthood. It is possible, and one might suggest likely, that presentation of symptoms among late-diagnosed adults may differ from individuals diagnosed earlier in life. Late-diagnosed adults may thus not be representative of the broader population of adults with ASD. Second, the usual overrepresentation of males with ASD reported in the literature was not evident in this sample. Rather, slightly more females ( $n = 22$ ) than males ( $n = 16$ ) were recruited. Further research is needed to determine whether the presentations reported in this chapter generalise to the broader population of adults with ASD and whether sex differences in the qualitative presentation of symptoms in adulthood emerge.

### **Approach to qualitative analysis**

The “conventional content analysis” approach outlined by Hsieh and Shannon (2005) was used to examine the qualitative responses provided by clinicians. This approach is well-suited to exploratory research and in the context of the present study afforded a means of analysis guided by the perspectives of adults with ASD, providing a contrast to earlier studies that relied more heavily on existing perceptions of symptoms within the literature based on childhood presentation. It was beyond the scope of the present study to have an independent rater evaluate the codings used or to use formal software such as Nvivo to assist with analyses, however this should be

considered for future research. Likewise, given the global scope and anonymity of participants' responses, it was not possible to meet with participants to clarify and discuss the coding chosen, facilitating this process in future research would however be valuable, perhaps by conducting the questionnaire as an in-person interview with a follow-up focus group.

### **Future Directions**

I sought to provide a comprehensive account of Domain B; some aspects of this domain require further research. First, exploring the presentation of Domain B in a sample of typically developing adults was beyond the scope of this study. However, this would serve to clarify whether behaviours such as knee jiggling or noticing continuity errors that presented frequently among adults with ASD are also diagnostically sensitive. Second, in exploring Criterion B1, the focus of the present chapter was on repetitive motor behaviours, given accounts of the manifestation, frequency and/or severity of repetitive speech in the literature (Robledo et al., 2012) and, both repetitive speech and object use in Study 1. However, repetitive object use did not emerge as characteristic of ASD in adulthood and there is a dearth of accounts of whether it may translate in a qualitatively different manner in adulthood. Creating and evaluating novel items to assess how repetitive object use may present in adulthood, as was done for insistence on sameness in the present chapter, may prove useful in clarifying presentation of this behaviour in this period of life. A similar approach should be adopted for assessing verbally based repetitive behaviours, which were explored in Study 1 rather than the present study, to examine whether a more behavioural approach to assessment may clarify the relevance of these behaviours in adulthood.

## Summary

The present study provides further insight into the manifestation, frequency and severity with which each of the four Domain B criteria present in adulthood. While the presentation of these criteria still requires further exploration, especially among adults with ASD diagnosed in childhood, this study provides insight into how ASD may manifest among adults seeking diagnoses. Primarily this study reinforces the idea that many of the specific behaviours that are characteristic of ASD present infrequently in adulthood and thus there is diversity in the expression of each criterion. However, many of the behaviours that do present among adults with ASD present with regularity that may assist in rating the severity of Domain B impairments in adulthood. It is clear however that Criterion B1 may have limited diagnostic relevance in adulthood, at least in so far as the repetitive motor behaviours and speech, since so few of these behaviours present frequently or regularly among adults with ASD as reported throughout this thesis.

Collectively, Studies 1, 2 and 3 offer clear insights into Domain A and B impairments as they present in adulthood. Specifically, a range of behaviour characteristic of ASD in this period of life due to its diagnostic sensitivity, frequency or the regularity of its presentation, has been identified. Some of these behaviours are not reflected in existing assessment tools and no diagnostic tool covers all of these behaviours adequately. In addition, many of these tools do not consider the quantity or regularity with which Domain B behaviours present that may be useful for differential diagnosis and judging symptom severity. Likewise, these tools have practical limitations such as age-inappropriate items (Holmes, 2011; NICE, 2012b) or lengthy administration times (Lord et al., 1994; Wing, Leekam, Libby, Gould, & Larcombe, 2002). Thus a comprehensive, practical and valid measure of ASD as it presents in adulthood is lacking to inform clinical judgements when identifying adults with ASD.

The purpose of Chapter 5 is to develop such a tool, informed by the findings presented thus far and, to evaluate its psychometric properties among a sample of adults with or without ASD.

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## **Chapter 5: Developing a Diagnostic Tool for Adults with Suspected ASD**

While the majority of individuals with ASD present for assessment in childhood, a growing number are diagnosed later in life (Jensen, Steinhausen, & Lauritsen, 2014). Clinicians evaluating these individuals must gather information about the course, manifestation and severity of their symptoms in order to determine whether they meet the DSM-5 criteria for ASD. Although assessment tools are valuable in assisting clinicians in information gathering that may help guide their clinical impression and subsequent diagnosis, these assessment tools are limited in their practicality and validity for adults. The purpose of this chapter was therefore to develop a more practical and valid diagnostic tool to assist clinicians in evaluating adults with suspected ASD.

### **Conducting Assessments for Adults with Suspected ASD**

As outlined in the DSM-5 criteria and NICE guideline for ASD in adulthood, clinicians must perform a variety of tasks when conducting diagnostic assessments (APA, 2013; NICE, 2012a). First, clinicians must establish whether symptoms presented in childhood. Second, they must gather information about the manifestation of impairments, that is, the qualitative manner in which they present within Domain A and Domain B. Third, clinicians must use this information to inform their clinical judgements about whether symptomatic behaviour is present across each of the three Domain A diagnostic criteria and, at least two of the four Domain B criteria. Fourth, they must establish the presence of clinically significant impairments and symptom severity by exploring whether symptoms are conspicuous, regularly present or, interfere with daily activities, interactions with others, and/or study or work. Finally, clinicians must assist the adult seeking the assessment in understanding ASD, their individual strengths and difficulties and develop recommendations for intervention.

Assessment tools are valuable in assisting clinicians to collect information about the manifestation and severity of ASD symptoms. The NICE guideline for adult ASD assessments (2012a) list a number of tools that may be used to assist clinicians in gathering this information. As discussed in Chapter 1, despite these tools being recommended for consideration when assessing adults with suspected ASD, their psychometric properties vary widely. The psychometric properties of the recommended clinical interviews, behavioural observation measure and self-report questionnaires among samples including adults with ASD, are summarised in Table 33.

The recommended assessment tools each meet the Glascoe (2005) and NICE (2012a) criteria for appropriate inter-rater reliability, sensitivity and specificity in adult samples.<sup>21</sup> Across the samples studied however, reports of adequate sensitivity and specificity are not consistent, particularly for the Autism Diagnostic Interview-Revised (ADI-R), Autism Diagnostic Observation Schedule-Generic (ADOS-G) and the Autism Asperger Assessment (AAA) that comprises the Autism Spectrum Quotient (AQ) and the Empathy Quotient (EQ). Further, the ADI-R and AAA have poor criterion validity while the psychometric properties of the Asperger Syndrome (and high functioning autism) Diagnostic Interview (ASDI) have not yet been studied beyond the initial validation sample. Data about the specificity of the Diagnostic Interview for Social and Communication Disorders (DISCO) is also lacking. Only the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R) appears to consistently present with appropriate inter-rater reliability, sensitivity and specificity among adults.

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<sup>21</sup> These guidelines recommends a minimum sensitivity of 70%; specificity of 80%; interrater reliability 80% and high criterion validity, i.e.  $r = \geq .50$

Table 33

*Psychometric Properties of the Recommended Assessment Tools Among Adults*

	Sensitivity (%)	Specificity (%)	Criterion validity	Inter-rater reliability	Studies
<i>Clinical Interviews</i>					
ADI-R (Lord, Rutter, & Le Couteur, 1994);	75 - 96	0 - 66	$r(\text{AQ}) = .18^a$	$\kappa = .42 - 1$	Hill, Bolte, Petrova, Beltcheva, & al, 2001; Howlin, Moss, Savage, & Rutter, 2013; Lai et al., 2011; Nygren et al., 2009; Wilson et al., 2013
ASDI (Gillberg, Gillberg, Råstam, & Wentz, 2001)	100	86	n.r.	$\kappa = .91$	Gillberg et al., 2001
DISCO (Wing, Leekam, Libby, Gould, & Larcombe, 2002)	80 - 100	n.r.	$\kappa(\text{ADOS}) = .64$	n.r.	Billstedt, Gillberg, & Gillberg, 2005; Brugha et al., 2012; Carrington et al., 2014
<i>Behavioural Observation Tool</i>					
ADOS-G (Lord et al., 2000)	61 - 93	72 - 93	$\kappa(\text{DISCO}) = .64$ RAADS-R % agreement = 100	% agreement 82 - 90	Bastiaansen et al., 2011; Brugha et al., 2012; Hus & Lord, 2014; Lord et al., 2000; Pugliese et al., 2015; Ritvo et al., 2011
<i>Self-Report Questionnaires</i>					
RAADS-R (Ritvo et al., 2011)	73 - 97	91 - 100	ADOS % agreement = 100	$r = .99$	Andersen et al., 2011; Ritvo et al., 2011; Sizoo et al., 2015
AAA (AAA; Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005) <sup>b</sup>	91	n.r.	n.r.	n.r.	Baron-Cohen et al., 2005
AQ (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001)	21 - 95	20 - 100	$r(\text{ADI-R}) = .18^a$ $r(\text{EQ}) =$ -.39 <sup>a</sup> - .56	$r = .70$	(Ashwood et al., 2016; Baron-Cohen et al., 2001; Bishop & Seltzer, 2012; Kanai et al., 2010; Takei et al., 2014; Wakabayashi, Baron-Cohen, Uchiyama, et al., 2006; Woodbury - Smith et al., 2005)5)
EQ (Baron-Cohen & Wheelwright, 2004).	79 - 81	46 - 88	$r(\text{AQ}) =$ -.39 <sup>a</sup> - .56	$r = .84$	(Baron-Cohen & Wheelwright, 2004; Groen, Fuermaier, Heijer, Tucha, & Althaus, 2015; Kim & Lee, 2010; Lepage, Lortie, Taschereau-Dumouchel, & Théoret, 2009; Wheelwright et al., 2006)

<sup>a</sup> Not significant at  $p < .05$  <sup>b</sup> The AAA comprises the AQ and EQ.

## **Developing a Diagnostic Tool for Adults with Suspected ASD**

Given the variety of assessment tools available to assist with adult ASD diagnoses and their variable psychometric performance across studies, selecting the most suitable is not an easy task. Suitable assessment tools should have two characteristics. First, these tools must be valid, assessing a range of symptoms that present among adults with ASD and that effectively differentiate them from adults without ASD. In the Australian context, assessment tools also need to be consistent with the DSM-5 conceptualisation of ASD that is used for diagnoses. Second, assessment tools must be practical, assisting with gathering accurate information in a user-friendly and efficient manner. The purpose of the present study was to identify limitations within the recommended assessment tools and develop a more appropriate diagnostic tool to assist clinicians in assessing ASD symptoms currently presenting in adulthood. This chapter thus outlines the limitations to the validity and practicality of the recommended assessment tools and how the proposed diagnostic tool was developed to address these limitations.

### **Addressing Limitations to the Validity of the Recommended Assessment Tools**

**The behaviours targeted for assessment.** The recommended assessment tools to assist with the diagnosis of ASD in adulthood all have limitations with regard to their validity and practicality. The primary limitation to the validity of these tools is that the behaviours they target for assessment are not fully representative of those behaviours characteristic of ASD in adulthood. First, many of the recommended assessment measures target behaviour more characteristic of ASD in childhood. For example, the ADI-R, ADOS-G and DISCO contain items that assess whether adults currently use other people as objects or, have difficulty with pretend play or nodding (Carrington et al., 2014; Le Couteur, Lord, & Rutter, 2003). As demonstrated in Study 2 and the broader literature (Carrington et al., 2014; Holmes, 2011), these behaviours do not

appear particularly salient in adulthood. The inclusion of these items is therefore inappropriate for the assessment of adults.

Second, the recommended assessment tools fail to fully address the criteria outlined within the DSM-5. For example, the AAA lacks items to assess Criterion B1 repetitive and stereotypical speech, behaviour and object use. Thus clinicians cannot rely on this tool for a comprehensive understanding of ASD symptoms presenting among adults. Further, the RAADS-R, ADOS, ASDI and the AAA, contain relatively few items characteristic of Criterion B4. The restricted range of behaviours capturing each diagnostic criterion across the aforementioned tools is thus inadequate in providing comprehensive information to inform clinical judgements and diagnostic decisions.

Due to the inclusion of childhood-orientated symptoms and inadequate coverage of diagnostic criteria, symptoms may be overlooked when using some of the recommended tools. These limitations may preclude diagnoses for some individuals with ASD. Thus, the first step in ensuring a tool provides a valid assessment of the presentation of ASD in adulthood is to ensure that it covers the full range of behaviour capturing each criterion in this period of life.

***Improving upon the scope of behaviours assessed.*** To ensure that the proposed tool can be used to evaluate a broader range of behaviours characteristic of ASD in adulthood, items were developed to target these behaviours identified in earlier chapters. In Study 1, behaviours that caused the most severe impairments in adulthood and/or appeared particularly characteristic of ASD in this period of life emerged from the reports of adults with ASD, significant others and clinicians. In Study 2, behaviour presenting with high frequency and diagnostic sensitivity among adults with ASD were identified. Finally, in Study 3, adults with ASD provided accounts of frequently presenting and regularly occurring behaviours characteristic of Domain B. These findings were thus used to select salient behaviour of diagnostic significance.

Given that symptoms varied widely in the frequency and regularity of their expression among adults with ASD (see Studies 1, 2 and 3), salient behaviours were defined as those presenting at least once a month, or among at least 50% of adults with ASD<sup>22</sup>. The behaviours meeting these criteria across earlier chapters targeted in the proposed tool are summarised in Table 34 under the relevant DSM-5 descriptors.<sup>23</sup> The proposed diagnostic tool will thus advance existing tools for ASD assessments by specifically targeting behaviours characteristic of ASD in adulthood across each of the DSM-5 criteria.

Table 34

*Manifestations of DSM-5 Domain A and B Behaviours in Adulthood*<sup>a</sup>

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A1: Deficits in social-emotional reciprocity:

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*Abnormal social approach:*

- Unusually detailed explanations or accounts;
- Need for others to be similarly detailed in their explanations;
- Difficulty changing topics or following multiple conversations;
- Lack of clarity in speech content, e.g. speech is misunderstood or unusually brief
- Difficulty interpreting metaphoric language

*Failure of normal back-and-forth conversation:*

- Challenges maintaining a conversation with appropriate comments or questions;
- Difficulty gauging when to contribute to a conversation

*Reduced sharing of interests, emotions or affect:*

- Difficulty commenting on own or others' emotions;
- Problems finding and discussing mutual interests

*Failure to initiate or respond to social interactions:*

- Prefers to avoid social interactions;
  - Social impairments prevent or discourage the individual from attempting to talk to other people
- 

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<sup>22</sup> In the absence of a frequency criterion for the fulfilment of each DSM-5 criteria, an arbitrary value of 50% was selected. Thus we can conclude that at least half adults with ASD will demonstrate these behaviours.

<sup>23</sup> Italicised (see DSM-5; APA, 2013, p. 50)

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A2: Deficits in nonverbal communicative behaviours used for social interaction

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*Poorly integrated verbal and nonverbal communication:*

- Difficulty giving eye contact while speaking

*Abnormalities in eye contact and body language:*

- Problems conveying emotion through facial expression;
- Unusual or impaired eye contact, e.g. eye contact may be fixed

*Deficits in understanding and use of gestures:*

- Inaccurate interpretation of nonverbal cues such as facial expression, gesture, posture and tone of voice. May not be able to use these cues to determine what other people may be feeling, thinking or, intending to convey;
- Gestures may be absent, unconventional or unusually timed

*Total lack of facial expressions and nonverbal communication:* Not reported

*Absent eye contact:* Not reported

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A3: Deficits in developing, maintaining, and understanding relationships

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*Difficulties adjusting behaviour to suit various social contexts:*

- Social faux pas e.g. rudeness, bluntness, age-inappropriate behaviour, failing to inform significant others about issues of mutual interest.

