# An Exploratory Study into the Cognitive Profile of those Ageing with Autism Spectrum Disorder

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**Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## Overview

The long-established view of Autism Spectrum Disorder being a childhood disorder has concentrated research on childhood and adolescence, while the study of adulthood Autism Spectrum Disorder has been neglected until recent years. Although research with young adults has been initiated, very little is known about the impact of ageing and the lifespan trajectory for those over the age of fifty and with high-functioning Autism Spectrum Disorder.

Part one of this thesis presents a systematic literature review of the efficacy of psychological interventions for adults with high-functioning Autism Spectrum Disorder and co-morbid psychiatric disorders. The literature review includes twelve studies. The findings suggest that the usual treatment interventions for neuro-typicals can be used with some adaptations for adults with high-functioning autism, and there is a need for robust evaluations of psychological interventions for different psychiatric disorders.

Part two presents an empirical paper that investigates the cognitive profile of adults over the age of fifty with high-functioning Autism Spectrum Disorder. A total of twenty-six adults participated in neuropsychological assessments of general abilities and memory. The results indicate that the cognitive profile may be uneven and that performance in some domains is weaker than others. The clinical implications are discussed with emphasis on the need for further research to improve the understanding of the ageing experience in those with Autism Spectrum Disorder.

Part three is a critical appraisal highlighting reflections on the research process undertaken in this thesis. It details the challenges experienced and the obstacles encountered during the process.

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**Part 1: Literature Review**



**Part 2: Empirical Paper**

# Part 1: Literature Review

## The Effectiveness of Psychological Interventions for Psychiatric Co-morbidity for Adults with Autism Spectrum Disorders

## Abstract

**Aims**: In the last few decades, the field of developmental disabilities has seen a surge of interest and growth in the research into Autism Spectrum Disorders (ASD). As the understanding of ASD increased, the overlap between ASD and other psychiatric disorders also emerged as an area of investigation. Affected adults may increasingly seek help from psychological interventions for psychiatric co-morbidity. This systematic review aims to evaluate the effectiveness of psychological interventions for psychiatric co-morbidity with adults who have been diagnosed with ASD.

**Methods:** Databases were searched for published papers between January 1993 and December 2015 that provided psychological interventions to adults with ASD and another psychiatric disorder. Twelve studies were identified and included in the review. A critical appraisal was conducted to assess the quality of the methodology of the studies.

**Results:** The review highlighted the scarceness of empirical studies in the area. Interventions focused mainly on cognitive behavioural aspects of therapy, with some adaptations of manualised treatment and mindfulness-based interventions, delivered via individual therapy or group based interventions.

**Conclusion:** The growth of research in psychological interventions is mainly in CBT interventions for adults with ASD, yet there is still a long way to go. There is evidence of a successful reduction of the symptoms of obsessive compulsive disorder, anxiety and mood disorder with the use of psychological interventions for adults with ASD. The review emphases the need for further rigorous research and highlights the limited therapeutic interventions available for adults with ASD.

# Introduction

## What is ASD?

Autism Spectrum Disorder (ASD) is a complex, lifelong neurodevelopmental condition, characterised by impaired social interaction, communication, restrictive interests and repetitive behaviour (Hill, 2004; Geurts & Vissers, 2012). ASD affects a person's ability to communicate, form relationships and respond appropriately to the environment (Newschaffer et al., 2007). What was once divided into diagnostic labels of Autistic disorder, Asperger's syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) is now Autistic Spectrum Disorder in the revised *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM–5*; American Psychiatric Association, 2013).

Traditionally, ASD was regarded as a severe neurodevelopmental disorder, characterised by overt language deficits, learning problems and low intellectual abilities (Levy & Perry, 2011). However, in recent years, there has been a greater recognition of individuals with ASD who do not have abnormal language, learning disabilities or low intelligence. DSM-5 describes individuals with ASD as having significant variability in symptom expression and in the level of cognitive functioning (De-la-Iglesia & Olivar, 2015). There is a growing understanding and increasing recognition of the etiological heterogeneity of ASD and this reformulation of the diagnostic criteria brings the attention back to the diversity within ASD (Bentacur, 2011). Alongside the core features of ASD, there are associated dimensions such as intelligence and language ability as well as characterisation defined by the presence of known medical, genetic and psychiatric disorders which highlight the multiplicity (Ousley & Cermak, 2014).

The relationship between anxiety and core ASD symptoms is complex because it is difficult to separate anxiety or OCD from the core features of ASD due to symptom overlap (Kerns & Kendall, 2012). Over the years, research into the difficulties children with ASD experience has received much more interest than adults with ASD. It has shown that, regardless of the intellectual abilities, age or ASD symptoms, children and adolescents with ASD have an increased risk of depression and/or anxiety (Strang, Kenworthy, Daniolos, Case, & Wills, 2012). Research has also found that children with ASD have high rates of Attention Deficit Hyperactive Disorder (ADHD) and other studies have found high rates of autistic symptoms among those with ADHD (Simonoff et al., 2008). Studies have found psychosocial treatments including CBT to be effective in reducing anxiety and OCD symptoms in children (Simonoff et al., 2008). Although research with children with ASD has found that the rates of co-morbidity are high (Buck et al., 2014) nonetheless it is not clear whether these findings reflect the adult population (Joshi et al., 2013). There is a high risk of young people and adults with ASD acquiring mental health problems and for that reason uncovering co-morbid disorder in this population is imperative (Findon et al., 2016).

**People with ASD have high psychiatric co-morbidity**

Psychiatric co-morbidity is understood as having the presence of another psychiatric disorder as categorised in DSM-IV-TR (4th ed., *DSM–IV–TR*; American Psychiatric Association, 2000) in conjunction with ASD. There is an uncertainty as to why adults with ASD have high rates of co-morbid disorders (Leyfer et al., 2006). Literature is gradually growing around the theme of co-morbidity in psychiatric disorders and shows that individuals with ASD seem to be vulnerable to various psychiatric and neurological disorders. What is certain is that co-morbid disorder can

impact the core ASD characteristics, which may worsen as well as increase functional impairment (Buck et al., 2014) and that quality of life can suffer due to the coexisting psychiatric conditions (Sterling, Dawson, Estes, & Greenson, 2008). Roy and colleagues (Roy, Prox-Vagedes, Ohmeier, & Dillo, 2015) investigated psychiatric co-morbidity across a broad age range of 20 – 62 years and they found that 70% of adults with ASD had at least one co-morbidity, emphasising the low levels of mental health. A possible explanation for the increase in co-morbid mental health problems in older adults is the increasing complexity of social interactions. As age increases, social interactions increase in complexity and become more demanding for those with hf-ASD and their difference is more noticeable (Hillier, Fish, Siegel, & Beversdorf, 2011).

Co-morbid mental health conditions are highly prevalent in ASD and include anxiety and mood disorders (Matson & Williams, 2014; Joshi et al., 2013; NICE 2012), obsessive compulsive disorder (OCD) and attention deficit disorder (Hesselmark, Plenty & Bejerot, 2014). In those with ASD without learning disabilities there is a greater rate of depression and anxiety (Hofvander et al., 2009). Mental health problems may co-exist with other problems such as anger, disrupted sleep, restricted appetite and social withdrawal (Maskey, 2013; Stewart, Barnard, Pearson, Hasan, & O'Brian, 2006); eating disorders, substance abuse and bipolar affective disorder are also experienced (Anderson, & Morris, 2006 and Matson, & Williams, 2014). Many people, who have less severe forms of ASD, can be misdiagnosed with depression, anxiety, schizophrenia, OCD, borderline or other personality disorders (Tebarzt van Elst, Pick, Biscaldi, Fangmeier, & Riedel, 2013).

Depression is possibly more common in adults with ASD and anxiety related concerns are a common problem for school-age children and adolescents (Ghaziuddin, Ghaziuddin, & Greden, 2002). The chances of depression increase with age, and adolescents and young adults with ASD are predominantly vulnerable (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). Individuals with ASD also frequently suffer from anxiety disorders (Sukhodolsky et al., 2008) and this may arise from the distinguishing features of ASD such as fear of change or uncertainty (Stewart et al., 2006). This adds to the complexities in assessing co-morbidities.

Those with ASD have certain characteristics such as neutral facial expressions, social withdrawal and self-injurious behaviour, all of which can mimic anxiety and depressive symptoms, highlighting the challenges of assessing for co-morbidity. Kerns and Kendall (2012) highlighted the need for greater clarification about the development and purpose of anxiety in people with ASD. They questioned whether anxiety can be understood as connected to features of ASD or an unconnected condition and they indicated that there is a possibility of overlap between the core symptoms of ASD and the symptoms of anxiety.

Alongside these conditions, adults with ASD may have faced bullying during school years (Bejerot & Humble, 2013), can also face social challenges and low self-esteem (Tantam, 2000). As adults, they report not having friends (Shattuck & Grosse, 2007) and remain single (Rydén & Bejerot, 2008). Impairment in social interactions is a feature in individuals with hf-ASD, adding to their difficulties in intuition regarding recognising non-verbal body language and applications of social rules (Roy et al., 2015). All of these factors multiply the existing difficulties with independent living and functioning both socially and occupationally (Matson & Williams, 2014).

Furthermore, individuals with hf-ASD may reach adulthood without being diagnosed and rely on carers and or family members; so, when they have a co-morbidity, the burden on carers is also increased (Cadman et al., 2012; Karst et al., 2012) and emphasises the need to develop appropriate treatment (NICE, 2012). To plan services in the community and increase the quality of life for individuals with ASD, it is essential to understand the adult outcomes linked with ASD (Howlin et al., 2004).

**Interventions for psychiatric co-morbidity**

Although ASD is a lifelong condition and has prevalence figures of above 1% (Brugha et al., 2012), the investigation of the efficacy of psychological therapies for co-morbid mental health conditions on this population is limited (Tebartz et al., 2013). It is reasonable to expect in the coming years an increase in the number of individuals with an ASD diagnosis reaching adulthood who do not have intellectual disabilities. This is because research shows that approximately 70% of people with ASD are aged less than 14 years (Gerhardt & Lainer, 2011) and many of these will have hf-ASD and are therefore not entitled to access learning disabilities services (Bishop-Fitzpatrick, Minshew, & Eack, 2013). With a growing population of individuals with ASD, there is a greater need to provide help and support. However, there is limited work around the best and most effective methods to treat adults with ASD in the community (Bishop-Fitzpatrick et al., 2013). Over the last two decades, various types of therapies have been proposed to improve symptoms of ASD such as pharmacological, behavioural and complimentary therapies such as diet modifications, vitamin therapy, occupational therapy and speech and language therapy (Ospina, Seida, Clark, & Karhaneh, 2008).

A considerable amount of literature has been published on psychological interventions mainly with children and adolescents, and a growing number of studies with adults with ASD. However, the focus has been to improve the symptoms associated with ASD (Joshi et al., 2013) rather than to improve psychiatric co-morbidity. One of the reasons for reduced interest in research may be due to the expectation that people with ASD may have difficulty in engaging in therapeutic relationships. More specifically, their difficulties in communication, social interaction, flexibility of thinking (Tebartz et al., 2013) and behaviour (Bishop-Fitzpatrick et al., 2013) have been thought to preclude psychotherapy. Empathy, warmth, congruence, (Lambert & Barley, 2001) working alliance and a therapeutic relationship are essential components to any intervention (Gelso & Carter, 1994). There is an assumption in psychotherapy that when an individual seeks therapy, they have the cognitive skills required as well as a certain level of perception and capacity to develop insight and self-awareness, though it has been suggested that such an assumption may not hold true for those with ASD (Anderson & Morris, 2006).

Nonetheless, several case studies of psychological interventions with individuals with ASD have highlighted elements of CBT to be effective despite difficulties in therapeutic relationships due to deficiencies in ToM (Hare, 1997). Various studies with children with ASD and co-morbidity have found psychological interventions effective. These raised the prospect for making adaptations to CBT techniques to aid treatment (Anderson & Morris, 2006). CBT is an appealing form of treatment due to the need for structure and predictability. Besides CBT, there are many more psychological interventions available, but can it be effective with adults with ASD.

**The rationale for this review**

There has been an increasing interest in providing psychological interventions to help individuals with ASD who have a co-morbid mental health diagnosis. Recent reviews have concentrated on ASD and certain co-morbid conditions, for example, anxiety, depression, bipolar and schizophrenia (Vannucchi et al., 2014; Seida et al., 2009; Ghaziuddin et al., 2002), and some have looked at interventions for these mental health conditions (Binnie, & Blainey, 2013; Lang, Regester, Lauderdale, Ashbaugh, & Haring, 2010; Ospina et al., 2006; Spain, Sin, Chalder & Murphy, 2015; Steward, Watson, Allcock, & Yaqoob, 2009). These reviews have mainly focused on CBT interventions including 'third wave' interventions. They have suggested that, alongside adaptation and modification, there is a need to develop specific tools (Stewart et al., 2006), add components of applied behaviour analysis and increase the number of sessions (Spain et al., 2015) with an emphasis on incorporating social and coping skills (Gaus, 2011). Spain and colleagues (Spain, Harwood, & O'Neill, 2015) presented an evaluation summary of a systematic review of studies that carried out CBT interventions for adults with co-morbidity and hf-ASD (Spain et al., 2015) and a systematic review of group social skills interventions with adults with hf-ASD (Spain & Blainey, 2015). They highlighted the dearth of research in the area of interventions for co-morbidity with hf-ASD. The majority of the studies included in previous reviews did not fully employ randomised control trial (RCT) conditions therefore quality assessment was not conducted. However, since these reviews were published, further research has taken place and other interventions have been evaluated; exploring these findings will add to the current knowledge in this area.

To date, there has not been a review of the efficacy of the various psychological interventions implemented or an assessment of the quality of the studies for hf-ASD and psychiatric co-morbidity. There is a need to learn about the efficacy of psychological interventions for adults with hf-ASD and whether they help reduce the symptoms of co-morbidity. These findings make new contributions to the existing knowledge by highlighting the effectiveness of interventions and the quality of the studies evaluating the interventions. This review evaluated intervention for a number of psychiatric conditions using different psychotherapeutic modalities, which adds to previous reviews that have only looked at CBT for specific conditions. The findings can also have implications on the services and treatment provided to individuals with ASD.

**Research aims**

The aim of this review is to systematically explore and update the knowledge base on the available evidence, to look at the effectiveness of different psychological interventions provided to adults with ASD and to critically appraise evidence in relation to the following question:

- How effective are psychological interventions for adults with high functioning ASD to help reduce co-morbid psychiatric symptomology?

## Methods

This review used quantitative studies and supplemented the use of a formal checklist with critical appraisal. It is advised to use a mixed-method approach when conducting a systematic review, as it helps to retain the authenticity of the findings, as both qualitative and quantitative research are examined to give a complete understanding (Harden & Thomas, 2005). A systematic review of the effectiveness of psychological interventions for co-morbidity with adults with ASD was conducted. Searches were carried out in PubMed, PsycInfo, and Web of Knowledge databases. Studies were identified and copies obtained, then a critical appraisal was carried out to assess the methodological rigour of each study using the Clinical Trial Assessment Measure (CTAM) (Tarrier & Wykes, 2004). This instrument was specifically designed to include features that are important in assessing psychological treatments in mental health. The CONSORT (Consolidated Standards of Reporting Trials) guidelines, which help in the reporting of randomised controlled trials, were used in the development of the CTAM. Clinical trials of CBT interventions have been assessed using the CTAM. The rating scale of CTAM examines variability in clinical trials through answering a number of questions pertaining to methodology.

### Search strategy

Electronic searches were conducted using PubMed, PsycINFO and Web of Knowledge databases. A list of search terms were identified based on previous review and after preliminary searches as well as several trial and error attempts (Binnie & Blainey, 2013; Bishop-Fitzpatrick et al., 2013; Spain et al., 2015; Steward et al., 2006; Vannucchi et al., 2014). The final search terms included: autis*, autis* spectrum

disorder*, Asperger*, development* disorder and psychological therap*, talking therap*, behavio* therap*, cognitive therap*, psychodynamic therap*, third wave approaches, psychological intervention*, treatment*, mindfulness, ACT, metacognitive therap*, self-help, psycho-education. To maximise the scope of the search no stipulation was made on outcomes. As the Cochrane guidelines suggest the searches incorporated Boolean operators so 'AND' and 'OR' were used. The same procedure was used for each of the databases. Searches were for studies published between January 1993 and December 2015. This timespan was chosen in line with previous reviews, which did not offer studies earlier than this date for ASD and co-morbidity (Bishop-Fitzpatrick et al., 2011; Spain, Harwood & O'Neill, 2015; Stewart et al., 2006; Vannucchi et al., 2014). The screening of titles and abstracts took place as well as checking of references to identify eligible articles and, when required, full publications were examined to check suitability.

**Inclusion criteria**

Inclusion criteria for the study design were left broad, in order to capture as many articles as possible. Any study evaluating interventions targeting conditions commonly associated with ASD was included, such as all types of anxiety including stress, social anxiety, generalised anxiety, post-traumatic stress disorder and obsessive compulsive disorder (OCD), various affective disorders including depression, bipolar disorder and mania. The study population comprised adults with ASD with or without any major physical illnesses. McGillivray and Evert (2014) characterised young adults as those over the age of 15 years and previous reviews (Spain et al., 2013) have included studies (Russell et al., 2013) with older adolescents alongside adults with ASD due to the substantial lack of studies (Vannucchi et al., 2014); therefore, studies

with adolescents over the age of 15 years were included. Studies that provided a quantitative evaluation of psychological intervention (NICE, 2011a, 2012) were included. Studies that were published in English were included.

**Exclusion criteria**

Exclusion criteria included studies that were not primary research articles (commentaries, theses, and books) and studies that were not published in English. Studies without ASD participants, and those with adults with ASD and also learning disabilities or substance misuse were excluded. Studies that looked at physical illness only or did not measure psychiatric co-morbidity or did not include a psychological intervention were excluded. Studies that focused on children only or both children and adults together were excluded. Studies that focused on improving the core symptoms of ASD rather than psychiatric co-morbidities were also excluded.

The titles and abstracts were screened to identify suitable publications. Following the selection, full articles were obtained and references were hand searched for other eligible publications; none were included in the review. Figure 1 shows the selection process. The articles were evaluated against the inclusion and exclusion criteria. A citation program, EndNote Web, was used to collate the articles viewed and searches made for later usage.

**Data extraction**

A total of 1356 articles were initially retrieved; in the early screening duplicates were removed and screening took place. The remaining articles (293) were screened against the inclusion and exclusion criteria resulting in the removal of 252 articles. The full texts of the remaining studies were obtained and read (N = 41) of which 29 articles

were excluded (reasons are summarised in Figure 1). A total of 12 articles were identified and included in the review. Then the data extraction and quality assessment on each study was performed.

Data extraction included the identification of the same information from each paper based on the CTAM and other factors relevant to critically appraising the paper. The essential information was organised and presented in Table 1.

## Results

The searches were conducted on PubMed (93), PsycINFO (391) and Web of Knowledge (872). The searches yielded a total of 1356 studies between the year 1993 and 2015. Initially, duplication of studies removed a further 105 and a further 958 studies were excluded after screening of the titles. After the inclusion and exclusion criteria were applied, a further 275 articles were excluded.

Finally, 12 studies were recognised as providing psychological interventions to adults with hf-ASD who had other psychiatric co-morbidity. The included studies were generally similar in their methodologies and represented a few categories of intervention. The final studies were then summarised in terms of the following features: a) year and country of publication, b) sample characteristics, allocation to treatment and co-morbid diagnosis, c) intervention type, number of sessions, duration, description of treatment and techniques used, d) assessment of outcome and measures used, e) findings and analysis, f) study strengths and limitations. Various procedural aspects were also noted alongside aspects of study design that may bias findings such as allocation concealment, randomisation, and descriptions of dropouts, withdrawals,

follow-up procedures and blinding. A list of studies and their characteristics are detailed in Table 1.

