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Exploring the Experiences, Views and Perceptions of Adults on the Autism Spectrum

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A thesis submitted in partial fulfilment of the requirements for the
degree of

Doctor of Clinical Psychology

Coventry University, Faculty of Health and Life Sciences

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List of Abbreviations

AS	Autism Spectrum
APA	American Psychological Association
UK	United Kingdom
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
CAF	Critical Appraisal Framework
USA	United States of America
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
CRHT	Crisis Resolution and Home Treatment Team
CBT	Cognitive Behavioural Therapy
ACT	Acceptance and Commitment Therapy
ABA	Applied Behaviour Analysis

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- N Example Extracts from Coded Transcripts
- O Photos from Stages of Data Analysis
- P Gibbs' (1988) Model of Reflection

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Declaration

This thesis is an original piece of my own work, that has been submitted as part of the fulfilment of requirements for the degree of Doctor in Clinical Psychology, to the Universities of Coventry and Warwick. The work included in this thesis has not been submitted for any other qualification or to any other institution. Emergent findings from the empirical paper will be presented as a poster presentation at the University of Warwick Postgraduate Research Conference and Coventry University's Faculty of HLS Postgraduate Research Conference. The thesis was undertaken with the clinical and academic supervision of Ms Jacky Knibbs and Dr Magdalena Marczak, both of Coventry University. Except for the collaborations stated, all material presented within this thesis documents my own work. Both the literature review and empirical paper were written for submission to the journal Autism.

Summary

The first chapter of this thesis contains a review of existing literature regarding the views, perceptions and experiences of autistic females. Whilst it is recognised that the autism phenotype is altered for females, there is limited research exploring the lived experiences of autistic women. A systematic search was conducted, and a meta-ethnographic method was adopted. Two meta-themes regarding autistic females' experiences of accessing healthcare, education, employment and relationships were identified. This review identified gender specific challenges and offered insights into the impact of autism on gender identity. Clinical and research implications of the findings are discussed.

Chapter two presents a qualitative exploration of autistic adults' experiences of low mood and depression. An interpretative phenomenological approach was adopted to explore the experiences of eight adults (aged 19 to 51) who had a diagnosis of autism and experienced low mood or depression. Emergent findings highlighted factors that contribute to and maintain negative affect for this population. Clinical implications regarding these findings are discussed alongside recommendations for future research.

Within chapter three, a first-person reflective account of conducting the research contained within this thesis is presented. The author reflected on their motivations for researching autism and low mood, ethical and methodological considerations and the impact of this research on them as a clinician and a researcher.

Recommendations for adapting qualitative research when exploring the lived experience of autistic adults are discussed.

Overall word count: 18,890

Chapter One

Experiences, perceptions and views of females on the autism spectrum: A meta-ethnographic review

This chapter was prepared for submission to the journal Autism. Appendix A provides detailed author guidelines for submission to this journal. The word count for this chapter, excluding abstract, footnotes, figures, tables and references, is 7,545.

1.0 Abstract

It is recognised that the experiences of autistic women are underrepresented in the literature. The aim of this systematic review was to explore the experiences, views and perceptions of females on the autism spectrum, across all domains of life. A meta-ethnographic method was used to systematically extract and synthesise findings from studies that had qualitatively explored the experiences of women on the autism spectrum. A total of five electronic databases were searched, and thirteen studies were identified for analysis. Two meta-themes were identified: '*Wearing a mask*' and '*Who am I?*'. Various experiences that contributed to these themes, including being misunderstood and dismissed by others, receiving a diagnosis and attempting to conform to societal norms are explored and discussed. Emergent findings indicated that women with autism experience several gender specific challenges. Clinical and research implications are considered to improve the experiences and well-being of women who are on the autism spectrum.

Key words: Autism, autism spectrum condition, women, females, experiences, meta-ethnography

Abstract word count: 150

1.1 Introduction

This review examines the experiences, perceptions and views of females who are on the autism spectrum (AS), across all domains of life. The AS encompasses neurodevelopmental conditions characterised by social communication challenges and restricted patterns of behaviour, interests or activities (American Psychiatric Association, 2013). Approximately one percent of people living in the United Kingdom (UK) are affected by autism spectrum conditions¹ (ASC; Brugha et al., 2016), and ASC is diagnosed four times more often in males than females (American Psychiatric Association, 2013).

Autism is a lifelong condition which contributes to significant challenges across the lifespan (Hedley et al., 2016). Individuals with autism² have high rates of unemployment (Howlin & Moss, 2012), are often in low paying jobs below their level of education (Holwerda, Van Der Klink, Groothoff & Brouwer, 2012) and are more likely to experience co-morbid mental health difficulties compared to the general population (Smirnoff et al., 2008; Kanne, Christ & Reiersen, 2009). Furthermore, research indicates that adults with autism face limited resources and pervasive barriers when attempting to access healthcare services (Turcotte, Mathew, Shea, Brusilovskiy & Nonnemacher, 2016; Nicolaidis et al., 2013). A timely diagnosis of autism can improve access to services, reduce self-criticism and judgement from others, and increase positive self-identity (Ruiz, Pistrang & Mandy, 2012; Wong et al., 2015).

Evidence suggests that the autism phenotype is altered for females. Reported differences include a greater interest in socialisation, a broader behavioural repertoire and interests that are more in line with social and gender norms (Kirkovski, Enticott & Fitzgerald, 2013; Van Wijngaarden-Cremers et al., 2014).

¹ In line with the views of members of the autism community, and to be respectful of neurodiversity, the term ‘autism spectrum condition’ (ASC) is used as a synonym for the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) term ‘autism spectrum disorder’ (ASD). Furthermore, ‘ASC’ is used interchangeably with ‘autism’ and ‘autism spectrum’ throughout this review.

² There is no one preferred way to talk about autism, and there are different perspectives on the issue within the autism community. To be sensitive to this issue, identity-first language, such as ‘autistic person’, and person-first language, such as ‘person with autism’, is used interchangeably throughout this review.

Additionally, compared to males with ASC, autistic women consistently score lower on measures of stereotyped and repetitive behaviours, hyperactivity and impulsivity (Huke, Turk, Saeidi, Kent & Morgan, 2013; Sedgewick, Hill, Yates, Pickering & Pellicano, 2016; Van Wjingaarden-Cremers et al., 2014). Females also develop strategies to cope with social communication challenges, subsequently ‘camouflaging’ their difficulties (Attwood, 2007). Consequently, compared to males, females are more likely to receive their diagnosis later, be misdiagnosed, or never come to clinical attention (Rynkiewicz & Lucka, 2018; Lai & Baron-Cohen, 2015; Giarelli et al., 2010).

The gender bias has serious health implications; a higher incidence of mental health problems is reported for women and girls on the AS (Gould & Ashton-Smith, 2011; Baldwin & Costley, 2016). There is also evidence to suggest that females with autism are more vulnerable than males to developing internalising problems such as anxiety, depression and eating disorders (Mandy et al., 2012; Huke et al., 2013).

Qualitative research exploring the lived experiences of adults with autism is growing. DePape and Lindsay (2016) conducted a qualitative meta-synthesis of 33 articles to understand the experiences of autistic children, adolescents and adults, across multiple areas of life. Four themes emerged from and were discussed in this review: 1) perception of self, 2) interactions with others, 3) experiences at school and 4) factors relating to employment. However, DePape and Lindsay’s (2016) findings were based mostly on the perspective of males with ASC. They concluded that future research should examine the experiences and perceptions of those living with ASC and how these vary depending on various socio-demographic factors, including gender.

Hayward, McVilly and Stokes (2016) conducted a review to synthesise what is known about the experiences of women with autism within the workplace. Eleven studies were included in the review, and studies were not excluded if they did not necessarily focus on women. Key workplace challenges were reported to be communication, social interaction, stress and negative physical and mental health. It was concluded that some of the challenges for females with autism may be similar to those experiences of males. However, women represented a small number of total participants in this review, and only one paper differentiated female data in the

analyses. It is concluded that there may be gender-based differences that require further attention.

1.1.1 Rationale

Previously, autism research has been biased towards child populations and has focused on the perspectives of parents, siblings and healthcare providers, rather than those who live with the condition (DePape & Lindsay, 2016). Furthermore, as autism has been viewed as a predominantly male condition, research focusing specifically on females with ASC has been limited (Baldwin & Costley, 2016). Previous literature reviews examining the lived experience of individuals with autism have drawn conclusions from a predominantly male perspective (DePape & Lindsay, 2016; Hayward et al., 2016). A recent increase in qualitative research in this field has changed the focus of enquiry to include exploration of women's experiences of autism. As such, a qualitative synthesis has the potential to provide a more nuanced and contextualised understanding and contribute to policy, practice and decision-making.

Meta-ethnography is a developed method of synthesis that involves induction and interpretation, thus resembling the qualitative methodology of the studies that are being synthesised (Britten et al., 2002). The inclusion of participant findings and authors' interpretations in the analysis allows for a rich synthesis that develops new interpretations and insights (Campbell et al., 2003; Atkins et al., 2008). Meta-ethnography was therefore chosen for this review.

1.1.2 Aim

This meta-ethnographic review aims to synthesise and integrate qualitative research regarding the lived experiences, perceptions and views of females who are on the autism spectrum, to answer the research question: "What are the lived experiences, views and perceptions of females with ASC across all areas of life?"

1.2 Methods

1.2.1 Systematic Literature search

Ethical approval for this review was obtained from Coventry University Ethics Committee (Appendix B).

1.2.1.1 Search strategy

A systematic search of the literature, for studies that had qualitatively explored the experiences of females with autism, was conducted in December 2018. This search was completed by the lead researcher. Prior to the search being conducted, a qualified librarian was consulted regarding the use of appropriate databases. PsychInfo, MEDLINE (OVID), EMBASE, CINAHL and Scopus databases were selected and systematically searched for published articles. The reference lists of all included articles were subsequently searched by hand. Additionally, the ‘cited by’ function on Google Scholar was used to forward search for articles that may have been missed during the database search. No date limit was set for the beginning point of the search.

1.2.1.2 Search terms

Search terms were identified according to the aims of this review and were informed by previous reviews on the topic (DePape & Lindsay, 2016; Hayward et al., 2016). A Boolean search strategy was used to identify relevant articles; an overview of the key search terms and synonyms used are included in Table 1.1. Search terms were truncated to capture all variations of the words.

Table 1.1 *Search terms, truncation and Boolean operators.*

Category	Main term	Synonyms	Location
Population	Autism	Autis* Autism Spectrum Disorder /ASD Autism Spectrum Condition/ASC Asperger*	Title Abstract
	Women	Wom?n Female* Girl*	Title Abstract
Outcome	Experiences	Lived experience Perception* Perspective* View*	Title Abstract
Design	Qualitative	Ethnography Phenomenology Interpretative phenomenological Analysis/IPA Grounded theory	Title Abstract

1.2.2 Inclusion and exclusion criteria

Articles published in English were included if they were (a) empirical studies (b) peer reviewed (c) of qualitative or mixed-methods design (d) reporting on the experiences, views or perceptions of females (aged 13+) with a primary diagnosis of ASC (e) female experiences, views and perceptions were differentiated from male experiences, views and perceptions. Full inclusion and exclusion criteria are included in Table 1.2.

Table 1.2 *Inclusion and exclusion criteria*

Criteria	Inclusion	Exclusion
Language	English	Articles not published in English
Design	Empirical research articles	Non-empirical articles, including literature reviews and editorials
	Peer reviewed articles	Grey literature
Epistemology	Qualitative Mixed methods	Quantitative
Age	13 years of age and over	12 years of age and under
Diagnosis	Primary diagnosis of ASC	No participants with a primary diagnosis of ASC included
	Diagnosis can include co-occurring symptoms (i.e. cognitive impairment)	
Gender	Female	Male only, or male accounts are not distinguishable from female accounts

1.2.3 Study identification

The process of study selection was recorded using the ‘Preferred Reporting Items for Systematic Reviews and Meta-analyses’ (PRISMA) flow diagram (Figure 1).

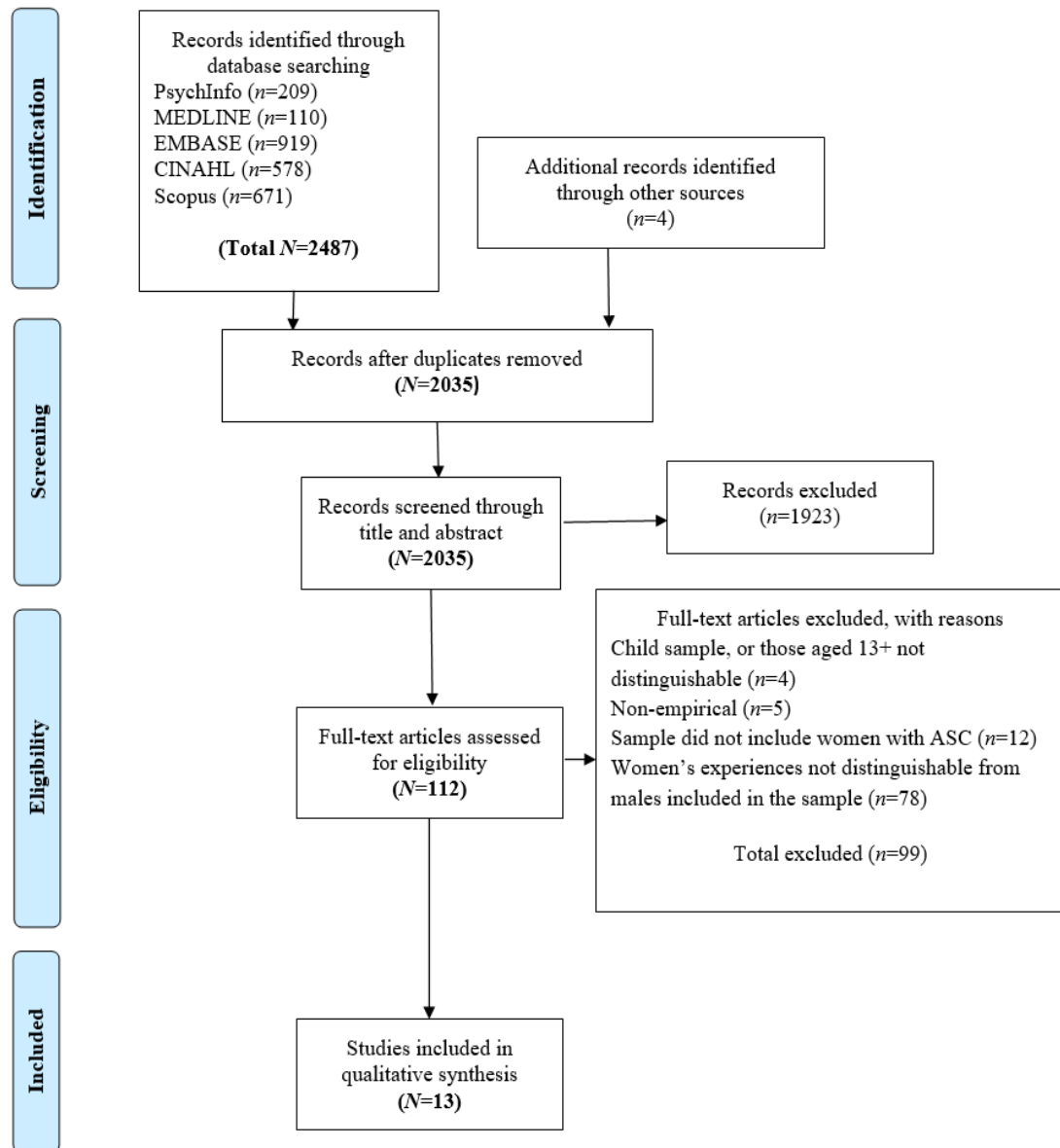


Figure 1.1 ‘Preferred Reporting Items for Systematic Reviews and Meta-analyses’ (PRISMA) flow diagram (Moher, Liberati, Tetzlaff, Altman, & The PRISMA group, 2009)

Following a search of electronic databases 2487 articles were identified. A further 4 records were identified through hand searching references and using the cited by function on Google Scholar. Following the initial search 456 duplicates were removed. Subsequently, 2035 article titles and abstracts were screened, and 1923 records were removed as they were not relevant to the topic. One hundred and twelve remaining articles were retrieved in full and reviewed for potential inclusion. In line with the exclusion criteria, 99 articles were removed (see Figure 1.1 for

reasons). Thirteen articles satisfied the inclusion criteria and were identified for quality appraisal.

1.2.4 Quality appraisal

Quality appraisal is the process of assessing the validity of research evidence before using it to inform a decision. Caldwell, Henshaw and Taylor's (2005) Critical Appraisal Framework (CAF) was used to assess the quality of the thirteen studies identified for inclusion in this review. This framework was chosen as it is a suitable tool to appraise both qualitative and quantitative methodologies and is frequently used in health and clinical psychology (Caldwell, Henshaw & Taylor, 2011). Papers were assessed against different criteria depending on their design; those with mixed methods were assessed against thirty criteria, whilst qualitative studies were assessed against nineteen that were applicable to that design (Appendix C). For each question, a paper scored 0 if the criteria were not met, 1 if the criteria were partially met and 2 if the criteria were fully met. The raw scores for each paper were converted into a percentage score (Table 1.3).

1.2.4.1 Quality checks

The overall quality of the studies included in this review was good, with percentages ranging from 71% to 95%. All studies were conducted by credible authors, included comprehensive literature reviews and clearly described their methodologies. Studies did not always adequately report on ethical issues, authors' philosophical background or impact of their relationship with participants and the research, but it is plausible that this information was missing due to the word constraints in peer reviewed journals.

No studies were excluded based on the quality assessment. The CAF was used to inform discussion around the studies rather than to exclude less rigorous articles, as less well conducted studies may still provide important new insights into a phenomenon (Dixon-Woods et al., 2007; Atkins et al., 2008). To enhance the rigour of the synthesis the results of the quality appraisal are available for the reader (Appendix C; Lachal, Revah-Levy, Orri & Moro, 2017).

1.2.4.2 Reliability checks

To enhance the reliability of the quality assessment a second researcher independently rated 100% of the articles identified for inclusion in this review. Inter-rater reliability analysis was conducted using the Kappa coefficient (Cohen, 1960). Scores ranged from .62 to 1.00 for each of the thirteen studies (Table 1.3). The overall Kappa score was .85 ($p < 0.001$) indicating good inter-rater reliability (Appendix D).

1.2.5 Method for synthesis of the studies

As qualitative research has become more commonplace, methods for synthesising the findings of individual studies have developed (Jones, 2004; Britten et al., 2002). Meta-ethnography is a method that is often used in health and social care research (Atkins et al., 2008) that aims to synthesise qualitative research findings into a whole that is greater than the sum of the original parts (Noblit & Hare, 1988). A meta-ethnographic approach was adopted for this review and was guided by Noblit and Hare's (1988) seven phases (Appendix E). To begin, the lead researcher read and re-read the thirteen articles to familiarise with the content and begin extracting metaphors or emerging themes from each study. Data were extracted across the full primary studies, rather than from the findings alone. This was to ensure that conceptual data that occurred throughout the studies could be found, and the context of the data was retained (France et al., 2019). At this stage, both first order constructs, including participant quotes, and second order constructs, such as concepts developed by authors, were extracted. Moreover, to preserve the meaning of, and relationships between concepts within individual studies, a record of the author's interpretations were kept regarding women's experiences and their impact.

To determine how the individual studies were related, and to translate the studies into one another, common and recurring themes were identified across studies. To achieve this, studies were arranged in date order, and themes and concepts within paper 1 were compared with those found in paper 2. The resulting synthesis was then compared and revised considering paper 3. This process of reciprocal translation was repeated until third order concepts were derived from all 13 studies (Noblit & Hare, 1988). Three reviewers then worked together to finalise the meta-themes that are presented within this review.

1.3 Results

1.3.1 *Characteristics of the literature*

Table 1.3 provides an overview of the characteristics of the studies included in this review. The studies had a variety of aims, but all reported qualitative findings regarding the experiences, views or perceptions of females who are on the AS. All studies were published in peer reviewed journals between 2016 and 2018. Five of the studies were conducted in Australia (Baldwin & Costley, 2016; Hayward, McVilly & Stokes, 2018; Rogers, Lepherd, Ganguly & Jacob-Rogers, 2017; Vine Foggo & Webster, 2016; Webster & Garvis, 2017), four in the UK (Bargiela, Steward & Mandy, 2016; Kanfischer, Davies & Collins, 2017; Sedgewick, Crane, Hill & Pellicano, 2018; Steward, Crane, Roy, Remington & Pellicano, 2018), one in Canada (Tint & Weiss, 2018), two in the United States of America (USA; Gardner, Suplee, Bloch & Lecks, 2016; Haney & Cullen, 2017), and one in Ireland (Goodall & MacKenzie, 2018). Five studies conducted semi-structured interviews (Bargiela et al., 2016; Goodall & MacKenzie, 2018; Kanfischer et al., 2017; Rogers et al., 2017; Vine Foggo & Webster, 2016). One study conducted focus groups (Tint & Weiss, 2018), one study collected data via both phone interviews and email correspondence (Webster & Garvis, 2017), and one study conducted a secondary analysis of a qualitative dataset that evolved during the process of developing a research questionnaire (Gardner et al. 2016). Additionally, one study collected data from an online autism community website (Haney & Cullen, 2017). A further four studies used a mixed-methods approach (Baldwin & Costley, 2016; Hayward et al., 2017; Sedgewick et al., 2018; Steward et al., 2018). Three of the mixed methods papers used surveys with both open ended and closed questions, whilst one study collected data using standardised measures and a semi-structured interview (Sedgewick et al., 2018). One study included males and females (Hayward et al., 2018), whilst the other twelve studies included females only. All participants in the studies were aged 13-69. Sample sizes varied from 1-212 for qualitative studies, and 38-237 for those with mixed-methods. A range of data analysis methods were used to analyse the qualitative data; nine studies used thematic analysis, two studies used narrative analysis (Kanfischer et al., 2017; Webster & Garvis, 2017), one used a phenomenological approach (Haney & Cullen, 2017) and one used framework analysis (Bargiela et al., 2016).

Table 1.3 *Characteristics of included studies*

Author, year, location, Quality Rating (QR), Kappa coefficient (K)	Aim	Design and Sampling method	Sample characteristics	Data collection method and method of analysis	Main findings
Baldwin & Costley, 2016 Australia QR=83% K=.79	-To explore the lived experiences of females with ASC in the areas of health, education, employment, social and community activities.	Mixed methods Purposive sample	N=82 women with a diagnosis of autism Age range: 18-64 (M= 32.7, SD=12.3) ³	Survey Thematic analysis	Six themes were identified through thematic analysis of open comments: <ol style="list-style-type: none"> 1. Diagnosis and ASC symptomology <ul style="list-style-type: none"> -Belief that life would have been easier if diagnosis had been confirmed earlier -Difficulties with executive functioning -Difficulties in social understanding and communication 2. Health and mental health <ul style="list-style-type: none"> -Stress and anxiety are common and debilitating factors across all areas of life 3. Education <ul style="list-style-type: none"> -Inconsistent support mechanisms in education across ages and settings -Recognised as different by teachers but difficulties were still overlooked 4. Employment <ul style="list-style-type: none"> -“Pinned back” from fulfilling job and career potential -Skills unrecognised or de-valued in the workplace 5. Social experiences

³ Mean and standard deviation for sample age is included where available.

					-Need to learn how to interact in a way that is perceived as appropriate. 6. General support needs -On-going struggle to cope with everyday life -Lack of recognition
Bargiela, Steward & Mandy 2016 UK QR=92% K=.81	-To explore the female autism phenotype and its impact upon the under-recognition of ASC in girls and women	Qualitative Purposive sample	N=14 women diagnosed with ASC in late adolescence or adulthood Age range: 22-30 ($M=26.7$, $SD=2.3$)	Interviews (Face-to-face, videoconference and telephone) Framework analysis	Four themes were identified: 1. “You’re not autistic” -Autistic difficulties are ignored, misunderstood and dismissed by health professionals -Stereotypes delay diagnosis -Some capacity to socialise increases professional’s reluctance to diagnose 2. Pretending to be normal -Costs of pretending to be someone else -Confusion about own identity 3. Passive to assertive -Passivity leads to high risk situations -Victim of sexual abuse -Learning to be assertive 4. Forging an identity as a woman with ASC -Uncertainty and intensity in friendships -Interests define identity and self-confidence
Gardner, Suplee, Bloch & Lecks	-To explore the childbearing experiences of	Qualitative Purposive sample	N=8 women with a diagnosis of Asperger’s syndrome ⁴ and	Secondary analysis of a qualitative dataset which evolved from the	Four key themes were identified: 1. Processing sensations -Enhanced sensitivities

⁴ Although the diagnosis ‘Asperger’s syndrome’ no longer exists in the DSM-5, the term is included to represent the study samples included in this review, as described by their authors.

