"I feel I'm no longer an alien": The Experiences of Females who receive a diagnosis of Autism Spectrum Condition late in life

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Abstract

The purpose of this study was to explore the lived experiences of females who receive a late diagnosis of Autism Spectrum Condition (ASC). A growing number of women identify and receive diagnoses of ASC in adulthood after years of unexplained difficulties. However, as societal understandings of ASC are male-dominated, autistic females are underrepresented and frequently diagnosed late, leaving their needs misunderstood. This study aims to provide further insight into women's lived experiences with ASC to increase awareness of their specific needs. Interpretative Phenomenological Analysis (IPA) was used to analyse the accounts of nine females diagnosed with ASC late and the significance this had on their lives. The participants described their experiences prior to and then post-diagnosis. Prior to diagnosis, common barriers included cost, gendered misconceptions, and male-dominated ASC stereotypes. The participants were aware of being different prior to diagnosis and expressed difficulty fitting in, particularly with gendered and social norms. This led to coping strategies such as camouflaging (masking) and often poor coping such as emotional focused coping strategies ultimately, leading to mental distress.

Each participant had a unique journey to diagnosis, with three seeking help in their teens, while the remaining women were diagnosed in adulthood. Despite the differences, all the participants went through a period of adjustment and made changes in their lives once they identified as autistic. While these changes were specific to each individual, they were largely positive, including forming connections with the Autism community, adapting to accommodate social challenges and sensory sensitivities, and conducting their own research. The diagnosis was tied to a better sense of self (self-acceptance), a sense of belonging to a community (shared social identity), and an increased awareness of triggers that could lead to meltdowns or autistic burnout. Despite the positive aspects of diagnosis, the participants reported ongoing challenges with socialisation, friendships, understanding social norms around relationships. An important

finding in the study is the high level of self-awareness and sociality participants reported. Participants described awareness of the social and communication challenges they face and clearly expressed the impact of the gender expectations and pressures placed on them. Alongside the high level of awareness concerning social and gender expectations, many participants described adopting compensatory strategies to comply with these expectations and mitigate the sense of difference and exclusion they felt. These findings highlight the complexity of navigating identity as acting 'neurotypical' and acting like a woman. Lastly, irrespective of age, experiences of stigmatisation related having ASC was mentioned by all the participants, indicating the challenges of living as a marginalised identity.

In summary, social representations of ASC are complex as it is largely an invisible condition that presents differently for females. More work needs to be done to increase awareness and acceptance surrounding ASC, particularly the unique way in which ASC presents in females and the effects of gender on the experience of ASC. These findings have implications for clinicians and provide insight into areas where support can be provided to females who receive a late diagnosis of ASC.

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CHAPTER ONE

Introduction

This chapter covers some points on terminology and diagnostic criteria for Autism, a brief history of Autism, discussion of the prevalence of Autism, and the theoretical constructions of females with ASC. There is limited information from Aotearoa, New Zealand so I outline the latest statistics from New Zealand. I then outline my research aims.

Terminology

Within the latest version of the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013), Autism was labelled Autism Spectrum Disorder or ASD. However, within autism research, there is a lack of consensus concerning Autism terminology with multiple terms and identifying labels associated with Autism (Kenny et al., 2016). While the term 'disorder' continues to be utilised within Autism research, there is a growing emphasis within mainstream literature to counter the associated stigma and move away from deficit-based terminology (Leatherland & Chown, 2015). Therefore, I have chosen to use the term Autism Spectrum Condition (ASC) in place for 'disorder' throughout this research to convey areas of both strengths and difficulties, in addition to showing respect for neurodiversity. Importantly, this terminology is supported by the Autism community, with the majority of participants in a survey-based study conducted by The National Autistic Society (UK) (Kenny et al., 2016) stating that the term 'condition' is the preferred terminology used to describe Autism.

The terms 'non-autistic' and 'neurotypical' will be used interchangeably as descriptors for individuals who are not on the autism spectrum. In recognising that individuals may have differing opinions and perspectives of autism terminology, I will use the language referred to by the participant in the interview when interpreting the individual

experiences to allow each participant to produce a label to identify themselves. This terminology enables the participants to have agency over their identity and identify in a way that is meaningful for them (Kenny et al., 2016). Furthermore, when referring to individuals, I will use both person-first (e.g. female with ASC) and identity-first language (e.g. autistic female). Finally, the use of functioning labels including the terms 'high-functioning' and 'low-functioning' will not be utilised by the researcher as the autism community has widely criticised these terms for creating a misleading description of an individual's level of functioning by reducing the impact of the social and emotional difficulties associated with autism (Evans-Williams & Williams, 2016; Kenny et al., 2016; Pellicano & Stears, 2011).

ASC

Autism Spectrum Condition (ASC) is a neurodevelopmental condition characterised by persistent difficulties in social communication and interaction, and restricted and repetitive patterns of behaviour (American Psychiatric Association, 2013). ASC is considered a 'spectrum condition', as the severity and clinical presentation of these symptoms are heterogeneous. Symptoms are thought to appear in childhood and persist across the lifespan, with a number of features including behavioural, cognitive, motor, emotional and sensory domains (Mandy & Lai, 2017; Volkmar et al., 2005). Current estimates indicate a gender ratio of 3:1, however neurobiological reasons for this gender disparity are not yet understood (Hull et al., 2017; Loomes et al., 2017). To understand this gender imbalance, research has started to examine the role of social, cultural, and psychological factors to explore the female experience of ASC (Duvekot et al., 2017; Geelhand et al., 2019; Green et al., 2019; Kreiser & White, 2014).

Until recently, autistic females have been largely neglected from research and clinical practice (Gould & Ashton-Smith, 2011; Gould, 2017; Krahn & Fenton, 2012; Kreiser & White, 2014; Lai et al., 2011). However, over the past decade, overwhelming research

suggests that females are at a significantly elevated risk of being diagnosed with ASC later than males and are more likely to be misdiagnosed, diagnosed later in life or overlooked completely (Baldwin & Costley, 2016; Bargiela et al., 2016; Duvekot et al., 2017; Dworzynski et al., 2012; Gould, 2017; Rivet & Matson, 2011; Russell et al., 2011). These risks are even higher for cognitively able females who represent a population that are at heightened risk of being overlooked and identified with ASC later in life (Begeer et al., 2013; Bumiller, 2008; Lai et al., 2015; Loomes et al., 2017; Rutherford et al., 2016; Van Wijngaarden-Cremers et al., 2014). Therefore, it is important to understand women's experiences of living with undiagnosed ASC and receiving a diagnosis as there remains limited research that provides an 'insider account'.

A review of this literature suggests that receiving a diagnosis of ASC is a life-changing and often complex experience, particularly when diagnosis occurs late in life (Bargiela et al., 2016; Leedham et al., 2020; Webster & Garvis, 2017). Many women reported the desire for an earlier diagnosis and described feeling disadvantaged, noting that late diagnosis had adverse impacts on their sense of identity and mental health (Baldwin & Costley, 2016; Bargiela et al., 2016; Leedham et al., 2020; Milner et al., 2019). However, encouraging findings across studies have suggested there are positive psychological impacts of gaining a diagnosis of ASC, including reduced self-blame, the development of a positive autistic identity and increased self-acceptance through group belonging (Bargiela et al., 2016; Leedham et al., 2020; Milner et al., 2019; Webster & Garvis, 2017). For cognitively able autistic women, the diagnostic journey is particularly challenging due to difficulties having their needs recognised as they appear to be capable (Baldwin & Costley, 2016; Bargiela et al., 2016; Kanfiszer et al., 2017).

Historical conceptualisations of ASC continue to contribute towards the stigmatising stereotypes, misconceptions, and subsequent marginalisation of female knowledge within

ASC. This was evident when 17-year old climate change activist Greta Thunberg discussed her diagnosis of Asperger's on Twitter in 2019, stating "I'm not public about my diagnosis to 'hide' behind it, but because I know many ignorant people still see it as an 'illness,' or something negative." The criticism Thunberg received exposed the widespread lack of understanding surrounding female ASC as media outlets labelled her "mentally ill", "deeply disturbed", and an "overemotional girl" ('World Leaders', 2019). Against this backdrop, it is apparent that ASC remains controversial and misunderstood, especially when females are affected.

In Aotearoa New Zealand (NZ), there is limited research on autistic adults, particularly females. A recent report titled *'The Autism Diagnostic Process in New Zealand'* suggested that "females may be slipping through the cracks" (van der Meer et al., 2021, p.27). Furthermore, they found that 71% of autistic adults receive a diagnosis in private practice, suggesting the high and prohibitive expense of gaining an ASC diagnosis as an adult is a significant obstacle to accessing a diagnosis (van der Meer et al., 2021). Alongside this, there remains the absence of a formal diagnostic pathway in the public system. Interestingly, the report also found gender-specific concerns from women, notably the lack of clinicians' understanding of the ASC presentation in females and the reliability of assessment tools. Therefore, consistent with international research, there appear to be additional complexities and obstacles diagnosing females in adulthood.

Despite the increasing acknowledgement of the longstanding gender imbalance within ASC research, the historical exclusion of females from research has created a strong male-centric bias within the literature (Kirkovski et al., 2013; Shefcyk, 2015; Werling & Geschwind, 2013). Consequently, research disproportionately reflects male ASC experiences (Kirkovski et al., 2013; Mandy & Lai, 2017), leaving female experiences across the lifespan relatively unknown (Baldwin & Costley, 2016; Halladay et al., 2015; Shefcyk, 2015). The

gender bias within research is evident as Watkins et al., (2014) found a male-to-female ratio of 6.07:1 in studies of people with ASC, 40% higher than in the general population, while Lai et al., (2015) found that on average, four males for every one female were recruited for studies on ASC. Furthermore, 17.79% of studies did not include any females or excluded females entirely from samples (Lai et al., 2015; Watkins et al., 2014).

The gender bias inherent in ASC research has been identified as a key priority area of research by the autistic community (Pellicano et al., 2014) and represents an area of systematic disadvantage. Given that research informs the diagnostic criteria and assessment tools (Happé & Frith, 2020; Hiller et al., 2014), the exclusion of autistic females within research leads to a behavioural description of ASC most representative to males, therefore neglecting the potential of female presentations, and perpetuating the bias towards a male presentation of ASC. Therefore, it is critical that there is a pivot away from the male-centric focused discussions to facilitate the inclusion of female voices, and challenge the biases, beliefs and inequalities that exist by using qualitative methods (Happé & Frith, 2020; Kirkovski et al., 2013).

Existing research exploring ASC within female populations have largely utilised a positivist ontological stance, focused on finding differences between autistic and neurotypical individuals at the population level while attempting to understand the sex differences at the aetiological and behavioural levels (Halladay et al., 2015; Lai et al., 2015; Pellicano et al., 2014). This broad-brush methodological approach focusing on comparing males and females in terms of their core ASC symptoms neglects the role of gender in the presentation and experiences of autistic females and fails to address the specific questions raised by the clinical literature and the ASC community (Pellicano et al., 2014). Therefore, it is critical to understand the female experience of receiving a late diagnosis of ASC to better understand how to support individuals during and after diagnosis.

