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## PROFESSIONAL DOCTORATES

### Autism Diagnosis Late in Life and the ADHD Prevalence Rates in Psychiatric Population

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Submitted in partial fulfilment for the degree of  
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## **Dedication**

I would like to dedicate this thesis to my wonderful children Laurence and Antonia. Being away from you for days every week for almost three years was the most difficult thing I have ever done. Thank you for loving me nonetheless. I han eu ganz, ganz fescht gern!

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## **Thesis abstract**

### **Autism Diagnosis Late in Life and the ADHD Prevalence Rates in Psychiatric Population**

Two neurodevelopmental disorders in adults are explored in this thesis: attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (autism).

Chapter 1 investigates the prevalence of ADHD in the psychiatric population in a systematic literature review. Fifteen articles reporting on prevalence rates in psychiatric in and outpatient services in international settings were identified. Estimated prevalence rates of ADHD varied widely due to heterogenic assessment methods and inclusion criteria. However, all reported prevalence rates were considerably higher than the 2.8% estimated for the adult general population. ADHD is thought to be underdiagnosed in individuals with psychiatric disorders. Directions for future research are discussed. Recommendations are made about employing a routine ADHD screen for all individuals accessing psychiatric services in order to optimise identification and treatment.

Chapter 2 reports on a qualitative study investigating what motivated middle-aged adults to seek an autism diagnosis. A thematic analysis was conducted, three main themes are described: road to self-acceptance, diagnosis as a way of overcoming a crisis and autism tailored support for future proofing. These themes were part of the motivation for seeking a diagnosis, however, the processes they involved continued after receiving it. The importance of post-diagnostic support is discussed.

Chapter 3 contains clinical and theoretical implications arising from the previous chapters. Some reflections on conducting the empirical study and the systematic literature review conclude this thesis.

## **Chapter 1: Literature Review**



## **ADHD Prevalence in the psychiatric population**

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#prep

## **Abstract**

This article presents a systematic literature review of the prevalence of Attention Deficit Hyperactivity Disorder (ADHD) in the adult psychiatric population. Three databases were searched using keywords relating to ADHD and psychiatric disorders. Fifteen studies published before May 2020 met inclusion criteria.

Prevalence rates ranged from 6.9% to 38.75%. There was considerable heterogeneity with regards to the assessment methods of ADHD and comorbidities, the sampling as well as inclusion and exclusion of psychiatric comorbidities. Research concluded that ADHD is underdiagnosed in this population. Gender ratios also varied between 1.8:1 and 1:2.5 (male:female).

All ADHD prevalence rates for the psychiatric population were considerably higher than the 2.8% estimated for the general adult population. Assessment in psychiatric services should include a screen for ADHD to ensure accurate diagnosis and optimal treatment options.

*Keywords: ADHD, Attention Deficit Hyperactivity Disorder, Hyperkinetic Disorder, psychiatric disorders, prevalence, comorbidity*

## **Introduction**

Attention-deficit hyperactivity disorder (ADHD) is a neurocognitive disorder marked by symptoms of hyperactivity, impulsivity and inattention (American Psychiatric Association, 2013). Previously believed to affect only children, it is now recognised that an estimated 57% of individuals with a childhood diagnosis of ADHD and 41% of adults with a history of subthreshold childhood ADHD meet ADHD diagnostic criteria as adults (Fayyad et al., 2017). The prevalence of ADHD in adults in the general population is estimated to be 2.8% when averaged across surveys in high to low-income countries (Fayyad et al., 2017). ADHD is associated with disability in social functioning (Fayyad et al., 2007), lower level of education (Fayyad et al., 2017; Hechtman et al., 2016), lower occupational achievement, increased contact with police, high risk sexual behaviour, substance and alcohol use, and mental health difficulties (Hechtman et al., 2016).

High incidents of psychiatric disorders in the adult ADHD population is well documented for mood and anxiety disorders, alcohol and/or substance use or dependency disorders, bipolar disorder, personality disorders and eating disorders (Fayyad et al., 2007; Holst & Thorell, 2018; Katzman, Bilkey, Chokka, Fallu & Klassen, 2017; Yoshimasu et al., 2012, 2018). The combination of psychiatric disorders and adult ADHD makes the diagnosis and management of the latter challenging, not least because of overlapping symptomologies (Mao & Findling, 2014). Given the high rate of psychiatric comorbidities among individuals with ADHD, one would expect the prevalence of ADHD in the psychiatric population to be higher than in the general population. Only a fraction of all adults with ADHD are diagnosed (Lines & Sadek, 2018) and underdiagnosis is likely high for the clinical population due to diagnostic overshadowing and individuals presenting in psychiatric services for assessment and treatment of the comorbidities.

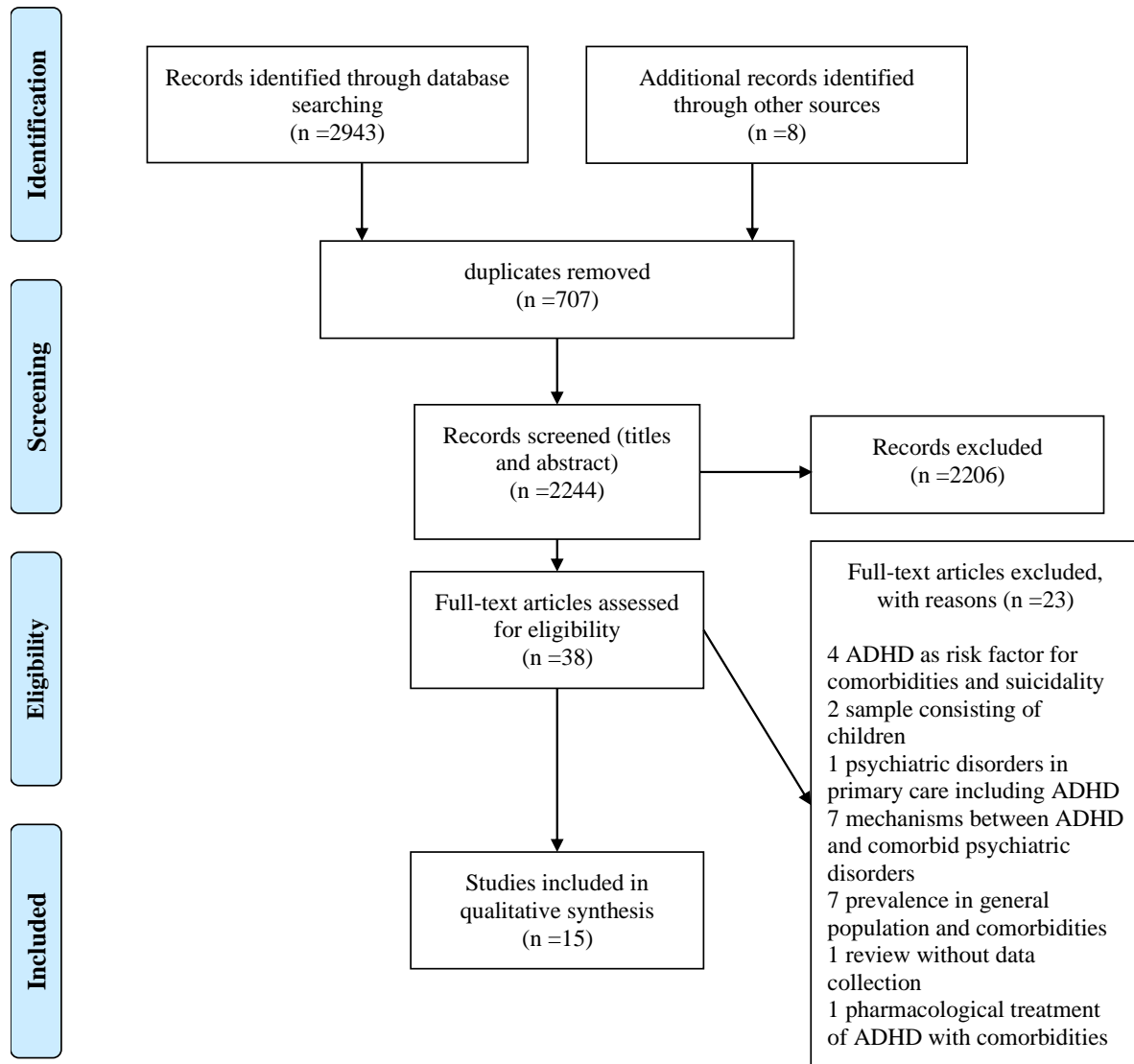
Estimating the prevalence of ADHD in the psychiatric population has become a topic of interest in recent years and several national and international studies have been published. However, these studies have not been examined together yet. The aim of the current article is therefore to carry out a systematic literature review on the prevalence of ADHD in the psychiatric population.

## **Method**

The systematic literature review was undertaken in May 2020 using the PRISMA guidelines and checklist (Moher et al., 2009). Electronic searches were conducted using the following databases: ProQuest (all databases), ScienceDirect, and PubMed. A combination of the following search terms was used: *Prevalence AND (ADHD OR Attention Deficit Hyperactivity Disorder OR Hyperkinetic Disorder) AND (Psychiatric Population OR Psychiatric Patients)*. Only English publications in peer-reviewed journals were included and filters (adult samples and human research only) applied to limit the search.

### *Study Selection*

Figure 1 depicts the study selection. The search identified 2243 articles; 707 duplicates were removed. 2206 articles were excluded after screening titles and abstracts if the sample was not human or adult, the research was not relevant to our search or the article discussed the comorbidity of psychiatric disorders in the ADHD population. The remaining 38 articles were read in full and included in the analysis if they 1) used a sample of individuals accessing psychiatric services, 2) assessed ADHD in this population via self-report questionnaires and/or clinical interviews completed by suitably trained clinicians, 3) reported the participants' psychiatric diagnoses and 4) the prevalence of ADHD diagnoses within the sample. Based on these criteria, 23 articles were excluded for reasons noted in the diagram.



**Figure 1: PRISMA flow diagram**

All included articles reported on cross-sectional and cross-sectional cohort studies. Some of these articles fulfilled our inclusion criteria and reported the prevalence of ADHD in their

sample but had a different focus (e.g. the association between ADHD and suicidal behaviour). This often meant that confidence intervals for relevant data were not noted in these studies.

### *Data Extraction and Analysis*

Relevant article data was extracted using a coding spreadsheet. This included: author name, publication date and study location, sample size, age (range or mean), tools and methods used to assess ADHD, tools and methods used to assess other psychiatric diagnoses, psychiatric diagnoses other than ADHD included in the study, study design, sample recruitment, prevalence rate and notes. The quality of the studies was assessed based on guidelines published in Boyle (1998) during data extraction. These guidelines were developed for the evaluation of prevalence studies involving psychiatric disorders and were therefore deemed an appropriate tool for the current literature review. The data was appraised based on pre-defined criteria from the literature: sample size and representativeness; method of assessment of ADHD and comorbid psychiatric diagnoses (such as self-report questionnaires, structured clinical interviews, patient chart review, measure of functional impairment); methods of statistical analysis and whether these provided unbiased, correct statistical estimates of prevalence; and the manner of reporting the results.

Studies differed greatly with regards to how ADHD and psychiatric problems were assessed and which diagnostic manuals these assessments were based on. Also, psychiatric diagnoses included and excluded for each sample varied enormously. A narrative systematic review was therefore conducted.

## **Results**

### *Study Characteristics*

The systematic literature search yielded 15 articles meeting the inclusion criteria: they were used in this review. All studies were published between 1996 and 2019. Diverse populations were represented in the samples with data collected in countries in North and South America (United States of America (2x), Canada, Colombia, Mexico (2x)), Europe (Austria, Belgium (2x), Germany, United Kingdom (2x), Ireland, Italy, Greece, France, Spain, Sweden (2x), The Netherlands (3x), Denmark, Czech Republic, Hungary), and Asia (Lebanon, China, Japan). Most studies used a convenience sample of individuals accessing outpatient psychiatric services. Two studies included psychiatric inpatients deemed to be able to give informed consent whose current presentation did not prevent them from participating. One study used participants enrolled in an ongoing cohort study investigating consequences of depressive and anxiety disorders. Two articles described a cross-sectional cohort study, the others used a cross-sectional design, but did not always report this explicitly.

### *Sample size and recruitment*

A summary of sample size ranging from 32 to 2053 is provided in Table 1 below. Ten studies recruited a sample between 32 and 254, five studies achieved a sample greater than 634: two of these studies recruited their participants via large ongoing studies (Bron et al., 2016; Stickley et al., 2018), the others achieved their higher participant numbers by including several sites. Response rates were reported in eleven articles: 35.4% for the only study using postal recruitment, and a range of between 63.4% to 98.9% for the other ten. Only two studies reported drop-out rates of 6.1% and 1.2% respectively. One study used a sample of psychiatric inpatients, one a combination of psychiatric inpatients and outpatients, one recruited participants from a large ongoing cohort study by adding ADHD assessments to the four year follow-up contacts,

and the other twelve studies used psychiatric outpatients. All studies using in- and outpatients recruited individuals accessing services consecutively during a specified time frame.

### *ADHD assessment*

Studies assessed ADHD in various ways based on the Diagnostic and Statistical Manual of Mental Disorders, editions three, four and five (DSM-III, DSM-IV and DSM-5; American Psychiatric Association, 1980, 2000, 2013) with two studies comparing the prevalence figures based on DSM-IV and DSM-5 for their sample. Both studies found that the prevalence based on DSM-5 criteria were higher than those based on DSM-IV. There were three approaches: diagnosis via 1) self-reports (n=4), 2) clinical interview with trained clinician (n=2), or 3) a combination of both often in a two-step process (n=9). Translated self-report measures were used in many cases which had been validated for the relevant country. One study reported the prevalence of ADHD subtypes.

Ramsay (2017) and Kooij et al. (2010) stipulated that a combination of a structured clinical interview, norm-based ADHD inventories and impairment measures increase diagnostic accuracy and also serve as monitoring tools of treatment response. Both articles stated that all three assessment methods were needed to achieve the assessment gold standard. Based on this, only two of the studies reviewed in this article used all three methods; studies utilising two or more were classed to be of superior quality and are reviewed in more detail in a separate section.

### *Psychiatric diagnoses*

Four studies concentrated on a population with one specific psychiatric diagnosis (panic disorder (n=1), major mood disorder (n=2), bipolar mood disorder (n=1)) , the others included participants with a variety of primary psychiatric comorbidities. The studies varied widely in



exclusion and inclusion criteria, however, all excluded individuals unable to consent to taking part in the study (which could be based on the severity of their psychiatric problems), dementia or any other cognitive impairment, and serious medical conditions. Seven studies excluded individuals with a diagnosis of schizophrenia or psychosis, bipolar mood disorder was excluded in four studies, and five excluded participants with substance and/or alcohol use and/or dependency. Nine studies included five or more disorders as primary diagnosis in their sample.

Four studies ascertained psychiatric diagnoses with a patient file review, for three of these, this was the sole source of information. All other research utilised various self-report measures based on DSM-III to DSM-5 or the International Statistical Classification of Diseases and Related Health Problems-10 (ICD-10; World Health Organisation, 1994). Severity measures were used by three studies, functional impairment scales by four.

#### *Prevalence of ADHD in psychiatric populations*

Estimated prevalence rates of ADHD in psychiatric populations are summarised in Table 1. Estimates ranged from 6.9% to 23.8% for 13 studies, and the other studies reported estimates of 38.8% and 37.8% respectively. There are several reasons impacting on the prevalence estimates: vastly different inclusion and exclusion criteria, diagnostic criteria (with DSM-5 being the most inclusive), and the assessment methods used, both with regards to what combination of assessment methods were utilised as well as the measures themselves. The following paragraphs are attempting to shed light on this methodological variability and how this resulted in the range of estimates.