2016 USA QR=71% K=.89	women with ASC		childbearing experiences Age range: 27-52 (M=39)	development of a research questionnaire, which was designed to assess the childbearing experiences of women with Asperger's Thematic analysis	-Negative sensory experiences during pre-natal check-ups 2. Needing to have control -Birth experienced led to feeling out of control 3. Walking in the dark -Emotional attachment to the infant is delayed -High need for information -Difficulties with adult social interaction post-partum 4. Motherhood on my own terms -Parenting skills and decisions are judged by professionals and friends
Goodall & MacKenzie 2018 Ireland QR=79% K=1.00	-To understand the experiences of girls with ASC who attend mainstream schools	Qualitative Purposive sample	N=2 adolescent girls with a diagnosis of ASC Age range 16-17 (M=16.5)	Semi-structured face to face interviews Thematic analysis	Three themes were identified: 1. Educational experiences -Negative experiences of mainstream education contributing to feelings of exclusion 2. Impact on well-being -Chaos of secondary school is overwhelming -Hunger, fear and despair dominate the school day 3. Bullying and friendships -Bullying leads to social isolation and loneliness -Feeling hurt when excluded by friends 4. Inclusion -Support is needed for inclusion to be experienced in mainstream schools -Everyone should get a chance to be involved and have fun

<p>Haney & Cullen</p> <p>2017</p> <p>USA</p> <p>QR=95%</p> <p>K=.77</p>	<p>-To develop an understanding of how females with ASC describe their experiences</p>	<p>Qualitative</p> <p>Purposive sample</p>	<p>N=212 women with a diagnosis or self-diagnosis of ASC</p> <p>Age range: 18-50+</p>	<p>Content from an online autism community website</p> <p>Phenomenological thematic analysis</p>	<p>Four main themes were identified</p> <ol style="list-style-type: none"> 1. Impact of diagnosis <ul style="list-style-type: none"> -Difficulties and delays obtaining a diagnosis due to ability to cope with social challenges and mask symptoms -Misdiagnosed with mental health conditions -Reactions to receiving a diagnosis are mixed 2. Symptom discussion <ul style="list-style-type: none"> -Validation of symptoms such as meltdowns and sensory difficulties -Symptoms and challenges are normal components of having ASC 3. Impact of ASC on relationships <ul style="list-style-type: none"> -Platonic relationships with men are more comfortable than with women -Being judged by neurotypical women -Concerns about disclosing their diagnosis in platonic relationships -Dealing with own issues as well as partners issues is stressful -Dating is awkward -Preferring socialisation with like-minded people -Lack of shared interests is a catalyst for bullying -Reactions and perceptions of others make relationships difficult, not diagnostic characteristics 4. Impact of ASC on employment <ul style="list-style-type: none"> -Social demands and difficulties recognising social cues make employment stressful -Difficulties with schedules and staying organised
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<p>Hayward, McVilly & Stokes</p> <p>2018</p> <p>Australia</p> <p>QR=90%</p> <p>K=.90</p>	<p>-To ascertain the extent to which employment issues were a function of gender or autistic traits</p>	<p>Mixed methods</p> <p>Purposive sample</p>	<p>N=83</p> <p><i>n</i>=28 women with high autistic traits</p> <p>Age range: 18-60 (<i>M</i>=33.79, <i>SD</i>=11.09)</p> <p><i>n</i>=21 typically developing women</p> <p>Age range: 24-62 (<i>M</i>=37.81, <i>SD</i>=10.62)</p> <p><i>n</i>=18 men with high autistic traits</p> <p>Age range: 20-68 (<i>M</i>=46.17, <i>SD</i>=12.69)</p> <p><i>n</i>=16 typically developing men</p> <p>Age range: 23-61 (<i>M</i>=39.13, <i>SD</i>=10.20)</p>	<p>Survey</p> <p>Thematic analysis</p>	<p>Three main themes regarding employment for women with autism were identified</p> <ol style="list-style-type: none"> 1. Unfavourable employment history <ul style="list-style-type: none"> -Not fitting in or becoming the target of bullying -Negative experiences from management 2. Difficulty maintaining employment <ul style="list-style-type: none"> -Staying in a job means navigating complex interpersonal developments that are overwhelming 3. Unstable employment history <ul style="list-style-type: none"> -Difficulties gaining or maintaining work due to need to fit in with other people
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Kanfiszer, Davies & Collins 2017 UK QR=95% K=.64	-To enable the marginalised voice of women diagnosed with ASC in adulthood and answer the question “what are the lived experiences of women with ASC?”	Qualitative Purposive sample	N=7 women with diagnosis of ASC in adulthood Age range: 20-59	Semi-structured face-to-face interviews Narrative analysis	Two overarching categories emerged from broad questioning around life experiences: 1. Gender identity, which includes themes that reflect how the women developed a sense of self pre and post knowledge of their autism diagnosis -“I was just so different” -“I think there’s some sort of gender identity thing” -“I never had any mothering instincts” 2. Social relationships, which incorporates themes around interpersonal difficulties -“When I try, the conversation just goes dead” -“People didn’t want to know me”
Rogers, Lephed, Ganguly & Jacob-Rogers 2017 Australia QR=82% K=.86	-To explore the particular issues and experiences of birthing women who have ASC, through pregnancy, birth and early mothering	Qualitative Purposive sample	N=1 woman with a diagnosis of autism Age: 26	E-mail correspondence pre and post birth, and a semi-structured face-to-face interview post birth Thematic analysis	Three themes were identified: 1. Communication and service difficulties -Sense of the loss of independence -Interacting with hospital staff is stressful 2. Sensory stress -Compounding stress of one sensory experience after another -Hallucinations during pregnancy -Difficulties being touched by staff 3. Parenting challenges -Being overruled by healthcare staff -Feeling blamed by healthcare staff for having ASC -Medical professionals don’t understand ASC
Sedgewick, Crane, Hill & Pellicano	-To examine the differences in the social	Mixed methods	N=38	Semi-structured face to face interviews	Six subthemes related to friendships were identified by both neurotypical and autistic women 1. Friends provide emotional support

<p>2018</p> <p>UK</p> <p>QR=88%</p> <p>K=1.00</p>	<p>relationships of autistic women in relation to their neurotypical counterparts</p>	<p>Purposive sample</p>	<p>$n=19$ women with a diagnosis of ASC</p> <p>Age range: 20-50 ($M=30.3$, $SD=6.11$)</p> <p>$n=19$ neurotypical women</p> <p>Age range: 21-39 ($M=29.1$, $SD=4.74$)</p>	<p>Thematic analysis</p>	<ol style="list-style-type: none"> 2. True friends are people who let you be yourself 3. Relational conflict with people around you 4. Ending friendships to manage conflict 5. Relationships mature with age 6. Increase in relationship satisfaction from adolescence <p>Three subthemes relating to friendships were identified only by autistic women</p> <ol style="list-style-type: none"> 1. Friendship definition developed with age 1. Social ambivalence 2. Fewer more intense friendships <p>Two subthemes related to romantic relationships were identified by both neurotypical and autistic women</p> <ol style="list-style-type: none"> 1. Quality and length of relationships are similar for neurotypical women and women with autism 2. Approach to romantic relationships <p>Three subthemes relating to romantic relationships were identified by women with autism only</p> <ol style="list-style-type: none"> 1. Romantic partners act as social gatekeepers 2. Autistic women reported higher levels of non-heteronormality in their sexualities 3. Challenges with relationships
<p>Steward, Crane, Roy, Remington & Pellicano</p> <p>2018</p>	<p>-To explore the menstrual experiences of women on the autism spectrum</p>	<p>Mixed methods</p> <p>Convenience sample</p>	<p>$N=123$ women with a diagnosis of autism</p> <p>Age range: 16-59</p>	<p>Survey</p> <p>Thematic analysis</p>	<p>Five Key themes were identified, each describing the experiences of menstrual related issues. Four themes were identified from the experiences of both autistic and non-autistic participants:</p> <ol style="list-style-type: none"> 1. It's a normal and natural part of life 2. Understanding the varied ways it can affect you <p>-Periods "can be painful"</p>

UK QR=82% K=.79			N=114 neurotypical women Age range: 16-60+		<ul style="list-style-type: none"> -Periods vary widely from person to person -“It can affect your moods” <ol style="list-style-type: none"> 3. Understanding what’s not “my normal” 4. Knowing what to expect is key <ul style="list-style-type: none"> -Practical information on the very varied products -Being prepared is essential <p>One theme was unique to the experiences of people with autism</p> <ol style="list-style-type: none"> 5. Periods exacerbate autism-related challenges <ul style="list-style-type: none"> -Sensory issues are intensified -Difficulties regulation emotions and behaviour worsened during their period
Tint & Weiss 2018 Canada QR=87% K=.69	<ul style="list-style-type: none"> -To describe the service experiences of women with ASC -To identify unmet service needs of women with ASC - To identify barriers to care for this population 	Qualitative Purposive sample	N=20 women with a diagnosis of ASC Age range: 19-69 (<i>M</i> = 35.45, <i>SD</i> =12.26)	5 Focus groups ranging in size from 2 to 6 participants Thematic analysis	<p>Three primary themes were identified, each describing experiences of accessing services:</p> <ol style="list-style-type: none"> 1. Masking service needs <ul style="list-style-type: none"> -Not looking the part -Hidden hurt of maintaining the mask -Unworthy of services 2. (Mis)communication with service providers <ul style="list-style-type: none"> -Not speaking the same service language -(In)Experienced experts -Feeling heard 3. Accessing appropriate services: “a constant struggle” <ul style="list-style-type: none"> -Not fitting the bill -“A broken system” -Getting there is half the battle -Square peg in a round hole -Looking outside of the box for social support

Vine Foggo & Webster 2016 Australia QR=95% K=1.00	-To explore the insights and perceptions of adolescent females on the autism spectrum regarding their social experiences and relationships with their female peers	Qualitative Purposive sample	N=7 Age Range: 13-17 with a diagnosis of autism	Semi-structured interviews Thematic analysis	Two key themes were identified: 1. Social interactions are important -Happiness and emotional support are major benefits of friendships -Trust, support and respect are key characteristics of a friend 2. Social interactions are difficult -Disagreements and arguments are a difficult part of friendships -Difficulties understanding the perceptions of others
Webster & Garvis 2017 Australia QR=87% K=.62	-To enable women with ASC to discuss the factors that enabled them to achieve success in different aspects of their life	Qualitative Purposive sample	N=10 women with a diagnosis of ASC Age range: 28-55	Semi-structured interviews conducted over the phone or via computer conference Narrative themed analysis	Women's perceptions of success were shaped by four key factors: 1. Being an agent of change -Able to take positive action when faced with difficulty -Able to bring about change -Achievement in raising children, thriving in work, maintaining healthy relationships and completing study. 2. Experiencing the belief of others in their capability -Influential people increased their self-belief -Influential people persuaded them to develop their agency for current and future action 3. Changed identity of diagnosis -Initial period of reflection, readjustment and depression -Diagnosis helped the women to construct a new identity -Diagnosis enables attaining support in the workplace -Ability to focus on a goal helped most when problems were encountered

1.3.2 Synthesis of the findings

Two meta-themes were identified through synthesis of the thirteen articles included in this review: ‘*Wearing a mask*’ and ‘*Who am I?*’. Within ‘*Wearing a mask*’ two subthemes were developed: ‘*Threat*’ and ‘*Lack of understanding*’. Two subthemes also related to the meta-theme of ‘*Who am I?*’: ‘*A difference not a disorder*’ and ‘*Gender identity*’. Participant quotes, that were extracted from the primary studies included in the synthesis, are included to illustrate meta-themes and subthemes.

Table 1.4 *Meta-themes and subthemes*

Meta-themes	Subthemes
<i>Wearing a mask</i>	1) <i>Threat</i> 2) <i>Lack of understanding</i>
<i>Who am I?</i>	1) <i>‘A difference not a disorder’</i> 2) <i>Gender identity</i>

Table 1.5 illustrates which articles contributed to each meta-theme and subtheme.

Table 1.5 *Summary of papers contributing to each meta-theme and subtheme*

	Meta-themes	Wearing a mask		Who am I?	
Included papers	Subthemes	Threat	Lack of understanding	“A difference not a disorder”	Gender identity
Baldwin & Costley, 2016		✓	✓	✓	
Bargiela, Steward & Mandy, 2016		✓	✓	✓	✓
Gardner, Suplee, Bloch & Lecks, 2016			✓		✓
Goodall & MacKenzie, 2018		✓	✓	✓	
Haney & Cullen, 2017		✓	✓	✓	✓
Hayward, McVilly & Stokes, 2018		✓			
Kanfiszer, Davies & Collins, 2017		✓	✓	✓	✓
Rogers, Lepherd, Ganguly & Jacob-Rogers, 2017			✓	✓	
Sedgewick, Crane, Hill & Pellicano, 2018		✓			✓
Steward, Crane, Remington & Pellicano, 2018		✓			✓
Tint & Weiss, 2018		✓	✓		
Vine Foggo & Webster, 2017		✓	✓		✓
Webster & Garvis, 2017				✓	✓

1.3.2.1 Wearing a mask

This meta-theme describes the need felt by the women with autism to ‘*mask*’ what they are thinking and ‘*try hard to be normal*’ in order to ‘*pass*’ socially (Baldwin & Costley, 2016; Tint & Weiss, 2018; Bargiela et al., 2016). ‘*Wearing a mask*’ is comprised of two subthemes: ‘*Threat*’ and ‘*Lack of understanding*’.

1.3.2.1.1 Threat

The subtheme ‘*Threat*’ denotes both the helpful and unhelpful implications of masking the difficulties associated with autism, and the drivers for doing so. Ten out of thirteen articles contributed to this subtheme (Table 1.5).

Seven papers presented accounts of women with autism being bullied, feeling isolated or excluded by peers (Hayward et al., 2018; Kanfischer et al., 2017; Baldwin & Costley, 2016; Bargiela et al., 2016; Sedgewick et al., 2018; Haney & Cullen, 2017; Goodall & MacKenzie, 2018). Masking ASC symptom expression, or ‘*honing something of a persona*’, is described by women on the AS as a coping mechanism that is developed during youth to protect the self from ‘*victimisation*’ and increase social acceptance (Tint & Weiss, 2018; Kanfischer et al., 2017; Bargiela et al., 2016).

“It’s like, uh-oh, that person has received weirdness now I have to amend my presentation so that I can pass better.”

(Tint & Weiss, 2018, p. 930)

“I’ll mask if I act weird which is typical of ASC, I’ll make a joke about it.”

(Bargiela et al., p. 3287)

Experiences of being victimised and excluded, across all domains of life, creates and reinforces a belief that the problem lies within the self. There is a perceived need to learn how to relate to others in a way that is deemed appropriate, as being themselves increases individuals’ social vulnerability.

“When I was being bullied, I was told not to antagonise these girls and actually, I was only antagonising them by being myself.”

(Bargiela et al., 2016, p. 3286)

“... it’s my reactions, and the way I interacted with people wasn’t appropriate ... they just ostracised me.”

(Kanfiszer et al., 2017, p. 666)

Women describe actively learning various adaptive masking strategies including mimicking others’ speech and behaviours, creating and memorising set responses and drinking alcohol (Bargiela et al., 2016; Baldwin & Costley, 2016; Tint & Weiss, 2018). However, Bargiela and colleagues (2016) describe these strategies as ‘*superficial*’, as ‘*maintaining the mask*’ is impossible to sustain; it expends a lot of energy and often leads to ‘*internal exhaustion*’. Females with autism also highlighted that rather than mitigating stress, having an ability to present ‘*in a socially normal way*’ increases the pressure and expectation that they will do so at all times (Baldwin & Costley, 2016). However, across studies, it emerged that women experience their ability to mask as one that fluctuates, with women in Tint and Weiss’ (2018) study describing how their ability to ‘*act normal*’ ‘*breaks down*’ at the point of exhaustion.

“Learning how to be social doesn’t make it easier or less stressful because it’s still against my natural grain. If I behave in a socially normal way, then that’s how people perceive me, and I have to keep up that standard, which is impossible.”

(Baldwin & Costley, 2016, p. 91)

The perceived societal pressure to ‘*act normal*’ extends to intimate relationships. Women describe feeling obliged to conform to expectations regarding intimate behaviours that are otherwise against their wishes and interests. An incongruence between the desire for successful relationships, and the ability to make and sustain them, also increases their vulnerability within relationships; being ‘*desperate for friends*’ compromises their ability to understand others’ intentions and motives.

“There’s that whole ulterior motive thing that I just end up missing.”

(Sedgewick et al., 2018, p. 8)

“Because we don’t sense danger and can’t. That’s one reason, I think you’re not reading people to be able to tell if they’re being creepy, you’re that desperate for friends and relationships that if someone is showing an interest in you, you kind of go with it.”

(Bargiela et al., 2016, p. 3288)

Participants in Bargiela and colleague’s (2016) study also recounted how social mimicry contributed to them finding themselves in situations where their safety and rights were compromised. This paper achieved a very good quality rating; data collection and analysis methods were clearly described, and several credibility checks were completed to ensure interpretations of the data were sound. Supporting Bargiela and colleague’s (2016) findings, several accounts of sexual assault were also included across the papers, highlighting increased social vulnerability for women with autism.

“There’s potential for you copying a guy’s flirtatious behaviour without realising that’s what you’re doing.”

(Bargiela et al., 2016, p. 3288)

1.3.2.1.2 Lack of understanding

This subtheme arose from participants’ accounts of communicating their needs to others across all spheres of life including health, education, employment and relationships. This subtheme encapsulates a disconnect between the needs of women with autism and what others perceive their needs to be. Nine articles included accounts of feeling misunderstood or dismissed by others and contributed to this subtheme (Table 1.5).

Seven papers (Tint & Weiss, 2018; Rogers et al., 2017; Baldwin & Costley, 2016; Gardner et al., 2016; Haney & Cullen, 2017; Goodall & MacKenzie, 2018; Webster & Garvis, 2017) highlighted how professionals’ lack of understanding, and reliance on stereotypes regarding autism, prevents women from attaining recognition of their difficulties across all life domains.

“Well, you’re making eye contact with me, so you can’t have autism.”

(Tint & Weiss, 2018, p. 930)

“I’ll always remember my special needs teacher saying I’m too poor at maths to be autistic.”

(Baldwin & Costley, 2016, p. 488)

Women perceived their ability to mask and minimise their social difficulties as a factor that contributed to their needs being misunderstood, particularly by healthcare professionals. A diagnosis of autism was often dismissed as they were perceived as ‘*not looking the part*’ (Tint & Weiss, 2018). As well as being dismissed, others experienced being misdiagnosed, or having to reach crisis point before being able to access support.

“They have to know how girls present, because if they don’t get the diagnosis, they don’t get the early help.”

(Webster & Garvis, 2017, p. 674)

“It seems like if you have a job and live alone, no-one thinks you might still need help. In my experience, you cannot access help until you reach rock bottom.”

(Baldwin & Costley, 2016 p. 491)

Participants within Tint and Weiss’ (2018) study also highlighted that, because they do not always present with stereotypical autistic behaviours, others are less willing to be accommodating of their needs. Women described noticing gender disparity, with men with autism being more accommodated within society.

“I’ve noticed that regarding the guys with Asperger’s that I know, people just dismiss them as oh, he’s being his usual quirky self. But If I impose the same request and accommodations and whatnot, because I look too high functioning or whatever, I’m too high maintenance.”

(Tint & Weiss, 2018, p. 931)

Although the rationale for choice of design was not stated by Tint and Weiss (2018), the procedures were clearly described and auditable. Results from this study were therefore interpreted with confidence.

Accounts of negative interactions with healthcare professionals highlighted how the lack of others’ understanding made accessing healthcare services difficult and even

distressing. Women often experienced professionals as unwilling or unable to tailor support to their individual needs. They also reported that they were prescribed interventions that did not work for them (Tint & Weiss, 2018). In particular, women who had experienced childbearing felt threatened and persecuted by professionals who did not understand what it was like to be pregnant as a woman with autism (Rogers et al., 2017; Gardner et al., 2016). The need to feel understood and heard is therefore evident in the women's narratives.

"No matter how many times I tried to explain that what they were doing was aggravating the Asperger's syndrome because the hospital was stressing me out, they would not listen."

(Rogers et al., 2017 p. 92)

"I felt that they thought I was an incompetent parent because I had Asperger's syndrome. The medical profession doesn't seem to understand or care about how pregnancy and Asperger's syndrome interact. Some people are just out to get you."

(Rogers et al., 2017, p. 93)

"I had frequent conflicts with staff who did not want to inform me, did not want to adhere to my choices, and did not respect my authority over my son."

(Gardner et al., 2016, p. 34)

Five papers included themes which highlighted that women with autism had negative school experiences because of others' lack of understanding of their strengths and difficulties (Kanfischer et al., 2017; Baldwin & Costley, 2016; Bargiela et al., 2016; Vine Foggo & Webster, 2017; Goodall & MacKenzie, 2018). Women reported that their difficulties were frequently overlooked or dismissed as they were often academically capable and not disruptive.

"No one really made any attempt to ask about how I was doing. They [teachers] didn't really notice."

(Goodall & MacKenzie, 2018, p. 11)

“The reward for trying hard to be normal was to be ignored because you were acting normal and I look at stories online of kids who were going off the rails and I think, I should have just burnt more cars.”

(Bargiela et al., 2016, p. 3286)

Masking as a coping strategy is therefore not always effective in protecting women from being bullied or becoming isolated. On the contrary, it can increase social vulnerability and may contribute to needs being misunderstood or even dismissed by others.

1.3.2.2 Who am I?

This meta-theme describes the process of constructing an identity as a woman who is on the autism spectrum. It encompassed two subthemes: ‘*A difference not a disorder*’ and ‘*Gender identity*’.

1.3.2.2.1 ‘A difference not a disorder’

This subtheme arose from participants’ accounts of receiving a diagnosis of autism, including their initial thoughts and reactions, and the impact of diagnosis on their sense of identity. Seven out of thirteen articles explored women’s experiences of receiving and living with a diagnosis of autism (Table 1.5).

Women in Haney and Cullen’s (2017) study reported that they experienced mixed emotions after receiving a diagnosis of ASC. They experienced relief, as a diagnosis provided context for the difficulties they had encountered throughout their childhood and adolescence. However, they also experienced anxiety and denial. To protect participants’ anonymity, Haney and Cullen (2017) did not include any quotations to support their findings. The relationship between the data, and the interpretation of the data, is therefore not transparent. However, this study scored well on all other quality assessment criteria, indicating that the findings are methodologically sound. Additionally, participants within Webster and Garvis’ (2017) and Baldwin and Costley’s (2016) studies support their findings. They reported that, following diagnosis, women experienced hopelessness because autism is a lifelong condition, anxiety because they had not yet made sense of their diagnosis, and anger as they had not received recognition of their difficulties sooner.

“At that time, I was thinking it was all doom and gloom ... I was depressed because everything said it was a lifelong condition and there’s nothing you can do about it.”

(Webster & Garvis, 2017, p. 673)

“Even though I have known I am wrong for a very long time, it has only been the last couple of years that I suspected I had Asperger’s. I received a formal diagnosis this month and am just going through the motions of feeling relief, anger and a certain amount of confusion. Now that I understand the reason for my differences (I am not calling them disabilities) I can see clearly that a little help much earlier would have been incredibly useful.”

(Baldwin & Costley, 2016, p. 487)

The findings reported by Webster and Garvis (2017) were unique in that the focus was on the success as well as the challenges faced by women with ASC. Positively, a good sample size was recruited, and a comprehensive discussion was included. However, regarding data-analysis, credibility checks were not reported. The findings were therefore interpreted with some caution.

After a period of adjustment, women explain that a diagnosis provides an explanation for and contextualises differences which have always been apparent, but never labelled or explained. Making sense of these differences, in the context of a diagnosis of autism, allows for the construction of a new identity, whereby difficulties are understood as differences. Participants within Webster and Garvis’ (2017) study also explain that reading literature on autism, and reading about others on the AS, contributed to the development of a new identity and gave them a sense of hope and purpose. These findings were supported by Bargiela and colleagues (2016) and Baldwin and Costley (2016).

“It’s a difference not a disorder...it was really helpful because it made me feel good about myself.”

(Bargiela et al., 2016, p. 3289)

“The last 14 years have been a quest for me to understand what is different about me, why normal things don’t seem normal to me.

Getting the Asperger's diagnosis was at the end of a long search and has made sense of a lot of things through my life."