While research on the lived experience of autistic individuals has emerged in recent years (e.g. De Pape & Lindsay, 2016), and the experience and needs of individuals who receive a diagnosis of ASC in adulthood (Crane et al., 2018; Lewis, 2016), there is limited research that focuses specifically on females. Female experiences of ASC remain largely unheard, despite research indicating that the female experience of ASC is qualitatively different from males (Gould, 2017; Lai & Baron-Cohen, 2015; Saxe, 2017). In recent, years a small, growing body of qualitative research focused on exploring the lived experience of female ASC has appeared (Baldwin & Costley, 2016; Bargiela et al., 2016; Kanfiszer et al., 2017; Leedham et al., 2020; Milner et al., 2019; Webster & Garvis, 2017). To date, only two studies have explicitly focused on the lived experience of females diagnosed who receive a diagnosis of ASC late in life (Bargiela et al., 2016; Leedham et al., 2020). These studies will be discussed in more depth in the following sections.

A brief history of ASC

The label 'Autism' was first used in 1911 by Swiss psychiatrist Eugene Bleuler to describe a state of social withdrawal, a symptom that was indicative of Schizophrenia (Bleuler, 1911). Later in 1943, the term was used by child psychiatrist Leo Kanner, documenting the first clinical account of Autism in his paper entitled "Autistic Disturbances of Affective Contact" (Kanner, 1943). Kanner used the term 'autistic' to describe the impairments he observed in a group of eleven children that he examined. The description focused on the associated challenges in language and intellectual functioning including, difficulty relating to people and situations in a typical way, intolerance to loud noises, elaborate repetitive behaviour, desire to maintain routine and tendency towards repetitive words and actions. Therefore, Kanner's term 'infantile autism' perpetuated the notion that ASC was primarily found in children with intellectual impairments, largely ignoring the

lifelong impacts of ASC and arguably adversely impacting autistic individuals that did not fit this stereotype.

A year later, paediatrician Hans Asperger (1944) published an independent study about a condition named 'autistic psychopathy', including four children displaying a similar set of features. In contrast with Kanner's descriptions of autism defined by language and intellectual impairments, Asperger noted that some of his participants demonstrated paradoxical skills, stating that he saw "threads of genius and disability inextricably intertwined in his patients' family histories" (Silberman, 2015, p.188). Savant or genius abilities described by Asperger remain a stereotypical characteristic of ASC, frequently associated with male ASC. However, Asperger noted similarities to Kanner's earlier description, including difficulties with social skills and features such as repetitive movements and difficulty maintaining eye contact.

Initially, Asperger (1944) proposed that ASC was specific to boys, but clinical evidence changed his assumption as he observed that the mothers of some of his case studies behaviour had autistic features. Asperger stated, "It could be chance that there are no autistic girls among our cases, or it could be that autistic traits in females only become evident after puberty. We just do not know" (p. 85). Asperger's observations demonstrate an early awareness that autistic females may present in a way that does not fit our current male-biased understandings (Lehnhardt et al., 2016). However, Asperger's initial observations on the gender disparity within ASC did not gain traction until 1991, when his work was translated into English. Later Asperger's research was uncovered through the research of Lorna Wing, whose interest was driven by having an autistic daughter of her own (Chown & Hughes, 2016).

In the context of understanding how ASC in females became overlooked by research, it is noteworthy that the children observed by both Kanner and Asperger were predominantly male, with Kanner including only three girls and Asperger studying a group of four boys. While these initial samples and social representations of ASC were established upon anecdotal evidence, the assumption that ASC is predominantly an adolescent, male condition has pervaded academic thought and arguably continues to contribute towards the underrepresentation of female knowledge within ASC as a discipline (Happé & Frith, 2020; Saxe, 2017). Therefore, even from the founding days of its study, ASC was a gendered concept.

Earlier conceptualisations of ASC were challenged in 1979 when Lorna Wing and Judith Gould published findings from an epidemiological landmark study titled the 'Camberwell Study'. Wing and Gould (1979) found significant heterogeneity in the children's presentations, suggesting that ASC was a spectrum that encompassed a range of unique and continuous individual profiles. The reconceptualisation of ASC as a spectrum played a pivotal role in broadening the concept of ASC as it included individuals who met the criteria for an ASC diagnosis but did not have co-occurring ID (Fletcher-Watson & Happé, 2019). Resultingly, cognitively able autistic women who had been historically overlooked for diagnosis were recognised.

Following the Camberwell Study there was increased recognition that ASC was under-diagnosed. Nonetheless, ASC was still considered a rare condition until the 1990s (Happé & Frith, 2020). The translation of Asperger's earlier work in 1991 built on Lorna Wing's findings and generated significant changes surrounding the heterogeneity of ASC. Shortly after, the introduction of Asperger's syndrome in the *Diagnostic and Statistical Manual of Mental Disorders I-V* (4th ed.; DSM-4, American Psychiatric Association, 2000) played a critical role in recognising psychological differences within ASC and the

heterogeneity in language and cognitive abilities by widening the behavioural criteria of ASC (Happé & Frith, 2020). These changes are credited for increasing the numbers of individuals receiving a diagnosis of ASC in adulthood and have played a significant role in recognising females on the spectrum.

Prevalence of ASC in females

The past 50 years have seen a general trend of the increasing prevalence of ASC in the developing world, with estimates in high-income countries between 1% and 2%, yet, it is unclear if the male-to-female ratio of diagnosed cases is also changing (Bent et al., 2017; Lai et al., 2015). Gender discrepancies are a striking feature of ASC, with estimates long reflecting that males are diagnosed at significantly higher rates (Dworzynski et al., 2012; Rivet & Matson, 2011; Russell et al., 2011; Trubanova et al., 2014). Earlier estimates of ASC in females proposed a male-to-female ratio between 2.1 and 16.1 (Fombonne, 2003), suggesting that for cognitively able females, this decreases to 10:1, and for females with learning difficulties, the gender ratio is 2:1 (Dworzynski et al., 2012).

These initial estimates of the gender-ratio represent a self-fulfilling prophecy whereby the prevailing social understandings of ASC as a 'rare' condition in females was predicated to be proven. Ascertainment bias created significant bias as the samples were obtained from clinical or special needs registers, consequently overrepresenting the number of females with co-occuring ID and underrepresenting cognitively able autistic females (Happé & Frith, 2020; Lai et al., 2011; Loomes et al., 2017). These findings reinforced the notion that intellectual ability had a modulatory effect on ASC prevalence rates in females, suggesting that while females were less likely to be affected ASC, they were more likely to be affected more severely.

Until recently, the 4:1 male-to-female ratio was the most widely cited gender ratio, based on the average mean across population prevalence studies (American Psychiatric Association, 2013; Fombonne, 2009). Recent findings from epidemiological studies have challenged the reliability of this longstanding gender ratio and found that when using active case ascertainment, the ratio drops to 3:1 (American Psychiatric Association, 2013; Dworzynksi et al., 2012; Loomes et al., 2017). A recent meta-analysis (Loomes et al., 2017) played a pivotal role in recognising the gender bias within current statistics. They examined all of the published epidemiological studies on the gender ratio in ASC and found significant variability between passive (4.56) and active ascertainment (3.25) (Loomes et al., 2017). These findings indicate that passive ascertainment measures that rely on a formal diagnosis of ASC may be overlooking women who have clinically significant symptoms but remain undiagnosed. Furthermore, these estimates contribute to the growing acknowledgement that the current diagnostic measures of ASC may be gender-bias and may not reliably capture the female presentation of ASC.

Within the NZ context, prevalence rates of ASC remain best guesses as there is no national data monitoring registry of ASC (Bowden et al., 2020; Ministries of Health and Education, 2016). A recent nationwide NZ based study attempted to bridge this gap, including 10,000 individuals diagnosed with ASC aged from 0-24. They found that relative rates across gender were consistent with widely cited international estimates (4:1), proposing a male to female ratio of 3.6:1 (Bowden et al., 2020). The study did not find any substantive ethnically related differences in the male to female gender ratio between Māori (3.6) and Pakeha (3.7). ASC diagnostic rates in females varied significantly between those residing in rural (20.0) and urban areas (24.9). These findings indicate that Māori female populations may be disproportionately affected in this statistic as there are higher rates of Māori living rurally throughout NZ.

These findings fail to build an accurate picture of the gender-ratio in NZ for several reasons. First, the women included in the study are those who have already been diagnosed with ASC. As previously highlighted by Loomes et al., (2017), the reliance on passive ascertainment measures (e.g. requirement of formal diagnosis) may overlook women who meet the clinical threshold or are yet to be assessed. Alongside this, the measures rely on diagnostic tools, which have limitations in diagnosing autistic females (Gould, 2017). Second, these estimates exclude individuals who receive a diagnosis in the private sector and is likely to underrepresent individuals who receive a diagnosis later in life as research suggests that 71% of autistic adults receive an ASC diagnosis in the private sector in NZ (van der Meer et al., 2021). Finally, the sample's age range is narrow and only includes individuals under the age of 24. Given that international estimates indicate that women receive a diagnosis later than males, and often in adulthood, the sample underrepresents both women and diagnosis rates across the lifespan.

Theoretical Construction of Female ASC

Many studies have attempted to locate a biological difference to explain the high rate of ASC diagnoses in males. Interestingly, even the earliest scientific theories surrounding ASC have involved gender, notably Bruno Bettleheim's theory titled the 'refrigerator mother', which blamed mothers for their children's condition (Bettleheim, 1967). More recently, various genetic and cognitive theories have attempted to understand the gender discrepancies associated with ASC, primarily focused on understanding the aetiology of ASC (Pellicano et al., 2014; Trubanova et al., 2014). In recognising that ASC has historically been viewed through a biomedical lens (Asperger, 1944; Kanner, 1943; Wing & Gould, 1979), there remains a strong focus on understanding biological causes within contemporary theories (American Psychiatric Association, 2013; World Health Organisation, 2019). Two prominent

theories associated with ASC and gender are the Extreme Male Brain (EMB) hypothesis and the Female Protective Effect (FPE) theory. These two theories will be examined below.

The explicit gendering of ASC is apparent in the widely cited Extreme Male Brain (EMB) hypothesis by Baron-Cohen (2002a). The EMB theory posits that the cognitive profile of autistic individuals matches an extreme version of the male profile and therefore argues that all autistic individuals have an exaggeration of typical male traits (Baron-Cohen & Wheelwright, 2004). Despite no convincing evidence for a 'male brain' and empathy deficits, the EMB theory suggests that autistic individuals have a reduced capacity for empathy (Baron-Cohen, 2002a; Ridley, 2019). Therefore, inherent in the EMB theory is that the female brain is biased towards empathising while the male brain is biased towards systemising.