*Difficulties in sharing imaginative play:*

- Disinterest in fantasy related games;
- Difficulty playing imaginative games with children

*Difficulties in making friends:*

- Limited relationship building social skills, e.g. may infrequently demonstrate acts of friendship such as spending time together;
- Few platonic or romantic relationships;
- Difficulty differentiating between acquaintances and friend;
- Relationships are typically formed and/or maintained in structured settings

*Absence of interest in peers:*

- Social isolation due to the fatigue resulting from the degree of effort required to manage social impairments
- 

B1: Stereotyped or repetitive motor movements, use of objects or speech

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*Simple motor stereotypies:*

- Flapping, finger flicking, hand wringing or twisting; twirling or waving items; mouthing objects, hands, nails or hair; tapping, rubbing or scratching objects or body; tensing muscles, knee jiggling, rocking, bouncing or spinning

*Lining up toys or flipping objects:* Not reported

*Echolalia or idiosyncratic phrases:* Not reported

*Stereotyped speech:*

- Speech characterised by unusual grammar (not attributable to language disorder), tone, pace or style, e.g. pedantic
-

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B2: Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour

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*Extreme distress at small changes:*

- Changes include adopting a novel approach to an activity, managing the removal of structured activities, disruption to patterns or continuity in factual, verbal or visual information
- Distress may be emotional and/or behavioural, e.g. the individual may become anxious or frustrated or have difficulty accommodating the change

*Difficulties with transitions:*

- Problems switching activities, may experience emotional and/or behavioural distress as above

*Rigid thinking patterns:*

- Black and white thinking,
- Strict adherence to rules

*Greeting rituals:*

- Not reported. Verbal and nonverbal rituals may however manifest as ordering or, verbal listing

*Need to take same route or eat same food everyday:*

- Elaborate routines / plans that must be followed and may interfere with relationships and activities of daily living
- In addition to travelling and eating, routines may extend to bathing, preparing for the day ahead and end of day tasks

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B3 Highly restricted, fixated interests that are abnormal in intensity or focus

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*Strong attachments to or preoccupation with unusual objects:* Not reported

*Excessively circumscribed or perseverative interests:*

- Investing significant concentration and/or time in an area of interest, e.g. gathering facts, keeping lists, gaming

Interests may interfere with relationships, activities of daily living and/or cause distress when interrupted

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B4 Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment

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*Apparent indifference to pain / temperature:*

- Tolerating excessive pain, e.g. may not notice injuries, can tolerate high temperatures
- Hyper-reactive responses to pain, e.g. pain is unusually persistent or disproportionate to injury<sup>a</sup>

*Adverse response to specific sounds or textures:*

- Being unusually aware or bothered by sensations, e.g. high pitched noise, faint noise, clothing texture, food texture
- Emotional distress or avoidance of challenging auditory environments which may affect social relationships

*Excessive smelling or touching of objects:*

- Seeking out deep pressure or touching fabrics
- Being unusually aware of or bothered by particular scents, e.g. perfumes, smoke, food<sup>a</sup>

*Fascination with lights or movement:*

- Being unusually aware or bothered by sensations, e.g. lights or colour
- Seeking out vestibular sensations, e.g. spinning, fidgeting
- Difficulties processing vestibular information resulting in lack of co-ordination, balance and motion sickness<sup>a</sup>

Hyper- or hypo-reactivity to gustatory stimuli,<sup>b</sup>

- May be unusually sensitive or indifferent to spicy, salty, sweet or bitter food. May prefer bland food.
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<sup>a</sup> American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: Author.

<sup>b</sup> Not a specific subdomain of the criterion but associated within the broader DSM-5 definition of the criterion

While Table 34 summarises a range of behaviour characteristic of ASD in adulthood, earlier chapters did not provide information about every descriptor for the DSM-5 criteria. For example, the data gathered from earlier chapters suggested that Criterion B1, specifically repetitive use of objects, posed little significance to adults and thus there are few accounts of these behaviours in Table 34. Nonetheless, to ensure the comprehensiveness of the instrument, items were also developed to address manifestations of the DSM-5 criteria not elucidated earlier.

**The diagnostic algorithms of the recommended assessment tools.** With the exception of the DISCO, none of the diagnostic cut-off scores for the recommended assessment tools used to assist in determining the presence of ASD, are linked to the DSM-5 criteria. Only the DISCO algorithm can be used to support a DSM-5 diagnosis of ASD because cut-off scores are provided for each of the seven diagnostic criteria (Carrington et al., 2014). In contrast, the diagnostic algorithms of the AAA, RAADS-R, ADOS-G, ADI-R and ASDI do not provide cut-off scores that allow clinicians to readily determine which of these criteria have been met. Instead, these algorithms inform clinicians about the extent of symptoms overall (AQ: Baron-Cohen et al., 2008; RAADS-R: Ritvo et al., 2011), the extent of symptoms within Domain A and Domain B (Lord et al., ADOS-G; 2000, ADI-R; 1994) or, whether each of the Gillberg Criteria for Asperger's Syndrome have been met (ASDI: Gillberg et al., 2001).

In Australia, the DSM-5 conceptualisation of ASD is used to guide diagnostic decision-making. Therefore, it is important that clinicians use assessment tools that assist them in identifying whether the required DSM-5 criteria have been met. The tool developed for this study includes a DSM-5 compliant diagnostic algorithm modelled on that of the DISCO (Carrington et al., 2014). Specifically, diagnostic cut-off scores will be developed to allow clinicians to readily determine whether the necessary combination of Domain A and Domain B diagnostic criteria have been met.

**Scoring systems.** While it is important that assessment tools correctly identify persons meeting the DSM-5 criteria for ASD, they must also correctly identify persons without ASD. It is understood that typically developing individuals may present with one or two behaviours characteristic of Domain B (Barrett et al., 2015; Harrop et al., 2013). In contrast, individuals with ASD present with multiple examples of repetitive behaviours, routines, interests or hyper- or hypo-reactive sensory responses that present several times a week or more (see Study 3; APA, 2013; Barrett et al., 2015; Harrop et

al., 2013). The quantity and regularity of Domain B behaviours presenting among adults with ASD thus appears useful for differential diagnosis. Nonetheless, the recommended assessment tools do not consistently operationalise Domain B impairments as numerous or regularly presenting. For example, tools such as the AQ, ASDI and RAADS-R do not require respondents to consider the quantity or regularity of symptoms when indicating whether Domain B impairments are present. Thus many of the scoring systems within the recommended assessment tools have limitations in how they operationalise behaviour consistent with Domain B which may affect their specificity. In the present study, the scoring system for the proposed tool will thus emphasise the quantity and regularity of behaviour presenting for each Domain B criterion.

### **Addressing Practical Limitations to the Recommended Assessment Tools**

While it is important that the proposed tool provides a valid measure of ASD in adulthood it must also be practical. The recommended tools assist clinicians in gathering information about the manifestation and severity of symptoms. However, the format and requirements of the three types of recommended assessment tools: clinical interviews, behavioural observation measures and self-report questionnaires pose a number of practical limitations.

**Clinical interviews.** The literature highlights that collecting information from caregivers using the recommended clinical interviews, the ADI-R, ASDI and DISCO, presents various practical difficulties. These tools are typically used to gather information about symptoms presenting in early life but are time consuming to administer, taking up to three hours to complete (Lord et al., 1994; Wing et al., 2002). They may thus be impractical for clinicians in private practice who have a median of two 90-minute sessions to assess symptoms and discuss the diagnostic outcome (Taylor et al., 2016). Accessing caregivers or other relatives who can provide comprehensive

and accurate retrospective accounts of symptoms is also particularly difficult for adults (Pijnacker, Hagoort, Buitelaar, Teunisse, & Geurts, 2009). Indeed, in Study 1, many of the adults with ASD who were willing to recruit a parent or significant other were unable to do so ( $n = 23$ ) and one individual had no such informants available to them. Consequently, in many instances the recommended clinical interviews used to gather information from caregivers may not be practical due to time constraints or difficulties accessing other informants. Given these difficulties, the proposed diagnostic tool does not draw upon the reports of caregivers or other relatives. Participants will thus be asked if impairments presented in childhood to confirm that impairments presented in earlier life.

**Behavioural observation.** Behavioural observation tools may offer clinicians a more practical alternative to assessment tools intended for use with caregivers. These behavioural observation tools are designed to elicit symptoms characteristic of ASD through activities led by the clinician and provide valuable insight into current symptom manifestation in daily life. However, these tools have practical limitations. First, the recommended behavioural observation tool, the ADOS-G, is not age-appropriate for adults. This tool contains childish activities that include reading from children's storybooks and miming teeth brushing (Lord, Rutter, DiLavore, & Risi, 2009) which adults with ASD may find condescending or inappropriate (Holmes, 2011; NICE, 2012b). A more age-appropriate means of behavioural observation is thus required.

Second, the ADOS-G can be impractical for eliciting information about particular symptom domains. While this measure is effective in eliciting information about many symptoms consistent with Domain A (Hus & Lord, 2014), Domain B symptoms, particularly those characteristic of Criterion B1: repetitive behaviour, are difficult to assess using this tool. Behaviours characteristic of this criterion present infrequently in adulthood and usually only in private settings (APA, 2013; see Chapter

4), so are unlikely to present in situ throughout the course of an assessment. Indeed, the test authors of the ADOS-G, caution against relying on behavioural observation alone to assess Domain B (Lord et al., 2000). Similarly, behavioural observation may be ill-suited to assessing some aspects of Domain A in adulthood, namely the development and maintenance of relationships. Indeed, the ADOS-G assesses these symptoms via interview. An alternative to behavioural observation is required to more reliably gather information about Domain B and some aspects of Domain A in adulthood.

**Self-Reporting.** Collecting information about the manifestation and severity of symptoms through self-reporting may be a useful adjunct to behavioural observation for clinicians. The recommended self-report questionnaires, the AAA (Baron-Cohen et al., 2005) and RAADS-R (Ritvo et al., 2011), present adults with descriptions of symptoms. Respondents then rate the course of these symptoms across the lifespan and/or how strongly they apply to them. This assessment approach may be particularly useful for evaluating symptoms less practical to assess through behavioural observation such as Domain B impairments and the aforementioned aspects of Domain A ill-suited to behavioural observation in adulthood.

Despite the value of the recommended self-report tools, they too have practical limitations in assisting with ASD diagnoses. The key limitation of these tools is that adults with ASD find them difficult to complete (Holmes, 2011; NICE, 2012b). Researchers have speculated that these difficulties arise due to the need to reflect on social cues and norms to judge whether one's social skills and/or behaviour is unusual (Johnson, Filliter, & Murphy, 2009). Difficulties interpreting social cues and norms are characteristic of ASD (Happé, 1994; Howlin, 2004) and thus, it has been hypothesised that self-report tools may be impractical. Nevertheless, studies suggest that having ASD does not preclude accurate self-reporting and adequate agreement about the manifestation of symptoms in adulthood has been reported between adults

with ASD and their caregivers (Ashwood et al., 2016; Baron-Cohen et al., 2001; Wakabayashi et al., 2006; see Study 1). Further, Domain A related symptoms including the ability to interpret social cues, do not predict differences in the extent of symptoms reported by adults with ASD using the AAA and RAADS-R, in comparison to their clinicians or caregivers (Holmes, 2011).

Instead, it appears that the format of the recommended self-report tools may account for difficulties in completing these measures. Clinicians and adults with ASD report that adults with ASD experience difficulties interpreting rating scales and judging whether their symptoms match the descriptions provided. For example, the use of double negatives and agree/disagree scales can be confusing (Bishop & Seltzer, 2012; NICE, 2012b). Likewise, symptoms manifesting in the manner described but not with the frequency, severity or course specified are also difficult to rate using these tools (Holmes, 2011). Some items may also be interpreted in a way that was not originally intended. For example, anecdotally, adults report interpreting the AQ item “I am fascinated by dates” as fascination with romantic dates, the edible fruit or, calendar dates (Holmes, 2011). Difficulties knowing how best to rate symptoms may result in valuable information about the course and manifestation of symptoms being overlooked. A means of self-reporting that does not require adults to judge whether their behaviour is unusual relative to their typically developing peers is required.

### **Developing the Proposed Diagnostic Tool**

As summarised in Table 35, validity and practicality are of concern in the recommended assessment tools. Of the three clinical interviews: the ADI-R, ASDI and DISCO, none assesses each DSM-5 criterion as it presents in adulthood, instead featuring items that focus on childhood presentation. Further, while the format of the interviews are age-appropriate, only the ASDI can be administered in an hour or less and only the DISCO has been modified for administration to adults with suspected ASD

should a caregiver be unavailable. The recommended behavioural observation tool, the ADOS-G is likewise limited in a number of ways. First, by its diagnostic algorithm which is not compliant with the DSM-5, second by its age-inappropriate activities and third because it requires the demonstration of Domain B behaviours that may not be demonstrated in situ. Finally the two self-report tools: the AAA and RAADS-R, are limited by their diagnostic algorithms and difficulties interpreting items and response scales.

Table 35

*The Validity and Practicality of the Tools Recommended for Adult ASD Assessments*

	Validity			Practicality		
	Assesses each DSM-5 criterion as it presents in adulthood	Has a DSM-5 Algorithm	Considers the quantity and regularity of Domain B behaviours	Time efficient	Age appropriate	User friendly <sup>a</sup>
ADI-R	x	x	✓	x	✓	x
ASDI	x	x	x	✓	✓	x
DISCO	x	✓	? <sup>b</sup>	x	✓	✓
ADOS-G	✓	x	✓	✓	x	x
AAA	x	x	x	✓	✓	x
RAADS-R	✓	x	x	✓	✓	x

<sup>a</sup> Target respondents are accessible; measure is accessible, easy to interpret and reliably assesses each domain

<sup>b</sup> The nature of the DISCO scoring system could not be clarified as it is not explicitly described in the available literature neither can clinicians purchase the tool unless they have completed the requisite training which is not offered in Australia.

Each of the recommended assessment tools has strengths and limitations but none provide a suitable, valid and practical assessment of both Domain A and B in adulthood. A diagnostic tool that is both valid and practical is needed to assist clinicians in assessing the manifestation and severity of impairments currently presenting among adults with suspected ASD. The present chapter therefore sought to develop a battery of assessment activities that would reflect the strengths of the recommended tools and address their limitations to target each of the DSM-5 criteria as they present in adulthood. Specifically, age-appropriate and user-friendly behavioural observation and self-reporting activities were developed to assess behaviours characteristic of Domain A and B in adulthood that would contribute to a DSM-5 compliant diagnostic algorithm. The rationale and development of the behavioural observation and self-reporting activities are discussed below. Further information about each component of the proposed diagnostic tool is provided in the Method. An example item from each component of the diagnostic tool may also be found in Appendix D.

**Behavioural observation component of the proposed tool.** Role-plays and vignettes were chosen to assist clinicians in gathering information about Domain A and some aspects of Domain B through behavioural observation. These activities were selected for two reasons. First, they do not rely on childish materials and can easily be adapted to reflect social interactions in adulthood to ensure their age-appropriateness. Second, existing role-play and vignette measures have been successful in highlighting impairments across Domain A among adults with ASD (Dziobek et al., 2006; Heavey, Phillips, Baron-Cohen, & Rutter, 2000; Mathersul, McDonald, & Rushby, 2013; Ponnet, Buysse, Roeyers, & De Clercq, 2008; Ratto, Turner-Brown, Rupp, Mesibov, & Penn, 2010; Verhoeven, Smeekens, & Didden, 2013). The role-play measures and vignettes in the proposed tool were modelled on those in the existing literature but adapted in a number of ways to improve their validity and practicality as discussed

below.

**Role-Plays.** Two role-play tasks have been described in the ASD literature: the Contextual Assessment of Social Skills (CASS; Ratto et al., 2010) and the Social Skills Performance Assessment (SSPA; Patterson, Moscona, McKibbin, Davidson, & Jeste, 2001). These tools require the examiner to role-play a scripted character with which the examinee interacts. These tools reportedly elicit Criterion A1 impairments in maintaining a conversation with appropriate questions and comments and Criterion A2 difficulties in the use of nonverbal communication (Ratto et al., 2010; Verhoeven et al., 2013). However, neither the CASS nor the SSPA reliably capture impairments in nonverbal communication (Ratto et al., 2010).

The role-plays in the proposed diagnostic tool were thus loosely modelled on the CASS and SSPA but extended to assess every manifestation of Criteria A1 and A2 in adulthood. In the proposed tool, the researcher role-plays a series of scripted characters with which the participant interacts and presents opportunities to ask questions and make comments as in the aforementioned tasks. However, these role-plays differ from those within the CASS and SSPA in a number of ways. Rather than relying on social interactions to prompt nonverbal communication as in the CASS (Ratto et al., 2010), props and demonstration activities were embedded within the role-plays in the proposed tool to assess Criterion A2. This approach was loosely modelled on the ADOS-G (Lord et al., 2009) though the props and demonstration activities were adapted to ensure age-appropriateness. For example, rather than mime teeth brushing, participants will be invited to demonstrate how to operate a DVD player in the absence of any props. The role-plays within the proposed diagnostic tool were thus designed to be sensitive to each of the manifestations of Criteria A1 and A2 characteristic of ASD in adulthood described in Table 34. Table 36, provides examples of how the role-plays were developed for the proposed tool to target behaviours known to present among adults

with ASD. Further information about scoring is provided in the Method.