*Figure 1: Search and screening process*

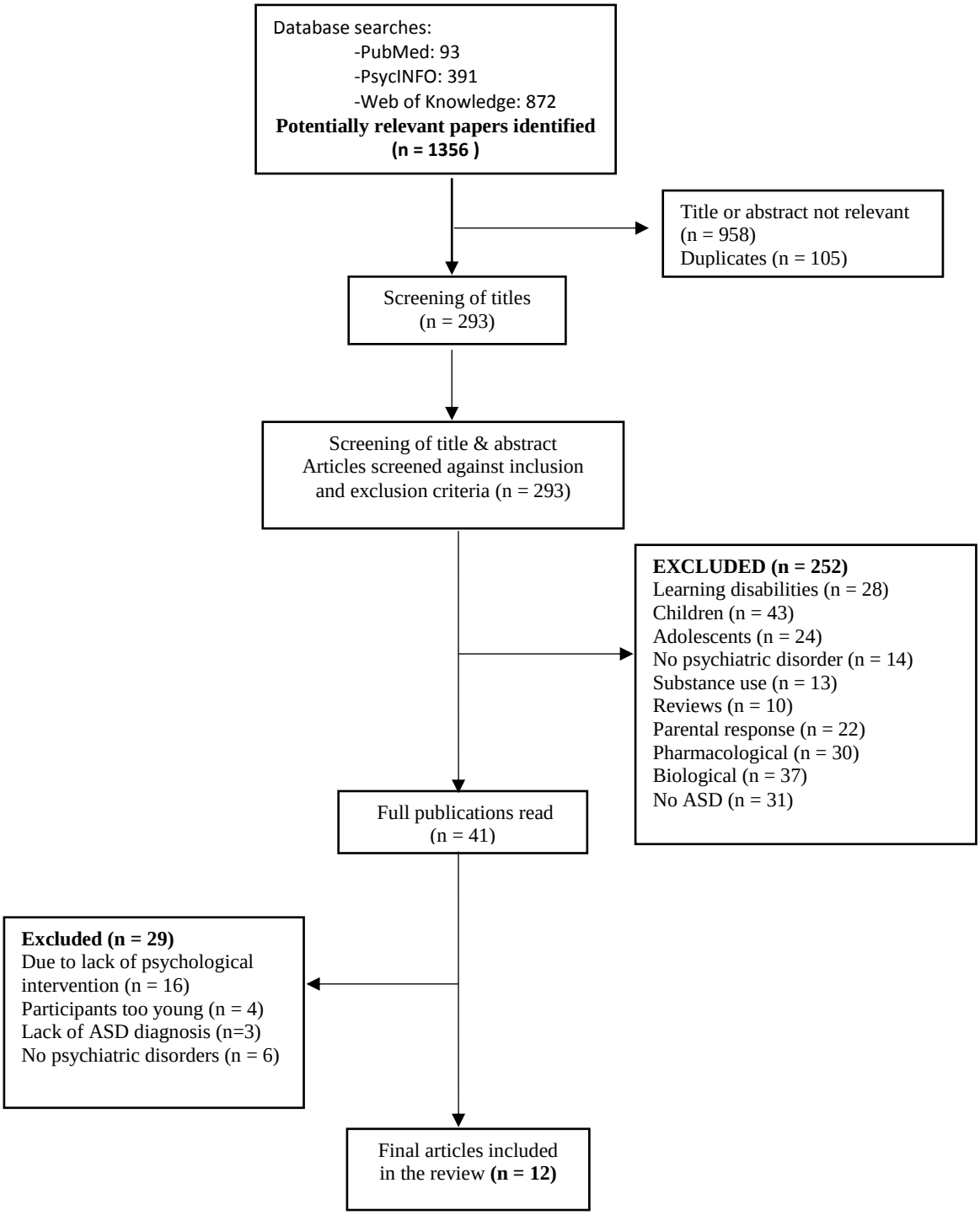

Table 1: SUMMARY OF STUDIES:

**The effectiveness of psychological interventions for adults with psychiatric co-morbidity and ASD**

| Study & Location | Method & Sample | Intervention | Outcome measures | Key findings |
|---|---|---|---|---|
| Cardaciotto and Herbert (2004)<br><br>USA | Case Study<br><br>N = 1 adult<br>male, 23yrs old<br><br>Asperger's syndrome<br>Depressive symptoms and Social phobia | *Number of sessions:* 14 weeks<br>*Session duration:* not specified<br><br>*Techniques:* CBT based treatment protocol, focusing on reporting feared and avoided situation, initiating, maintain and ending conversations. Social skills training, skills rehearsal (role plays), cognitive restructuring, weekly homework, thought listing, cognitive restructuring. | ASDI<br>SPAI (1st session)<br>LSAS,<br>BDI-II<br>CGI-S (role-play)<br>1) Pre<br>2) mid treatment<br>3) Post<br>4)follow up- 2 mths | • Social anxiety and low mood improved.<br>• Improvement in social skills was limited, possibly more profound impairments.<br>• May require longer course of social skills training<br>• Treatment modified social skills training may address the more fundamental deficits.<br>• Independent assessor rated CGI-S, videoed tasks were randomly presented and raters blind to assessment.<br>• At follow-up reduced anxiety, but avoidance of social situations<br>• Evidence of maintenance of treatment gains. |
| Hare 1997<br><br>UK | Case study<br><br>N = 1 adult<br>male, 26 yrs old<br>Asperger's syndrome<br>Severe depression, low mood, self-harm | *Number of sessions:* 15 weeks<br>*Session duration:* 30-60 min<br>2 session = Assessment<br>10 session = weekly<br>5 weekly = fortnightly<br><br>*Techniques*: emotional literacy, graded exposure, cognitive restructuring, relaxation and distractio**n** | BDI-II (weekly)<br>WASI-R<br>Idiosyncratic record of self-harm incidents<br><br>1) Pre<br>2) Post<br>3) Follow-up 6mths<br>3) Follow up- 8mths | • Improvements in low mood symptoms – BDI 55% reduction at end of sessions.<br>• Majority goals achieved<br>• Reduced frequency of self-harm<br>• Anxiety high initially for 6wks, then reduction - BDI scores<br>• Individualised adaptation of CBT<br>• Accurate diagnosis of AS may have helped reduce depressive symptoms.<br>• Evidence of maintenance of treatment gains |

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| Hare, Gracey & Wood (2016)<br><br>UK | Randomised Control Trial- Pilot study<br><br>N=9 adults<br>5 males, 4 females<br>Age range 18-65<br>HFA, Mean IQ = 120 | *Number of sessions:* 6 days (3 baseline phase and 3 RTSM phase)<br>*Session duration:* between 10am-4pm, 10 reminders for 3 days to complete personal digital assistance PDA<br><br>*Techniques:* Personal Digital Assistance device used to complete questions about thought content, form of thoughts, attentional style, length and level of rumination of subjective anxiety, for baseline.<br>Then 3 days of real time stress management (RTSM) intervention phase – programmes on relaxation, attention shifting, deep breathing, positive self-talk, positive & distracting imagery-strategies presented when their reported anxiety levels were high | AQ<br>HADS<br>WASI<br>BPVS-II<br><br>1) Pre<br>2) Post<br>No follow up | • 'Proof of Principle' study using new method of recording thoughts. Used phenomenology to code and investigate anxiety<br>• Significant reduction of subjective reporting of anxiety. Anxiety decreased from the pre-treatment baseline level to the RTSM phase and after a stress management technique was used.<br>• Measuring and rating phenomenology is difficult. Electronic/digital gadgets reliability (people getting frustrated etc detailed questions) |
| Hesselmark, Plenty and Bejerot (2014)<br><br>Sweden | Preliminary randomised controlled trial<br><br>N = 54 adults<br>Age range 19-53yr (Mean = 31.8yr) | *Number of sessions:* 36<br>*Session duration:* 3 h<br><br>*Techniques:* CBT-manualised interventions, introducing 'acceptance & change' from Dialectical Behavioural Therapy (adapted). Included 5 elements of CBT structure, group setting, psycho-education, social training, cognitive behavioural techniques | QOLI<br>SoC<br>RSES<br>PCGI<br><br>SCL-90, AQ, ADOS, BDI, ASRS, CGI-S, CGI-I<br>1) Pre | • There was an increase in quality of life reported by participants in both groups.<br>• Both interventions seem to be effective treatment for adults with ASD.<br>• CBT has additional benefits of increasing specific skills and minimise dropout.<br>• Highlighted shortage of treatment options for ASD. CBT intervention used manualised approach. |

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| | CBT group (n = 35) Vs Social group (recreational activity n = 40) | Recreational activity included visiting suggested activities, and designed to control for social interaction effects | 2) Post<br>3) Follow up between 8 to 57 months | • CBT resulted in less attrition than RA. CBT group rated themselves more improved post treatment |
| Hillier, Fish, Siegel and Beversdorf (2011)<br><br>USA | Quasi-experimental Study<br><br>N = 49 young adults<br>42 males, 7 females<br>Age range 18-28, (Mean age 21)<br><br>9 groups of 5-7 young adults | *Number of sessions:* 8<br>*Session duration:* 1 h weekly<br><br>*Technique:* Group of 5-7 participants, group discussions- focused on improving social and vocational skills<br><br>Curriculum covered:<br>1. Introduction<br>2. Social Communication<br>3. Relationship<br>4. Social event<br>5. Independent living<br>6. Independence and college<br>7. Employment<br>8. Conclusion & Review | BDI-II<br>STAI<br>IPR- introduced later<br><br>1) Pre<br>2) Post<br>No follow up, but monthly reunions to transfer skills learned | • The Aspirations Program model used in group settings to reduce self-reported feelings of anxiety and depression in young adults<br>• Significantly lower rates of depression and anxiety.70% reported reduced anxiety, 77% reduced dep.<br>• Effect size small for anxiety & depression<br>• (58% reported improvement in peer r/ship – not sig)<br>• Group interactions helped social interactions.<br>• Format approximate a counselling support group<br>• Parents also encouraged to attend weekly self-directed parent's group |

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| Kiep, Spek and Hoeben (2015)<br><br>The Netherlands | Quasi-experimental study<br><br>N = 50 adults<br>34 males (Mean 42.1yr)<br>16 females, (mean 37.9)<br>Matched on age<br><br>5 Training groups x 10 participants. 9wk program<br><br>Depression, anxiety and/or rumination | *Number of sessions*: 9<br>*Session duration:* 2.5 hrs<br><br>*Technique:* Practice 40-60 min meditation at home for 6 days a week. 5 min breathing exercise instead of 3 mins<br><br>(Followed sessions plan -Spek et al 2013)<br><br>Practice 40-60 mins of meditation at home, 6 days a week and incorporate mindfulness skills into daily routine | Primary measures<br>SCL-90-R,<br>RRQ,<br>GMS<br><br>ADI-R<br>Effects measured at 3 intervals, 3 self-reported ques.<br><br>1) Pre- MBT<br>2) Post<br>3) Follow up- 9 wks | • Significant decline in symptoms of anxiety, depression, agoraphobia, somatisation, etc.<br>• Positive affect increased, rumination declined. Hostility symptoms did not decline<br>• All symptoms stable between phase 2 and 3 MBT-AS effective in reducing psychological and physical symptoms for longer<br>• Larger sample size = statistical power. Inclusion exclusion provided.<br>• Average to high intelligent adults can be easier to be taught<br>• Positive effects of MBT-AS can be linked to ruminations<br>• Not known whether effects remain later.. |
| Koenig and Levine (2011)<br><br>USA | Case Study<br>N = 1 adult<br><br>1 female, 24 yrs old<br>Asperger's syndrome<br><br>Obsessive-compulsive symptomology | Psychodynamic therapy<br><br>Learning to accept alternative set of expectations others may have<br>Anger, screams and violent when in conflict | Not mentioned | • Details are vague<br>• Recommends – Psychotherapy may be appropriate for individuals with ASD with adjustment<br>• Does not provide details of adaptations<br>• Danger of misinterpreting |

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| McGillivray and Evert (2014) Australia | Quasi-experimental study<br><br>N = 32 young adults, aged 15-25<br>Mean age 20.6<br>Asperger's (n=23, 72%)<br>HFA (n=9, 28%)<br><br>Group CBT(n=26) vs Waiting list (n=16)<br><br>[6 from waiting list later completed program] | *Number of sessions:* 9<br>*Session duration:* 2 h<br><br>*Techniques:* Manualised<br>'Think well, feel well and be well' program<br>Curriculum covered:<br>1. Introduction<br>2. Recognise stressful situations<br>3. Recognition emotions<br>4. Re/ship between events thoughts & feelings<br>5. Review key concepts<br>6. Managing own critical voice<br>7. Re/ship between thoughts, feelings and beliefs<br>8. Coping styles<br>9. Review, summation and celebration | DASS<br>ATQ<br>ASSQ<br><br>1) Pre- group<br>2) Post –group<br>3) Follow up- 3mths<br>4) Follow up- 9 mths | • Group CBT for depression and stress<br>• Manualised intervention developed to address social difficulties young adults with ASD experience, which can lead to negative view of themselves and r/ship with others<br>• Group CBT intervention found reduction of negative symptoms in depression.<br>• No significant change in anxiety<br>• The way anxiety was measured may have prevented change.<br>• Improved over time regardless which group.<br>• Cognitive techniques - not possible in groups<br>• Inclusion criteria needs to be more stringent |
| Russell, Mataix-Cols, Anson and Murphy (2009)<br><br>UK | Quasi-experimental, non-randomised trial<br><br>N = 24 adults<br>21 males, 3 females<br>CBT for OCD (n=12) vs TAU (n=12) | *Number of sessions:* 10-50 sessions (mean 27.5 sessions)<br>*Session duration*: 1hr<br>*Technique:* Treatment not manualised or protocol driven.<br>Standard CBT for OCD with some adaptations – comprising exposure and response prevention & cognitive appraisal of OCD related beliefs | YBOCS<br>BDI<br>BAI<br>50% of the YBOCS completed by treating therapists<br>1) Pre-<br>2) Post<br>No follow up | • OCD symptoms in ASD do not show change over time in absence of treatment<br>• Considerable improvement shown with standardised CBT for OCD with ASD population<br>• CBT for OCD can be conducted as usual with some adaptations<br>• 7 participants (58%) improved with CBT, 2 participants (16%) improved in TAU group<br>• 40% of participants in CBT group were non responders.<br>• CBT group had severe OCD symptoms |

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| Russell, Jassi, Fullana et al. (2013)<br><br>UK | Randomised Control Trial<br>N = 35 adults<br>Age range 14-65,<br><br>CBT for OCD (n=20) vs anxiety management (AM) (n=17)<br><br>CBT-Mean age 28.6<br><br>AM - Mean age 25.2<br><br>A proportion of those under the age of 18<br>N = 6 (AM) N =3 (CBT) | *Number of sessions:* 20 sessions<br>Mean CBT: 17.4<br>Mean AM: 14.4<br>*Session duration:* 1h<br>*Techniques*: Adapted CBT for OCD including emotional literacy, exposure-based tasks, cognitive restructuring<br><br>**CBT**-predominantly exposure and response prevention based (ERP) Standard CBT for OCD adapted by<br>1. Ensuring building blocks for treatment<br>2. If required additional sessions provided<br>3. Visual tools and special analogies used to convey psychological concepts<br>4. Structured, therapist directed approach to sessions and homework<br>**AM**- General anxiety reducing teaching inc. Psycho-education, relaxation, healthy habits and problem solving | YBOCS<br>BDI<br>BAI<br>CGI<br>WSAS<br><br>Blind clinical assessor, self and informant ratings at<br><br>1) Pre<br>2) Post<br>3) Follow up at 1mth<br>4) Follow up at 3mths<br>5) Follow up at 1year | • First RCT for CBT, OCD and ASD.<br>• CBT for co-morbid OCD in high functioning ASD<br>• Both CBT and AM conditions found improvements in OCD symptoms.<br>• CBT had 45% treatment responders whereas 20% in AM group<br>• There was no differences between treatment at pre, post and no significant differences between CBT and AM<br>• AM also effective in reduction of OCD symptoms although did not contain any ‘active’ elements used for OCD treatment.<br>• Manualised approach |

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| Spek, van Ham and Nyklicek (2013)<br><br>The Netherlands | Randomised Control Trial<br><br>27 males, 14 females<br>Mean age 44.4 (MBSR)<br>Mean age 40.1 (WL)<br>MBSR n =20, WL=21<br><br>Manualised approach<br>ASD diagnosis<br>anxiety, depression<br>rumination | *Number of sessions:* 9<br>*Session duration:* 2.5 h<br>*Techniques:* Mindfulness-based techniques including meditation<br><br>Program covered:<br>1. Rationale & program content<br>2. Body scan<br>3. Physical reactions to stress<br>4. A sitting meditation, focused breathing<br>5. Review key concepts<br>6. Managing own critical voice<br>7. Re/ship between thoughts, feelings and beliefs<br>8. Coping styles<br>9. Review, summation and celebration | ADI-R<br>SCL-90-R<br>RRQ<br>DGMS, positive affect sub-scale<br><br>Verbal comprehension on WAIS-III<br><br>1) Pre<br>2) Post<br>No follow up | • Group MBT-AS showed improvements in depression, anxiety and rumination compared to waiting list control group.<br>• Increase in positive affect<br>• Rumination may be helpful<br><br>• Group training of 10/11 patients<br><br>• Therapists were trained in Mindfulness and practiced MBT-AS individually for 8 mths<br>• Small sample, reduced power may increase Type I error. |
| Weiss and Lunsky (2010)<br><br>USA | Group-based case series<br><br>2 males in mid 50s and 1 female in 30s | *Number of sessions:12*<br>*Session duration: 60 mins*<br>*Techniques:* emotional literacy, cognitive restructuring, behavioural experiments | BDI-II<br>SCID<br>BAI<br>WASI | • CBT has benefits<br>• Group CBT can be advantageous<br>• Reduction on anxiety near end but no change reported in self report<br>• Structure and predictability is useful<br>• First group therapy targeting mood and anxiety in adults |

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| Asperger's syndrome<br>Depression, PTSD, agoraphobia<br>Manualised approach<br>Community services or self referral<br><br>Group CBT – structured<br>'Mind over Mood' workbook | General topics covered:<br>1. Explanation of CBT<br>2. Explanation of cognitive model<br>3. Delineation of moods + ratings<br>4. Situation/activity/mood monitoring<br>5-7. Thought records, hot thought, examining and balanced thoughts<br>8. Explored strengths<br>9. Behavioural experiments<br>10-11. Action plans<br>12. Termination and feedback | 1) Pre<br>2) Post<br>3) Follow up- 1wk with two of the three participants | • Clients had heterogeneous array of problems, lack of uniformity therefore comparisons cannot be made<br>• Same structure every week<br>a. Setting agenda<br>b. Check in & homework review<br>c. New content<br>d. Assigning homework<br>e. Feedback |

AQ = Autism Spectrum Quotient; HADS = Hospital Anxiety & Depression Scale; WASI = Wechsler Abbreviated Scale of Intelligence; QOLI = The Quality of Life Inventory; SoC = Sense of Coherence; RSES = The Rosenberg Self-Esteem Scale; SCL-90 = The Symptom Checklist; BDI = Beck Depression Inventory; ASRS = The Adult ADHD Self-Report Scale; CGI-S = Clinical Global Impression Scale-Severity; CGI-I = Clinical Global Impression Scale- Improvement; DASS = Depression Anxiety Stress Scales; ATQ = Automatic Thoughts Questionnaire; ASSQ = Anxious Self-Statements Questionnaire; BDI-II = Beck Depression Inventory; BAI = Beck Anxiety Inventory; STAI = State-Trait Anxiety Inventory; IPR = The Index of Peer Relations; SPAI = Social Phobia & Anxiety Inventory; LSAS = Social Anxiety Scale; SUDS = Subjective Units of Discomfort Scale; ASDI = Asperger's Syndrome Diagnostic Interview; ADI-R = The (Dutch) Autism Diagnostic Interview; ADOS = The Autism Diagnostic Observation Schedule; SCL-90-R = The Symptom Checklist -90-Revised; RRQ = The Rumination Questionnaire; GMS = The Dutch Global Mood Scale; ADI = Autism Diagnostic Interview; YBOCS = Yale-Brown Obsessive Compulsive Scale; WSAS = The Work & Social Adjustment Scale; PR-CHOCI-R = Children's Obsessive Compulsive Inventory – Parent Version; SCID-I/P = Structured Clinical Interview of DSM-IV; SSTC = The Suitability for Short-Term Cognitive Therapy Interview; AAA = Adult Asperger's Syndrome Assessment

Table 2: Quality assessment of included studies using - The Clinical Trials Assessment Measures (CTAM) {case studies not included}

| **Study & Year** | **Psychological Intervention** | **Sample** | **Allocation** | **Assessment** | **Control** | **Analysis** | **Treatment Description** | **TOTAL CTAM** |
|---|---|---|---|---|---|---|---|---|
| | | *(Max 10)* | *(Max 16)* | *(Max 32)* | *(Max 16)* | *(Max 15)* | *(Max 11)* | *(Max 100)* |
| Hare, Gracey & Wood (2016) | Real-Time Stress management for everyday stress and anxiety | 3 | 0 | 17 | 0 | 10 | 5 | **35** |
| Hesselmark, Plenty and Bejerot (2014) | Group CBT for various psychiatric co-morbidity | 7 | 14 | 29 | 12 | 11 | 8 | **81** |
| Hillier, Fish, Siegel and Beversdorf (2011) | Social & vocational skills for anxiety and depression | 5 | 0 | 6 | 0 | 9 | 5 | **25** |
| Kiep, Spek and Hoeben (2015) | Mindfulness based therapy for depression, anxiety and rumination | 5 | 0 | 15 | 0 | 7 | 8 | **35** |
| McGillivray and Evert (2014) | Group CBT for depression and stress | 6 | 7 | 13 | 10 | 11 | 6 | **53** |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Russell, Mataix-Cols, Anson and Murphy (2009) | CBT for OCD | 4 | 0 | 6 | 6 | 4 | 8 | **28** |
| Russell, Jassi, Fullana et al (2013) | CBT for OCD | 7 | 14 | 30 | 14 | 12 | 9 | **86** |
| Spek, van Ham and Nyklicek (2013) | Mindfulness-based therapy for depression, anxiety and rumination | 7 | 14 | 18 | 10 | 10 | 6 | **65** |

**Studies included in the review**

A total of four papers were based on case studies and were therefore not evaluated using the CTAM. Of these case studies three used individual cognitive behavioural therapy (CBT) (Cardaciotto & Herbert, 2004; Hare, 1997; Weiss & Lunsky, 2010) and one used psychodynamic therapy (Koenig & Levine, 2011). The remaining eight papers were included in the CTAM appraisal, of which four were randomised control trials (RCT) (Hare, Gracey, & Wood, 2016; Kiep, Spek, & Hoeben, 2015; Russell et al., 2013; Spek, van Ham, & Nyklicek, 2013), two were preliminary randomised control trials (Hesselmark, Plenty, & Bejerot, 2014 and Hillier et al., 2011) and two were quasi-experimental studies (McGillivray & Evert, 2014; Russell, Mataix-Cols, Anson, & Murphy, 2009).