The EMB theory is widely criticised for promoting an understanding of ASC that perpetuates gender stereotypes (Bumiller, 2008; Krahn & Fenton, 2012). The association between stereotypically 'male' behaviours and interests ignores the influence of the social and cultural contexts in which gendered behaviours arise and creates misconceptions surrounding behaviours considered to be 'autistic'. For cognitively able autistic females, the EMB theory is particularly exclusionary as it implies that individuals tend to present with more 'extreme' or severe symptoms, perpetuating earlier misrepresentations of ASC. Therefore, the EMB theory exacerbates the barriers autistic women face when seeking a diagnosis and contributes to the under-diagnosis of females (Dworzynski et al., 2012; Krahn & Fenton, 2012; Kresier & White, 2013).

An alternative explanation for the gender disparity is the Female Protective Effect (FPE) theory. The FPE posits that females are more resistant to the genetic mutations that cause ASC, and therefore requires greater genetic and environmental risk to push them over

the threshold to the level where ASC would be expressed and diagnosed (Robinson et al., 2013). Therefore, the FPE suggests that are less likely to have ASC as the threshold at which mutation produces behavioural symptoms is higher in females than in males. The beliefs that underpin FPE theory are damaging for autistic females and further exacerbates the notion that ASC is a rare condition in females.

Research aims

The overwhelming majority of research on ASC has focused on males, children, and those with severe difficulties, thus marginalising females' experiences of ASC (Pellicano et al., 2014; Saxe, 2017). This is particularly true in NZ, where there is currently only one study examining the lived experience of unrecognised ASC in females (Hefferon, 2020). Accordingly, there is a lack of relevant, rich, detailed knowledge about NZ females' experiences of receiving a late ASC diagnosis. Therefore, this thesis will contribute to the current gap in the literature through the exploration of the experiences of females' who receive a diagnosis of ASC late in life. This qualitative study will be conducted through the analysis of interviews with nine autistic female adults.

CHAPTER TWO

Social Representations of ASC

The purpose of this chapter is to highlight the impact gender has on the diagnostic process, stigma, expectations, and the barriers this creates for autistic females. Then I discuss identity and ASC.

The historical exclusion of autistic women from research continues to permeate societal attitudes and beliefs surrounding ASC. Constructions of ASC within mainstream media continue to endorse and depict ASC in unidimensional and stereotypical ways (e.g. the idea of a white, male, nonspeaking child) (Botha & Frost, 2020; Zener, 2019). Homogeneous representations perpetuate misleading, stereotyped and often harmful representations, subsequently invalidating individual experiences, particularly late-diagnosed females who often assimilate and evade diagnosis. Women in two studies reflected on how they differed from dominant ASC stereotypes (Bargiela et al., 2016; Webster & Garvis, 2017), with many participants referencing notable media portrayals of ASC, including Raymond Babbitt in the movie *Rain Man* and Sheldon Cooper from the television show *The Big Bang Theory*.

The absence of 'success stories or 'normal' representations of autistic females in societal representations of ASC was raised by participants in a study examining autistic women's narratives of success (Webster & Garvis, 2017). Underpinned by self-efficacy theory (Bandura, 1997), the authors used the concept of *vicarious experience* to understand how women achieved success in their lives. They found that *vicarious experience*, which is gained by reading or watching videos of individuals in similar contexts overcome challenges, positively influenced the women to develop self-efficacy. This study provided a valuable perspective by applying a strengths-based approach by not only looking at the difficulties that autistic females face but also the successes they achieved in their lives. These findings

suggest that seeing other autistic women stories of success in the media may play a protective role in the development of a positive ASC identity, echoing the findings in Macleod et al., (2013) study, which found a strong association between positive ASC role models and positive ASC identity, suggesting the impact of wider social systems and interactions in fostering a view of self.

Current research on the social representations of ASC raises important questions about the psychological impact of not being able to 'see yourself' within mainstream media. For some women who gain an understanding of their own lived experience through comparisons made to media portrayals, this may exacerbate feelings of difference (Baldwin & Costley, 2016), while other women have reported using media representations of ASC to identify autistic traits in themselves (Zener, 2019). Therefore, only women who identify with the male symptoms associated with ASC can relate to the media's construction of ASC, disadvantaging and invalidating many women's experiences.

Two recent studies have examined the misrepresentation of autistic females in the media. Tharian and colleagues (2019) explored the depiction of autistic females in fictional works to understand the media's role in shaping public attitudes towards autistic women. They found that while cognitively able women are represented, some depictions appeared to endorse outdated myths and stereotypes. Stigmatising representations of ASC were also found in an explorative study by Treweek et al., (2019) which examined ASC stereotypes from the perspective of autistic adults. The participants perceived stereotypes to be highly damaging, homogenising and reported feeling restricted by the stereotypical beliefs that non-autistic individuals held.

Within this social context, it is unsurprising that women report gender-specific concerns regarding the impact of social representations of female ASC within the media. In

two studies (Bargiela et al., 2016; Treweek et al., 2019), autistic women believed that societal stereotypes of ASC impacted their subjective experiences of diagnosis. They felt that their ASC was dismissed because they presented in counter-stereotypical ways, such as having social skills and making eye contact. These findings suggest that social representations of female ASC may exacerbate the challenges autistic women face when attempting to have their needs recognised. Alongside challenges having their unique ASC needs met, autistic females appear to encounter unique challenges from not fitting dominant stereotypes of ASC perpetuated within the media, which appear to be exacerbated by the limited representation of ASC. These challenges likely impact how females react to, identify and experience their diagnosis.

Social Compensatory Behaviours

Social compensatory behaviours (also referred to as 'camouflaging' and 'masking') is the suppression of aspects of ASC symptomology by monitoring or modifying behaviour to conform to neurotypical social behaviour (Hull et al., 2017). Many late-diagnosed autistic women report camouflaging behaviours. Social mimicry (copying gender normative or neurotypical behaviours) and masking (hiding ASC related difficulties) are described as 'pretending to be normal' and 'putting on a mask' (Bargiela et al., 2016; Leedham et al., 2020). These strategies include making eye contact and rehearsing social scripts and are utilised to appear socially competent and reduce the social difficulties associated with ASC (Bargiela et al., 2016).

While masking appears to be more prevalent in females (Hull et al., 2020; Lai et al., 2017), it is not a gender-specific phenomenon or universal behaviour for autistic females (Bargiela et al., 2016; Davidson & Henderson, 2010). Accordingly, a recent study by Cage & Troxell-Whitman (2019b) found that 70% of autistic adults report they consistently mask, suggesting that masking is widespread across both genders. However, research suggests that

cognitively able females are more likely to mask due to the ability to identify and understand how to conceal their differences (Baldwin & Costley, 2016; Bargiela et al., 2016; Dworzynski et al., 2012; Hull et al., 2017; Kresier & White, 2014; Lai et al., 2017; Tint & Weiss, 2018). These findings indicate the importance of studies that focus on cognitively able autistic women and, specifically, those whose ASC was only identified in adulthood to understand the reciprocal relationship between masking and late diagnosis (Kanfiszer et al., 2017; Leedham et al., 2020; Stagg & Belcher, 2019; Webster & Garvis, 2017).

While still in its infancy, research focused specifically on autistic women suggests camouflaging use may vary across the lifespan. The drive to be 'normal' appears to be particularly prevalent in adolescence (Tierney et al., 2016), as adult women report the reduced need to adopt social strategies with age (Baldwin & Costley, 2016; Bargiela et al., 2016; Webster & Garvis, 2017). A recent mixed methods study by Sedgewick et al., (2019) suggested that females diagnosed later in life may have different masking experiences than those who receive a timely diagnosis. Consistent with this, participants in a study by Milner et al., (2019) linked increased masking behaviour to delayed diagnosis and limited access to support. These findings suggest that individuals diagnosed late in life may mask more due to growing up undiagnosed in a society or era that is less accepting of neurodiversity, highlighting the influence of social and cultural context in the use of masking behaviours.

To date, research on masking is limited by the reliance on quantitative methodologies. These studies have focused on quantitative differences between genders focused on observable or external behaviours (Lai et al., 2017). This research has overlooked the internal inclinations of masking and produced a significant gap in current knowledge surrounding masking motivations and consequences (Green et al., 2019). Moreover, given that camouflaging is a social phenomenon, the quantitative approach has failed to acknowledge the socio-cultural context in which masking behaviours occur. In recognising that masking is

a social phenomenon and masking behaviours and strategies change across different social contexts (Cage & Troxell-Whitman, 2019b), it is critical to understand the socio-cultural context in which camouflaging behaviours occur. Therefore, while the qualitative studies on the masking strategies of adult females are limited (Baldwin & Costley, 2016; Bargiela et al., 2016; Kanfiszer et al., 2017; Leedham et al., 2020; Milner et al., 2019; Stagg & Belcher, 2019; Webster & Garvis., 2017), they are well-positioned to understand masking due to the ability to engage in personal experiences.

Masking appears to be motivated by the desire to 'fit in' to a non-autistic world, develop and maintain friendships, manage socio-communication impairments, prevent others from noticing their socio-communication difficulties and attempt to behave in compliance with societal standards (Bargiela et al.,2016; Cage & Troxell-Whitman, 2019b; Leedham et al., 2020; Livingston et al., 2019; Tierney et al., 2016). Late-diagnosed autistic women report they are motivated by a desire to 'fit in' with some feeling the pressure to act or behave in a way that is deemed socially acceptable (Bargiela et al. 2016; Leedham et al., 2020), including fulfilling 'wife' and 'mother' roles, despite feeling that this feel incongruent with their identity (Bargiela et al., 2016; Kanfiszer et al., 2017). Therefore, the experience of masking occurs within a social context and appears to be closely associated with broader societal expectations, suggesting that exposure to social representations of gender and ASC may impact women's use of compensatory strategies and behavioural presentations.

The interaction between the social environment and masking is largely neglected from research, perpetuating the notion that masking is an individual is a 'choice', thus overlooking the unconscious aspects of masking (Pearson & Rose, 2021). While women report conscious aspects of masking, including 'learnt' strategies by observing female peers and the media (Bargiela et al., 2016), subconscious aspects of masking remain neglected. However, emerging research provides a broader understanding surrounding the motivations for

masking, particularly the role of the social context and notably the influence of stigma on the use of masking. Recent research by Botha and Frost (2020) suggests a strong association between stigma and masking behaviour, providing further evidence that heightened use of masking may reflect autistic female's minority social status in society.

While research remains in its infancy, there appear to be high costs and consequences for the use of compensatory strategies. Qualitative research has found that women who engage in these strategies find it cognitively and emotionally exhausting, challenging to one's identity, and in some cases, negatively affected their mental health (Baldwin & Costley, 2016; Bargiela et al., 2016; Hull et al., 2017; Tierney et al., 2016; Tint & Weiss, 2018). Only one study (Cage & Troxell-Whitman, 2019b) attempted to theorise the motivations and consequences of camouflaging. They used Disconnect Theory (Ragins, 2008) to understand the intersection between stigmatised aspects of identity and masking by examining the costs and contexts of masking. Cage and Troxell-Whitman (2019b) found that autistic adults individuals who reported higher levels of masking also reported higher levels of stress. This is consistent with the idea that disconnection from one's identity causes psychological distress. These findings add to growing evidence that suggests that camouflaging has negative impacts on mental health.