Table 36

*A Selection of Role-Play Tasks In the Proposed Tool Targeting DSM-5 Behaviour*

Role-play task	DSM-5 Behaviour targeted <sup>24</sup>
<p><b>Bus passenger</b></p> <p>The researcher poses as a bus passenger having a bad day. The researcher then evaluates the participant's use of appropriate comments and questions in responding to the 'bus passenger.'</p>	<p><b>Criterion A1:</b></p> <p>Abnormal social approach; failure of normal back-and-forth conversation; reduced sharing of interests, emotion or affect; failure to initiate or respond to social interactions.</p>
<p><b>DVD player</b></p> <p>The researcher poses as an employee with limited experience using a DVD player who requires help understanding how to remove and insert a DVD. The researcher then evaluates whether the participant explained to the 'employee' how to do so in appropriate detail and whether they used conventional gestures, e.g. for pressing buttons, holding a DVD or ejecting the DVD tray</p>	<p><b>Criterion A1:</b></p> <p>Abnormal social approach; failure of normal back-and-forth conversation</p> <p><b>Criterion A2:</b></p> <p>Poorly integrated verbal and nonverbal communication; abnormalities in body language; deficits in understanding and use of gestures; total lack of facial expression and nonverbal communication</p>

### Vignettes

Vignettes were also created to elicit and thus observe Domain A behaviours. In particular, dynamic stimuli (i.e. filmed vignettes) were created as they are known to be more effective than static stimuli in eliciting impairments in understanding nonverbal communication, social relationships and social etiquette (Ponnet et al., 2008; Roeyers, Buysse, Ponnet, & Pichal, 2001). Various filmed vignettes have been used for this purpose among adults with ASD in the literature including the Movie for the Assessment of Social Cognition (MASC; Dziobek et al., 2006), the Awkward Moments

<sup>24</sup> The relevant DSM-5 descriptors are listed here (c.f. DSM-5; APA, 2013, p. 50)

Test (Heavey et al., 2000), The Awareness of Social Inference Test (TASIT; Mathersul et al., 2013) and an empathic accuracy task developed by Ponnet et al. (2008). Each of the filmed vignettes used in the aforementioned tasks depict real or scripted social interactions, providing examinees with verbal and non-verbal social cues they must then use to interpret characters' emotions, thoughts, feelings, motives and/or the social appropriateness of behaviour. These judgements provide in situ accounts of impairments in emotional reciprocity, understanding nonverbal cues and social relationships and social norms characteristic of Domain A in adulthood (Dziobek et al., 2006; Heavey et al., 2000; Mathersul et al., 2013; Ponnet et al., 2008).

While filmed vignettes have been used to assess Domain A in the broader literature, it is recognised that these tasks may have limitations. First, these tasks require examinees to track multiple characters across scenes and differentiate between them (Dziobek et al., 2006; Heavey et al., 2000). Difficulties with face recognition are considered a comorbid feature of ASD and are commonly reported among these adults (Cook, Shah, Gaule, Brewer, & Bird, 2015; Kirchner, Hatri, Heekeren, & Dziobek, 2011; O'Hearn, Schroer, Minshew, & Luna, 2010). Problems with facial recognition may impair examinee's ability to respond to filmed vignette tasks, making it difficult to discriminate impairments in facial recognition from Domain A related impairments. Thus, a means of identifying and accommodating potential difficulties with face recognition are required so that filmed vignettes may be reliably used to assist behavioural observation of Domain A.

Second, problems arise with the use of response scales within these tasks and other tasks that likewise assess understanding of nonverbal cues, social relationships and etiquette. When invited to identify emotional expressions or socially inappropriate behaviours, adults with ASD are often presented with multiple choice response scales (Golan, Baron-Cohen, & Hill, 2006; Golan, Baron-Cohen, Hill, & Rutherford, 2007;

Zalla, Sav, Stopin, Ahade, & Leboyer, 2009). These scales increase the likelihood of guessing the correct answer, do not appear sensitive to Domain A impairments in adulthood and, provide limited information to clinicians about the nature of one's impairments (Channon, Crawford, Orłowska, Parikh, & Thoma, 2013; Golan et al., 2007; Zalla et al., 2009). Indeed, some adults with ASD appear to 'pass' some assessments of social etiquette that use dichotomous response scales by always responding that the behaviour is socially inappropriate rather than appropriate (Zalla et al., 2009). Only when asked to justify their selections do impairments in social understanding manifest (Zalla et al., 2009). Response scales that are more sensitive to impairments, less susceptible to response biases and that reduce the likelihood of correct guessing are required to assess Domain A impairments more effectively.

The vignette activities within the proposed tool present participants with films that depict multiple characters interacting in various social contexts. These films require participants to consider characters' facial expressions, tone of voice, gestures and body language to judge their likely thoughts, feelings, motives and the appropriateness of their behaviour. However, these activities were designed to address the limitations of existing behavioural observation tasks: facial recognition difficulties, response biases and age-inappropriateness.

First, to identify and address potential problems with facial recognition, comprehension questions about character identities and labelled pictures of characters will be provided to participants. Second, to ensure less susceptibility to response biases, participants will be invited to describe the emotions, thoughts and/or social appropriateness of the characters depicted and to justify these responses. A control vignette was also included to assist in identifying possible response biases. Specifically, participants view a film in which no socially inappropriate behaviour occurs and are asked to rate the appropriateness of characters' behaviour. Whether

participants identify socially inappropriate behaviour when not present, can be identified. Third, to ensure age-appropriateness, the vignettes were designed to reflect the social demands of adult life. In particular the contexts in which adults with ASD reported experiencing social impairments are targeted such as the workplace or group settings. Table 37 provides an example of how the vignettes were developed for the proposed tool to target Domain A behaviours. Further information about scoring is provided in the Method.

Table 37  
*A Selection of Vignettes Tasks Developed for the Proposed Tool to Target DSM-5 Behaviour*

Vignette task	DSM-5 Behaviour targeted <sup>25</sup>
<p>Office workers</p> <p>An employee arrives for her first day at work and is greeted by her new officemate. She is not paying attention to the colleague and replies, “good thanks, I’m Emma,” despite not being asked how she was feeling.</p> <p>The researcher evaluates whether the participant can correctly identify how appropriately Emma handled the conversation and adequately justify their answer.</p>	<p>Criterion A1: Abnormal social approach</p>
<p>Customer service</p> <p>A patient arrives an hour early to his doctor’s appointment and takes out his frustration on the receptionist, i.e. huffing, making gestures to hurry her along, using curt speech and walking off without replying to the receptionist saying goodbye.</p> <p>The researcher evaluates whether the participant can correctly identify how the customer is feeling and adequately justify their answer using nonverbal cues.</p>	<p>Criterion A2: Deficits in the understanding and use of nonverbal cues</p>

Other behavioural observation items. Other activities and items were developed for the proposed tool to gather information about ASD symptoms from Domain B presenting in situ. At this time, no behavioural observation activities specifically

<sup>25</sup> The relevant DSM-5 descriptors are listed here (c.f. DSM-5; APA, 2013, p. 50)

developed to elicit Domain B behaviours among adults are reported within the published literature. The present study thus developed activities for this purpose, guided by understanding of Domain B behaviours. These are summarised in Table 34. Specifically, activities were designed that required participants to demonstrate Domain B behaviours. Further, in a similar manner to the ADOS-G (Lord et al., 2009), items were developed to allow the researcher to rate Domain B behaviours observed across the assessment session. In contrast to the ADOS-G, these items targeted only Domain B behaviours that adults with ASD report arise in public settings with some regularity as established in earlier chapters, for example stereotyped speech. Table 38, provides examples of how activities were developed for the proposed tool to target Domain B behaviours known to present among adults with ASD.

Table 38

*A Selection of Behavioural Observation Tasks Developed for the Proposed Tool to Target DSM-5 Behaviours*<sup>a</sup>

Behavioural observation item	DSM-5 behaviours targeted <sup>26</sup>
<p>Observations of repetitious or stereotyped speech:</p> <p>The researcher rates the extent of unusual speech features presenting across the assessment period. These behaviours include neologisms and repetitious phrases.</p>	<p>Criterion B1: Echolalia or idiosyncratic phrases; stereotyped speech</p>
<p>Presenting an argument:</p> <p>Participants are invited to indicate whether they support government control of free speech and why. They must then provide an argument for the opposing view.</p> <p>The researcher then rates their ability to independently generate a counter-argument.</p>	<p>Criterion B2: Rigid thinking patterns</p>

Though Criteria B3 and B4 behaviours present regularly in adulthood (see Study 3), behavioural observation activities were not developed to assess these criteria for several reasons. First, earlier chapters and the broader literature provide few examples

<sup>26</sup> The relevant DSM-5 descriptors are listed here (c.f. DSM-5; APA, 2013, p. 50)

of how such behaviour may be elicited through behavioural observation. Second, adults with ASD reported that sensory hyper-reactivity can be particularly painful and may lead to sensory shutdown, thus exposure to such stimuli was not considered ethical or appropriate.

**Self-reporting component of the proposed tool.** Self-reporting was chosen as an adjunct to behavioural observation for the proposed tool as it is more practical for assessing Domain B and to supplement the behavioural observation of Domain A. An interview to be administered by clinicians or researchers and a self-administered questionnaire were created for this purpose. The interview assesses each manifestation of Domain B outlined within the DSM-5. The questionnaire assesses Criterion A3: difficulty developing and maintaining relationships. The questions for the interview and the questionnaire were modelled on prompts that proved effective in collecting similar information from adults with ASD in Studies 1, 2 and 3, for example, ‘Have you engaged in any of the following repetitive movements at least once a month?’<sup>27</sup> Was this true for you as a child?<sup>28</sup>

To ensure that self-reporting is user-friendly, participants will be presented with explicit qualitative examples of how symptoms typically manifest among adults with ASD via interview and questionnaire. Participants then confirm whether they experience the symptoms described, and if so, provide further detail about the regularity, manifestation and impact of these symptoms on everyday life where appropriate. The researcher or clinician can then use this information to judge whether the behaviours described are characteristic of ASD. Example items from the interview and questionnaire are described in Table 39.

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<sup>27</sup> The criterion of behaviour presenting once a month was chosen because in earlier chapters adults with ASD were able to report about the nature of behaviours presenting with this frequency in sufficient detail and indicated that these behaviours caused clinically significant impairments in their everyday life.

<sup>28</sup> These probes about childhood presentation were used to confirm manifestation of symptoms in early life.

Table 39

*A Selection of Self-Report Tasks for the Proposed Tool Targeting DSM-5 Behaviour*

Self-report items	DSM-5 behaviours targeted <sup>29</sup>
<p style="text-align: center;">Questionnaire: Maintaining friendships</p> <p>As part of the questionnaire participants report about their relationship with their closest friend. They are asked to describe the regularity with which they perform socially reciprocal behaviours that assist in maintaining friendships e.g. ringing the person to chat, offering help or support, inviting them to their home for a meal, doing the friend a favour etc.</p> <p>The researcher then rates the degree to which the participant is able to engage in socially appropriate behaviours that maintain friendships.</p>	<p>Criterion A3: Difficulty maintaining relationships; absence of interest in peers.</p>
<p style="text-align: center;">Interview: Interests</p> <p>Participants are asked whether they have engaged in a range of interests and with what degree of regularity. For interests presenting in adulthood, they are also asked to explain how being disrupted from pursuing them may affect how they feel, their social relationships and responsibilities.</p> <p>The researcher then rates the intensity of the interests according to their quantity, regularity and adverse impact.</p>	<p>Criterion B3: Highly fixated interests abnormal in their intensity</p>
<p style="text-align: center;">Interview: Sensory Responses</p> <p>The researcher describes specific types of hyper- and hypo-reactive sensory responses that present among adults with ASD and invites participants to indicate whether these or similar behaviours present for them e.g. noticing sounds before others do such as the hum of electrical lights; apparent indifference to temperature or pain; seeks out particular tactile sensations such as soft fabric.</p> <p>The researcher then rates the scope of these sensory responses according to the number of hyper- or hypo-reactive responses presenting.</p>	<p>Criterion B4: Hyper-or hypo-reactivity to sensory input; unusual interest in sensory aspects of the environment</p>

<sup>29</sup> The relevant DSM-5 descriptors are listed here (c.f. DSM-5; APA, 2013, p. 50)

## Summary

Clinicians assessing adults with suspected ASD must determine the course, manifestation and severity of impairments experienced by these individuals. A range of assessment tools has been recommended to assist with gathering this information. While each of these tools has strengths in assessing Domain A and B behaviours in adulthood, they also have limitations to their practicality and/or validity. The present study developed a battery of activities that draw upon the strengths of existing tools and address their limitations to provide a valid, practical and comprehensive assessment of currently presenting symptoms characteristic of ASD in adulthood.

## Method

### Participants

A university research participation pool and a database of people with ASD were used for recruitment.<sup>30</sup> Participants were 33 adults with ASD (20 males, 13 females) and 44 typically developing (TD) adults (14 males, 30 females). Participants were assigned to the ASD or TD group. ASD diagnoses were verified by confirmation that one or more health practitioners trained in ASD assessment had made the diagnosis. Approximately half the participants with ASD ( $n = 14$ ) had been diagnosed in adulthood. Information about diagnostic classification was available for most participants (Asperger's disorder:  $n = 17$ ; ASD:  $n = 7$ ; autistic disorder:  $n = 1$ ). For persons who reported that they had not been diagnosed with ASD, inclusion within the TD group was verified by scoring below the ASD cut-off score on the RAADS-R. Five males and seven females from the TD group scored above the RAADS-R ASD diagnostic cut-off score ( $n = 12$ ). These individuals were assigned to a third participant group: 'Other.' The participant characteristics for each group are reported in Table 40.

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<sup>30</sup> Individuals given a formal diagnosis of ASD via a health professional trained in autism assessment were invited to join the database to be informed about research projects. Advertisement occurred via mail-outs and flyers.

Table 40  
Participant Characteristics

	ASD (N = 33)		TD (N = 32)		Other (N = 12)	
	<i>M(SD)</i>	Range	<i>M(SD)</i>	Range	<i>M(SD)</i>	Range
Age (years)	31.27 (14.15)	18 - 63	27.09 (11.38)	18-61	20.58 (4.62)	18 - 32
VCI	105.48 (14.52)	70 - 143	102.41 (11.64)	80 - 128	100.75 (7.36)	91 - 114
PRI	105.67 (13.88)	79 -126	104.66 (12.73)	71 - 131	105.75 (9.73)	92 - 124
FSIQ	106.42 (14.27)	86 - 132	104.09 (11.96)	78 - 127	103.75 (8.34)	93 - 117
RAADS-R	166.29 (42.47)	42 - 236	32.41 (14.51)	7 - 60	90.83 (16.36)	69 - 124

*Note.* ASD: 20 males, 13 females; TD: 9 males, 23 females; Other: 5 males, 7 females

To determine that variables not thought to underpin ASD were consistent across the groups, further analyses were performed. The typically developing adults did not significantly differ in age or intellectual ability from the adults with ASD. A greater proportion of participants were female in the TD group than the ASD group  $\chi^2(1, N = 65) = 6.94, p < .01, \Phi = .33$ . Mean intellectual ability, age and proportions of female participants were comparable between the TD and ‘other’ groups. However, the ‘Other’ group had lower Mean RAADS-R scores,  $t(38) = -8.10, p < .001$ , Cohen’s  $d = 2.35$ , and were younger than individuals in the ASD group,  $t(38) = -3.82, p < .001$ , Cohen’s  $d = 1.02$ .

## Measures

**Tools for verifying diagnoses.** Two tools were initially used to verify the self-reported absence of ASD. The first tool, the 80-item Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R; Ritvo et al., 2011), evaluates the presence and longevity of ASD symptomatology across the lifespan across four subscales: social relatedness, circumscribed interests, language and sensory motor. Total scores range from 0 to 140. Higher scores reflect more numerous restricted, repetitive behaviours and social and

communication difficulties and scores of 65 or greater support an ASD diagnosis. Items are typically rated according to whether the behaviour is present across the lifespan, only in childhood, only in adulthood or never.

The 50-item Autism Spectrum Quotient (AQ: Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) was also used to assess attention switching, attention to detail, communication and imagination. This measure presents participants with statements regarding their behaviour, experiences and partialities that they then rate according to whether they definitely or slightly agree or disagree. Total scores range from 0 to 50, higher scores signify more ASD traits and individuals who score 32 or above likely have ASD.

Evaluations of the psychometric properties of these self-report tools were guided by recommendations for screening tools (Cicchetti, 1994; Glascoe, 2005) where sensitivity is ideally 70%, specificity, 80% and internal consistency at an alpha level of .8 or higher. Among the TD adults and adults with ASD, the RAADS-R performed with appropriate sensitivity (93.3%) and specificity (100%) in the present study. Treating individuals in the 'other' group as TD reduced specificity to 72.7%. The internal consistency of the RAADS-R was appropriate for the total scale ( $\alpha = .98$ ) and most subscales (language  $\alpha = .62$ ; circumscribed interests  $\alpha = .85$ ; sensory motor  $\alpha = .85$ ; social relatedness  $\alpha = .95$ ).

In contrast, the AQ performed with appropriate specificity (100%) but poor sensitivity (41.4%) among the TD and ASD groups in the present study. Relaxing the diagnostic cut-off score from 32 to 26 as suggested by Woodbury-Smith et al. (2005) resulted in only minor improvements to sensitivity (58.6%). Specificity did not change when treating individuals in the 'other' group as TD. The internal consistency of the AQ was appropriate for the total scale ( $\alpha = .91$ ) but varied somewhat across the subscales (imagination  $\alpha = .57$ ; attention to detail  $\alpha = .71$ ; attention switching  $\alpha = .77$ ;

communication  $\alpha = .81$  and social skill  $\alpha = .83$ ). Given the poor sensitivity of the AQ, it was excluded from further analyses and was not used to verify diagnostic status.