The 12 articles investigated psychological interventions for adults with hf-ASD and the primary presenting problems were anxiety, depression, stress and OCD. A couple of studies investigated social anxiety (Cardaciotto & Herbert, 2004 and Weiss & Lunsky, 2010) and the remaining studies investigated depression, stress, anxiety disorder or OCD (Hare, 1997; Hare et al., 2016; Hillier et al., 2011; Kiep et al., 2015; Koenig & Levine, 2011; McGillivray & Evert, 2014; Russell et al., 2009; Russell et al., 2013; Spek et al., 2013). Two studies investigated rumination as well as depression and anxiety (Kiep et al., 2015; Spek et al., 2013). One study explored a whole array of difficulties faced by people with ASD such as anxiety, depression, somatisation, inadequacy in thinking and acting, distrust and interpersonal sensitivity, hostility, sleep problems, general well-being, rumination and positive affect (Kiep et al., 2015). Hesselmark et al., (2014) was the only study that accepted most forms of psychiatric co-morbidity except substance misuse, high suicide risk and inpatients. They changed

the inclusion to allow individuals with suicidal ideation and those under inpatient care. Most studies highlighted the exclusion criteria to include drugs and alcohol dependency (Kiep et al., 2015; Spek et al., 2013), psychotic symptoms (Hare, 1997; Russell et al., 2013; Weiss & Lunsky, 2010), no severe behavioural challenges (Hillier et al., 2011) or uncontrolled epilepsy (Russell et al., 2013).

**Quality assessment**

The researcher assessed the methodological rigour of each study using CTAM, which provided ratings for 15 questions in the following six subscales: sample characteristics, allocation of treatment, assessment of outcome, control groups, description of treatments and analysis. Each sub-scale's score contributed a different weight towards the total score. The rating provides an evaluation of each category and a subscale score that also contributes towards an overall score (out of 100) for the quality of the study (see Appendix A for full set of questions). Wykes and colleagues (Wykes, Steel, Everitt, & Tarrier, 2008) suggested a total CTAM score of 65 or above to indicate adequate methodology, however further examination is needed for the validity of this marker of methodological rigour.

**Sample characteristics**

The studies examined a total of 300 participants. The number of participants in each study ranged from nine (Hare et al., 2016) to 54 (Hesselmark et al., 2014) participants. The three case studies discussed individuals (Cardaciotto & Herbert, 2004; Hare, 1997; Koenig & Levine, 2011) and the case series had three individuals (Weiss, 2010). All the studies included in this review recruited convenience samples

and were recruited from ASD clinics and community based groups for people with ASD. The studies were conducted in five different countries, the largest contributors of studies being the UK (33%), USA (33%), The Netherlands (17%), Sweden (8%) and Australia (8%).

Hesselmark et al. (2014) was the only study to recruit 27 or more participants in both conditions. McGillivray and Evert (2014) had 26 participants in the CBT condition, however only 16 participants in a recreational activity group. Most studies recruited samples over the age of 18, however two studies also included participants aged 15 and 16 (McGillivray & Evert, 2014: Russell et al., 2013). The demographic details were not disclosed equally by the studies; some provided a detailed analysis of ethnicity, education, employment, marital status, involvement with mental health and medication details (Hare et al., 2016; McGillivray & Evert, 2014; Hillier et al., 2011; Kiep et al., 2015; Hessellmark et al., 2014), whereas others provided minimal information (Russell et al., 2009; Russell et al., 2013; Spek et al., 2013). Mental health and psychiatric disorder details were provided in all the studies and none reported changes in physical health.

One study reported a priori power calculation (Russell et al., 2009). Most of the RCTs stated that the study was powered, however only Russell et al. (2013) provided further information which stated that the power analysis was 19 and their sample size exceeded that to allow for dropouts (N=20 in the treatment group and N=17 in the control group) showing that the study was powered. One quasi-experimental study also scored highly for randomisation of allocation (McGillivray, & Evert, 2014) and another scored highly on the randomisation process being blind (Hesselmark et al., 2014).

Most of the participants were diagnosed with ASD prior to taking part in the research. Two studies gave no indication about the diagnosis nor provided details (Hare, 1997 and Koenig & Levine, 2011) and two studies required participants to provide verification of diagnosis from a psychiatrist or psychologist (Hare et al., 2016 and Hillier et al., 2011). The participants in the remaining seven studies had undergone a standardised diagnostic process which was then verified by a clinical interview. Two studies carried out further assessment using the Autism Diagnostic Observation Schedule (ADOS) for a few of the cases (Russell et al., 2009; Russell et al., 2013). Most of the studies provided information on cognitive and language levels. All the studies stated inclusion and exclusion criteria, however there were differences in the amount of detail provided.

**Allocation to treatment**

Four studies described the randomisation process into allocation groups, blind randomisation by a team member (Hesselmark et al., 2014), table of random numbers (Russell et al., 2013) and numbers on a computer (Spek et al., 2013). One quasi-experimental study described the allocation process by alternating the order of enrolment (McGillivray & Evert, 2014). All the studies highlighted randomisation as a limitation and included recommendations for future studies.

**Assessment of outcome**

All the studies used pre and post outcome measures with adequate reliability and validity. The studies used established measures and reported that the validity had been established previously and most provided references. Four studies described the

rater-blinding process in detail, but highlighted that blind raters were not used (Hare et al., 2016; Kiep et al., 2015; McGillivray et al., 2014 and Spek et al., 2013). Hesselmark et al. (2014) and Russell et al. (2013) were the two studies where the rating of outcome measures was carried out by therapists that were blind to the intervention. The primary and secondary outcomes were clearly specified in all the reported studies. Two studies collected additional outcomes from sources appropriate to the target outcome such as parents and therapists (McGillivray et al., 2014 and Kiep et al., 2015).

Follow-up outcomes were collated by most studies; however, they did vary in the duration of time between the last session and follow-up. Three case studies had follow-up outcomes (Cardaciotto & Herbert, 2010; Hare, 1997; Weiss & Ludsky, 2010). One study did not have follow-up outcomes, but it did continue to have monthly reunions of the group for individuals with ASD and a parents group to help support and consolidate the learning that continued (Hillier et al., 2011). Russell et al. (2009) carried out follow-up after one month of treatment completion and reported that it would be unethical to have delayed treatment to those participants that requested treatment from the waiting list control group. Kiep et al. (2015) completed follow-up nine weeks after treatment and three studies did not have follow-up outcomes (Hare et al., 2016; Koenig & Levine, 2009; Russell et al., 2009). The high scoring studies had follow-up at intervals following the completion of intervention. Russell et al. (2013) carried out follow-up at three months, six months and at 12 months, and the Hesselmark et al. (2014) study had follow-up outcomes collected over a long period of time, from eight months to 57 months.

## Control group

As most of the studies were preliminary studies or investigating new areas of interest, they varied in their methods and usage of control groups. Several had control groups such as a treatment as usual group (Russell et al., 2009), an anxiety management group (Russell et al., 2013) and a recreational group (Hesselmark et al., 2014) or a waiting list group that later completed the program (McGillivray et al., 2014). Three studies did not have controls (Hare et al., 2016; Hillier et al., 2011; Kiep et al., 2015).

## Description of treatments

The studies varied in the description and detail of the intervention procedures; some provided references to previous studies where the procedure has been described fully (Hillier et al., 2011; Kiep et al., 2015). There was insufficient detail to allow replication of the intervention in two preliminary studies (Hare et al., 2016; Russell et al., 2009). All the studies described the timing, duration, intensity of the intervention and size of the groups. All the studies reported the number of hours of treatment and description of the treatment sessions. Some studies provided detailed descriptions of the weekly sessions of the interventions (Hillier et al., 2011; McGillivray et al., 2014; Russell et al., 2013; Spek et al., 2013) and one case study also provided details of the weekly group sessions (Weiss & Lunsky, 2010). Most of the studies reported the range of skills, knowledge and expertise of therapists delivering the intervention. Two studies gave details of the therapists' experience of using mindfulness (Kiep et al., 2015; Spek et al., 2013). One 'Proof of Principle' study (Hare et al., 2016) used experience sampling methodology as an assessment to capture moment-to-moment cognitive and behavioural events. They also employed mobile technology of a personal

digital assistant to assess phenomenological data. They provided detailed questions that were asked of the participants.

## Analysis

All studies reported analyses appropriate to the design and outcome measures. Three studies (McGillivray et al., 2014; Russell et al., 2009; Russell et al., 2013) reported the use of an intention-to-treat (ITT) principle where missing data were substituted with the last observation carried forward. Not all studies reported dropouts or whether all participants were included in the final analysis. Of the higher quality studies, one study reported the clinical significance of the intervention (Russell et al., 2013) and another critiqued the methodology (Hesselmark et al., 2014). Both these studies included discussions about the optimism of power calculations and effect size as well as the generalisability of the study findings.

## Findings on co-morbidity

The interventions can be divided into two main methods: group based interventions or individual intervention. Group CBT was used by three studies (Hesselmark et al., 2014; McGillivray & Evert, 2014; Weiss & Lunsky, 2010) and found a significant reduction for depression, stress, PTSD, agoraphobia and anxiety disorders. Mindfulness-Based Therapy for ASD (MBT-AS) in groups was investigated by two studies (Kiep et al., 2015; Spek et al., 2013) and both found a significant reduction for depression, anxiety and rumination. The group based social skills

program was used by a study (Hillier et al., 2011) and found a significant reduction of anxiety and depression symptoms. Four studies used individual CBT interventions to address psychiatric co-morbidity, including social anxiety (Cardaciotto & Herbert, 2004) depression and self-harm (Hare, 1997) and OCD with anxiety (Russell et al., 2009; 2013). Individual psychodynamic sessions were used in one case study (Koenig) for OCD with anger and provided minimal information. One study investigated stress management via digital devices providing stress management strategies including relaxation, attention shifting, deep breathing, positive and distracting imagery, delivered via technology (Hare et al., 2016). The findings deliberate the outcomes for the different co-morbid disorders in turn.

**Social anxiety**

One case study focused on social anxiety (Cardaciotto & Herbert, 2004) and was not included in the quality assessment. Cardaciotto and Herbert (2004) found improvements and clinically significant decreases in the symptoms of social anxiety and depression, in an individual. At the two month follow-up there was maintenance of treatment gains and the individual's anxiety and avoidance symptoms had reduced. However, the fear ratings of social situations increased slightly at follow-up, but avoidance decreased. The individual's gains in social skills were limited and not maintained over time. It was concluded that the limited improvement may be due to profound impairments and deep-seated deficits that may require a longer social skills course. The study highlighted the profound social skills impairment that is associated with ASD and how individuals with ASD may have various "difficulties in perceiving social emotional reciprocity, engaging in perspective-taking and in perceiving social nuances in general" (Cardaciotto & Herbert, 2004).

The group-based case series was with three individuals suffering from depression, Post-Traumatic Stress Disorder (PTSD), panic disorder and agoraphobia (Weiss & Lunsky, 2010). The fear rating of social situations was slightly increased from post treatment to follow-up, while the avoidance rating decreased. It was difficult to draw conclusions from individual case studies due to the individuals having an array of disorders. Both studies included elements of psycho-education, social training and CBT techniques. Weiss and Lunsky (2010) highlighted some aspects of the group activity that were novel experiences, such as the experience of meeting others with ASD and co-morbidity; they appreciated the predictability of the intervention, the repetition and the focus on skill building. The group allowed them to learn experientially and liked the 'scientific' aspects of the CBT model with concrete evidence and lack of abstract ideas. These studies highlighted the difficulty of distinguishing between symptoms that are commonly found in social anxiety and also present as core symptomology associated with ASD.

**Stress and anxiety**

Most of the studies investigated interventions for either stress or anxiety using a few different methodologies including group CBT, MBT-AS groups, social skills and discussion groups as well as individual CBT interventions. Most of the studies found improvements and clinically significant decreases in symptoms of anxiety (Hare et al., 2016; Hillier et al., 2011; Kiep et al., 2015; Russell et al., 2009; Spek et al., 2013). One study found an increase in the sense of coherence (Hesselmark et al., 2014).

McGillivray et al. (2014) found that group CBT had less impact on anxiety symptoms and anxious self-statements. The measures used in the study focused on "symptoms of autonomic arousal, effects on musculature, situational anxiety and

subjective experiences of anxiety" (McGillivray et al., 2014). The group intervention included relaxation techniques to manage anxiety and discussions about where in the body anxiety is located, rather than using graded exposure tasks to address the fears or worries. With anxiety symptoms, there was evidence of maintaining treatment gains and although a few studies found a relapse of symptoms, the scores did not return to the baseline.

One study used technology-based interventions (Hare et al., 2016) and Experience Sampling Technique (EST) to reduce everyday anxiety and stress in adults with hf-ASD. The study was AB exploratory design and of somewhat moderate quality, scoring 35. They used a form of mobile technology known as personal digital assistant (PDA) to deliver real-time stress management techniques (RTSM) which included interventions such as relaxation, attention shifting, positive self-talk, deep breathing, and positive and distracting imagery. They used a visual medium to provide therapeutic interventions which allowed participants to have control over the pace of delivery. The technology is seen as a method which functions like 'a coach' and removes the social demands of therapeutic work as well as reducing reliance on memory, which may be challenging for those with hf-ASD. The findings indicated a significant decrease in participants' subjective ratings for anxiety after the intervention was employed. The study provided preliminary data for the feasibility of ESM based intervention with hf-ASD and gave a snapshot of experience of anxiety in this population. It also highlighted difficulties faced by those participants that are high functioning yet experience difficulty in keeping within research boundaries and need ongoing support.

Russell et al. (2013) had a control treatment group which provided anxiety management and found a significant reduction in the symptoms of OCD. It was

suggested that a reduction in symptomology may have been because the group focused on psycho-education about anxiety and learning relaxation techniques helping those with less severe OCD and anxiety.

**Obsessive Compulsive Disorder**

The quasi-experimental study (Russell et al., 2009, quality score of 28) and the randomised control trial (Russell et al., 2013, quality score of 86) both found improvements in OCD symptoms following individual interventions. Between both studies there were a total of 59 participants. Russell et al. (2009) found a 58% improvement in severity scores on the YBOCS outcome measure for OCD using individual CBT, compared to a 16% improvement with the treatment as usual group. The researchers considered a <25% reduction on the YBOCS to be a clinically significant improvement. There was a significant reduction in the severity and obsession scores in the CBT group compared to the TAU group. However, they found that 40% of the participants did not respond in the CBT intervention group, whereas Russell et al. (2013) found that 45% of the participants responded to CBT treatment and 20% of the participants responded to the treatment in the comparison anxiety group. This study addressed many of the methodological issues and was the highest scoring quality study that used random allocation; the randomising was done blind by therapists not involved in the interventions. The usual CBT intervention for OCD that is used with neurotypicals was used in these studies with some adaptations for individuals with ASD. However, the details of the adaptations were not provided by either study. Russell et al. (2013) found that individuals with ASD and OCD had a

significant improvement with standard psychological treatment with a few adaptations and the treatment gains were sustained over a one year follow-up.

The single case study described possible issues that may arise when psychodynamic therapy is employed with a client with ASD, obsessive-compulsive symptoms and aggressive behaviours (Koenig & Levine, 2011). The authors state that a psychodynamic approach can be effective with individuals with ASD. However, this study was not included in the quality assessment and details of the intervention were not provided. Although the study suggests that psychodynamic therapy was effective with an individual with ASD, there are a number of limitations as to what conclusions can be drawn from a single case study using psychodynamic therapy. Further studies using this approach with individuals with ASD are therefore required to conclude whether these findings are generalisable.

**Depression and rumination**

Seven studies investigated interventions that reduced depression and depressive mood in conjunction with other co-morbidity. The interventions were case studies (Hare, 1997; Weiss & Lunsky, 2010), group CBT (Hesselmark et al., 2014; McGillivray et al., 2014), a social and vocational skills program (Hillier et al., 2011), and group MBT-AS (Kiep et al., 2015; Spek et al., 2013). The case studies observed a reduction of depressive mood and negative symptoms when adapting therapeutic techniques used with neuro-typicals and those without learning disabilities (Hare, 1997), and through using manualised workbooks (Weiss & Lunsky, 2010). A quasi-experimental study that scored 53 on quality assessment found a reduction of symptoms of depression using group CBT with manualised interventions when compared to a waiting list control group (McGillivray et al., 2014). Another

preliminary RCT that scored 81, the second highest on the quality assessment, found an increase in the reported quality of life outcome measures for both CBT and the recreational activity group (Hesselmark et al., 2014). McGillivray et al. (2014) found group CBT to have a clinically significant reduction of depressed mood and stress, but not a significant reduction in anxiety. Hesselmark et al. (2014) investigated two group activities, either CBT-manualised interventions or the social activity group, which included a recreational activity intervention that aimed to support social interaction and reduce isolation. They found that group settings increased quality of life at the end of treatment, but no difference was found in the sense of coherence or self-esteem.

The Aspirations Program model (Hillier, Fish, Cloppert & Beversdorf, 2007) was used in group settings to allow young people to have the experience of meeting and connecting with others with ASD. The discussion based format encouraged small groups of participants to fully engage in conversations on a particular topic. The eight one-hour weekly meetings with five-seven participants focused on improving social and vocational skills. The group members directed the discussions, guided by group facilitators. The study had a total of 49 participants, in nine separate groups. Hillier et al. (2011) found a significant reduction in depression and anxiety amongst young people at the end of the treatment, although the size of the effect was small. They concluded that even a short group program (eight weeks) can create an impact in the lives of young people. It highlighted the importance and relevance of discussion topics; for example, a discussion about employment may have provided insight into the topic which helped reduce anxiety and depression. It also provided a space and opportunity to meet others with ASD and to help them achieve a sense of acceptance, socialising and planning for future interactions. This was a preliminary study with a quasi-experimental design and was of a lower quality, scoring 31. The limitations included

the lack of control group, not randomised allocation and lack of follow-up sessions, which make it difficult to understand whether the significant changes would happen anyway.