In addition, the use of compensatory strategies may play a role in the late or missed diagnosis of females with ASC (Gould & Ashton-Smith 2011; Kirkovski et al. 2013; Lai et al. 2017; Livingston et al., 2019). An exploratory mixed-methods study by Tint and Weiss (2018), including twenty autistic women, found that masking behaviours negatively impacted interactions with service providers. These behaviours minimised their service needs as service providers perceived women as malingering or exaggerating their needs. Consistent with this, many women across the studies have reported how masking during the assessment has adversely impacted their chances of being diagnosed (Bargiela et al., 2016; Milner et al.,

2019). These findings suggest that some women employ compensatory strategies during a diagnostic assessment, perhaps as a habitual response, which may negatively impact their likelihood of receiving a diagnosis.

The use of compensatory behaviours has adverse consequences for autistic women, as burgeoning research indicates elevated rates of perceived and observed sexual abuse, victimisation, and exploitation (Bargiela et al., 2016; Kanfiszer et al., 2017). Concerning reports about sexual vulnerability within sexual relationships have emerged as participants in Bargiela et al., (2016) study reported high levels of sexual abuse within the context of a relationship, while similar concerns were raised in a recent study by Milner et al., (2019), as one participant stated, "I'm prey in the world of predators" (p. 2393). The miscommunication of intent and desire for social acceptance indicative of masking may play a role in the elevated rates of exploitation. A recent study by Sedgewick and colleagues (2019) found that women linked their social and sexual vulnerability to social inferencing difficulties. Interestingly, the women associated specific vulnerabilities to the lack of self-awareness related to late diagnosis, suggesting that timely diagnosis may play a protective role against exploitation. The additional pressure to adhere to feminine gender expectations appears to significantly influence autistic women (Kanfiszer et al., 2017). It appears that feeling obligated to comply with gender expectations may leave autistic women particularly vulnerable to exploitation.

Stigma

Autistic individuals are a highly stigmatised group, as evidenced by research exploring the public perceptions of ASC which that individuals found had negative and even dehumanising attitudes towards those with ASC (Cage et al., 2018; Treweek et al., 2019). Within this social context, it is essential to recognise the role of stigma within autistic women's experiences. Stigma refers to an attribute that gives the bearer a discredited status

which is different from others in their social category (Goffman, 1963). Experiences of stigma are heightened for autistic women as they occupy two marginalised and intersecting identities, being both autistic and female. Therefore, intersectionality provides a useful lens for understanding autistic women's experiences of stigma and living with an ASC diagnosis.

Intersectionality recognises that the interaction between having a disability alongside other oppressed identities (e.g. gender) results in various barriers due to the unequal structures within society (Crenshaw, 1989; Saxe, 2017). According to Saxe (2017), autistic females occupy three explicit identities that contribute to the barriers they experience, as they are female, disabled, and a minority within the male-centric ASC community. Therefore, an intersectional framework is well aligned with emerging research examining stigma as it provides scope to understand how societal barriers mediate the experience of living with ASC.

To date, research on stigma and ASC has primarily focused on how stigmatic beliefs surrounding ASC influence how others view autistic individuals and how others treat them. However, recent research is beginning to acknowledge how stigma is experienced. A recent study by Botha and Frost (2020) extended research to recognise the impact of stigmatic stereotypes on the mental health of autistic adults. They used the minority stress model (Meyer, 2003) to examine how social stressors, such as internalised stigma and discrimination, impact mental health. This model is valuable as it addresses the personal effects of living in a social environment characterised by stigma, prejudice, and discrimination towards minority groups (Meyer, 2003). They reported close connections between self-reported psychological stress, including discrimination in daily life, internalised stigma, and concealment of their autistic identity.

Likewise, Cage et al., (2018) found that negative societal perspectives surrounding ASC and poor acceptance from others were key factors in developing mental distress. They utilised the social model of disability (Shakespeare, 2013), positing that the cause of distress is moderated by broader social structures within the individual's surrounding environment. Likewise, Cooper et al., (2017) acknowledged the impact of discrimination and social stigma on negative self-conceptualisation. Importantly, these studies recognise the association between stigma and mental health, thus challenging the causal link between ASC and increased mental health rates within the autistic population perpetuated by the biomedical model. Therefore, current findings from limited research in this area suggest that autistic individuals are negatively affected by broader societal factors, in particular the stigmatising attitudes and beliefs about ASC.

Gender Expectations

The influence of the sociocultural contexts in which gendered behaviour develops and is expressed has been neglected within the literature. The impact of gender-based socialisation practices on the behavioural presentation and perception of symptoms is underestimated within the ASC literature and contributes to the under-recognition of autistic females (Cheslack-Postava & Jordan-Young, 2012; Geelhand et al., 2019; Goldman, 2013; Kreiser & White, 2014). Consequently, there is limited understanding about how gender expectations are experienced by autistic females. However, recent research has begun to acknowledge the limitations in current research and recognise the importance of separating sex and gender to understand the impact of gender on the presentation, diagnosis, and development of ASC (Lai & Szatmari, 2020; Strang et al., 2020).

Recent qualitative research has recognised the impact of gender on the experiences of living as an autistic woman and diagnosis. Within a context of gendered expectations, existing research indicates that social expectations are greater and different for women (Dean

et al., 2017; Kreiser & White, 2014). The influence of gender expectations is a salient theme across the studies as women report a strong feeling of difference from their female peers, such as not having the same interests and not possessing maternal instincts as a girlfriend, wife or mother as an adult (Bargiela et al., 2016; Davidson, 2007; Kanfiszer et al., 2017; Leedham et al., 2020). Furthermore, research suggests that women are more likely to feel shame regarding the challenges they face with the feminine gender norms inherent in society (Green et al., 2019).

Accordingly, it is unsurprising that research indicates that females engage in camouflaging to meet gendered social behaviours (Bargiela et al., 2016; Milner et al., 2019; Saxe, 2017) and conform to social norms (Kanfiszer et al., 2017; Kreiser & White, 2014; Lai et al., 2015). Across several studies it is apparent that autistic females are aware of gender expectations, with many women feeling pressured to adhere to these. For autistic women, these feelings of exclusion may be exacerbated by feeling different and disconnected from both males with ASC and predominant stereotypes of femininity (Davidson, 2007). Socialisation practices and cultural expectations play a protective role in the difficulties associated with ASC and contribute to the under-diagnosis of autistic females (Krahn & Fenton, 2012). Against this backdrop, it essential to recognise the role that gender expectations and intersectional impacts (e.g. having ASC) have in women's experiences of being both autistic and female.

Skewed Diagnostic Criteria

Growing evidence challenges the longstanding belief that females are less likely to develop ASC and suggests that current diagnostic procedures contribute to the under-diagnosis and misdiagnosis of females with ASC (Loomes et al., 2017; Ratto et al., 2018; Rynkiewicz et al., 2016). Research suggests that autistic females present with unique characteristics and exhibit subtler presentations of ASC (Dworzynski et al., 2012; Hiller et

al., 2014; Kresier & White, 2014). Therefore, current literature indicates a lack of confidence in the reliability of standard diagnostic assessment tools for identifying ASC in the female population, particularly cognitively able autistic females, as they are most vulnerable to being missed by diagnostic tools.

The suitability of the ASC diagnostic criteria for females continues to generate widespread criticism despite changes to the DSM-5. The revision of the DSM-5 in 2013 brought fundamental changes to the diagnosis of ASC. Asperger's Syndrome, Atypical autism, Autistic Disorder and Pervasive Development Disorder– Not Otherwise Specified (PDD-NOS) were removed as separate diagnostic conditions and absorbed into the broader category of ASD, with autistic disorder renamed Autism Spectrum Disorder (ASD) (American Psychiatric Association, 2013). For the first time, gender and adult diagnosis are recognised within the DSM, allowing the late recognition of characteristics that had not been present in early childhood. This also included a manual in the DSM-5, specifically related titled 'Gender-related diagnostic issues' (Happé & Frith, 2020; Lai & Baron-Cohen, 2015).

However, despite the changes that have been made to enhance inclusivity, the suitability of the diagnostic criteria in the DSM-5 is widely criticised for being "sex/gender blind" as the diagnostic criteria for both males and females remains identical (Lai et al., 2013, p.3). As diagnostic criteria are established based on male populations, current diagnostic assessment tools are unreliable (Hull et al., 2019; Kirkovski et al., 2013; Lai et al., 2015). Therefore, given the diagnostic criteria' exclusionary nature, concerns remain around discrimination and inequity (Shefcyck, 2015).

Barriers to Diagnosis

Challenges obtaining a diagnosis in the healthcare system is a key issue for females who suspect they have ASC, particularly when a diagnosis is sought in adulthood.

Overwhelming research suggests that autistic females encounter a disproportionate number of barriers when attempting to obtain a diagnosis (Green et al., 2019; Lewis, 2017), as many women have reported that accessing an ASC was a time-consuming process (Bargiela et al., 2016; Milner et al., 2019; Zener, 2019). Even once an assessment is sought, women in several studies report that their needs are misunderstood, reflecting on how appearing capable negatively impacted their ability to receive a diagnosis and for health professionals to take their needs seriously (Baldwin & Costley, 2016; Bargiela et al., 2016; Kanfiszer et al., 2017). These barriers appear to be gender-specific, including concerns that they will be overlooked and told that they are making up the symptoms or are seen as "not looking the part" (Tint & Weiss, 2018, p. 930).

Emerging evidence suggests that the threshold required to gain a diagnosis is significantly higher for females who require higher symptom expression, including presenting with more behavioural and co-occurring difficulties in order to receive a diagnosis (Carpenter et al., 2019; Duvekot et al., 2017; Dworzynski et al., 2012; Russell et al., 2011). These findings suggest that clinicians may be less likely to diagnose a female who meets the diagnostic criteria for ASC. Alongside these findings, the influence of gender bias beyond the diagnostic measures is beginning to emerge, which appears to give credence to the stereotype of ASC as a male disorder within clinical practice, thus highlighting a failure to recognise the complexity of ASC outside the unidimensional construction of ASC.

Moreover, healthcare professionals are reluctant to provide a formal diagnosis for females with ASC. Autistic women across several studies have reported that they were misunderstood and dismissed by health professionals when attempting to access diagnostic services, with some women associating the reluctance to diagnose to be a consequence of prevailing gender stereotypes (Bargiela et al., 2016; Lewis, 2017; Tint & Weiss, 2018; Treweek et al., 2019; Zener, 2019). Therefore, gendered assumptions of ASC appear to

disadvantage females accessing diagnosis and present as a significant barrier to obtaining a diagnosis.

Despite widespread recognition of male bias inherent in diagnostic measures, there remains little acknowledgement of the subjectivity, potential biases and the role of gender that may permeate clinical judgement. Given that a diagnosis of ASC is reliant on observable behaviours (American Psychiatric Association, 2013; World Health Organisation, 2019), there is increased potential for social and cultural expectations to define and diagnose ASC implicitly. Therefore, it is critical to understand how social and cultural ideas of gender impact the timely diagnosis of ASC in females. Emerging research suggests that healthcare professionals may misinterpret behaviour due to gendered expectations (e.g. misattributing social withdrawal as shyness in females (Whitlock et al., 2020). These findings suggest that clinicians may hold gender stereotypes that may influence clinician expectations and reduce their sensitivity to ASC symptoms when they occur in females. Therefore, clinicians unfamiliar with the female presentation of ASC may implicitly hold bias and look for the symptoms of ASC commonly found in males, disadvantaging women who do not fit the stereotype.