**The Wechsler Abbreviated Scale of Intelligence.** The Wechsler Abbreviated Scale of Intelligence - Second Edition (WASI-II) was used to provide an index of intellectual functioning. This measure assesses verbal comprehension and perceptual reasoning abilities (Wechsler, 2011). WASI-II scores were used to confirm the absence of intellectual disability and to examine the relationship between IQ and ASD symptomatology evaluated using the proposed tool.

**The Autism Detection in Adult Populations Tool.** The Autism Detection in Adult Populations tool (ADAPT) was created for the purposes of this study. It is intended for use by psychologists to assist in evaluating currently presenting ASD symptoms across Domain A and B among adults without comorbid intellectual disability. The ADAPT has four components: role-plays, vignettes, a questionnaire and interview as described below. Each item within the ADAPT was coded according to the DSM-5 criterion it best represented, using the same coding system reported in Study 2 and verified independently by a clinician trained in ASD assessments (see Results). An example activity for each component of the ADAPT is described in Appendix D. The diagnostic algorithm is discussed in further detail within the results.

### **Behavioural Observation Components of the ADAPT**

**Role-Plays.** The ADAPT includes five role-plays designed to assess symptomatology within DSM-5 Criterion A1 and A2. Each role-play provides the researcher with a script to portray a character one might encounter in daily life e.g. a talkative bus passenger or an unhelpful sales assistant. Participants are invited to interact with each character as they would if they had encountered them in their daily lives. The researcher then uses these activities to consider the participant's use or understanding of gestures, their ability to engage in a reciprocal conversation, to

respond to others' emotions and interpret metaphoric language. All role-play items are scored according to the participant's degree of difficulty in the aforementioned areas using the following scale: 0: Unimpaired, 1: Mild impairment and 2: Marked impairment. Higher scores are indicative of greater impairment i.e. poorer conversational skills or more limited or atypical gesture use. Appendix D describes an example role-play and the types of behaviour attracting scores of 0, 1 or 2.

**Vignettes.** The seven vignettes within the ADAPT assess symptomatology within DSM-5 Criterion A. Each vignette comprises a short film depicting common events such as interacting with work colleagues. The vignettes are embedded with questions about the appropriateness or awkwardness of the social interaction depicted and/or the likely thoughts and feelings of characters. To aid participants with their facial recognition, labeled pictures of vignette characters are provided. A Likert Scale with five anchors: not at all; slightly; somewhat; moderately or very, is used to facilitate ratings of the extent to which the behaviour depicted is appropriate or awkward. Participants are then invited to justify their responses. Comprehension and control questions are included so factual misunderstandings such as characters' names may be corrected and response biases identified. All vignette items are scored according to the participant's degree of difficulty in identifying emotions or judging social etiquette using the following scale: 0: Unimpaired, 1: Mild impairment or, 2: Marked impairment. Appendix D provides the reader with a web link to one of the ADAPT vignettes and describes the types of behaviour that attract scores of 0, 1 or 2.

**Other behavioural activities.** Items were developed to assist in gathering information about Domain B symptoms presenting in situ. First, to assess stereotyped or repetitive speech characteristic of Criterion B1, researchers consider whether repetitious words, sounds, phrases, neologisms or mispronunciations were observed over the course of the assessment. This item is scored by the researcher as either 0: No

repetitious or stereotypical speech, 1: One instance of repetitious or stereotypical speech or, 2: Multiple examples of repetitious or stereotypical speech. Second, to assess rigid thinking patterns characteristic of Criterion B2, participants are asked whether it is ever appropriate for the government to stop people saying what they want to and to justify their answer. They are then asked to provide a counter argument about why it may or may not be appropriate to do so. This item is then rated according to the participant's ability to independently generate a counter-argument to their personal opinion using the following scale: 0: Unimpaired, 1: Mild impairment (i.e. requires assistance of prompting) or 2: Marked impairment (i.e. cannot generate a counter-argument).

### **Self-Reporting Components of the ADAPT**

**Questionnaire.** Participants independently complete a questionnaire as part of the ADAPT that is designed to assess DSM-5 Domain A. The questionnaire is divided into three parts. Part A presents participants with a social etiquette scenario for which they must indicate how they would respond and why. Part B consists of questions about the participant's friendships and Part C their romantic relationships. The researcher uses the information gathered in the questionnaire to rate differing aspects of the participant's social communication and interaction difficulties. All items are scored 0: Unimpaired, 1: Mild impairment or, 2: Marked impairment, with higher scores being indicative of more superficial relationships and limited reciprocity. Appendix D provides an example item from the self-report questionnaire and describes the types of behaviour that attract scores of 0, 1 or 2.

**Interview.** The self-report interview component of the ADAPT is directed by the researcher and assesses DSM-5 Criterion B. Specifically, scripted prompts are used to elicit information about the developmental course, and the impact and regularity of symptomatology across the four Domain B criteria in adulthood. A visual Likert Scale with the following anchors is used to assist participants in indicating the regularity of

behaviour: less than once a month; once a month; two to three times a month; once a week; two to three times a week; four to five times a week or daily.

All items are scored by the researcher according to the quantity and/or regularity of behaviours presenting using the following scale: 0: Limited, 1: Moderate or 2: Marked. The greater the number of Criterion B1 repetitive behaviours, the higher the score. The more regularly presenting and numerous Criteria B2, B3 or B4 impairments the higher the score. Appendix D provides an example item from the interview and describes the types of behaviour that attract scores of 0, 1 or 2.

### **Procedure**

Each participant was administered the ADAPT, WASI-II and completed the demographic questionnaire, the RAADS-R and the AQ independently of the research. A subset of participants ( $n = 4$ ) consented to have the assessment filmed for inter-rater reliability purposes and subsequently had their performance on the ADAPT recorded.<sup>31</sup>

An educational and developmental psychologist with training in ASD assessment used these recordings to independently score the ADAPT for inter-rater reliability purposes. Archival RAADS-R, AQ and WASI-II data were accessed for a subset of participants who had recently completed these measures ( $n = 33$ )<sup>32</sup>. The original ADAPT comprised 52 items and required 60 to 90 minutes to administer. However, as items were removed due to insufficient sensitivity, discussed further in the results, administration time was reduced to approximately 40 minutes.

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<sup>31</sup> Although it would have been preferable to have a larger sample available for inter-rater reliability analyses, few individuals were willing to have their participation filmed. Further, some of the data collected was lost due to a camera fault.

<sup>32</sup> Multiple researchers at the university access the database. Participants consent to have data from the studies they elect to participate in stored for use by other researchers whose studies they agree to participate in. This avoids redundant testing and practice effects for commonly used research instruments. These data are updated periodically so they still reflect current presentation. The archival data used in the present study had been collected within the previous 18 months.

## Results

### Developing a Valid Assessment Tool

**Selecting items.** Of interest was whether the ADAPT could be used to provide a valid measure of ASD in adulthood by assessing a range of behaviours consistent with the DSM-5 criteria. A number of items were initially developed to create the proposed test battery ( $N = 52$ ). The first phase of the evaluation involved determining whether these items were useful in eliciting diagnostically sensitive and frequently presenting symptomatic behaviour. Chi-square tests of independence were used to identify these diagnostically sensitive and frequently symptomatic items for inclusion within the final measure. Due to multiple comparisons, alpha levels for significance were set to  $p \leq .01$ . Fisher's exact tests were used when cells fell below expected counts.

Initially, items rated symptomatic for at least half of the participants with ASD that discriminated them from the TD group with moderate effect (Cramer's  $V \geq .3$ ) were regarded as suitable for inclusion. Though 12 items met these properties, few assessed Criteria A2 or B1. The inclusion threshold was therefore relaxed to encompass any items discriminating with moderate effect with alpha levels for significance set to  $p \leq .05$ . The 18 items subsequently included within the ADAPT are shown in Table 41.

Each of the items is listed under a DSM-5 criterion. An educational and developmental psychologist trained in ASD assessments watched videos of the ADAPT being administered and independently coded each item according to the DSM-5 diagnostic criteria. The only point of disagreement between this practitioner and the author was a subset of sensory orientated repetitive behaviours in the interview component, e.g. mouthing, scratching and picking, that might also capture Criterion B4 sensory interests. Indeed, other authors have reported difficulties differentiating similar behaviours (Taheri & Perry, 2012). These behaviours were thus removed from the scoring of the Criterion B1 repetitive motor behaviour item.

Table 41

*Items (N = 18) Included in the ADAPT*

	Activity	Behaviour targeted	Cramer's V	Sensitivity %	AUC	SE	95% CI
A1 items	Vignette	Difficulty understanding conversational rules	.47**	81.8	.871**	.054	.764 - .977
	Role play	Inadequate conversational detail or context	.38*	48.5	.653	.080	.496 - .809
	Role play	Difficulty maintaining conversation with comments and questions	.37*	63.6	.706 <sup>a</sup>	.015	.557 - .855
A2 items	Vignette	Problems judging feigned emotion from facial expressions	.56**	48.5	.729*	.075	.582 - .876
	Vignette	Inaccurately judging others' emotions using nonverbal cues	.34 <sup>a</sup>	36.3	.612	.082	.451 - .773
	Role play	Difficulty using gestures to explain a task	.32 <sup>a</sup>	42.5	.669 <sup>a</sup>	.079	.514 - .824
	Role play	Problems integrating verbal communication and gestures	.32 <sup>a</sup>	43.7	.592	.083	.430 - .754
	Role play	Limited understanding of common gestures and their use	.31 <sup>a</sup>	24.3	.564	.083	.401 - .728
A3 items	Questionnaire	Difficulty maintaining friendships	.47**	57.5	.688 <sup>a</sup>	.079	.533 - .842
	Questionnaire	Difficulty forming romantic relationships	.42*	60.7	.693 <sup>a</sup>	.078	.541 - .845
	Questionnaire	Difficulty maintaining romantic relationships	.39*	78.8	.667 <sup>a</sup>	.079	.511 - .822
B1 items	Interview	Unusual or repetitive use of phrases or words	.50**	57.5	.768**	.070	.631 - .906
	Interview	Unusual interest in objects or systems	.40*	27.2	.625	.082	.465 - .785
	Interview	Repetitive motor behaviours	.31 <sup>a</sup>	69.7	.630	.070	.493 - .767
B2 items	Interview	Routines and rituals unusual in their content or intensity	.56**	66.7	.705 <sup>a</sup>	.077	.554 - .856
	Interview	Being disrupted by small changes in the environment	.44*	52	.688 <sup>a</sup>	.078	.535 - .840
B3 item	Interview	Interests that interfere with adaptive functioning and/or cause emotional distress to the individual when they cannot be pursued	.49**	68.7	.770**	.071	.631 - .909
B4 item	Interview	Unusual hyper- or hypo-reactive responses to visual, auditory, tactile, gustatory, olfactory, proprioceptive (vestibular) sensations.	.41*	69.7	.707 <sup>a</sup>	.078	.554 - .859

\*\*  $p \leq .001$ , \*  $p \leq .01$ , <sup>a</sup>  $p \leq .05$ .

**Evaluating the subscales.** To ensure compatibility with the DSM-5, subscales for each DSM-5 criterion were created. Items were grouped into subscales according to criterion with which they had been coded and total scores created by summing scores across the relevant items for each criterion. Given that the DSM-5 criteria require that every Domain A social communication and social interaction diagnostic criterion is met, a Domain A subscale was created by summing the scores across the Criteria A1, A2 and A3 subscales, but only when symptomatology was reported across each of these three subscales.

To address criterion validity, the ADAPT was compared to the RAADS-R. Specifically, the DSM-5 item coding reported in Study 2 was used to code each RAADS-R item according to a DSM-5 diagnostic criterion. Domain A and Criteria A1, A2, A3, B1, B2, B3 and B4 subscales were then created for the RAADS-R by summing scores across the relevant items. Correlations were then used to examine the relationship between the DSM-5 subscales of the ADAPT and the RAADS-R.

As shown in Table 42, the corresponding ADAPT and RAADS-R DSM-5 subscales were generally moderately to strongly positively correlated to each other. An ADAPT total score, created by summing all items, was also strongly positively correlated with the RAADS-R, providing some evidence of its overall criterion validity as a measure of ASD. Moderate to strong correlations were also found between each of the ADAPT Domain A subscales. Similar relationships were reported for the ADAPT Domain B subscales with at least one moderate to strong correlation between these subscales for each criterion subscale. Further, most ADAPT subscales correlated strongly with the ADAPT total scale.

Table 42

*Correlations Between the ADAPT and RAADS-R DSM-5 Subscales*

	ADAPT									RAADS-R							
	A	A1	A2	A3	B1	B2	B3	B4	Total	A	A1	A2	A3	B1	B2	B3	B4
<b>ADAPT</b>																	
A1	.78**																
A2	.86**	.60**															
A3	.74**	.30**	.42**														
B1	.17	.14	.22	.03													
B2	.40**	.24	.36**	.35**	.25												
B3	.28	.20	.32**	.14	.18	.52**											
B4	.16	.10	.18	.1	.25	.49**	.22										
Total	.89**	.69**	.80**	.63**	.39**	.55**	.42**	.42**									
<b>RAADS-R</b>																	
A	.65**	.48**	.55**	.50**	.27	.51**	.61**	.26	.65**								
A1	.65**	.51**	.55**	.48**	.23	.51**	.56**	.29	.50**	.94**							
A2	.52**	.35**	.43**	.44**	.25	.43**	.61**	.23	.58**	.92**	.83**						
A3	.65**	.48**	.54**	.50**	.28	.50**	.58**	.25	.45**	.99**	.89**	.87**					
B1	.29	.31*	.30	.09	.58**	.33*	.37*	.31	.34*	.57**	.55**	.52**	.56**				
B2	.51**	.40**	.45**	.35*	.25	.65**	.54**	.45**	.56**	.78**	.81**	.66**	.76**	.49**			
B3	.65**	.55**	.65**	.35*	.22	.54**	.62**	.28	.61**	.76**	.75**	.68**	.74**	.41**	.74**		
B4	.51**	.40*	.54**	.28	.35**	.51**	.41**	.48**	.35*	.72**	.67**	.59**	.73**	.46**	.63**	.66**	
Total	.65**	.50**	.55**	.45**	.34*	.56**	.61**	.36**	.79**	.98**	.93**	.88**	.97**	.63**	.83**	.81**	.82**

\*\*  $p \leq .001$ , \*  $p \leq .01$ .

Internal consistency was best for the Domain A subscale ( $\alpha = .73$ ) but progressively poorer for the Criterion B2 ( $\alpha = .71$ ), A3 ( $\alpha = .52$ ), A2 ( $\alpha = .51$ ), A1 ( $\alpha = .47$ ), and B1 subscales ( $\alpha = .33$ ).<sup>33</sup> Inter-rater reliability was also evaluated. Point-by-point agreement across the 18 items ranged from 76.47% to 88.89% ( $N = 4$ ,  $M = 82.68\%$ ,  $SD = 7.17$ ). Agreement for overall classification using the DSM-5 algorithm was 100%.

**Developing a diagnostic algorithm.** The diagnostic algorithm was designed to reflect the combination of symptoms required to support a diagnosis of ASD consistent with DSM-5 criteria. Specifically, participants were classified as likely to have ASD if they met the diagnostic cut-off score for the Domain A subscale and at least two of the four Domain B subscales. ROC analyses were used to identify appropriate diagnostic cut-off scores for each subscale. Sensitivity was prioritised over specificity in selecting diagnostic cut-off scores given that the combination of thresholds to be met across the two domains to be classified as having an ASD would improve specificity. An algorithm for the ADAPT total subscale was created to provide an alternate means of classifying ASD for those countries that use diagnostic systems other than the DSM-5. As such a single diagnostic cut-off score for the total subscale algorithm was used to classify whether participants had ASD in this case.

Using the criteria outlined by Glascoe (2005) where appropriate sensitivity is equal to or greater than 70% and specificity is at least 80%, the majority of the ADAPT subscales performed with appropriate sensitivity among the TD and ASD group. As shown in Table 43, specificity was less consistent, with only the Domain A and Criterion B2 subscales performing appropriately. Nevertheless, the sensitivity and specificity of the DSM-5 and total subscale algorithms were appropriate. ROC analyses

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<sup>33</sup> The use of Cronbach's alpha has recently been contested in the literature with authors disputing that it adequately captures reliability or internal consistency (c.f. Sijtsma, 2009). Given that studies examining test validity among persons with ASD in the broader literature commonly report Cronbach's alpha, it has likewise been reported in this chapter.

also demonstrated that the majority of subscales performed appropriately with only the likelihood of the Criterion B4 subscale resulting in a correct classification being non-significant. Classifying participants in the ‘Other’ group as TD reduced the previously appropriate specificity for three subscales: Criterion B1 (45.5%), Criterion B2 (68.2%) and Criterion B3 (61.4%) but had no marked affect on the likelihood of correct classification according to the ROC analyses. Further, the specificity of the DSM-5 (100%) and total score algorithms (86.36%) were not markedly affected by the inclusion of the ‘other’ group within the TD group. This indicates that 6 individuals were classified as having ASD when they in fact had not received a diagnosis of ASD using the ADAPT total score algorithm. However, all but one of these individuals was also classified as having ASD using the RAADS-R.