Kiep et al. (2015) and Spek et al. (2013) examined the effectiveness of mindfulness-based therapy modified and adapted for high-functioning adults with ASD (MBT-AS). One was a RCT (Spek et al., 2013) that scored 65 on the quality assessment, signifying an adequate methodology. The other was a quasi-experimental designed study (Kiep et al., 2015) conducted more recently which scored 36, much lower on the quality assessment. Both studies provided information on the therapists carrying out the treatment and detailed the MBT training that therapists undertook as well as the duration of the practice of MBT with individuals with ASD. The studies investigated the effects of MBT-AS on co-morbid symptoms of anxiety, depression and rumination in adults with ASD. Kiep et al. (2015) reported on agoraphobia, somatisation, inadequacy in thinking and acting, distrust and interpersonal sensitivity, and sleeping problems. Both studies found a significant reduction in anxiety, depression and rumination in the intervention group and an increase of positive affect. They found a reduction in the symptoms of anxiety and depression to be related to the increase of positive affect. They also investigated the positive effects of MBT-AS and rumination and found that the decline in rumination was related to the effect of MBT-AS on symptoms of depression and anxiety. Interestingly, the studies found rumination to be a vital factor in the effectiveness of MBT. Spek et al. (2013) suggested that individuals with hf-ASD may experience rumination to have a positive aspect; for example, when faced with certain social interactions, or sarcasm and jokes, individuals with hf-ASD may spend time ruminating or evaluating past confusing situations. It was suggested that individuals with ASD may not have intuitive ToM, and that

rumination may help them to understand social situations by using cognitive, conscious reasoning mechanisms (Firth & Happé, 1999). The researchers concluded that MBT-AS is effective in improving various psychosomatic symptoms.

All the studies stated that the benefits of group therapy for adults with ASD served a powerful socialising function. Alongside learning the CBT model and learning skills to cope with co-morbidity there was an important opportunity to understand and discuss their concerns. All the studies highlighted the strengths of the CBT intervention and benefits for individuals with ASD. As participants in the control groups also made improvements, both studies (Hesselmark et al., 2014 and McGillivray et al., 2014) raised questions as to whether the group itself was a factor in the reduction of co-morbidity and providing some assistance in the improvements seen in the CBT groups. Hillier et al. (2011) recommended that a longer course of social skills training may be required to address the more fundamental shortfall in individuals with ASD.

One case study explored self-harm along with depression in an individual with ASD (Hare, 1997). After a total of 15 weeks of individual CBT for depression, the severity of depression had reduced and the frequency of self-harm had lessened. There were improvements in low mood symptoms according to scores on a depression scale; however, the scores remained high for the first six weeks and only reduced in the latter part of the intervention, though scores rose slightly in the penultimate session. After the intervention ended and before follow-up some relapse did occur, but the relapse was not as severe as at the baseline. The study collected weekly measures, as well as pre, post and follow-up at six months and eight months. The study used therapeutic techniques with adaptations and concluded that individual CBT can be effective for depression and anxiety; however they did not state what these adaptations were. These

were findings from a single case study which were not included in the quality assessment; therefore caution is required when applying and generalising the findings.

## Discussion

This review summed up the key findings from previous research on psychological interventions for adults with ASD who also had other psychiatric co-morbidities. Although research with adults with ASD is gradually growing there are many areas that require additional investigation such as psychiatric co-morbidity, its impact and the effectiveness of the available interventions. It has also highlighted the conceptual and practical difficulties of assessing and treating co-morbidity in the ASD population.

### Findings of this study

The findings of the current review suggest that psychological intervention for psychiatric disorders for adults with ASD can improve mental well-being. There has been a gradual growth in research into psychiatric co-morbidity; however, there are limited treatment options for adults with ASDs.

The review indicated that adapted interventions such as CBT for anxiety, OCD or social training are commonly used and are currently all that are available for adults with ASD (Hesselmark et al., 2014). The methodological qualities of these studies are moderate to high, as well as a few scoring low due to a lack of methodological rigour. There are also some new additions to the knowledge base, such as MBT-AS, demonstrating some success in reducing depression, anxiety and rumination as well as the use of new technologies to provide individualised therapeutic input.

More studies were identified as being published between 2009 and 2015 and these studies offer further support for improvements in mental well-being following treatment and evidence for generalisability. The follow-up outcomes show that there are greater possibilities of having lasting effects from the interventions. Studies have highlighted that relapse frequently takes place; however, outcome scores did not return to baseline levels therefore suggesting that participants maintain some of the reduction of symptoms. Whether factors such as anxiety impair the individual's ability to interact with others effectively or whether social interaction difficulties lead to increased anxiety remains ambiguous and there is a possibility that the relationships could be bidirectional (White, & Robertson-Nay, 2009). Certainly social skills, relationships with peers and anxiety are closely intertwined. Treating anxiety and depression could therefore improve other symptoms seen in ASD (Hiller et al., 2011).

The review has also highlighted differences in study design, the heterogeneity in the sample characteristics and the intervention types. However, research into psychological interventions for adults with ASD is at its earliest phase. Smith and colleagues (Smith et al., 2007) highlighted four phases of research designs for psychosocial interventions for ASD: i) firstly, single-case experimental designs conducted to establish initial efficacy, ii) then small pilot studies for feasibility which are to manualise and develop protocol, iii) then RCTs to evaluate the efficacy of an intervention, and finally iv) RCTs or between-group designs in the community to explore effectiveness. Currently, most of the studies reviewed are in the early stages, with a couple of studies that have attempted to address the requirements of RCT and have scored higher on quality assessments (Hesselmark et al., (2014); McGillivray & Evert, (2014); Russell et al., (2013).

As the studies are in the early phases, a few of them did not meet methodological expectations. The review highlighted difficulties with sampling, in employing control groups, having comparison groups, having blind allocation or blind raters. This inconsistency is perhaps due to an array of factors such as the sample size being small, selection bias and a range of interventions and outcome measures as well as the intellectual abilities amongst the participants (Stewart et al., 2006). However, the evidence indicates that it is possible to develop more rigour in methodology and conduct RCTs for co-morbid disorders such as OCD.

It is difficult to generalise from the findings of the studies reviewed. All the studies used convenience samples, which are linked to clinics, referrals from psychiatric units or community groups and they are not representative of all individuals with ASD. Research and clinical trials with adults with ASD are still in the initial phase, and require further development. The review has highlighted that there are studies that are making progress and developing from pilot studies to effective RCTs (Russell et al., 2009 and Russell et al., 2013) or exploring third wave approaches such as mindfulness-based therapy (Spek et al., 2013). It may be difficult to achieve true randomisation, however the review findings suggest that it is possible to reduce bias and conduct robust clinical trials.

In group settings it is difficult to establish the contribution of different techniques or aspects of group processes that takes place and it is possible that the social interaction provided by the group interaction helped reduce anxiety levels and reduced depression. A few studies employed the waiting list as the TAU group (McGillivray et al., 2014) whereas others have employed another type of group intervention such as anxiety management (Russell et al., 2013) or used the social/recreational group (Hesselmark et al., 2014). Nonetheless, it is difficult to assess

which component of group interaction brought about change for the individuals with ASD. Greater clarity is needed to support understanding of these factors.

There is a huge variability in reported rates of co-morbidity in adults with ASD. There are conceptual difficulties due to the ambiguity in identifying symptoms and difficulty in assessments because of symptoms overlapping not only between disorders, but with core ASD symptoms too. There is significant heterogeneity in the ASD population and often individuals suffer from numerous morbidities and are at a disadvantage for success in social status, employment or relationships. It is therefore difficult to assess the impact of each of these variables on individuals' mental health. Co-morbidity needs to be assessed regularly due to the high risk of it developing in this population, yet there is a lack of screening tools to assess psychiatric disorders; these are areas where further research is required.

Although limited, research shows that individuals with ASD are faced with various difficulties when accessing psychotherapy, such as social withdrawal (Munro, 2010), low expectations of receiving help because of being misunderstood (Gaus, 2007) and insufficiently trained and experienced therapists (Munro, 2010). Furthermore, alongside psychiatric co-morbidity, adults with ASD frequently have difficulty in gaining paid employment, even though educationally they may have performed well (Roy et al., 2015), and experience difficulties with independent living. Furthermore, they can also experience difficulties with sustaining relationships and starting a family (Roy et al., 2015). This emphasises the importance of developing specific treatments to help improve their mental health and social integration.

Another hindrance that was emphasised in the review was the variation of outcome measures used, and therefore a lack of consistency. All the studies used a

number of outcome measures for psychiatric disorders except one study that did not indicate the use of any measure (Koenig, & Levine, 2011). The studies used a range of measures to assess a common disorder; for example, anxiety and depression were measured with different scales. Some studies found evidence of improvements and clinically significant decreases in symptoms of anxiety and the maintenance of treatment gains with anxiety symptoms; however the depressive symptoms remained within a normal range. There were limited improvements on certain measures which may reflect more profound impairments in certain areas associated with ASD. This highlights the complexity surrounding the reliability and ecological validity of the measure and the capacity to be sensitive to the concept being measured.

Another issue was the reporting on the measures; a few of the studies found a reduction of symptoms, but not a significant difference, and raised the issue of whether the measures were sensitive enough. There was an inadequacy in measuring outcomes in a standardised way and defining what a successful or a positive outcome is. The majority of the studies used self-reporting in the measures and this may raise concern about the difficulties of introspection and the understanding of the individuals' emotional or mental state. Research has shown that people with ASD may be able to reflect and report their own emotions but experience difficulty identifying or analysing emotions (Hillier et al., 2011). Some studies utilised parents or caseworkers to complete measures which does not eliminate the possibility of over or under rating taking place.

Anxiety is common in ASD and it may overlap features of ASD. Anxious arousal in people with ASD perhaps is a core feature of the condition and therefore not possible to reduce significantly. However, assessment instruments may not be sensitive enough to detect the slight changes in the level of anxiety. There is the

suggestion that measures used to assess outcomes may need to determine the ability to cope with anxiety, rather than trying to eliminate anxiety, because of the connection to core features of ASD. Nonetheless, the studies do confirm that it is possible for those with ASD to acquire new skills that can help them attempt to solve problems and increase well-being.

**Limitations of the review**

There are limitations to the review. A systematic review requires being reviewed by more than one researcher to promote validity and reliability by reducing bias, however, due to time constraints the review and quality assessment was conducted by one researcher. Literature is still limited in this area and meta-analysis was not regarded appropriate for this review. It was not possible to group the outcome into categories based on psychiatric disorders or ASDs.

**Clinical relevance**

There is evidence of positive outcomes for many of the interventions examined in the review of ASDs and co-morbidity, suggesting that some form of treatment is more beneficial than no treatment. Though studies have focused on different disorders, different outcomes and different measures, it is challenging to draw conclusions on a particular intervention.

**Future research**

The studies in the current review highlight that the participants are not representative of the diverse population. Future research can attempt to recruit more

female participants and may need to focus on different subgroups, for example different socio-economic groups, ethnical or racial groups, intellectual and language ability groups. Further research is also needed to address the shortage of treatment options and focus on standardisation of adaptations to assist appropriate interventions. There is a greater need to have further evaluation of the various psychological interventions that are employed to treat people with psychiatric disorders and ASD. There are gaps in the knowledge, such as the known effects of interventions on parents and family well-being or the effect over the lifespan of the patient.

## Conclusion

To date, this is the first review that has systematically assessed the quality of reporting within the psychological interventions for adults with ASD literature by utilising a standardised trial reporting assessment tool. The findings of the review provide evidence that there is considerable systematic variability in reported studies. The studies reviewed focused on different outcomes and different measures, making general comparison difficult. The review found much heterogeneity within the sample and across studies in the types of psychological interventions for ASDs. It highlighted that although there are interesting interventions employed to reduce anxiety, such as group therapy, mindfulness groups or real-time stress management techniques, there are still many areas that need investigation. NICE guidelines recommend psychological interventions for the treatment of psychiatric disorders; however the evidence with individuals with ASDs is scarce. The area of research is still in its early phases and there is a greater need to develop interventions for mental health co-morbidities in those with hf-ASD.

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# Part 2: Empirical Paper

## An Exploratory Study of the Cognitive Profile of those Ageing with Autism Spectrum Disorder

## Abstract

**Background:** Research into ageing and the over 50s with Autism Spectrum Disorder (ASD) has not received much attention. Understanding cognition in autism has concentrated on children and young adults and has indicated that there are some differences in cognitive profiles between those with a diagnosis of autism and those without. There is a link with early neurodevelopmental deficits in the same cognitive areas that are also known to deteriorate with ageing. It is therefore of interest to understand how ageing impacts on cognitive functioning in those with autism. Studying the cognitive profile of those ageing with autism has been overlooked and it may have implications for service provision.

**Aim:** To establish the cognitive profile of the over 50s using gold standard measures for abilities and memory.

**Design:** An exploratory study, with a cross-sectional within and between design was used. A total of 26 adults over the age of 50 years with autism were recruited from the community to participate in the research.

**Results:** The over 50s with autism were of high intellectual ability. However, they had a significantly weaker processing speed compared to the other abilities. After controlling for their intelligence, they had a significantly weaker visual memory than predicted.

**Conclusions:** It may be too early to draw any considerable conclusions about the impact of ageing on the cognitive profile of individuals with ASD. However, the findings do suggest that the cognitive profile of these individuals may be uneven, with performance in certain domains weaker than others.

## Introduction

As people age, their needs change; typically developing (TD) adults experience changes to their cognitive abilities as they age. Those ageing with Autism Spectrum Disorder (ASD) encounter different personal and contextual difficulties (Wylie, Beardon, & Heath, 2014). ASD is a complex, lifelong neurodevelopmental condition, of a largely unknown cause (Newschaffer et al., 2007). It affects a person's ability to communicate, form relationships and respond appropriately to the environment. Whilst there has been a significant amount of research focused on children with ASD, there is limited research on adults with ASD and a dearth of research on those over the age of 50. It is an important area to explore because a decline in certain cognitive functioning, such as a decline in episodic memory, can be an indicator for dementia (Albert, 2011). Where ASD is concerned, questions arise regarding whether the cognitive changes that occur in TD adults also occur in people with ASD as they age. ASD is associated with early neurodevelopmental deficits in the same cognitive domains that are also known to deteriorate with ageing (Geurts & Vissers, 2012).

### Autism Spectrum Disorder

The revised *Diagnostic and Statistical Manual of Mental Disorders (5th ed.;* DSM–5*; American Psychiatric Association, 2013)* replaces previous diagnostic labels of Autistic disorder, Asperger's syndrome (AS) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) into the one diagnosis of Autistic Spectrum Disorder. The current criteria for ASD are to have deficits in social communication which include problems with socio-emotional reciprocity, non-verbal communication, and developing, maintaining and understanding relationships. Another part of the criteria are restrictive repetitive patterns of behaviour or interests,

including stereotyped or repetitive movements or speech, insistence on sameness, inflexible adherence to routines or rituals, fixed interests and hyper or hypo-reactivity to sensory input. These symptoms must be present in the early developmental period and the symptoms together limit and impair everyday functioning for the individual.

**ASD in adulthood**

Historically, ASD was seen as a childhood condition and research had concentrated on childhood years and early adulthood (Piven & Rabin, 2011). Various understandings about ASD have been challenged and updated over the years. Once it was thought to be mainly pertinent in people with low intellectual abilities (Geurts, Stek, & Comijs, 2016). However, it has been established that it is possible to diagnose ASD in (late) adulthood and it is common amongst all intellectual levels (Happé & Charlton, 2012; Piven & Rabins, 2011). Additionally, it has been shown that ASD is consistent across the lifespan (Geurts et al., 2016). Children that were first studied and given the diagnosis of ASD are now entering their 70s and 80s and this draws attention to the growing issues and service needs for this group.

The pace of ASD research has rapidly increased in recent decades (Fombonne, 2012). A systematic review of publications between 1990-2013 on ASD in adulthood and ageing suggested a growing interest in the area, however the literature is limited compared to the considerable amount that focuses on children and adolescents (Wright, Brooks, D'Astous, & Gradin, 2013). ASD affects approximately 1% of the adult English population and prevalence is higher amongst men (Brugha et al., 2011). The prevalence rates of people aged 45 to 74 years is 0.9%, and it is 0.8% for people aged 75 years and upwards (Brugha et al., 2011). Although there is a considerable number of adults with ASD, research has been scarce with adults with ASD who have

preserved language and cognitive skills (Fombonne, 2012). A study has shown that people with ASD develop a greater understanding of their strengths and abilities as they get older (Frith & Happé, 1999). Studying ageing in those with ASD is therefore important to increase understanding of the full trajectory of this condition and possible indicators towards the aetiology of ASD and help plan appropriate services (Happé & Charlton, 2011).

**ASD in older adults**

The social and care needs of ageing adults with ASDs are usually met by family members. A question about the needs and support of these individuals arises with the death or incapacity of their parents or siblings (Brugha et al., 2011; Piven, & Rabins, 2011). This was especially highlighted in a study which conducted semi-structured interviews with 13 older adults with ASD, and found growing old with ASD was generally experienced as difficult and lonely. It highlighted the need for greater support for this population with respect to reducing loneliness and improving access to diagnosis (Hickey, Crabtree, & Stott, 2017).

**Typical cognitive ageing**

As the elderly population grows, society has been concerned about 'age-related cognitive decline' in typically developing (TD) adults (La Corte, Dalla Barba, Lemaréchal, Garnero, & George, 2012). With age there are heightened risks of experiencing deterioration in various abilities including vision, cognition, psychomotor abilities and health (Clay et al., 2009). Typical ageing carries the risk of cognitive decline, which threatens independence and quality of life as well as presenting challenges to health care systems (Williams & Kemper, 2010). Some cognitive abilities are impervious to brain ageing and can remain stable, or even

improve with age, for example vocabulary (Hayden, & Welsh-Bohner, 2012 and Salthouse, 2009). Whereas, other cognitive abilities such as processing speed, memory and conceptual reasoning gradually weaken with age. The rate of this decline varies significantly amongst older adults (Wisdom, Mignogna, & Collins, 2012; Albert, 2011).

Studies have shown that there is heterogeneity in typical cognitive ageing, both within individuals and between different crystallised intelligences. Crystallised intelligence is those functions, skills, ability and knowledge that are familiar, well-practiced and over-learned (Lezak, Howieson, Bigler, & Tranel, 2012); these remain stable and can even improve in later life (Salthouse, 2012). General knowledge and vocabulary are examples of crystallised intelligence. Fluid cognition on the other hand includes one's ability to process, learn new information, solve problems and attend to and manipulate one's environment (Harada, Natelson, & Triebel, 2013); this shows a tendency, on average, to decline with age. Executive functions, processing speed, and memory are considered fluid cognitive domains (Harada et al., 2013).

'Executive function' is used as an umbrella term for abilities such as planning, working memory, impulse control, inhibition and shifting set as well as the initiation and monitoring of action (Hill & Bird, 2006). Goh, An and Resnick (2012) studied TD adults, over the age of 55, across a period of 14 years and found longitudinal declines in many executive tasks, including verbal fluency, digit span and Trails B all of which are tasks using executive skills.

Some fluid cognitive processes such as processing speed peak in the third decade of life and then decline (Salthouse, 2009). Indeed some have argued that much if not all reported cognitive change seen with typically developing adults is due to

slowed processing speed, which can impact performance on neuropsychological tests. The decline in processing speed can have implications on other cognitive domains (Harada, 2012).

Another common complaint of change in ageing adults is memory, which can have deficits in a number of areas. Research has found that age-related memory changes may be due to different reasons such as slower processing speed (Luszcz & Bryan, 1999), inability to disregard irrelevant information (Darowski, Helder, Zacks, Hasher, & Hambrick, 2008) and difficulty in learning strategies to improve memory (Davis et al., 2013 and Isingrini & Taconnat, 2008). The ability to encode new information into the memory declines with age (Haaland, Price, & Larue, 2003). However, when the acquisition is successfully learned then it remains preserved in cognitively healthy ageing adults (Whiting & Smith, 1997). Decline can also take place in memory retrieval of newly learned information (Haaland, Price, & Larue, 2003; Price, Said, & Haaland, 2004).