**Table 1: Summary of prevalence studies included in review**

Author, year, country	n=	Age	Assessment of ADHD	Ax of psychiatric diagnoses	Psychiatric Dx included	Design	Sample	Prevalence	Comments
Alpert et al. (1996), USA	116	18-65	Kiddie-SADS-E , clinician-rated module added if participant reported one or more ADHD symptoms causing moderate to marked impairment in childhood by age 7	PDQ-R, SCID-P, HAM-D-17	major depressive disorder	cross-sectional study	Psychiatric outpatients	7.6% full 8.5% subthreshold	high female prevalence compared to general population
Bitter et al. (2019), Czech Republic, Hungary	708	18-60	ASRS (6-question version); clinical interview based on symptoms list of ADHD in DSM-IV-TR; CAARS-S:L; Inconsistency Index.	MINI-PLUS (Czech and Hungarian version)	Depression, Suicide risk current, alcohol dependence, psychoactive substance dependence, anorexia, anxiety and stress related disorders	cross-sectional study	psychiatric outpatients and inpatients	DSM-IV-TR: 6.99% (CI 5.11%-8.86%); DSM-5: 9.27% (CI 7.13% - 11.40%)	no data on comorbidity severity 32.6% higher rate with DSM-5 criteria compared to DSM-IV
Bron et al. (2016), Netherlands	2053	21-69, mean: 46.3, SD=13.0	CAARS-S:SV	CIDI, LCI, IDS-SR, FTI	MDD	cross-sectional cohort study	sample from ongoing Netherlands Study of Depression and Anxiety	11.4%	ADHD rates increased as MDD stage advanced 5.7% in remitted MDD, 17.7% in current MDD
Deberdt et al. (2015), Austria, Belgium, Denmark, Germany, The Netherlands, Spain, Sweden, United Kingdom	1986	17-72	DIVA applying DSM-IV and DSM-5 criteria; ASRS	CGI-S; information about clinical status and medical history guided by DSM-IV-TR or ICD-10; SDS; EQ-5D; EQ VAS	Depression, Dysthymia, Bipolar Disorder, OCD, Anxiety disorders, eating disorders, substance abuse, substance dependence, alcohol abuse, non-substance dependence, antisocial personality disorders, borderline personality disorders, autistic spectrum disorders, other, no other psychiatric diagnosis, neurological symptoms/diagnoses	cross-sectional study	psychiatric outpatients	DSM-IV-TR: 15.8% (CI 14.2% - 17.4%); DSM-5: 17.4% (CI 15.7% - 19.0%)	variability of prevalence associated with regions and outpatient settings

Fones et al. (2000), USA	85	18-60	Kiddie-SADS-E with companion module for ADHD	HAM-A: HAM-D:	panic disorder with or without agoraphobia	cross-sectional study	psychiatric outpatients enrolled in pharmacological treatment trials for panic disorder, with or without agoraphobia	15.3%	high percentage of comorbid anxiety disorders DSM-III: 23.5% (20) significant ADHD features during childhood, 9.4% (8) full diagnosis, 14.1% (12) subthreshold; 87% of threshold and 50% of subthreshold endorsed persistence of ADHD features in adulthood
Karaahmet et al. (2013), Turkey	90	18-?	WURS in Turkish, Adult ADD/ADHD Diagnosis and Evaluation Inventory	SCID-I	Bipolar Mood Disorder	cross-sectional study	psychiatric outpatients in Bipolar Disorder Unit	37.8%	high percentage of comorbid anxiety disorders  23.3% (21): A-ADHD, 14.5% (13) C-ADHD.
Leung & Chan (2017), China	254	18-64	ASRS-v1 in traditional Chinese, SDS in Cantonese Chinese, interview phase: DIVA 2.0	patient chart review	depression, anxiety disorder, trauma and stress-related disorders, substance related and addictive disorder, bipolar disorder	cross-sectional cohort study	psychiatric outpatients	19.3% (CI 18.9%-19.7%)	24.7% in males (CI 24.3%-25.1%), 17.1% in females (CI 16.7%-17.5%)
Lines & Sadek (2018), Canada	31	20-84	ASRS clinical interview by psychiatrist based on DSM-5, Weiss Functional Impairment Rating Scale	Global Impression of Severity and Improvement Scale, full psychiatric assessment	schizophrenia, bipolar disorder, major depressive disorder	cross-sectional study	psychiatric inpatients	38.75%	participants with ADHD scored significantly higher on functional impairment
Montes et al. (2007), Mexico	161	18-55	FASCT, FASCTA, FASCTO	YMRS; AUDIT; SCL-90; HDRS; HARS.M.I.N.I.-Plus administered by 2 experienced clinicians, scored blindly by third clinician;	MDD, high suicide risk, Panic disorder, Dysthymic disorder, GAD, alcohol dependence, agoraphobic disorder, specific phobia, OCD, antisocial PD, substance dependence, PTSD, anorexia nervosa, hypochondriasis, pain disorder, adjustment disorder, premenstrual dysphoric disorder mixed anxiety-depressive disorder	cross-sectional study	non-psychotic psychiatric outpatients	16.80%	female prevalence higher than male; females also experience more severe psychopathology. 21.6% female, 8.5% male

Nylander et al. (2009), Sweden	141	mean age 35.8	WURS, clinical interview, AQ, AUDIT, SDS	MADRS, ICD-10 Personality Questionnaire, questionnaire for the use of illegal drugs; patient chart review	organic syndromes, alcohol/drug dependence, affective disorders, anxiety disorders, maladaptive reactions, PTSD, childhood disorders, personality disorders	cross-sectional study	psychiatric outpatients	22%	high drop-out rate due to methodology (398 approached); assessment also included a range of psychometric tests
Pehlivanidis et al. (2014), Greece	114	mean age 37.0 (SD 12.5)	interview with participant and family/friends, daily diary by psychiatrist based on DSM-IV criteria	BDI, STAI, SCL-90-R, patient chart review	mood and anxiety disorders	cross-sectional study	psychiatric outpatients	19.3%	male:female=2:1
Rao & Place (2011), England, UK	124	20-70	ASRS WURS	patient chart review	depression, anxiety, bipolar disorder, borderline personality disorder, alcohol dependence, psychosis	cross-sectional study	psychiatric outpatients	22%	12 male, 15 female
Stickley et al. (2018), Japan	864	18-65	ASRS	reports of suicidal behaviour, ICD-10 patient chart review CGI-S	psychoactive substance use/abuse, psychosis, mood disorders, anxiety disorders, eating disorders, personality disorders, autism spectrum disorder, other disorders	cross-sectional cohort study	psychiatric outpatients	20%	ADHD score stat sign associated with suicidal behaviour
Syed et al. (2010), Ireland	243	18-65	ASRS-IV.I	patient chart review	schizophrenia, bipolar disorder, affective, neurotic, personality disorder, substance abuse	cross-sectional study	psychiatric outpatients	23.8%	male:female - 2:1
Valsecchi et al. (2018), Italy	634	18-70, mean 47.2	ASRS-V 1.1, DIVA	MINI-Plus	psychotic disorders, bipolar disorders, depressive disorders, personality disorders, anxiety disorders, obsessive-compulsive spectrum disorders, adjustment disorders, substance use disorders, somatoform disorders	cross-sectional study	psychiatric outpatients	6.9%	

**Abbreviations:** **ADHD:** Attention Deficit Hyperactivity Disorder; **AQ:** Autism Quotient; **ASRS:** Adult ADHD Self-Report Scale; **AUDIT:** Alcohol Use Disorders Identification Test; **Ax:** assessment; **BDI:** Beck's Depression Inventory; **CAARS-S:L:** Conners' adult ADHD rating scale; **CGI-S:** Clinical Global Impressions-Severity; **CI:** confidence interval; **CIDI:** Composite International Diagnostic Interview; **Dx:** diagnosis; **EQ VAS:** EuroQol Visual Analog Scale; **EQ-5D:** EuroQol-5 Dimensions; **FASCT:** Friederichsen, Almeida, Serrano, Cortes, Test; **FASCTA:** self-report FASCT; **FASCTO:** observer FASCT; **FTI:** Family Tree Inventory Diagnostic Interview for ADHD in Adults; **GAD:** Generalised Anxiety Disorder; **HAM-A:** Hamilton Anxiety Scale; **HAM-D:** Hamilton Depression Scale; **HAM-D-17:** Hamilton Depression Rating Scale; **HARS:** Hamilton Anxiety Rating Scale; **HDRS:** Hamilton Depression Rating Scale; **IDS-SR:** Inventory of Depressive Symptomatology; **Kiddie-SADS-E:** childhood version of Schedule for Affective Disorders and Schizophrenia, Epidemiological version; **LCI:** Life Chart Interview; **MDD:** Major Depressive Disorder; **M.I.N.I.-Plus:** Mini International Neuropsychiatric Interview-Plus; **MADRS:** Montgomery-Asberg Depression Rating Scale; **OCD:** Obsessive Compulsive Disorder; **PD:** Personality Disorder; **PDQ-R:** Personality Disorder Questionnaire Revised; **SCID-P:** Structured Clinical Interview for DSM-III-R Diagnosis; **PTSD:** Post-traumatic Stress Disorder; **SCL-90:** Symptom Check List-90; **SCL-90-R:** Symptom Checklist 90-Revised; **SDS:** Sheehan Disability Scale; **STAI:** Spielberg's Anxiety Inventory; **WURS:** Wender Utah Rating Scale; **YMRS:** Young Mania Rating Scale.

### *Highest estimated prevalence rates*

One of the highest estimates included a sample of individuals with a bipolar diagnosis (Karaahmet et al., 2013; 37.8%), the other assessed psychiatric inpatients in acute care (Lines & Sadek, 2018). The latter recruited 31 newly admitted patients with the following primary psychiatric disorders: bipolar disorder (n=6; unclear if they were in a depressive or manic episode at the time of assessment), major depressive disorder (n=7), schizophrenia or psychotic disorder (n=18). Just under half of the participants had >1 additional psychiatric diagnosis. The participants were assessed for ADHD once their comorbid psychiatric disorder had “subsided enough to allow accurate interviewing”. The Adult ADHD Self-Report Scale based on DSM-IV (ASRS; Kessler et al., 2005) was used to assess ADHD. This questionnaire was validated on the general population, not patients during a mental health crisis, which might explain why many of the participants scored at/above threshold. A psychiatrist conducted a clinical interview based on DSM-5 in addition to the ASRS.

The authors acknowledged the small convenience sample was susceptible to volunteer bias. They did not discuss the psychiatric comorbidities as confounding factors. Given the symptomology of psychosis and bipolar disorder during a manic episode, diagnostic overshadowing must be considered in this study even with the addition of a clinical interview and the subsidence of psychiatric symptoms. Furthermore, Lines & Sadek (2018) based their diagnostic criteria on DSM-5, which has been found to be more inclusive. Estimates of prevalence were 10% and 32% higher compared to DSM-IV criteria for studies juxtaposing both diagnostic manuals (Bitter et al., 2019; Deberdt et al., 2015). This could have resulted in a higher estimation of prevalence (38.75%) in Lines & Sadek (2018) compared to 11/15 studies applying DSM-IV criteria and two using DSM-III criteria.

Karaahmet et al.'s (2013) sample consisted of 90 participants with a bipolar disorder diagnosis who were described as euthymic at the time of the ADHD assessment. ADHD was assessed via the translated self-report measure Wender Utah Rating Scale (WURS; Ward, Wender, & Reimherr, 1993) which was developed based on DMS-III. The Turkish version, however, had lowered the threshold score from 46 to 36 and reduced the reliability from 86% to 82.5% in the process. Participants also completed an unpublished Turkish questionnaire cited as Adult ADD/ADHD Diagnosis and Evaluation Inventory (Turgay, 1995) based on DSM-IV criteria (American Psychiatric Association, 2000). The overall estimated prevalence of 37.8% included both participants who would have attracted an ADHD diagnosis in childhood but did not meet ADHD criteria as adults (14.5%) and participants who met diagnostic criteria in childhood as well as adulthood (23.8%).

*Prevalence estimate based on clinical interview only*

Three studies based their ADHD assessment on a clinical interview with a psychiatrist. Pehlivanidis, Papanikolaou, Spyropoulou, & Papadimitriou (2014) reviewed patient notes for demographic data as well as psychiatric diagnoses. Only individuals with anxiety disorders and depression were included. A psychiatrist interviewed the participants in a “free interview context” answering six questions designed to help classify ADHD with 85% accuracy based on Barkley, Murphy, & Fisher (2007). This study paid particular attention to overlapping symptomology between ADHD and comorbid disorders as a confounding factor. Differentiation was attained via several clinical interviews with the participants and their informants as well as reviewing the participants’ diaries. An overall estimated prevalence of 19.3% of ADHD among adult outpatients with depressive or anxiety disorders was reported by Pehlivanidis et al. (2014).

Fones, Pollack, Susswein, & Otto (2000) established their ADHD prevalence estimates based on a structured clinical interview Kiddie-SADS-E with an additional clinician rated module for participants scoring above threshold (Orvaschel & Puig-Antich, 1987). This study concentrated on a population with panic disorder. This instrument is based on DSM-III, which divided ADHD diagnoses into full ‘threshold’ and ‘subthreshold’ ADHD (American Psychiatric Association, 1980). Symptoms were only considered for an ADHD diagnosis when they were also experienced during periods other than times of panic and anxiety. Estimates of prevalence were reported as 9.4% reaching threshold and 14.1% subthreshold diagnostic criteria. However, only a percentage of participants experienced ADHD symptoms in adulthood, which resulted in 7.1% threshold and 8.2% subthreshold diagnoses, which is the figure we will use in this review to standardise the reporting of prevalence rates.

*Prevalence estimates based on self-report measures only*

Four studies only included self-report measures for the assessment of ADHD, two based on a psychiatric outpatient sample in England (UK) and Ireland (Rao & Place, 2011; Syed et al., 2010). While Rao & Place (2011) used the 18 item Adult Self-Report Scale (ASRS), Syed et al. (2010) utilised the six item ASRS screen (Adler et al., 2006) in addition to the WURS (Ward et al., 1993). These studies had similar samples (consecutive attendees of a psychiatric outpatient clinic) with broad inclusion criteria. Estimated prevalence of ADHD in their sample was similar at 22% and 23.9% respectively based on a sample of 124 and 243 participants.

On closer inspection, however, it appears that Rao & Place’s (2011) prevalence rate (22%) was not only based on the WURS and ASRS but that a clinical interview was the decisive factor on whether or not a participant was deemed to meet diagnostic criteria for ADHD. This was not reported in the method section and only mentioned at the end of their discussion where

they explain that the cut-off scores for both self-report questionnaires had to be adjusted upwards to coincide with clinical judgement. The reported prevalence was likely a more conservative estimate compared to one gained via self-report measures only. The study's conclusion that ADHD is widely underdiagnosed in psychiatric outpatients seems valid, however, the incomplete method section is problematic and calls their prevalence rate into question.

Syed et al. (2010) came to the same conclusion with regards to the underdiagnosis of ADHD in psychiatric outpatients. They acknowledged that not adding a clinical interview to corroborate the outcome of the short version of the ASRS is a limitation, as was using this questionnaire designed to be administered in the general population. Their estimated ADHD prevalence reached 23.9%, with a gender ratio of 2:1 (male:female).

Bron et al. (2016) based their prevalence rates in their large scale survey on the screening version of the Conner's Adult ADHD Rating Scale (CAARS-S:SV; Conners, Erhardt, & Sparrow, 2002). Three questions were added to the self-report questionnaire to ascertain chronicity and functional impairment of ADHD symptoms from childhood/early adolescence onward. The sample was recruited from an ongoing cohort study on depression and anxiety in the Netherlands from the community, primary and secondary care. Participants had a history of both depression and anxiety, any other psychiatric diagnoses were excluded. The CAARS-S:SV was added as part of the four year follow up and participants completed several questionnaires to ascertain their current level of anxiety and depression.

Bron et al (2016) only concluded a participant had ADHD when they scored above threshold on the CAARS, and at least one of the added questions about early onset had been answered in the positive. This study compared ages of onset of ADHD and major depressive disorder (MDD) to control for diagnostic overshadowing. The prevalence of ADHD among



individuals with lifetime MDD (current or remitted) was estimated to be 8.9% when early onset ADHD symptoms were taken into account. MDD was divided into clinical stages and the estimated rates of probable ADHD increased as MDD advanced and ranged from 10.5% for individuals with a current first episode of MDD, to 12.1% for participants with recurrent MDD, to 22.5% for those with chronic MDD. The authors acknowledged that not using a clinical interview to confirm a probable ADHD diagnosis was a limitation; the additional questions developed to ascertain early onset of ADHD symptoms also used a higher onset age than DSM-IV criteria. Also, using self-report measures could mean under- or overreporting of ADHD symptoms. Furthermore, the authors recognised that the prevalence rates might be influenced by overlaps in symptomology.