Table 43

*Psychometric Properties of the ADAPT Subscales and Algorithms Among the TD Adults and Adults with ASD.*

Subscales	AUC	SE	95% CI		Cut-off score	Sensitivity	Specificity	
			Lower	Upper				
Domain A	.930**	.031	.870	.990	4	81.8	87.5	
Criterion A1	.842**	.050	.742	.939	2	87.9	68.8	
Criterion A2	.851**	.051	.752	.950	1	84.8	53.1	
Criterion A3	.809**	.054	.703	.916	2	87.9	68.8	
Criterion B1	.792**	.055	.684	.901	1	93.9	56.3	
Criterion B2	.803**	.057	.691	.914	1	78.8	81.3	
Criterion B3	.753**	.062	.631	.875	1	68.8	75	
Criterion B4	.675	.068	.541	.809	1	69.7	48.4	
<b>Algorithms</b>								
ADAPT Total	.972**	.019	.934	1	10	90.9	96.9	
ADAPT DSM-5 <sup>a</sup>	Domain A $\geq$ 4, at least two ‘B’ criteria $\geq$ 1						81.8	100

*Notes.*

<sup>a</sup> Recall that participants must meet the Domain A cut-off score and two of the four Domain B criteria cut-off scores to be classified as having ASD

\*\*  $p \leq .001$  \*  $p \leq .01$

Examining the subscales further, typically developing adults frequently presented with behaviour reflecting one Domain A criterion ( $n = 18$ ; 56.3%) or one ( $n = 9$ ; 28.1%) or two ( $n = 10$ ; 31.3%) Domain B criteria. However, as expected, significantly more adults with ASD presented with Domain A impairments indicative of multiple criteria ( $M = 2.58$ ,  $SD = .71$ ) than did adults without ASD ( $M = 1.09$ ;  $SD = .73$ ;  $t(63) = -8.28$ ,  $p < .001$ , Cohen's  $d = 2.07$ ). Similarly, significantly more adults with ASD presented with Domain B impairments consistent with multiple criteria ( $M = 3.06$ ,  $SD = 1.08$ ) than adults without ASD ( $M = 1.38$ ;  $SD = 1.04$ ;  $t(63) = -6.38$ ,  $p < .001$ , Cohen's  $d = 1.58$ ). Further, as mentioned previously, very few typically developing individuals met sufficient criteria to receive a classification of ASD ( $n = 0$ ), even when regarding the 'Other' group as typically developing ( $n = 6$ ).

**Examining ADAPT misclassifications.** Examination of the individuals incorrectly classified using the DSM-5 algorithm demonstrated that for each of these individuals previously diagnosed with ASD, misclassification occurred due to insufficient Domain A symptomatology ( $n = 6$ ). As shown in Table 44, the absence of Criterion A2 behaviour was responsible for misclassification for all but one participant who failed to meet Criterion A1.

Table 44

*Individuals Misclassified as Not Having ASD Using the ADAPT DSM-5 Algorithm*

Sex	Age	Timing Of Dx	A	A1	A2	A3	B1	B2	B3	B4	RAAD-S R	ADAPT total
F	25	Child	×	×	✓	✓	✓	✓	✓	✓	✓	✓
F	25	Adult	×	✓	×	✓	✓	✓	✓	✓	✓	✓
F	30	Adult	×	✓	×	✓	✓	✓	✓	✓	✓	✓
F	24	Child	×	✓	×	×	✓	✓	✓	✓	✓	✓
F	23	Child	×	✓	×	✓	✓	✓	×	✓	-	×
F	32	Teen	×	✓	×	✓	✓	×	×	×	✓	×

<sup>a</sup>✓ = symptomatic, × = asymptomatic.

<sup>a</sup>No adult was incorrectly diagnosed as having ASD from the TD group

The TD and ASD samples were not matched on gender,  $\chi^2(1, n = 65) = 6.94, p = .008, \Phi = .33$ , with more males than females in the ASD than TD group. The relationship between sex and classification was therefore explored further. Females were not significantly over-represented among the individuals being misclassified,  $\chi^2(1, n = 65) = 5.33, p = .02$ ; Cramer's  $V = .29$ . Nor did the proportions of adults with ASD who were correctly classified using the ADAPT differ according to timing of diagnosis (childhood, adolescence, or adulthood;  $\chi^2(2, n = 31) = 1.07, p = .585$ ; or, type of previous ASD diagnosis; AD, AS, ASD;  $\chi^2(2, n = 25) = 2.94, p = .230$ . Independent samples t-tests likewise demonstrated that participants who were correctly or incorrectly classified did not significantly differ in age,  $t(63) = -.54, p = .205$ , or full-scale IQ  $t(63) = .759, p = .451$ .

### **Practical Concerns**

**Self-Reporting.** Though the primary focus of this chapter was developing and evaluating a diagnostically valid measure of ASD in adulthood, the practicality of the ADAPT was considered. All participants were able to respond to the self-report interview component of the ADAPT with adequate detail to identify the presence or absence of symptomatology within Domain B. Anecdotally, some adults with ASD occasionally expressed a degree of uncertainty when rating whether behaviour had presented in childhood. Difficulty reporting the regularity with which behaviour presented was also occasionally observed, particularly when its timing varied from month to month. In these instances participants were invited to report only about the periods of life when symptoms presented with certainty or, to consider the regularity of their behaviour on average. Despite these anecdotal problems with the self-report interview, every participant was able to provide sufficient information for the interview items to be rated by the researcher.

**Response biases.** Several of the vignette items presented participants with clips of people committing social faux pas that required them to rate how appropriate the characters' behaviour had been. In addition, participants viewed a neutral vignette of people simply entering a lift without committing any social faux pas. To 'pass' this control item, participants needed to indicate that characters' behaviour was socially appropriate.

Of interest, was whether the response biases identified by Zalla et al. (2009), that is, consistently responding that socially inappropriate behaviour had presented, even when it had not, would manifest among the present sample of adults with ASD. Only a minority of adults with ASD ( $n = 7$ ) identified social faux pas where they had not occurred. Further, a comparable number of typically developing adults ( $n = 8$ ) likewise failed the control vignette item by reporting socially inappropriate behaviour. Collectively, none of these participants identified social faux pas across the remaining vignettes in any greater proportions than the participants who had passed the control item,  $\chi^2(2, N = 77) = .415, p = .93$ , Cramer's  $V = .07$ , suggesting a lack of response bias.

**Administration time.** Finally, the practicality of administering the ADAPT under time-constraints was considered. The original ADAPT comprised 52 items and required 60 to 90 minutes to administer. However, as items were removed due to insufficient sensitivity, administration time was reduced. Based on the participants who were filmed and for whom it was possible to remove superfluous items, on average it took approximately 40 minutes to participate in the final 18 item version of the ADAPT ( $N = 4$ ;  $SD = 5.97$ ; Range 36 - 50 minutes).

## Discussion

### Evaluating Validity

The purpose of the present study was to develop a valid, appropriate and practical diagnostic tool to assist clinicians in evaluating adults with suspected ASD. Promising evidence was found regarding the validity of the ADAPT. A range of items that reflected the DSM-5 symptom criteria and effectively differentiated between adults with or without ASD were identified. Appropriate criterion validity was also demonstrated between the ADAPT and RAADS-R total and DSM-5 based subscales. Further, using either a DSM-5 based algorithm or a total score, the ADAPT was used to correctly classify most participants. The reliability of the ADAPT was however more variable with poor internal consistency.<sup>34</sup> Adequate inter-reliability was reported between the experimenter and a clinician blind to diagnosis albeit in a small sample.

Despite these promising preliminary findings, further study is needed to verify and more rigorously explore the validity of the ADAPT. While the ADAPT performed with appropriate sensitivity and specificity overall, whether it provides an effective measure of ASD as defined by the DSM-5 requires further testing. Some uncertainty arises in this area because the majority of participants with ASD were diagnosed using the DSM-IV-TR criteria. It is understood that some individuals meeting DSM-IV-TR criteria may not meet the DSM-5 criteria (Wilson et al., 2013; Young & Rodi, 2014). Replication of the present study among participants diagnosed with ASD as defined by the DSM-5 would thus help to clarify the ability of the ADAPT to identify ASD as conceptualised by the DSM-5 criteria. Likewise, using the ADAPT among populations presenting for diagnosis in adulthood would provide a more rigorous test of its validity as recommended in the Standards for the Reporting of Diagnostic Accuracy

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<sup>34</sup> The use of Cronbach's alpha has recently been contested in the literature with authors disputing that it adequately captures reliability or internal consistency (c.f. Sijtsma, 2009). Given that studies examining test validity among persons with ASD in the broader literature commonly report Cronbach's alpha, it has likewise been reported here. Caution should nevertheless be interpreted when interpreting this statistic.

Studies (STARD; Bossuyt et al., 2015).

Further research into the psychometric performance of the ADAPT would also increase understanding of the validity of this tool. Specifically, it would be beneficial to directly evaluate the performance of the ADAPT against other tools recommended for the assessment of ASD in adulthood (NICE, 2011). In particular, comparisons with the DISCO which is recommended for use by the NICE and the ADI-R and ADOS-G which are commonly used and regarded as gold standard tools would be valuable. Likewise, given adults with ASD are commonly misdiagnosed with psychiatric disorders such as borderline personality disorder and schizophrenia (Elst et al., 2013; Hofvander et al., 2009), this study should be replicated with a psychiatric control group to determine whether the ADAPT can be used for differential diagnoses. In addition, inter-rater reliability needs to be re-assessed among a much larger sample. So few observations were available for comparison when conducting the present study due to difficulty recruiting individuals who permitted filming. Given the limited sample for these analyses, findings about inter-rater reliability are therefore preliminary.

### **Implications for Applying the DSM-5 Criteria**

**Clarifying diagnostically relevant behaviour.** While further work is needed to evaluate the ADAPT, these initial findings have implications for our understanding of behaviour thought to be consistent with the DSM-5 criteria in adulthood. The present study replicated findings concerning the diagnostic efficacy of a number of other behaviours. Specifically, items measuring difficulty providing appropriate detail, interpreting nonverbal cues, having routines, noticing patterns and, intense interests were diagnostically sensitive components of the ADAPT. These behaviours have performed similarly within other measures in the broader literature (Allison, Auyeung, & Baron-Cohen, 2012; Bishop & Seltzer, 2012; Eriksson, Andersen, & Bejerot, 2013) and have been identified as characteristic of ASD across the studies within this thesis.

Thus, these behaviours can now be regarded with some degree of confidence as characteristic of ASD in adulthood.

A number of behaviours indicative of Domain B in adulthood emerged in Study 3. These behaviours included repetitive motor movements such as knee jiggling and, insistence on sameness manifesting as spotting continuity errors in films, TV shows and books. In the present study, some of these behaviours lacked specificity. Thus despite the regularity and frequency of these behaviours among adults with ASD (see Study 3), they may have little diagnostic relevance.

It has been reported in the literature that adults with ASD have difficulty explaining whether behaviour is socially appropriate (Zalla et al., 2009). However, none of the vignette items that invited participants to provide these explanations to identify socially inappropriate behaviour proved useful in differentiating adults with ASD from adults without ASD. Whether this can be attributed to the tasks or scoring system used in the present study requires further attention.

**Impairments presenting among typically developing adults.** It is clear from the present study and the broader literature that while many typically developing adults may present with one or two isolated impairments characteristic of the disorder (Allison et al., 2012; Barrett et al., 2015), few will present with enough impairments to meet the threshold for satisfying Domain A and B. These findings reiterate that what is most characteristic of ASD in adulthood is not any one diagnostic criterion or behaviour, but the unique combination of impairments that present (Carrington et al., 2014; Harrop et al., 2013; McPartland, Reichow, & Volkmar, 2012).

**Impairments presenting among adults with ASD.** The present study identifies the frequency with which the DSM-5 criteria present among adults with ASD. In the present study, only a select number of behaviours, and indeed none consistent with Criterion B1, presented with adequate frequency in adulthood. Again, these

findings provide more support for the premise that in adulthood, the expression of each DSM-5 diagnostic criterion differs greatly between individuals and thus targeting a wide range of diagnostically sensitive behaviours in assessment is most prudent. Indeed, in adopting this approach in developing the ADAPT, even its Criterion B1 subscale was met with adequate frequency by persons with ASD, albeit at the expense of its specificity, with many typically developing individuals likewise presenting with these behaviours ( $n = 21$ ), similarly to reports in the literature (Barrett et al., 2015). It is important to note however, that despite some typically developing individuals presenting with some impairments consistent with ASD, very few met enough criteria to be classified as having ASD ( $n = 6$ ) when using the ADAPT.<sup>35</sup> Whether the specificity of the Domain B subscales can be improved requires further study.

**Patterns of misclassification.** While few individuals with ASD were misclassified using the ADAPT, all failed to meet sufficient Domain A criteria ( $n = 6$ ). In all but one case, this occurred due to failure to meet Criterion A2 in particular. This might have been anticipated given earlier research suggesting that Criterion A2 impairments do not present frequently in adulthood (see Studies 1 and 2). Whether the items assessing Criterion A2 or their scoring can be refined to improve the psychometric performance of this tool warrants consideration. Alternatively, it may be that Criterion A2 behaviours are not as sensitive in adults. These findings contribute to the ongoing debate as to whether the thresholds required to meet Domain A in the DSM-5 are too stringent. Indeed, the sensitivity of the DSM-5 criteria greatly improves for children, adolescents and adults with ASD when only two of the three Domain A criteria must be met as reported in Study 1 and the broader literature and (Hiller, Young, & Weber, 2014; Wilson et al., 2013). Further research assessing Criterion A2 via different methodologies may also clarify whether the apparent low incidence of these

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<sup>35</sup> Recall that the six typically developing individuals who were misclassified belonged to the 'Other' group, five of whom also met the RAADS-R diagnostic cut-off score for ASD.

behaviours may be attributed to manner of assessment rather than true low incidence.

### **Evaluating Practicality and Appropriateness**

The practicality and appropriateness of the ADAPT were also considered. Several steps were taken to maximise the practicality and appropriateness of the ADAPT. Specifically, the guided self-report interview appeared effective in eliciting information about Domain B related behaviour which has previously been difficult to gather using self-report or behavioural observation tools (Hus & Lord, 2014). Further, the administration time of the ADAPT at approximately 40 minutes on average is substantially shorter than that of other comprehensive assessment tools such as the DISCO or ADI-R.

Nevertheless, further assessment of the practicality and appropriateness of the ADAPT is warranted. In particular, it is unclear why the over-identification of social faux-pas and difficulty explaining social norms reported in the literature (Zalla et al., 2009) were infrequent in the present sample of adults with ASD. It may be that the response bias control question and vignettes were not sensitive to these difficulties. Exploring whether a direct replication of Zalla's study reproduces these impairments may clarify whether their absence among the present sample can be attributed to the measure used.

Future research evaluating the ADAPT should also evaluate its practicality from the perspective of examinees and examiners. Specifically, these parties could be asked to rate how user-friendly and appropriate they perceive the components of the ADAPT to be. Including a measure of strengths, modelled on the prompts that proved effective in eliciting such information within Study 1, could also improve its practicality for developing appropriate interventions and supports.

## **Summary**

In conclusion, the present chapter offers preliminary evidence for the validity, practicality and appropriateness of a diagnostic tool to assist psychologists in evaluating the presence of ASD as defined by the DSM-5 in adulthood. Further, this chapter corroborates previous reports of diagnostically sensitive Criterion A1, A2, B2 and B3 behaviour. Replication of the present study, among individuals with pre-existing DSM-5 diagnoses and a psychiatric control group is however warranted to increase confidence in the suitability of the ADAPT for assisting with diagnostic decision-making.

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## **Chapter 6: General Discussion**

While ASD is a developmental disorder that first manifests in childhood, a growing number of individuals are seeking diagnoses in adulthood (Jensen, Steinhausen, & Lauritsen, 2014). Diagnosing adults with ASD is a complex process given the scarcity of information about the presentation of ASD in this period of life and a lack of practical and valid assessment tools. My aim in conducting this research was to address uncertainty about the presentation of ASD in adulthood and to develop a practical and valid diagnostic tool to identify ASD as it presents in adults.

### **The Complexity and Value of Adult ASD Diagnoses**

Adults with suspected ASD and the health professionals to whom they present face a number of difficulties in confirming whether a diagnosis of ASD may be warranted. Primary care providers, the first point of contact for adults with suspected ASD, reportedly receive limited training about the disorder (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012; Warfield, Crossman, Delahaye, Der Weerd, & Kuhlthau, 2015). Further, few of these providers refer adults for a more comprehensive assessment when they suspect ASD may be present (Zerbo, Massolo, Qian, & Croen, 2015). Unsurprisingly, late diagnosed adults note difficulty accessing appropriate referrals from practitioners who lack awareness that ASD persists into adulthood (Bargiela, Steward, & Mandy, 2016; Jones, Goddard, Hill, Henry, & Crane, 2014; Punshon, Skirrow, & Murphy, 2009).