(Baldwin & Costley, 2016, p. 487)

Developing an understanding of their own differences enabled women to learn skills and strategies that increase opportunities for interpersonal success. For example, within the workplace, having a diagnosis increased the women's confidence to articulate their needs and access support, enabling them to perform better and make informed decisions about their careers (Webster & Garvis, 2017).

"I've learnt a lot of things subsequent to my diagnosis, like one of the things that I was never aware of was how important it was to engage in small talk with your colleagues."

(Kanfischer et al., 2017, p. 666)

Haney and Cullen (2017) explored the lived experiences of women from within an online community and reported that online groups are a valued place of support for women who are going through the process of obtaining or adjusting to a diagnosis. Being part of an online community is thought to increase feelings of '*belonging*' and reduce feelings of '*alienation*' (Haney & Cullen, 2017). Participants within Bargiela and colleague's (2016) study corroborate these views when discussing their use of online blogs; they reported that learning about other women's stories made them feel '*accepted*' and '*understood*' by others who had shared similar experiences. They also reported an increase in pride and confidence in having a diagnosis of autism after visiting online forums.

"Something that I really appreciate about having the diagnosis is actually being in this club now where people talk about their experiences and having so many echoes of my own."

(Bargiela et al., 2016, p. 3289)

In contrast, Goodall and MacKenzie (2018) reported that having a '*disability*' increased feelings of isolation and rejection by peers within school. Therefore, it is possible that a diagnosis also increases social distance from those who do not have a diagnosis or share similar lived experiences.

“It is all about themselves and if you have a disability they do not want to know, they look down at you and think no, I am not going to be with her.”

(Goodall & MacKenzie, 2018, p. 9)

A participant within Rogers and colleagues’ (2017) study, which explored perinatal issues for women with autism, reported that having a diagnosis caused professionals to question her ability to function as an effective parent. This highlights how having a diagnosis can increase perceived persecution from others.

“I’ve noticed that the more I strongly asserted my decisions on how to raise my own child, the more they put my behaviour down to some dysfunctional behaviour due to my Asperger’s syndrome.”

(Rogers et al., 2016, p. 93)

However, both Goodall and MacKenzie’s (2018) and Rogers and colleagues’ (2017) studies highlighted the experiences of only one participant, reducing the reliability and transferability of the themes reported within these articles.

1.3.2.2.2 Gender identity

This subtheme arose from participants’ narratives regarding school experiences, adolescence, friendships and intimate relationships. ‘*Gender identity*’ captures women’s experiences of attempting and failing to fulfil gender stereotypical roles, the importance of interests for the development of a self-concept and experiences of female physiology. Eight out of thirteen papers contributed to this subtheme (Table 1.5).

Women with autism describe a perceived pressure to fulfil gender stereotypical roles, such as wife and mother, that do not align with their wishes or interests (Bargiela et al., 2016; Kanfiszer et al., 2017). Participants in Bargiela and colleague’s (2016) paper describe experiencing a ‘*sense of lost identity*’ when attempting to fulfil socially expected gender roles. Moreover, women who discussed gender and social relationships explained that deviating from what was expected of them as females contributed to them being labelled as odd and excluded by female peers (Kanfiszer et al., 2017).

“I didn’t get on with other girls...I wasn’t behaving in a so-called normal manner.”

(Kanfischer et al., 2017, p. 664)

“Girls are bothered about what they’re wearing and what their hair looks like and their nails and who’s cute in what band ... it’s not actually possible for me to be less interested ... whereas the guys would be mucking about ... something I felt more inclined to be involved with”

(Kanfischer et al., 2017, p. 665)

When discussing friendships, women defined ‘*true friends*’ as people who ‘*let you be yourself*’ without judgement (Vine Foggo & Webster, 2017). Women also perceived men as more straightforward in their communication and less judgemental, making it easier and more desirable to spend time with and develop friendships with male peers (Kanfischer et al., 2017; Bargiela et al., 2016; Haney & Cullen, 2017). Whereas spending time with women, pretending to share gender stereotypical interests, was described as being detrimental to the sense of self. Women also highlighted how important it is that others share their interests, as shared experiences enforce a key emotional bond (Sedgewick et al., 2018).

“I just feel so much more comfortable with men because they’re more, you can take them at face value and it’s not that fear of them judging you or having alternative motives and thoughts and they kind of say things straight.”

(Bargiela et al., 2016, p. 3289)

Participants within Bargiela and colleague’s (2016) study also communicated the importance of pursuing interests to provide them with a focus, sense of personal wellbeing and sense of achievement. Women with autism therefore often form their identities through engaging with their special interests, rather than through relying on common social norms to define themselves.

“I was very obsessed, and still am, with creative writing and that kind of provides the entire focus of my life...I would say I forge most of my identity on that.”

(Bargiela et al., 2016, p. 3289)

Regarding interests, women also reported experiencing increased self-belief when they could do something that was recognised by others as ‘*beneficial and productive*’ (Bargiela et al., 2016). However, participants within Webster and Garvis’ (2017) study reflected on how recognising their own strengths and successes, and creating their own notions of success, was important for the development of their self-belief and efficacy. Creating their own notions of success was therefore thought to be more important than attempting to conform to societies expectations.

“But what if these roles were recast into something that better fit the way women with ASC see their world? And, in the process, if those different roles were also given the dignity and inherent worth of being considered just as much the norm as the norm itself?”

(Webster & Garvis, 2017, p. 674)

When reflecting on adulthood, several women shared that they questioned their gender identity (Kanfischer et al., 2017). In particular, they reported experiencing discomfort and being inconvenienced by their female physiology, including menstruation. Steward and colleagues (2018) explored autistic experiences of menstruation and corroborated Kanfischer and colleagues’ (2017) findings. They reported that having to attend to physical needs is a ‘*burden*’, and that sensory and self-regulation difficulties related to autism were exacerbated, making ‘*life much more difficult to manage during periods*’. Sensory sensitivity was also reported as a difficulty by women who had experienced childbearing (Gardner et al., 2016).

“Autism does play a role. It can become much more overwhelming and harder to maintain control of the things that already take a lot of effort for us to keep on top of during a period.”

(Steward et al., 2018, p.4290)

1.4 Discussion

This systematic review aimed to produce the first meta-ethnographic synthesis of qualitative findings relating to women's experiences of living with autism. Thirteen studies were included in the synthesis which led to the development of two meta-themes; '*Wearing a mask*' and '*Who am I?*'.

1.4.1 Summary of findings

Throughout their lifespan, many women with ASC experience bullying, exclusion and isolation and develop an awareness of their difference (Hayward et al., 2018; Kanfischer et al., 2017; Baldwin & Costley, 2016; Bargiela et al., 2016; Sedgewick et al., 2018; Haney & Cullen, 2017; Goodall & MacKenzie, 2018). Consequently, they learn strategies to '*mask*' their ASC expression and attempt to conform to societal norms to protect themselves from victimisation (Tint & Weiss, 2018; Kanfischer et al., 2017; Bargiela et al., 2016). However, these strategies are superficial, impossible to sustain and prone to '*break-down*', increasing their social vulnerability (Tint & Weiss, 2018; Baldwin & Costley, 2016; Bargiela et al., 2016).

The needs of autistic women are repeatedly misunderstood or dismissed by professionals and peers (Tint & Weiss, 2018; Baldwin & Costley, 2016; Rogers et al., 2017; Gardner et al., 2016; Haney & Cullen, 2017; Goodall & MacKenzie, 2018). This lack of understanding of the female presentation contributes to delayed diagnosis, distress for women when accessing healthcare services and a lack of support in school and subsequent employment.

Regarding diagnosis, females on the AS require a period of reflection before being able to make sense of their diagnosis and construct a new identity (Haney & Cullen, 2017; Webster & Garvis, 2017; Baldwin & Costley, 2016; Bargiela et al., 2016). Afterwards, having a diagnosis often increases women's sense of belonging and acceptance (Haney & Cullen, 2017; Bargiela et al., 2016). However, women with ASC also experience increased social distance and perceived prejudice from others who do not have a diagnosis (Goodall & MacKenzie, 2018; Rogers et al., 2017).

Many women experience pressure to fulfil gender stereotypical roles. They also experience a '*sense of lost identity*' and question their gender identity when attempting to fulfil those roles (Bargiela et al., 2016; Kanfischer et al., 2017).

Furthermore, women reportedly experience discomfort with their female physiology, and self-regulation difficulties may be exacerbated during menstruation, childbearing and childbirth.

This meta-ethnographic synthesis highlighted how integral pursuing specialist interests are for women with autism, not only for their wellbeing, but also for forming their identities. Additionally, whilst some women experience increased self-belief when their interests are valued by peers (Bargiela et al., 2016), others recognise the importance of creating their own notions of success, rather than attempting to conform to societal ideas.

1.4.2 Relation to previous literature

Concerning diagnosis, the findings in this review corroborate previous research which reported that individuals with ASC felt a sense of pride, as their diagnosis became an integral part of their identity (Hughes, 2012; Rosqvist, 2012), relief, as their diagnosis answered questions they had about themselves, and helplessness, as autism is perceived as lifelong (Haertl, Callahan, Markovics & Sheppard, 2013). However, where previous research has also reported that some individuals did not want to be associated with others who shared their diagnosis (MacLeod, Lewis, & Robertson, 2013), this research highlighted how learning about and hearing others' stories increased females' sense of belonging and acceptance (Haney & Cullen, 2017; Bargiela, et al., 2016).

Regarding interests, these findings support the conclusions of Depape and Lindsay (2016), who reported that pursuing interests provides individuals with autism a sense of personal wellbeing and shapes their identity. Previous research reported that females with ASC typically have interests that are more in line with social and gender norms than males who are on the spectrum (Kirkovski et al., 2013; Van Wijngaarden-Cremers et al., 2014). On the contrary, this review highlighted that women may attempt to fulfil gender stereotypical roles and interests because of a perceived societal pressure, rather than sincere interest in doing so. In attempting to fulfil gender stereotypical roles women report experiencing a '*sense of lost identity*' (Bargiela, et al., 2016; Kanfischer et al., 2017), highlighting the negative impact of this pressure on the wellbeing of women with ASC.

Previously, Hayward and colleagues (2018) concluded that workplace challenges for females with autism are similar to those faced by males, and include difficulties with communication, sensory issues and employer and colleague awareness of autism. This review supports this conclusion, as the women included described similar workplace issues. However, the findings here identified additional difficulties that may be unique to females with autism. As women with autism do not always present with stereotypical autistic behaviours, others have been experienced as less willing to accommodate their needs in the workplace. Furthermore, although men report difficulties with sensory sensitivities in the workplace, this issue is compounded for women who experience heightened sensory sensitivities and difficulties regulating themselves during menstruation. Furthermore, the findings presented here are supported by Nagib and Wilton (2019). Nagib and Wilton (2019) qualitatively explored the role of gender in career exploration amongst adults with autism. It was concluded that females encountered more unfavourable experiences than men and that gender sensitive approaches are needed.

Furthermore, through focusing on women's experiences, it became clear that women with ASC perceive their needs to be repeatedly misunderstood or dismissed by professionals and peers (Tint & Weiss, 2018; Baldwin & Costley, 2016; Rogers et al., 2017; Gardner et al., 2016; Haney & Cullen, 2017; Goodall & MacKenzie, 2018). Regarding the female presentation, this lack of understanding contributes to delayed or even missed diagnosis which is reported in the literature (Lai & Baron-Cohen, 2015).

1.4.3 Clinical implications

This review highlights the importance of diagnosis and the positive impact diagnosis has on identity formation for women with ASC. To support the implementation of the Adult Autism Strategy, it is important that access is provided to services that can diagnose autism, as outlined in the statutory guidance for local authorities (Department of Health, 2014). To ensure that access for women is improved, it is imperative that gatekeepers to diagnostic services, such as general practitioners (GP), receive training beyond general autism awareness. It is important that this training increases understanding of the female autism phenotype and challenges that are specific to women with autism. This will not only enable access to diagnostic

services but will also enable women to be supported more effectively from the start of the assessment process. This support should be tailored to address key social, health and wellbeing challenges that have been noted to be specific to women with autism. Additionally, training beyond general autism awareness should be available for educators, employers and the general public.

Furthermore, the benefits of being part of an online community and learning about other women's experiences of autism were emphasised in the women's narratives. It is important that women are signposted to relevant resources and support groups, both on and offline.

1.4.4 Limitations

The findings of this review were drawn from the experiences of women who were verbally able to report their experiences of autism. As a result, the findings may not be representative of women across the spectrum. Following the comprehensive literature search, no studies, that met inclusion criteria, included the experiences of women with ASC and co-occurring intellectual disabilities. This highlights the need for further research in this area.

Furthermore, as this area of research has gained traction only in recent years, there is a limited number of published, peer reviewed studies. The aim of this review therefore remained broad, examining the experiences, perceptions and views of women across several domains of life. Whilst the focus on peer reviewed studies increased the probability of the inclusion of credible, high quality research, the inclusion of grey literature may have provided opportunity for a more in-depth exploration of one area important to autistic women, such as education, health, employment or relationships.

Additionally, metaphors and emerging themes were extracted from individual studies by the lead researcher only. It is therefore possible that the results were influenced by the author's interpretations (Al-Natour, 2011). Moreover, synthesising the articles in chronological order may have impacted the development of meta-themes.

1.4.5 Future research

Many qualitative papers, which otherwise satisfied the inclusion criteria for this review, were excluded because it was not clear which themes were relevant to the

females' experiences (Figure 1.1). Future research exploring the lived experiences of individuals with ASC would contribute to the developing understanding of the female autism phenotype by making explicit which themes the female participants contributed to.

The paucity of research focusing solely on the experiences of females with autism also highlights the need for further qualitative exploration in this area. In particular, future research should seek to include the perspectives of all women with autism, including those with co-occurring intellectual disabilities. Furthermore, only one paper identified for inclusion in this review aimed to explore the successes of women with ASC. More research, examining the positive lived experiences of individuals with autism, as opposed to negative experiences, is required.

1.5 Conclusion

This is the first meta-ethnographic review of the literature examining women's experiences, perceptions and views of living with autism. Although previous research recognised that the autism phenotype is altered for women, previous reviews concluded that women with autism likely experience the same challenges as men. This review however identified several additional gender specific challenges and offered further insights into the impact of autism on gender identity. It is therefore important for educators, employers and healthcare professionals to have an awareness of autism, how it is experienced by women, and the key social, health and wellbeing challenges that are specific to women with ASC.

1.6 References

- Al-Natour, R. J. (2011). The impact of the researcher on the researched. *Media Culture Journal*, 14(6), 1-4. Retrieved from <http://journal.media-culture.org.au/index.php/mcjournal/view/428>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th Ed.). Washington, DC: American Psychiatric Association. doi:10.1176/appi.books.9780890425596
- Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC medical research methodology*, 8. doi:10.1186/1471-2288-8-21
- Attwood, T. (2007). *The complete guide to Asperger's syndrome*. London: Jessica Kingsley Publishers.
- Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, 20(4), 483-495. doi:10.1177/1362361315590805
- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46, 3281-3294. doi:10.1007/s10803-016-2872-8
- Britten, N., Campbell, R., Pope, C., Donovan, K., Morgan, M., & Pill, R. (2002). Using meta-ethnography to synthesise qualitative research: A worked example. *Journal of Health Services Research and Policy*, 7(4), 209-215. doi:10.1258/135581902320432732
- Brugha, T. S., Spiers, N., Bankart, J., Cooper, S., McManus, S., Scott, F.J., ... Tyrer, F. (2016). Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*, 209(6), 498-503. doi:10.1192/bjp.bp.115.174649

- Caldwell, K., Henshaw, L., & Taylor, G. (2005). Developing a framework for critiquing health research. *Journal of Health, Social and Environmental Issues*, 6(1), 45-54. Retrieved from <https://publons.com/journal/30764/journal-of-health-social-and-environmental-issues>
- Caldwell, K., Henshaw, L., & Taylor, G. (2011). Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today*, 31(8), 1-7. Retrieved from <https://www.journals.elsevier.com/nurse-education-today>
- Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: A synthesis of qualitative research on lay experiences of diabetes care. *Social Science & Medicine*, 56(4), 671-684. doi:10.1016/S0277-9536(02)00064-3
- Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, 20(1), 37-46. doi:10.1177/001316446002000104
- DePape, A., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities*, 31(1), 60-71. doi:10.1177/1088357615587504
- Department of Health. (2014). Think autism – Fulfilling and rewarding lives, the strategy for adults with autism in England: an update. Retrieved from <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>
- Dixon-Woods, M., Sutton, A.J., Shaw, R., Miller, T., Smith, J., Young, B., ... Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: A quantitative and qualitative comparison of three methods. *Journal of Health Services Research Policy*, 12(1), 42-47. doi:10.1258/135581907779497486
- France, E. F., Cunningham, M., Ring, N., Uny, I., Duncan, E.A.S., Jepson, R., ... Noyes, J. (2019). Improving reporting of meta-ethnography: The eMERGe reporting guidance. *BMC Medical Research Methodology*, 19(1), 447-458. doi:10.1186/s12874-018-0600-0

- France, E.F., Ring, N., Thomas, R., Noyes, J., Maxwell, M., & Jepson, R. (2014). A methodological systematic review of what's wrong with meta-ethnography reporting. *BMC Medical Research Methodology*, 14. doi:10.1186/1471-2288-14-119
- Gardner, M., Suplee, P.D., Bloch, J., & Lecks, K. (2016). Exploratory study of childbearing experiences of women with Asperger's syndrome. *Nursing for Women's Health*, 20(1), 28-37. doi:10.1016/j.nwh.2015.12.001
- Giarelli, E., Wiggins, L.D., Rice, C.E., Levy, S.E., Kirby, R.S., Pinto-Martin, J., & Mandell, D. (2010). Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal*, 3(2), 107-116. doi:10.1016/j.dhjo.2009.07.001
- Goodall, C., & MacKenzie, A. (2018). What about my voice? Autistic young girls' experiences of mainstream school. *European Journal of Special Needs Education*. doi:10.1080/08856257.2018.1553138
- Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice*, 12(1), 34-41. Retrieved from <http://www.bild.org.uk/our-services/journals/gap/>
- Haertl, K., Callahan, D., Markovics, J., & Sheppard, S.S. (2013). Perspectives of adults living with autism spectrum disorder: Psychosocial and occupational implications. *Occupational Therapy in Mental Health*, 29(1), 27-41. doi:10.1080/0164212X.2012.760303
- Haney, J.L., & Cullen, J.A. (2017). Learning about the lived experiences of women with autism from an online community. *Journal of Social Work in Disability & Rehabilitation*, 16(1), 54-73. doi:10.1080/1536710X.2017.1260518
- Hayward, S.M., McVilly, K.R., & Stokes, M.A. (2016). Challenges for females with high functioning autism in the workplace: A systematic review. *Disability and Rehabilitation*, 40(3), 249-258. doi:10.1080/09638288.2016.1254284

- Hayward, S.M., McVilly, K.R., & Stokes, M.A. (2018). "Always a glass ceiling." Gender or autism; the barrier to occupational inclusion. *Research in Autism Spectrum Disorders*, 56, 50-60. doi:10.1016/j.rasd.2018.09.001
- Hedley, D., Uljarević, M., Cameron, L., Halder, S., Amanda Richdale, A., & Dissanayake, C. (2016). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism*, 21(8), 929-941. doi:10.1177/1362361316661855
- Holwerda, A., Van Der Klink, J.J.L., Groothoff, J.W., & Brouwer, S. (2012). Predictors for work participation in individuals with an autism spectrum disorder: A systematic review. *Journal of Occupational Rehabilitation*, 22(3), 333-352. doi:10.1007/s10926-011-9347-8
- Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, 57(5), 275-283. doi:10.1177/070674371205700502
- Hughes, P. (2012). An autoethnographic approach to understanding Asperger's syndrome: A personal exploration of self-identity through reflexive narratives. *British Journal of Learning Disabilities*, 40(2), 94-100. doi:10.1111/j.1468-3156.2012.00738.x
- Huke, V., Turk, J., Saeidi, S., Kent, A., & Morgan, J.F. (2013). Autism spectrum disorders in eating disorder populations: A systematic review. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, 21(5), 345-351. doi:10.1002/erv.2244
- Jones, M, L. (2004). Application of systematic review methods to qualitative research: Practical issues. *Journal of Advanced Nursing*, 48(3), 271-278. doi:10.1111/j.1365-2648.2004.03196.x
- Kanfiszer, L., Davies, F., & Collins, S. (2016). "I was just so different": The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships. *Autism*, 21(6), 661-669. doi:10.1177/1362361316687987

- Kanne, S.M., Christ, S.E., & Reiersen, A.M. (2009). Psychiatric symptoms and psychosocial difficulties in young adults with autistic traits. *Journal of Autism and Developmental Disorders*, 39(6), 827-833. doi:10.1007/s10803-008-0688-x
- Kirkovski, M., Enticott, P.G., & Fitzgerald, P.B. (2013). A review of the role of female gender in autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(11), 2584-2603. doi:10.1007/s10803-013-1811-1
- Lachal, J., Revah-Levy, A., Orri, M., & Moro, M.R. (2017). Metasynthesis: An original method to synthesize qualitative literature in psychiatry. *Frontiers in Psychiatry*, 8, 1-9. doi:10.3389/fpsy.2017.00269
- Lai, M.C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013-1027. doi:10.1016/S2215-0366(15)00277-1
- MacLeod, A., Lewis, A., & Robertson, C. (2013). “Why should I be like bloody rain man?!” Navigating the autistic identity. *British Journal of Special Education*, 40(1), 41-49. doi:10.1111/1467-8578.12015.
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304-1313. doi:10.1007/s10803-011-1356-0
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS medicine*, 6(7). doi:10.1371/journal.pmed.1000097
- Nagib, W., & Wilton, R. (2019). Gender matters in career exploration and job-seeking among adults with autism spectrum disorder: Evidence from an online community. *Disability and Rehabilitation*. doi:10.1080/09638288.2019.1573936

- Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W.C., Ashkenazy, E., & Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*, 28(6), 761-769. doi:10.1007/s11606-012-2262-7
- Noblit, G., & Hare, R. (1988). *Meta-ethnography: Synthesising qualitative studies*. California: Sage Publications.
- Rogers, C., Lepherd, L., Ganguly, R., & Jacob-Rogers, S. (2017). Perinatal issues for women with high functioning autism spectrum disorder. *Women and Birth*, 30(2), 89-95. doi:10.1016/j.wombi.2016.09.009
- Rosqvist, H.B. (2012). Normal for an Asperger: Notions of the meanings of diagnoses among adults with Asperger syndrome. *Intellectual and Developmental Disabilities*, 50(2), 120-128. doi:10.1352/1934-9556-50.2.120
- Ruiz, C, L., Pistrang, N., & Mandy, W.P.L. (2012). High functioning autism and Asperger's disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders*, 42(2), 230-243. doi:10.1007/s10803-011-1238-5
- Rynkiewicz, A. & Lucka, I. (2018). Autism spectrum disorder (ASD) in girls. Co-occurring psychopathology. Sex differences in clinical manifestation. *Psychiatria Polska*, 52(4), 629-639. doi:10.12740/PP/OnlineFirst/58837
- Sedgewick, F., Crane, L., Hill, V., & Pellicano, E. (2018). Friends and lovers: The relationships of autistic and neurotypical women. *Autism in Adulthood*. doi:10.1089/aut.2018.0028
- Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender differences in the social motivation and friendship experiences of autistic and non-autistic adolescents. *Journal of Autism and Developmental Disorders*, 46(4), 1297-1306. doi:10.1007/s10803-015-2669-1
- Smirnoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence,

comorbidity and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8), 921-929. doi:10.1097/CHI.0b013e318179964f

Steward, R., Crane, L., Roy, E.M., Remington, A., & Pellicano, E. (2018). "Life is much more difficult to manage during periods": Autistic experiences of menstruation. *Journal of Autism and Developmental Disorders*, 48, 4287-4292. doi:10.1007/s10803-018-3664-0

Tint, A., & Weiss, J. (2018). A qualitative study of the service experiences of women with autism spectrum disorder. *Autism*, 22(8), 982-937. doi:10.1177/1362361317702561

Turcotte, P., Mathew, M., Shea, L.L., Brusilovskiy, E., & Nonnemacher, S.L. (2016). Service needs across the lifespan for individuals with autism. *Journal of Autism and Developmental Disorders*, 46(7), 2480-2489. doi:10.1007/s10803-016-2787-4

Van Wijngaarden-Cremers, P.J., Van Eeten, E., Groen, W.B., Van Deurzen, P.A., Oosterling, L.J., & Van der Gaag, R.J. (2014) Gender and age differences in the core triad of impairments in autism spectrum disorders: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44(3), 627-635. doi:10.1007/s10803-013-1913-9

Vine Foggo, R. S., & Webster, A.A. (2017). Understanding the social experiences of adolescent females on the autism spectrum. *Research in Autism Spectrum Disorders*, 35, 74-85. doi:10.1016/j.rasd.2016.11.006

Webster, A. A., & Garvis, S. (2017). The importance of critical life moments: An explorative study of successful women with autism spectrum disorder. *Autism*, 21(6), 670-677. doi:10.1177/1362361316677719

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, ...
Schultz, T.R. (2015). Evidence-based practices for children, youth, and young
adults with autism spectrum disorder: A comprehensive review. *Journal of
Autism and Developmental Disorders*, 45(7), 1951-1966. doi:10.1007/s10803-
014-2351-z

Chapter Two

“I felt like I was floating in space”: Autistic adults’ experiences of low mood and depression

This chapter was prepared for submission to the journal Autism. Appendix A provides detailed author guidelines for submission to this journal. The word count for this chapter, excluding abstract, footnotes, figures, tables and references, is 8,018.