Cognitive changes occurring in ageing are probably due to the structural and functional changes in the brain. Studies have found that ageing affects various areas in the frontal lobe (Galluzzi, Beltramello, Filippi, & Frisoni, 2008). Christensen et al. (2014) suggest that the ageing process is modifiable and that people are living longer with less severe disabilities. Positive effects of cognitive and physical activity, social engagement, and effective nutrition are found to improve cognitive ageing (Williams & Kemper, 2010).

**Cognitive ageing in ASD**

Some studies have found executive functioning deficits in middle-age adults with ASD, as found in younger adults with ASD, and similarly a decline in executive

functioning is found in typical ageing (Braden, Smith, Glaspy, & Baxter, 2015). Although the sample was small, the same study found a reduction in delayed verbal memory performance in middle-aged adults with ASD when compared to TD adults. This finding can be alarming because cognitive deficits in these domains are also affected by early dementia (Braden, Smith, Glaspy, & Baxter, 2015). There are various questions that arise if there is a possibility that those with ASD have an increased risk of being affected by dementia earlier than TD adults.

Some researchers have described a cognitive profile in children with ASD (Bolte, Dziobek & Poutska, 2009). These findings, though informative, cannot be directly transferred because of the change in cognition as people age (Lever & Geurts, 2015). However there is a lack of consensus as to the cognitive abilities of adults with ASD (Kanai et al., 2012). Studies have shown that in childhood and adulthood, individuals with ASD show a broad range of cognitive differences, between individuals and across studies (Geurts, Corbett, & Solomon, 2009; Hill, 2004; Geurts & Vissers, 2012). Research has found that individuals with high functioning ASD were significantly more impaired in processing speed, cognitive flexibility and sight words than controls without ASD and those with ASD and ADHD (Fried et al., 2016). Furthermore, cognitive skills do not operate in isolation; for example, verbal fluency is dependent on general processing speed (Spek, Schatorje, Scholte, & van Berckelaer-Onnes, 2009) and some executive function tasks require a level of theory of mind, which is significantly affected by autism, such as reflecting on one's own plans and goals (Wilson & Happé, 2014). A recent study found that older adults with ASD need more time to perform executive tasks to achieve the same results (or better) than typically developed controls (Davids et al., 2016). Inconsistent findings due to

heterogeneity have been a problematic factor in autism research (Williams, Goldstein, & Minshew, 2006).

These caveats aside, there are trends. Studies with children with ASD have found visual memory to be a strength; however, the complexity of the stimuli also plays a crucial part (Williams et al., 2006). Other studies with adolescents with ASD found that performance was worse than the control groups on visual memory tasks and weaker on visuo-spatial memory tasks (Salmanian, Tehrani-Doost, Ghanibari-Motlagh, & Shahrivar, 2012). These findings emphasise the variabilities found between individuals. Neuropsychological functioning in people with ASD has also tended to reveal impairments in executive functioning (Liss, Phares, & Liljequist, 2001; Ambery, Russell, Perry Morris, & Murphy 2006) and these impairments are thought to last a lifetime (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Howlin, Goode, Hutton, & Rutter, 2004). With regards to working memory, individuals with ASD may have impaired spatial working memory (Russo et al., 2007; Steele, Minshew, Luna, & Sweeney, 2007; Williams, Goldstein, Carpenter, & Minshew, 2005), yet intact verbal working memory (Williams et al., 2005). The impaired spatial working memory in ASD is consistently evident across child (Corbett, Constantine, Hendren, Rocke, & Ozonoff, 2009; Goldberg et al., 2005; Williams et al., 2005), adolescent (Steele et al., 2007) and adult populations (Williams et al., 2005).

In terms of overall intellectual abilities, Spek, Scholte and van Berckelaer-Onnes (2008) used The Wechsler Adult Intelligence Scale, Third Edition (WAIS-III, Wechsler, 2002) and found a slower processing speed in young adults with High Functioning Autism (HFA) compared to young adults with Asperger's syndrome. They did not find differences in the Verbal Intelligence (VIQ) and Performance Intelligence (PIQ) between groups.

To date, there have been two studies with individuals with ASD that have used the recent version of the Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV; Wechsler, 2010). Holdnack, Goldstein and Drozdick (2011) evaluated intellectual abilities in adolescents and young adults with HFA and AS and found an absence of significant difference between the AS group and the control group. However, the AS group performed worse than typical adults on subtests designed to assess processing speed. The cognitive profile of the AS group resembled the TD control group and performed substantially better than the HFA group. The researchers suggested that it is difficult to distinguish between the sub-groups of ASD using cognitive functioning because they can resemble a similar cognitive profile and are indistinguishable from the normative population; there is a presence of cognitive heterogeneity amongst individuals with ASD (Holdnack et al., 2011). Bucaille et al. (2015) used the French version of WAIS-IV and found, despite performing within 'normal' ranges for overall intellectual functioning, that the AS group had significant impairments on the processing speed index. Individuals with AS were also found to have difficulties in higher cognitive processes such as working memory and executive functions (Bucaille et al., 2015).

Williams et al. (2005) investigated the memory of adults with autism and an IQ greater than 80, using the Wechsler Memory Scale- Third edition (Wechsler, 1997b). They found deficits in memory for faces and common social scenes. They suggested that people with autism have difficulties in spatial working memory as opposed to verbal working memory because of the difficulty of engaging with the task in the absence of environmental cues. The memory of faces and social situations requires identification of themes or organising strategies and the autism group struggle

because of the dependence on concept formation, which is a complex information processing ability (Williams et al., 2005).

Researchers seldom use the whole array of neuropsychological tests, such as the gold standard measures of WAIS-IV or WMS-IV (Holdnack et al., 2011). More commonly, neuropsychological subtests are used to determine abilities; for example, the spatial span subtest is used as a measure of working memory (Geurts & Vissers, 2012) or matrix reasoning and vocabulary sub-tests are used to estimate the IQ and visual reproduction subtest for the visual memory (Lever & Geurts, 2016). Guerts and Vissers (2012) used various individual neuropsychological tests to assess ability area rather than the performance with a varied approach, which involves a variety of tests to assess cognitive ability areas (Harvey, 2012). This is an issue, however this may lead to some of the observed inconsistencies in findings because reliability and validity are enhanced by using the full range of tests and index rather than the subtest scores (Crawford, Garthwaite, Longman, & Batty, 2012). To date, where older adults with ASD are concerned, there are no studies that have used the full WAIS-IV or Wechsler Memory Scale- Fourth Edition (WMS-IV; Wechsler, 2010).

**Cognitive ageing in the over 50s with ASD**

There has been an increased interest in adults who were diagnosed with Asperger's syndrome or high functioning autism later in life and with normal intelligence (Spek et al., 2009). However, the cognitive profile is not known and there are limited studies about adults with ASD who function reasonably well in society (Howlin et al., 2004). Research has shown some structural changes in the brains of individuals with ASD that are not found in typically ageing brains (Murphy, Beecham, Craig, & Ecker, 2011). So far, there have been very few published accounts of whether

age-related cognitive decline is different in those with or without ASD. This has been a gap in the knowledge regrading ASD.

Two studies have looked specifically at cognitive functioning and older adults with ASD. Geurts and Vissers (2012) carried out research on 23 participants with ASD, aged 51-83 years of age, with a mean age of 63 years. They compared the cognitive profile of older adults with ASD to matched controls, to determine which cognitive deficits are present in older adults with ASD. They found evidence that older people with autism have subtle deficits in sustained attention, working memory and fluency. However, other cognitive domains including processing speed, visual and verbal memory remain intact. Lever and Geurts (2016) investigated whether people with ASD also experience the age-related deterioration in cognitive functioning found in typical ageing. Using 236 matched participants with and without ASD with an age range of 20-79 years, they found that ASD participants over 50 years had higher scores on visual memory and immediate recall, and lower scores on phonemic fluency, compared to the comparison group. This may have resulted from sampling bias or cohort effects.

Geurts and Vissers (2012) proposed three varying hypotheses regarding ageing with ASD. Adults with ASD have similar cognitive decline to those without ASD, known as the ‘parallel ageing’ hypothesis. The ‘double jeopardy’ hypothesis suggests that ASD and ageing can jeopardise each other and that cognitive decline may be increased. Consequently individuals with ASD have a larger risk of steeper decline. Finally, the ‘safeguard’ hypothesis where individuals with ASD may acquire compensatory strategies, therefore with age there is an increase in cognitive performance, suggesting that older adults may experience some relative improvement compared to the functioning of younger people (Geurts et al., 2016).

Earlier studies have shown that children and young adults with ASD have deficits in planning and cognitive flexibility (Hill, 2004), though Geurts and Vissers (2012) did not find a consistent deficit in these higher-level executive functions and speculated that deficits may disappear before the age of 50. They suggested that cognitive reserve used from a young age may explain the disappearance of these deficits found in younger people with ASD. They also suggested that there are different developmental patterns for different aspects of cognition as some deficits remain stable while others seem to disappear.

Nonetheless, Lever and Geurts (2016) indicate that the cognitive pattern resembles, or is less pronounced in, individuals with ASD. Research into this area is however new and results have been mixed. These results are similar to findings from brain studies (Oberman & Pascual-Leone, 2014) that highlighted that individuals with ASD may have protective qualities from age-related cognitive decline due to hyperplasticity (easily adaptive to the environment and adjusts to synaptic changes). They argue that a person's risk of age-related decline and risk of dementia depends on their starting point and how the change in plasticity efficiency happens over their life (Oberman & Pascual-Leone, 2014).

Based on the limited amount of research completed to date, the trajectory of cognitive ageing for people with ASD is in line with the literature on ageing in TD older adults with regards to most cognitive domains. Nevertheless, there are some cognitive domains on which the performance of those with ASD appear atypical and diverge from the normal pattern. There are clearly limitations in the research to date and therefore there is a need for further research to explore this area.

**Present study**

The focus of this study was to investigate the cognitive profile in adults over the age of 50 with a diagnosis of ASD. We know that there are cognitive changes associated with the typical ageing process, such as a decline in processing speed, episodic memory, working memory, theory of mind and executive functioning, although it is generally after the age of 50 (Wright, 2016, p154). Due to the lack of research on those ageing with ASD we are unaware of whether these changes are also evident within the ASD group. Previous research has highlighted that cognitive skills such as language skills, memory and executive functions are different in those with ASD.

This exploratory research used gold standard measures WAIS-IV and WMS-IV to investigate the cognitive profile of adults with ASD aged over 50. This research is looking to build on previous research by administering the complete range of tests in the WAIS-IV (Wechsler, 2010) which is the updated version of the widely used IQ assessment. This would give greater reliability as the cognitive profile would be based on four index scores, namely, verbal comprehension, perceptual reasoning, working memory and processing speed, therefore giving a complete IQ score. The use of WMS-IV indices (Wechsler, 2010) provides greater reliability and content validity as a wide range of tests are used to assess different types of memory, including auditory memory, visual memory, visual working memory, immediate memory and delayed memory.

As both the WMS-IV and WAIS-IV have normative data from the general population, the current study aimed to compare the manuals' normative data with the data from this study to determine whether different aspects of IQ and memory differ

between the over 50s with and without ASD. Furthermore, as both measures have been co-normed using 40 adults aged below 40 years with Asperger's syndrome, the current study tentatively aimed to build on previous research by comparing the findings of the cognitive profiles of younger and older (those aged over 50) individuals with ASD. The study also investigated the discrepancy between predicted memory and actual memory, to control for any differences in IQ between the sample in the present study and the standardisation sample.

**Aims and hypotheses**

The study aim was to measure the cognitive profiles of the over 50s with ASD, to establish:

1. **Whether there is a difference in cognitive abilities between the over 50s with ASD and the normative sample in the WAIS-IV, WMS-IV and TMT**

   It is tentatively predicted that there will be a difference in the performance of the over 50s with ASD compared to people of the same age without ASD.

2. **When intellectual abilities are controlled for, is there a difference in the predicted and obtained memory scores of the over 50s with ASD?**

   It is tentatively anticipated that the predicted memory scores will be different to the obtained scores.

3. **Whether the cognitive profile of the over 50s with ASD is similar to that found in younger adults with ASD in terms of scores on the WAIS-IV and WMS-IV**

   It is tentatively predicted that the over 50s with ASD would perform differently to the younger group.

# Methods

## Ethics approval

This study received ethical approval from the research committee in the Clinical, Educational and Health Psychology Department in University College London. The Ethics Approval reference number is 5446/001.

## Power analysis

The sample size was based on a power calculation for an independent t-test, as this was the planned main method for statistical analyses. The G*Power 3.1.9.2 program for Windows was used to compute effect size. For a large effect size (0.8) based on Guerts and Vissers (2012) study which found differences of a large effect between those with HFA and a TD control, specifying a power of 0.80 and a Type 1 error of 5% (p=0.05), the calculation suggested that a minimum sample of 26 participants was required.

## Design

This is an exploratory study. It is a cross-sectional design with between and within group elements.

## Participants and setting

For the purpose of this exploratory study, the participants were aged 50 years and over with a diagnosis of ASD. While 50 years is not old enough to capture changes in ageing, this was chosen due to the very small number of people diagnosed with ASD over this age and this was the age chosen in previous literature in the area (Geurts & Vissers, 2012).

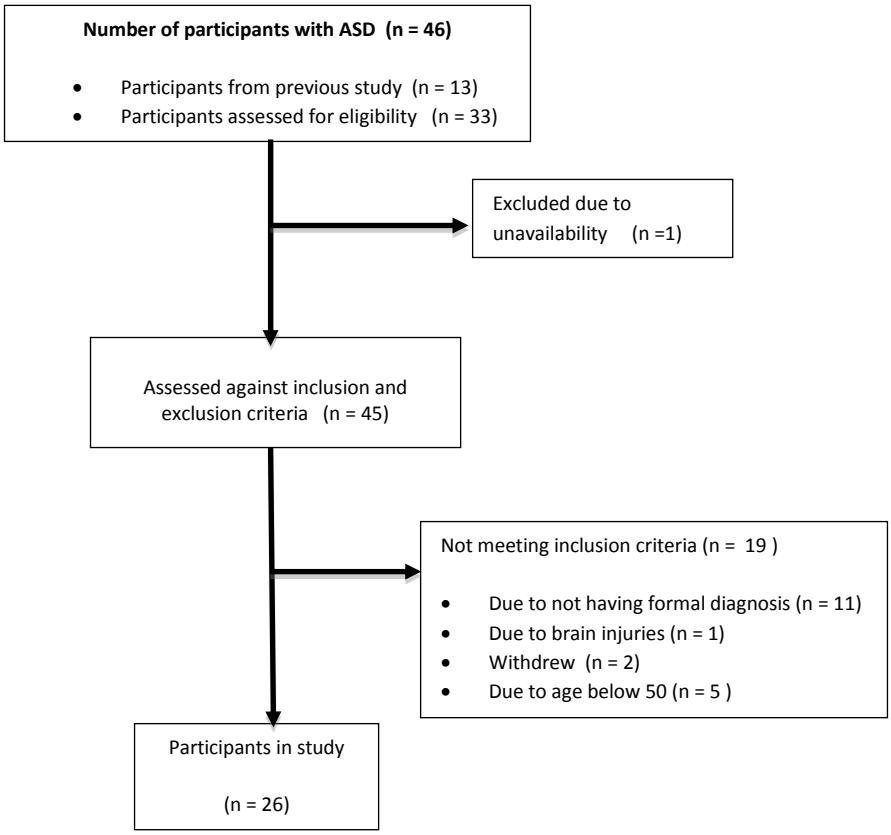
The participants were individuals diagnosed with Autism Spectrum Disorder, without a co-morbid diagnosis of learning disabilities. Twenty six participants were recruited to take part in the study, of which 12 participants were invited and recruited from the 13 participants who had taken part in a previous study (Hickey, Crabtree, & Stott, 2017) and agreed to be contacted about future research. The remaining participants were recruited from an autism research register held at UCL and community-based groups such as Asperger London Area Group (ALAG), Clearer Perspectives and Bridging the Gap Group, where the researcher presented the information and aims about the research and invited the over 50s with ASD to participate. Individuals who met the inclusion criteria were provided with information regarding the study via letters (see Appendix B). It was the responsibility of the individuals to contact the researcher. The diagnostic status of most participants was verified by a diagnostic clinic in London, and the remaining participants provided the details of the clinicians and services where they received the diagnosis.

Individuals were included in the study if they:

1. Had received a diagnosis of an autism spectrum disorder (Asperger's syndrome, autistic disorder or PDD-NOS) in adulthood
2. Did not have a co-morbid diagnosis of learning disabilities
3. Were aged 50 years and over
4. Had adequate hearing, vision, motor abilities and language skills
5. Had English as their first language (the tests requirement)
6. Were resident in the UK

The recruitment process and flow through is illustrated in Figure 1.

Figure 1: Flow chart of recruitment process




## Demographic information

A brief self-reported history of medical and psychiatric issues was obtained from participants as well as details regarding their demographic information such as age, gender, ethnicity, education, marital status and living arrangements (see Appendix C). Participants consented to the research by signing the consent form (see Appendix D). Table 1 shows the demographic information of the over 50s.

Table 1: Participant Characteristics

Over 50s with ASD sample

| | M | SD | Range |
|---|---|---|---|
| Mean age | 59.35 | 5.99 | 50 - 72 |
| Age at diagnosis | 52.50 | 7.44 | 35 - 65 |

| | N | % |
|---|---|---|
| Gender | | |
| Male | 20 | 76.9 |
| Female | 6 | 23.1 |
| Ethnicity | | |
| White / British | 20 | 76.9 |
| Black / British | 1 | 3.8 |
| White / Other | 5 | 19.2 |
| Education | | |
| Secondary school level | 8 | 30.8 |
| College level | 6 | 23.1 |
| Degree level | 8 | 30.8 |
| Postgraduate level | 4 | 15.4 |
| Diagnosis | | |
| Asperger's Syndrome | 22 | 84.6 |
| Autism Spectrum Disorder | 2 | 7.7 |
| High Functioning Autism | 2 | 7.7 |
| Employment status | | |
| Employed | 9 | 34.6 |
| Unemployed | 5 | 19.2 |
| Retired | 8 | 30.8 |
| Voluntary work | 4 | 15.4 |
| Current living circumstances | | |

| | | |
|---|---|---|
| Lives independently | 16 | 61.5 |
| Lives with family | 9 | 34.6 |
| Lives with partner | 1 | 3.8 |
| Marital status | | |
| Single | 16 | 61.5 |
| Married | 6 | 23.1 |
| Partnership | 2 | 7.7 |
| Divorced | 2 | 7.7 |
| Health | | |
| Good health | 21 | 80.8 |
| Poor health* | 5 | 19.2 |

Note: * Participants indicated their own understanding of their health

**Neuropsychological (NP) assessments**

All participants were administered the following tests.

**General intellectual abilities**

The Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV, UK; Wechsler, 2010) is a range of tests designed to evaluate intellectual abilities in adults and older adolescents. It has fairly high consistency, with test-retest reliabilities ranging from 0.70 (7 subscales) to 0.90 (2 subscales). According to the manual the inter-scorer coefficients are very high, all being above 0.90.

The range of tests is composed of 10 core subtests (vocabulary, information, similarities, digit span, arithmetic, block designs, matrix reasoning, visual puzzles, coding and symbol search). The scaled scores for the subtests within an index are summed and used to derive the index scores. The index scores are standardised with a

mean of 100, a standard deviation of 15 and a range of 40-160. There are four index scores (verbal comprehension [VCI], perceptual reasoning [PRI], working memory [WMI], and processing speed [PSI] and two overall measures of cognitive functioning, the general abilities index [GAI] and full scale IQ [FSIQ]. There is a large well described typically developing normative dataset which provides a comparison for the index score (Wechsler, 2014).