Once referred for a comprehensive diagnostic assessment, further complexities arise for adults with suspected ASD and the clinicians who conduct these assessments. Clinicians have observed that some commonly used assessment tools such as the Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord et al., 2000), are age-inappropriate and can be damaging to the rapport between clinician and client (NICE, 2012b). This is perhaps unsurprising given that the ADOS-G presents adults

with activities such as reading children's story books and miming brushing one's teeth as part of the assessment (ADOS-G; Lord, Rutter, DiLavore, & Risi, 2009). Further, in the absence of a clear, empirically rigorous diagnostic protocol for best practice assessment, the available guideline present clinicians with an array of possible tools to consider when assessing adults (NICE, 2012a). Selecting appropriate assessment tools from these recommendations is far from straightforward given the plethora of limitations to the practicality and validity of these tools for use with adults. These limitations include but are not limited to: poor psychometric properties; failure to provide a comprehensive assessment of each of the DSM-5 criteria; lengthy administration times; inability to access these tools and, difficulty accessing suitable informants to complete these measures.

Very little is known about the manner in which ASD presents in adulthood. The DSM-5 (APA, 2013) offers little age-specific guidance as to how the criteria present in this period of life, despite acknowledging that presentation is likely to change across the lifespan and that adults may seek diagnoses. Adults with ASD were not included in the field trials used to develop the latest revisions to the DSM (Clarke et al., 2013; Narrow et al., 2013; Regier et al., 2013) and as a result the DSM-5 may not reflect adult presentation. Likewise, few studies in the broader literature provide specific information about how symptoms present in adulthood. Much of the information that is available is drawn from small qualitative studies, data pooled between children, adolescents and adults or, individuals with or without intellectual disability. Whether these findings may generalise to adults specifically, and in particular, individuals seeking diagnoses in this period of life who typically do not present with intellectual disability is uncertain (Geurts & Jansen, 2012).

Despite the complexities, late diagnoses can be valuable. Most individuals diagnosed with ASD in adulthood reportedly view validation of their suspicions as a

beneficial outcome. In particular, they cite feeling reassured, more self-aware and having a newfound sense of belonging with other people similarly experiencing ASD (Bargiela et al., 2016; Jones et al., 2014; Punshon et al., 2009). Further, diagnosis may prompt intervention and increased access to support services, though much work is needed to increase intervention options and ensure that they are routinely offered to adults with ASD where appropriate (Edwards, Watkins, Lotfizadeh, & Poling, 2012; Jones et al., 2014). Clearly ASD diagnoses have value, even for individuals diagnosed in adulthood. However, much uncertainty about the presentation and best practice assessment of ASD in this period of life contributes to difficulties in obtaining a diagnosis. This thesis sought to improve our understanding of ASD and its assessment in adulthood to reduce some of the complexities of the diagnostic process for adults with ASD and clinicians.

### **Summary of Findings**

One of the key aims in conducting this thesis was to clarify the presentation of ASD in adulthood, specifically among adults without intellectual disability. Of interest was the qualitative manner, frequency and severity with which symptoms presented in this period of life. In Australia, the DSM-5 criteria (APA, 2013) are used to support a diagnosis of ASD, and thus this conceptualisation of ASD was used when evaluating symptoms presenting in adulthood throughout this thesis.

**Study 1.** Study 1 sought to clarify presentation of the DSM-5 diagnostic criteria in adulthood. Each of the three participant groups: adults with ASD, significant others and clinicians, responded to an online questionnaire about the frequency and severity of behaviour associated with these criteria. Symptom frequency was of particular interest given that at this time only one other study has considered the frequency with which these individual criteria present among adults (Wilson et al., 2013). Findings indicated that each criterion presented with adequate frequency in the present sample (i.e. among

at least 70% of adults with ASD). The notable exception was Criterion B1 that encapsulates repetitious and stereotyped speech, object use and motor behaviour. Thus most DSM-5 criteria appeared salient in adulthood. Discrepancies emerged in the frequency with which the Domain B criteria presented in the present sample in comparison to that studied by Wilson et al. (2013). Raising the threshold so that behaviour had to present 'Often' or 'Always' to be deemed present meant that only Criterion B4 continued to manifest among significantly greater proportions of adults with ASD in the present study than in Wilson et al. (2013). However, few individuals met Criterion A2 using this more stringent threshold. Consequently, the majority of adults with ASD reportedly failed to meet the combination of criteria needed to satisfy a diagnosis of ASD according to each participant group. The assessment of these nonverbal communication impairments in adulthood thus requires further consideration.

Symptom severity was also investigated. No single DSM-5 diagnostic criterion clearly emerged as more severe in adulthood, corroborating reports in the literature of symptom improvement with increasing age (Hus & Lord, 2014; Lai et al., 2011; Seltzer et al., 2003). Nonetheless, the majority of adults with ASD experienced marked Domain A impairments, and/or, 'non-DSM-5 impairments' attributed to ASD but no specific criterion, such as emotional distress or adaptive functioning difficulties. It thus appears that for the majority of adults with ASD, Domain B impairments do not interfere with everyday functioning. When participants reported the nature of their symptoms, their descriptions of behaviour presenting in adulthood were very diverse. Indeed, none of the symptoms reported presented among the majority of adults with ASD. Some of the behaviour described within the DSM-5 diagnostic criteria (APA, 2013), was not reported at all, including unusual interests in one's sensory environment and absence of interest in peers. These behaviours may thus be less salient in adulthood.

**Study 2.** Understanding the behaviours most likely to be salient to each DSM-5 diagnostic criterion is valuable for assessment purposes. The purpose of Study 2 was therefore to clarify which behaviours consistent within each DSM-5 diagnostic criterion presented frequently and with diagnostic sensitivity (i.e. differentiated between adults with or without ASD with moderate effect). Many behaviours of uncertain diagnostic relevance due to previously conflicting reports of their frequency in the literature (Allison, Auyeung, & Baron-Cohen, 2012; Bishop & Seltzer, 2012), emerged as diagnostically relevant with the addition of data from Study 2. These behaviours were predominantly characteristic of Domain A and included difficulty with perspective taking and maintaining a conversation. Overall, a greater number of diagnostically sensitive than frequently presenting behaviours were identified for each criterion. This was particularly true for Criteria A2, B1 and B4. A range of diagnostically sensitive Criterion A2 but not Criteria B1 or B4 behaviour was identified including difficulty using nonverbal cues. Considering diagnostically sensitive but low incidence Criterion A2 behaviours may thus be particularly important when evaluating adults with ASD.

**Study 3.** Given that the manifestation of Domain B in adulthood remained unclear across earlier chapters, I sought to clarify its presentation further in Study 3. Adults with ASD completed an online questionnaire about the qualitative manifestation, frequency and severity (as indexed by its regularity) of the Domain B behaviours with which they presented. Findings replicated observations that Criterion B2 manifests as routines for sleeping, eating and leisure activities in adulthood (Georgiades, Papageorgiou, & Anagnostou, 2010). Additional manifestations of Domain B behaviour, not currently operationalised in existing assessment tools recommended for adults, were also identified. These behaviours included Criterion B1 repetitive behaviours such as tapping objects or one's body. Further, Criterion B4 sensory differences in the vestibular domain, including poor balance and lack of spatial

awareness were also reported. These behaviours thus have potential value for adult assessments.

Many participants indicated that they engaged in multiple repetitive behaviours, routines, interests or sensory differences. Further Domain B behaviours reportedly presented at least multiple times a week for the majority of adults with ASD. The quantity and regularity of impairments presenting in Domain B thus appears particularly characteristic of ASD in adulthood. Nonetheless, few salient behaviours presenting among at least 70% of adults with ASD were identified that reflected Criterion B1, reiterating that these behaviours may have little relevance for most adults with ASD.

**Study 4.** Given new insights about the presentation of ASD in adulthood, developing a practical and valid diagnostic tool for adults with suspected ASD was the aim of Study 4. I developed a comprehensive battery of activities that would capture each DSM-5 criterion, drawing upon the strengths and addressing the limitations of the existing tools recommended for use with adults (NICE, 2012). This measure, the Autism Detection in Adult Populations Tool (ADAPT), comprises brief behavioural observation activities, a clinician led interview and a self-report questionnaire.

Subscales for Domain A and each of the Domain B diagnostic criteria were developed from the items that best differentiated adults with ASD from adults without ASD. A DSM-5 diagnostic algorithm was then created from these subscales to assist in classifying whether an individual met the three Domain A criteria and at least two of the four Domain B criteria required to support a diagnosis of ASD. This diagnostic algorithm performed with appropriate sensitivity (81.8%) and perfect specificity among a sample of adults with or without ASD. Factors including age, gender, and whether previously diagnosed in childhood, were not associated with diagnostic accuracy. The small number of individuals who were misclassified when using the ADAPT failed to meet sufficient Domain A criteria, predominantly Criterion A2, reiterating the need to

further investigate the assessment of this criterion in adulthood. Inter-rater reliability was adequate for both the point-by-point item agreement and diagnostic algorithm. While comprehensive validation of the ADAPT is still required, this measure showed promise and is the first specifically designed to assess ASD as it presents in adulthood consistent with the DSM-5 criteria.

### **The Presentation of ASD in Adulthood**

**Domain A.** This thesis provides a number of contributions to current understanding of the presentation of Domain A impairments in adulthood and their best practice assessment. Findings consistently demonstrated that each of the Domain A criteria and a range of related behaviours presented with adequate frequency in adulthood, i.e. among at least 70% of adults with ASD. Further, a number of behaviours presented with both adequate frequency and diagnostic sensitivity. These behaviours of diagnostic relevance drawn from Studies 2 and 4 are presented in Table 45 according to the DSM-5 descriptor<sup>36</sup> that they best capture.

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<sup>36</sup> DSM-5 descriptors are italicised, see (DSM-5; APA, p.50)

Table 45

*Behaviours of Diagnostic Relevance to Domain A in Adulthood*

Criterion A1
<i>Abnormal social approach</i>
<ul style="list-style-type: none"> <li>▪ Provides inappropriate detail when communicating</li> <li>▪ Does not understand conversational rules e.g. timing of talking and listening</li> </ul>
<i>Failure of normal back-and-forth conversation</i>
Has difficulty maintaining a conversation with appropriate comments and questions
Criterion A2
<i>Poorly integrated verbal and nonverbal communication</i>
<ul style="list-style-type: none"> <li>▪ Does not point to items of interest when speaking</li> </ul>
<i>Deficits in the understanding and use of gestures</i>
<ul style="list-style-type: none"> <li>▪ Has difficulty reading facial expressions, especially disinterest or shock.</li> </ul>
Has difficulty gauging feelings from body language, gestures or tone of voice
Criterion A3
<i>Difficulties adjusting behaviour to suit various social contexts</i>
<ul style="list-style-type: none"> <li>▪ Social rules are learned not intuitive and may not be followed</li> <li>▪ May make inadvertently socially inappropriate comments</li> </ul>
<i>Difficulties in sharing imaginative play</i>
<ul style="list-style-type: none"> <li>▪ Has difficulty working out whether someone is pretending or serious</li> </ul>
<i>Difficulties in making friends</i>
Forming friendships and making acquaintances is difficult

While these behaviours reflect those that are both frequently presenting and diagnostically sensitive, other behaviours may also be of value for diagnostic purposes though they are of lower incidence. Specifically, considering diagnostically sensitive but not frequently presenting impairments when assessing adults, may better capture the diversity with which each diagnostic criterion appears to present in this period of life. Given that each Domain A criterion must be met to consider a diagnosis of ASD under the DSM-5, it may be particularly important to target infrequent but diagnostically sensitive behaviours when assessing this domain. These behaviours include providing too little context in conversation (Criterion A1), not pointing to objects of interest (Criterion A2) and engaging in few behaviours that help maintain friendships such as inviting friends to visit, offering them support or doing them a favour (Criterion A3).

Further, in evaluating Domain A it is important to note that Criterion A2 behaviours do not present regularly for many adults. The DSM-5 manual notes that factors such as the regularity with which symptoms present can assist with differential diagnosis. However, it appears that this approach may be unwise when evaluating Domain A in adulthood. Indeed, this thesis demonstrated that very few adults with ASD experienced these impairments ‘often’ or ‘always’ and may be precluded from diagnosis if the regularity with which these symptoms present is used to determine whether impairments are characteristic of ASD. Thus to ensure that adults with ASD are not precluded from diagnosis, it appears that either the number of criteria required to satisfy Domain A in this period of life must be relaxed as advocated by other authors (Wilson et al., 2013; Young & Rodi, 2014) or, the regularity with which Domain A impairments present should not be considered for differential diagnosis.

**Domain B.** Likewise, this thesis provides a number of contributions to our understanding of Domain B impairments in adulthood. Overall, findings demonstrated that each Domain B criterion and a range of related impairments present with adequate frequency in adulthood. The notable exception was Criterion B1, which consistently presented with inadequate frequency at the criterion and behavioural level. Nonetheless, some behaviours of diagnostic relevance were identified for each of the remaining Domain B criteria. These behaviours presenting with both adequate frequency and diagnostic sensitivity were drawn from Studies 2 and 4 and are presented in Table 46 under their relevant DSM-5 descriptors.<sup>37</sup>

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<sup>37</sup> DSM-5 descriptors are italicised, see (DSM-5; APA, p.50)

Table 46

*Behaviours of Diagnostic Relevance to Domain B in Adulthood*

Criterion B2
<i>Inflexible adherence to routines or ritualised patterns of verbal or nonverbal behaviour</i>
<ul style="list-style-type: none"> <li>▪ Prefers routine and stability</li> </ul>
<i>Insistence on sameness</i>
<ul style="list-style-type: none"> <li>▪ Experiences difficulty multi-tasking</li> <li>▪ Notices patterns</li> </ul>
Criterion B3
<i>Highly restricted, fixated interests that are abnormal in intensity or focus</i>
<ul style="list-style-type: none"> <li>▪ Collects categorical information, is interested in details</li> <li>▪ Interests are all-consuming and may distract individuals from other tasks</li> <li>▪ Disruption of interests causes distress</li> </ul>
Criterion B4
<i>Hyper- or hypo-reactivity to sensory input</i>
<ul style="list-style-type: none"> <li>▪ Hyper-sensitivity to faint noises</li> </ul>

As mentioned previously, each Domain B criterion presents in a diverse manner in adulthood with many more diagnostically sensitive than frequently presenting behaviours manifesting in this period of life. Given that there appear to be so few behaviours of diagnostic relevance to Domain B in adulthood, as with Domain A, considering diagnostically sensitive behaviour that is not frequently presenting when evaluating this domain may be important. Indeed, a number of diagnostically sensitive but infrequently presenting Criterion B1 behaviours assessed in the ADAPT and RAADS-R have been reported in this thesis. These behaviours included unusual pacing and tone of speech, preoccupation with moving parts of objects or disassembling objects and engaging in multiple types of repetitive motor behaviour.

When evaluating Domain B in adulthood, it also appears particularly important to consider differential diagnosis. Indeed, it has been noted within the broader literature that many typically developing adults may present with isolated behaviours consistent with Domain B (Barrett et al., 2015; Jordan & Caldwell-Harris, 2012). The DSM-5 manual acknowledges that in addition to the qualitative manner in which behaviours present, their severity and regularity may assist with differential diagnosis (DSM-5;

APA, 2013). This thesis demonstrated that many adults with ASD regularly experience impairments consistent with Criteria B2, B3 and B4. Further, adults with ASD appeared to present with numerous repetitive motor behaviours, routines, interests and/or sensory behaviours which may provide an additional index of their severity.

The clinical usefulness of considering the regularity and quantity of Domain B behaviours presenting in adulthood for differential diagnosis was considered when developing the ADAPT. Thus the scoring system for this tool was designed so that individuals presenting with more numerous and regular Domain B impairments would attract higher scores. The adequate specificity of the ADAPT Criterion B2 subscale (81.3%) and promising specificity of the Criterion B3 subscale (75%) provided preliminary evidence that the regularity and quantity of behaviours characteristic of these criteria may assist with differential diagnoses. Nevertheless, further research is needed. Only the specificity of the Criterion B1 and B4 subscales of the ADAPT was poor. It may be that these behaviours occur with regularity and frequency in typically developing populations as reported by other authors (Barrett et al., 2015). Determining how best to differentiate adults with ASD from typically developing adults when assessing these criteria thus requires attention.

**The role of gender.** The samples reported in Studies 1 and 3 predominantly featured females with ASD, in contrast to much of the available research about symptom presentation literature (Russell, Rodgers, Ukoumunne, & Ford, 2013; Windham et al., 2010). This bias thus provided the opportunity to examine sex differences in presentation. Interestingly, no biases were observed among the symptoms observed or reported. Further research is needed to confirm whether this absence of a bias in symptom presentation between the sexes may be replicated and thus the representativeness of the symptoms reported to the broader population of adults with ASD of either sex.

## **Evaluating Whether Impairments are Clinically Significant**

When assessing adults with suspected ASD, clinicians must also ascertain whether symptoms cause clinically significant impairments. The DSM-5 defines these impairments as impediments to social or adaptive functioning in multiple contexts (DSM-5; APA, 2013). These impairments do not need to be attributed to any particular domain or criteria. The ‘non-DSM-5 impairments’ identified in this thesis thus offer one avenue for evaluating the clinical significance of impairments. These non-DSM-5 impairments were elicited when inviting adults with ASD and their significant others to report what affected these adults most about having ASD or seemed harder to manage in this period of life than in childhood and adolescence. The majority of respondents identified social and adaptive difficulties that they attributed to ASD but no one domain or criterion in particular. Difficulty maintaining employment, completing household chores, managing finances, achieving independence and managing emotional distress were some of the non-DSM-5 impairments identified.