2.0 Abstract

It is recognised that a high proportion of adults on the autism spectrum experience depressive symptoms. However, limited research has explored autistic peoples' experiences of low mood and depression. The aim of this study was to explore the lived experiences of low mood and depression for adults on the autism spectrum. The study employed Interpretive Phenomenological Analysis to investigate the experiences of 8 adults (7 males and 1 female), aged between 19 and 51, who had a diagnosis of autism without co-occurring learning disabilities, and experienced low mood or depression. All participants recorded their thoughts and feelings in a mood diary for one week and participated in a semi-structured interview. Three superordinate themes emerged from the data: *"Autism has made me the person I am"*, *"I can't function in the world"* and *"It's like trying to do accounts on the futures market"*: *Making sense of emotions*. Various experiences that contributed to these themes, including receiving a diagnosis of autism, struggling to fit in with society, and seeking support are explored. Findings highlight a need for specialist mental health provision for adults who are on the autism spectrum. Limitations of this study and implications for future research are discussed.

Key Words: Autism, autism spectrum condition, mental health, low mood, depression, support, experiences, interpretative phenomenological analysis

Abstract word count: 198

2.1 Introduction

2.1.1 Background

This study explored how adults with autism⁵ experience low mood and depression. Autism Spectrum Conditions⁶ (ASC) are life-long neurodevelopmental conditions that affect at least one percent of the population (Brugha et al., 2016; Lai & Baron-Cohen, 2015). ASCs are characterised by difficulties with social communication, social interaction and restricted and repetitive patterns of behaviours, activities, and interests (American Psychiatric Association, 2013).

Depression is a broad and heterogenous diagnosis characterised by lowered mood, loss of pleasure in most activities and somatic or intellectual changes that affect an individual's ability to function in daily life (American Psychiatric Association, 2013). Depression has been identified as a major public health concern because of its chronic, reoccurring nature and impact on physical health (World Health Organisation, 2018).

Individuals with autism are more likely than the general population to experience co-occurring mental health difficulties (Smirnoff et al., 2008; Kanne, Christ & Reiersen, 2009), and approximately 65 to 80 percent of people with autism are diagnosed with at least one co-existing psychiatric condition (Sterling, Dawson, Estes & Greenson, 2008). Depression is thought to be the most common mental health condition experienced by autistic people (Ghaziuddin, Ghaziuddin & Greden, 2002). Evidence indicates that the presence of depression may worsen the degree of ASC related impairment (Roy, Prox-Vagedes, Ohlmeier & Dillo, 2015), negatively impact on support networks (Gold, 1993) and increase risk of suicide (Cassidy et al., 2014).

The emotional processing and communication difficulties that are typical for people with autism make it challenging to accurately diagnose depression in this population

⁵ There is no one preferred way to talk about autism, and there are different perspectives on the issue within the autism community. To be sensitive to this issue, identity-first language, such as 'autistic person', and person-first language, such as 'person with autism', is used interchangeably throughout this report.

⁶ In line with the views of members of the autism community, and to be respectful of neurodiversity, the term 'autism spectrum condition' (ASC) is used as a synonym for the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) term 'autism spectrum disorder' (ASD). Furthermore, 'ASC' is used interchangeably with 'autism' and 'autism spectrum' throughout this paper.

(Leyfer et al., 2006). Symptoms of depression may also present differently for autistic people, with increases in social withdrawal, aggression and crying being more common (Ghaziuddin et al., 2002). Furthermore, depressive symptoms overlap with behaviours typical to ASC (Mazzone Ruta & Reale, 2012). Prevalence rates have therefore been inconsistently reported to range from 5 to 82 percent (Shtayermman, 2007). Due to the challenges outlined above, mental health services have failed to meet the needs of adults with autism (Healthcare Today, 2012). Further understanding of depression, when experienced by autistic adults, is needed to improve assessment procedures, interventions and support for this population (Wigham, Barton, Parr & Rodgers, 2017).

2.1.2 Previous literature

Previous research has explored the aetiology of depression in the ASC population. Sterling, Dawson, Estes and Greenon (2008) examined the relationship between severity of ASC symptoms, level of cognitive ability and the occurrence of depressive symptoms in adults with ASC. It was concluded that individuals with ASC, who have an awareness of their social difficulties, are more likely to experience depression than those without awareness. Additionally, it was reported that individuals who have an interest in social interaction, but do not have the skills to execute successful social relations, are at increased risk of experiencing depression (Ozonoff, McPartland & Dawson, 2002). It is therefore possible that having the motivation to form social relationships, and an awareness of an impaired ability to do so, contributes to negative affect (Sterling et al., 2008; Vickerstaff, Heriot, Wong, Lopes & Dossetor, 2007).

Hedley and Young (2006) investigated social comparison processes and depression in children and adolescents with autism. The perception of differences between self and others was reported to be related to depressive symptoms, and it was concluded that social comparison is a prominent factor related to depressive symptoms in this group. Sterling and colleagues (2008) supported this finding and reported that depression is more common in autistic adolescents as they develop an awareness of societal expectations to establish significant relationships, increase independence, and gain employment. Awareness of a developmental gap between themselves and their peers may therefore be part of the experience of depression for this population.

However, this research focused on depression in children and adolescents and therefore lacks generalisability to the adult population.

Depression in ASC has also been associated with increased suicidality, with up to 72 percent of cases reporting suicidal ideation (Zahid & Upthegrove, 2017). A history of depression has been identified as a significant risk factor, however, Cassidy and colleagues (2014) found that more individuals in their study reported suicidal ideation than had a history of depression. This may indicate a different route to suicidality for persons with ASC. Alternatively, depressive symptoms may have been under reported by this sample because of their difficulties describing their subjective emotional experiences (Lombardo, Barnes, Wheelwright & Baron-Cohen, 2007).

Penney (2013) explored experiences of four adolescents diagnosed with ASC and co-occurring depression, as well as those of their parents. The participants discussed school related issues, prevention of victimisation and mental health issues. Findings indicated that significant teasing from peers, and an awareness of difference, contributed to the experience of low mood. Additionally, depressive symptoms, such as becoming increasingly withdrawn and losing interest in favourite topics, were reportedly dismissed by professionals as being part of ASC. The young people and their parents therefore felt left to navigate mental health issues on their own, with little support from professionals. As this study focussed on the experiences of adolescents further research is required to develop an understanding of the experiences of adults with ASC and depression.

Capps, Kasari, Yirmiya and Sigman (1993) pointed to a lack or absence of emotion in people with ASC. However, Jones, Zahl and Huws (2001) used a thematic approach to analyse first-hand accounts of five autistic people, who had published their experiences online, and found evidence to the contrary. This study reported that emotional issues were important to this population and depression was communicated as a significant emotion. Within these accounts, depression was related to a sense of not belonging, difficulties understanding why they were different and being ridiculed by others. As analysis was conducted on accounts that were published online, it was not possible for the researchers to further explore the individuals' experiences of depression.

2.1.3 Rationale

Research has primarily focused on measuring the prevalence of depression in ASC. Nevertheless, there are inconsistencies in the rates reported, highlighting the need for further understanding of depression, how it presents, and how it is experienced by individuals with autism. Research has begun to uncover a relationship between social difficulties, awareness of these difficulties, social comparisons and depression. However, research in this area has largely situated itself within a positivist approach, leaving the subjective lived experiences of persons with ASC poorly understood (Gaudion, Hall, Myerson & Pellicano, 2015). This may be due, in part, to the difficulties individuals with autism have verbally describing their subjective emotional experiences (Lombardo et al., 2007). However, Jones and colleagues (2001) highlighted the importance of communicating about depression for people with autism. What is needed is an innovative approach to accessing the subjective emotional experiences of autistic individuals.

2.1.4 Aim

This study aimed to explore how autistic adults experience depression and low mood.

2.2. Method

2.2.1 Research Design

An Interpretative Phenomenological Analysis (IPA) design was employed to explore the lived experiences of adults with autism who experience low mood or depression. IPA is grounded in the fundamental principles of three different theoretical orientations; phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009). IPA is rooted in phenomenology as it is concerned with how individuals perceive objects and events, rather than with objective records of the object or event itself (Arroll & Senior, 2008). IPA is also grounded in hermeneutics; in a bid to get as close to the participants' world as possible, the researcher engages in a dynamic, dual interpretation process, whereby the participants make meaning of their world, through actively interpreting the events, objects and people in their lives, and the researcher decodes that to make sense of the participant's meaning making

(Smith & Osborn, 2003). Finally, IPA focuses on the particular rather than the universal, thus drawing upon idiography (Smith, Harre & Van Langenhove, 1995).

IPA is an appropriate method of analysis because it is concerned with understanding lived experience and how participants themselves make sense of their experiences. As IPA acknowledges potential discrepancies between the participants' words and the researcher's interpretations, treats participants as experts, and attempts to equalise the balance of power between autistic informants and non-autistic researchers, it can be argued that it is an effective qualitative approach in autism studies (MacLeod, Allan, Lewis & Roberston, 2018; Howard, Katsos & Gibson, 2019).

2.2.1.1 Reflexivity and the researcher's position

Researcher's reflexivity is fundamental in the validity of qualitative research as the researcher's experiences are brought to the research (Patton, 2002). The author's position as a white, female professional who does not have lived experience of being on the autism spectrum (AS) will have somewhat impacted the interpretation of the data. To address the challenge of remaining objective and impartial, all members of the research team engaged with a bracketing interview (Tufford & Newman, 2010). The lead researcher also kept a reflective journal throughout the research process to record thoughts and feelings that arose in response to the research process and to reflect on her relationship with the participants.

The researcher adopted an interpretivist position when conducting this research. In contrast to positivism's naïve realism, rather than believing that there is a single objective external reality, interpretivism theorises that multiple, equally valid realities exist (Schwandt, 1994). Thus, it is posited that reality is constructed in the mind of the individual (Hansen, 2004). It is also thought that meaning can be brought to the surface through reflection stimulated by an interactive researcher-participant dialogue (Schwandt, 2000). Through this process, the researcher and participant co-construct findings and attempt to gain insight into what life is like for an individual.

2.2.2 Participants

2.2.2.1 Sampling design

A non-probability, purposive sampling method was adopted, specifically seeking to include adults who had experience of both autism and low mood or depression. As this research was concerned with the detailed accounts of individual experiences, a small sample was recruited. The concentrated focus on a small number of cases allowed for the unique quality of individual stories to be explored (Weber Cannon, Higginbotham & Leung, 1998).

2.2.2.2 Inclusion and exclusion criteria

To maximise homogeneity of the sample, a range of inclusion and exclusion criteria were employed (Table 2.1). Adults aged 18 to 65 years with a formal diagnosis of autism, who also identified as having current difficulties with low mood or depression, were eligible to participate in this study. Individuals with formal diagnoses of learning disability or bipolar disorder were excluded from participation. Furthermore, to minimise risk to participants, individuals were excluded if they were in receipt of intervention from Crisis Resolution and Home Treatment Services (CRHT). Participants were not excluded if they had received care from a CRHT historically.

Table 2.1 *Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
Identify as having autism	Additional learning disability
Aged 18-65	Aged <18, or >65
Diagnosis of depression or self-reported low mood	Diagnosis of depression as part of Bipolar disorder
Not in receipt of crisis intervention	In receipt of crisis intervention
Able to give informed consent	Not able to give informed consent

2.2.2.3 Participant characteristics

A total of seven men and one woman with a formal diagnosis of Asperger's syndrome⁷ took part in the study. Participant ages ranged from 19 to 51 ($M=31.75$, $SD=12.7$). Six participants had received a formal diagnosis of depression, whilst two identified as experiencing low mood that affected their functioning. Table 2.2 provides further demographic information for the participants.

⁷ Although Asperger's syndrome is no longer recognised as a diagnostic label in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013), all participants were diagnosed with and continued to identify with the label.

Table 2.2 *Participant characteristics*

Participant (pseudonym)	Age	Gender	ASC Diagnosis	Mood	Employment status	Medication for mood/anxiety	Marital status	Ethnicity
Dawn	35	Female	Asperger's syndrome	Diagnosis of depression	Student	Lamotrigine Fluoxetine	Single	White British
Jason	21	Male	Asperger's syndrome	Diagnosis of depression	Student	None	Single	White British
Dennis	39	Male	Asperger's syndrome	Diagnosis of depression	Student	None	Single	White British
Howard	19	Male	Asperger's syndrome	Low mood that affects functioning	Student	None	Single	White British
David	20	Male	Asperger's syndrome	Diagnosis of depression	Employed	None	Single	White British
Michael	46	Male	Asperger's syndrome	Low mood that affects functioning	Employed	Fluoxetine	Co-habiting	White British
Ryan	23	Male	Asperger's syndrome	Diagnosis of depression	Employed	None	Single	White British
Peter	51	Male	Asperger's syndrome	Diagnosis of depression	Self-employed	None	Married	White British

2.2.3 Procedure

2.2.3.1 Ethics

Ethical approval was received from Coventry University Ethics Committee (Appendix F).

2.2.3.1.1 Consent

Written informed consent was obtained from all participants in accordance with the British Psychological Society Code of Ethics and Conduct (2018). A Participant Information Sheet (Appendix G) and Informed Consent Form (Appendix H) were co-designed with experts by experience to ensure that the information was accessible to individuals with ASC without co-occurring learning disabilities. Potential participants were all informed about what participation would involve, their right to withdraw from the study and their rights to anonymity and confidentiality.

2.2.3.1.2 Protecting participants from harm

As participants were asked to think about and reflect upon depression and low mood there was potential to elicit strong emotions. Clinical judgement was used throughout the research process to ensure that participants' wellbeing was of primary concern. Participants were offered breaks during interview and provided with debrief information (Appendix I).

2.2.3.1.3 Confidentiality and anonymity

Personal details were provided by participants so that they could be given further information about the study, and if appropriate, invited to interview. Personal data was stored for the minimum time necessary; until the information had been used to contact the individual, provide information, and arrange an interview. Following the completion of these tasks personal data was deleted. Furthermore, whilst being stored, the information was saved on an encrypted digital storage device.

Interviews were recorded and transcribed verbatim. To ensure confidentiality, all data, including audio files, were saved on a password protected data storage device, and all transcripts were pseudonymised at the point of transcription. Edited transcript excerpts are included in the results section.

2.2.3.2 Materials

A short Screening Questionnaire (Appendix J) was used to ensure participants met the inclusion criteria outlined in Table 2.1. Demographic information was also collected using a short questionnaire (Appendix K).

A semi-structured Interview Schedule (Appendix L) was prepared in line with the recommendations of Smith and colleagues (2009). Questions were open-ended and designed to invite participants to narrate, and then reflect upon, their experiences of depression and low mood. Three experts by experience were consulted on the design of the interview schedule.

A specially formatted Mood Diary (Appendix M) was also designed in collaboration with the experts by experience. The diary prompted participants to record thoughts, feelings and behaviours associated with their mood. Space was also provided for drawings, to enable participants to communicate however they felt most comfortable.

2.2.3.3 Recruitment

Participants were invited to participate through online advertisements posted by Warwick University's Disability Services and Coventry University's Health and Wellbeing Department. Potential participants were also informed about the research by clinicians at a private assessment service based within the West Midlands. Eleven potential participants contacted the lead researcher to express an interest in taking part. All responders were sent the Participant Information Sheet (Appendix G) and Screening Questionnaire (Appendix J). Eight out of the eleven individuals met the inclusion criteria and were eligible to take part. Three potential participants were excluded due to experiencing depression as part of bipolar disorder.

Eligible participants were invited to attend a preparatory meeting where they were provided with opportunity to ask questions before signing consent. In line with previous autism studies, participants also had opportunity to familiarise themselves with the Interview Schedule (Cridland, Jones, Caputi & Magee, 2014; Griffith, Totsika, Nash & Hastings, 2012; Huws & Jones, 2015; MacLeod et al., 2018; Petalas, Hastings, Nash & Duff, 2015). Furthermore, during this meeting participants completed the Demographic Information Form, collected their Mood Dairy and arranged for interview.

2.2.3.4 Data collection

Two data collection methods were employed to explore the perspective of individuals who typically have difficulty verbally expressing their experiences.

2.2.3.4.1 Interviews

All participants took part in a semi-structured interview. Interviews were conducted between 6th August 2018 and 30th November 2018. The location of the interview varied to accommodate the needs of each participant and included the participants' home ($n=1$), Warwick University premises ($n=2$) and Coventry University premises ($n=5$). Interviews lasted between 38 and 85 minutes ($M=56$). Time was allocated at the end of each interview for participants to reflect on the process of taking part. Debrief Information was also provided (Appendix I).

2.2.3.4.2 Diaries

Autistic people can have difficulties with social communication (Leyfer et al., 2006). Diaries are a useful, less intrusive data collection tool that can be used in addition to interviews to provide access to meaningful information (Humphrey & Lewis, 2008). Participants were invited to complete daily entries in a semi-structured diary (Appendix M) for one week prior to attending for interview. Participants were encouraged to communicate in their diaries through any medium that conveyed their experience of mood, including drawings. Inviting participants to express their experiences of mood in this way offered an innovative way for persons who may struggle to express themselves verbally to communicate their experiences (Coates, 2002). All participants made daily entries in their diaries and were invited to refer to their entries during interview.

2.2.4 Data Analysis

All interviews were audio-recorded and transcribed verbatim, with identifying information omitted or substituted to preserve participants' identity. Following transcription, the interview transcripts and diary entries were analysed using IPA. In line with the procedure set out by Smith and colleagues (2009), the researcher began by listening to the first audio recording and reading the corresponding transcript multiple times, whilst writing freely in the margins about initial thoughts, emotions, and interpretations of the content. This technique, 'free coding', allowed for the

recognition of any preconceptions, and their impact on the researcher's understanding of the data to be minimised (Elliott, Fischer & Rennie, 1999). Next, the researcher annotated each transcript line by line highlighting objects of concern; things that mattered to the participant. The focus was on experiential content and on identifying what the objects of concern meant to the participant, to allow for the identification of emerging themes. This process was repeated for each individual transcript and diary entry. The emerging themes were then clustered together, given labels, and the relationships between them were considered. At this point themes that had not been supported by evidence were eliminated. An account of the IPA procedure, including extracts from coded transcripts and maps of emergent themes are included in Appendix N and Appendix O.

One participant opted to draw in their diary to communicate regarding their experience of low mood. The power of drawings is not in the diagnostic power of the images themselves, but in the discussions that emerge because of them (Vince, 1995). To interpret the drawings independent of the participants would likely result in omissions and misinterpretations (Kearney & Hyle, 2004). As such, the participant was invited to discuss their drawing, and a copy of the image has been included in the results to supplement the findings.

2.2.4.1 Validity and credibility

To increase validity of the initial coding, a second researcher provided peer validation by coding transcript extracts. Procedures and initial interpretations of participants' responses were also recorded in a research diary. Additionally, themes were co-developed by all members of the research team and relevant transcript excerpts have been included in the results to validate the emergent themes and give readers a sense of the participants' experience.

2.3 Results

Three superordinate themes emerged from the analysis: *"Autism has made me the person I am"*, *"I can't function in the world"* and *"It's like trying to do accounts on the futures market"*: *Making sense of emotions*. Each superordinate theme consists of three subordinate themes which are outlined in Table 2.3. Throughout the results, consideration is given to convergence and divergence within themes.

Table 2.3 *Superordinate and subordinate themes*

Superordinate themes	Subordinate themes
<i>“Autism has made me the person I am”</i>	a) <i>“I can’t say I’m normal”</i> b) <i>“Suddenly I had a reason”: Impact of diagnosis</i> c) <i>“I’m proud to say I’m on the spectrum”</i>
<i>“I can’t function in the world”</i>	a) <i>“I don’t really have a good enough working knowledge of relationships”</i> b) <i>“Trying to act normal”</i> c) <i>Finding “Common Connection”</i>
<i>“It’s like trying to do accounts on the futures market”: Making sense of emotions</i>	a) <i>Disconnect between mind and body: “It’s like someone has cut the cable”</i> b) <i>“Do my best to be a better me”</i> c) <i>“And then I had the therapy”</i>

Table 2.4 highlights which participants contributed to each subordinate theme.

Table 2.4 *Summary of Participant contributions to subordinate themes*

Participant (pseudonym)	Gender	“Autism has made me the person I am”			“I can’t function in the world”			“It’s like trying to do accounts on the futures market”: Making sense of emotions		
		“I can’t say I’m normal”	<i>“Suddenly I had a reason”: Impact of diagnosis</i>	<i>“I’m proud to say I am on the spectrum”</i>	<i>“I don’t really have a good enough working knowledge of relationships”</i>	<i>“Trying to act normal”</i>	<i>Finding “Common Connection”</i>	<i>Disconnect between mind and body: “It’s like someone has cut the cable”</i>	<i>“Do my best to be a better me”</i>	<i>“And then I had the therapy”</i>
Dawn	Female	✓	✓		✓	✓		✓	✓	✓
Jason	Male	✓	✓	✓	✓		✓	✓	✓	✓
Dennis	Male	✓	✓	✓			✓	✓	✓	
Howard	Male	✓	✓		✓	✓		✓		
David	Male	✓	✓	✓	✓	✓		✓	✓	✓
Michael	Male	✓	✓	✓	✓	✓		✓	✓	✓
Ryan	Male	✓	✓	✓	✓		✓	✓	✓	
Peter	Male	✓	✓		✓	✓	✓	✓	✓	✓

2.3.1 “Autism has made me the person I am”

All participants reflected on how autism had shaped their identity. This superordinate theme consists of three subordinate themes: “*I can’t say I’m normal*”, “*Suddenly I had a reason*”: *Impact of diagnosis* and “*I’m proud to say I’m on the spectrum*”.

2.3.1.1 “I can’t say I’m normal”

Five participants reflected that, from a young age, they developed an awareness that they were “*significantly different*” from their peers. Dennis described himself as “*weird compared to other people*” and reflected that many of his “*autistic traits*” such as being “*blunt*”, and fixating on limited interests, were “*not normal in society*”. Several participants also shared that they think differently, with David explaining that he “*computes things differently*” to other people. Across the narratives, there is a sense that awareness of these differences has a negative impact on both their beliefs about themselves, and their mood.

“Being on the - adults on the spectrum ... I can't say we're normal. I can't say I'm normal. Erm, it's hard to sort of fit in. Erm, and I think that also has a bit of an impact on having low mood and depression. Especially if you can't fit in.”

(Jason, 348-351)

For Dawn, being unable to “*fit in with what the world was doing*” contributed to the belief that she is “*a failed person*” and “*a loser*”. Similarly, Peter talked of how he would often be engaged with “*negative self-conversation*”, in which he would attack and criticise himself for his perceived social failings, thus maintaining his low mood.

Additionally, several participants intimated that being autistic made up a large part of who they were as an individual. Peter shared that autism was at the “*root*” of his social and emotional difficulties and was therefore not a positive condition to have. Conversely, Dennis viewed autism as only one part of his identity and communicated that he would likely struggle to regulate his emotions even if he was not on the spectrum.

“A lot of that that probably naturally comes from just being who I am without - you know, you take the Asperger’s away and I’d probably be reasonably frustrated and angry with a lot of stuff.”

(Dennis, 316-319)

2.3.1.2 “Suddenly I had a reason”: Impact of diagnosis

All participants spoke about receiving a diagnosis of autism. Six participants reached adulthood before their ASC was recognised, whereas two participants received a diagnosis in primary school. When reflecting on life pre-diagnosis, those who were diagnosed in adulthood described a desire to understand themselves and find a satisfactory explanation for their difficulties.

“I have had so much, you know, experience of depression and anxiety from my teen years really. You know, I’d been always looking for a cause or you know, a reason and err, erm, you know, couldn’t really find anything satisfactory. You know, err, I - I just - most of my adult life I think has been spent trying to home in on what might be at the route of, you know.”