**Memory**

The Wechsler Memory Scale, Fourth Edition (WMS-IV, UK; Wechsler, 2010) is designed to measure different memory functions in adults and older adolescents. It measures the ability to learn and remember information presented verbally and visually and it is designed to be used with the WAIS-IV. It consists of 10 subtests: spatial addition, symbol span, design memory, general cognitive screener, logical memory, verbal paired associates, and visual reproduction. The subtests provide index scores for auditory memory [AMI], visual memory [VMI], visual working memory [VWMI], immediate memory [IMI] and delayed memory [DMI]. For the analyses, the standard scores for each subtest and index/composite scores were used. The working memory constructs are arranged in WAIS-IV and WMS-IV, so that both auditory and visual subtests are measured. The WAIS-IV working memory index includes auditory working memory and the WMS-IV includes the visual working memory.

**Cognitive flexibility**

The Trail Making Test (TMT) was used to assess cognitive flexibility. It provides information on visual search, scanning, and speed of processing (Lezak, 1995), mental flexibility, executive functions (Tombaugh, 2004) as well as visual attention and task switching (Lezak, 1995). It is also sensitive to a variety of

neurological impairments and processes. It has norms that are stratified over a wide range of ages, education and intelligence (Tombaugh, 2004). The TMT is a timed task that consists of two sections, and requires the participant to draw a line to connect numbers and letters in consecutive order. In the first section, participants join numbers 1 to 25 in ascending order as quickly as possible without mistakes. In the second section the participant alternates between numbers and letters and connects them (1 to A, A to 2, 2 to B and so on until 13). Cognitive flexibility is established from the discrepancy in scores between both sections (Tombaugh, 2004). The measure used here was the difference in the time it took to complete section A and section B (Reitan & Wolfson, 1985). Performance is expected to decrease with age, however it is known that education level may influence the deficit process (Tombaugh, 2004).

**Procedure**

Participants were recruited using the multipronged approach as outlined above. During recruitment all participants who contacted the researcher were spoken to over the phone or met by the researcher to screen for eligibility. The eligibility screening was conducted by the researcher in discussion with participants. Participants meeting the inclusion criteria were provided with aims and information on the research process. An information sheet (see Appendix B) was emailed to them or a copy was provided at the initial meeting. Participants concerns or queries were answered. Thereafter, all participants gave written informed consent on the research process (see Appendix C) and completed a demographic information sheet (see Appendix D). Participants were invited to meet at the university or in their homes to administer the tests. To account for order effects, the test orders were counterbalanced across participants.

## Data analysis

To analyse the data, the SPSS statistical package (Version 22) was used. An initial descriptive analysis was conducted to ensure that the normality assumptions were observed. The Kolmogorov-Smirnov tests and Skewness kurtosis were investigated to test for significance of any deviation from normality. T-tests were used to compare the differences in the scores on WAIS-IV and WMS with a standardised population and younger adults with ASD. The WAIS-IV and WMS-IV manuals regression equation was used to establish the predicted memory scores according to their general abilities and compared to the actual memory scores obtained.

# Results

The demographic details for all participants are presented in Table.1. The majority of participants were single and only one participant was non-white. The gender breakdown of 20 males to six females was in line with the male-to-female ratio in ASD (Brugha et al., 2011). All participants completed a minimum of secondary level education. On average, participants received a diagnosis 6.9 (SD) years before taking part in the study. One participant undertook the older adult category tests in WMS-IV, age range 69-90, which does not include a number of subtests, therefore no scores were acquired for the designs I, designs II and spatial addition subtests for this participant. As these subtests are not used in the calculation of the auditory memory index, the participant's scores were included for this index, but not the others.

**Question 1: What is the difference in cognitive abilities between our over 50s with ASD sample and the normative sample in the WAIS-IV, WMS-IV and TMT?**

To do this, we compared the sample scores with the scores from the WAIS-IV and WMS-IV standardisation samples. In the normative group the index mean is 100 with a standard deviation of 15. The basic descriptive statistics for WAIS-IV are presented in Table 2.

**Differences in WAIS-IV indices**

The index means in our sample for VCI, PRI, WMI, FSIQ and GAI are all within the high average range except the PSI, which was within the average range. To examine the difference in cognitive abilities between our sample of over 50s with ASD and the normative sample, one sample t-tests were used to determine whether index scores in the sample differed significantly from the standardisation sample. Assumptions of normality in the clinical sample were investigated using histograms, Kolmogorov-Smirnov tests and Shapiro-Wilks tests; the data were normally distributed. One-sample t-tests were conducted to compare the mean scores for the group, with the standardisation sample. The alpha level was adjusted to compensate for the number of comparisons made and was set at .008 with Bonferroni correction. Table 2 shows the WAIS-IV index means, standard deviations and statistics for the over 50s with ASD and the normative sample.

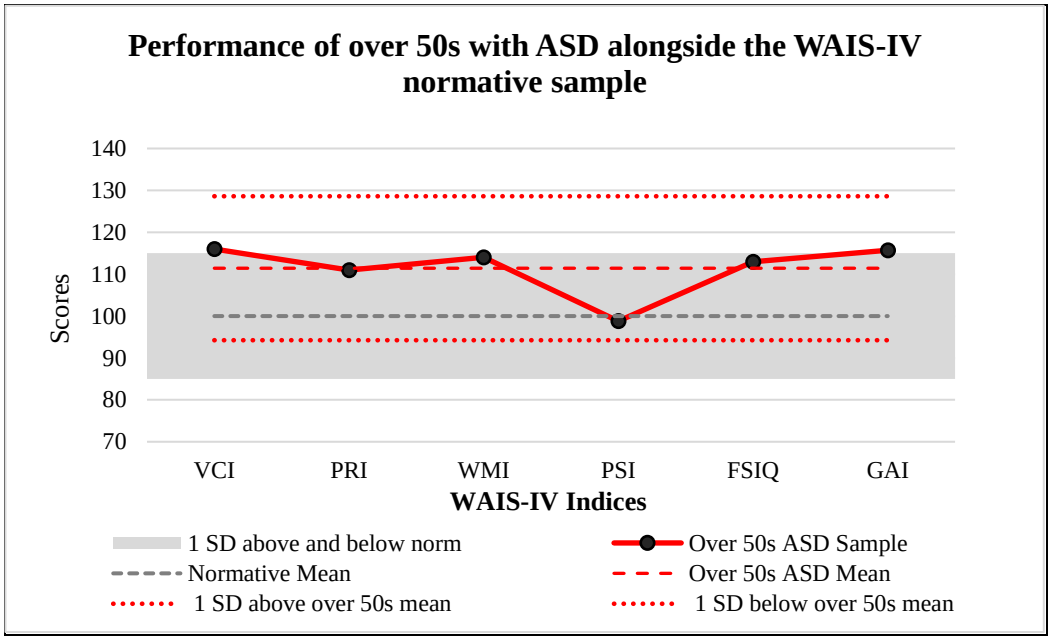
Table 2: The WAIS-IV index scores for over 50s with ASD and normative group

| WAIS-IV Composite | Standardised Norms (SD) | Over 50s with ASD Sample Mean (SD) | Statistics (P = .008) |
|---|---|---|---|
| **Verbal Comprehension*** | 100 (15) | 116.35 (15.8) | **t(25) = 5.288, p < .001** |
| **Perceptual Reasoning*** | 100 (15) | 110.85 (18.7) | **t(25) = 2.950, p < .007** |
| **Working Memory (Auditory)*** | 100 (15) | 114.38 (17) | **t(25) = 4.323, p < .001** |
| Processing Speed | 100 (15) | 98.8 (15.3) | t(25) = - .396, p = 0.695 |
| **Full Scale IQ*** | 100 (15) | 113.04 (18.5) | **t(25) = 3.602 , p < .001** |
| **General Abilities*** | 100 (15) | 115.73 (17.8) | **t(25) = 4.515, p < .001** |

*Note.* *In bold are the indices on which significant differences emerged
WAIS-IV = Wechsler Adult Intelligence Scale – Fourth Edition; Verbal Comprehension Index =VCI; Perceptual Reasoning Index = PRI; Working Memory Index = WMI; Processing Speed = PSI; Full Scale IQ = FSIQ; General Abilities Index = GAI

For VCI, PRI, WMI, FSIQ and GAI the mean for the over 50s with ASD sample scores is significantly different from, and nearly one standard deviation above, the scores in the standardisation sample, as displayed in Figure 2. The processing speed index was the only index which was not significantly different. PSI scores were just below the normative mean.

Figure 2: Graph of over 50s WAIS-IV scores and normative group scores




The over 50s with ASD sample had a similar processing speed to the normative sample. They had significantly better verbal comprehension, perceptual reasoning, working memory and general abilities. This group of individuals were high functioning ASD and it is therefore difficult to draw conclusions about the hypothesis that there is a cognitive difference between the over 50s with ASD and the normative sample.

**Differences in WMS-IV indices**

The over 50s with ASD index means for auditory, visual, visual-working, immediate and delayed memory were all within the average range, as shown in Table 3. To examine the difference in memory scores between the over 50s with ASD and the normative sample, assumptions of normality in the clinical sample were investigated using histograms, Kolmogorov-Smirnov tests and Shapiro-Wilks tests; the data were normally distributed. The alpha level was adjusted to compensate for the

number of comparisons made and was set at 0.01 with Bonferroni correction. One sample t-tests were conducted to determine whether the sample scores were different from the standardised normative data.

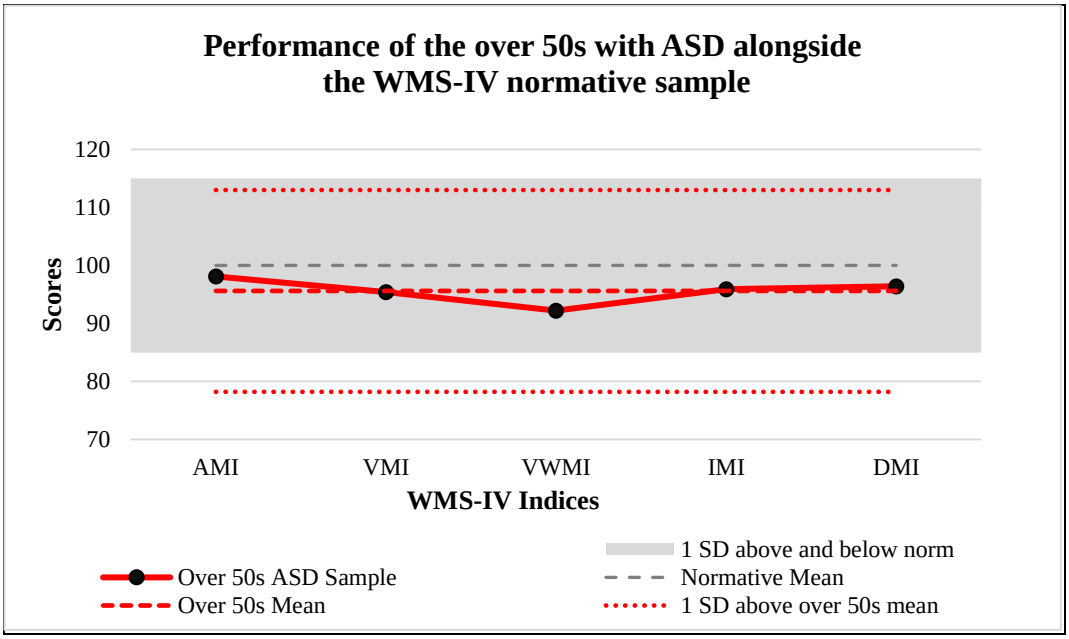
Table 3: The WMS-IV index scores for over 50s with ASD and normative group

| WMS-IV Composite Scores | Standardised Norms (SD) | Over 50s with ASD Sample Mean (SD) | Statistics (P = .01) |
|---|---|---|---|
| Auditory Memory Index | 100 (15) | 108.88 (18.5) | t(25) = 2.397, p = 0.024 |
| Visual Memory Index | 100 (15) | 98.92 (14.05) | t(24) = -0.384, p = 0.305 |
| Visual Working Memory Index | 100 (15) | 103.92 (17.48) | t(24) = 1.149, p = 0.533 |
| Immediate Memory Index | 100 (15) | 104.16 (17.05) | t(24) = 1.19, p = 0.316 |
| Delayed Memory Index | 100 (15) | 105.48 (19) | t(24) = 1.440, p = 0.212 |

Note. Auditory Memory Index = AMI; Visual Memory Index = VMI; Visual Working Memory Index = VWMI; Immediate Memory Index =IMI; Delayed Memory Index = DMI

The over 50s with ASD did not score significantly differently to the general population on any of the memory indices. The auditory memory index and delayed memory scores were above the mean. Visual and immediate memory indices scores were average, however, the visual-working memory index was below the mean, but within one standard deviation of the normative group.

Figure 3: Graph of over 50s WMS-IV index scores and normative group scores




Relative to the general population, this sample of over 50s with ASD had a higher intellectual and general ability scores, however, their memory abilities were not different. Thus, comparison to the normative data set suggests our sample has a higher IQ than average. This means that it is hard to interpret the lack of difference in memory as it may be due to no difference or the fact that their IQ is higher thus artificially inflating their memory scores relative to those with an average IQ.

**Differences in Trail Making Tests (TMT)**

Cognitive flexibility was measured using TMT trails. One sample t-tests were conducted to compare the performance of the over 50s with ASD with that of the normative group on this task (Tombaugh, 2004). There was no significant difference in the Trail A scores for the over 50s with ASD (M=34.92, SD =14.75) and norm (M= 32.55, SD = 8.59); t (119) = 1.5431. The Trail B scores for the over 50s with ASD (M= 69.58, SD = 60.71) and norm (M= 66.39, SD = 16.32); t (119) = 0.4593 were not

significantly different. Therefore, these findings of cognitive flexibility were not supported.

**Question 2: When intellectual abilities are controlled for, is there a difference in the predicted and actual memory scores of the over 50s with ASD?**

In order to do this, we used the regression equation within the WMS- IV (WMS-IV, UK; Wechsler, 2010) to predict memory index scores for each individual that would be expected based on the obtained GAI scores (in this way controlling for high IQ). To assess whether performance on memory indices was different to that expected given the IQ we compared the mean predicted index scores with the mean obtained index scores.

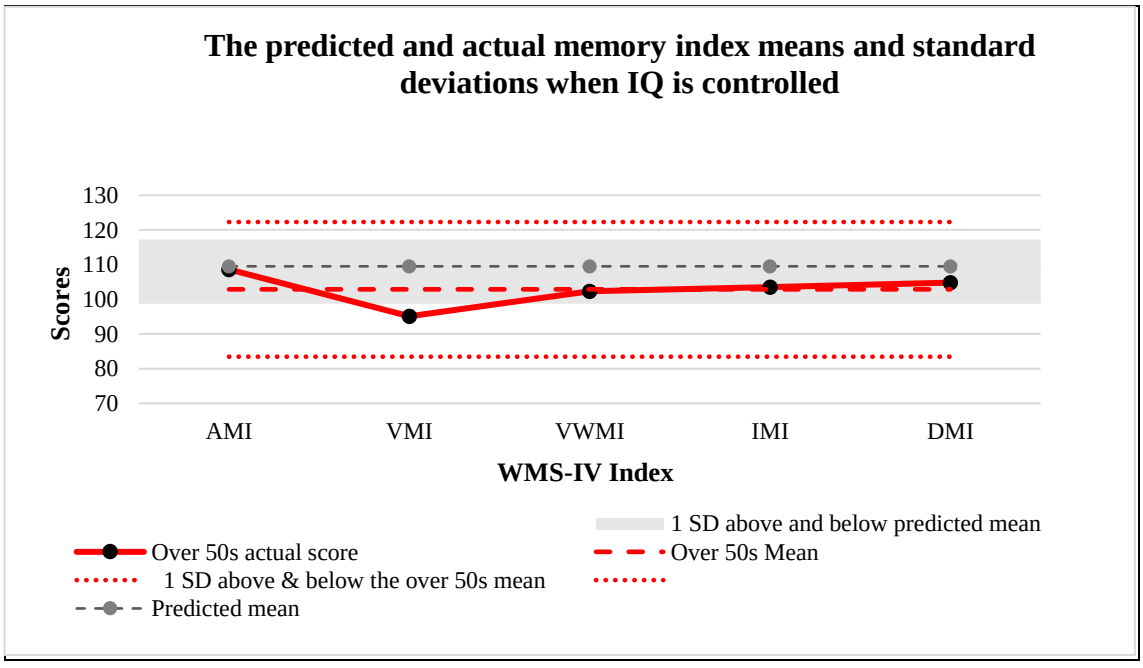
It was hypothesised that there would be a difference between the predicted and actual memory scores of the over 50s with ASD when their general abilities are controlled for. To examine this hypothesis, within subjects t-tests were used as data met all the assumptions of normality. The alpha level was set at 0.01 with Bonferroni correction. The mean scores of predicted and actual memory scores and the findings of the t-tests are presented in Table 4.

Table 4: The predicted and actual memory scores on WMS-IV

| WMS-IV Composite Scores | Predicted mean score (SD) | Actual mean score (SD) | Statistics ( P = 0.01) |
|---|---|---|---|
| Auditory Memory | 108.3 (9.4) | 108.6 (18.2) | t(25) = 0.080, p = 0.947 |
| **Visual Memory** | **109.3 (17)** | **98.9 (14)** | **t(49) = - 4.640, p = 0.004** |
| Visual Working Memory | 110.5 (11.9) | 103.9 (17.1) | t(25) = -2.396, p = 0.117 |
| Immediate Memory | 110.4 (11.8) | 104.2 (17.5) | t(25) = -2.338, p = 0,139 |
| Delayed Memory | 109 (10.4) | 105.5 (19) | t(25) = - 1.188, p = 0.409 |

Note: Bonferroni adjustment set

Figure 4: Graph of WMS-IV predicted and actual index scores for the over 50s with ASD




The over 50s with ASD performed lower than expected on the visual memory index and in all the other indices they performed as expected. The hypothesis that there would be a difference between the predicted and actual memory scores of the over 50s

with ASD, when their intellectual abilities are controlled, was partially supported. The over 50s with ASD performed as predicted in the auditory, visual-working, immediate and delayed memory subtests. However, their visual memory was significantly worse than predicted when their intelligence was controlled for.

**Question 3: Does the cognitive profile of the over 50s with ASD follow similar patterns to younger adults with ASD scores on the WAIS-IV and WMS-IV?**

An exploratory hypothesis is that there is a difference in cognitive abilities between the over 50s with ASD and the younger adults (YA) with ASD from the WAIS-IV and WMS-IV clinical samples. A sample size of 40 participants was used in the younger adults with a diagnosis of Asperger's syndrome sample in the WAIS-IV and WMS-IV. Participants were aged 16-40 years, with a mean age of 22.5 years; 77.5% were males (N=31) and 22.5% were females (N= 9). In order to evaluate this hypothesis the index scores of the over 50s with ASD were compared with those of the younger adult ASD sample reported in the WAIS IV and WMS IV manual. To compare mean index scores, a one-sample t-test was conducted following the data being analysed for normality assumptions. The alpha level was adjusted to compensate for the number of comparisons made and set at .008 with Bonferroni correction. The findings are presented in Table 5.