Individuals with ASD without intellectual disability have often been considered less impaired than those with intellectual disability. However, this thesis and recent research (Baldwin & Costley, 2016; Happé et al., 2016; Howlin, Moss, Savage, & Rutter, 2013) suggests that functional impairments and comorbid anxiety and depression may frequently present in adults with ASD without intellectual disability. As such it is suggested that tools to address these considerations should be included when evaluating adults with suspected ASD (NICE, 2012a).. For example, measures such as Beck’s Depression Inventory (Gotham, Unruh, & Lord, 2015), may be helpful in assessing emotional wellbeing. Further, the outcome measure proposed by Howlin, Goode, Hutton and Rutter (2004) for adults with ASD may also assist in assessing functional difficulties. This measure captures level of independence, social functioning and employment. Conversely, social or adaptive functioning difficulties

disproportionate to one's age and intellectual ability may thus be considered as warning signs for possible ASD in adulthood. Indeed, some late diagnosed adults indicate that they had regular contact with mental health providers, but their ASD was not recognised by these providers (Bargiela et al., 2016; Punshon et al., 2009). Further research is needed in this area to evaluate the usefulness of such impairments for adult assessments.

### **Evaluating Symptom Severity**

The DSM-5 also requires that clinicians consider the severity of Domain A and B impairments when assessing individuals with suspected ASD. Severity is indexed by the degree to which impairments are conspicuous, present across contexts and/or impair functioning. The findings of this thesis highlight that the majority of adults with ASD reported impairments consistent with Domain A that have become harder to manage in adulthood than in earlier life. In particular, these impairments appeared to interfere with navigating workplace politics and the formation of friendships. Thus, enquiring about social difficulties experienced at work and in the community may assist with rating the severity of Domain A impairments in this period of life.

In contrast, only a minority of adults with ASD appeared to present with impairments consistent with Domain B that interfered with their functioning. This absence of impairments for most adults has implications for evaluating the severity of this domain. Specifically, the severity with which Domain B presents in adulthood may be particularly difficult to rate given that even the mildest severity rating requires "significant interference" with functioning (DSM-5; APA, 2013, p. 52). Guidance is thus needed for rating the severity of Domain B in adulthood among the majority of individuals for whom these symptoms do not cause marked impairments.

This thesis presents some valuable accounts of how Domain B impairments may arise for the adults for whom they do manifest. In particular, Criterion B3 interests can cause financial burdens and interfere with social relationships in adulthood as

previously reported in a small qualitative study (Mercier, Mottron, & Belleville, 2000). For example, sensory differences characteristic of Criterion B4 can cause discomfort or health complications arising from failure to notice the severity of injuries. Indeed, the broader literature suggests that significantly fewer adults with ASD than typically developing adults perceive that they can accurately gauge when they need to seek medical help (Nicolaidis et al., 2012). While Domain B impairments may not interfere with functioning for the majority of adults with ASD, it appears they may cause significant difficulties for the individuals who do experience them. Educating medical professionals about how sensory differences may impact the health of adults with ASD may be particularly important given many of these professionals may be unaware that these symptoms are characteristic of ASD (Zerbo et al., 2015).

Further, this thesis provides some guidance for the evaluation of the severity of Domain B among the adults with ASD who do not report that these impairments interfere with everyday functioning. As discussed previously, the DSM-5 requires severity to be rated according to how conspicuously impairments present across contexts. Arguably, more regularly presenting behaviours are more conspicuous and likely to present in various settings. Given that behaviour consistent with each Domain B criterion presented regularly for the majority of adults with ASD in this thesis, considering this aspect of symptom presentation may assist in applying the DSM-5 severity ratings to adults for whom Domain B impairments do not interfere with everyday functioning.

It must be noted that power analyses were not conducted throughout this thesis because the research was exploratory and there was no available literature from which to calculate expected effect sizes and thus appropriate sample size. Replicating the studies presented in this thesis in larger samples may clarify whether some absent or low incidence symptoms can be more readily identified or provide further support that

these behaviours lack relevance in adulthood. For the range of behaviours that were identified among adults with ASD throughout this thesis, these findings provide an initial framework for future researchers in considering expected effect sizes and power.

### **The Diagnostic Assessment of Adults with Suspected ASD**

This thesis also provides a number of contributions to our understanding of available assessment tools for adults for whom ASD is suspected. In exploring symptom manifestation in this thesis, the limitations of existing assessment tools in capturing behaviour characteristic of adults with ASD became apparent. Many of the behaviours assessed within the AQ, RAADS-R and SCQ presented infrequently and/or were not diagnostically sensitive. Further, these and other recommended assessment tools appear to overlook a number of manifestations characteristic of ASD in adulthood. For example, ADAPT items assessing Criterion B1 interests in determining how objects work had adequate diagnostic sensitivity but this symptom is not explicitly assessed in the recommended assessment tools. The recommended tools therefore need to be updated to ensure they provide a comprehensive assessment of ASD as it presents in adulthood. Examining whether the behaviours characteristic of each DSM-5 criterion reported in this thesis may be identified in other samples of adults with ASD would provide further guidance as to which behaviours should be included in assessment tools intended for use with adults.

**Assessment approaches.** Though each of the recommended assessment tools has strengths in informing clinical judgements about impairments presenting among persons with suspected ASD, none of these tools is without significant limitations to their practicality and/or validity. Given these limitations the ADAPT was developed. In developing this tool, I sought to determine whether a comprehensive battery of activities designed to capture the strengths of the recommended assessment tools and address their limitations might prove useful for adult diagnostic assessments. I also

sought to determine whether the findings about the presentation of ASD in adulthood throughout this thesis could be applied to assist with adult diagnoses.

A plethora of self-report, interview and behavioural observation activities were therefore designed to assess each of the behaviours that appeared characteristic of ASD in adulthood throughout this thesis. Many of the items and activities originally developed for the ADAPT proved not to be sufficiently sensitive in identifying adults with ASD. However, a series of items from each component of the original diagnostic tool appeared to capture the DSM-5 criteria with adequate diagnostic sensitivity.

Specifically, it appears that role-plays and vignettes can be used to effectively capture behaviour consistent with Criteria A1 and A2 in adulthood. Interestingly, the self-report questionnaire alone appeared successful in evaluating Criterion A3. This questionnaire assessed difficulties developing and forming relationships. None of the vignettes intended to assess participant's understanding of social norms proved effective. This stands in contrast to reports that dynamic vignettes such as those developed for the ADAPT (Roeyers, Buysse, Ponnet, & Pichal, 2001) are effective for assessing these Criterion A3 impairments. Given that these same vignettes successfully identified Criteria A1 and A2 impairments, why they failed to highlight difficulties understanding social rules and norms that appear characteristic of ASD in adulthood is unclear. Further research is needed to identify how best to evaluate the aforementioned Criterion A3 impairment in adulthood.

In contrast, much of the interview originally intended to assess Domain B in adulthood was retained within the final version of the ADAPT. Indeed, throughout this thesis self-reporting proved effective in eliciting information about the qualitative presentation, frequency and regularity with which Domain B impairments manifested in this period of life. This finding has important implications given gold standard tools such as the ADOS-G rarely elicit information about these behaviours (Hus & Lord,

2014). Further, it has also been observed that existing self-report tools can be difficult to interpret for some adults with ASD, precluding their use (Holmes, 2011; NICE, 2012a). However, it appears that the ‘guided self-reporting’ approach used in this ADAPT in which specific examples of symptoms were provided alongside opportunities to describe behaviours that may have been overlooked, shows promise in evaluating Domain B in adulthood. It should be noted that the individuals who participated in the ADAPT validation study had pre-existing diagnoses. Therefore, they may have been more aware of their difficulties and thus better able to provide information about their symptoms in the self-reporting components of this tool than individuals presenting for diagnoses otherwise would be. Evaluating the ADAPT among adults presenting for diagnosis is thus an important consideration for future research.

*The psychometric properties of the ADAPT.* Despite the poor specificity of some of the DSM-5 subscales developed for the ADAPT, the Domain A, Criteria B2 and B3 subscales were adequate. Similarly, the overall DSM-5 diagnostic algorithm and total scale algorithm had adequate sensitivity and specificity. Indeed, the ADAPT performed comparably to the RAADS-R and, markedly better than the AQ in the sample studied. The manner in which diagnostic cut-off scores were chosen may explain the poor specificity of some ADAPT subscales. It is understood that some typically developing adults will present with isolated symptoms characteristic of ASD (Barrett et al., 2015) and that the defining feature of the disorder is therefore the combination of symptoms that present (Carrington et al., 2014; Wilson et al., 2013). Thus, sensitivity was prioritised over specificity in selecting the individual criterion cut-off scores given that participants would be required to meet a series of these cut-off scores to satisfy a DSM-5 classification of ASD.

A similar approach to choosing diagnostic cut-off scores was adopted by Carrington et al. (2014) in developing thresholds for DSM-5 subscales for the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing, Leekam, Libby, Gould, & Larcombe, 2002). These authors reported inadequate specificity for their DSM-5 subscales, however specificity was inadequate for each of their DSM-5 criterion subscales. Further, in many cases, specificity was poorer than that reported for the equivalent ADAPT DSM-5 criterion subscale.

Collectively, these findings may suggest that individually some of the DSM-5 criteria have poor specificity in adulthood, particularly Criteria A2, B1 and B4. Nonetheless, beyond Study 4, information about the specificity of the DSM-5 criteria among adults is lacking. Carrington et al. (2013) only examined specificity among children and adolescents. Further study of the specificity of the individual criteria among adults may assist in clarifying whether the poor specificity of some subscales is a reflection of the manner in which they were assessed, or, the high incidence of isolated impairments characteristic of ASD among typically developing adults.

The development of the ADAPT and initial promising findings about its psychometric performance overall have a number of implications. The ADAPT may be a suitable adjunct measure or alternative to some of the existing assessment tools recommended for use with adults. Of these recommended tools, the DISCO, ADI-R and RAADS-R appear the most suitable. Nevertheless, the DISCO can take several hours to administer, the ADI-R is likewise time-consuming and requires access to other informants and, both it and the RAADS-R do not have a DSM-5 compliant diagnostic algorithm. Thus, the ADAPT may offer a practical alternative or adjunct to these tools when assessing adults with suspected ASD given that it addresses these limitations. Specifically, it takes less than an hour to administer, does not rely on other informants and has a DSM-5 compliant algorithm. Further, given the scripted nature of the

ADAPT, it is likely to require less training than many of the recommended assessment tools.

While the initial findings about the ADAPT presented in this thesis are promising, before it can be recommended for use with adults, much research is still needed. Specifically, the psychometric performance of the ADAPT should be studied in additional samples with other administrators and raters to ensure that it remains effective beyond the initial validation study presented in this thesis. Further, its ability to distinguish adults with ASD from adults with other disorders requires examination. Whether items in the ADAPT can be refined to further improve their sensitivity and specificity also warrants attention.

### **Conclusion**

Adults with ASD present for diagnosis but little is known about ASD in this period of life. This thesis makes a number of contributions to research in this field by addressing uncertainty about the presentation and best practice assessment of adults with ASD. Specifically, it clarifies the manner in which the DSM-5 criteria present, outlines a number of behaviours that appear useful in identifying adults with ASD and provides preliminary evidence for the validity of an assessment tool specifically for the identification of ASD in adulthood. Research is still needed to replicate the findings in this thesis to confirm the behaviours of diagnostic relevance reported and the apparent diversity of expressions of each criterion in adulthood. Further, the ADAPT requires additional validation before it can be considered for use with adults. Nevertheless, this thesis provides valuable insights into ASD as it presents in adulthood and potential avenues for its assessment.

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## Appendix A

### Questionnaire for Adults with ASD

11. What is your gender/sex?
12. How many years old are you?
13. Which country are you living in?
14. Which autism spectrum disorder have you been diagnosed with?
  - Autistic disorder
  - Asperger's Disorder
  - PDD-NOS
  - ASD
  - Other (please specify)
15. How old were you when you were diagnosed with an autism spectrum disorder?
16. Have you ever been diagnosed with another disorder?
  - Yes (please specify)
  - No
17. What is it about having an autism spectrum disorder as an adult that affects you the most (if anything)?
18. What about having autism spectrum disorder as an adult, affects others the most (if anything)?
19. What do you find harder to manage about having autism spectrum disorder in adulthood than childhood or adolescence (if anything)?
20. What strengths do you have because of having autism spectrum disorder?
21. To what extent do the following affect you now, as an adult?  
(Never, Rarely, Sometimes, Often, Always)
  - Not knowing what to say and/or how to react in social conversations
  - Difficulty understanding and using gestures, facial expressions, eye contact and/or body language
  - Challenges forming relationships, maintaining relationships (friendships or intimate relationships) or observing social rules
  - Unusual or repetitive speech, movements (e.g. bouncing, flapping, other hand or motor mannerisms) or interaction with objects (e.g. being more interested in the wheel of a Sellotape dispenser than using the Sellotape dispenser)
  - Need for routine, familiarity or rituals
  - Intense or unusual interests
  - Unusual reaction to sensory information (lights, sounds smells, tastes, textures or pain)
22. Do you give permission for me to pair your answers with those from your spouse, parent or caregiver, should they want to participate?
  - Yes
  - No

### Questionnaire for Significant Others

1. **What is your gender/sex?**
2. **How many years old are you?**
3. **Which country are you living in?**
4. **What is your relationship to the adult with autism spectrum disorder you are responding about?**
  - Parent / caregiver
  - Spouse
4. **Which autism spectrum disorder has the person you are responding about been diagnosed with?**
  - Autistic disorder
  - PDD-NOS
  - Asperger's Disorder
  - ASD
  - Other (please specify)
6. **How old were they when they were diagnosed with an autism spectrum disorder?**
7. **Have they ever been diagnosed with another disorder?**
  - Yes (please specify)
  - No
8. **What is it about having an autism spectrum disorder as an adult that affects them the most (if anything)?**
9. **What about having autism spectrum disorder as an adult affects others the most (if anything)?**
10. **What do they find harder to manage about having autism spectrum disorder in adulthood than childhood or adolescence (if anything)?**
11. **What strengths do they have because of having autism spectrum disorder?**
12. **To what extent do the following affect them now, as an adult?**  
(Never, Rarely, Sometimes, Often, Always)
  - Not knowing what to say and/or how to react in social conversations
  - Difficulty understanding and using gestures, facial expressions, eye contact and/or body language
  - Challenges forming relationships, maintaining relationships (friendships or intimate relationships) or observing social rules
  - Unusual or repetitive speech, movements (e.g. bouncing, flapping, other hand or motor mannerisms) or interaction with objects (e.g. being more interested in the wheel of a Sellotape dispenser than using the Sellotape dispenser)
  - Need for routine, familiarity or rituals
  - Intense or unusual interests
  - Unusual reaction to sensory information (lights, sounds smells, tastes, textures or pain)

## Questionnaire for Clinicians

1. **What is your gender/sex?**
2. **How many years old are you?**
3. **Which country are you living in?**
4. **Which autism spectrum disorder have the people you have worked with primarily been diagnosed with?**
  - Autistic disorder
  - Asperger's Disorder
  - Other (please specify)
  - PDD-NOS
  - ASD
5. **Please indicate whether you are a:**
  - Psychiatrist
  - Psychologist
  - Speech Pathologist
6. **How old were they when they were diagnosed with an autism spectrum disorder?**
7. **How many years of experience do you have working with adults with autism spectrum disorder?**
8. **Were the majority of adults with autism spectrum disorder with whom you have worked diagnosed**
  - In childhood or adolescence
  - In adulthood
9. **Have the majority of the adults whom you have worked with had a comorbid disorder?**
  - Yes (please specify the most common)
  - No
10. **What in your opinion are the most characteristic features of autism spectrum disorder in adulthood?**
11. **What strengths do the adults you have worked with have because of having autism spectrum disorder?**
12. **To what extent do the following affect the adults you have worked with?**  
(Never, Rarely, Sometimes, Often, Always)
  - A1 DSM-5 definition
  - A2 DSM-5 definition
  - A3 DSM-5 definition
  - B1 DSM-5 definition
  - B2 DSM-5 definition
  - B3 DSM-5 definition
  - B4 DSM-5 definition

## **Appendix B**

### The Adult Autism Spectrum Quotient (AQ)

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 31, 5–17.

Below are a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer.