(Peter, 113-119)

Commonly, participants described how receiving a diagnosis of autism helped contextualise and make sense of their difficulties, including depression. Peter felt that being depressed and anxious “*stemmed err, you know, in large part from being autistic in the first place*”, whilst Michael explained that a diagnosis of autism contextualised his “*less favourable traits*” and allowed for the development of a more favourable self-opinion.

“I said in the past I was either autistic or I was an arsehole. Erm, you know, and it’s nice that there might be a reason.”

(Michael, 241-244)

Six participants spoke about a need to process and come to terms with the diagnosis, which was described as “*poignant*” by Peter. There was a sense that Peter was mourning for the “*prime of [his] life*” and felt as though he had been held back from achieving his full potential.

“Having that diagnosis at such a late stage, you know, erm, you know when the prime of life is in the past really so err, that was erm, I think I needed help as well.”

(Peter, 143-147)

Both Ryan and Jason were diagnosed in childhood and reflected more on the impact of diagnosis on others’ understanding of their difficulties, rather than their own. They perceived others to be less judgemental and more understanding towards their behaviours, particularly within their school environments. On the contrary, Dennis communicated that being labelled as having *“high functioning autism”* perpetuated others’ misunderstanding of his difficulties, as they assumed that being autistic did not significantly impact his ability to function.

“I think the biggest problem is that high functioning autism - I like the term but I don't like the understanding of the term because it seems to me that because people think that high functioning is my ability to function. It's not, it's my impact on other people, and I think that's the bit they don't get.”

(Dennis, 879-885)

2.3.1.3 *“I’m proud to say I am on the spectrum”*

Several participants reflected that there are benefits to being autistic. For example, Michael reflected that *“autism has made [him] a very driven and high functioning individual”*, whilst David noted that he had *“intrinsic technical abilities”* that had served him well. Ryan also attributed his positive personality traits, such as being *“honest”* and *“moralistic”*, to being autistic, and shared his belief that being autistic had more benefits than drawbacks.

“What it's like to have autism though is interesting. Because a lot of people see it as a negative, I don't really see it as a negative. Even though it has negative connotations in social settings I think that there's more benefits to the condition than there are drawbacks.”

(Ryan, 75-80)

Jason echoed Ryan's sentiment and stated that he is "*proud to say [he is] on the spectrum*". There is a sense that the unique qualities possessed as a result of being on the spectrum are integral to the participants' identity.

2.3.2 "*I can't function in the world*"

All participants reflected on their experience of interpersonal difficulties and the impact of those experiences on their mood. Three subordinate themes are discussed: "*I don't really have a good enough working knowledge of relationships*", "*Trying to act normal*" and Finding "*common connection*".

2.3.2.1 "*I don't really have a good enough working knowledge of relationships*"

Evident within many of the participants' narratives was the belief that they cannot, or should not, reach out to others for emotional support, or be honest with them about how they are feeling. Having to be self-reliant is described by Howard as "*one of [his] biggest problems*". He recounted how trying to deal with his problems alone often resulted in his problems becoming more difficult to deal with, rather than being resolved. Howard reflected that a key barrier preventing him from sharing his experiences with friends is his lack knowledge regarding social boundaries.

"I didn't really know what the boundaries are concerning emotional things so I just generally tend not to talk about that sort of stuff."

(Howard, 270-272)

This notion was supported by Michael, who shared that he had felt the need to be "*fiercely independent*" his whole life, and by Peter, who highlighted that being unfamiliar with the intricacies of relationships leaves him feeling unable to rely on others.

"I just don't really have a good enough working knowledge of relationships really - I can't count on anybody else really."

(Peter, 498-500)

Additionally, Peter highlighted that being "*isolationist*" was the only way to be "*fair*" to others, as he held the belief that being relied upon is burdensome for the other. Similarly, Dawn shared that she should "*tackle things on [her] own*" so as not to be a burden. A need to take personal responsibility and be proactive is therefore evident across participants' accounts.

Many participants shared that pursuing employment was difficult. Having limited capacity to read social situations contributed to Peter feeling like he was “*easy meat*” and “*a target*” in work environments. Dennis also recounted how, for the duration of his adult life, he had had difficulty maintaining steady employment. Dennis communicated that his employment difficulties were caused by the employers’ failure to make reasonable adjustments. Locating the problem externally, appeared to enable Dennis to continue pursuing employment. Conversely, Peter located the problem internally, and experienced high levels of shame regarding his occupational history, resulting in him isolating himself, for fear that others would cast judgement on his lack of success.

“I reached a point a long time ago where your employment history becomes a vast negative, erm, you know ... so social isolation has increased because I haven’t really been able to manage relations where you know it’s a case of erm, trying to cover up what you’re doing or not doing in terms of career path or even a job.”

(Peter, 229-244)

Feeling isolated as a result of interpersonal difficulties was a common theme. Dawn described feeling lonely and isolated even when in the company of others. Dawn’s use of the simile “*I felt like I was floating in space*” highlighted how disconnected, alone and helpless she can feel in social situations.

“I also felt lonely... isolated because people were talking and having fun but not with me. Erm. And that makes me feel sad because then I thought that people don’t enjoy talking to me so much. Erm, and - and err, that made me feel, erm, made me feel isolation and fragility. And lonely. [pause] because I felt like I was floating in space.”

(Dawn, 542-548)

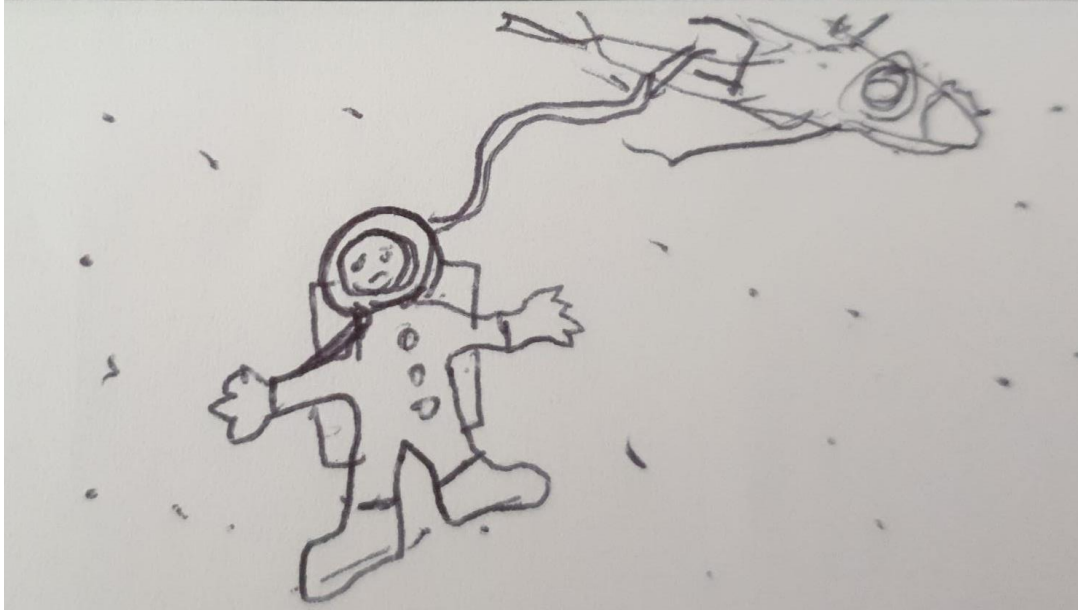


Figure 2.1 *“I felt like I was floating in space” as depicted in Dawn’s mood diary*

Furthermore, when discussing her experience of intimate relationships, Dawn highlighted that she lacked the necessary knowledge to enter into and sustain a meaningful intimate relationship. There is a sense in her account that being unable to fulfil the desired role of a partner negatively impacted her self-concept.

“Well I’d like to be in a relationship, but I don’t know how.”

(Dawn, 422-423)

2.3.2.2 *“Trying to act normal”*

Many participants reflected that typically, humans are *“social animals”*, and that to be *“normal”* they had learned strategies to navigate social interaction and *“fit in”*. Dawn explains how acting in line with what she *“should be doing and saying”* serves a social function, but also prevents her from engaging in a way that is authentic, leaving her with a sense of lost identity.

“I quite often feel like I’m somebody else that I know or I’ve seen talking or I remember talking with and then I feel like I’m them. Sometimes that’s fine and sometimes it’s not fine.”

(Dawn, 508-511)

Several participants also described limiting their interaction with others when feeling low in mood, as their capacity to draw on strategies that they had

developed to engage in social interaction was reduced. The perceived need to “*act normal*” was therefore related to the need to withdraw when feeling low.

“When I’m not feeling great I just don’t really have capacity to interact with people normally because I’m thinking about whatever is making me upset, and I just don’t feel like I have any capacity to recall what it is I’ve planned to say in the event of this conversation.”

(Howard, 256-261)

Additionally, participants spoke about the need to “*mask*” or hide their emotions from other people, in order to “*act normal*”. Michael communicated the impact of internalising his emotions in a bid to appear “*normal*”, highlighting how hiding his emotions appeared to perpetuate his low mood.

“I think I’ve tried to mask it. So, if I know I’m in a bad mood I still - I try not to show it, I still try to be civil to people. I don’t share the fact I’m in a bad mood. And I think I appear quite even. But I’m internalising it all. You’re not being honest with yourself or your emotions ... I think that is a stressor in itself.”

(Michael, 286-293)

2.3.2.3 Finding “*common connection*”

Four participants spoke about finding “*common connection*” with others who identified as autistic or had difficulties with their mental health. Ryan talked about befriending others who have “*something wrong with them*”, as they have shared experiences.

“You recognise when something isn’t quite right because you’ve got something not quite right with yourself. It could be that. It could just be that you tend to gravitate towards those that are a bit unusual because you feel an association with that.”

(Ryan, 48-56)

Similarly, Jason talked to the importance of being “*accepted*” and described being able to be his true self when around friends who also have Asperger’s. Dennis also highlighted that his friend who has personal experience of Asperger’s and bipolar is

“well used to dealing with people that are neuro-atypical”, indicating that having a *“shared experience”* increases understanding within the relationship, making it easier to sustain.

2.3.3 *“It’s like trying to do accounts on the futures market”: Making sense of emotions*

This superordinate theme arose from discussions of what it is like to feel low in mood or depressed. Three subordinate themes are considered: *Disconnect between mind and body*: *“It’s like someone has cut the cable”*, *“Do my best to be a better me”* and *“And then I had the therapy”*.

2.3.3.1 *Disconnect between mind and body: “It’s like someone has cut the cable”*

When talking about emotions, several participants described a very cognitive experience, whereby they would attempt to analyse their thoughts and reactions to ascertain what it was they were feeling.

“I just think this is what happened I felt x because of y that's interesting and why don't I research the neurochemistry behind it.”

(Howard, 134-137)

A desire to understand and make sense of their emotional experiences was also evident across the narratives. Michael shared that he felt able to recognise and understand how he was feeling without much difficulty, whereas all other participants spoke about how difficult, or even impossible it was for them to understand emotions.

“I guess it's like doing accounts basically except with emotions. You've got to kind of tally up and work out what's going on except emotions it's a lot harder to quantify and they're not always the same and they're also assumptions. It would be like trying to do accounts on the futures market.”

(David, 277-282)

David’s analogy of *“like trying to do accounts on the futures market”* highlighted that, because emotions are intangible and constantly changing, reconciling them is a difficult, if not impossible task.

Conversely, when talking explicitly about low mood, most participants described a physical embodiment, rather than a cognitive experience.

“It’s hard because you don’t exhibit things emotionally, but you do exhibit things physically. I am going to the toilet I am locked up, I am those things so you can physically see there is something going on ... it’s all sort of locked in ... I’m sort of inwardly exhibiting those symptoms and it’s all in the body not in the mind.”

(Ryan, 517-525)

Several participants reflected that they felt unable to control their physiological responses, or how their emotions are expressed. This is highlighted by Ryan who shared that when experiencing low mood, it is as though *“somebody has cut the cable”* between his mind and his body. This difficulty communicating and expressing emotions in a socially appropriate way also increases self-consciousness and fears of being negatively judged by others.

“What happens if people look at me and I’m not crying? Does that mean they think I’m insensitive? Or you know, you get quite self-conscious about it.”

(Ryan, 379-381)

Dennis also highlighted that having difficulty recognising and communicating about emotions is a barrier to being able to seek support.

“Asperger’s isn’t a lack of emotion, it’s an inability to process that emotion, or an ability to express that emotion to other people.”

(Dennis, 614-616)

2.3.3.2 *“Do my best to be a better me”*

All participants talked about various coping mechanisms that they had employed to cope with low mood and depression. Commonly, participants spoke about self-improvement and *“constantly striving”* to achieve. Dawn explained how achieving something was an effective way to *“offset the negativity”* that often accompanied daily life. David also spoke about being in a *“constant battle”* to *“do more”* when talking about coping with low mood, highlighting how difficult it is for him to do so.

Jason also reflected that pursuing personal and professional development opportunities helped him to be less critical and more accepting towards himself.

“It sort of settled with me that I can’t change who I am but I can like definitely do my best to be a better me I suppose.”

(Jason, 71-73)

Michael and Dawn spoke about using alcohol to cope with difficult feelings. Both reflected that relying on alcohol was maladaptive in the long term, and for Dawn, her reliance on alcohol became a problem.

“I felt depressed and erm started drinking more. Erm, and I carried on drinking a bit more and more. And that became a problem.”

(Dawn, 127-129)

Conversely, Dennis, Jason and Ryan identified coping mechanisms which they had found to be adaptive. For example, Dennis shared that joining the gym helped improve his mood, as did eating healthily. Whereas Jason noted that listening to his favourite music helped him cope. Several participants also commented on how talking to and spending time with friends and family helped lift their mood. Dennis found *“putting the world to rights with [his] mates”* beneficial, whereas Jason turned to his family and friends for help and support.

“I’ve always been able to bring myself back up with the sort of help and support of family and friends. And sort of knowing that I have people around me to support me and are always there for me. So erm, yeah for me it’s just remembering that.”

(Jason, 104-108)

Several participants spoke about their interests in the context of coping. It was evident that being able to pursue their interests was integral to the participants’ wellbeing, and Jason made reference to his interests providing him some relief and escapism.

“Gaming for me is my coping mechanism. Erm the sort of erm take myself away from reality and erm [pause] sort of put myself in that position instead.”

(Jason, 45-48)

Practical, problem solving approaches to emotional difficulties were discussed, with several participants referring to “*getting on with stuff*” and not letting emotions “*come out to play*”. Ryan also shared how he compartmentalised different areas of his life to maintain productivity and prevent emotional difficulties from hindering his ability to function.

“I think I’ve got a very unique way of living my life. I think - I’ve always referred it to people as compartments. I’m very good at dealing with situations because those situations themselves are isolated ... That’s how I am, and I think I’ve developed those spaces because of the bullying, because of the problems I had in school, and it was a way of dealing with it. Confine it to that compartment and you’ll be fine.”

(Ryan, 758-775)

2.3.3.3 “*And then I had the therapy*”

Five participants spoke about seeking professional support for their low mood or depression. Michael, Dawn, Peter, Jason and David all reflected on difficulties they had encountered when accessing or engaging with therapeutic support. Within the narratives a common theme of being dismissed or ignored by services arose.

“They were like we- yeah because I wasn’t a threat to myself, so they referred me to the university counsellor and then - but I heard nothing back.”

(Jason, 293-295)

David and Dawn both reflected on their experiences of Cognitive Behavioural Therapy (CBT). David’s overall experience of CBT was that it was helpful. However, he recognised that he struggled to complete between-session tasks and that being unable to fulfil the therapist’s expectations negatively impacted his mood. Furthermore, Dawn highlighted how having a poor therapeutic relationship with her therapist exacerbated her problems.

“And then had the CBT and that made - it didn't make things worse but it - [laughs] well it did makes things worse [laughs] I didn't get on well with it, or the person doing it.”

(Dawn, 137-140)

Several participants who had accessed therapy felt as though their therapist did not have a good enough understanding of autism. Dawn felt as though her therapist failed to acknowledge her “*suggestibility*”, or that she may have difficulty communicating.

“Give the person time to finish explaining. Don't put words in their mouth. Don't assume that you know what they're trying to say. Give them time to fully express.”

(Dawn, 165-167)

2.4. Discussion

This study was conducted to explore the lived experiences of autistic adults who experience low mood and depression. The participants' accounts revealed new insights regarding experiences that negatively impact mood for adults with autism.

2.4.1 Summary of findings

2.4.1.1 “Autism has made me the person I am”

Nearly all participants reflected that they were different from their peers, and that awareness of their differences negatively impacted their beliefs about themselves and their mood. This finding supports previous research that concluded that the perception of difference between self and others, and a sense of not belonging, is related to depressive symptoms (Hedley & Young, 2006; Jones et al., 2001).

Previous research also highlighted how experiencing feelings of difference, without a real understanding of why, causes individuals to internalise the negative attitudes of others and develop low self-esteem (Davies & Neal, 1996).

Punshon, Skirrow and Murphy (2009) reported that accommodating a diagnosis of ASC is a process that may take several months, if not years and highlighted how important receiving a diagnosis was to provide an explanation of behaviour. The current study supported these findings, as nearly all participants expressed 1) the belief that being diagnosed helped contextualise their difficulties and contributed to

improved self-opinions and 2) a period of readjustment was required to come to terms with the news. Moreover, participants reported pride in their unique abilities and personality characteristics, supporting previous research which highlighted that autistic traits can be helpful, depending on context (Russell et al., 2019).

2.4.1.2 “*I can’t function in the world*”

All participants reflected on their experience of interpersonal difficulties, and the impact of those experiences on their mood. Common amongst participant narratives was the belief that they did not have a good enough understanding of relationships. As a result, many participants chose to be self-reliant and experienced feeling alone and isolated. These findings support the assertion that increased levels of negative affect may be related to poor quality social relationships for people with ASC (Whitehouse, Durkin, Jaquet & Ziatas, 2008). These findings also support Gable and Sheen (2000) who highlighted that lower self-perceived social competence predicts depression.

Acting “*normal*” was a feat that participants felt was important. These findings highlighted that engaging in a way that is not authentic can contribute to a sense of lost identity. Additionally, attempting to “*mask*” or hide difficulties appeared to perpetuate low mood. Furthermore, several participants described withdrawing from social interaction when their ability to “*act normal*” was impacted by low mood, perpetuating their difficulties. This finding further supports Hedley and Young (2006) who concluded that a sense of loneliness, driven by poor social relationships, contributes to levels of depression.

Several participants made connections between their perceived limited capacity to read social situations, employment difficulties and subsequent negative affect. This finding supports Hurlbutt and Chalmers (2004) who reported that many people with ASC experience difficulties gaining and maintaining employment. Analysis of these accounts indicated that high levels of shame, and consequent withdrawal from social situations, can accompany difficulties maintaining employment. These findings corroborate previous research which asserted that employment difficulties negatively affect the wellbeing of autistic adults (Blustein, Kozan & Connors-Kellgren, 2013).

2.4.1.3 “It’s like trying to do accounts on the futures market”: Making sense of emotions

Regarding emotions, participants described a very cognitive experience whereby they attempt to develop insight into how they feel by analysing their thoughts, reactions, and the context around them. Several participants also identified a desire to understand their emotions, but an inability to do so. Many people with ASC report difficulty identifying and describing their emotions (Bird et al., 2010). Within this research, the inability to recognise and communicate emotions was understood as a barrier to seeking support. Similarly, participants within Camm-Crosby, Bradley, Shaw, Baron-Cohen and Cassidy’s (2018) study reported that having poor emotional literacy made it difficult for them to recognise and communicate that they needed support.

However, regarding low mood, nearly all participants described a very physical experience. It was reflected that having an inability to control their own physiological reactions increased feelings of self-consciousness and fears of being judged by others. This finding offers new insights into how low mood is experienced for this population.

Finally, it was evident that several participants experienced difficulties when accessing therapeutic support. It was felt that there is not enough mental health provision, and that clinical staff do not have a good enough understanding of autism, contributing to negative outcomes and perpetuating negative self-beliefs. These experiences are not unique to the participants included in this study; previous research highlighted that receiving support that is not tailored to individual needs contributes to feelings of disempowerment, isolation and hopelessness for autistic adults (Camm-Crosbie et al., 2018).

2.4.2 Limitations and future research

As only one female participant was eligible to take part in this research, the findings are based primarily on the experiences of males. It is recognised that the autism phenotype is altered for females, and that females with ASC are typically under-represented in research. Further research is therefore required to explore how females with ASC experience low mood and depression.

Three individuals were excluded from participating in this study because they had a diagnosis of bipolar disorder. Bipolar disorder is frequently diagnosed amongst adults with ASC (Magan-Maganto et al., 2018), however, there is a dearth of research on the experience of living with bipolar disorder (Proudfoot et al., 2009). A need for further research in this area is therefore indicated.

Experts by experience were consulted during the design stage of this study. However, individuals with ASC were not involved in the data-collection or data-analysis stages of this research. The exclusion of individuals with ASC from meaningful involvement, in all stages of the research process, is problematic and constitutes a barrier to research impact (Milton & Bracher, 2013). Further participatory action research, in which people with ASC engage as equal partners throughout the research process, is required (Nicolaidis et al., 2011).

Furthermore, validation strategies, such as member checking, were deemed inappropriate for this IPA study; the consolidation of several accounts, combined with the interpretation of the researcher and the passage of time, can make member checking counter-productive (Larkin & Thompson, 2012). Sample validation however may have further increased the validity of the results.

2.4.3 Clinical implications

This study indicated that achieving a late-in-life diagnosis can be valuable for adults; it can improve self-awareness and access to limited support. The need for tailored post-diagnostic support, to ensure individuals positively accommodate the diagnosis and identify their individual skills and strengths, is also evident.

Additionally, this research highlights the need for specialist services that cater to the diverse needs of adults with ASC. Clinicians working within mental health services require training to ensure they are knowledgeable about mental health and autism and are able to make reasonable adaptations (Ghaziuddin et al., 2002; Camm-Crosby et al., 2018).

Furthermore, as many people with ASC have difficulty identifying and describing their emotions, they may benefit from support with emotional literacy prior to engaging with psychological therapies. (Camm-Crosby et al., 2018). Psycho-education regarding emotions, and the link between feelings and physiology, may

also reduce the difficulties experienced by individuals who describe embodying their emotions. Moreover, several participants reported that they found the visual aid included with the mood diary incredibly helpful when attempting to identify and describe their emotions (Appendix M). Having access to visual aids may support communication regarding emotions, both inside and outside of therapy.

Finally, participants in this study described difficulties with establishing rapport with their therapist and with completion of in-between session tasks. These findings indicate that more long-term therapy is needed (Anderberg et al., 2017) and that in order to build mastery, assigned therapeutic tasks should be small. Recruiting a family member to support the individual with their therapy may also be beneficial.

2.5 Conclusion

This study has contributed to the limited literature concerning adults' experiences of ASC and low mood or depression. Supporting findings from previous research, participants shared how awareness of difference, feeling unable to "*function in the world*", and being unable to communicate a need for and access adequate support contributes to and maintains negative affect. These findings have significant clinical implications for healthcare providers.