Stickley et al. (2018) used the ASRS screen to assess ADHD symptoms in their 864 outpatients. The main focus of their study, however, was ascertaining the association between ADHD symptoms and suicidal behaviour. The ADHD prevalence was based on a score  $\geq 14$  on the ASRS and reached 20% exactly. Several limitations were reported, particularly based on only using self-report measures for the assessment of ADHD symptoms and suicidal ideation/behaviour, identifying psychiatric disorders from chart review only.

#### *Prevalence estimates based on ADHD assessments using two or more methods*

Eight studies established prevalence rates based on a combination of assessment methods. Prevalence rates are summarised in Table 2. All but three qualitatively superior prevalence studies reported prevalence rates based on DSM-IV. While Bitter et al. (2019) and Deberdt et al. (2015) demonstrated that DSM-5 results in higher prevalence rates due to more inclusive diagnostic criteria, no such shift was found between DSM-III-R and DSM-IV (Biederman et al., 1997). We therefore include Alpert et al. (1996) in this section as overall prevalence rates based

on DSM-III-R and DSM-IV appear to be comparable, even though they categorise sub-types differently. Lines and Sadek (2018) and Leung and Chan (2017) based their ADHD assessment on DSM-5, which will have to be taken into account in the comparison of prevalence rates.

**Table 2: Estimated prevalence rates for research using self-report and clinical interviews for the identification of ADHD**

Author, year, country	n=	Prevalence	Diagnostic manual
Alpert et al. (1996)	116	16.4% (7.6% full, 8.5% subthreshold)	DSM-III-R
Bitter et al. (2019)	708	6.99% (CI 5.11%-8.86%) 9.27% (CI 7.13%-11.40%)	DSM_IV and DSM-5 (32% higher)
Deberdt et al. (2015)	1986	15.8% (CI 14.2%-17.4%) 17.4% (CI 15.7%-19.0%)	DSM-IV-TR and DSM-5 (10% higher)
Leung & Chan (2017)	254	19.3% (CI 18.9%-19.7%)	DSM-5
Lines & Sadek (2018)	31	38.75%	DSM-5
Montes et al. (2007)	161	16.8%	DSM-IV-TR
Nylander et al. (2009)	141	22.0%	DSM-IV
Valsecchi et al. (2018)	634	6.9%	DSM-IV

Leung and Chan, (2017), Lines and Sadek (2018) and Nylander, Holmqvist, Gustafson, and Gillberg (2009) were studies employing self-report measures, clinical interview and impairment questionnaires in their assessment of ADHD following the recommendations published by Kooij et al. (2010) and Ramsay (2017). The samples for two studies were drawn from psychiatric outpatient clinics with broad inclusion criteria and Lines and Sadek (2018) had a psychiatric inpatient sample. Leung and Chan (2017) based their ADHD diagnosis on Chinese versions of the Adult ADHD Self-report Scale (ASRS; Kessler et al., 2005), the Diagnostic Interview for ADHD in Adults (DIVA; Kooij, 2010) and the Sheehan Disability Scale (SDS; Sheehan, Harnett-Sheehan & Raj, 1996). They reported an estimated prevalence rate of 19.3% (CI 18.9%-19.7%). Nylander et al. (2009) supplemented the SDS with the Wender Utah Rating Scale (WURS; Ward et al., 1993) and a clinical interview, which resulted in an estimated

prevalence of 22.0%. Lines and Sadek (2018) cited a prevalence estimation of 38.75% based on the ASRS, a clinical interview and the Weiss Functional Impairment Rating Scale (Canu et al., 2016).

A further three studies chose the ASRS as their self-report screen in addition to a clinical interview. Deberdt et al. (2015) and Valsecchi et al. (2018) complemented this questionnaire with the DIVA, Bitter et al. (2019) added the Conners' Adult ADHD Rating Scale (CAARS-S:L; Conners, Erhardt, & Sparrow, 1999) and a clinical interview. All three samples were based on broad psychiatric inclusion criteria with participants recruited from psychiatric outpatient clinics and additionally psychiatric inpatients for Bitter et al. (2019). Despite the methodological similarities in assessment as well as inclusion criteria, the estimated prevalence rates for ADHD vary greatly between 6.9% and 7% respectively for Valsecchi et al. (2018) and Bitter et al. (2019) and 15.8% (CI 14.2%-17.4%) in Deberdt et al. (2015) and the reason for this is not entirely clear.

All studies were conducted on multiple sites with large sample sizes, with Bitter et al. (2019) and Deberdt et al (2015) being international endeavours. Deberdt et al. (2015) is the study with the greatest sample recruited in eight Western European countries. Sample sizes for these countries varied greatly as did the estimated prevalence rates. The authors acknowledged that these rates might not be representative of non-psychotic psychiatric outpatients in general due to small sample sizes and/or the number and type of sites involved. Indeed, they recognised that prevalence estimates were not comparable between participating countries because of this heterogeneity. Due to it being a multinational study, it was not recorded how experienced and qualified clinicians were in the assessment of ADHD. It is possible that the different countries in the three studies have varying criteria with regards to what level of mental health problems

warrants primary and/or secondary care psychiatric support. All these factors may play a role in the disparity between prevalence rates.

Alpert et al. (1996) employed the Kiddie SADS (including the ADHD module; Orvaschel & Puig-Antich, 1987) self-report questionnaire to screen for ADHD for their sample of individuals with MDD. A clinical interview was conducted if the participants screened above threshold on the Kiddie SADS and a clinician rated ADHD module was added. ADHD symptoms needed to be present between periods of depressions to be considered indicative of ADHD. Alpert et al. (1996) reported a combined estimated prevalence of 16.1% based on DSM-III-R, with 7.6% meeting full criteria and 8.5% being subthreshold.

Almeida Montes, Hernández García, & Ricardo-Garcell (2007) reported an estimated prevalence of 16.80% in their sample of non-psychotic psychiatric outpatients. When this was broken down by gender, 21.6% of female participants and 8.5% of male participants met ADHD diagnostic criteria. They assessed ADHD with a clinical interview establishing a psychiatric history and the Friedrichsen, Almeida, Serrano, Cortés Test (FASCT) including the self-report (FASCTA) and observer (FASCTO) versions which had been developed and validated in Mexico (Almeida Montes et al., 2006). As many other studies reviewed here, the inclusion criteria for the sample of psychiatric outpatients were broad.

Table 3 summarises the prevalence of comorbid psychiatric diagnoses for ADHD positive participants as reported in each study. What stands out is the high prevalence of psychotic and bipolar disorders in the Lines & Sadek (2018) sample compared to all the other studies. Combined with the DSM-5 ADHD criteria, this may be the reason for the higher prevalence estimation. The authors did not report if the composition of psychiatric diagnoses in ADHD positive participants was representative of the prevalence rates of psychiatric diagnoses

in their inpatient setting. Bitter et al.'s (2019) article is the only other one examining an inpatient sample along with outpatients. Psychotic disorders were an exclusion criterion and no bipolar disorder diagnoses were reported in their sample; this might contribute to their low ADHD prevalence rate of 6.99%. Valsecchi et al. (2018) only cited the psychiatric comorbidities for approximately half their ADHD positive sample. It is unclear what psychiatric diagnoses the other ADHD positive participants had; they stated, however, that 61.4% of them had two or more comorbid psychiatric disorders. Psychiatric comorbidity (excluding alcohol and substance use

**Table 3: Composition of psychiatric comorbidities in ADHD positive participants by study**

Reference	ADHD prevalence in %	Comorbid psychiatric disorders in ADHD positive participants in %						Comments
		Psychotic disorder	Bipolar disorder	Depressive disorder	Anxiety disorders <sup>1</sup>	Substance use disorder <sup>2</sup>	Personality disorders	
Alpert et al. (1996)	16.4			100.0 33.6	33.6	31.6		primary Dx MDD secondary Dx
Bitter et al. (2019)	7.0			43.6	66.7	27.5		multiple Dx possible
Deberdt et al. (2015)	15.8		8.3	52.7	41.3	29.5	10.3 16.0	multiple Dx possible
Leung & Chan (2017)	19.3		6.1	36.7	34.7	14.3		only main Dx reported
Lines & Sadek (2018)	38.8	58.0	19.0	23.0				48% of participants had more than 1 additional psychiatric diagnosis
Montes et al. (2007)	16.8			73.5	53.2	9.5	3.4	multiple Dx possible
Nylander et al. (2009)	22.0			35.1	30.7	2.7	8.1 14.0	only main Dx reported
Valsecchi et al. (2018)	6.9	9.9	4.9	9.9	1.2		28.4	only main psychiatric Dx reported; 61.4% of participants with ADHD attracted 2+ comorbid psychiatric disorders
<b>Abbreviations:</b> Dx: diagnosis; MDD: Major Mood Disorder								
<b>1</b> anxiety disorders incl. trauma; <b>2</b> substance and alcohol use/dependence disorders								

disorder) stood at 18% for the entire sample (n=634). What is worth noting is their high prevalence of personality disorder diagnoses in their sample (23.5% for the whole sample, 28.4% of ADHD positive participants). No other study in this review reported such a high prevalence of personality disorders. It appears the population accessing the study sites used for the Valsecchi et al. (2018) research differed from other samples with regards to psychiatric diagnoses. This may be a function of the eligibility criteria these services have – the lower ADHD prevalence estimate might result from this difference in population.

Although Table 3 allows a rough overview of psychiatric comorbidities in the ADHD population for the reviewed studies, direct comparisons can only be made with caution. The

articles based their psychiatric diagnoses on various diagnostic manuals and disorder severity was not always measured. Furthermore, in some studies, the prevalence rates for psychiatric diagnoses were not exclusive criteria, while others only cited primary diagnoses or only mentioned the most frequent ones.

Two large surveys (n=3199 and 11,422) examined the relative risk of different comorbidities conditional on a primary diagnosis of ADHD (based on DSM-IV criteria) over the previous twelve months (Fayyad et al., 2007; Kessler et al., 2006). Kessler et al. reported disorder categories as well as individual diagnoses. The highest odds ratio (OR) within mood disorders were bipolar disorder (see Table 4) and dysthymia (7.5, 95% CI 3.8-15.0). The two highest ORs in anxiety disorders were for agoraphobia (5.5, 95% CI 1.6-18.5) and social phobia (4.9, 95% CI 3.1-7.6), and drug dependence was the single highest OR for any substance use disorder at 7.9 (95% CI 2.3-27.3). Groenman, Janssen, & Oosterlaan (2017) found in their meta-analysis that ADHD increased the risk of developing subsequent substance use disorders (OR 2.61, 95% CI 1.77-384). Dalteg, Zandelin, Tuninger, & Levander (2014) cited an OR of >5 between ADHD and psychotic disorders (excluding drug-induced psychosis).

While these numbers do not demonstrate causation or any underlying mechanisms between ADHD and various psychiatric diagnoses, they do show the high functional and psychosocial burden (Katzman et al., 2017). These ORs for different comorbid psychiatric disorders might also give an insight into ADHD prevalence rates cited in this review, particularly for studies using a sample with more participants with psychotic or bipolar disorders.

**Table 4: Odds Ratios\* of psychiatric disorders comorbid to ADHD compared to the general population**

<b>DSM-IV disorders</b>	<b>Fayyad et al. (2017)</b>	<b>Kessler et al. (2006)</b>
Mood disorders	3.9 (CI 3.0-5.1)	5.0 (CI 3.0-8.2)
<i>Bipolar disorder</i>		7.4 (CI 4.6-12.0)
Anxiety disorders	4.0 (CI 3.0-5.2)	3.7 (CI 2.4-5.5)
Substance use disorders	4.0 (CI 2.8-5.8)	3.0 (CI 1.4-6.5)

**CI:** confidence interval at 95%

\*  $p < 0.05$  for all ORs

Another interesting finding of the current review is the variability in gender ratios reported in higher quality studies summarised in Table 5. Fayyad et al. (2017) cited a ratio of 3.4% of males to 2.2% of female individuals in their sample (approximately 1.5:1;  $n=26,744$ ). This difference, however, did not reach statistical significance.

Two studies did not report figures in a way gender ratios could be extracted, three were similar to Fayyad et al. (2017). Three of the reviewed studies reported gender ratios out of the

**Table 5: Gender ratios**

<b>Reference</b>	<b>male</b>	<b>female</b>	<b>Simplified ratio</b>
Alpert et al. (1996)	21.6%	12.3%	1.8:1
Bitter et al. (2019)	n/r	n/r	
Deberdt et al. (2015)	21.6%	14.4%	1.5:1
Leung & Chan (2017)	24.7%	17.1%	1.4:1
Lines & Sadek (2018)	n/r	n/r	
Montes et al. (2007)	8.5%	21.6%	1:2.5
Nylander et al. (2009)	20.9%	22.4%	1:1.1
Valsecchi et al. (2018)	6.0%	8.8%	1:1.5

**n/r:** not reported

expected with female ADHD being more prevalent. Montes et al. (2014) wondered if their result caused by a reference bias because more female patients accessed the psychiatric outpatient



clinic during their recruitment. However, women with ADHD have a higher prevalence of anxiety and depressive disorders, which were two of the main psychiatric comorbidities observed in their sample. Nylander et al. (2009) stated that their gender ratio might be explained by the fact that men with ADHD/ADHD like symptoms were likely to access different treatment centres for comorbidities associated with men (e.g. alcohol and substance dependency, offending). They also hypothesised that women were more likely to give information on ADHD like symptoms or are more often diagnosed with psychiatric comorbidities resulting in high scores on their ADHD assessment tool WURS.

## **Discussion**

This systematic review identified 15 studies examining the estimated prevalence of ADHD in the psychiatric population. We discovered a wide range of reported prevalence estimates between 6.9% and 38.75% for this population. This variance is likely the result of a variety of inclusion and exclusion criteria with regards to psychiatric disorders studied and methodological differences. However, all included articles – including the most conservative estimates – cited a prevalence considerably higher than the 2.8% prevalence in the general population (Fayyad et al., 2017). Prevalence rates of 19.3% and 15.3% based on ADHD assessment by structured clinical interview were reported. The latter figure was calculated from the data cited in Fones et al. (2000) to include only participants who still experienced ADHD symptoms as adults by the author of the current review to standardise the reports. Prevalence rates estimated based on self-report measures ranged from 10.5% to 23.9%. However, the greatest range was cited within one study (Bron et al., 2016) 10.5%-22.5%: the prevalence rates were found to be associated with the severity of MDD, with the highest rate noted in participants with a diagnosis of chronic MDD. The other three studies using self-report measures ranged

from 20% to 23.9%. Prevalence rates between 6.9% and 22% were cited in studies using both structured clinical interviews and self-report measures for the assessment of ADHD.

Only three articles reported on a study using the gold standard assessment method of clinical interview, self-report questionnaire and an impairment measure (Leung & Chan, 2017; Lines & Sadek, 2018; L Nylander et al., 2009) with prevalence rates of 19.3%, 22% and 38.75%. Lines and Sadek's (2018) rate of 38.75% is the highest overall in this review, which could be based on being the only inpatient sample and one of two studies only assessing ADHD using DMS-5 diagnostic criteria, which have found to be more inclusive than DSM-IV and DSM-III-R criteria. If one were to adjust this rate based on Bitter et al. (2019) and Deberdt et al.'s (2015) reports that DSM-V criteria attract a 10% to 32% higher prevalence compared to DSM-IV-TR, the estimated prevalence rate would be reduced to 26.4%-34.9%. Although this is still higher than any other prevalence estimation reported in this review, the lower end is more in line with the other studies. Also, considering the small sample (n=31) consisted of participants with more serious psychiatric illnesses, one would expect a higher prevalence as ADHD has been linked to high rates of comorbid psychiatric disorders (J Fayyad et al., 2007; Kessler et al., 2006).

The rest of the studies utilised self-report measures and a clinical interview to diagnose ADHD in their sample of psychiatric outpatients (and additional psychiatric inpatients for one) with prevalence rates ranging from 6.9% to 16.8%. Valsecchi et al. (2018) and Bitter et al. (2019) had considerably lower estimates compared to the other three studies that quoted 15.8%-16.8% (Alpert et al., 1996; Deberdt et al., 2015; Montes et al., 2007).