Table 5: Comparison of WAIS-IV scores between over 50s and younger adults

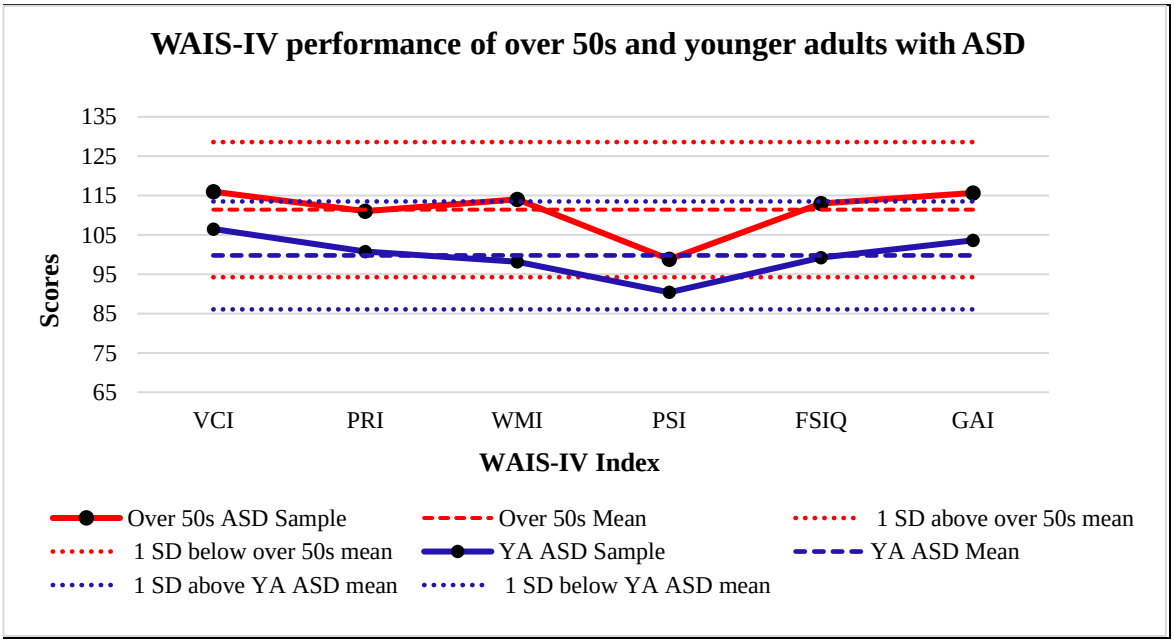
| WAIS-IV Composite Scores | Over 50s with ASD Mean (SD) | YA-ASD Mean (SD) | Statistics (P = 0.008) |
|---|---|---|---|
| Verbal Comprehension | 116.35 (15.8) | 106.5 (14.9) | t(57) = 2.3676, p = 0.0213 |
| Perceptual Reasoning | 110.85 (18.7) | 100.8 (13.1) | t(56) = 2.4379, p = 0.018 |
| **Working Memory (Auditory)*** | **114.38 (17)** | **98.2 (15.6)** | **t(57) = 3.7127, p = 0.0005** |
| Processing Speed | 98.8 (15.3) | 90.4 (13.7) | t(57) = 2.2209, p = 0.0303 |
| **Full Scale IQ*** | **113.04 (18.5)** | **99.2 (12)** | **t(56) = 3.4278, p = 0.0011** |
| **General Abilities*** | **115.73 (17.8)** | **103.6 (13)** | **t(56) = 2.9895, p = 0.0041** |

Note. * Significant difference

Verbal comprehension and general abilities are above the respective mean score for both groups. The perceptual reasoning mean is average as is the full-scale IQ for both groups. Both groups have a processing speed that is below average and nearly one standard deviation below the mean index score. Both the over 50s with ASD and YA groups had similar patterns of index scores where no one index score differed by more than a standard deviation from the mean of all the index scores.

The WMS-IV mean indices were compared between younger participants and the over 50s with ASD, as shown in Figure 5. To investigate further, independent t-tests were carried out as all the normality assumptions were met and the alpha level was set at 0.01. Findings are presented from the t-tests in Table 6.

Figure 5: Graph of WAIS-IV index scores of younger sample and over 50s with ASD



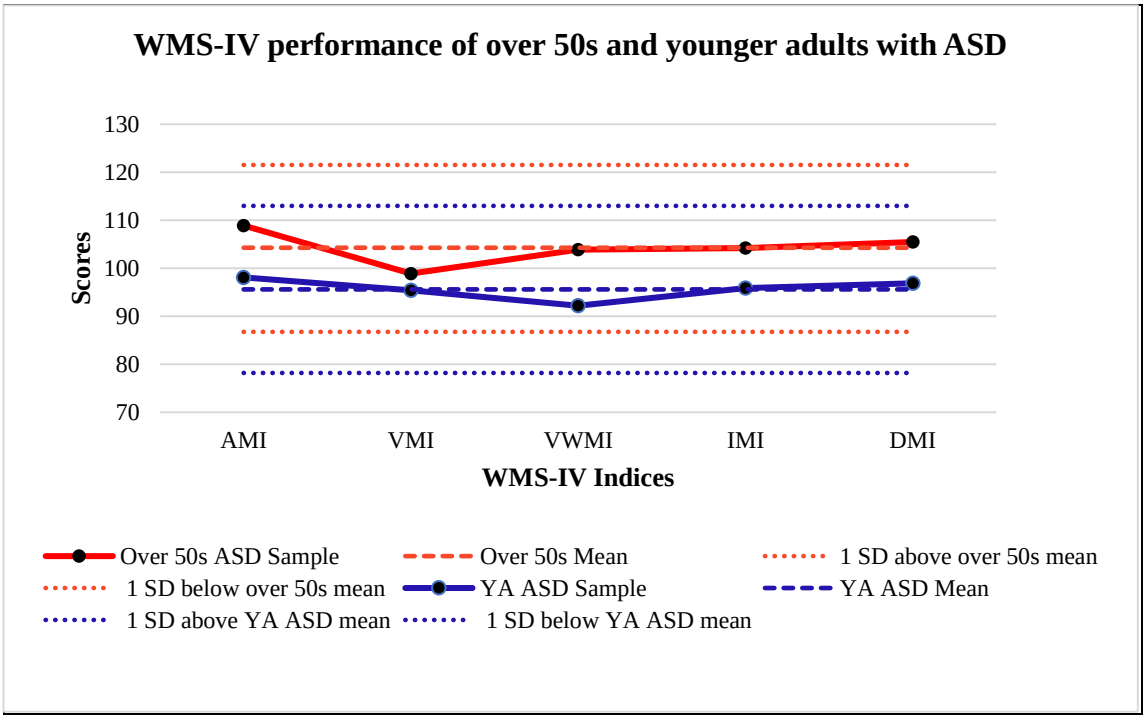

The over 50s with ASD performed significantly better than younger adults with Asperger's on the visual working memory index, but not on other indices.

Table 6: Comparison of WMS-IV scores between over 50s and younger adults

| WMS-IV Composite Scores | Over 50s with ASD Mean (SD) | YA-ASD Mean (SD) | Statistics (P = 0.01) |
|---|---|---|---|
| Auditory Memory | 108.6 (18.2) | 98.1 (17.5) | t(55) = 2.2476, p = 0.0286 |
| Visual Memory | 98.9 (14) | 95.4 (19.6) | t(56) = 0.7613, p = 0.4497 |
| **Visual Working Memory** | **103.9 (17.1)** | **92.2 (12.1)** | **t(58) = 3.0720, p = 0.0032** |
| Immediate Memory | 104.2 (17.5) | 95.9 (19.4) | t(57) = 1.6842, p = 0.0976 |
| Delayed Memory | 105.5 (19) | 96.4 (18.4) | t(54) = 1.8082, p = 0.0761 |

Note. Bonferroni adjustment applied

Figure 6: Graph of WMS-IV index scores of younger sample and over 50s with ASD




## Discussion

### Summary of results

To our knowledge, this is the only study to date that investigated the cognitive profile of those ageing with ASD using the full range of tests of the WAIS-IV and WMS-IV.

Very little previous research and literature was found regarding the cognitive profile of over 50s with ASD. The present study therefore set out to explore the strengths, weaknesses and any patterns in the cognitive profile of those ageing with ASD.

### Over 50s with ASD versus the normative sample

An initial objective of the project was to investigate the cognitive profile of the over 50s with ASD using the gold standard measures WAIS-IV and WMS-IV. The first research question explored whether there was a difference in the abilities between the over 50s with ASD and the normative sample. In view of the literature on ageing and the cognitive deficits found in adolescents and adults with ASD, it was tentatively predicted that there would be a difference in the performance of the over 50s with ASD compared to the normative sample.

The overall intellectual ability of the over 50s with ASD was high as evidenced by the high index scores. Their full scale IQ mean was 113.04 and the general abilities index was slightly better at 115.73. A closer look at the participants GAI scores showed that 61.5% of the sample can be placed in the 'high average' to 'very superior' category, 30% within the average range and 7.7% in the low average category. The means were significantly better in the verbal comprehension, perceptual reasoning, working memory (auditory) and general ability indices and full-scale IQ scores than people without ASD. However, the group performed within the average range for processing speed index, cognitive flexibility as measured by the TMT and the memory indices of the WMS.

The cognitive profile that featured was that processing speed and cognitive flexibility are within the average range and that all the other abilities were significantly better. Previous studies showed that individuals with Asperger's syndrome or those with ASD and without language deficits had strong verbal comprehension (Kanai et al., 2012) and the majority of the sample (84.6%) in this study have Asperger's syndrome as their diagnosis. This finding may tentatively provide some support to previous research that found strong general abilities in individuals with ASD

(Asperger's) who also have significantly better language abilities (Ambery et al., 2006; Kanai et al, 2012). However, this may be an area for future investigations.

The findings of the current study do not entirely support the findings of previous research which showed individuals with Asperger's to have better developed verbal abilities compared to perceptual abilities (McCrimmon, Schwean, Saklofske, Montgomery, 2012 and Spek et al., 2007). No differences were found between verbal comprehension and perceptual reasoning indices; however, processing speed was significantly weaker than all the other abilities indices. These findings broadly support the studies with adolescents and younger adults, which demonstrate that individuals with ASD have a 'spikey' cognitive profile with significant variability in their cognitive development (Joseph, Tager-Flusberg, & Lord, 2002).

**Predicted memory scores of the over 50s with ASD**

In spite of high abilities, the group's performance on the memory indices was not different from the normative sample. The next objective was to explore whether the actual memory scores of this group of participants would differ to the scores predicted by their general intellectual abilities. The results demonstrated that the over 50s actual memory scores generally were consistent with their predicted scores based on their performance on the WAIS-IV. However, one unanticipated finding was in the domain of visual memory, in which their performance was found to be significantly lower than predicted. This finding is in line with the findings of younger adults (Ambery et al., 2006), but contrasts with Lever and Geurts (2016) who found that the

over 50s with ASD yielded higher scores in visual memory. There are several possible explanations for this finding.

Firstly, as a group the participants had significantly weaker processing speed, which may have had a part to play. It is probable that their slower processing speed impacted the performance on visual tasks. Another explanation may be the pace of acquisition of new visual information, as ageing adults with weaker processing speed may give rise to the inability to disregard irrelevant information (Darowski et al., 2008). The stimuli for these tasks were unfamiliar shapes and designs, which may require incorporation of various executive skills to complete the task. The 10-second time scale to encode novel information, process and later retrieve information on certain visual presentations may have been a challenge for these participants, as the ability to encode new information into memory declines with ageing (Haaland et al., 2003). The current study found that there was not a significant discrepancy between the actual and predicted scores in delayed memory in the over 50s with ASD, signifying that items that were effectively processed were retained for longer, and remained preserved, and that decline can happen to newly learned information (Whitington et al., 1997).

A second explanation for the significantly lower than predicated performance in the domain of visual memory pertains to the nature of the tasks employed to assess this ability. The visual memory index is composed of subtests that measure the ability to recall designs from memory, draw them and replicate the placement of designs. Visual memory assesses both memories for visual details and for spatial location, so the incorrect identification, incorrect location or missing details of the designs can contribute to lower scores. It is possible that the tasks contained an element of 'grouping' which may be difficult for those with ASD who have difficulties with

grouping and tend to focus on individual parts of the stimuli rather than global design (Carther-Krone, Shomstein, & Marotta, 2016).

The visual memory subtests in WMS-III (Wechsler, 1997b) consisted of family pictures and also had a faces subtest, which has been replaced by visual reproduction as a core subtest in WMS-IV. Previously, there were many criticisms of the assessment of visual memory, especially with ASD groups and recognising faces and social situations (Williams et al., 2005). The studies with older adults with ASD used the subtests from WMS-III (Geurts & Vissers, 2011; Lever & Guerts, 2016). Although the new visual memory subtest has probably reduced ambiguity for individuals with ASD, it may have introduced an element of difficulty by making drawing a part of the core subtests. Williams et al. (2005) referred to findings from a study (Ameli et al., 1988) that found that individuals with high functioning ASD performed worse than matched controls on visual recognition memory for complex meaningless shapes. This group of over 50s with ASD may have performed poorly on visual memory simply because of difficulty with difficult tasks. The theory of weak 'central coherence', which is the tendency to pull together diverse information to construct a higher level meaning, can explain some of the patterns of strengths and weaknesses and the information processing style of individuals with ASD (Happé, 1999). Individuals with ASD are thought to prefer a cognitive style typified by local processing rather than global or Gestalt processing (Bolte, Holmann, Poustka, Scheurich & Schmidt, 2006). They can easily focus on local information and overlook the overall essence of visual items (Rensink, 2002). The Enhanced Perceptual Functioning theory (Mottron et al, 2006) suggests that there is an inherent bias for such processing of visual information.

Thirdly, individuals with ASD may also experience sensory perceptual difficulties when completing the visual stimuli as well as difficulties with attention and

processing. The focus on perception by individual elements rather than the fundamental nature of the whole (Mottron & Burack, 2001) might impact on their ability to recall the visual stimuli of the WMS-IV subtests.

Finally, the finding of significantly weak visual memory is in line with the findings of younger adults (Ambery et al., 2006) but not with recent findings with older adults with ASD (Geurts & Vissers, 2011; Lever & Guerts, 2016). These inconsistencies are perhaps explained by differences in the stimuli used between studies.

**Over 50s with ASD versus younger adults with ASD**

As explained in the introduction, it is clear that there is a different trajectory of cognitive change in those with ASD compared to typically developing adults. We compared our results with data from a group of younger adults with ASD who were administered the full range of WAIS-IV and WMS-IV and whose results are presented in the manuals. The sample used was aged between 16-40 years, with a mean FSIQ of 99.2 and a mean score of 103.6 on GAI. It was tentatively hypothesised that the ability scores of the over 50s with ASD, when compared to younger adults with ASD, would show an uneven profile in line with previous research with younger people with ASD (Kanai et al., 2012).

Whilst the findings should be interpreted with caution, because comparisons were not from matched participants, both the younger and older ASD groups had a varied presentation of abilities, which was different from the more uniform scores found in the standardised TD population. The over 50s group performed significantly better on working memory (auditory) index, FSIQ and GAI than the younger adults

group. For both groups the strongest ability was verbal comprehension and the weakest was processing speed. A similar pattern was also seen with the memory measures for both groups. The over 50s with ASD performed significantly better than the younger group on visual working memory index. Thus, overall, the results suggest that in the context of memory and general abilities, the over 50s with ASD sample had particular strengths relative to younger adults with ASD in working memory (visual and auditory). The older group had a better working memory, which may suggest that ageing may not have an adverse effect on this group. These findings have to be considered tentatively due to various methodological issues including generalisability from such a small sample. These results may possibly provide some support for the 'safeguard' hypothesis suggested by Geurts and Vissers (2012). The findings may also point towards the presence of subgroups within ASD, highlighting the heterogeneity within ASD.

**Clinical and research implications**

*Clinical implications* - the findings have shown an uneven profile in individuals with ASD. This has some implications when it comes to the assessment of age-related cognitive decline. While the sample in the present study overall had a high level of cognitive functioning, they performed significantly worse in some domains of memory compared to their score predicted based on their performance in the WAIS. This is useful when trying to understand the impact of ASD on an individual as they age and may help limit misinterpretation of deficits due to autism as being due to dementia.

In addition, it is important to question the lack of impairment found in delayed memory for this group of over 50s with ASD. There was no significant impairment in delayed memory suggesting it does not appear to represent a risk factor for the most common form of dementia. Further studies regarding the role of delayed memory in ASD with over 50s would be worthwhile to investigate.

*Research implications* - future work with larger samples, with the robust, gold standard measures used here along with a control group would be useful to combine the benefits of this small scale study with the larger scale work of Lever and Guerts, (2016).

More research on this topic needs to be undertaken before the association between ageing and ASD is more clearly understood. For example, future research should examine subgroups of those with differing profiles as the differences in results between previous research and the present study could be due to heterogeneity in cognitive profiles in those with ASD. More specifically, earlier studies have highlighted that an 'individual differences' approach may provide further information about potential subtypes in ASD (Guerts, Sinzig, Booth, & Happé, 2014), suggesting that individuals with ASD who have weaknesses in certain cognitive abilities differ in aetiology and prognosis from those who have deficits in other areas or abilities.

**Strengths and limitations**

As an exploratory study this work offers a starting point to understanding the cognitive profile of individuals with ASD as they age. Strengths of this study were the usage of the gold standard measures WAIS-IV and WMS-IV and the full range of tests to produce a more reliable and valid understanding of the abilities rather than using shorter versions of tests or using a subtest to represent a domain.

There are several limitations of the study including design, sampling method and selection process. The study design was not the most appropriate for investigating change due to ageing. The cross-sectional nature of the current study also limits conclusions as to the trajectory of decline and there is a need for longitudinal work to investigate these changes.

Another limitation was the lack of matched controls or a younger group of adults with ASD to conduct the comparisons; this limits the ability to draw strong conclusions regarding the strengths and difficulties in ASD compared to a normative population. Our study also had a relatively small sample size and we corrected results for type 1 error using Bonferroni corrections. This may have led to a type 2 error, particularly in comparing predicted vs obtained memory scores where t-values for visual working memory and immediate memory were approaching the Bonferroni adjusted p value for significance. A larger group of people with a wider range of old people (young, mid-older and older) with and without ASD would be recommended in future studies.

The neuropsychological tests utilised do not measure every executive functioning skill, organisational and planning skill that may be necessary to complete such a task. It is possible that these unmeasured variables could account for some aspects of the results.

Another limitation is the relatively young age of the sample with some areas of cognition (in particular executive functioning) not starting to decline until the age of 70 in typically functioning adults (Andres and Van der Linden, 2000); therefore there is a need for further research in older age groups. A confounding variable may have been the selection methodology for the research. Individuals who took part in the study

were aware of their above average abilities, therefore opted to be tested and volunteered to participate in the study. Due to a lack of resources it was not possible to re-establish or verify the ASD diagnosis of participants and this was a study limitation. Some considerations had to be provided for the number of tests participants had to undertake and the possible biases this may introduce. As some participants were diagnosed with sub-groups of ASD, this may have implications when attempting to generalise findings. It was important to confirm that participants do meet the inclusion criteria. This can impact the representativeness of the participants and the extent to which these findings can be generalised.

**Conclusion**

Ageing in autism cannot be explained using studies with children or even young adults and there is a need to expand research in this area. Future research into the understanding of cognitive processes in those ageing with ASD needs to include a larger sample size employing the robust measures used here. The current study has shed some light on the cognitive and memory profiles of individuals with ASD and the findings suggest that the over 50s profiles follow a similar pattern to those of younger adults with ASD. There may be some protective elements from the risks of dementia. These findings contribute in several ways to our understanding of individuals with ASD and provide a basis for further research into ageing with ASD.

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# Part 3: Critical Appraisal

## Introduction

The aim of this critical appraisal is to emphasise the key issues and the challenges encountered during the process of carrying out the current project. It details reflections on the complexities when conducting the empirical paper and the systematic review. It highlights the personal change of attitude towards researching a topic that is unfamiliar and not in receipt of as much exploration as other areas of autism. It concludes with links to issues that need to be addressed in future research.

## Complexities surrounding Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) refers to a group of neurodevelopmental disorders which, although not regarded as a mental illness, is included in the Diagnostic and Statistical Manual of Mental Disorders (DSM). There are many complexities involved and interplay between genes and environment. There is an assumption that the knowledge on Autism Spectrum Disorders (ASD) is extensive and rapidly growing. What is less obvious is the complexity surrounding ASD research and it easily slips the mind that ASD was not known as a distinct diagnosis until 1980. Since then it has been subjected to revisions for the diagnostic criteria, understood as separate sub-groups and dissolved into one mass description. With new understanding there is advancement and realisation of undiscovered answers to many questions. Little is known about the experience of growing old with high-functioning autism, the general cognitive abilities, weaknesses, as well as the broader consequence and impact on mental health.

Consideration of the theoretical understanding of ASD sheds some light on the complexities involved in ASD. One of the major psychological theories of ASD is the theory-of-mind deficit hypothesis which proposes that a fault in one of the many

components of the social brain can lead to an inability to understand certain basic aspects of communication (Baron-Cohen, Tager-Flusberg & Cohen, 2000). People with ASD have a diminished capacity to understand the thoughts, beliefs, intentions and emotions of other people and perhaps themselves (Rajendran & Mitchell, 2007).