2.6 References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th Ed.). Washington, DC: American Psychiatric Association.
doi:10.1176/appi.books.9780890425596
- Anderberg, E., Cox, J.C, Neeley Tass, E.S., Ereksan, D.M., Gabrielsen, T.P., Warren, J.S., ... South, M. (2017) Sticking with it: Psychotherapy outcomes for adults with autism spectrum disorder in a university counselling center setting. *Autism Research*, 10(12), 2048-2055. doi:10.1002/aur.1843
- Arroll, M.A., & Senior, V. (2008). Individuals' experience of chronic fatigue syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis. *Psychology and Health*, 23(4), 443-458.
doi:10.1080/14768320701246469
- Bird, G., Silani, G., Brindley, R., White, S., Frith, U., & Singer, T. (2010). Empathic brain responses in insula are modulated by levels of alexithymia but not autism. *Brain*, 133(5), 1515-1525. doi:10.1093/brain/awq060
- Blustein, D.L., Kozan, S., & Connors-Kellgren, A. (2013). Unemployment and underemployment: A narrative analysis about loss. *Journal of Vocational Behavior*, 82(3), 256-265. doi:10.1016/j.jvb.2013.02.005
- British Psychological Society. (2018). *Code of Ethics and Conduct*. Leicester: British Psychological Society.
- Brugha, T. S., Spiers, N., Bankart, J., Cooper, S., McManus, S., Scott, F.J., ... Tyrer, F. (2016). Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*, 209(6), 498-503. doi:10.1192/bjp.bp.115.174649
- Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2018). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*. doi:10.1177/1362361318816053

- Capps, L., Kasari, C., Yirmiya, N., & Sigman, M. (1993). Parental perception of emotional expressiveness in children with autism. *Journal of Consulting and Clinical Psychology, 61*, 475-484. doi:10.1037/0022-006X.61.3.475
- Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: A clinical cohort study. *Lancet Psychiatry, 1*, 142-147. doi:10.1016/S2215-0366(14)70248-2
- Coates, E. (2002). "I Forgot the Sky!" Children's stories contained within their drawings. *International Journal of Early Years Education, 10*, 21-35. doi:10.1080/09669760220114827
- Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders, 44*, 1261-1274. doi:10.1007/s10803-013-1985-6
- Davies, D. & Neal, C. (Eds.). (1996). *Pink therapy: A guide for counsellors and therapists working with lesbian, gay and bisexual clients*. Buckingham: Open University Press.
- Elliott, R., Fischer, C.T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229. Retrieved from <https://onlinelibrary.wiley.com/journal/20448260>
- Gable, S.C., & Sheen, G.D. (2000). Perceived social competence and depression. *Journal of Social and Personal Relationships, 17*(1), 139-150. doi:10.1177/0265407500171007
- Gaudion, K., Hall, A., Myerson, J., & Pellicano, L. (2015). A designer's approach how can autistic adults with learning disabilities be involved in the design process? *Co-Design, 11*(1), 49-69. doi:10.1080/15710882.2014.997829

- Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in persons with autism: Implications for research and clinical care. *Journal of Autism and Developmental Disorders*, 32(4), 299-306. doi:10.1023/A:1016330802348
- Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders*, 23(1), 147-163. doi:10.1007/BF01066424
- Griffith, G. M., Totsika, V., Nash, S., & Hastings, R.P. (2012). 'I just don't fit anywhere': Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, 16(5), 532-546. doi:10.1177/1362361311405223
- Hansen, J.T. (2004). Thoughts on knowing: Epistemic implications of counseling practice. *Journal of Counseling & Development*, 82(2), 131-138. doi:10.1002/j.1556-6678.2004.tb00294.x
- Healthcare Today. (2012). *Mental health services failing young people with autism*. Retrieved from <https://tinyurl.com/lc925ux>
- Hedley, D., & Young, R. (2006). Social comparison processes and depressive symptoms in children and adolescents with Asperger syndrome. *Autism*, 10(2), 139-153. doi:10.1177/1362361306062020
- Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism*. doi:10.1177/1362361318823902
- Humphrey, N. & Lewis, S. (2008) "Make me normal": The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism: An International Journal of Research and Practice*, 12(1), 139-62. doi:10.1177/1362361307085267
- Hurlbutt, K., & Chalmers, L. (2004). Employment and adults with Asperger syndrome. *Focus on Autism and other Development Disabilities*, 19(4), 215-222. doi:10.1177/10883576040190040301

- Huws, J.C., & Jones, R.S.P. (2015). 'I'm really glad this is developmental': Autism and social comparisons :An interpretative phenomenological analysis. *Autism*, 19(1), 84-90. doi:10.1177/1362361313512426
- Jones, R.S.P., Zahl, A., & Huws, J.C. (2001). First-hand accounts of emotional experiences in autism: A qualitative analysis. *Disability and Society*, 16(3), 393-401. doi:10.1080/09687590120045950
- Kanne, S.M., Christ, S.E., & Reiersen, A.M. (2009). Psychiatric symptoms and psychosocial difficulties in young adults with autistic traits. *Journal of Autism and Developmental Disorders*, 39(6), 827-833. doi:10.1007/s10803-008-0688-x
- Kearney, K., & Hyle, A. (2004). Drawing out emotions: The use of participant-produced drawings in qualitative enquiry. *Qualitative Research*, 4(3), 361-383. doi:10.1177/1468794104047234
- Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013-1027. doi:10.1016/S2215-0366(15)00277-1
- Larkin, M., & Thompson, A. (2012). Interpretative phenomenological analysis. In A. Thompson, & D. Harper (Eds.), *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. (pp. 99-116). Oxford: John Wiley.
- Leyfer, O.T., Folstein, S.E., Bacalman, S., Davis, N.O., Dinh, E., & Morgan, J., ... Lainhart, J.E. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. *Journal of Autism and Developmental Disorders*, 36(7), 849-861. doi:10.1007/s10803-006-0123-0
- Lombardo, V., Barnes, L., Wheelwright, J., & Baron-Cohen, S. (2007). Self-referential cognition and empathy in autism. *Plos One*, 2(9). doi:10.1371/journal.pone.0000883

- Macleod, A., Allan, J., Lewis, A., & Robertson, C. (2018). 'Here I come again': The cost of success for higher education students diagnosed with autism. *International Journal of Inclusive Education*, 22(6), 683-697.
doi:10.1080/13603116.2017.1396502
- Magan-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Monsterrat, A., Jenaro-Rio, C., Diez, C., & Canal-Bedia, R. (2018). Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders*, 59, 22-23.
doi:10.1016/j.rasd.2018.12.004
- Mazzone, L., Ruta, L., & Reale, L. (2012). Psychiatric comorbidities in Asperger syndrome and high functioning autism: Diagnostic challenges. *Annals of General Psychiatry*, 11(16). doi:10.1186/1744-859X-11-16
- Milton, D., & Bracher, M. (2013). Autistics speak but are they heard? *Medical Sociology online*, 7(2), 61-69. Retrieved from <http://www.medicalsociologyonline.org/>
- Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Ashkenazy, E., Boisclair, C., ... Baggs, A. (2011). Collaboration strategies in non-traditional community based participatory research partnerships: Lessons from an academic-community partnership with autistic self-advocates. *Progress in Community Health Partnerships: Research, education and Action*, 5(2), 143-150.
doi:10.1353/cpr.2011.0022
- Ozonoff, S., McPartland, J., & Dawson, G. (2002) *A parent's guide to Asperger's syndrome and high functioning autism: How to meet the challenges and help your child thrive*. USA: Guildford Press.
- Patton, M.Q. (2002). *Strategic themes in qualitative inquiry: Qualitative Research and Evaluation Methods* (3rd ed.). Thousand Oaks, CA: Sage Publications Ltd.
- Penney, S.C. (2013). Qualitative investigation of school-related issues affecting individuals diagnosed with autism spectrum disorder and co-occurring anxiety and/or depression. *Autism Insights*, 5, 75-91. doi:10.4137/AUI.S10746

- Petalas, M., Hastings, R., Nash, S., & Duff, S. (2015). Typicality and subtle difference in sibling relationships: Experiences of adolescents with autism. *Journal of Child and Family Studies*, 24(1), 38-49. doi:10.1007/s10826-013-9811-5
- Proudfoot, J. G., Parker, G.B., Benoit, M., Smith, M., & Gayed, A. (2009). What happens after diagnosis? Understanding the experiences of patients with newly-diagnosed bipolar disorder. *Health Expectations*, 12(2), 120-129. doi:10.1111/j.1369-7625.2009.00541.x
- Punshon, C., Skirrow, P., & Murphy, G. (2009). The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, 13(3), 265-283. doi:10.1080/1362-3613.2009.00541.x
- Roy, M., Prox-Vagedes, V., Ohlmeier, M.D., & Dillo, W. (2015). Beyond childhood: Psychiatric comorbidities and social background of adults with Asperger syndrome. *Psychiatria Danubina*, 27(1), 50-59. Retrieved from <http://www.psychiatria-danubina.com/>
- Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the autistic advantage from the accounts of adults diagnosed with autism: A qualitative study. *Autism in Adulthood*, 1(2). doi:10.1089/aut.2018.0035
- Schwandt, T.A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 118-137). Thousand Oaks, CA: Sage.
- Schwandt, T.A. (2000). Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructionism. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 189-213). Thousand Oaks, CA: Sage.
- Shtayermman, O. (2007). Peer victimization in adolescents and young adults diagnosed with Asperger's syndrome: A link to depressive symptomatology, anxiety symptomatology and suicidal ideation. *Issues in Comprehensive Pediatric Nursing*, 30(3), 87-107. doi:10.1080/01460860701525089

- Smirnoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8), 921-929. doi:10.1097/CHI.0b013e318179964f
- Smith, J.A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative Psychology: A practical Guide to Methods* (pp. 53-80). London: Sage.
- Smith, J.A., Harre, R., & Van Langenhove, L. (1995). Idiography. In: J.A. Smith, R. Harre, & L. Van Langenhove (Eds.), *Rethinking psychology* (pp. 56-69). London: Sage.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London, England: Sage.
- Sterling, L., Dawson, G., Estes, A., & Greenson, J. (2008). Characteristics associated with presence of depressive symptoms in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 38(6), 1011-1018. doi:10.1007/s10803-007-0477-y
- Tufford, L., & Newman, P. (2010). Bracketing in qualitative research. *Qualitative Social Work*, 11(1), 80-96. doi:10.1177/1473325010368316
- Vickerstaff, S., Heriot, S., Wong, M., Lopes, A., & Dossetor, D. (2007). Intellectual ability, self-perceived social competence, and depressive symptomology in children with high-functioning autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 37(9), 1647-1664. doi:10.1007/s10803-006-0292-x
- Vince, R. (1995). Working with emotions in the change process: Using drawings for team diagnosis and development. *Organisations and People*, 2(2), 11-17. Retrieved from <https://www.amed.org.uk/page/organisations-people-magazine>

- Weber Cannon, L., Higginbotham, E., & Leung, M.L.A. (1998). A conceptual framework for understanding race, class, gender, and sexuality. *Gender & Society*, 22(1), 13-32. doi:10.1111/j.1471-6402.1998.tb00139.x
- Whitehouse, A.J., Durkin, K., Jaquet, E., & Ziatas, K. (2008). Friendship, loneliness and depression in adolescents with Asperger's syndrome. *Journal of Adolescence*, 32(2), 309-22. doi:10.1016/j.adolescence.2008.03.004
- Wigham, S., Barton, S., Parr, J.R., & Rodgers, J. (2017). A systematic review of the rates of depression in children and adults with high-functioning autism spectrum disorder. *Journal of Mental Health Research in Intellectual Disabilities*, 10(4), 267-287. doi:10.1080/19315864.2017.1299267
- World Health Organisation. (2018, March 22). *Depression*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/depression>
- Zahid, S., & Upthegrove, R. (2017). Suicidality in autistic spectrum disorders: A systematic review. *The Journal of Crisis Intervention and Suicide Prevention*, 38(4), 237-246. doi:10.1027/0227-5910/a000458

Chapter Three

Reflections on conducting autism research

The word count for this chapter, excluding references and footnotes, is 3,327

3.1 Introduction

The concept of reflective practice is well established in clinical psychology; that is, the necessity of being aware of your own thoughts, feelings and position, and how they impact upon the therapeutic, or in this instance, research process (Johnstone & Dallos, 2014). Reflective practice is increasingly valued in the area of clinical psychology training (Binks, Jones & Knight, 2013). Additionally, I value the importance of self-awareness and the need to reflect on my own practice in order to continue my personal and professional development.

Within this chapter, I present first-person reflections on the research contained within this thesis. Throughout my time on clinical training I kept a record of my learning experiences in a reflective journal. This report has been shaped by key themes that were identified within the journal. Themes include my motivations for researching autism and low mood, ethical and methodological considerations made due to the nature of the research and recognising and challenging my own assumptions.

Each theme is discussed in turn, and reflections were guided using Gibbs' (1988) six step model of reflection (Appendix P). This model offers a framework for examining experiences, and its cyclic nature facilitates learning and planning for future situations. Throughout this paper, in line with Gibbs' (1988) model, I have included descriptive information, reflected on my feelings and evaluated what worked and what did not in order to draw conclusions. Additionally, I have discussed ways in which I will adapt my clinical and research practice following these reflections. Where appropriate, Acceptance and Commitment Therapy (ACT) has also been drawn upon to shape the presented reflections. ACT is an action-oriented psychological model, which aims to increase psychological flexibility; being open to and aware of your experiences so that you can move forward in valued directions (Hayes, Strosahl & Wilson, 2012). ACT is drawn upon to consider my experiences in the context of my values as a clinician and a researcher.

3.2 Why research autism and low mood?

My interest in autism was sparked when I was completing my undergraduate studies, and I volunteered as an applied behaviour analysis (ABA) therapist for children with

autism and their families. Through this work, I began to learn about autism, and the impact it can have on children and their caregivers. I was interested in learning about how autism is experienced by adults, and quickly became aware of the lack of research in this area, despite autism being a life-long condition. It was when working in a private clinical psychology service that my interest in exploring autism and mood was ignited. During initial assessments, clients with autism⁸ repeatedly recounted how they had struggled to access appropriate mental health support, have their needs met and have their voices heard. I therefore recognised opportunity to meaningfully contribute to an area of neglected research, whilst also giving voice to a population who are under-represented in the literature.

I felt motivated to enable people with autism to tell their stories and share their experiences. However, I also felt apprehensive. Endeavouring to give voice to a population, who inherently have difficulties with social communication, was recognised as a challenge (Lombardo, Barnes, Wheelwright & Baron-Cohen, 2007). Significant thought was required to ensure that the research could successfully access the subjective experiences of adults with autism. Several methodological and ethical considerations were therefore made and are discussed below.

3.3 Ethical and methodological considerations

3.3.1 Meaningful involvement

Before embarking on clinical training, I completed a research project which evaluated participatory action research methods within the context of mental health. It was whilst completing this research that I became aware of, and passionate about, the meaningful involvement of relevant stakeholders, in all stages of research. Regarding autism studies, it has been recognised that people with autism are often treated as objects of research, rather than active participants, thus limiting research impact (Milton & Bracher, 2013).

Thought was therefore given to how to involve experts by experience in the empirical research project, beyond the role of participant. As reported, three autistic volunteers were involved in the initial stages of the research. The experts by

⁸ Use of language when referring to people who have received a diagnosis of autism is discussed within this chapter, under the heading 'What is in a name?'.

experience made invaluable contributions to the research question, research design and study materials. For example, to facilitate communication regarding emotions, one volunteer recommended providing participants with a visual aid that could be utilised both when writing in their mood diaries and participating in interview (Appendix L). Additionally, through this collaboration, it was highlighted that some of the proposed questions included figurative, none-literal language, that may have acted as a barrier to communication for some autistic individuals. Moreover, the experts by experience brought to my attention some assumptions I had, which were conveyed in the included questions. For example, when asking participants to talk about support that they had received, the phrasing of the question assumed that participants would have sought and received support, whereas this may not necessarily have been the case.

Drawing on the expertise of adults with autism at the design stage of this research was therefore invaluable. However, experts by experience were not directly involved in the data collection or analysis processes. This raises issues, as the validity of autism research is complicated by the ‘double empathy problem’ (Milton, 2012). The ‘double empathy problem’ refers to the breakdown in reciprocity and mutual understanding that can occur between people of very differing dispositions (Chown, 2014). This misunderstanding threatens to undermine the validity of qualitative research which aims to explore the lived experiences of autistic people. As I was an ‘outsider’ researcher, with no lived experience of autism, the ‘double empathy problem’ posed a methodological issue. However, because of its double hermeneutic nature, interpretative phenomenological analysis (IPA) went some way to lessening the ‘double empathy problem’ and is one reason why this methodology was identified as appropriate for this project.

I felt that involving participants in validation processes such as member checking would be tokenistic, as from an IPA perspective, understanding was co-created, and there was no objective truth or reality to which the results of the study could be compared (Angen, 2000). Additionally, the results were a synthesis of several participants’ accounts, meaning ethical issues would have been raised if some participants validated the results whilst others did not. Whilst reflecting on the lack of stakeholder involvement in the data-collection and analysis stages of this research

I noticed myself feeling disappointed. Limited resources and the constraints of completing research as an academic component of a training course restricted opportunities for stakeholder involvement to a degree. However, if this research project was repeated, or I have opportunity to undertake autism research in the future, I would prioritise this issue and endeavour to involve stakeholders in all stages.

3.3.2 *What is in a name?*

3.3.2.1 *Person-first or identity-first language?*

Collaborating with experts by experience also led me to critically evaluate my use of language when referring to autism. Initially, I had assumed that ‘person with autism’ was the most respectful way to refer to an individual who had a diagnosis of autism, as it puts the person-first, and does not allow the condition to define the person. However, experts by experience highlighted that many people prefer identity-first language, such as ‘autistic person’, as they believe that autism is foundational to their identity, rather than an ‘add on’. The language used within the research materials was adapted to reflect this. However, there is no firm consensus within the community, with some people preferring person-first language. To be sensitive to this issue, the decision was made to use the terms ‘person with autism’ and ‘autistic person’ interchangeably throughout this thesis.

3.3.2.2 *ASC or ASD?*

Moreover, the term autism spectrum condition (ASC) is referred to throughout this thesis, whereas autism spectrum disorder (ASD) is not. This choice was made as the term ‘condition’ recognises both the disabling aspects and a profile of strengths. In contrast, the term ‘disorder’ implies broken and can perpetuate stigma. This linguistic choice is representative of my wish to empower autistic people to recognise their strengths as well as difficulties. Moreover, completing this project has made me more aware of my need to reflect on and challenge my own assumptions regarding the language I use in my clinical practice.

3.3.3 *Deviation from traditional IPA methodology*

To enable individuals with ASC to articulate their lived experience, conventional IPA guidelines were somewhat deviated from during data collection. For example,

during interview, rather than treating the interview as a one-sided conversation (Smith, Flowers & Larkin, 2009) content was regularly summarised back to participants to ascertain if I had understood what they were communicating to me. Smith and Colleagues (2009) assert that it is reasonable to check that you have understood the participant, but to be cautious in doing so, to avoid testing out interpretations and connections. However, frequently summarising back to the participants proved useful, as on occasion, participants told me I had not quite grasped their full meaning, prompting them to elaborate, thus furthering my understanding and enriching the data. This adaptation may benefit future autism research and enable autistic voices to be heard.

As a clinician, I value the importance of facilitating a therapeutic space in which I am working collaboratively with the client. IPA informed interviewing was therefore not too much of a departure, as the focus was on what the participant deemed important. In line with Smith and colleague's (2009) guidelines, the interview schedule was used as a guide, and was often deviated from to follow the concerns of the participant. However, a challenge arose when attempting to strike a balance between providing space for participants to talk about their interests and guiding the interview to ensure the research question was being addressed. This challenge was particularly pertinent, as it is recognised that people with autism can become fixated on topics of personal interest (American Psychiatric Association, 2013). Several participants spontaneously chose to self-monitor and apologised if they recognised that they had been talking about something that they thought was not directly related to low mood for a significant amount of time. For example, Peter stated "*Sorry, I've digressed, as is the want of autistics*".

As a researcher, with no 'insider' experience of autism, I was unsure whether lengthy digressions regarding interests were helpful, and therefore noticed an increase in my anxiety when these departures occurred. However, I recognised that for several participants, these discussions appeared to provide light relief and facilitated engagement with the interview. Additionally, these conversations provided opportunity for participants to successfully communicate about their world, amidst stories of being dismissed and unheard. Furthermore, these discussions contributed to important findings within the research regarding interests and low

mood, that had not been considered during the design stage of this research. These reflections highlight the benefit of allowing for additional time and space, within interviews, for autistic adults to talk freely about their interests.

3.3.4 Reflections on my position as a non-autistic researcher

On occasion, I felt uneasy during interviews when participants spoke about negative interchanges they had had with ‘neurotypical people’. I noticed that I felt particularly uncomfortable when participants were referring to difficulties that they had had communicating with professionals who had no lived experience of autism. I was very aware of my position as a non-autistic researcher, and of the possibility of replicating the experience of not being heard or understood within the context of interview. Being an ‘outsider’ meant that I could not claim to understand what it is like to be autistic and experience low mood. However, being an ‘outsider’ also meant that participants did not assume similarity. As such, participants may have explained their experiences more fully, facilitating a deeper insight into their experience and enriching the data.

Additionally, I was inviting participants to talk about their mood and emotions. Several participants spoke, in detail, about how they avoid sharing their feelings with other people, particularly those close to them, for fear of becoming a burden, and because of a limited understanding of what is acceptable to share. However, all participants did share their emotional experiences with me. My position as a researcher, who made explicit that my primary goal was to develop an understanding of how low mood is experienced, may have enabled participants to speak at length about their subjective experiences; something participants described having difficulty doing in both social and therapeutic contexts.

3.3.5 Making room for difficult emotions

Despite efforts to make interview questions accessible, prepare participants for the questions that would be asked and enable participants to feel comfortable during interview, it was my impression that, at times, some participants felt uncomfortable as a result of the questioning. For example, David communicated that on occasion, when engaging in conversation, he had difficulty responding to questions. David used a simile to illustrate how uncomfortable being in that position makes him feel:

“It's like sticking needles into a tensed muscle. That's like when someone is trying to ask you something and you just can't respond and they're like making it worse. But just yeah, it's literally like you tense up like a really tense muscle and if someone just accepts it and moves on you just kind of relax and flop and go back to wherever you were.”

(David, 594-599)

David made this statement after being asked “could you tell me a little bit more about that?” regarding a time when he had had difficulty communicating with a peer. In that moment I became acutely aware of the potential to cause discomfort or distress, even when talking about topics that I may perceive to be innocuous. Furthermore, I wondered if David was letting me know that prompting him to expand on his answer was “*making it worse*” for him. The thought of contributing to or causing discomfort as a result of participation in the research was a difficult one for me to tolerate. I was asking participants to reflect on personal and sensitive topics, and therefore the potential to elicit strong feelings was real. When working in a therapeutic capacity, I often support clients to connect with and accept difficult emotions, to assist them in reaching their therapeutic goals. Within my role as researcher however, I was asking people to reflect on and connect with strong emotions but felt that I was not giving anything back in return. As such, I noticed a pull to work therapeutically with the participants. However, after completion of interview, several participants, including David, reflected that having opportunity to tell their stories had validated their experiences. Several participants also offered to return for a second interview, indicating that although challenging, participating in interview had been a positive experience. I was therefore reminded that although participants received no direct benefit from taking part in the research, participation provided an opportunity to be listened to by someone that wanted to hear their story; an experience that many participants reflected was missing within their narratives.

Challenges associated with data analysis were overlooked when thinking about the ethical issues that may arise during this research. I was particularly struck by how emotional I found the transcription process. During interview, participants shared personal and sensitive information, and I heard what participants said. However,

when listening back, I had increased capacity to hear what the participants had said and to pay attention to my own reactions. I found myself feeling sad, and at times hopeless, when hearing about participants' experiences of low mood. Initially, in a bid to avoid these difficult emotions, I found myself avoiding transcribing. Through accessing supervision, I was able to make room for the difficult feelings that arose and consider how they may impact my interpretation of the data. Reflecting on this challenge also helped me to recognise the value of increasing my reflexive capacity within clinical sessions, to ensure that I can effectively use transference and countertransference to inform therapeutic decisions.

3.4 Challenging my assumptions

3.4.1 Addressing my own stereotypical beliefs

The way in which several participants communicated about their experiences brought to my attention my own stereotypical beliefs regarding how individuals who are on the autism spectrum may present. For example, in my reflective journal, I noted that I was surprised by several of the participants' abilities to use metaphors and similes to illustrate a point. I also noted that I was surprised by participants' apparent desire to engage in small talk pre and post interview. My surprise led me to wonder; if I had met these individuals in my capacity as clinician, would I have become just another 'professional' who had failed to recognise their difficulties in the context of autism? Reflecting on this issue has made me critical of my understanding of autism, and my clinical practice as a result.

3.4.2 Reflections on the utility of diagnosis

One outcome of the research detailed within this thesis was the recommendation that autism diagnoses be accessible for adults. As a trainee clinical psychologist, I value formulation and continually reflect on, and critically evaluate, the value of mental health diagnoses. Diagnoses presented in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) are based largely on social norms, and it can be argued that they reflect normal individual variation (Johnstone, 2013). It can also be argued that mental health diagnoses pathologise normal human suffering, and label what is 'wrong' with a person, whilst doing little to identify what a person needs. This critical position regarding mental health diagnoses is evidenced in the methodological choice to include participants

who identified as experiencing low mood but did not necessarily have a diagnostic label of depression. This methodological choice was also important given the difficulties that are evident in accurately identifying and diagnosing depression in the autistic population. Along the same line, individuals were invited to enquire about participation if they identified as autistic but did not necessarily have a formal diagnosis. However, all those who enquired about the research did in fact have a formal diagnosis.

Prior to conducting this research, I had also queried the value of autism as a diagnosis. I recognised that the DSM-5 (American Psychiatric Association, 2013) deficit and behaviour-based criteria for autism located the problem within the autistic person and failed to consider the interpersonal and societal factors that contribute to the challenges faced by autistic people (De Jaegher, 2013; Kapp, Gillespie-Lynch, Sherman & Hutman, 2013; Kenny et al., 2016). Being aware of my preconceived ideas regarding diagnoses enabled a more objective analysis of the participants' accounts. Had I not reflected on, and 'bracketed off' these opinions (Tufford & Newman, 2010), I may have been less able to identify the positive discourse regarding autism diagnosis that was included within participant narratives.