Variability of psychiatric comorbidities and severity thereof appear to be a reason for the discrepancy of prevalence rates between studies. ADHD prevalence rates in the psychiatric populations included in the review range from 6.9% to 38.75% depending on samples

and assessment methodologies. Studies conducting a patient chart review as part of their method discovered that ADHD was underdiagnosed and patients were therefore not treated for ADHD. The presentation of ADHD and comorbid psychiatric disorders often overlap and make differential diagnosis challenging (Katzman et al., 2017). While not all underlying mechanisms between various comorbidities are yet understood, Reimherr, Marchant, Gift, & Steans (2017) found that treating participants diagnosed with ADHD and anxiety disorders with psychostimulants not only reduced impairments associated with ADHD but also attenuated anxiety symptoms. Katzman et al's (2017) suggested that treating ADHD not only decreased functional impairment but also reduced the severity of psychiatric comorbidities. Furthermore, they reported that treating ADHD in young adults could change the trajectory of psychiatric comorbid disorders later on.

### **Limitations**

There are several limiting factors in this review. On a study level, included research employed a variety of methods to assess ADHD that were based on a range of diagnostic manuals. This made a meta-analysis impossible. Furthermore, it was acknowledged in some articles that their assessment tools had not been validated for the sample they were testing, which might have resulted in false positives. Most research conducted recruitment in psychiatric outpatient clinics, however, we are aware that each country has their own health service with psychiatric outpatient services providing support for slightly different populations based on their individual eligibility criteria. This resulted in samples with a variety of inclusion and exclusion criteria, which probably contributed to the range in prevalence estimates. Furthermore, only three of the eight higher quality studies conducted their ADHD assessment based on the gold standard

approach of structured clinical interview, self-report measures and a measure of functional impairment.

This review attempted to provide an estimated ADHD prevalence for the psychiatric population. It is possible that studies not using the term “psychiatric” in conjunction with ADHD in their article were missed because they studied a specific psychiatric comorbidity in relation to ADHD. Any studies published in a foreign language or in journals that had no peer-review process were excluded. In addition, only research using at least two out of three recommended assessment methods for ADHD were reported on in detail. This resulted in a small sample of eight meeting all the inclusion criteria. Also, only the first author assessed the identified records for eligibility: interrater reliability can therefore not be demonstrated with regards to study selection.

### **Future directions**

Future research would benefit from standardising their ADHD assessment methods based on the same diagnostic manual and following the gold standard for assessment. Also, it would be interesting to see how the ADHD rates differ with the various psychiatric comorbidities. More research is also needed in the treatment of individuals with ADHD and psychiatric comorbidities to improve their wellbeing as well as reduce the functional and psychosocial impairment associated with these disorders.

### **Conclusions**

The current review examined ADHD prevalence rates in the psychiatric population. Estimates varied depending on sampling, inclusion criteria as well as assessment methods. All prevalence rates were well above the 2.8% quoted by Fayyad et al. (2017) for the general

population. ADHD often goes undiagnosed in the psychiatric population, which has treatment implications. Research has found that treating ADHD not only improves ADHD symptoms and reduces associated psychosocial impairment but has also a positive effect on the severity of the comorbid psychiatric disorder. Increased recognition of ADHD could be achieved by routinely using an ADHD screen during the assessment of this population. Gender ratios cited in some of the studies did not align with the one quoted by Fayyad et al. (2017) for the general population of 1.5:1 (male:female). Three of the reviewed articles found an equal or reversed gender ratio. It is therefore important to run adequate assessments on all genders.

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## **Chapter 2: Empirical Paper**

**“My resilience was stronger than it was practical.”: What motivates middle-aged individuals to seek an autism diagnosis.**

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**Abstract**

As more adults are seeking and receiving autism diagnoses later in life, there has been increasing interest in the factors underlying this trend. Few studies have explored middle and late adulthood despite the recent development of adult diagnostic services. The current study examined what motivated middle-aged and older adults to seek an autism diagnosis at this stage of their lives. Eight adults were interviewed, and the transcripts were analysed using Thematic Analysis. Three main themes were extracted: road to self-acceptance, diagnosis as a way of overcoming a crisis and autism tailored support for future proofing. While they were catalysts for seeking a diagnosis, these processes continued past receiving it. This highlighted the importance of post-diagnostic support.

**Keywords:** *autism, Asperger's, late life diagnosis, qualitative, Thematic Analysis*

## **Introduction**

Autism Spectrum Disorder (ASD) is defined by a dyad of persistent deficits in a) social communication and interactions and b) restricted, repetitive behaviour and interests. These deficits need to be present from early development and cause the individual clinically significant impairment in important areas of functioning (American Psychiatric Association, 2013b). This paper uses the term ‘autism’ to refer to Autism Spectrum Disorder in general. Asperger’s will be used where it is necessary to denote autism without intellectual disabilities. This was deemed acceptable despite the problematic history of the nomenclature because the term is used within current research and by the National Autistic Society. It also follows the participants’ lead with regards to the terminology they used during the interviews.

It has been over a decade since the Welsh Autism Spectrum Disorder Action Plan (2008) was launched, which made Wales the first country in the world to create an all-age autism strategy (ASDInfoWales, n.d.). The Refreshed Autism Spectrum Disorder Action Plan (2016) reported that the Action Plan increased awareness of autism across groups and services, which saw a surge in individuals accessing diagnostic services across the age range. The Welsh government released funds to expand the Integrated Autism Service (IAS) in 2017. This allowed the establishment of adult diagnostic and support services throughout Wales (Welsh Government, 2019). All four countries of the United Kingdom have now developed autism strategies and actions plans that have increased the availability of diagnostic services for adults without learning disabilities (National Autistic Society, 2016).

Autism awareness has grown over the last few years as has the literature about individuals receiving an autism diagnosis in adulthood (e.g. Camm-Crosbie, Bradley, Shaw, Baron-cohen, & Cassidy, 2019, Crane, Hearst, Ashworth, Davies, & Hill, 2020; Griffith, Nash, & Hastings, 2012; Powell & Acker, 2016). The prevalence of autistic adults living in the

community was estimated to be 1.04% for the UK (Mackay et al., 2018), with rates of autism not significantly associated with age, i.e. rates of autism being stable across age groups (Brugha et al., 2011). Reasons for late autism diagnoses are believed to be professionals' unawareness of autism without intellectual disabilities, misdiagnosis of autism as mental health disorders, and the individuals' ability to adjust to the neurotypical world (camouflaging) even though this comes at a cost of exhaustion (Wylie, 2014). A person's cognitive ability and the development of coping strategies can mask the individual's autism traits and difficulties (Happé et al., 2016). The perceived resilience can contribute to the late diagnosis once a crisis point has been reached (Crane et al., 2018; Camm-Crasbie et al., 2019).

Due to the relatively recent access to diagnostic services, it is likely that there are generations of undiagnosed autistic individuals in their middle to late adulthood. Research has started to explore the experience of middle-aged and older adults (e.g. Griffith, Totsika, Nash, & Hastings, 2012; Hickey, Crabtree, & Stott, 2018; Stagg & Belcher, 2019), however, most of the studies to date concentrate on children and young adults.

A recent study explored the experience of autism in individuals age 50+ and how they viewed the later life diagnosis (Hickey & Crabtree, 2018). This study found that the participants had been aware of their differences compared to peers since early childhood and consciously worked on their social skills to fit in. Having the diagnosis also allowed them to "externalise the problem" and see difficult experiences in the past through an autism lens. The third finding was a wish to belong to a social group and how valuable the acceptance within the newfound social identity was for the participants. Stagg & Belcher (2019) discovered very similar themes in their analysis of accounts by participants aged 50+. Their participants struggled to access autism specific services and often did not know that there were services available at all.

Both studies found that the psychological processes older individuals experience were similar to what research into young adults had discovered: integrating the diagnosis into their identity, re-attributing negative experiences to autism rather than their person and the need for post-diagnostic support to reduce isolation. This suggests that interventions developed for the younger population could be useful across the age range. So far, it has not been explored if and how these processes and the timing of seeking a diagnosis are connected. The current study aimed to answer this question by investigating what motivated individuals to seek an autism diagnosis later in life and what caused delays if there were any. As far as we are aware, no study has examined what motivates individuals in their middle adulthood or later to seek an autism diagnosis and if there are common factors to their motivation.

## **Method**

### ***Design***

The present study used a qualitative design. The first author collected data via semi-structured interviews. Thematic Analysis (TA) was deemed the most suitable method of analysis as it is a flexible and pragmatic approach that allows the analysis of individuals' experiences without requiring layers of interpretation. A reflexive approach of TA was used within which themes are conceptualised meaning-based patterns on a semantic as well as latent level (Braun et al., 2018). The first author aimed to listen to the participants and describe their perspectives as they were presented, exploring what motivated the participants to seek and receive an autism diagnosis late in life. The first author attempted to be aware of her own assumptions and preconceptions so as not to influence the participants' narrative and/or the analysis unwittingly. Regular discussions with the other two authors helped examine assumptions and how they might impact on the analysis. A realist approach was utilised, taking the participants' accounts as their



truth. The first author coded the transcripts: the initial summary-based codes were developed into interpretive themes during the analysis to establish a story around the motivation to seek an autism diagnosis.

### ***Recruitment Strategy***

An opportunistic sample was used comprised of participants recruited via the first author attending a post-diagnostic group and a Dialectical Behavioural Therapy (DBT) group organised by the local autism service IAS. The first author was unknown to the participants and had only worked with autistic individuals in the context of mental health services. Participants were introduced to the study and provided with written information including the researcher's contact details. Inclusion criteria were: autism diagnosis via the National Health Service and being 40+ years old at diagnosis. Intellectual disabilities and current severe mental health (MH) problems constituted exclusion criteria. Eight individuals made contact with the researcher and interviews were arranged over six weeks.

### ***Ethical Review***

Ethical approval (application number 2019-16600) was received from the Bangor University School of Psychology Ethics Committee. The Integrated Research Application System was consulted and confirmed that ethical approval and Research and Development clearance from the local health board were not needed for this study (see Appendix 1).

### ***Participants***

Eight participants attended interviews and their demographic information is summarised in Table 1. Five participants initiated the referral to the IAS themselves, three were referred by clinical psychologists working in a memory service or a community mental health team (CMHT)

they had accessed for different reasons. Participants had received their diagnosis via the NHS an average of 13.3 months prior to the interview (range 6-20 months).

**Table 1: Demographic Information**

<b>Name<sup>1</sup></b>	<b>Gender</b>	<b>Age</b>	<b>Age at Diagnosis</b>
Donald	M	59	57
Derek	M	54	54
Gloria	F	47	45
Maddie	F	44	43
Marion	F	69	68
Jenny	F	48	47
Gladys	F	57	57
Andrew	M	52	50
<b><i>Means</i></b>	<b><i>M: 3 F: 5</i></b>	<b><i>53.8</i></b>	<b><i>51.9</i></b>

Seven participants had children, six of which had at least one child with an autism diagnosis. One participant did not have any professional qualification and was working as a carer to their children; two of the participants with professional qualification were retired and/or part-time self-employed, one was a student, one was home-schooling their children, two were employed, and one was currently suspended from employment for autism related reasons. All participants identified English as their first language, however, several spoke Welsh to some degree.

### ***Procedure***

Participants received written information about the study. Participants could ask questions about the study before the interview, gave written consent and were given the option to receive the article resulting from the study. Five participants preferred to meet in person, three

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<sup>1</sup> All names are pseudonyms

were interviewed via video call. All participants received a £20 Amazon voucher for their time and travel. The interviews were audio-recorded, transcribed in an anonymised fashion and stored in accordance with National Health Service (NHS) data protection policies.

### ***Data analysis***

The analysis was based on the Braun and Clarke (2006) approach for conducting TA, which included six phases of analysis (see Table 2). The interviews were transcribed verbatim, and the transcripts were coded using an inductive approach (Braun and Clarke 2006). The analysis was data driven, which meant the coding did not attempt to fit into existing theoretical frameworks. This bottom-up process was thought to be the best fit considering the aim of this study: giving the participants a voice to inform the understanding of this population. It was hoped that this would make it less likely for important themes to be missed than if the (neurotypical) first author had attempted to interpret the interviews in the light of frameworks such as “identity” for example.

**Table 2: Phases of thematic analysis**

<b>Phases of thematic analysis</b> (Braun et al., 2008)	
1)	<b>Familiarising yourself with your data:</b> reading data repeatedly, noting initial ideas
2)	<b>Generating initial codes:</b> documenting interesting features of the data in a systematic fashion across entire data set, collating data for each code
3)	<b>Searching for themes:</b> collating codes into potential themes, gathering all data relevant to each potential theme
4)	<b>Reviewing themes:</b> checking if themes work in relation to the coded extracts (level 1), and the whole data set (level 2), generating a thematic map of the analysis
5)	<b>Defining and naming themes:</b> ongoing analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for each theme
6)	<b>Producing the report:</b> the final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of extracts, relating back of the analysis to the research question and literature, producing a report of the analysis

The first author endeavoured to ask clear, direct questions (see Appendix 2 for the interview schedule) that allowed effective communication and for the participants to express their experience without trying to fit into the researcher's perceived expectations. All participants asked the researcher during the interview if they were answering the questions correctly. The first author re-iterated the validity of their experiences each time and how it was not a matter of right or wrong. This was particularly important to the first author: fitting in with the neurotypical society had contributed to the participants' distress that led to a crisis for all of them. The first author had some hypotheses regarding what might have led participants to seek an autism assessment based on clinical experience in mental health services and conversations with colleagues. However, care was taken to keep an open mind during the interviews so as not to ask any leading questions or influence the participants' answers.

Several themes were excluded from the analysis due to not answering the specific research questions for this study. The "fallout of the diagnosis", i.e. the impact of the diagnosis on the individual's mental health and general wellbeing was one of them. "Coping strategies acquired after the diagnosis" was another example along with individuals "recognising advantages of autism". While all the excluded themes gave an insight into how the participants processed the diagnosis and how the diagnostic process as well as the groups helped them in this, they did not pertain to the motivation for seeking an autism assessment.

All participants were eloquent individuals who had reflected a great deal on their autism diagnosis and reasons for seeking one. Three interviews were conducted via video call as per the participants' preference. Two of these were markedly shorter (approximately 30 minutes instead of a full hour) than the face to face interviews. There were different possible explanations for this: for all video calls, the sound quality was sub-optimal, and the line was interrupted. This

made a coherent conversation difficult at times. The interviewer attempted to remedy this by summarising and reflecting the participant's comments back to them frequently so as not to lose any content. It is possible that the technical issues impacted on the participant's ability to relax fully into the interview process, and that some of the anxiety that was likely to be induced by talking about personal experiences with a stranger remained.