The lack of understanding and recognition of the female phenotype permeates the diagnostic bias, exacerbating barriers towards accessing a diagnosis and contributing to delayed diagnoses. A systematic review of international ASC assessment clinical guidance documents from governments and organisations, including NZ, highlighted a lack of clarity surrounding adult ASC diagnosis (Penner et al., 2018). Accordingly, '*The autism diagnostic process in New Zealand*' found that clinicians requested extra training on diagnosing ASC within adult and female populations. Similarly, autistic adult women reported a "limited understanding of women of my age getting a diagnosis", suggesting a specific gap in health professional knowledge (van der Meer et al., 2021, p.76). These findings echo international

research, which indicates a lack of understanding about how ASC affects girls and women among clinicians (Crane et al., 2018; Mandy & Lai, 2017).

Development of an Autistic Identity

Across multiple studies, women reported the pivotal impact of diagnosis in shaping a new identity as many women described holding self-critical beliefs about their ASC related difficulties, for example, internalising the belief that they were "different" and "wrong" prior to receiving a diagnosis (Baldwin & Costley, 2016, p. 487; Leedham et al., 2020, p. 138). However, for many women, receiving a diagnosis provided a framework for understanding past difficulties, enhancing self-awareness, and reducing self-blame (Leedham et al., 2020; Tan, 2018; Webster & Garvis, 2017). Therefore, the increased self-understanding associated with the diagnosis facilitated the positive integration of ASC into self-identity (Leedham et al., 2020; Tan, 2018; Webster & Garvis, 2017).

Emerging research suggests that a "positive autism identity" may act as a protective mechanism against low self-esteem and psychological difficulties (Cage et al., 2018; Cooper et al., 2017, p.844). A recent online survey by Cooper et al., (2021) (n=140, with 71 autistic females) found an association between identification with other autistic individuals, collective self-esteem, and the number of positive attributes they associated with ASC. Therefore, it is critical to understand the factors influencing a 'positive autism identity' for late-diagnosed autistic females.

Webster and Garvis (2017) was the only study to use a theory (self-efficacy theory) (Bandura, 1997) to link the development of identity formation with experiences of ASC. The participants described the diagnosis as a pivotal moment in positively integrating the diagnosis into their self-identity and enabled self-efficacy across many facets of their life. However, the findings may be positively skewed as the sample used a social media site run

by a psychologist specialising in working with women with ASC to recruit most of the participants. Therefore, the sample may over-represent women who have access to professional post-diagnostic support, which may impact the positive experiences of diagnosis and the ability to integrate ASC into their identity successfully.

In addition to the diagnosis fostering a positive self-concept, many participants reflected on the benefits of forming connections with individuals within the ASC community (Bargiela et al., 2016; Leedham et al., 2020; Webster & Garvis, 2017; Zener, 2019). This involved building connections with other autistic individuals and the wider ASC community via online or face-to-face ASC support groups and self-directed research. These connections played an essential role in developing a positive autistic identity. They supported women to integrate ASC as part of their identity by normalising the difficulties associated with ASC and reducing isolation. Given that the experiences of women with ASC are "characterised by a profound sense of alienation" (Davidson, 2007, p. 673), it is unsurprising that so many women reported the importance of group belonging or forming a collective ASC identity to support the integrations of ASC as part of their identity.

While the women reported the diagnosis in largely positive terms, the stigma often associated with ASC raised concerns and acted as a barrier. For some women, the anticipated fear or judgement posed as a barrier to integrate ASC as part of their identity and, in some cases, impacted their reluctance to disclose their ASC diagnosis (Bargiela et al., 2016; Leedham et al., 2020). The experience of living with a stigmatised identity such as an ASC diagnosis is present in many various accounts across the literature, including social exclusion, bullying and discrimination, suggesting autistic adults experience high rates of stigma (Cage et al., 2018; Treweek et al., 2019).

Two recent studies (Botha & Frost, 2020; Cage et al., 2018) found that the development of a 'positive autism identity' is highly mediated by the beliefs of ASC within wider society, such as the attitudes and beliefs about ASC. Botha and Frost (2020) found a strong association between self-reported psychological distress and stressors, including internalised stigma, experiences of stigma and concealment of autistic identity. Similarly, Cage et al., (2018) found that perceptions of societal ASC related acceptance influenced autism-related personal acceptance. Therefore, research suggests that an individual's autistic identity may be shaped by others' perceptions.

Summary

The research to date highlights that autistic women experience various disadvantages due to their gender. The role of male-centered social representations of ASC within society plays a significant role in ongoing marginalisation, contributing to the gendered expectations and norms that many autistic women feel obliged to fulfil. The pressure to adhere to these expectations, 'fit in' with the neurotypical world and avoid stigma impacts autistic women's sense of identity and social behaviours. Alongside the gender-specific challenges women face, gender bias permeates the diagnostic process, contributing to the various gender-specific barriers autistic women face while attempting to obtain an ASC diagnosis in adulthood. It is therefore important that is more research focusing on the lived experience of females who get a later diagnosis.

CHAPTER THREE

Methodology

Aims and Rationale

This project aimed to explore the lived experiences of females' who receive a late diagnosis of ASC. A qualitative method was utilised using *interpretative phenomenological analysis* (IPA) to gain a rich and detailed insight into the personal, lived experiences of nine females with ASC and how they make sense of those experiences.

Cognisant of the longstanding misrepresentation and exclusion of the female experience of ASC, the idiographic approach of IPA enables participants to co-produce understanding of their experience and enable their 'voice' to be heard (Shefcyck, 2015; Smith et al., 2009). IPA's commitment to illuminating participants' lived experience provides an opportunity to counterbalance existing medical and academic discourse, which is dominated by theoretical conceptions based on the male experience of ASC and facilitates rich, in-depth knowledge of receiving a late diagnosis from an insider perspective.

Furthermore, in recognising the potential impact of the 'double empathy problem' (Milton, 2012), described as the potential mutual misunderstanding of autistic and non-autistic individuals within ASC research, it is important that the perspectives of the participants are accurately reflected throughout the research. IPA's commitment to treating participants as experts and researcher reflexivity lends well to illuminating the experiences of autistic individuals (Howard et al., 2019; Pellicano et al., 2014). This chapter outlines the processes taken to address the research aim, collect the data and the analyses taken to address the research aim.

Research Approach

The methodology utilised in this project was IPA, a qualitative approach developed by Jonathan Smith (Smith et al., 2009). IPA's primary aim is to explore how individuals

interpret, respond to, and make sense of their subjective life experiences (Pietkiewicz & Smith, 2014). IPA recognises the value of subjective knowledge and demonstrates a commitment to understanding meaning-making from a first-person perspective (Eatough & Smith, 2011). IPA also acknowledges the role of the social context in shaping meaning-making, enabling an understanding of how gender interacts with the experience of receiving a late diagnosis. Furthermore, IPA's idiographic approach is committed to examining the diversity of each individual experience and considers participants to be experts in their own experiences, therefore enables participants to express an account of their lived experiences in their own terms (Smith & Osborn, 1998).

IPA is informed by three key theoretical frameworks, including phenomenology, hermeneutics and idiography (Smith & Osborn, 2008; Pietkiewicz & Smith, 2014). Phenomenology is concerned with the world as it is experienced by individuals at particular times and in particular contexts. Foundational phenomenological philosopher Husserl (1931) proposed that reality is composed of our subjective conscious experience of the world (Hammond et al., 1991). Therefore, reality is internal to the individual, requiring an understanding of the phenomena as it is lived and perceived by the individual's consciousness (Neubauer et al., 2019). Husserl argued that in order to penetrate deeper into reality and achieve a deeper level of understanding, we must go "back to the things themselves" (Smith et al., 2009, p. 12) by attempting to neutralise the preconceptions and predetermined categorical systems which are understood to obscure the true nature of the experience (Smith et al., 2009). This process involves actively stepping out of the 'natural attitude' to reflexivity 'bracket' or suspend any preconceived ideas about the phenomena in terms of its own inherent meaning (Smith et al., 2009).

Hermeneutics, the second major theoretical foundation of IPA, refers to the theory of interpretation. Heidegger (1962) introduced hermeneutic theory to phenomenology and

proposed that individuals' experiences are inextricably derived from the context that surrounds them and cannot be meaningfully detached from their context (Langdridge, 2007). Therefore, maintaining awareness of the context is paramount, as these interpretive influences impact an individual's interpretations (Laverty, 2003). Accordingly, Heidegger proposed that individuals play an active role in making sense of their lived experiences (Eatough & Smith, 2011) and suggested an interpretive process is required to understand the meaning that individuals ascribe to their being (Smith et al., 2009; van Manen, 2016).

The interpretive approach involves both the participant and the researcher, who are interactively linked in the production of findings (Laverty, 2003). This process involves the 'double hermeneutic', whereby the researcher aims to make sense of the participant trying to make sense of their lived experience (Smith & Osborn, 2008). Central to the interpretive process is the hermeneutic circle, which involves the dynamic relationship between the parts and the whole and highlights the circular nature of the interpretation in IPA. Within this process, the meaning of any given part can only be understood in relation to the whole, and the meaning of the whole can only be understood in relation to the parts (Smith et al., 2009). This process increases the depth of understanding by increasing awareness of the possible interpretive influences (Laverty, 2003).

The third central tenet of IPA is idiography, which refers to the detailed and in-depth examination of the participants' experiences of the phenomenon being explored. IPA's idiographic commitment balances the uniqueness of each individual's lived experience with the commonalities shared by the group to illuminate the nuances of each experience in detail (Smith et al., 2009). Therefore, the present study does not aim to generalise any knowledge gained but will remain valuable by recognising and validating the experiences of autistic females. The research will contribute to a growing number of IPA studies which provide greater insight about how females experience an ASC diagnosis late in life. The individual

experiences in this study aim to add to and extend existing literature related to the female population's experience of ASC.

Participants

In recognising IPA's idiographic aim and the feasibility of the researcher's timeframe, the study utilised a small sample of nine (Pietkiewicz & Smith, 2014). Consistent with IPA's requirement for a purposive and homogeneous sample (Smith et al., 2009), the researcher employed purposive sampling techniques to ensure that the participants were all able to reflect upon the phenomena of interest under study (Creswell, 2018). The research project was open to females who had received a late diagnosis of ASC and lived in NZ. Two participants had a co-morbid diagnosis of Borderline Personality Disorder, one with Attention Deficit Hyperactivity Disorder, four diagnosed with depression and three with anxiety. Due to the frequent co-occurrence of these conditions diagnoses in ASC (Lai & Baron-Cohen, 2015; van der Meer et al., 2021), it was not surprising to find so many participants with co-morbid conditions.