A3 1. I prefer to do things with others rather than on my own.	definitely agree	slightly agree	slightly disagree	definitely disagree
B2 2. I prefer to do things the same way over and over again.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 3. If I try to imagine something, I find it very easy to create a picture in my mind.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 4. I frequently get so strongly absorbed in one thing that I lose sight of other things.	definitely agree	slightly agree	slightly disagree	definitely disagree
B4 5. I often notice small sounds when others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 6. I usually notice car number plates or similar strings of information.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 7. Other people frequently tell me that what I've said is impolite, even though I think it is polite.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 8. When I'm reading a story, I can easily imagine what the characters might look like.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 9. I am fascinated by dates.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 10. In a social group, I can easily keep track of several different people's conversations.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 11. I find social situations easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 12. I tend to notice details that others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 13. I would rather go to a library than a party.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 14. I find making up stories easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 15. I find myself drawn more strongly to people than to things.	definitely agree	slightly agree	slightly disagree	definitely disagree

B3 16. I tend to have very strong interests which I get upset about if I can't pursue.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 17. I enjoy social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 18. When I talk, it isn't always easy for others to get a word in edgeways.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 19. I am fascinated by numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 20. When I'm reading a story, I find it difficult to work out the characters' intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 21. I don't particularly enjoy reading fiction.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 22. I find it hard to make new friends.	definitely agree	slightly agree	slightly disagree	definitely disagree
B2 23. I notice patterns in things all the time.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 24. I would rather go to the theatre than a museum.	definitely agree	slightly agree	slightly disagree	definitely disagree
B2 25. It does not upset me if my daily routine is disturbed.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 26. I frequently find that I don't know how to keep a conversation going.	definitely agree	slightly agree	slightly disagree	definitely disagree
A2 27. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 28. I usually concentrate more on the whole picture, rather than the small details.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 29. I am not very good at remembering phone numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
B2 30. I don't usually notice small changes in a situation, or a person's appearance.	definitely agree	slightly agree	slightly disagree	definitely disagree
A2 31. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree
B2 32. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 33. When I talk on the phone, I'm not sure when it's my turn to speak.	definitely agree	slightly agree	slightly disagree	definitely disagree
B2 34. I enjoy doing things spontaneously.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 35. I am often the last to understand the point of a joke.	definitely agree	slightly agree	slightly disagree	definitely disagree

A2 36. I find it easy to work out what someone is thinking or feeling just by looking at their face.	definitely agree	slightly agree	slightly disagree	definitely disagree
B2 37. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 38. I am good at social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 39. People often tell me that I keep going on and on about the same thing.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 40. When I was young, I used to enjoy playing games involving pretending with other children.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 41. I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 42. I find it difficult to imagine what it would be like to be someone else.	definitely agree	slightly agree	slightly disagree	definitely disagree
B2 43. I like to plan any activities I participate in carefully.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 44. I enjoy social occasions.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 45. I find it difficult to work out people's intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
A1 46. New situations make me anxious.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 47. I enjoy meeting new people.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 48. I am a good diplomat.	definitely agree	slightly agree	slightly disagree	definitely disagree
B3 49. I am not very good at remembering people's date of birth.	definitely agree	slightly agree	slightly disagree	definitely disagree
A3 50. I find it very easy to play games with children that involve pretending.	definitely agree	slightly agree	slightly disagree	definitely disagree

**The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R):**

Ritvo, R. A., Ritvo, E. R., Guthrie, D., Ritvo, M. J., Hufnagel, D. H., & McMahon, W. (2011). The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R): A scale to assist the diagnosis of autism spectrum disorder in adults: An international validation study. *Journal of Autism and Developmental Disorders*, 41, 1076–1089.

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A2 1.

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B1 2.

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A3 3.

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A3 4.

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A1 5.

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A3 6.

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A1 7.

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A3 8.

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B3 9.

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B4 10.

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A3 11.

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A3 12.

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B3 13.

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A3 14.

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A3 15.

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B1 16.

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A3 17.

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A3 18.

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B4 19.

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A3 20.

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A1 21.

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A3 22.

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A3 23.

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A1 24.

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A2 25.

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A1 26.

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A1 27.

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A2 28.

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B4 29.

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B2 30.

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A3 31.

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A1 32.

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B1 33.

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B4 34.

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A1 35.

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B4 36.

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A3 37.

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A1 38.

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A2 39.

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B3 40.

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B3 41.

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B4 42.

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A1 43.

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A2 44.

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A2 45.

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B4 46.

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A3 47.

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A3 48.

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B1 49.

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A1 50.

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B1 51.

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B3 52.

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A3 53.

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A3 54.

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A1 55.

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B2 56.

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B4 57.

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A1 58.

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B4 59.

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A1 60.

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A3 61.

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B1 62.

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B2 63.

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A3 64.

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B1 65.

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A1 66.

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B4 67.

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A1 68.

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A3 69.

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B3 70.

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B4 71.

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A3 72.

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B4 73.

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B4 74.

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B2 75.

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A2 76.

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A3 77.

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A1 78.

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A3 79.

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A3 80.

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**Social Communication Questionnaire (M-SCQ)**

Adapted from the SCQ (Rutter, Bailey, Berument, Lord, Pickles, 2003)

Directions: Thank you for taking the time to complete this questionnaire. Please answer each question by circling yes or no. A few questions ask about several related types of behaviour; please circle yes if any of these behaviours were present during the past 3 months. Although you may be uncertain about whether some behaviours were present or not, please answer yes or no to every question on the basis of what you think.

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A1 1.

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A1 2.

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B1 3.

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A3 4.

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B1 5.

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B1 6.

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A1 7.

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B2 8.

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A2 9.

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A2 10.

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B3 11.

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A3 12.

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B3 13.

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B4 14.

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B1 15.

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B1 16.

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B1 17.

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B3 18.

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A1 19.

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A1 20.

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A1 21.

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A2 22.

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A2 23.

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A2 24.

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A2 25.

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A2 26.

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A2 27.

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A1 28.

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A1 29.

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A1 30.

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A1 31.

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A2 32.

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A2 33.

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A1 34.

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A3 35.

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A3 36.

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A1 37.

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A1 38.

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A3 39. Do you ever find it difficult to work out whether someone is   yes   no  
being serious or just pretending?

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A3 40.

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### Behaviours from the AQ Presenting with Adequate Frequency Across the Samples<sup>38</sup>

	Study 2	Allison et al.	Bishop & Seltzer
AQ01	×	✓	✓
AQ02	✓	✓	×
AQ03	×	×	✓
AQ04	✓	✓	✓
AQ05	✓	✓	✓
AQ06	✓	✓	✓
AQ07	×	✓	×
AQ08	×	×	✓
AQ09	×	×	×
AQ10	✓	✓	×
AQ11	✓	✓	×
AQ12	✓	✓	✓
AQ13	✓	✓	×
AQ14	×	×	×
AQ15	✓	✓	×
AQ16	✓	✓	×
AQ17	×	✓	×
AQ18	×	✓	×
AQ19	×	×	×
AQ20	×	×	×
AQ21	×	×	✓
AQ22	✓	✓	✓
AQ23	✓	✓	✓
AQ24	×	✓	×
AQ25	×	✓	✓
AQ26	✓	✓	×
AQ27	×	✓	×
AQ28	×	✓	✓
AQ29	×	×	×
AQ30	×	×	✓
AQ31	×	✓	×
AQ32	✓	✓	×
AQ33	×	✓	✓
AQ34	×	×	✓
AQ35	×	×	×
AQ36	✓	✓	×
AQ37	×	✓	×
AQ38	✓	✓	×
AQ39	✓	✓	✓
AQ41	✓	✓	✓
AQ42	✓	✓	×
AQ43	✓	✓	✓
AQ44	×	✓	✓
AQ45	✓	✓	✓
AQ46	✓	✓	✓
AQ47	×	✓	✓
AQ48	×	×	×
AQ49	×	×	×
AQ50	×	✓	×

<sup>38</sup> Adequate frequency (70%)

See Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief “red flags” for autism screening: The Short Autism Spectrum Quotient and the Short Quantitative Checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51, 202–212

Bishop, S. L., & Seltzer, M. M. (2012). Self-Reported autism symptoms in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*.

## Appendix C

## Repetitive Patterns of Behaviour, Interests or Activities Questionnaire

1. **What was your gender assigned at birth?**
  - Male
  - Neutral
  - Female
2. **Is your current gender identity different from your gender at birth?**
  - Yes (what is your gender identity?)
  - No
3. **What is your date of birth (DD/MM/YYYY)?**
4. **In which country are you living?**
5. **With which autism spectrum disorder have you been diagnosed?**
  - Asperger's Disorder
  - Autism Spectrum Disorder
  - Autistic Disorder
  - Other (please specify)
  - Pervasive Developmental Disorder Not Otherwise Specified
6. **How old were you when you were diagnosed with an autism spectrum disorder?**
7. **Have you ever been diagnosed with another disorder?**
  - Yes, please specify \_\_\_\_\_
  - No
8. **How often do you engage in these finger, hand and motor mannerisms?**

<b>Flapping</b>	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Hand-wringing or twisting</b>	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Finger flicking</b>	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Rocking</b>	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Bouncing</b>	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Spinning</b>	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Knee jiggling (restless knee)</b>	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily

**9. For each behaviour in Q8 occurring at least once a month participants are asked when they are most likely to engage in the behaviour i.e.:**

- When are you most likely to flap?
- When are you most likely to twist or wring your hands?
- When are you most likely to flick your fingers?
- When are you most likely to rock?
- When are you most likely to bounce?
- When are you most likely to spin?
- When are you most likely to have a restless knee or jiggle your knee?

**10. Do you have any hand, finger or motor mannerisms in addition to those listed above?**

- **Yes**
  - **Please describe one of your additional finger, hand or motor mannerisms**
  - **When are you most likely to engage in the additional finger, hand or motor mannerism you described?**
  - **How often do you usually engage in the additional hand, finger or motor mannerism you described?** Less than Once a Month, Once a Month, 2 -3 Times a Month, Once a Week, 2-3 Times a Week, Daily.
- **No**

**11. In which activity do you spend most of your spare time?**

**12. How often do you participate in this activity?**

- Less than Once a Month
- Once a Month
- 2-3 Times a Month
- Once a Week
- 2-3 Times a Week
- Daily

**13. How do you feel when you cannot participate in this activity (e.g. when you are interrupted or have other commitments)?**

<b>Collecting things (e.g. figurines, stamps, DVDs, books, magazines etc.)</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Gathering factual information (e.g. learning about a topic of interest just for fun rather than for work or study)</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Keeping lists of things (e.g. your collections, to-do lists, statistics)</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Gaming (e.g. video or computer games, board games, iPad etc.)</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Social media (e.g. Facebook, Twitter, MySpace, Pinterest, Tumblr etc.)</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily
<b>Fantasy play (e.g. imaginary friends, cosplay, role-playing games etc.)</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily

**14. How often do you engage in the following routines or rituals?**

<b>Putting things in order</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a week	2-3 Times a Week	Daily
<b>Saying a certain word or phrase as part of a routine or ritual.</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a week	2-3 Times a Week	Daily
<b>Following a specific routine or order for the way I do things (e.g. eating, bathing, travelling, getting ready, arriving home etc.).</b>	Never	Less than Once a Month	Once a Month	2-3 Times a Month	Once a week	2-3 Times a Week	Daily

**15. Please describe your main routine or ritual which may be different to the examples listed above.**

**16. How often do you usually participate in your main routine or ritual?**

- Never
- Less than Once a Month
- Once a Month
- 2-3 Times a Month
- Once a Week
- 2-3 Times a Week
- Daily

**17. How often do you notice continuity problems (e.g. mistakes or lack of consistency in a TV show, film, book or play)?**

- Never
- Rarely
- Sometimes
- Frequently
- Almost always

**18. If the participant indicates that they notice continuity problems at least sometimes, they are asked: Q18 What sorts of continuity problems do you notice?**

**19. Sensory differences in the following areas create difficulties in my daily life**

<b>Hearing</b>	Never	Rarely	Sometimes	Frequently	Almost always
<b>Smell</b>	Never	Rarely	Sometimes	Frequently	Almost always
<b>Touch, texture and / or pressure</b>	Never	Rarely	Sometimes	Frequently	Almost always
<b>Vision (e.g. colour, lighting, watching things that spin or move etc.)</b>	Never	Rarely	Sometimes	Frequently	Almost always
<b>Taste</b>	Never	Rarely	Sometimes	Frequently	Almost always
<b>Vestibular / motion (e.g. the sensation of moving, spinning, being upside down, sense of balance etc.)</b>	Never	Rarely	Sometimes	Frequently	Almost always
<b>Pain tolerance</b>	Never	Rarely	Sometimes	Frequently	Almost always

**20. How sensitive are you to the following sensory information compared to people without autism?**

<b>Sounds</b>	No different	Less sensitive (e.g. less likely to catch my attention, interest me, and / or bother me than someone without autism)	More sensitive (e.g. more likely to catch my attention, interest me, and / or bother me than someone without autism)	Unsure
<b>Smells</b>	No different	Less sensitive	More sensitive	Unsure
<b>Taste</b>	No different	Less sensitive	More sensitive	Unsure
<b>Touch / pressure or texture</b>	No different	Less sensitive	More sensitive	Unsure
<b>Visual things (e.g . lighting, colour, watching things that spin or move etc.)</b>	No different	Less sensitive	More sensitive	Unsure
<b>Vestibular (e.g. the sensation of moving, spinning, being upside down, balance etc.)</b>	No different	Less sensitive	More sensitive	Unsure
<b>Pain</b>	No different	Less sensitive	More sensitive	Unsure

**21. Participants indicating that that a particular domain is more or less sensitive they are asked to provide examples:**

- **More sensitive**
  - **Please give an example of the sorts of [sounds, tastes, smells, touch sensations, visual sensations, vestibular sensations] you are more sensitive to than people without autism**
  - **Please select the statement/s which best describes how this sound affects you:**
    - I notice it more than people without autism
    - I am more interested in it than people without autism
    - I am more bothered by it than people without autism
- **Less sensitive**
  - **Please give an example of the sorts of [sounds, tastes, smells, touch sensations, visual sensations, vestibular sensations] you are less sensitive to than people without autism**
  - **Please select the statement/s which best describes how this sound affects you:**
    - I notice it less than people without autism
    - I am less interested in it than people without autism
    - I am less bothered by it than people without autism
  - **Pain: Please given an example of your [high (less sensitive) / low (more sensitive)] pain tolerance**

## **Appendix D**

## Example items from the ADAPT

### Newcomer Role-Play

EXAMINER: I haven't lived in Adelaide very long. [*Waits 3 seconds for a response*]. It's so much warmer here. [*Waits 3 seconds for a response*].

#### SCORING:

0. Appropriate comments or questions that add to the conversation are used to respond to both prompts (i.e. the examiner's recent move AND the weather):
1. Responses to one prompt block further conversation:
  - E.g. the examinee does not respond or gives a monosyllabic reply
2. Responses to both prompts block further conversation

### Lift Vignette

#### VIGNETTE:

<http://bit.ly/2ddoyoS> [.mov file, opens with QuickTime or VLC Player]

EXAMINER: How appropriate was Sally's behaviour?

*1) Not At All Appropriate, 2) Slightly Appropriate, 3) Somewhat Appropriate, 4) Moderately Appropriate, 5) Very Appropriate.*

Why was Sally's behaviour X appropriate?

#### SCORING:

0. Gives a correct rating of 1, 2 or 3 AND an appropriate justification:
  - Sally was facing the lift passengers rather than the door
1. Gives an *incorrect* rating but an appropriate justification
2. A justification inconsistent with a 0 or 1 point response  
e.g. the examinee only refers to pushing in or phone use.

## Friendship Questionnaire

### INSTRUCTIONS:

Please describe your closest friend, if not applicable describe the person with whom you spend the most time beyond your spouse or partner.

#### a. I will be answering questions about

- My closest friend
- The person I spend the most time with
  - Neighbour
  - Sibling
  - Workmate
  - Other

#### b. When did you first meet this person?

- Days ago
- Weeks ago
- Months ago
- Years ago

#### c. This person lives

- An hour away or less
- Interstate
- Overseas
- Other \_\_\_\_\_

#### d. This person is \_\_\_\_\_ years older / younger than me

#### e. I see this person outside of work, university, TAFE or a group we both attend

- Daily
- Weekly
- Monthly
- Every couple of months
- Twice a year or less

#### f. How do you interact with this person?

- Face to face
- Virtual face-to-face communication e.g. FaceTime, Skype etc.
- Phone calls
- Emails, letters or texting
- Social media

**SCORING:**

0. The nominated friend meets the following criteria:
  - Differs from the examinee in age by no more than 5 years,
  - Lives in the same state,
  - Was met “months” or longer ago
  - Is seen face to face on a monthly basis, outside of a structured activity
1. As above but, the nominated friend reflects any of the following qualities
  - Has lived interstate for most of the friendship; is seen less than once a month; was met “weeks or days” ago.
2. The nominated friend is a spouse or family member

## Interview about Insistence on Sameness

### EXAMINER:

I am going to read out a list of errors people may notice in TV shows, films and books. Tell me which ones you notice:

- Lack of continuity to layout/appearance of characters, objects or places
- Plot or story universe error
- Characters actions inconsistent with plot / dialogue
- Factually incorrect
- Sound errors
- Editing errors (grammar, film editing)

*For each error endorsed.*

- How often you notice these errors?  
*Never, Rarely, Sometimes, Frequently or Almost Always*
- How do these errors affect you?

### SCORING

0. The examinee notices four or fewer errors at least sometimes
1. The examinee notices five or more errors at least sometimes
2. The examinee indicates that continuity errors cause adverse impact i.e. must stop reading or watching, feels angry or stressed,

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