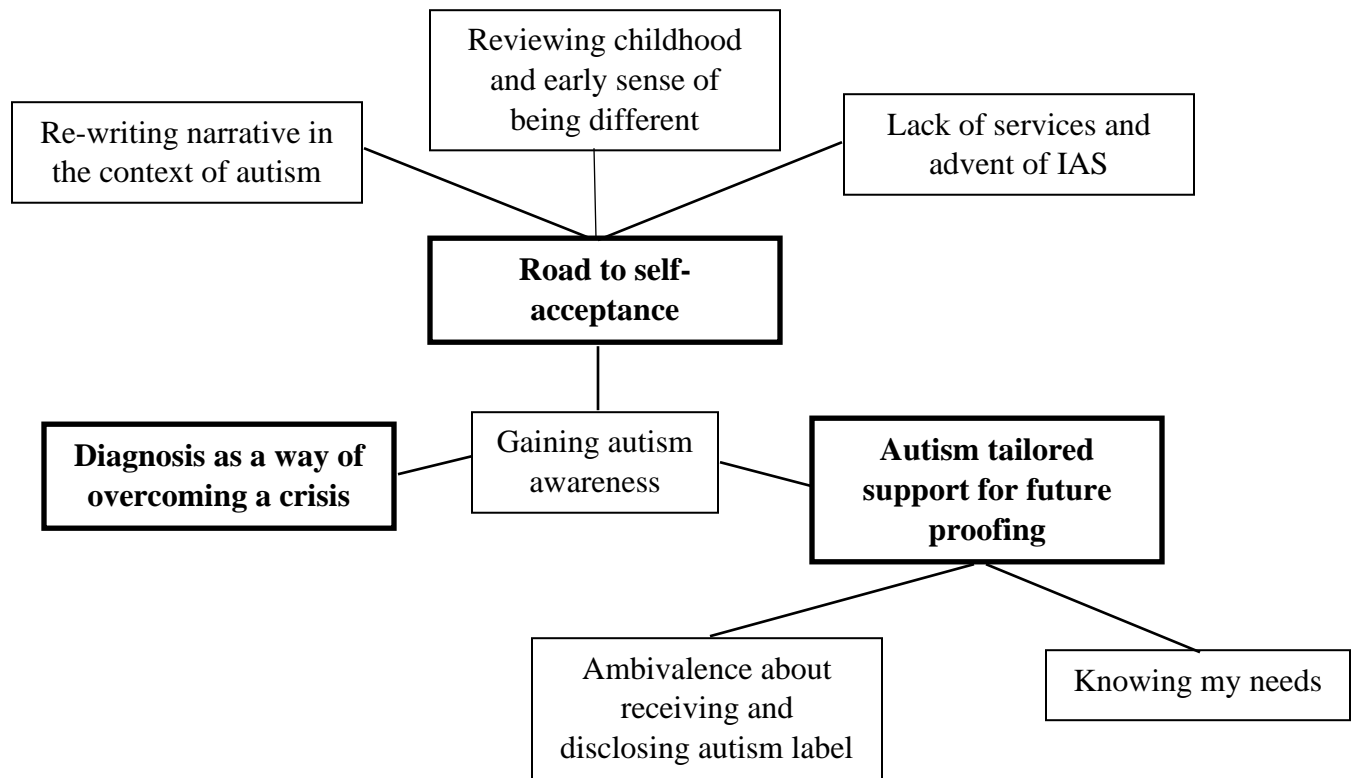
All interviews started with the collection of demographic information designed to put participants at ease. However, often these questions were not answered as easily as anticipated and quickly led to the autism diagnosis. Individuals attending a face to face interview visibly relaxed over the course of the interview, which was also reflected in the language they used as it tended to become less formal. Topics participants discussed were more personal in nature during the later stages and evoked strong emotions, particularly with regards to difficult experiences in the past.

It was not always possible to control all potential sensory issues (e.g. background noise or lighting), however, pointing out awareness of this and adjusting what was possible seemed to be appreciated, as was having consent forms and study information printed bilingually and on different coloured paper for anyone with a preference.

## **Results**

Fifteen second order codes remained after excluding codes unrelated to the research questions (see Appendix 3 for excerpt of coding process; early thematic map in Appendix 4 and a collection of quotes for a subtheme in Appendix 5). The codes were developed into three main themes answering the question *Why now?* and *Why so late in life?* (see Figure 1 for an outline of the final thematic map). The themes and codes were checked against the data corpus and

adjusted for the best possible fit. Initial themes and the thematic map were discussed among all authors to increase validity and accuracy.



**Figure 1: outline of thematic map**

**1) From “*What’s the matter with this boy?*” to “*I’m not the bad person everybody thought I was.*” The road to self-acceptance.**

This theme captures a complex process all participants went through in relation to their desire to receive an autism diagnosis, albeit in a slightly different order. There were three fundamental components: 1) gaining awareness of autism, which could happen based on experiencing health or mental health problems and looking for explanations thereof, or their child going through the diagnostic process. It is important to note that this process was ongoing

even after diagnosis. 2) reviewing their childhood and their early awareness of being different, including attributions they had made for this; 3) being able to explain their difficult experiences in the context of autism and rewriting the narratives; 4) lack of services during childhood and learning about a new diagnostic service.

### ***Gaining autism awareness***

The participants grew up in a society unaware of autism, particularly Asperger's. Marion was one of the participants who only came to recognise autism as a possible explanation for certain difficulties late in life. She recalled her own reaction to an acquaintance's revelation that her grandson was autistic only five years ago: *"If I'd been less polite, I would have laughed in her face, because to ME it was like a death sentence to bandy that sort of filth around, you know, just give that boy a chance!"* Autism meant that someone would need to attend a *"special school"*. The idea that the boy who was *"bright as a button"* was autistic was laughable. Being given the autism label would probably destroy the boy's life, eliminating any chance of success. Autism was something to keep to oneself for fear of *"stigmatisation"* because it was tightly linked to intellectual disabilities and special needs.

*"You're in that pigeonhole, I don't mind the labels but it's that ... never to be seen as a whole"*. Marion had been involved within CMHTs for years and had been given several diagnoses. The autism diagnosis was *"a jigsaw piece that was missing, yeah, ... found my missing piece"* – the picture felt holistic now, and many difficulties made much more sense. Marion realised that her previous opinion of autism was based on *"very poor knowledge"*. She felt that her views had been *"judgemental"* and *"based on missing information"* – just like the opinions typically presented in the *"tabloid press"*, i.e. poorly informed. Other participants also realised that their view of autism was very *"narrow"*. Not having more encompassing knowledge about

Asperger's meant participants could not develop insight into their difficulties. How do you build the jigsaw puzzle of your life if major pieces are missing?

*“While we were answering the questionnaires [autism screening] for my 15 year old erm I just keep thinking: ‘Oh, that’s me! Oh, that’s me!’ and ‘Oh, that’s you! That’s you!’”* Gloria’s repeated exclamations captured her surprise and seeming epiphany when she recognised that many of her differences could be explained by autism. This appeared to be the starting point of getting to know herself from a different perspective. She hoped – *“and this sounds really strange”* - that receiving a diagnosis would vindicate her and show that she was *“not the bad person everybody thought I was”*. Gloria described this wish to be *“really strange”*, almost as if - once again - she did not fit the norm. The diagnosis was for herself, however: *“it’s not about me going to people from my childhood and saying: ‘see, there was a reason, I wasn’t naughty’”*. She had come to accept herself: *“this is me, like it or lump it”*.

### ***Reviewing childhood and the early sense of being different***

*“In the end I think I NEEDED the diagnosis because it explained so much of (...) my past”* (Gladys). Participants reported feeling different to people around them from a very early age. Gloria even thought that she *“must have been adopted”*, which demonstrated quite how isolated she felt in her own family, as if she had nowhere to belong. She described herself as an *“against the grain person”* who went *“right when everybody else went left”*.

I was just odd, weird, got my head kicked in for being a weirdo quite often erm learned to keep my head down low once I left school erm just keep your head down, just be yourself and keep your head down, ignore everybody. (...). Just walk on, look the other way. Anybody try to challenge you, pfff, leave it cos I'm the weirdo, the kids like they'll hurt me. Only a couple of times, I have been seriously hurt erm but ... for being the effing



weirdo, but... I always.... I always thought I'd .... I'd rather be the effing weirdo than the effing bully. (Donald)

The words Donald used to describe himself were harsh and carried judgement. The repetitiveness of “*weird/weirdo*” appeared to reflect the number of times he was insulted and attacked as a child for being “*odd*”. “*Cos I’m the weirdo*” and not the others he seemed to say, setting himself apart from his peers and finding the reason for his beatings in himself rather than the cruelty of his peers. He repeated his coping strategy like a mantra, internal instructions to himself: “*head down*” to be less likely to be (physically) hurt by others, even if the emotional impact could not be avoided. Donald’s word choice conveyed (contained) anger: at this stage of the interview he still softened swear words, something he dropped further into the conversation.

Even though Donald described himself as the “*effing weirdo*” and tried to escape his peers’ abuse, he still wanted to “*be [him]self*”, “*always*” keeping hold of his values: he preferred being assaulted to becoming the “*effing bully*” himself. Being himself was better than being like the others if fitting in meant being malignant. Again, he set himself apart from the others but for different reasons entirely: “*I’d like to fit in if everybody else was like me.*” Growing knowledge about autism meant he started to be able to explain some of the childhood experiences and why he was struggling with certain situations. Part of his motivation to refer himself to the IAS was to confirm the self-diagnosis he had arrived at through research for his autistic son.

### ***Rewriting narratives in the context of autism***

Increased understanding of autism led to a review of their childhood and the diagnosis was a way of explaining and re-attributing the negative labels the participants had received in the past. It directly motivated their request for an assessment. Andrew spoke about his childhood memories from his parents’ perspective. His parents were concerned about his social isolation

and perceived failure at school. Andrew recalled being taken to various services because “*my parents thought I had some form of retardation, you know*”. The headteacher also believed that mainstream school “*[couldn't] help*” Andrew because he was not able to tolerate the school environment and therefore “*buggered off*” most days, which was interpreted as truancy and inability to learn. “*Nothing came back of course, they didn't really understand it, just said, he's a quiet lad, that was the diagnosis you'd get bloody 40 years ago*”. Andrew's frustration at their ignorance was reflected in his swearing. Being declared “*a quiet lad*” by professionals was the only explanation given for his behaviour, which in turn precluded any support and/or adaptations.

The general unawareness of autism had him labelled as “*retarded*” and he was eventually home-schooled. This contrasted starkly with his academic and professional achievements once he attended college in small classes and was allowed to follow his interests. Andrew's demeanour changed completely when he spoke about his job and what he had achieved. The “*physical [compulsion]*” that had driven him to achieve in his profession was palpable in the room and was reflected in the language he used: “*It was a lovely thing, you know, that how the bloody hell I'd done this myself and I'm so fucking - sorry - I'm so PLEASED that I'm here, how cool am I?*” Andrew caught himself swearing in this context and corrected himself, which he did not do when discussing his childhood experiences. Swearing appeared to mirror the emotional charge of the negative context.

The circumstances of Andrew's almost accidental diagnosis after a head injury was an extremely difficult experience. Andrew felt the private service diagnosing him eight years ago “*treat(ed) you like a retard*” and that “*the whole experience was actually horrendous*”. He had worked hard all his life to dispute this label and his perceived treatment as a “*retard*” during this

entirely “*horrendous*” process was in the face of all of his achievements only eight years ago. It was interesting that Andrew’s phrasing changed when he talked about his autistic son: “*his learning age is lower than his physical age*” in contrast to “*retarded*”, even though he also stated “*my son is the same as me*” (autistic). Understanding of his son’s needs and no doubt fatherly love softened his words and his perspective of autism and intellectual disabilities. Requesting an NHS assessment appeared to be part of a need to reframe and explain his own experiences.

### ***Lack of services and the advent of IAS***

Most participants wondered what their childhood would have been like had their families and schools known about their autism. There was a sense of grief for a “*lost life*” as Donald described it, and Gladys depicted it as follows:

I did feel sad for the little girl I was in that... it was just so hard, it really was... looking back every day was hard, a battle to get through. I was for a while thinking, if I had known, if my parents had known, would I have had more help? But you know, we're talking about the late sixties, early seventies and (...) It wouldn't have been any good even if they had known.

She used words such as “*hard*” and “*battle*” to describe everyday life. Each day “*the little girl*” woke up to another day of waging war against an environment that did not understand her needs and “*bullied*” her for being different. It appeared masking became her armour over the years, which fooled professionals into thinking that she “*[didn't] have it*” because she “*made eye contact*”. Gladys had been involved within CMHTs for years and had questioned if her diagnoses really did encompass all her difficulties. Her requests for an autism assessment were ignored: the clinicians had “*quite a narrow idea/view of what it is to be autistic*”. Even professionals a decade

ago did not understand how Asperger's and female autism presented and her concerns were belittled. Her "*battle*" to receive a diagnosis and support continued far into adulthood.

There was only implicit acknowledgement that there were no services a few decades ago, particularly for Asperger's. Gladys wondered if having a diagnosis back then would have made a difference because of societal views and prejudices at the time. Gloria stated: "*I can't blame people for the way [they treated me] but still it upsets me that I missed out on a possibly happier childhood because of that*". The validation of a diagnosis via the NHS was part of the motivation for referring themselves. One participant felt that a private service would not have offered the same level of credibility. Some spoke about the advent of IAS, which had made a diagnostic service accessible for the first time, others reflected on how society's views on autism and Asperger's had developed in the last few years. Both were factors for the timing of their diagnosis.

**2) "*I've held my shit together in a reasonable way. And then in the end it was like actually, I can't, I'm done, I've had enough*". Diagnosis as a way of overcoming a crisis.**

Most participants recounted an accumulation of difficulties and/or transitions that prompted them to investigate an autism assessment. Their hope was to understand their difficulties better and to access support. Derek questioned why he would need a diagnosis:

I'm 50 years old, I've lived my life like this, I've coped okay (...) and then gradually came to the point, well, I need this because I'm not coping, I'm not coping at work, I get problems at work, I'm getting problems at home and I need to understand more (...) answers for why it's happening, you know, to try and stop it happening again.

Like for others, it was an accumulation of difficulties that signalled to Derek that a diagnosis was necessary, which is reflected in the repetitions of “*not coping*” and “*problems*”. The purpose of the diagnosis was twofold: it would explain why he had these problems and provide a solution to prevent them from repeating themselves.

The words “*coping*” and “*struggling*” were often used in explanations why someone would or would not seek a diagnosis. None of the participants had thought about a diagnosis while they were managing well. Donald thought his adult daughter would probably receive an autism diagnosis but added that “*she does not feel the need at this moment in time [because] she’s [not] struggling enough*”. Similarly, Marion thought there was no need to put her grandson through the diagnostic process because he was not experiencing any problems and “*is bright as a button*”. There was no value in adding a label to one’s person whilst managing well most of the time.

None of the participants wanted a diagnosis for the sake of having a label. It was always linked to understanding themselves better and to finding a way of managing difficulties more effectively because their own coping strategies were no longer working in their favour:

*Andrew:* I’ve become very, very resilient and I could do it (job) because it was a means to an end. (...) I think my resilience was more powerful than it was practical in that regard

*Interviewer:* mh, that’s a lovely way of putting that actually because you just plodded on

*Andrew:* powerfully

*Interviewer:* yeah, yeah till there was a breaking point

*Andrew:* and that was it

It seemed important to Andrew that the interviewer know how resilient he had been as it was a word he used repeatedly during the interview to describe himself in various settings, as if he

wanted to ensure that his seeking help was not perceived as a weakness. While Andrew agreed with the interviewer's "*plodding on*", he added that he did so "*powerfully*", another word to emphasise the strength this had necessitated. However, he had come to the insight that pushing on for so long was to his own detriment. He had completely "*exhausted*" himself and resigned from his job. His retirement and the subsequent loss of focus, routine and complete "*alienation*" from others appeared to be the tipping point leading to the referral. Requesting a diagnosis and support was a last resort after spending a lifetime battling with the difficult sides of his job.

For Derek, the diagnosis would hopefully offer some protection at work as well as explanations for the difficulties he had identified as part of a pattern in his life. His request for adaptations had gone unheard by managers and he felt "*vulnerable*" without the diagnosis, particularly because of repeated suspensions. The official label was something his employer would not be able to ignore and force them into action. Derek thought adaptations at work and a better understanding of himself would help him break the problematic patterns that had led to his breaking point.

**3)      "*I know what I'm dealing with, this knowledge gives me power.*" Using autism tailored support for future proofing.**

***Knowing my needs***

Marion described the process she went through discovering she was autistic as well as having psychiatric diagnoses. She found gaining knowledge empowering:

I can then like in my mind regroup, ok, so it's not ONLY bipolar, it's also autism, so what can we do to erm contain all of those feelings (...) make your own strategy (...) but unless you know what you've got to deal with, it's oh it's like if you think you've only

sprained your ankle, you'd have a different strategy than if you've find out you've broken it.

Knowing exactly what she was dealing with was important. She believed that having the correct diagnosis meant being able to find the right coping strategies. Not having the diagnosis was equivalent to treating an ankle as “*sprained*” when it was really “*broken*”; the diagnosis explained why her strategies never fully worked for her. She stated that she had self-harmed for over thirty years and understanding how autism affected her allowed her to deal with overwhelming emotions differently. This in turn had greatly improved her relationship with her spouse and overall quality of life. She concluded that “*I was born with it and I'll die with it and there's not an awful lot I can do apart from designing my life around it*”. The diagnosis had given her knowledge which “*empowered*” her to change her coping strategies.