Although I still maintain a critical stance, and feel uncomfortable regarding the pathologising of human suffering, I am more accepting of the utility of diagnoses as a result of completing this research. This process has therefore made me more flexible in my thinking regarding diagnosis and has made me aware of the need to reflect on the function of diagnosis for each individual when working in clinical settings.

3.5 Conclusion

This paper aimed to present reflections on carrying out qualitative autism research. Reflecting on some of the methodological and ethical challenges encountered when conducting this research highlighted the need to adapt IPA methodology when exploring the lived experience of adults with autism. Additionally, through a process of continual reflection, I was able to identify and acknowledge my own values and assumptions regarding issues relevant to this research, including the utility of diagnoses and how autism may present. In doing so, I recognised that I

bring myself and my values to my work, and therefore cannot facilitate completely objective research. However, I also learned that in addressing my assumptions, their impact upon the research can be limited. Moreover, completing this research provided opportunity for me to reflect on and identify areas for improvement within my clinical practice.

3.6 References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th Ed.). Washington, DC: American Psychiatric Association.
doi:10.1176/appi.books.9780890425596
- Angen, M.J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. *Qualitative Health Research*, 10(3), 378-395.
doi:10.1177/104973230001000308
- Binks, C., Jones, F.W., & Knight, K. (2013). Facilitating reflective practice groups in clinical psychology training: A phenomenological study. *International and Multidisciplinary Perspectives*, 14(3), 305-318.
doi:10.1080/14623943.2013.767228
- Chown, N. (2014). More on the ontological status of autism and double empathy. *Disability & Society*, 29(10), 1672-1676. doi:10.1080/09687599.2014.949625
- De Jaegher, H. (2013). Embodiment and sense-making in autism. *Frontiers in Integrative Neuroscience*, 7(15). doi:10.3389/fnint.2013.00015
- Gibbs, G. (1988). *Learning by doing: a guide to teaching and learning methods*. Oxford: Further Education Unit, Oxford Polytechnic.
- Hayes, S., Strosahl, K.D., & Wilson, K.G. (2012). *Acceptance and commitment therapy: The process and practice of mindful change* (2nd ed.). London: Guildford Press.
- Johnstone, L. (August 19, 2013) *Alternatives to Psychiatric Diagnosis: Psychological Formulation*. Retrieved from <http://dxsummit.org/archives/1208>
- Johnstone, L., & Dallos, R. (2014). *Formulation in Psychology and Psychotherapy: Making sense of people's problems* (2nd ed.). Routledge: East Sussex.
- Kapp, S.K., Gillespie-Lynch, K., Sherman, L.E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*. 49(1), 59-71. doi:10.1037/a0028353

- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462. doi:10.1177/1362361315588200
- Lombardo, V., Barnes, L., Wheelwright, J., & Baron-Cohen, S. (2007). Self-referential cognition and empathy in autism. *Plos One*, 2(9). doi:10.1371/journal.pone.0000883
- Milton, D. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, 27(6), 883-887. doi:10.1080/09687599.2012.710008
- Milton, D., & Bracher, M. (2013). Autistics speak but are they heard? *Medical Sociology Online*, 7(2), 61-69. Retrieved from <http://www.medicalsociologyonline.org/>
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London, England: Sage.
- Tufford, L., & Newman, P. (2010). Bracketing in qualitative research. *Qualitative Social Work*, 11(1), 80-96. doi:10.1177/1473325010368316

Appendix A

Author Guidelines for Submission to the Journal Autism

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the [Aims & Scope](#).

1.2 Article Types

The Journal considers the following kinds of article for publication:

1. Research Reports. Full papers describing new empirical findings;
2. ReviewArticles
 - (a) general reviews that provide a synthesis of an area of autism research;
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1.3 Writing your paper

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As part of the submission process, you will be asked to provide the names of 2 peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
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All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

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6. On acceptance and publication

6.1 Lay Abstracts

Upon acceptance of your article you will be required to submit a lay abstract of your article to the Social Media Editor, Laura Crane (journalautism@gmail.com). Lay abstracts are brief (max 250 words) descriptions of the paper that are easily understandable. These abstracts will be made available to researchers and clinicians, as well as the general public (including individuals with autism spectrum disorders and their families). These abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

6.2 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.3 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the [SAGE Journals help page](#) for more details, including how to cite Online First articles.

6.4 Access to your published article

SAGE provides authors with online access to their final article.

6.5 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the [Promote Your Article](#) page on the Gateway for tips and advice. In addition, SAGE is partnered with Kudos, a free service that allows authors to explain, enrich, share, and measure the impact of their article. Find out how to [maximise your article's impact with Kudos](#).

Appendix B

Coventry University Ethics approval for Chapter One Systematic Review



Certificate of Ethical Approval

Applicant:

Amy Jordan

Project Title:

Experiences, perceptions and views of women on the autism spectrum: A systematic literature review

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

06 December 2018

Project Reference Number:

P79803

Appendix C

Critical Appraisal Framework (CAF) Criteria and Scores

	Bargiela et al., (2016)	Baldwin & Costley (2016)	Gardner et al., (2016)	Goodall & MacKenzie (2018)	Haney & Cullen (2017)	Hayward et al., (2018)	Kanfiszer et al., (2017)	Rogers et al., (2017)	Sedgewick et al., (2018)	Steward et al., (2018)	Tint & Weis (2018)	Vine Foggo & Webster (2017)	Webster & Garvis (2017)
1. Does the title reflect the content?	2	2	2	2	2	2	2	2	2	2	2	2	2
2. Are the authors credible?	2	2	1	2	2	2	2	2	2	2	2	2	2
3. Does the abstract summarise the key components?	2	2	1	1	2	2	2	2	2	2	1	2	2
4. Is the rationale for undertaking the research clearly outlined?	2	2	1	2	2	2	2	2	2	2	2	2	2
5. Is the literature review comprehensive and up to date?	2	2	2	1	2	2	2	2	2	2	2	2	2
6. Is the aim of the research clearly stated?	2	1	1	1	2	2	2	2	2	2	2	2	2
7. Are the ethical issues identified and addressed?	1	0	1	1	2	1	2	1	2	1	1	2	1
8. Is the methodology identified and justified?	2	2	2	2	2	2	2	2	2	1	2	2	2

9. Are the results presented in a way that is appropriate and clear?	2	2	2	2	2	2	2	2	1	2	2	2	2
10. Is the discussion comprehensive?	2	2	2	1	2	2	2	1	2	2	2	2	2
11. Is the conclusion comprehensive?	2	2	1	1	2	2	2	2	2	0	2	1	2
12. Is the mixed methods research design relevant to address the research questions?		2				2			2	2			
13. Is the integration of qualitative and quantitative data (or results) relevant to address the research question?		2				2			2	2			
14. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data?		1				1			1	1			
15. Is the study design clearly identified? Is the rationale for choice of design evident?		1				1			1	1			
16. Is there an experiential		1				2			2	1			

hypothesis clearly stated? Are the key variables clearly defined?													
17. Is the population identified?		2				2			2	2			
18. Is the sample adequately described and reflective of the population?		2				2			2	2			
19. Is there a control group? Are samples matched?		1				1			1	1			
20. Is the method of data collection valid and reliable?		2				2			2	2			
21. Is the method of data analysis valid and reliable?		2				2			2	2			
22. Are the results generalizable?		2				2			2	2			
23. Is the philosophical background and the study design clearly identified? Is the rationale for choice of design clear evident?	1	1	1	2	2	2	1	2	1	1	1	2	1
24. Are the major concepts identified?	2	2	2	2	2	2	2		2	2	2	2	2
25. Is the context of the study outlined?	2	2	1	2	2	2	2	2	2	1	1	2	1
26. Is the selection of the participants	2	2	1	2	2	2	2	2	2	2	2	2	2

described and the sampling method identified?													
27. Is the method of data collection auditable and relevant to address the research question?	2	2	1	2	1	1	2	2	2	2	2	2	2
28. Is the method of data analysis credible, confirmable and relevant to address the research question?	2	1	2	2	2	2	2	1	2	2	2	2	1
29. Is appropriate consideration given to how the findings relate to the researcher's influence?	1	1	1	0	1	1	1	0	0	1	1	1	1
30. Are the results transferable?	2	2	2	2	2	2	2	2	2	2	2	2	2
Total	35/38	50/60	27/38	30/38	36/38	54/60	36/38	31/38	53/60	49/60	33/38	36/38	33/38
Percentage	92%	83%	71%	79%	95%	90%	95%	82%	88%	82%	87%	95%	87%

Appendix D
Inter-rater Reliability Coefficient (Kappa) Scores

Authors	Kappa Value	Significance
Baldwin & Costley (2016)	.792	.000
Bargiela et al. (2016)	.808	.000
Gardner et al. (2016)	.894	.000
Goodall & MacKenzie (2018)	1.000	.000
Haney & Cullen (2017)	.771	.001
Hayward et al. (2018)	.898	.000
Kanfiszer et al. (2017)	.642	.003
Rogers et al. (2017)	.862	.000
Sedgewick et al. (2018)	1.000	.000
Steward et al. (2017)	.790	.000
Tint & Weiss (2018)	.790	.000
Vine Foggo & Webster (2017)	1.000	.000
Webster & Garvis (2017)	.617	.007
Overall	.849	.000

Appendix E

Meta-ethnographic Method

The seven steps to conducting a meta-ethnographic review identified by Noblit and Hare (1988), as summarised by France et al. (2014, p. 3).

Phase	Noblit and Hare's description
Phase 1: Getting started	'Identifying an intellectual interest that qualitative research might inform' ([15], p.26). The focus of the synthesis may be revised through reading interpretive qualitative studies.
Phase 2: Deciding what is relevant to the initial interest	Study selection should be 'driven by some substantive interest derived from comparison of any given set of studies' ([15], p.28). Searches for studies need not be exhaustive: 'unless there is a substantive reason for an exhaustive search, generalizing from all studies of a particular setting yields trite conclusions' ([15], p.28).
Phase 3: Reading the studies	The repeated reading of studies and noting of metaphors with close attention to details in the studies and what they tell you about your area of interest ([15], p.28).
Phase 4: Determining how the studies are related	Noblit and Hare recommended that reviewers create 'a list of key metaphors, phrases, ideas and/or concepts (and their relations) used in each account, and [to] juxtapose them' ([15], p.28) in order to make an initial assumption about how the studies relate to one another. This informs the type of synthesis that will be carried out – a reciprocal or refutational translation or line of argument synthesis.
Phase 5: Translating the studies into one another	The metaphors and/or concepts in each account and their interactions are compared or 'translated' within and across accounts while retaining the structure of relationships between central metaphors/concepts within accounts. The translations taken together are 'one level of meta-ethnographic synthesis' ([15], p.28). These are systematic comparisons and reciprocal translation is key to a meta-ethnography.
Phase 6: Synthesising translations	If there are many translations from phase 5 these can be compared with one another to see if there are common types of translations or if some translations or concepts can encompass those from other studies. 'In these cases, a second level of synthesis is possible, analyzing types of competing interpretations and translating them into each other' ([15], p.28) to reach new interpretations/conceptual understandings.
Phase 7: Expressing the synthesis	Tailoring the communication of the synthesis to the intended audience's culture and language so that it is intelligible and meaningful to them - 'the written synthesis is only one possible form' ([15], p.29).

Appendix F

Coventry University Ethics Approval for Chapter Two Empirical Paper



Certificate of Ethical Approval

Applicant:

Amy Jordan

Project Title:

How do adults on the autism spectrum experience depression and low mood?

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

14 February 2018

Project Reference Number:

P62407

Appendix G

Participant Information Sheet



Participant Information Sheet

How do adults on the Autism Spectrum experience depression and low mood?

We would like you to consider this research study and then decide if you would like to take part. Before you decide to participate or not it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information and decide whether you wish to take part.

1. What is the purpose of this study?

Previous research has shown that many people who identify as autistic experience depression and/or low mood. However, depression and how it is experienced by people who identify as autistic is poorly understood. This research aims to develop further understanding of what it is like to be autistic and experience low mood or depression, so that improvements can be made to assessment procedures, interventions and supports.

2. Why have I been invited to take part?

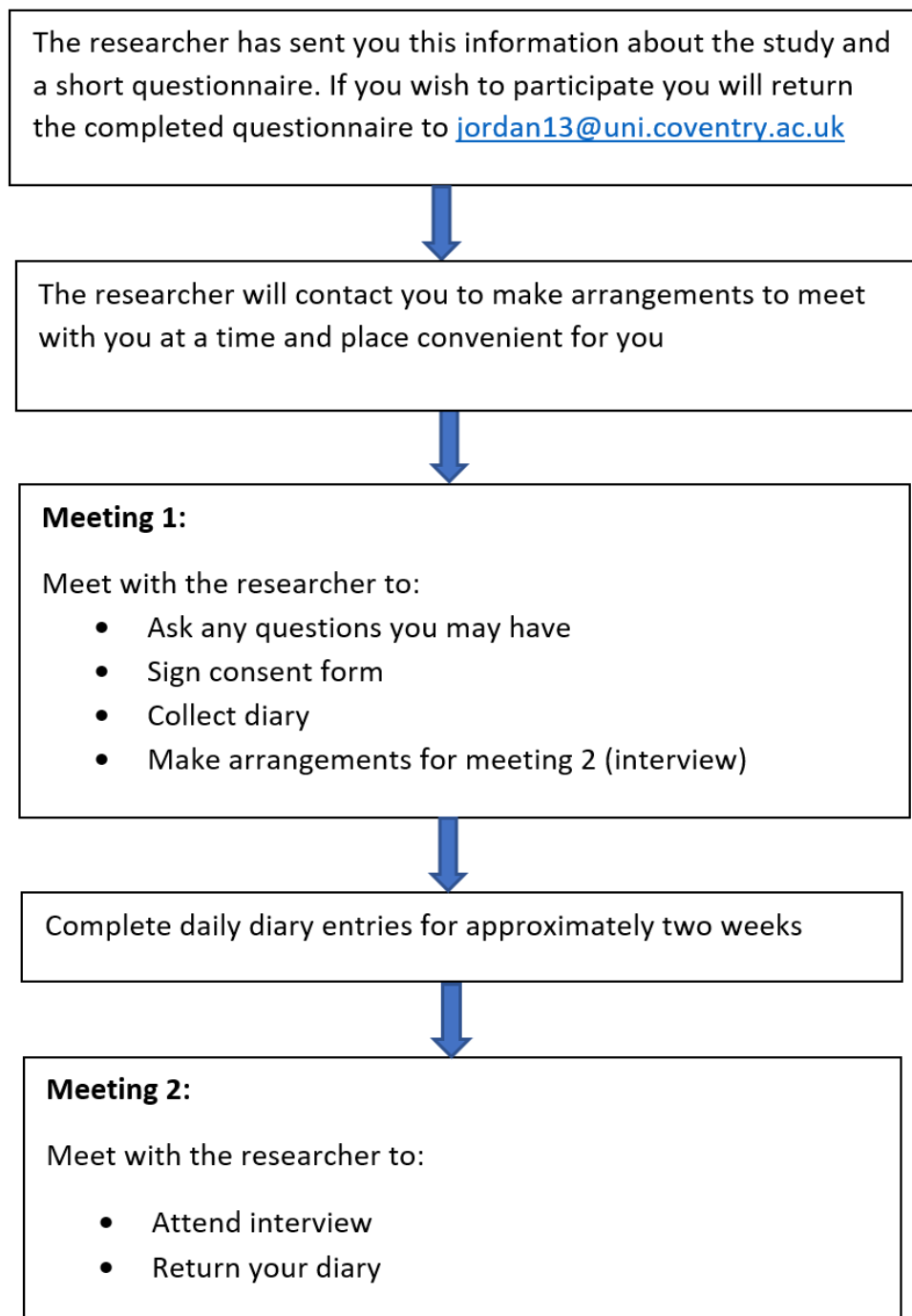
You have been invited to take part because you identify as autistic without intellectual disability, and experience low mood and/or depression. Your experiences are important to us and will help us to understand what it is like to be autistic and experience low mood and/or depression. Anyone who has experienced depression as part of bipolar disorder will not be included in this research.

3. Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part, we will ask you to sign a consent form indicating your willingness to participate in the study. Taking part in the study is voluntary.

4. What will happen if I take part?

Participation flowchart:



If you would like to take part you will need to let the researcher know by returning the questionnaire attached to this information sheet. If you are eligible to participate you will be invited to attend a total of two meetings with the researcher. These meetings will be arranged for a time and place convenient for you.

Meeting 1

During this meeting you will have opportunity to ask any questions that you may have about the research. If you would like to take part, you will be asked to sign a consent form, and will be given a structured diary. You will be invited to complete an entry in the diary each day until you attend the second meeting, which will take place approximately two weeks after meeting 1. The diary will have prompts, and space for drawing if that is how you would like to communicate. During this meeting the researcher will arrange a time and place to meet with you to complete the interview. The questions that will be asked during meeting two (the interview) will be shared with you during this meeting.

If you do not wish to complete the diary entries, you will still be invited to take part in the interview.

Meeting 2

During this meeting the researcher will interview you about your experiences of low mood and/or depression. You will also be invited to talk about the entries you made in your diary. The interview will be semi-structured, which means it will be guided by your experiences. The interview will last approximately one hour and will be audio recorded for it to be transcribed word for word. Once transcribed your interview will be analysed to understand your experiences.

5. What are the risks associated with this project?

Some people may find it difficult to talk about their experiences of low mood and/or depression and this may cause distress. If this were to happen, you will be offered a break from the interview and we would discuss together how best to support you. You will also be provided with some telephone contact details of additional sources of support.

6. What are the benefits of taking part?

You will not necessarily directly benefit from taking part in this study, but your contributions will help improve our understanding of how adults with autism experience low mood or depression. It is hoped that this understanding will contribute to developments in assessment and intervention approaches for depression.

7. What if I change my mind about taking part?

You are free to withdraw from the study at any time before attending for interview, during the interview and during a one-week reflection period post interview, without giving any reason. After the one-week reflection period analysis of your data will have begun and it may not be possible to withdraw all of your data. If after the one-week reflection period, you would like to withdraw your data, an agreement will be made with the research team as to whether complete or partial withdrawal can be granted.

8. Will my taking part be kept confidential?

Your taking part will be kept confidential, and once your participation in the study is complete your personal details will no longer be stored. All data will be stored on a password protected storage device accessible only by the research team members involved in this study. You will be allocated a unique study number and your interview transcript will be anonymised at the point of transcription. Research staff not directly involved with your interview will know you only by this number.

9. What if there is a problem?

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Olivier Sparagaro at ab8677@coventry.ac.uk (Chair of University Applied Research Ethics Committee).

10. What will happen with the results of the study?

The results will be written up for inclusion in a doctoral thesis. The results may also be published in an academic journal so others can read about and learn from the outcomes of the study. A newsletter will also be produced at the end of the study to inform all those who were involved about the findings. Any information used will be anonymised.

11. Who is organising and funding this research?

The research is being organised by Coventry University. This is a non-funded research project.

12. Who has reviewed this study?

Coventry University Applied Ethics Committee have reviewed this study and given ethical approval.

13. Further information/key contact details

If you have any questions or would like more information about this research, please contact:

Amy Jordan

Email address:

jordan13@uni.coventry.ac.uk

If you wish to complain about the way you have been treated during the course of this study please contact:

Prof. Olivier Sparagano

Email address:

ab8677@coventry.ac.uk

Appendix H

Informed Consent Form



Informed Consent Form

How do adults on the Autism Spectrum experience depression and low mood?

Name of researcher: Amy Jordan

1. I confirm that I have read and understood the participant information sheet dated 12/01/2018 (Version 2) for the above study. I have had opportunity to ask questions, and have had these answered satisfactorily.

Please initial

2. I understand that my participation is voluntary and that I am free to withdraw before or during the interview, or during a one-week reflection period post interview without giving any reason. If after the one-week reflection period I would like to withdraw my data an agreement will be made with the researcher as to whether complete or partial withdrawal will be granted.

3. I understand that all the information I provide will be treated in confidence

4. I agree to be audio recorded

5. I agree for quotes to be used as part of the research project, including within published papers. I understand that all quotes will be anonymised

6. I would like to receive a summary of the results and have opportunity to provide feedback before results are finalised (If yes, please provide your email address below)

7. I agree to take part in the research project

Name of participant:Signature of participant:.....

Participant email address: Date:.....

Name of Researcher:.....Signature of researcher:.....

Date:.....

Consent form date of issue: 22/01/2018

Consent form version number: 1.1

Appendix I
Debrief Information



Debrief information

How do adults on the autism spectrum experience low mood
and depression?

Thank you for taking part in the above study. You may find the following information useful.

What if I wish to withdraw from the study?

You are free to withdraw from the study at any time before attending for interview, during the interview and during a two-week reflection period post interview, without giving any reason. After the two-week reflection period analysis of your data will have begun and it may not be possible to withdraw all of your data. If after the two-week reflection period, you would like to withdraw your data, an agreement will be made with the research team as to whether complete or partial withdrawal can be granted.

Will my participation in the study and the data be kept confidential?

Your taking part will be kept confidential, and once your participation in the study is complete your personal details will no longer be stored. All data will be stored on a password protected storage device accessible only by the research team members involved in this study. You will be allocated a unique study number and your interview transcript will be anonymised at the point of transcription. Research staff not directly involved with your interview will know you only by this number.

What will happen to the results of the study?

The results will be written up for inclusion in a doctoral thesis. The results may also be published in an academic journal so others can read about and learn from the outcomes of the study. A newsletter will also be produced at the end of the study

to inform all those who were involved about the findings. Any information used will be anonymised.

Useful contact information

If you have any questions or concerns regarding this study, or if you feel a need to speak to a professional concerning any uncomfortable feelings raised by this research, you may contact the researcher using the contact details below. If you feel distressed following this research please make an appointment with your GP who can direct you to appropriate support.

Principle researcher:

Amy Jordan

Trainee Clinical Psychologist

Clinical Psychology Doctorate

Coventry University

Richard Crossman Building, RC341

Priory Street, Coventry,

CV1 5FB

02477658328

Jordan13@uni.coventry.ac.uk

Some useful helplines include:

Samaritans – 08457 90 90 90

Mental Health Matters – www.mentalhealthmatters.com -0800 61 61 71

Mind – www.mind.org.uk

Debrief information form date of issue: 22/01/2018

Debrief information form version number: 1.0

Appendix J
Screening Form



Screening form

How do adults on the autism spectrum experience low mood and depression?

If you are interested in taking part in this research study, please answer the questions below and return this form to jordan13@uni.coventry.ac.uk.

1. Name.....

2. Age.....

3. Have you been diagnosed or identify as autistic without intellectual disability?

Yes ☐ No ☐

4. Have you ever experienced any of the below (please mark all that apply)

Low mood that affects your functioning ☐

A diagnosis of depression ☐

Depression as part of bipolar disorder ☐

5. Would you describe your current mood as low or depressed?

Yes ☐ No ☐

6. Have you ever received a diagnosis of learning disability?

Yes ☐ No ☐

If yes, please provide details.....

7. Are you currently accessing mental health services for your depression/low mood?

Yes ☐ No ☐

If yes please tell me about the type of service you are accessing.....

.....

Thank you!

Screening form date of issue: 22/01/2018

Screening form version number: 2.0

Appendix K
Demographic Information Form

Page 1 of 1



Demographic Information Form

**How do adults on the autism spectrum experience low mood
and depression?**

Instructions: Please provide a response for each of the following questions:

1. What is your name?

2. What is your gender?

Female ☐ Male ☐ Other ☐ (please specify) _____

3. What is your marital status?

Single ☐ Cohabiting ☐ Married ☐ Separated ☐ Divorced ☐ Widowed ☐

4. What is your ethnicity?

5. What are your current employment circumstances?

Student ☐ Employed ☐ Seeking employment ☐ Retired ☐

In receipt of Employment and Support Allowance or Personal Independence Payment ☐

Other ☐ (please specify) _____

6. Do you currently take any medication?

No ☐

Yes ☐ (please specify) _____

Thank you

Demographics form date of issue: 26/01/2018
Demographics form version number: 1.0

Appendix L

Semi-structured Interview Schedule

Page 1 of 2



Interview Schedule

How do adults on the Autism Spectrum experience depression and low mood?

1. Please can you tell me a little bit about your autism?

- What is it like to have autism?
- When were you diagnosed?
- Has your diagnosis of autism changed the way you think or feel about yourself? In what ways?