Baron-Cohen (2002) described the 'extreme male brain theory of autism' which shows a weakness in empathising and strengths in systemising.

The theory of executive dysfunction in autism can be seen to underlie key characteristics of autism both in the social and non-social domains. This theory explains the difficulties around 'rigidity and perseveration' (Hill, 2004; Hill and Bird, 2006). There is a general acceptance that all cognitive and behavioural symptoms of ASD cannot be explained by these theories, however they do provide some explanation to various atypical behaviours found in ASD (Wilson & Happé, 2014) and how they process information. Also, these understandings surrounding ASD add to the difficulty of researching aspects and implications of the disorder.

These different understandings of the causes and impact of ASD highlight the effectiveness of having the 'label' of a diagnosis. The participants expressed some usefulness to having an explanation of their difficulties and a sense of acceptance that this is how life is and externalising the problem associated with ASD. Upon reflection, I understand that individuals will be labelled throughout life correctly or incorrectly. Sometimes however, having a diagnosis may serve some purpose and benefit, rather than being mislabelled as stubborn, lazy, difficult or unmotivated without a diagnosis.

**Reflection on the recruitment and selection process**

This project is a follow-on to a project about growing older with autism. The previous study interviewed and investigated the lived experience of 13 individuals

over the age of 50 who have autism and were diagnosed later in life. The participants agreed to take part in the current project and were waiting for contact to be made. Therefore, I assumed it would be a relatively straightforward process. The benefits of being diagnosed with ASD in later life did provide an explanation for the struggles they faced in life, but then there is no such service that can help those who continue to struggle with aspects of social interactions (Hickey, Crabtree, & Stott, 2017).

However, upon reflection I realised that it was my lack of awareness of the difficulties that an individual with high functioning autism faced every day such as social interactions and anxiety. The difficulties during recruitment included finding the appropriate participants who were willing to take part, others who were keen but did not have a formal diagnosis, and those that met the criteria but were reluctant due to other difficulties such as anxiety or difficult memories of early schooling. It was helpful to ask the participants whether they knew of others who would be interested in participating; this method of snowballing was effective to recruit the remaining participants.

The group of people in the current study grew up in a culture that had no diagnosis of autism, and a very limited understanding of it. When the diagnosis was established they were at least in their late teens if not older. The diagnosis did not initially include adults; consequently it is difficult to imagine the personal struggle they may have encountered during their school life. Having intellectual abilities within the average range possibly highlighted the inadequacies in social interactions more. As a result of a lack of understanding of the presentation of autism across all the intellectual functions, those individuals were often missed when diagnosing ASD.

During the recruitment process I only interacted with a handful of support groups for individuals with Asperger's syndrome within London and Kent. This took me by surprise because I imagined there would be more organisations assisting this population as they are high functioning and do not require services such as learning disabilities support. All the groups were run by volunteers who have dedicated their time and effort to help because there is a need and a gap in the service, but without much help from statutory services.

Nearly half the participants had taken part in a previous qualitative study where they were interviewed about their experience of being diagnosed with ASD in adulthood. This provided a great deal of assistance in the current study as they had the opportunity to speak about their experiences as well as the opportunity to discuss this procedure; they therefore appeared less anxious about completing neuropsychological assessments. Participants who were new to research required a greater need for flexibility in arranging appointments, the opportunity to discuss their life experiences and the offer of further appointments. Although it is generally accepted that, when conducting research, confounding variables are kept to a minimum and discussions are reduced, in this incident the engagement process was extremely important. I decided that to encourage participants to perform to the best of their abilities and reduce performance anxiety, it was appropriate to engage them in some conversation prior to starting the testing. Unlike when assessing in a clinical capacity, during research it is correct to keep conversation a minimum.

As someone who has undergone clinical training I appreciated spending time with the participants, however, it was concerning learning about the lack of available services and the need for providing therapeutic interventions for this population. There is a need to enhance and update the expertise required to understand the different

presentations of ASD. It may have been useful to have carried out some screening of whether the participants have received individual therapy. This may also be an interesting area to explore further.

**Gender and ethnicity**

ASD is diagnosed more commonly in males than females. The study had 23.1% females compared to 76.9% males. Research has found that females with ASD may be more at risk for specific co-morbidity (Kreiser & White, 2015). There has been limited attention paid to the understanding of whether ASD differs in presentation in females (Werling & Geschwind, 2013). This then drew attention to whether females are being misdiagnosed with other psychiatric disorders and if hf-ASD is missed. The study only included one participant from an ethnic minority community. Future research needs to recruit from diverse ethnic and cultural backgrounds, so that there is some indication of the needs and understanding in those communities. Alongside this, there has to be some consideration about the assessments used and cultural appropriateness and suitability. Most neuropsychological assessments are validated with English speaking participants and this brings forth the argument of validity and reliability issues if used with those whose first language is not English.

**Conducting the research**

My inexperience of working with this population group was apparent from the initial stage of recruiting participants and conducting the research. There was an assumption on my part that this activity would be seemingly straightforward, and this was reflected by my reluctance to engage with support groups early on and make efforts to recruit suitable participants. Another limitation on my part was the inexperience of carrying out the following neuropsychological assessments - the

Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV, UK; Wechsler, 2010) and the Wechsler Memory Scale, Fourth Edition (WMS-IV, UK; Wechsler, 2010) - with individuals with high functioning ASD (hf-ASD). My previous experience was generally assessing individuals who had ASD and borderline learning disabilities. I underestimated the amount of time required for completing all the subtests for both ranges of tests and not being able to discontinue due to incorrect responses. Future researchers may find it helpful to allow time for engagement prior to commencing the research and allowing extra time to conduct the tests. It is helpful to offer more than an appointment to complete the range of tests bearing in mind the duration does not invalidate the data.

Due to the time limitation, other measures were not applied although it would have been helpful to assess the levels of subjective anxiety or the interference on sensory perception. Many participants reported having sensory sensitivity, especially when completing visual tasks on the subtests. The study results found that the group had a significantly weaker visual memory index than predicted. Normal ageing research has shown a decreasing performance in visual memory (Vakil, Greenstein & Blachstein, 2010). Clay et al. (2009) suggested that if visual sensory functioning and processing speed can be maintained then ageing may not result in a loss of fluid intelligence. They found older age to be linked with visual decline, which was linked with a slower speed of processing, which in turn linked with greater cognitive deficits. It was interesting to find that the study sample had a weaker visual memory index and their processing speed was weaker than other abilities. Whether there is an interaction or relationship can be the focus of future research. It may have been useful to carry out screening for such issues using appropriate measures. There was consideration of overwhelming participants with questionnaires and this needs to be considered

carefully, as various biases can be introduced as well as an ethical concern about the reasons for the usage of measures.

There were limitations to the design of the study. It would have been fitting to have comparisons with another group, either a control group or a matched younger group of participants. As an exploratory study it was deemed appropriate to make some tentative, between-sample comparisons with the normative sample used in the manuals. To establish some indication of the cognitive profile, tentative comparisons were made with the younger clinical group in the manual. The findings showed that the study sample had above average general abilities and it is difficult to draw many comparisons from that. Exploring the predicted and actual memory scores was interesting and rather unexpected. The findings suggested that there were some domains that may be weaker. This could possibly add support to the previous research findings of an uneven cognitive profile in ASD.

**Clinical implications of ageing and ASD**

The findings of this study made some reference towards possible links with dementia. This could be an interesting area for further research especially if an individual with hf-ASD may show possibilities of protection from this debilitating disorder. It also highlights the uniqueness about sub-groups within ASD. The recent categorisation of DSM-5 (American Psychiatric Association, 2013) may be too restrictive for those with the diagnosis of Asperger's syndrome because of the requirements of various symptoms to be present. Those who were previously given an Asperger's diagnosis may have different social and therapy needs.

**Reflections on the literature review**

The NICE guidelines recommend talking therapy or psychotherapy which primarily aims to help individuals with psychiatric disorders. Practitioners working in mental health services have made adaptations to interventions to provide effective treatment for hf-ASD. This means adapting their understanding of the presentation of illness, adapting treatments and increasing their knowledge of ASD. One of the aims of the World Psychiatric Association is to promote mental health and increase the knowledge and skills about mental disorders and how they can be prevented and treated. This has huge implications to how mental health practitioners work with individuals with ASD. Therefore the effectiveness of interventions is a growing research area. It is important to understand the impact that ASD may have on an individual for us to truly be able to understand their difficulty. The decision to conduct the literature review was established on those assumptions.

It transpired very quickly that there was a scarcity of studies investigating the psychological interventions for co-morbidity for adults with hf-ASD. In recent years a few reviews have been conducted, but none have assessed the quality of the studies, therefore I pursued with the review. The current review consisted of 12 studies, six of which were included in the review carried out for Cognitive Behaviour Therapy (CBT) in 2013 (Spain, Sin, Chalder, & Murphy, 2015). During the short space of time there were other evaluations of psychological interventions, signifying the rapid growth of interest in the area. There was a wide range in the quality scores for the studies.

The studies were mainly individual or group CBT interventions. I reflected on the reasons for this. The services that are available mainly use CBT intervention and it is one that is structured, and outcomes are readily measured, using standardised

questionnaires. As an evidence-based intervention it is not a surprise that CBT is most favoured. The group interventions also provided the social interactions that are difficult for hf-ASD individuals to engage in, therefore the intervention accomplished far beyond what was proposed. There were a few exceptions to CBT in the review of the studies; one such exception was a case study using psychodynamic therapy. Psychodynamic therapy is difficult to measure outcomes for and the approach focuses on relational activity, therefore the essence may be difficult to evaluate. The latest research has used a psychodynamic approach with learning disabilities and it may be an area for further investigation to explore interventions with hf-ASD. Mindfulness based therapy (MBT-AS) was adapted to use with hf-ASD. MBT-AS was an effective intervention to reduce symptomology in co-morbidity.

The components of CBT were emphasised in the studies; some explicitly focused on thinking errors and restructuring activities and this was interesting to reflect on. Individuals with ASD have rigidity in their thinking, black and white thinking errors, catastrophising or worrying excessively, all of which are addressed in CBT. It may then be possible that addressing these issues helped reduce anxiety and initiate change.

**Issues evaluating studies with ASD**

Amongst the co-morbidity with hf-ASD, anxiety disorder was the most common followed by depression. This is not alarming especially as research has revealed that anxiety is an inherent part of ASD (Kern & Kendall, 2012). I had expected to find more interventions on social anxiety; however, the review did not indicate that. Whether that is because there is a lack of studies with hf-ASD adults or whether the presentation of general anxiety is varied and may not be captured by the

measures used remains to be seen. I reflected on the symptomology of social anxiety and generalised anxiety; there is overlap and it is possible as the studies did not screen for social anxiety, that this was not captured or that the symptoms are mimicking other disorders.

**Personal change in attitude towards research**

Having conducted this study and review, it has stressed the need for further research. I had started the research with little knowledge about hf-ASD and an assumption that the knowledge base is vast. Upon completion I have recognised that the work with hf-ASD has only just begun and there are many areas that need attention and coverage. It has also made me aware of the possibility of many people who are not diagnosed and are functioning below the radar of services. It saddens me to think that there is hardly any service that is serving the hf-ASD population. The work is enormous, from knowing what the difficulties are to providing the appropriate therapeutic intervention and social support.

Clinicians need to familiarise themselves with suitable interventions and increase their understanding of the disorder and developments in research. There is a need to conduct more research from individual case studies to more rigorous randomised control trials.

On a societal and political level, an increase in awareness of the existence of hf-ASD would need to happen as well as investments into services that assist and support individuals with hf-ASD. The need to understand the complications faced by individuals with hf-ASD in every area of life such as independent living skills, education, housing, employment, physical health needs and psychological health needs is important.

This research has helped me to develop my skills in conducting research carrying out statistical analysis and although the most difficult part was the process of writing up the thesis, it has left me feeling positive about conducting research. The value of research may have been an area I have overlooked during my desire to train as a clinical psychologist. I am pleased to have overcome my fear and truly appreciate the relevance for clinicians conducting research. This may have been the valuable lesson for me to have learned and one that I am willing to incorporate into my career.

## Conclusion

There is a need to increase the understanding around ageing and hf-ASD and the impacts of mental health. There are physical and emotional difficulties that are associated with ageing. The knowledge is growing in the area, however, there is a huge amount that is still not known and requires robust investigation. Despite the limitations of this thesis, it has provided some direction for future research and an indication towards understanding ageing and hf-ASD. Hopefully other researchers find this critical appraisal useful when conducting research in the area.

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## Appendix A: CTAM Questions

| Clinical Trials Assessment Measure (CTAM) |
|---|
| **Sample** – *two questions*: maximum score = 10<br><br>Q1: is the sample a convenience sample (score 2) or a geographical cohort (score 5), highly selective sample, e.g., volunteers (score 0)<br>Convenience sample – e.g., clinical attenders, referred patients or Geographical cohort – all patients eligible in a particular area<br><br>Q2: is the sample size greater than 27 participants in each treatment group (score 5) or based on described and adequate power calculations (score 5)<br><br>**Allocation** – *three questions*: maximum score = 16<br><br>Q3: is there true random allocation or minimisation allocation to treatment groups (if yes score 10)<br><br>Q4: is the process of randomisation described (score 3)<br><br>Q5: is the process of randomisation carried out independently from the trial research team (score 3)<br><br>**Assessment** (for the main outcome) – *five questions*: maximum score =32)<br><br>Q6: are the assessments carried out by independent assessors and not therapists (score 10)<br><br>Q7: are standardised assessments used to measure symptoms in a standard way (score 6), idiosyncratic assessments of symptoms (score 3)<br><br>Q8: are assessments carried out blind (masked) to treatment group allocation (score 10)<br><br>Q9: are the methods of rater blinding adequately described (score 3)<br><br>Q10: is rater blinding verified (score 3)<br><br>**Control groups** – *one question*: maximum score = 16<br><br>Q11: TAU is a control group (score 6) and/or a control group that controls for non-specific effects or other established or credible treatment (score 10)<br><br>**Analysis** – *two questions*: maximum score = 15<br><br>Q12: the analysis is appropriate to design and the type of outcome measure (score 5)<br><br>Q13: the analysis includes all those participants as randomised (sometimes referred to as an intention to treat analysis) (score 6) and an adequate investigation and handling of drop outs from assessment if the attrition rate exceeds 15% (score 4)<br><br>**Active treatment** – *two questions*: maximum score = 11<br><br>Q14: was the treatment adequately described (score 3) and was a treatment protocol or manual used? (score 3)<br><br>Q15: was adherence to the treatment protocol or treatment quality assessed (score 5) |
| Where the criterion in not reached for any question score = 0<br><br>Total score: maximum score = 100 |

**Appendix B: Information sheet**

**RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY**

## Information Sheet for Older People (over 50 years) with an Autism Spectrum Disorder (ASD)

## Title of Study: Exploratory Study of Growing Older with ASD


| | | |
|---|---|---|
| **Researcher** | Shamsun Islam | [redacted] |
| | | [redacted]1 |
| **Research Supervisors** | Dr Joshua Stott | [redacted] |
| **Address** | Research Dept. of Clinical, Educational and Health Psychology<br><br>1-19 Torrington Place<br>University College London<br>Gower Street<br>London WC1E 6BT | |
| | Dr Jason Crabtree | [redacted] |
| | Westminister Learning Disabilities Partnership<br>215 Lisson Grove<br>London<br>Nw8 8LW | |


Hi, my name is Shamsun and I would like to invite you to take part in our research study. Before you decide whether you would like to take part, it is important for you to know what the research is about and what it will involve. Please read this information carefully and discuss it with others if you wish. If there is anything that is

unclear, or if you would like some more information, you can contact me on [redacted]

**What is this study about?**

The aim of this study is to explore what it is like to grow older with an ASD (i.e. High Functioning Autism, Asperger's Syndrome or PDD-NOS). In particular, we want to understand if growing older with ASD has any relation to cognitive abilities and memory.

**Why is this study being done?**

The goal of this study is to understand the cognitive profile and abilities of people with ASD as they grow older. Although a lot of research has been done with younger people with ASD, very little research has looked at what it is like to grow older with the diagnosis. If we know more about the impact on cognitive abilities of growing older with ASD, then we may be able to help people with ASD do well in their old age and cope better with difficulties related to ageing.

**What will happen if I take part?**

If you are happy to take part in this study, we will meet for about two to three hours, at UCL or in your own home. You will be asked to complete some questionnaires and do some assessments of your memory and general cognitive functioning, which includes thinking, reasoning abilities and memory. You are not required to do any preparations for these tests. Although some of these tests are used to establish the level of intelligence this is not how we would be using the findings. It is important for you to know that no one else apart from the researchers in this study will have access to the results of these assessments and questionnaires. Participating will take around two to three hours in total. You will be offered breaks and you can opt to participate over two sessions instead of one, if you wish.

**What will I be asked to do?**

You will be asked to participate in one session with us, which will focus on your strengths and abilities in different areas of memory, executive functioning and general cognitive abilities. It will include you being asked to do some tasks where I ask you to think about things, memorise things and perform certain tasks. If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. Your participation in this study will not be affected should you choose not be re-contacted.

**Are there any risks in taking part?**

We do not anticipate any significant risks to people taking part in this study. However, the study does involve taking part in some timed activities. If you become distressed during the interview, we can take as many breaks as you need or we stop the interview or test entirely. The study has been approved by the UCL Research Ethics committee.

**What are the potential benefits?**

You will be provided with a summary of results at the end of the study. Individualised results of quantitative measures will be provided upon request. Your performance on the questionnaires and tasks in this study is not intended to be diagnostic. We hope that with your help and that of other older people with ASD we will develop a better understanding of whether there is a pattern in the memory and cognitive abilities of older people with ASD. Although there will be no immediate benefit for the participants taking part in this study, we hope that their participation will benefit other people with ASD as they age.

**Do I have to take part in this study?**

It is entirely up to you whether or not you take part in this study. If you do decide to take part, you will be asked to sign a consent form. If you decide now, or at a later date, that you do not wish to participate in this research, you are free to withdraw your participation. If you wish to stop or withdraw your participation, you do not need to give a reason.

**Will information about me be available to anyone?**

All information collected from you during the course of this research will be kept strictly confidential, unless required by law. For example, the police authorities will not have access to our research records. It is important for you to know that we are interested the average results of questionnaires and tests, not in the scores of any individual participant.

**How to contact the researchers**

You can ask any questions that you have about the study. If you have a question that you didn't think of now, you can ask it later. You can contact me on [redacted] or by email at [redacted] if you need any more information about the study. If, for some reason, you cannot reach me, you can contact my research supervisors (contact details above).

Please discuss the information above with others if you wish and ask us if there is anything that is not clear or if you would like more information. It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

**Appendix C: Demographic details**

**RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY**

UCL

## Demographic Information

Age: ……..

Gender: Male / Female

Date of birth: ___/___/ 19___

Occupation: ……..

Marital status: ……

Living arrangements: ……

Ethnicity: ……..

Level of education: ……

Age of receiving diagnosis: ……

Diagnosis: …….

General health status: ……

**Appendix D: Consent form**

**RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY**

**All data will be collected and stored in accordance with the Data Protection Act 1998.**

**Thank you for taking the time to read this information sheet.**

**Your help makes our research possible.**

## Consent Form for People (over 50 years) with an ASD

**Please tick (✓) appropriate box:**

☐Yes, I would like to participate in this study.

☐No, I do not want to participate in this study.

**If Yes, please complete the following:**

☐I have read the Information Sheet and I understand what the study involves.

☐I understand that I do not have to take part in this study if I do not want to.

☐I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.

☐I have had the opportunity to ask any questions I wish to ask.

☐ I consent to the processing of my personal information for the purposes of this research study.

☐ I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

☐ I understand that the information I have submitted will be published as a report and I will be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

☐I understand that some of my personal details will be passed to UCL Finance for administration purposes.

☐ I agree that my non-personal research data may be used by others for future research. I am assured that the confidentiality of my personal data will be upheld through the removal of identifiers.

☐ I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

☐ I have the names and telephone numbers of the research team in case I have any queries in the future.

☐ I would like to be contacted regarding future studies regarding getting older with an ASD spectrum disorder.

Name: Date:

Signature: _____