For Maddie, getting to know herself in the context of autism was very much still in progress and she observed that “*I've never had the words to turn around to say ... I need to do this because... this is who I am*”. There was hesitation in her statement, as if she were unsure of this new ability. Looking after her children and their needs had been her priority so far. Standing up for her own was a different matter, not least because she was still “*trying to find out who [she] actually [was]*”. Access to support was a motivator for Maddie, even though she recognised that she was not certain yet what she needed and therefore where to access it. Maddie felt going through the assessment and attending the DBT group was giving her the vocabulary to describe strategies to her children, to “*give them tools from an early age*”.

Donald stated that he was asked to “*sort [himself] out*” by his wife when he “*became much more autistic (...) almost overnight*” after big life events. He phrased his motivation as “*preserving mental health in old age*” and continued: “*Don't go into really old age with profound*

*mental health issues, cause it'll have you, it'll... you might think you dealt with it, but it will fall off the shelf and bite you on the arse!"* He had researched autism in adulthood and recognised himself in the picture he discovered. Donald wanted to learn strategies that he could also teach his son. There was acknowledgement of having “*mental health issues*” and the “*dealt with it*” seemingly referred to suppressing or ignoring the problem. Accessing support was a way of planning for “*old age*”.

### ***Ambivalence about receiving and disclosing the autism label***

*“That doesn't make sense, does it, (...) saying that out loud it's like I'm only accepting myself because somebody is saying that I'm autistic and what I'm doing is okay.”* Maddie stated that they did not “*need labels*”, but also thought that “*unfortunately*” society was more likely to support you if you had one: the label had become a necessity. She did not “*need*” a label for her own sake and yet noticed that having an external authority tell her that she was autistic might help her with acceptance and reduce self-blame for certain difficulties. There was an ambiguity between wanting and needing a label, almost a desire to be self-sufficient and independent of anyone else's views, which was vital in her everyday life. She had come to the conclusion that she needed outside help, however, this was a departure from how she would normally have managed her difficulties.

There was apprehension about the consequences disclosing the diagnosis might have. All participants had described negative life events they ascribed to autism, so “*coming out*” as autistic was understandably anxiety provoking. Jenny had positive experiences informing others about her autism, which had helped her cope in situations, however, she stressed that she only did this in selected situations when she was struggling. Donald appeared wary of disclosing his diagnosis, particularly to services: *“I don't mention me being autistic at all. That's ... I don't*



*trust them. At all.*” This was based on negative personal experience and reports from acquaintances.

## **Discussion**

Eight individuals participated in this study. Sample size vary greatly in studies using TA, ranging from 2 to 400 (Fugard & Potts, 2015). Assuring that themes are developed based on thorough, inclusive and comprehensive coding is one of the important criterion for quality assurance in TA (Braun & Clarke, 2019). It was felt saturation was achieved: all themes could be found in every transcript. Discussions with local clinicians about the findings uncovered that the themes were also borne out in their experience. Also, themes developed from the current data set bore a distinct similarities to findings in other studies using comparable samples (Hickey et al., 2018; Stagg & Belcher, 2019) and managed to build on previous findings by investigating the participants’ motivation for seeking an autism diagnosis and its timing.

This study aimed to explore why middle-aged individuals sought an autism diagnosis at this stage of their lives. All but one participant experienced some kind of crisis in their life that made them research and request an autism diagnosis. These individuals entered the diagnostic process with a view of accessing support for themselves hoping to understand themselves better in the context of autism and learning about coping strategies that would improve their quality of life. In hindsight, autism was linked to negative, traumatic childhood experiences that were validated by being given the diagnosis. Professionals’ lack of knowledge about Asperger’s and the female presentation of autism, as well as the individual’s own lack of understanding created a delay in diagnosis. Participants had previously attributed the feeling of being different to having mental health problems, being flawed and defective as a person and/or struggling intellectually.

Participants hoped a diagnosis would help them understand themselves better. Their growing autism awareness allowed them to re-evaluate difficult experiences in the past. The

diagnosis was seen as a way of accessing autism friendly support to overcome a crisis. Accessing help was not only important for the current situation, but also for the management of their difficulties later in life. Looking forward to a better future was part of the motivation to seek a diagnosis.

A major part of starting the journey to request an autism assessment was increased awareness of autism and how this affected the participants. Although described under the first theme, it was an integral part of all three. It was at the heart of understanding themselves better, how some difficulties created by their autism led to the crisis point and how their personal strengths could be used to improve their quality of life. Lack of knowledge about autism as a delaying factor in an individual's diagnostic journey has not been documented in previous research to our knowledge. The Refreshed Autism Spectrum Disorder Strategic Action Plan Wales (2016) reported heightened awareness of autism throughout services and the population, which increased the demand for autism assessments in the last few years. This augmented knowledge benefited several of our participants and also allowed their awareness to develop with regards to their own presentation. Several participants stated their autism knowledge had been incomplete before, similar to professionals they had encountered in their (not so distant) past. A recent study on late life autism diagnosis in women reported that professionals had stereotypical views on autism which did not include the female presentation (Bargiela et al., 2016), which was reflected in our female participants' experiences.

What is typically described in previous research is a sense of being different that started in childhood (Kosger et al., 2015; Lewis, 2016; Punshon et al., 2009; Tan, 2018). Studies describe the detrimental effects this would have had on the person's self-esteem and levels of depression and anxiety (Cooper et al., 2017) and the belief that "something is wrong with me"

(Leedham et al., 2020; Lewis, 2016). In an attempt to “fit in”, individuals would mask and learn how to imitate neurotypical peers, study and research their behaviour (Leedham et al., 2020; Punshon et al., 2009). These findings were reproduced in our study and contributed to the delay in diagnosis.

Happé et al.'s (2016) interpretation of their data is that general cognitive ability and the development of coping strategies do not reduce autism traits but may attenuate their effect on an individual. This could influence an external person's perception of an individual. Our participants reported being seen as resilient, strong individuals by friends and family because they had developed such convincing “masks”. This perceived resilience potentially added to the delay in diagnosis, as well as precluded them from receiving support until a crisis point was reached, which was also described in Crane et al. (2018) and Camm-Crosbie et al. (2019).

Masking (using compensatory strategies in order to fit in, also termed camouflaging (Lai et al., 2017)) was mentioned by all participants, female and male, although research suggests that levels of camouflaging are overall higher for autistic women (Lai et al., 2017). Getting to understand masking as a strategy helped them realise why social interactions were so exhausting, even if some participants reportedly enjoyed them. This in turn supported the development of additional and/or alternative strategies for these situations and allowed forward planning.

Research has described the participants' internalisation of negative experiences, the interpretation that something was inherently wrong with them, “*a character flaw*” as Maddie called it. Getting to know themselves through the lens of autism allowed the participants to re-evaluate and re-write some of the difficult narratives. This is in line with Leedham et al.'s (2019) “unhelpful internalised messages and a devalued sense of self” and is also documented in other research (Powell & Acker, 2016b; Punshon et al., 2009). Hickey et al. (2018) described a “life

review”, which included understanding the past in the light of autism and being able to separate autism from the self as an externalised entity. This allowed the participants to re-attribute difficult experiences to autism rather than themselves and helped develop self-acceptance based on adjusted expectations of themselves. Our participants described the same process, starting once they became aware of autism and continuing throughout the diagnostic process and attending the post-diagnostic groups. Even after years of researching autism and almost two years after his diagnosis, Donald stated that he was “*still learning*” how autism affected him personally. The crucial point seems to be the applied knowledge of autism, being able to individualise it to reach understanding of themselves.

Punshon et al. (2009) described a similar process whereby the diagnosis gave participants a framework to explain difficult experiences and absolve themselves of blame. Powell et al. (2009) wrote about the relief this brought their participants. While our sample did not name blame as such, statements such as “*it’s not my fault, I didn’t do it deliberately*” were almost ubiquitous. Tan (2018) viewed this process in the light of “biographical illumination”, which creates new knowledge about the self that is applied over time. The diagnosis gave an explanation why the participants were unable to “be normal”, it provided relief from attempting to “normalise” and a basis for acceptance.

Cooper et al. (2017) suggested that building a positive autism identity could support individuals to achieve psychological wellbeing. Their results suggested that positive personal self-esteem was associated with positive collective self-esteem (group membership) and this in turn was related to lower levels of anxiety and depression. Cooper et al. (2017) stipulated that social identity processes are applicable to autistic individuals despite deficits in social communication and interactions. MacLeod and Johnston (2007) investigated the development of

a positive autism identity and how this can be facilitated in group interventions, urging autism services to make these interventions available preventatively rather than as a reaction to crisis to improve quality of life.

## **Limitations**

There are several limitations to this study. The sample of eight participants was purposive. It is possible that the participants' stories were not representative of the diverse autism population. The recruitment happened via groups. Any diagnosed individual unable to attend these was missed during recruitment. Also, the gender ratio of five women to three men was not typical of IAS referrals: between January 2019 and June 2020, 349 men and 305 women were referred to the local diagnostic service<sup>2</sup>. Furthermore, the sample excluded individuals with intellectual disabilities, which means that this study is not representative of the whole autistic population.

Three interviews were conducted via video call, two of which were only half the length of all the others. It is possible that the technical difficulties during the interviews as well as not being face to face had a detrimental effect on how comfortable the participants felt. The first author assumes that the participants chose video calls for logistical reasons and/or to reduce anxiety about the interview. Offering video calls was based on a suggestion by an autistic individual during a service user forum where the research proposal was presented for feedback. The pros and cons of this medium will have to be evaluated carefully in future research with this population.

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<sup>2</sup> Personal communication with administrative assistant of local IAS

## **Clinical implications**

Despite several participants reporting difficulties in accessing mental health support when in crisis, nobody stated that they wished to receive intensive therapy. What they found helpful was a) being believed that they were autistic and supported in their wish to receive a diagnosis, b) getting to know themselves better in the context of autism and how it affected them individually, which started during the diagnostic process and continued in the post-diagnostic groups, and c) meeting other individuals with a diagnosis where, it appeared, they formed friendships and a sense of belonging to a “tribe” as a few described it.

Research indicates a dearth of post-diagnostic support and how valued it is when it is available (Hickey et al., 2018; Stagg & Belcher, 2019). All participants had attended at least the DBT skills course or post-diagnostic group. Feedback on these groups was overwhelmingly positive: they increased knowledge about how autism affected them and gave them strategies to manage difficulties as a way of future proofing their lives. It also put them in touch with each other, which reduced the sense of isolation also found in other research (Griffith et al., 2012; Macleod & Johnston, 2007).

Research suggests that mental health difficulties are more common and more severe in autistic individuals compared to the general population (Moss et al., 2015; Roy et al., 2015) and that CMHTs are often ill equipped at delivering autism friendly services (Lipinski et al., 2019). There is a need for continuous autism training for CMHT staff and means to adapt interventions to suit autistic individuals’ needs (Camm-Crosbie et al., 2019; Lipinski et al., 2019) to bridge the gap of services autistic individuals often encounter (Au-yeung et al., 2019).

Lack of guidance and advice post-diagnosis was cited as a particular difficulty in Crane et al. (2018) with services only being offered when a crisis point had been reached. Crane et al. (2020) explored the motivation for attending post-diagnostic groups and reported themes similar

to those found in our study: exploring autism, empowerment and developing practical strategies and coping mechanisms. Some of their participants expressed how valuable any form of post-diagnostic support was, the positive experience of meeting other individuals and feeling “normal”, getting to know themselves in the context of autism, both weaknesses as well as strengths they had not noticed before, and being able to overcome difficulties based on the understanding of where they came from. This picture was extremely similar to what we found in our study when participants reflected on the group they attended. Andrew stated that meeting other people with Asperger’s had “switch[ed] on a bloody big light” and reduced the “alienation” he had experienced before.

The diagnostic process and courses appeared to continue the development of self-understanding that was one of the catalysts for seeking a diagnosis for our participants. The group processes also seemed to nurture the social identity mechanism of collective self-esteem, which has been linked to increased person self-esteem which was found to be related to improved mental health (Cooper et al., 2017). Cooper et al. (2017) stipulated the importance of positive autism identity for the individual’s emotional wellbeing, and how this could be supported by offering psychoeducational and support/advocacy groups face to face and online.

In summary, this study explored what motivated individuals in their middle to late adulthood to seek an autism diagnosis. Three themes were identified within the data: getting to know oneself in the context of autism, which often commenced a process of re-evaluating difficult experiences; enduring a crisis which had pushed the individual to a breaking point with the usual coping mechanisms no longer working – the diagnosis was seen as a means of accessing autism specific support; and lastly improving one’s future quality of life by developing coping strategies based on a better understanding of one’s difficulties. While these were the

catalysts for seeking a diagnosis, they were part of continuous processes. Going through the diagnostic assessment and attending post-diagnostic groups supported these developments. Even though all participants reported at least temporary difficulties coming to terms with the diagnosis, they all emphasised how valuable the process had been, as Jenny stated: “It saved my life!”



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## **Chapter 3: Contributions to Theory and Practice**

## **Clinical and theoretical implications of chapters 1 and 2**

### **Introduction**

My thesis examines two neurodevelopmental conditions in adults. Both autism spectrum condition (autism) and attention deficit hyperactivity disorder (ADHD) are underdiagnosed in the adult population, which has implications for the individual's wellbeing and functioning. My empirical study explored why middle-aged adults would seek an autism assessment when they had lived half their lives without one and seemingly coped. It was interesting that most participants initiated their referral for assessment themselves and at times had to fight to be taken seriously. The systematic literature review attempted to establish a prevalence for ADHD in the psychiatric population.

Not being diagnosed with ADHD and/or autism means that potentially, not all possible treatment options are considered, or treatments are offered in an unadapted manner, which could make interventions less efficacious. This third paper will look at clinical and theoretical implications for parts one and two and contain my reflections on both.

### **Empirical study: ‘My resilience was stronger than it was practical’**

#### **Clinical implications of my empirical study**

Three of the participants reported being discharged from CMHTs upon receiving an autism diagnosis with the justification that they would receive “*more appropriate care*” from the Integrated Autism Service (IAS). In my own experience of working in CMHTs, autism has been used as an exclusion criterion despite clear mental health difficulties of the referred person. It appears that the realm of the IAS is somewhat blurred in local services and there seems to be a misconception that the IAS provides therapy for severe and enduring mental health problems. It is clear that public services cannot afford to be duplicated, however, the interface between social

and mental health services is currently gap-like with individuals in need of dual input often falling through the net. The importance of the interface between services has been highlighted in the evaluation of the IAS report (Holtom & Lloyd Jones, 2019) for Wales, however, disjointed services around the care for autistic individuals is an issue also found in other countries (Lipinski et al., 2019). Two main clinical implications arise based on my empirical study:

- 1) Continuous autism training for staff in services, particularly Community Mental Health Services (CMHT).

There are several reasons why CMHTs are reluctant to offer autistic individuals care: local services are strained and waiting lists are long. It is possible that some referrals are rejected to preserve already overstretched resources. Secondly, research suggests that clinicians feel ill-equipped to provide interventions because of a lack of knowledge about autism and how to adapt their work (Au-yeung et al., 2019; Camm-Crosbie et al., 2019; Lipinski et al., 2019). This highlights a need for staff training, both during their professional training and later during their roles. Some of this could happen in form of consultancy via the IAS.

- a) As a first step, staff need to become more aware of how autism presents in mental health services. The National Institute for Clinical Excellence (NICE, 2016) set out general principles of care for autistic individuals as well as how to identify and assess autism in by trained professionals. Importantly, it also recommends the assessment of “mental disorders”, making it clear that autism and psychiatric disorders can co-exist in a person. Having worked in several mental health services, it almost felt as if autism was seen as a separate entity, which ignores the symptomatic overlap of diagnoses and current interactions between autism and mental health difficulties and how autism is likely to have contributed to the

development of their psychological problems. Autistic individuals have been found to have significantly higher rates of psychiatric comorbidities (Joshi et al., 2013; Joshi & Wilens, 2009) as adults and adolescents. Research reported that autistic children have significantly higher rates of anxiety compared to neurotypical peers (van Steensel et al., 2013).