The term 'late diagnosis' was purposively not clarified to allow the women with ASC to define late diagnosis. In accordance with previous studies with an experiential focus on the diagnosis of female ASC (Bargiela et al., 2016; Kanfiszer et al., 2017), the participants were required to be at least 18 years of age and must have received a diagnosis from a health professional within the last ten years. This included a diagnosis of either Asperger's or Autism Spectrum Disorder (ASD) as Asperger's was formally recognised in the *Diagnostic and Statistical Manual of Mental Disorders* as a diagnostic category until 2013 (4th ed.; DSM–4; American Psychiatric Association, 2000). The 10-year time frame was chosen to reduce recall bias associated with recalling memories about the experience of receiving a diagnosis.

During an interview with a participant, it became apparent that she was self-diagnosed and had not yet received a formal diagnosis due to the financial cost. In recognition of the challenges and time-consuming process to access ASC assessments, particularly for females in adulthood (Bargiela et al., 2016; Milner et al., 2019; Zener, 2019), the researcher decided to include the participant interview in the study. In this case, the focus for analysis the participants personal meaning-making of self-diagnosis rather than the experience of receiving a diagnosis of ASC. In addition, while completing an interview, a participant who self-selected to participate in the research project disclosed that she received a diagnosis of Asperger's nineteen years ago and therefore was outside the 10-year time frame. The researcher chose to include this participant as she was very motivated to contribute to the current research project and had important insights to offer regarding the historical situatedness of ASC.

Sampling

Participants were recruited through social media platforms, NZ based Autism organisation Altogether Autism and using snowball sampling techniques. NZ news media articles about females with ASC were noted, and the names were captured. Potential participants were contacted via social media platforms Facebook and LinkedIn, which included a brief message from the researcher introducing themselves and the research project. If the potential participant showed interest, the researcher emailed through the project advertisement (see Appendix A), participant information sheet (see Appendix B), the interview schedule (see Appendix C) and encouraged any further questions about the study.

The researcher sent the interview schedule to all potential participants to enable adequate time to familiarise themselves with the topics, particularly for autistic participants to enhance comfortability with the topics before the interview was conducted (Howard et al., 2019). This resulted in the initial recruitment of five participants. It may be expected that the

females identified in news articles within NZ would be open to discussing their experiences as this was something they had previously done and therefore, a selection bias may exist, however, the other four participants were recruited through other methods.

Snowball sampling involved asking participants if they knew other individuals who may qualify for participation in the research (Robinson, 2014). This method is a suitable sampling method when the population-of-interest has low social visibility (Biernacki & Waldorf, 1981; Woodley & Lockard, 2016). As autistic women remain a minority group and often experience marginalisation, snowball sampling was an appropriate method to effectively engage and increase access to marginalised populations (Saxe, 2017; Pellicano et al., 2014). Furthermore, autistic women often know each other (Crompton et al., 2020; Leedham et al., 2020), and recruitment from individuals who share 'insider' status reduce the barriers to participation that individuals may experience, for example, reluctance to respond to an advertisement sheet (Biernacki & Waldorf, 1981).

Therefore, the recruitment strategy involved the peer and support communities frequently utilised by females, with ASC and snowball sampling provided the opportunity for participant recruitment via peer and support groups, enabling the "sampling of natural interactional units" (Biernacki & Waldorf, 1981, p. 141). At the end of each interview the researcher asked the participant if they know of any other individuals who may be eligible to participate in the research. If the participant did make a referral, the researcher gained consent from the potential participant(s) to forward their contact details to them. One participant was recruited via snowball sampling.

Early in the research process, the researcher established relationships with Autism organisations in NZ to discuss the research project and the prospective recruitment of participants. Altogether Autism granted the researcher permission to advertise the research

project through an online national database. The advertisement included a brief message about the research and the participant information sheet (see Appendix B) was attached. Participants were invited to contact the researcher via telephone or email. This resulted in the recruitment of four participants.

The researcher chose to advertise recruitment through Altogether Autism as the organisation is a free nationwide information and advisory service which provides support for individuals and families with ASC. The services provided by the organisation are recommended to individuals following a diagnosis of ASC, and it was expected that some women may be accessing the services provided. Advertisement through the organisation represented an active attempt to gather various socio-economic, cultural and age range for the study as the services are free and the database is nationwide. Furthermore, Altogether Autism demonstrated interest and value in the research objectives of the current research project. The organisation did not attempt to influence the research project and were not seeking compensation; however, in return for help to source the sample the researcher offered to produce a report of the findings for the organisation.

Altogether Autism was a gatekeeper in the recruitment process and enabled access to potential research participants. When researching minority or 'hard to reach' populations, such as autistic females, gatekeepers are important (de Laine, 2000). In recognising the stigma associated with being an autistic female, and the potential impact that this may have on the willingness for autistic females to engage in research, it was important that gatekeepers were part of the recruitment process. Therefore, the organisation enhanced the researcher's credibility within the community (de Laine, 2000), which was particularly important, given that the researcher was not an 'insider' in the community.

The participants demographics are outlined in Table 1. The average age of the participants was 33 years and the average age at diagnosis was 26.8 years.

Table 1

Participant Characteristics

Name	Age at time of interview	Employment	Location	Age of diagnosis	Diagnosis received	Diagnostic pathway
Kirsty	40	Stay at home mother	Auckland	36	Self-identified	N/A
Esther	27	PhD student	Wellington	14 24	[1]PDD-NOS ASD	Clinical Psychologist
Belinda	56	Disability advocate	Wellington	48	Autism Spectrum Condition	Developmental Paediatrician-specialising in Autism and ADHD
Katie	19	University student, part-time NCEA tutor and retail worker	Wellington	18	Autism Spectrum Disorder	Psychiatrist
Chloe	26	Postgraduate University student	Auckland	15 or 16	Asperger's	Psychiatrist
Karen	35	Part-time special needs teacher aid	Whakatane	16	Asperger's	N/A
Edith	23	Case Manager	Christchurch	23	Autism Spectrum Disorder	Clinical Psychologist
Sophia	33	Customer support agent for an IT company	Whangarei	33	Autism Spectrum Disorder	Clinical Psychologist

[1] PDD-NOS stands for Pervasive Developmental Disorder-Not Otherwise Specified. PDD-NOS was one of several previously separate subtypes of autism that were folded into the single diagnosis of autism spectrum disorder (ASD) with the publication of the DSM-5 diagnostic manual in 2013.

| Sarah | 40 | Postgraduate University Student | Hamilton | 38 | Autism Spectrum Disorder | Clinical Psychologist |

Data collection

The methods used in this research project were flexible and allowed the participants to share their views in ways that suited them individually. The researcher offered a range of communication choices of the interview format, including videoconferencing, phone calls and typed email responses to reduce excluding participants who might prefer not to interview in person due to sensory sensitivities or social challenges and cater to individual preferences (Bargiela et al., 2016; Howard et al., 2019). In practice, three interviews were conducted using videoconferencing application Google Zoom, three participants were interviewed on the telephone, two were conducted face-to-face, and one response was typed. Interviews lasted 30-90 minutes.

Potential meeting locations included participants' homes, public places or Massey university spaces. One participant opted to be interviewed at home, and another selected a room in a public library. The remaining seven participants were at home during the interview. Interviews were recorded on the researcher's iPhone 6 using the audio and transcription app Otter Voice Notes (2019), which transcribes audio recordings into written transcripts. A digital voice recorder was also utilised. A packet of biscuits and coffee were brought to each face-to-face interview to share with participants.

The interview began with informal discussions to build rapport with the participants and the completion of general research tasks. The researcher spent approximately 5-10 minutes introducing herself and detailed her personal interest in the research project and discussed her background and motivation for completing the present study. Establishing rapport and trust early in the research process is paramount in IPA as this facilitates two-way

dialogue, thus reducing the power imbalance and enabling access to the participants' experiences (Smith & Osborn, 2015). The development of a rapport and a trusting relationship was critical as the research involved personal and sensitive topics (Murray, 2003; Pietkiewicz & Smith, 2014). The consent forms were then signed in the face-to-face interviews, and the consent process was verbally conducted in videoconferencing and telephone interviews.

Semi-structured interviews

The one-on-one interviews followed an in-depth, semi-structured format which allowed the participants to speak openly about their experiences while enabling flexibility to explore and develop unanticipated topics (Pietkiewicz & Smith, 2014). A semi-structured interview schedule (see Appendix C) allowed the interviews to be participant-led (Smith et al., 2009). It provided a platform for the participants to discuss topics that held importance to them while allowing the opportunity for the joint exploration of experience (Pietkiewicz & Smith, 2014). The researcher used the interview schedule as a reference to check the coverage of the scheduled topics and used prompts in situations where the participant required further guidance. Prompts included "How did you feel about that", "That is interesting, can you tell me more about that?" and "Do you have any examples?".

Informed by IPA's commitment to idiography, the researcher used open-ended questions and a non-directive format to encourage rich and detailed information about the participants' lived experience (Smith et al., 2009). The questions were informed from current research literature and gaps which the researcher identified, and feedback was sought from the research supervisor. The interview schedule was developed around themes such as receiving a diagnosis, managing the process of what diagnosis meant, coping mechanisms utilised, adjustment to the diagnosis, experiences of seeking support and understanding of gender in relation to receiving an ASC diagnosis. The format enabled flexibility and allowed

the communication strategies utilised to be adapted to the requirements of the individual. The flexibility was advantageous as individuals diagnosed with ASC can sometimes experience difficulty responding to open-ended questions (Howard et al., 2019). Therefore, dependent on the participant requirements', the researcher took direction from the participants during the interview and some open-ended questions were broken down into a more structured format, with more prompts to support the participants' understanding of the question and encourage further exploration where it seemed appropriate. Upon completion of the interview, the participants were asked if they would like to be emailed a copy of the project findings. All of the participants requested a copy of the project findings and they were thanked for their time.

Analysis

Interpretative Phenomenological Analysis (IPA) was selected for analysing the participant interviews. IPA utilises dynamic, inductive, and iterative processes to analyse data (Pietkiewicz & Smith, 2014). This process requires in-depth exploration of the data, which involves continuously moving between the parts and the whole, known as the hermeneutic circle (Smith et al., 2009). According to Smith et al., (2009), the principles, processes and strategies can be adapted and applied flexibly by the researcher. Fundamental principles include attempting to make sense of the participants meaning-making and seeing the world from the participants' perspective (Smith et al., 2009). Processes involved moving between the descriptive and interpretive, and between emic and etic perspectives (Pietkiewicz & Smith, 2014). The product of analysis results in the researcher's interpretation of what the researcher perceives the participant to be thinking (Smith et al., 2009).

To ensure an individual and systematic process, the researcher utilised the set of guidelines outlined by Smith et al., (2009) to guide the analysis process, however, maintained a flexible approach throughout. In recognition of IPA's idiographic commitment, the researcher analysed the participants' transcripts individually line by line. This involved

repeatedly rereading and engaging with the transcript to gain familiarity while listening to the audio-recording to recall the atmosphere and setting of the interview (Smith et al., 2009). Recollections of the interview, observations and reflections were noted in the right margin, and distinctive phrases were highlighted (Smith et al. 2009). The researcher categorised exploratory comments into three key areas; conceptual, descriptive or linguistic, using coloured highlighters (Smith et al., 2009). Following this, the researcher analysed the comments and the transcript and noted the emerging themes in the left margin of the transcript. The iterative nature of the hermeneutic circle was demonstrated as the researcher continuously engaged with the text, moving between the individual parts of text and the whole account (Smith et al., 2009).