2. Can you tell me about your mood?

- How do you know when you are feeling low/depressed?
- What does it feel like/did it feel like to be low/depressed?
- Can you tell me about a recent time when you felt low/depressed?
- What can/did cause you to feel low/depressed?
- Do you notice when you are happy/sad?
- What factors define a good day? What factors define a bad day?
- Can you describe how feeling low/depressed affects your relations with other people?

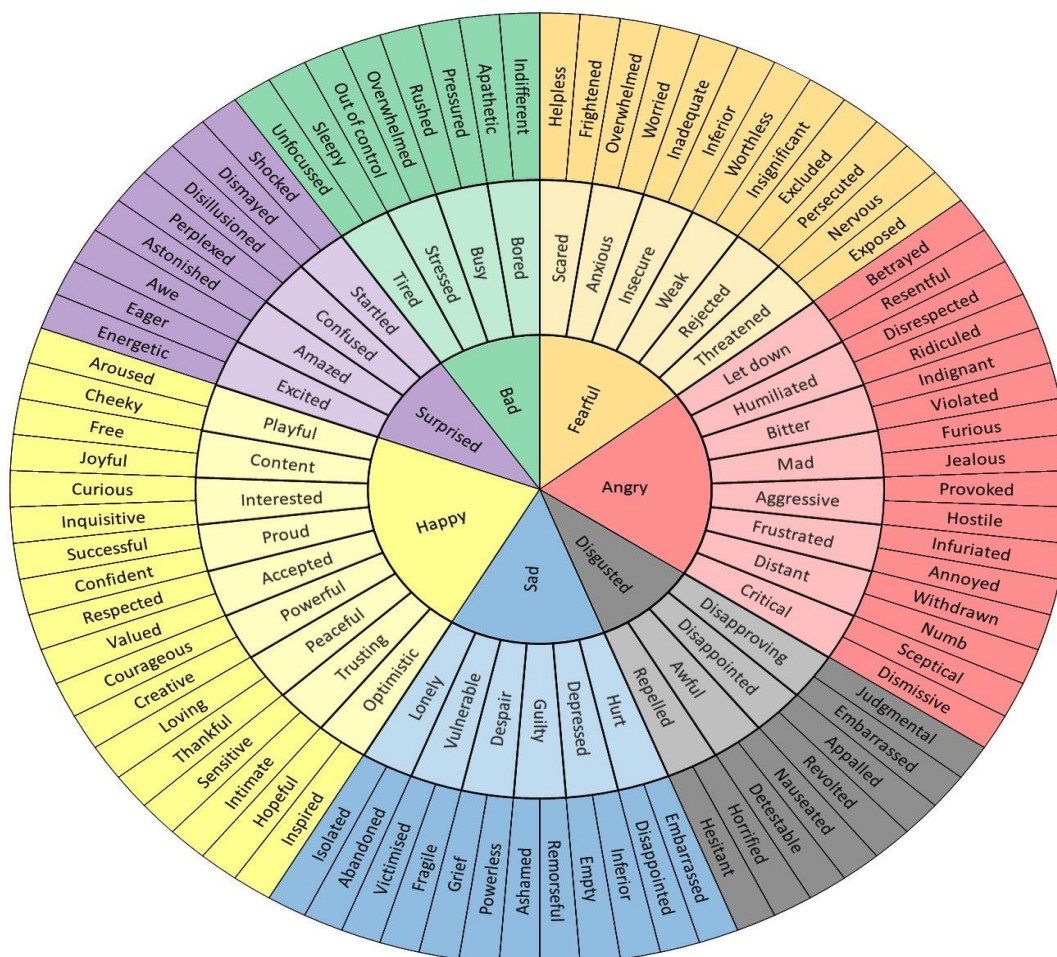
3. Could you share with me/tell me about the entries you have made in your diary?

- i. Please tell me about any pictures you have drawn

4. Have you had any support for your depression/low mood?

- i. Have you had support from friends/relatives/other?
- ii. Is there one person that stands out as supportive? What did they do that was helpful?
- iii. Have you had support from services? What was helpful? What was unhelpful?
- iv. What support would you like to receive?
- v. What if anything could services do to support you further?

Note: The questions in bold are the questions that all participants will be asked. The questions contained in bullet points are prompts that may not be applicable to all participants. The focus for question one is rapport building and ascertaining the language that the participant uses, in order for the researcher to use appropriate language throughout.



Note: This feeling wheel will be available during interview as a visual prompt for participants to refer to when talking about their mood.

Interview schedule date of issue: 22/01/2018

Interview schedule version number: 2.0

Mood Diary



Mood diary

How do adults on the autism spectrum experience low mood and depression?

Please complete one entry per day for the next fourteen days. If you would like to make more than one entry per day, please do so. You may find the coloured wheel included in this diary helpful when thinking about how you feel. Thank you.

Date:	Today I felt:	<u>Comments/drawings:</u> (For example, what made you feel like that? What thoughts/images went through your mind?)

Appendix N

Example Extracts from Coded Transcripts

1 I: So it would be interesting to hear, to start with, about
 2 when you received your diagnosis of autism?
 3 P: Yes. Erm, so I think it was 2015. Erm, I think, I think I -
 4 went to the Dr - no, I was having some therapy and doing
 5 that, started doing it and then I was referred, erm, not
 6 testing, you know, testing I suppose, yes. I think it was a few
 7 years, erm. My Mum, my Mum is an educational
 8 psychologist and she, she thought - sort of retrospectively
 9 she sees it, erm, and it makes sense to her. But I think at
 10 the time when I was younger and having some problems
 11 she thought that because I laughed and smiled and things
 12 that it wasn't, erm - it was still thought of being just for boys
 13 mainly, and very particular behaviours. So, she hadn't
 14 thought of it but I had thought of it before when I was a bit
 15 younger as well. Erm, but yeah, but then, but then, yes, I
 16 went for the sort of tests and things, and they diagnosed it I
 17 think 2015.
 18 I: So you would have been an adult when you got the
 19 diagnosis?
 20 P: Yes, yes.
 21 I: What was that like getting that diagnosis after so long?
 22 P: It was good. Erm. It was good because, erm, it made - I
 23 don't want to say like an excuse, but it sort of made sense.
 24 And, erm, helpful for me to know that maybe some of the
 25 problems - why trying to - trying all the things that other
 26 people had said to try change things haven't worked very
 27 well. So it made sense to me, so it was good to get the
 28 diagnosis. But what I felt that was a bit hard was, erm, lots of
 29 people thinking maybe that I don't have it. And people that
 30 had known for me a bit maybe who, again, sort of had set
 31 ideas about what it is to be autistic, and so - I sort of felt a
 32 bit like a fraud at times with that. Erm, so, sort of managing
 33 people's expectations, so they don't need to have
 34 expectations. And it's individual so it's - what is me, so yeah.
 35 Does that answer your question?
 36 I: It does, thank you. And you mentioned getting a diagnosis
 37 helped make sense of why you had some of your difficulties,
 38 would you mind telling me a little bit more about that?
 39 P: Yes. Erm, so communication, erm, troubles. Erm, not
 40 [pause] not sort of seeming to understand other people's
 41 thoughts. So, erm, if people didn't smile and things - I sort of
 42 felt people were cross with me. So, I thought people were a
 43 bit cross quite a lot. Whereas smiling meant friendly. But
 44 sometimes I didn't quite understand whether I was friends
 45 with somebody because they were nice to me, but actually
 46 friendship is different to just being pleasant to people I think.
 47 Erm, so there was sort of confusion with that. Things like
 48 entering a relationship just because I was being told that
 49 that's what I should do. But not being comfortable with it.
 50 Erm, and doing things, doing things for - doing them
 51 because that's what normal people were doing, and things.
 52 And when I was at school, erm, not wanting to do things that

Page 1 of 13

DIAGNOSIS MAKING
 SENSE OF
 HISTORICAL
 DIFFICULTIES

NARROW UNDERSTANDING
 OF ASC

AT-TYPICAL
 PRESENTATION -
 DIFFICULTIES
 DISMISSED/MISSED

DIAGNOSIS
 COUNTERINTUITIVES
 DIFFICULTIES

ATTEMPTING TO
 CHANGE - FAILURE

STEREOTYPICAL VIEWS
 OF AUTISM -
 BEING DISMISSED

SOCIAL/INTERPERSONAL
 CONFUSION

TRYING TO
 BE NORMAL

UNCERTAIN/CONFUSED RE:
 ORDER OF EVENTS

ACCESSING THERAPY
 PROMPTED ASC INVESTIGATION

MUM WORKS IN
 EDUCATIONAL PSYCHOLOGY -
 ? SHOULD HAVE KNOWN

DIFFICULTIES RECOGNISED
 WITH HINDSIGHT

ATYPICAL ASC
 PRESENTATION

THINKING OF /LOOKING
 FOR EXPLANATION

BEING TESTED

RECEIVING A DIAGNOSIS

POSITIVE REACTION TO
 DIAGNOSIS

DIAGNOSIS IS HELPFUL
 - EXPLANATION

? NEED TO ADAPT AND
 CHANGE ASC SYMPTOM
 EXPRESSION TO PLEASE
 OTHERS

NOT BEING BELIEVED

OTHERS' LIMITED UNDERSTANDING
 OF ASC

FEELING LIKE A FRAUD
 ? IMPORTANCE OF
 OTHERS' ACKNOWLEDGEMENT
 /SOCIAL ACCEPTANCE

DIFFICULTIES WITH COMMUNICATION
 LACK OF THEORY OF MIND

MINIMISING LANGUAGE -
 ? JUDGING SELF FOR
 THIS EXPERIENCE

SIMPLISTIC RULE
 FOLLOWED

DEVELOPED UNDERSTANDING
 OF FRIENDSHIP/DIFFICULTY

UNDERSTANDING WHAT
 CONSTITUTES A FRIEND

SOCIAL PRESSURE
 FROM OTHERS

ACTING AGAINST
 OWN INTERESTS +
 WISHES.

THEM AND US -
 NOT ONE OF THE
 'NORMAL' PEOPLE

TRYING TO BE
 NORMAL

ATYPICAL INTERESTS -	53	my peers were wanting to do. And, <u>even my sort of Mum,</u>	ATYPICAL INTERESTS -
NOT FITTING IN	54	<u>sort of said it's not normal for someone to stay in and watch</u>	? MUM SHOULD HAVE ACCEPTED HER UNCONDITIONALLY
WITH PEERS	55	<u>Gardener's World on Friday evenings and should be going</u>	- NEGATIVE SELF VIEW
OTHERS VIEWS	56	<u>out with their friends, and that, that - so I felt just like a loser.</u>	EXPECT OTHERS TO JUDGE
IMPACT SENSE OF SELF	57	<u>What people would say is like sad or a loser or something.</u>	RECOGNISING DIFFERENT
BEING DIFFERENT / NOT FITTING IN -	58	<u>Erm, but, but even, even validation of - that's OK, it still</u>	SOCIAL COMMUNICATION DIFFICULTIES
OWN UNDERSTANDING	59	<u>didn't fit in with what the world was doing. And so a bit of</u>	TRUST - ? INCREASES VULNERABILITY AS WELL AS GOOD FOR DEVELOPING RELATIONSHIPS
DESPITE OTHERS	60	confusion with what people were doing and saying mixed	
SOCIAL COMMUNICATION DIFFICULTIES	61	with not being able to - not finding it very easy to read -	
	62	people's body language. Erm, so that was hard. And just,	
	63	just not thinking the same way sometimes, I think. Erm, -	
	64	being very, very trusting of people, erm, which, which is a	
	65	good thing as well. Which is good thing so there are	
	66	positives. Erm, but, yeah. Yeah, just [pause] I think yeah.	
	67	I: Hmmhmm. Thank you. So it sounds like getting a	
	68	diagnosis helped put some of those difficulties into context,	
	69	or helped make sense of those difficulties?	
	70	P: Yes, and I think things like not, so like sucking my thumb	NEEDING TO UNDERSTAND SELF SOOTHING BEH.
CHILDLIKE BEHAVIOURS IN ADULTHOOD	71	and stroking material to comfort myself made sense when	NEED TO MAKE SENSE OF SELF
COPING MECHANISMS	72	I've, sort of, behaviour. Hiding - into adulthood <u>hiding even</u>	HIDING - CAN'T TOLERATE LOUD NOISES / CROWDS
COPING	73	under the stairs when there's an argument or sort of loud-	? CHILD LIKE BEH - SHOULD HAVE STOPPED
OVERWHELMED + ANGER	74	noises. And hiding in the garage and things. Maybe	COPING ONLY WHEN SHE KNOWS HOW
DIFFICULT EMOTIONS	75	maladaptive coping mechanisms but it was sort of the only	UNABLE TO COPE
NOT COPING	76	thing I knew how to deal with being overwhelmed and I'd get	PRACTICAL STRATEGIES TO MINIMISE DIFFICULTIES
	77	overwhelmed a lot, and I'd get angry a lot [pause] and not	STRESS & IN CROWDED PLACES
	78	having, not being able to deal with those things. And erm,	DIAGNOSIS EXPLAINS DIFFICULTIES
	79	really like - really liking - I <u>had ear defenders</u> that I asked my	
	80	Mum and Dad to buy me I think when I was about eighteen	
	81	nineteen that I could put on and they would clamp your	
	82	head. And that was comforting and would block out noise.	
	83	And I sort of would break out into sweats if we went	
	84	shopping or would feel like being sick. Things like that they	
	85	all made more sense. Erm, and I know other people have	
	86	them as well and they're not on the autistic spectrum, so,	
	87	but it made sense that OK yes that seems familiar.	
	88	I: And did, did being able to make sense - did that change	
	89	the way you thought about yourself at all?	
	90	P: Initially yes. Initially yes it did it made me feel a lot less	- IMPROVED SENSE OF SELF
	91	bad. I didn't feel so much like a failed person or bad. Erm,	FAILED PERSON
	92	which stayed for a bit after diagnosis and then, and then	FLUCTUATING SENSE OF SELF
	93	sort of comes back sometimes.	
	94	I: Hmmhmm. That leads quite nicely onto talking about	
	95	mood a little bit if that's OK? So, thinking about feeling low	
	96	in mood, how do you know when you're feeling low?	
	97	P: Erm, <u>because I want to die [laughs]. Because I - I feel I'm</u>	LAUGHING ? MINIMISING ? DIFFICULT TO TOLERATE
	98	<u>aware my default is feeling of, erm, there's no - not no point</u>	SADISM NO POINT
	99	<u>to anything, that I can't function in the world and so there's</u>	? DON'T BELONG TO THIS WORLD
	100	<u>no point. It's that sort of feeling. Not a, not erm, it's like - it's</u>	COMMON EXPERIENCE
	101	<u>like being low because - it jumps to that too much. It's not</u>	
	102	<u>[sighs] it's not a helpful place to go to but it's a feeling of - if I</u>	
	103	<u>feel out of control I suppose. Erm, then I know I feel low.</u>	
	104	And erm, and also like, can I refer to this? [picks up diary]	

Appendix O

Photos from Stages of Data Analysis

Photo one of emerging themes:

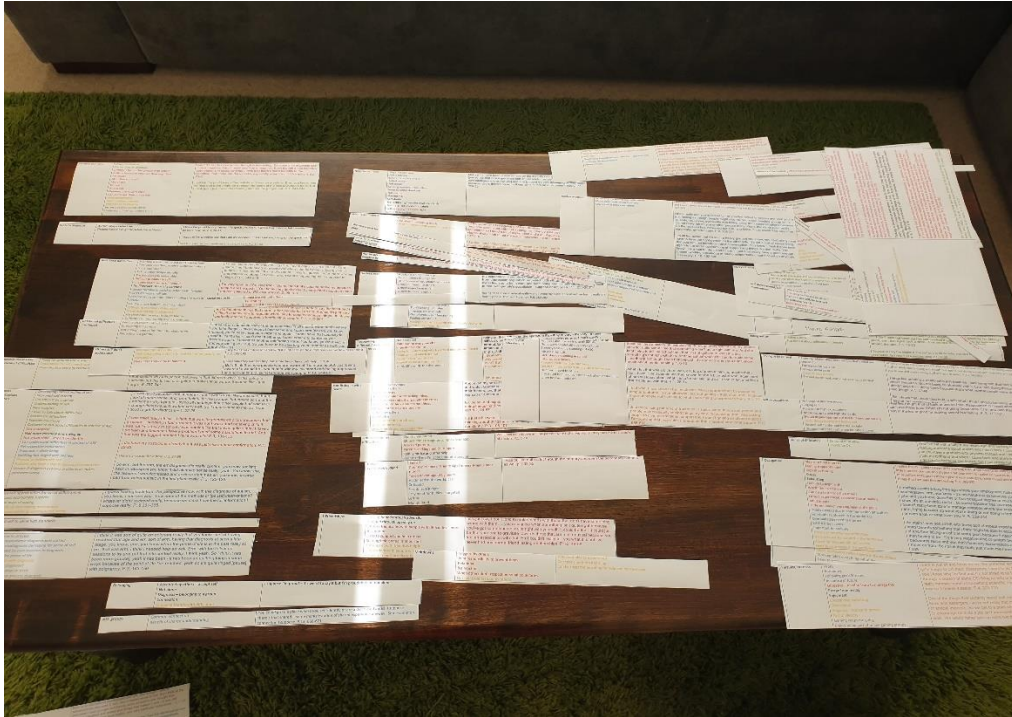


Photo two of emerging themes:

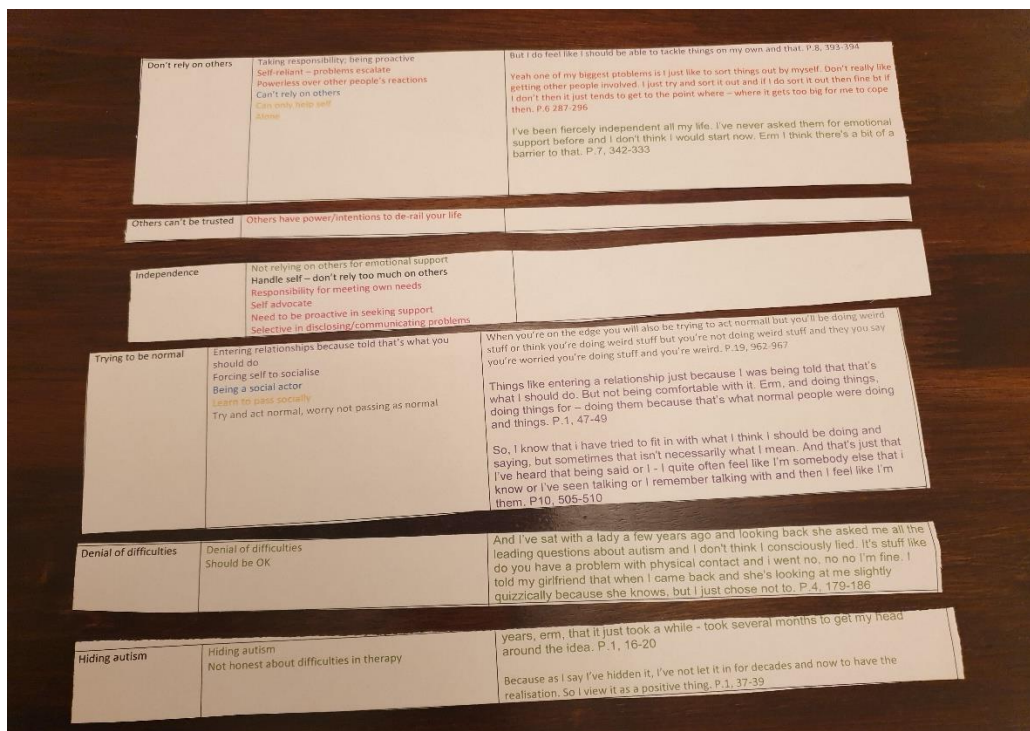


Photo three of emerging themes:

Relational difficulties	<p>Wanting a relationship but not knowing how</p> <p>Confused by other people's wishes/intentions</p> <p>Social confusion</p> <p>Taking other people literally</p> <p>Trust makes you vulnerable</p> <p>Difficult to calibrate self</p> <p>Inappropriate sense of humour</p> <p>No filter/lack of social awareness</p> <p>Uncomfortable in social situations with females</p> <p>Can't manage small talk</p> <p>Reciprocity issue – not understanding the rules of relation</p> <p>Can't manage banter – feel victimised</p> <p>Difficult to maintain relationships</p> <p>Many relationship breakdowns</p> <p>No clear rules on what is OK re: banter</p> <p>Difficulty communicating own experiences</p> <p>Others experienced as manipulative</p> <p>Others learn to exploit others</p> <p>Others take their moods out on other people</p> <p>Need to process during conversations, often shocked</p> <p>Analysing interactions is overloading</p> <p>Often misses the point</p>	<p>I mean some people enjoy rolling dice. I quite enjoy rolling dice but at the same time I hate being screwed over when I get bad results. [sigh] yeah, I dunno. It's just me so I'm kind of used to it. Yeah. I guess I'm far more worried and concerned about like dealing with what's happening as to opposed to things. P.11, 541-545</p> <p>I'm very open and I'm very frank. Sometimes that's caused problems because people don't expect it. You know they don't expect a very frank response that's not really filtered or PC as it were P. 2, 96-103</p> <p>Well I'd like to be in a relationship but I don't know how</p> <p>I'm very aware that I'm - that my sense of humour is dark to say the least and I just think about things that norm - other people just do not. And so it's just very difficult to know how to regulate what I say to people because things I think are perfectly innocent apparently horrify other people. P.7, 350-354</p> <p>social interaction [pause] forced to err, go out for things after work. So, especially when some of my colleagues talk about work after work I just I don't want to. And I know I've got a reputation for being a bit strange because I just withdraw and stare at the wall or whatever and I don't engage with people. P.5, 223-228</p>
Not fitting in with peers	<p>Childlike behaviours</p> <p>Judged by others</p> <p>Dark interests</p> <p>High threshold for disturbing things</p> <p>Don't understand other people's interests</p> <p>Others don't think about same things</p> <p>Others' interests are mundane</p> <p>Judged by others</p> <p>Vulnerable</p> <p>Think differently to others</p> <p>Different interests</p> <p>Others don't see my perspective</p>	<p>And, even my sort of Mum, sort of said it's not normal for someone to stay in and watch Gardener's World on Friday evenings and should be going out with their friends, and that, that - so I felt just like a loser. What people would say is like sad or a loser or something. P.2, 53-59</p> <p>for the sake of expediency and comfort I do try and fit in and it means time doing things that I could do with my eyes closed half the time. So it's just a bit sad p.2, 64-87</p> <p>It's just a bit weird - it feels very odd that everyone else is happy and just not thinking about things and I'm thinking about everything that's going on constantly. P.3, 105-107</p>
Don't belong to this world	<p>Can't function in the world</p> <p>Don't belong – burden</p> <p>Impacts sense of self</p> <p>Out of work = not functioning</p> <p>Feeling alienated</p> <p>Having to cope in a world where people deal with emotions differently</p>	
Burden to others	<p>When sharing feeling low with others</p> <p>Mood negatively impacts others</p> <p>Low mood is heavy on others</p>	<p>I feel like I'm a burden sometimes. If I feel low and I share it with people... I'm an adult and I don't think I should be – well not complaining but be sad when I talk to her. P.7, 343-348</p> <p>I think really and you're forced to - or you feel forced to explain and then you're just feeling as though people might also be, you know, sending you up or - it all ends, you know, eventually with falling away from social situations because it's not really fair on you or other people really. Yeah, there's no point really. So the isolation has increased but erm, you know, it just couldn't be any other way really, unfortunately. P.6, 265-271</p> <p>I'm all too aware that it's such a heavy [pause] you know, you can't really - you have to have the right person on the other side. It's not a sort of casual thing that you can just introduce into a conversation. You know, I think it goes back again to the social conventions of support and things like that really. You know, it is a real burden. And I think - I just don't really have a good enough [pause] working knowledge of relationships really - I can't count on anybody else really. P.10, 492-500</p>
Societal expectations	<p>Not functioning in society</p> <p>Expect others to judge you</p> <p>Others view of you shapes your view</p> <p>Disappointment to others</p> <p>Others expect you to fail</p> <p>Others think differently</p> <p>Impacts your own self view</p> <p>Ashamed of lack of own career path</p>	<p>my experience is people expect or, erm, yeah they expect to see you improve from depression say, which err, which didn't ever happen so I think people are expecting you to be in work and functioning and it's been always very difficult to deal with people's scepticism I suppose or err, yeah. P.5, 255-260</p> <p>having to be a social animal really – and having my experience of autism hasn't really er hasn't gone all that well together. P.6, 280-282</p>

Appendix P

Gibbs' (1988) Model of Reflection