- b) Staff should also be trained in the adaptation of interventions. Research suggests consistent therapist, time and location for appointments, low stimulus environment and a clear agenda and consistent structure for sessions to reduce stress and anxiety (Cai et al., 2018; Camm-Crosbie et al., 2019; Lipinski et al., 2019). The implementation of certain adaptations will be limited by the building in which a service is based as well as how many clinicians share therapy rooms. However, it would be interesting to ascertain if acknowledging these limitations to clients would have a positive effect – both on the client’s anxiety and stress levels as well as the therapeutic relationship. This would demonstrate the clinician’s autism awareness: perceived lack of autism knowledge in clinicians was stated as a reason for negative therapy experiences, and participants felt it was not their responsibility to educate their therapist (Camm-Crosbie et al., 2019).

From an intervention point of view, the suggested adaptations do not appear unachievable, particularly if one considers a therapy such as Cognitive Behavioural Therapy (CBT) with its structured sessions and protocols when used in its pure format, and CBT is the recommended treatment for many psychiatric diagnoses by the National Institute of Clinical Excellence (NICE). As for the evidence base of CBT for the treatment of autistic individuals, a recent meta-analysis was not able to present a clear picture due to the lack of high-quality studies with big enough samples (Weston et al., 2016).



NICE have published guidance (2012) for psychosocial interventions targeting core symptom of autism and life skills, however, it seems more practical adaptations for interventions have only been established for under 18's (National Institute of Clinical Excellence, 2013). A recent review of these for autistic children and adolescents was cautiously optimistic that adapted CBT interventions targeting depression, obsessive compulsive disorder and anxiety appeared to be efficacious (Walters et al., 2016). Other therapies, e.g. Dialectical Behaviour Therapy (DBT) are being explored for their efficacy in this population (Hartmann et al., 2012, 2019). Appendix 6 contains a document with concrete adaptations to CBT developed by a local IAS clinician based on autistic individuals' needs. This is an example of how IAS can support local CMHTs on a practical level while a concrete evidence base for specific adaptations is outstanding.

- 2) Developing the post-diagnostic support for autistic individuals to facilitate a positive autism identity as well as reduce isolation.

Post-diagnostic support has been reported to be valued when it was available (Hickey et al., 2018b; Stagg & Belcher, 2019). This was also the distinct message I received during the interviews. All participants were enrolled in either a post-diagnostic group or a Dialectic Behaviour Therapy Skills only group (DBT) at the time of the interviews. The post-diagnostic group was described as extremely helpful to increase their knowledge of autism and how this affected them on a personal level, as well as meeting other autistic adults with similar background stories.

To my knowledge, only one participant attended the DBT group without having gone to the post-diagnostic group. I got the impression that she would have benefitted from the latter first. This person was very reflective and had researched autism for a long time but

found it hard to apply the theory of autism to herself, particularly with regards to strengths. It appeared she was learning about coping strategies in the DBT group while still searching for who she was and what she needed. As described in my third theme “I know what I’m dealing with and this gives me power”, this individual did not have a full understanding of what she was dealing with just yet. Attending the post-diagnostic group first might have facilitated this.

Providing post-diagnostic support is not only important for the individual’s understanding of themselves but can also have a positive impact on their wellbeing by developing a positive autism identity even if commonalities between autistic individuals are limited due to the diversity within this population (Cooper et al. 2017; Macleod & Johnston, 2007; Macleod, Lewis, & Robertson, 2013). Using groups as a way of post-diagnostic support can reduce the social isolation and alienation autistic individuals experience (Crane et al., 2020). This was borne out by my participants’ reports. Macleod and Johnston (2007) stipulate that this type of support should be available to individuals as preventative measures instead of only at point of crisis.

### **Theoretical implications of my empirical study**

Mental health problems are common comorbidities in autistic individuals with higher severity as well as frequency compared to the general population (M.-C. Lai et al., 2019). Thus far, the prevalence of autism in the psychiatric population is unclear and likely underdiagnosed (Tromans et al., 2018). Tromans et al. (2018) conducted a systematic literature review into the estimated prevalence of autism in psychiatric inpatients and came to the conclusion that prevalence rates of autism are likely higher in this population, however, methodological issues and heterogeneity of inclusion/exclusion criteria did not allow firm conclusions. Prevalence rates

in their review ranged from 2.4%-9.9%. A recent systematic review on the estimated prevalence of autism in individuals with a psychosis diagnosis found a similar picture: the prevalence is probable to be higher than in the general population, but no clear rate could be deduced due to lack of high-quality studies (Kincaid et al., 2017). Both systematic reviews point out the dearth of research into prevalence rates of autism in the psychiatric population.

Few studies have examined specific adaptations to interventions for autistic children, fewer even for autistic adults. Walters et al., (2016) recommended more high-quality studies on the efficacy of adapted interventions to build on the case studies and feasibility studies they reviewed. Macleod and Johnston (2007) stated that more participant-based interventions should be developed and evaluated for efficacy. Further research into the efficacy of interventions for autistic individuals and the adaptation of existing interventions is required to meet this population's needs. Also, involving autistic individuals in the planning and conduct of research as well as the adaptations themselves would be of great value (Fletcher-watson et al., 2019).

Although all participants felt that receiving a diagnosis had been positive, all also described a challenging period following it. Even though most participants had initiated the process themselves based on their suspicions, having those suspicions confirmed caused anger, distress and/or sadness. This appeared to be based on the realisation that there is no cure for autism and that the difficulties they were experiencing would therefore not resolve with the right medication and/or therapy. There has been extensive research into receiving a diagnosis of chronic illness and the biographical disruption this causes based on Bury's article in 1982. Could receiving an autism diagnosis also cause biographical disruption?

Two recent qualitative studies explored the impact an autism diagnosis for a child has on the parents using the biographical disruption model (Rasmussen et al., 2020; Raymond-Barker et

al., 2018). To our knowledge, no research has explored biographical disruption and cohesion in adults receiving an autism diagnosis themselves. The experiences my participants described, however, seem to fit this disruption/cohesion model. After the initial “shock”, as Gloria called the disruption, the participants started to look back on their lives, particularly on difficult experiences in childhood and were able to make sense of them within an autism context. This allowed them to re-write some difficult narratives, and they were able to attribute hurtful labels they were given as a child to autism (process of biographical cohesion). Some even reflected on the relationship with their parents and how their autism had affected the way they had been parented. Future research could explore if and how receiving an autism diagnosis in adulthood affects a person’s sense of self the way a medical diagnosis does.

## **Systematic literature review: ADHD prevalence in the psychiatric population**

### **Clinical implications of my systematic literature review**

The ADHD prevalence rates found in the literature review suggest that every fifth to sixth person accessing psychiatric outpatient care and up to every third individual in psychiatric inpatient care has ADHD. Research reported that ADHD is greatly underdiagnosed in psychiatric settings (Lines & Sadek, 2018). This may result in suboptimal treatment for these individuals. One way of improving the rates of diagnosis would be by including a short ADHD screen in the usual assessment protocol. The World Health Organisation ADHD self-report scale (ASRS) is a six-question screening instrument originally developed for the identification of ADHD in adults of the general population. However, it was concluded that this would also be a suitable instrument in other settings for case finding initiatives and clinical outreach (Kessler et al., 2005). This self-report questionnaire could even be used by general practitioners before referring individuals on to appropriate services for a full assessment if needed.

Nylander, Holmqvist, Gustafson, & Gillberg (2009) reviewed in my article examined staff's retrospective opinions of which participants in their sample they thought had ADHD. While staff identified 11 of 12 ADHD positive individuals correctly, they missed 19 individuals the researchers had diagnosed with ADHD based on their assessment. It is possible that staff missed over half of ADHD positive participants because they did not present with typical externalising behaviours associated with the hyperactive-impulsive subtype. Nylander et al. (2009) reported two participants with a predominantly inattentive subtype and 28 with the combined subtype. This highlights the importance of instating a screening instrument and follow up individuals scoring above threshold with a complete assessment based on the gold standard recommended in the European consensus statement on diagnosis and treatment of ADHD (Kooij et al., 2010). ADHD is divided into subtypes of inattentive, hyperactive-impulsive and combined (American Psychiatric Association, 2013a). Research found that the prevalence of the hyperactive-impulsive subtype in childhood shifts to the inattentive type in adulthood; estimated prevalence rates in adulthood for the subtypes are 58.5% inattentive, 7% hyperactive-impulsive and 34.6% combined (Ohnishi et al., 2019).

Ohnishi et al. (2019) reported that internalising disorders such as dysthymia, anxiety disorders and bipolar disorder were associated with the inattentive subtype. Externalising disorders such as conduct disorder, substance use disorder, impulse control disorder and oppositional defiant disorder were associated with the hyperactive-impulsive subtype. Depression was found to be independent of ADHD subtype. This demonstrates that ADHD comorbidity is found throughout all psychiatric disorders and not only the externalising disorders staff might more readily associate with ADHD. Staff training on ADHD symptomology as well

as the need for administering screens routinely is therefore important. Diagnostic accuracy can also improve affected individuals' treatment and therefore their quality of life.

### **Theoretical implications of my systematic literature review**

The studies identified for the systematic literature review used a wide range of ADHD assessment methods, recruitment strategies and inclusion criteria. This variability precluded me from conducting a meta-analysis that would have resulted in a valid prevalence estimate for the psychiatric population. The reviewed studies based their ADHD diagnostic criteria on the Diagnostic and Statistical Manual of Mental Disorder (DSM; American Psychiatric Association, 1980, 2000, 2013), which was updated twice in the period during which these studies were published. Comparing prevalence rates based on different diagnostic criteria without adjusting them for the changes will not result in a valid prevalence rate. However, more research into how the changed diagnostic criteria affect the diagnostic rates would be needed first.

Future research should attempt to standardise ADHD assessments and/or follow assessment recommendations including a self-report measure, structured clinical interview and a functional impairment measure (Katzman et al., 2017; Kooij et al., 2010). This, however, could prove logistically difficult for research with large samples as it is a time consuming and therefore expensive process.

Varying inclusion and exclusion criteria with regards to psychiatric comorbidities were other factors that prevented a firm conclusion about prevalence rates in my review. Trends could be observed for certain psychiatric conditions (e.g. bipolar and psychotic disorder) seemingly increasing the prevalence rates if the sample included a high rate of these diagnoses. It would be challenging for research to include only one psychiatric disorder because of the high comorbidity rates among psychiatric disorders, as well as ADHD and other disorders. Over half of ADHD

positive participants were found to have two or more comorbidities (Ohnishi et al., 2019; Valsecchi et al., 2018).

More attention is required on the diagnosis of psychiatric comorbidities and how these impact on the ADHD prevalence rates. Overlapping symptomology between ADHD and other disorders can make accurate diagnosis challenging (Katzman & Sternat, 2014) and this should be at least acknowledged in research methods.

## **Reflections**

There are several reasons why I decided to conduct my empirical study in autism spectrum condition. I had very little experience in working with autistic adults when I started my adult mental health placement in my first year of training. One of the individuals I was allocated to work with was a gentleman in his fifties diagnosed with Bipolar Disorder (BD) who was also a voice hearer. During the assessment phase of our work together, many of the difficulties he reported did not appear to fit BD and our formulation grew as time went on. We discovered that he had been in several accidents and he scored well above threshold on a trauma screening tool.

Within this developing formulation, I had a feeling that he struggled with sensory issues and found interpersonal interactions challenging because he was not able to read non-verbal communication, which had caused difficulties in several jobs. All this information was pointing in the direction of autism and he agreed to an assessment: my hunch was proven right. My placement finished just as we had completed the assessment. I amalgamated all the information in a formulation with a diagram, explaining how his difficulties interacted, I spoke with his wife, support worker and care co-ordinator to explain it to them... and nothing changed with regards to his care, everything continued as was. It felt as if I had opened a Pandora's box for this person and then left him to deal with the consequences.

There are many reasons why I still wonder about this person: he had been under the Community Mental Health Team (CMHT) for years and nobody had recognised the signs for trauma or autism. When I liaised with the professionals involved in his care, seemingly nothing was taken on board – or perhaps it was a matter of not knowing what to do with the information, or being so overstretched as a service that changes were impossible to implement even if they were willing, which was something research has found to be the case (Lipinski et al., 2019). Due to a lack of training in identifying autistic individuals in the CMHT and understanding how autism might affect a person, individuals miss out on optimal care. I gave this gentleman additional labels and no way of helping him (and his wife) to assimilate the information. I now know how crucial post-diagnostic support is for individuals on their journey of getting to understand themselves in an autism context, in developing a positive autism identity, which can contribute to emotional wellbeing. I would like to think that I would approach the same piece of work differently now, particularly if I had more time.

Conducting a study on the motivation for seeking an autism diagnosis in middle age has opened my eyes to the process my participants went through on their diagnostic journey, what had been helpful and what they found challenging. This has no doubt changed the way I think about autism. One of my anxieties for the interviews was if I would be able to adapt my communication to hold a conversation about their experience. I had written direct, clear questions as prompts for myself because I was aware that open vague questions could be difficult to answer for autistic individuals. What I found during the interviews, was that the participants were all extremely eloquent and very willing to talk about their experiences. I only remember a couple of situations when something I said was misinterpreted in line with communication deficits in autism.



For the most part, talking to my participants using basic counselling skills such as active listening, summarising and reflecting back worked well to conduct the interviews. Participants were comfortable to ask for clarification when my questions were not clear, and the formality of their language decreased as the interviews progressed. I would like to think that this was based on my respectful and non-judgemental approach. I was surprised how emotional parts of the interviews were: participants became tearful at times, but we also shared laughs. I had expected more of a divide between the autistic participants and the neurotypical researcher I am; what seemed to take over, however, was a common humanity. I felt an emotional connection to my participants, empathised with many experiences they described outside of autism. I had to remind myself of the interview purpose in most conversations because this connection could have easily led to a chat about life in general.

I was humbled by their openness and the topics they approached. All of them reported extremely difficult experiences and stated that these were the reason they participated in my research: they hoped that my study would help others on their diagnostic journey: *“I will jump on any research because I don't want that kids that are probably seen as weird now to have to go through all the shit I've [gone through]”* (Jenny). It felt as if they placed a lot of hope in my research, that it would improve the service autistic individuals receive. I really hope that I will be able to honour by translating my findings into clinically relevant information.

I have learnt a great deal writing the literature review. Three “false starts” with other topics meant I was fairly fluent in the “how to” of conducting a literature search, exporting and sorting the results. Knowing what I know now (things to avoid, searches to conduct before the “real thing”) would have saved me a lot of time. Dissecting the studies included in the review

made me realise that not all research published in peer-reviewed journals is flawless. As a result, I take better care of how and who I quote in my own work.

Conducting a systematic literature review on ADHD brought up an interesting dilemma. If someone were to ask me what the difference between psychiatrists and psychologists is, I would probably explain to them that the former deal in diagnoses and medication and the latter explain a person's difficulties by establishing a formulation before deciding on an intervention together. And yet, above are two articles about accessing diagnostic assessments, and the fact that both ADHD and autism are currently underdiagnosed in adults. Also, for individuals with certain psychiatric disorders comorbid with ADHD, taking medication for ADHD has been found to be beneficial not only for ADHD symptoms, but also for the psychological distress the comorbid psychiatric disorders cause (Katzman et al., 2017). This highlighted to me that being a scientist practitioner and following evidence-based practice can and should involve medication when indicated. On a pragmatic level, this means a good working relationship with the psychiatrist in the service you work is a necessity. A further realisation arose from writing the review: I would not normally speak in terms of "psychiatric diagnoses" and "deficits" or even "patients". However, this is the language used in scientific journals, even if writing in this style almost felt against my nature at first.

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# Appendices

## Appendix 1: Ethical Approval

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### Previously approved applicaitons and amendments

Project	PI	Study End Date	Use as template	Amend
<b>Approved Ethics Applications</b>				
<a href="#">2019-16600 Why now? Why middle-aged individuals seek an Autism Spectrum Conditions (ASC) diagnosis. A thematic analysis of experiences of individuals seeking an autism diagnosis in adulthood.</a>	Gerhand, Mrs Sina	30 Jun 2020	Create a new application based on this project	Apply for an amendment to this project
<b>Approved Amendments</b>				
No approved amendments found				

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**Sent:** 20 November 2019 08:41

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**Subject:** IRAS Project ID 269239. Blank email template

Dear Dr Moseley,

<b>Study title:</b>	<b>Why now? Why middle-aged individuals seek an Autism Spectrum Conditions (ASC) diagnosis in a new Autism Service. A thematic analysis of experiences of individuals seeking an autism diagnosis in adulthood.</b>
<b>IRAS project ID:</b>	<b>269239</b>

I am in the process of both validating and assessing your study and can confirm that REC review and HRA Assessment is not required due to the lack of NHS involvement in the study i.e. no involvement on NHS sites and participants are being recruited via a job centre so are not deemed NHS patients.