When attempting to develop emergent themes, the researcher focused on different sections of text and notes while concurrently considering the experience and context of the interview itself (Smith & Osborn, 2015). In alignment with IPA's inductive approach, the researcher ensured that potential themes emerged from the transcript which involved continually referencing the themes against each individual's case in the original transcript to ensure they were grounded in the data and representative at an individual level. The researcher attempted to keep the analysis as idiographic as possible and opted to use the vocabulary expressed by the participants to label themes wherever possible. In addition, the transcript extracts were utilised in the analysis, demonstrating congruence with IPA's idiographic commitment.

Following this, the themes were ordered chronologically, and the location of where each theme had arisen in each participant's account was identified (Smith et al., 2009). This involved creating a 'summary table' for each participant, including the names of the various themes, page and line numbers identifying where the theme was located in the transcript and relevant short extracts from the transcript (Smith et al., 2009). This process ensured ease

when returning to the transcript to check the extract in context. Themes were compiled for the whole transcript before the researcher looked for connections and clusters across participants (Pietkiewicz & Smith, 2014). Themes were grouped according to conceptual similarities, or chronological links, and each cluster was provided with a descriptive label. The same process was completed for each participants' transcript.

When analysing each account, the researcher bracketed ideas emerging from different individual cases (Willig, 2013). Cyclical reflective practices are paramount during the analysis as preconceptions are not always apparent until beginning the interview (Smith et al., 2009). The researcher utilised a research journal to facilitate bracketing, including thoughts and reflections during the research process. These processes maintained the idiographic focus of analysis, encouraging an awareness of preconceptions and openness towards each individual case.

Following the identification of themes with the transcript, the researcher identified connections and patterns across themes placed these in clusters (Willig, 2013). This involved integrating the summary tables from different participants and identifying meaningful similarities between themes. This included themes, sub-themes, participant pseudonyms, transcript extracts and identifying page numbers (Willig, 2013). Themes were analysed in relation to their direct relationship to the overall research aim and phenomena-of-interest, with unrelated information or themes excluded (Willig, 2013). The frequency with which themes appeared and the corresponding individual were identified (Smith et al., 2009). Following this, psychological theory was used to interpret the themes represented across cases.

Reflexivity

In recognition of the researcher's interactive role in co-producing data, reflexivity plays a critical role in this project (Langdridge, 2007). Reflexivity encourages the researcher to actively engage, interrogate and reflect upon one's own subjectivities throughout the research process (Gough & Madill, 2012). The ongoing process necessitates the researcher to critically consider how the research context and responses to the data influence particular understandings and clarifies the researcher's involvement in the research findings (Willig, 2013). Therefore, reflexivity has a valuable role in research, ensuring that the researcher's role in the research is continuously engaged throughout the research process, thus enhancing transparency and validity (Willig, 2013).

It is critical that the researcher's experience, motivations for conducting the research and position in relation to the population group under study are explicitly outlined (Berger, 2013). The researcher was inspired by the experience of working with children diagnosed with ASC, however, had not worked directly with autistic adult females. The research idea was inspired by a sense of empathy for females who are dismissed due to their gender. This dismissal motivated the researcher to begin this research project driven by a desire to improve the lives of females with ASC, particularly those who receive a late diagnosis.

The researcher had preconceptions and biases that are anticipated to have influenced the interpretation of the data. These are based on their postgraduate psychology studies, experience working with children on the autism spectrum, extensive research on the topic and generalised life experiences. Furthermore, the researcher recognised the importance of maintaining awareness of her position as an 'outsider' and the impact this is anticipated to have on the research, for example, the ability to identify subtle themes or clues that may be clear to an insider (Berger, 2013).

The researcher incorporated reflexive practices throughout all stages of the research. These practices are critical as the researcher may not always have a complete awareness of their preconceived ideas prior to beginning the interpretive exercise (Smith et al., 2009). Reflexivity was supported throughout the process during regular discussions with the researchers' supervisor and the qualitative research group which encouraged the researcher to consider and engage with the influences that impacted them during the interpretive process (Laverty, 2003). Additionally, the use of a reflexive journal enabled these influences to be brought into the researchers' conscious awareness, encouraging consideration of how personal values, beliefs and experiences may impact the research insights, understandings, and interpretations (Berger, 2013).

Quality

While there is widespread agreement for criteria evaluating quantitative research, the criteria for evaluating validity and quality within qualitative research remains a contentious issue (Gough & Lyons, 2016; Langdridge, 2007). The researcher enacted a number of principles to enhance the quality of the research. This included frequent discussions between the researcher and their supervisor regarding the reasoning behind emergent themes, interpretation of the data, and identifying themes that had not been coded (Smith & Osborn, 2015). The researcher rigorously considered and generated ideas about the different possibilities of analysis to ensure the depth of themes (Willig, 2013). This process did not intend to produce a single analytic account but rather verify that the procedures conducted were achieved systematically (Smith & Osborn, 2015). Therefore, this acted to enhance the validity of the analysis and provided the required clarifications to ensure that the analysis was consistent with the data (Smith & Osborn, 2015; Yardley, 2011).

The researcher prioritised transparency throughout the research process. In recognition of the intersubjective dynamics of IPA, the participants were provided with their

transcripts to comment on the thematic analysis as appropriate. In congruence with IPA's commitment to honour participants realities and truth, this process ensured that the participants' felt accurately represented by the analysis (Yardley, 2011). Additionally, the researcher provided verbatim evidence throughout the analytic process to provide evidence of the annotated transcripts, development of the codes and interpretations (Yardley, 2011). This process enhances the credibility of the analysis by providing reasoning behind the analytic decisions made, thus allowing interrogation of the interpretation (Smith & Osborn, 2015). Moreover, the researcher utilised a reflexive journal to continuously record and review the process of learning, interpretation, and bracketing. The reflexive journal included post-interview field notes and detailed reflections during the process of analysis. The development of reflexive analysis throughout the research project enhanced the validity of the research by evidencing transparency and provided valuable insights to the research project (Gough & Madill, 2012).

Ethical Considerations

As the research involved human participants, several ethical issues were considered. Prior to beginning the project, ethical issues were considered in addition to an application to the Massey University Human Ethics Committee (MUHEC). The MUHEC application was conducted under the supervision of my research supervisor and a cultural advisor who has clinical experience working with individuals with ASC, from the Massey School of Psychology. The Code of Ethical Conduct for Research, Teaching and Evaluation Involving Human Participants (Massey University, 2017) was used to guide the project.

Participant autonomy was a priority throughout the research. Participants received an information sheet or email detailing important information about the study. The information sheet clearly stated the importance of participant privacy and confidentiality, that the interview will be audio recorded, the uses and process for managing data and details

describing how the findings will be disseminated. The researcher verbally outlined the contents of the information sheet and other relevant information to each participant individually to ensure the participants' comprehension before obtaining consent. Measures taken to minimise the potential risk of coercion included emailing the participants the questions before the interview takes place and allowing the participants the opportunity to build a relationship with the researcher through phone calls and email exchanges. Additionally, participants were provided the opportunity to request a summary of the project research results if they decided to share their email address with the researcher.

The participants' wellbeing was the researchers primary concern and careful consideration was taken to ensure the wellbeing of participants taking part in the project. While there was no anticipated harm in taking part in the research project, it is important to recognise that females with ASC often experience challenges surrounding identity, isolation and discrimination (Bargiela et al., 2016; Baldwin & Costley, 2016; Milner et al., 2019; Leedham et al., 2020). Therefore, in consideration of these factors data collection had the potential to cause psychological discomfort or distress, particularly when answering questions about mental health and the diagnosis of ASC.

The researcher employed various strategies to mitigate potential harm. This included sending the interview questions before conducting the interview, conducting two interviews (one to get to know the person and the other for the interview) and providing the opportunity to bring support people or objects (e.g. weighted blankets). In addition, the researcher aimed to optimise autonomy in the process by providing the participants with different formats for answering the questions. This included typed responses via email and using the audio function instead of video call for the interview. Furthermore, the use of a semi-structured interview format was valuable as this provided sufficient flexibility and allowed the researcher to be responsive to the participants' emotional state. Finally, contact information to

several national helplines were offered on the information sheet, and following completion of the interview and the participants were encouraged to access the support they required.

Participants' privacy and confidentiality were carefully managed throughout data collection and data management. Only the researcher and the research supervisor had access to the data. Interviews were arranged via phone or email communication, with participants contacting the researcher with the project Gmail account. The medium with which the interview was conducted was decided upon by the participants, including video chat, phone call via Google Zoom or Skype and typed responses via email. This necessitated the use of a research specific Gmail and Skype account to ensure privacy and confidentiality were maintained across the different mediums.

During data collection, the researcher used a voice-recorder and an audio recording and transcription application, Otter Voice Notes (2019). This application was protected with a password that was only known to the researcher which ensures data is secure and was accessed on the researcher's personal phone, which is also protected with a password, known only to the researcher. During the transcription phase, the researcher removed any identifiable information to ensure identifiable data is not included, and the completed transcripts were returned to the participants to check that their confidentiality has been maintained.

During data management, each participant was assigned a pseudonym which was used to refer to participants on audio-recordings, transcripts and research notes to ensure anonymity. On copies of interviews or transcripts the participants names were protected with passwords that only the researcher could access. The master sheet with the information linking the pseudonyms and codes will be held securely by the researcher. The data was stored on the researcher's password-protected laptop, which only the researcher has access to. Signed informed consent forms, transcripts, and any other paper-form data created will be

sent to my supervisor Dr Kathryn McGuigan for safe keeping once the project has been completed. The signed consent forms will be held securely by my supervisor for five years, as per Massey University requirements. Data will be stored for the duration of the Master's project and then five years following submission.

Cultural Considerations

Participation in the research project was open to participants from all cultural backgrounds. The researcher consulted with a Massey University cultural advisor Dr Matt Shepherd prior to commencing the research. This consultation provided direction on working with Māori participants and encouraged consideration of the potential impacts of the research on Māori. The implementation of the COVID-19 restrictions was discussed with the cultural advisor as this impacted the researcher's ability to establish traditional face-to-face relationships with the participants. The cultural advisor recommended that the researcher spend 5-10 minutes, establishing whakawhanaungatanga by using a personal introduction or pepeha (Shepherd, personal communication, March 24, 2020).