I will go ahead and withdraw your study.

The HRA have developed a helpful tool to help applicants decide what approvals (if any) are needed which you may find helpful:

<http://www.hra-decisiontools.org.uk/ethics/>

<http://www.hra-decisiontools.org.uk/research/>

Please do not hesitate to contact me should you have any queries.

Kind regards,

**Hayley Henderson**

**Approvals Manager**

## *Appendix 2: Interview schedule*

### **Interview schedule: What motivates adult individuals to seek an autism diagnosis?**

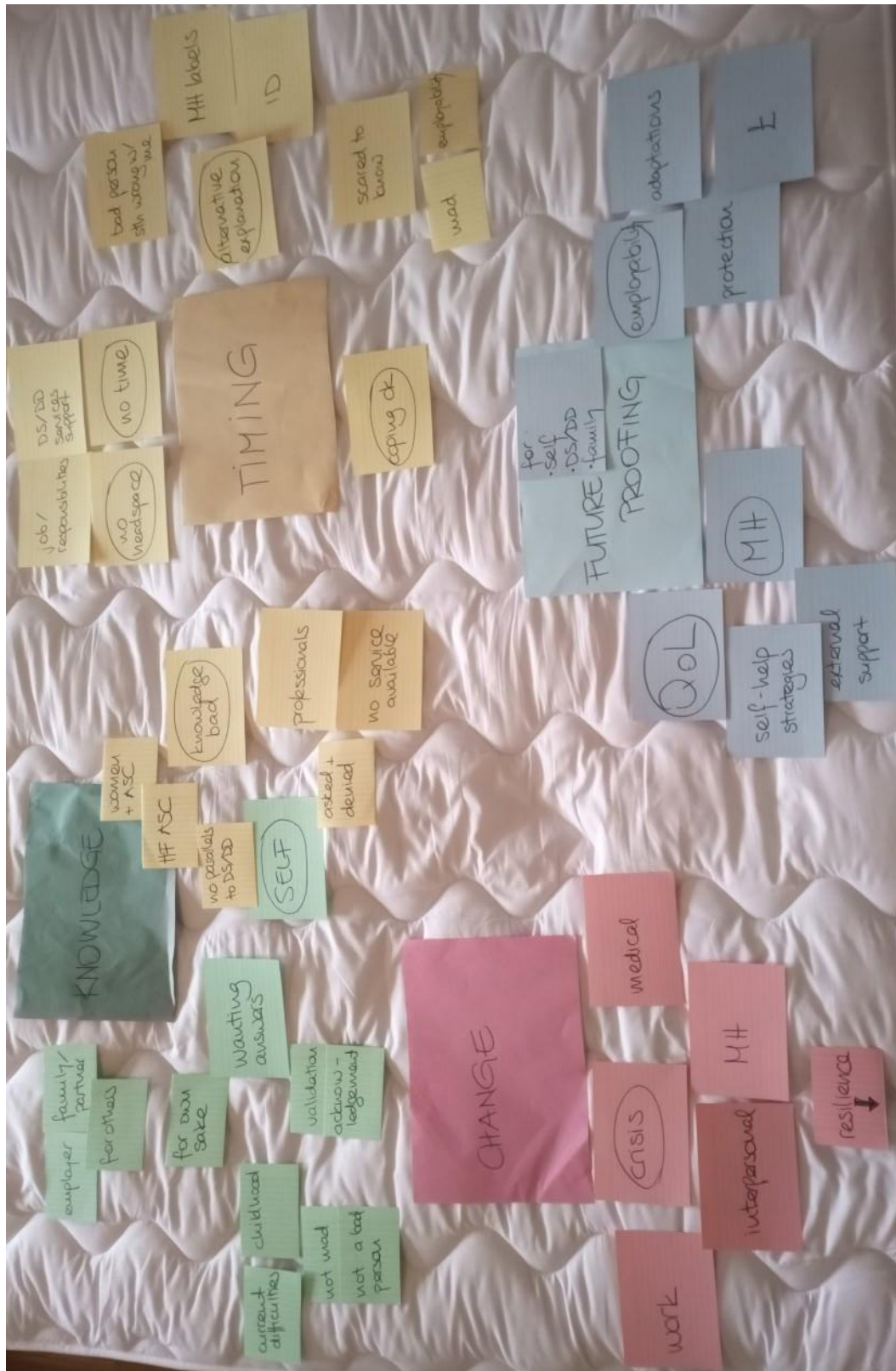
1. Demographics
  - a. Age
  - b. Age at diagnosis
  - c. Referral source
  - d. Profession
  - e. Employment
  - f. First language
  - g. Relationship / family?
2. When did you first think about seeking a diagnosis?
3. How long had you had suspicions that you might have autism? Based on what?
4. Why now? What made you agree to the referral to IAS?
  - a. What events/situations made you seek an assessment?
  - b. Did anything specific happen before deciding to seek diagnosis?
5. If delay: what made you hesitate?
6. What were you hoping to achieve with the assessment?
7. Do you have any past experiences of mental health (with or without service involvement)?
8. What hopes did you have for the service in general? Hopes met?



*Appendix 3: Example of coding in progress for research question “why now?”*

Participant.Line	Codes	2 <sup>nd</sup> order codes
1.354 I would say possibly yes, but she does not feel the need at this moment in time that she's struggling enough to go and and and and get a diagnosis. As neither did I for a while.	not struggling enough, doesn't feel the need	Only if struggling
1.355 I sussed it a little bit "Haha, oh yeah, hahaha, tsss, fancy that!" and carried on... erm.. it was only as I learned more.... cause I was already autism campaigning cause of my son, it was only as I learned more and I read more that I think... actually I can't ignore this any more, I can't just go "oh, haha, yeah that's interesting haha, fancy that!" about... this is too much, there's too much going on here	Campaigning for autism, getting more informed, recognising self more and more => too much to ignore	Increased knowledge Too many traits to ignore
1.363 I was trying to find out more about what [son]'s future might look like. So I am looking at him as an adult now. He was still a child then. but I'm thinking: what's life like for an autistic adult like [son]? So I'm starting to look at that. and then "you know, actually, you know what, that's my life! My autistic adult life I'm looking at, that's me!	Looking into adult autism, planning ahead for DS's future: that's me, my life;	Increased knowledge Future proofing DS's life Others seeing traits
1.376 everybody else had sussed that. In fact when I first started going through the Axia.. or looking - hoping to go down the Axia route, Axia sent me a form with questions and things on and erm... I thought I'll I'll I'll do this properly and I set.. I had a little folder on my desktop and it was called "Is [petname] autistic?" and now, I was putting all my little bits of work in there and everything. And my son saw it and erm... see, he has to be supervised using the computer... my son saw it and said: "What's that?" I said: "oh, it's what it says. Says it: is [petname] autistic?" and then: "you hadn't worked that out yet?!" (laughing)	Everyone else had recognised ASC in me but me	Others seeing traits
1.656 I was looking after my... I was a fulltime carer for my father for 18 years and I looked after another older person after my dad died. For a couple of years. And it was after all that had finished... my [wife] noticed, she said: "when you stopped being a carer, that's when your mask came down. Almost over night. and you suddenly became much more autistic. I hadn't even thought about you being autistic".	Long-time carer – deaths: mask came down; wife: you became more autistic when it was never obvious before	Change Time on hand Increased traits: MH? Grief? Loss?
1.668 wow, she really saw me struggling. She saw me struggling towards the end of caring, but particularly once ... once I wasn't caring any more...I guess there was a big space....	Big space (after caring role ended), time to think	Time / space / energy available Change / Loss of role
1.677[wife] was concerned, [wife] had seen me melt down a few times, and I'd not done that for a long time. I'd done that a handful, quite a long period of time, in public at least	Wife saw my meltdowns	Impact on others
1.684 You know, I hurt myself quite a lot (miming slapping both hands over ears) ARGH! and headbutting the wall cause I just can't deal with the frustration and the rage anymore. erm, and I don't want her to see that. I don't. I don't... that's, that's, that's shit. That's a shit thing. Saying autistic people don't connect... we connect! I don't want people I care about seeing me do that! Would I want somebody I care about do that? Would I hell!! That would, that would, that would be distressing! Jesus, that's distressing!	Don't want my wife to see my meltdowns, it's shit	Impact on others

Appendix 4: Early theme map



*Appendix 5: Collection of quotes for subtheme “autism awareness” (not exhaustive)*

Participant.Line	Quote
Donald.360	It was only as I learned more.... cause I was already autism campaigning cause of my son, it was only as I learned more and I read more that I think... actually I can't ignore this anymore, I can't just go "oh, haha, yeah that's interesting haha, fancy that!" about... this is too much, there's too much going on here and I'm recognising more erm.. and especially as I was trying to find out more about what [son]'s future might look like. So I am looking at him as an adult now. He was still a child then. but I'm thinking: what's life like for an autistic adult like [son]? So I'm starting to look at that. and then "you know, actually, you know what, that's my life!
Derek.422	When your child is diagnosed, you question why, where does this come from? Has it come from his mum? Has it come from me? ... didn't really understand a lot about autism erm... it's only when I saw the patterns in him that do... I remember that time... ... the rages that he gets where he can't express himself and he gets into a rage and he can't understand why other people can't see things from his point of view. I remember that clearly as a teenager. I think all teenagers are like that to an extent... but this is a.... this is heightened
Gloria.41	It was while we were answering the questionnaires for my 15 year old erm I just keep thinking: "oh, that's me! oh, that's me!" and (unintelligible) "oh, that's you! that's you!"
Maddie.85	so I started home educating and started meeting other people and then a person turned around to me and went "you're using the techniques that erm... I've been told to use by the autism team when you are managing your children". and erm, it kind of like planted a seed and then all of a sudden, I started connecting all the different dots, the different things
Marion.184	I thought woah! and something went bing! (laughs) and I started looking into erm autism... as well as other things on there (diagram in book). So I'm thinking what/where ...erm could I be here, because it seemed to link in. It it just pinged in me. And erm the more I looked into it, the more I thought: yeah, I can relate to all of this
Jenny.74	oh my god, oh my god, oh my god! it was like everything just like, you know, THAT's why everything doesn't fit the criteria for borderline personality, THAT's why I didn't fit bipolar, THAT's why it's NOT just depression, NOT just anxiety, that's why
Gladys.248	the way I behaved and all these things over a period of time builds up in combination with (...) when I look back on my childhood, there was lots of different things, but not ONE, I don't really remember one breakthrough moment
Adam.630	A: I knew I would have to do something at some point... but there was always constant reminders when I was at home ... erm... I: could you tell me a bit more about that? A: erm, just because of my reclusiveness, not being able to because I wasn't in this forced environment as I was with my career not that I hated it or anything I love it, but.I wouldn't socialise and I had no interest in socialising.

## Appendix 6: Modifications in CBT for Autism



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Modifications in CBT for Autism. v1	
<b>Communication: Verbal</b>	Literality, <i>faux-pas</i> , non-verbal differences, one-sided conversations, details at expense of theme, hyper-focus slows verbal processing.
	1. Explicit, crystal clear, assumption free communication and goals
	2. Say what you mean - mean what you say; no jokes, sarcasm, hints
	3. Say one thing at a time – be concise
	4. Slow pace - give time to process and respond (deep processing)
	5. Encourage person to TELL YOU
	6. Check shared understanding
	7. Write down bullet points, summaries, ideas
<b>Communication: Visual</b>	8. Social Stories (descriptive, perspective, affirmative, instructional statements) for a situation & generally use this clear style
	Visual minds - or other thinking mode differences
	1. Share Mind Maps / spider diagrams
	2. Encourage doodles / illustrations or pictures
	3. Consider visual processing issues - font size / colour
	4. Co-produce Comic Strip conversation: stick figures, speech bubbles, thought clouds;
<b>Cognitive processing</b>	5. Observe their behaviour: what are they trying to convey? Check out.
	6. Show / model / demonstrate
	Differences in attention, social processing; tendency to completion, constant “doing mind”, worry, rigidity, black and white thinking; difficulties with initiating, inhibiting, planning, transitioning / switching.
	1. Provide information about unwritten “NT” social rules / perspectives
	2. Ensure they are focused – use their NAME; minimise distractions
	3. Assist moving focus from specific to more general rules / summarising step by step (not all at once) – take your time!
	4. Observe and contain systemizing / hyperfocus
	5. Timelines – build up individual “snapshots” towards coherent whole
	6. Help consider alternative perspectives / dialectics – step by step with illustrations and concrete examples; consider validation AND radical acceptance “it’s just like that” – often strong capacity for this.
	7. Identify cognitions / schemas / thinking patterns and use concrete examples / visualization and step by step exploration / rationally consider alternative adaptive cognitions (use more REBT style than Socratic approach) – be pragmatic / solution driven
	8. Preparation cue for / start / stop / change

	9. Skills to reduce worry e.g. Mindfulness / “STOP”
	10. Planning / routine / lists / reminders
<b>Emotional processing</b>	High emotional reactivity but struggle with emotional understanding
	1. Never assume emotional experience – always check
	2. Emotional labelling: establish trigger, physiological change / body maps, thinking and behavioural responses, elicit examples
	3. Emotional modulation: similarly, establish range and degrees, visual analogies e.g. thermometer scale, rev counter etc.
	4. Emotional reactivity / dysregulation: use Emotional Regulation / Distress Tolerance skills as needed (DBT skills); beware of therapist emotional communication and affects (slow, calm, step by step)
	5. Beware of strong emotional empathy vs different social empathy; hypersensitive to emotional atmospheres / other’s distress
<b>Sensory Processing</b>	Sensory processing / integration differences can lead to physiological and emotional distress and exhaustion; hyper and hypo sensitivity effects.
	1. Consider the environment: noise, lighting, heat, need for breaks
	2. Consider / encourage need to “Stym” / soothe – (can look like OCD) – only limit set / divert when it becomes a problem to them / co-habitees
	3. Energy accounting – observe, monitor and manage sensory (and emotional) accumulation
	4. Check interoception effects e.g. poor awareness of hunger (ED), poor self-monitoring / self-care and unusual sensory integration effects
<b>Use of psychometrics, understanding symptoms, clinical decisions</b>	Use psychometrics with care, consider Autistic compensatory effects in mental health formulation
	1. Check questionnaire responses with concrete examples
	2. Anxiety can be hidden in plain sight as it is a lifelong “trait” i.e. anxiety=normal, so check descriptions of effects
	3. Depression can be more about exhaustion / overwhelmed / over stimulated – check
	4. OCD – may be more about Stymming / fixed interest / sensory coping rather than “neutralizing” effects - ED and other repetitive conditions may be similar – formulate accordingly
	5. “Psychosis” – can be related to attempts to make sense of things i.e. self instruction, reference to memes, “filling the gaps” in narrative coherence (can be misattributed as “lying”) efforts can be stressful and lead to dysregulation / distressing experiences
	6. Explore compensatory effects: masking / camouflaging / assimilating effortful and stressful; differing between session presentations
	7. Don’t assume traumas have to be processed – differences in habituation / narrative memory / resolution / acceptance
	8. Caution on “treatment”; focus more on coping skills, problem solving, self-care, validation and celebration of Autistic minds and strengths, and finding social and vocational niche

## *Appendix 7: Word count statement*

Thesis Abstract: 238

### **Chapter 1 – Literature Review**

Abstract: 131

Main text (excluding abstract, highlights and keywords, tables, figures and references): 5611

Tables, figures and references: 3112

### **Chapter 2 – Empirical Paper**

Abstract: 117

Main text (excluding tables, figures and references): 7717

Tables, figures and references: 1400

### **Chapter 3 – Contributions to Theory and Clinical Practice**

Main text (excluding references): 3868

References: 1048

Appendices: 2467

### **Overall Thesis**

Total word count (excluding tables, figures, references and appendices): 18,451

Total word count of tables, figures, references and appendices: 8033

Total thesis word count (including acknowledgements, dedication, declaration, table of contents, thesis abstract, title pages, tables, figures, references, and appendices): 26,484