The researcher also ensured protocol for engaging with Māori was prepared before beginning the interviews to ensure that Māori participants had opportunities for Whānau support during the interview, and the interview will be led with a karakia and pepeha. The researcher prepared two karakia, should the participant request the researcher to conduct this prior to beginning the interview, which was encouraged by the cultural advisor. The cultural advisor also suggested being sensitive to the Māori participants in the case they perceived a topic of discussion as tapu (sacred or spiritually restricted) and wished not to discuss it. The cultural advisor offered to be available throughout the research for further consultation

CHAPTER FOUR

Findings

The objective of this research project was to explore the experiences of females who received a late diagnosis of ASC. This chapter outlines the findings. It became clear in the analysis that there were two clear points in time that defined all the women's journeys with ASC. Firstly, there was a time prior to clinical or self-diagnosis (only one woman self-identified as having ASC), and the women reflected on this time. Secondly, the process of being diagnosed and the impact that this had on them; for their identity and coping with their everyday lives. Therefore, the chapter is laid out in two main sections. There were distinct themes that emerged for each period of time, and these are summarised in Table 2. In the spirit of IPA and ensuring the participants are leading the findings, the chapter starts with the reflections of the participants on their awareness of being different and the consequences of this.

Table 2

Summary of themes and subthemes

	Theme	Subtheme
Pre-diagnosis	Gender Expectations	"We are trying to be the good women"
	Disinterest in Gendered Norms	"I just didn't get it"
	Learning to Camouflage	"It just fully feels like an act"
Post-diagnosis	Misdiagnosis and missed diagnosis	"I wasn't coping"
	Reactions to Receiving the diagnosis	"I feel I'm no longer an alien"
	Who am now? Living with ASC	"This makes sense"
	Adapting to life with ASC	Connection
	Disclosure	"I am very careful about who I tell"

"I knew I was different"

Prior to diagnosis, all the participants reported a pervasive and longstanding awareness of being different from their peers. The context of school was significant for the women's individual experiences of learning they were different and living with a difference as they were rejected from their social peers and regularly the target of bullies. Initial awareness of feeling different was closely entwined with difficulties fitting in and self-blame. The participants also mentioned puberty as being difficult. All of the participants reflected on the difficulty of developing and maintaining peer relationships and friendships throughout their education years and closely associated this with feeling different from those around them.

Katie found her experiences of school improved over time and described primary school and high school as a set of *"two extremes"*.

Katie said, *"I found primary school horrific um I was constantly bullied… high school for me was pretty good actually so I started doing physics and I did a competition and it's like sooo cool…It was just so fun and so like my brain and we were known as like the physics kids and it was the first time, I had proper friends who understood my brain"*.

Katie spoke about her experiences of school from her mother's perspective as her mum was concerned about her social isolation at school.

Katie said, *"My mum used to say that um I was a square peg trying to fit into the round whole of the society and when I turned about 13 I told her that school was sandpaper and they were sanding away my edges so I would fit into the round hole"*.

Using her mother's analogy, Katie poignantly described this characteristic as central to herself as it was at school where she felt that her differences were not accepted and where she felt like she was being changed to fit or mould her into societal norms.

Chloe described misunderstanding social situations and being socially excluded from her female peers at high school.

Chloe said, *"At high school I hardly ever spoke and I didn't really have any friends, well I thought I had friends but I didn't understand the rules like they always accused me of following them around because I would want to sit next to them in class and they told me not to so I sat by myself and they all sat with their friends and it was really confusing I still don't get it like it still get that problem sometimes… I just don't understand friendship rules"*.

Chloe said, *"I spent all my life wondering what was wrong with me"*.

Chloe's experience mirrors those in Dean et al., (2017) study, which found that although autistic girls are frequently engaged in social groups, they struggle to integrate with peers and often remain on the periphery. Chloe expressed that despite her efforts, she experienced frequent social rejection and misunderstanding in social situations, which was distressing and anxiety-provoking.

Esther pinpointed a pivotal age in early adolescence, where she gained awareness that it was increasingly difficult to fit in with female peers and began being treated differently for being an 'outsider'.

Esther said, *"Then you hit puberty and social rules change all over again and it suddenly becomes massively complex and you can say this, you can't say this, this person is not talking to this person, this person is her boyfriend and you struggle to keep track of it"*.

Esther said, *"You just get labelled weird, freak um difficult um bossy. God knows the number of times I was called rude by other adults because I didn't understand tone"*.

Similarly, Belinda described how her differences to female peers became more pronounced at high school.

Belinda recounts, *"It was initially not too bad until the age of 10 onwards…I didn't relate to pop culture and pop music. This escalated once I reached high school where I struggled even more to bit in and was ostracized for being too different".*

Belinda said, *"I just thought I was weird and unlikeable".*

Kirsty reflected on the difficulties she encountered as a teenager and described feeling distressed because she knew she was different but could not understand why.

Kirsty said, *"Hitting the teenage years and I had all this pressure… I was bullied horrendously by a group of kids… I couldn't understand what on earth they were on about… you become more self-aware and more of people and your connection with people starts changing and I just didn't get it".*

Kirsty said, *"I hated myself. I just hated myself. I did not understand people and I didn't understand why I didn't fit in and why people treated me the way they did why they teased me so much why I was always the nerdy one in the class".*

These brief accounts of the participants also highlight that puberty and transition to high school was an age period where differences become more pronounced, social complexity and bullying increased. These findings are consistent with Tierney et al., (2016) IPA study, which found that the transition into high school is often associated with increased difficulties due to the need to make new friends. Consistent with this, autistic women have reflected on high school representing a 'cultural shift' where there was an increased awareness of social expectations that emphasised their differences (Baldwin & Costley, 2016; Kanfiszer et al., 2017).

Edith and Sophia talk of the inability to understand and make sense of unexplained 'differences' prior to the diagnosis.

Edith said, *"I wasn't able to actually connect the dots until I learnt more about what autism is because it presents so differently to the typical picture that you get in the media of autism in boys"*.

Sophia said, *"I've had this kind of question about like am I bipolar? Like what's going on with me because I'm so different from one moment to the next, what's the thing that's changing me?"…I basically had no idea what was wrong with me I just thought maybe I'm depressed and by what was wrong with me I mean like what's going wrong, something's not aligned with how I see myself"*.

Sophia said, *"I had had an inkling that I was autistic, um but I had no idea that I had such a large net of experiences that were defined by that"*.

Similarly, Edith did not associate her perceived differences to be experiences of ASC and instead thought she was anxious.

Edith said, *"I just thought that I had like generalised anxiety because I really had that intense sort of like panic, overwhelming feeling like then I would have a meltdown"*.

Edith added, *"My parents thought that I was just a bit um spoilt and I think childish sometimes"*.

Similarly, Sarah reported awareness of her differences and described how these were attributed to negative personality traits.

Sarah said, *"I think that the way I behave around people is that they see me as cold and unemotional"*.

The participants expressed a strong sense of awareness that they were 'different' from childhood. The inability to explain 'difference' impacted how other people perceived them as the participants explained that their social difficulties were attributed to negative personality

traits. Esther and Sarah described the negative labels they received for not communicating or behaving in a way that is expected by the neurotypical majority. This experience exemplifies the 'double empathy problem' (Milton, 2012). The double empathy theory posits that individuals with ASC do not lack empathy but rather experience the world and express emotions differently to non-autistic individuals.

The ability to make sense of 'difference' was constrained by the absence of a framework to understand and explain their difficulties. According to Troiden (1988), individuals must have an awareness and information that an identity exists in order to identify with it. Existing research suggests that autistic women report a pervasive sense of feeling different as they lack a meaningful way of making sense of their perceived differences (Lewis, 2016). In an attempt to make sense of the unexplained differences, the participants a prevailing sense of being *"weird"* or that something was *"wrong"* with them and used self-deprecating language to emphasise the negative conceptualisation of self they created.

Participants felt personally responsible for their differences. They described how the internal confusion and distress associated with not understanding why they are 'different' led to internalising the belief that there was something intrinsically wrong with them (Baldwin & Costley, 2016; Leedham et al., 2020; Tan, 2018). For many women, this resulted in continuous attempts to make sense of their differences (Baldwin & Costley, 2016; Leedham et al., 2020; Lewis, 2016; Tan, 2018). The psychological impact of feeling different and not understanding why this was evident as all the women reported co-occurring mental health difficulties including depression, anxiety, borderline personality disorder and anorexia.

Therefore, perceptions of the self and meaning-making are socially and culturally situated, with individual subjectivities influenced by social practices and interactions (Elder-Vass, 2012). The influence of the social context is particularly highlighted in Kirsty, Karen,

and Belinda's experiences, who are a decade older than the other women in the study. Kirsty and Karen had not been exposed to the possibility that they may be autistic as the condition was not discussed within society.

Kirsty and Karen reflected on growing up in a time where knowledge of female ASC was limited.

Kirsty said, *"People hadn't heard of autism back then, my parents had never heard of depression, they had no idea what they were dealing with, you know so for them they didn't have a clue…it took them enough just to accept depression and anxiety"*.

Similarly, Karen said, *"I think she suspected it but back in the 80's autism wasn't very…people weren't aware of it back then…if I had lived, say if I was born in the 90's instead of the 80's I would have been diagnosed a lot younger. I would have been diagnosed at 6 or 7 or something"*.

The social and historical context appeared to act as a barrier, both for understanding the differences and receiving an ASC diagnosis. Karen described that while her mother was aware of her differences in childhood, she was unable to attribute these differences to an ASC diagnosis due to the general lack of recognition of ASC during the 1980's. Similarly, Kirsty described how the lack of awareness surrounding ASC impacted her parent's perceptions of ASC. These findings illustrate the extent that female ASC is socially and culturally located as older generations are more likely to adopt the values of traditional gender expectations and hold the perception that ASC is a male condition.

Part 1: Pre-diagnosis

This section details the women reflections on their life and the difficulties they faced prior to receiving a diagnosis. The first theme is concerned with *'Gendered Expectations'* captured how the participants make sense of their position as both female and autistic. The second theme *'Disinterest in Gendered Norms'* outlines the confusion and inability to meet societal gendered expectations, while the third theme *'Learning to Camouflage'* concerns the motivation, use and consequences of camouflaging behaviour.

Gender Expectations- "We are trying to be the good women"

This theme details the participants' strong views regarding the role of gender expectations and described how, as a female, greater expectations are placed upon them to present as neurotypical and socially adept. All the women in the study compared girls to boys and females to males, pulling on gendered stereotypes to make sense of why females with ASC are typically diagnosed much later than males.

Esther discussed how women have more rigorous 'rules' to follow in terms of behaviour.

 Esther said, *"A lot of it comes down to societies teachings in that girls are taught to be quiet and they are taught to wait and listen and boys will be boys as they hit each other and girls are taught very quickly that they don't hit each other and they don't do this and they don't do that so even as an autistic person you still learn some of those societal things ingrained among you even without realising it. Yeah those basic assumptions that get drowned into young children".*

Similarly, Kirsty suggested that boys do not experience the same pressure to hide their symptoms.

Kirsty said, *"I think boys are so open they don't care. Women care more about what people think about them than boys do…that's why we are so often diagnosed with anxiety and depression is because we can't verbalise it we can't show it because we are trying to be the good women… women are hating themselves because they're not good enough wives or good enough partners or good enough girlfriends… you know you think if only you could understand"*.

As further evidence of the presence of gendered expectations, Sarah identified that females are more likely to get 'penalised' for behaviour that deviates from normative gendered expectations.

Sarah said, *"I think we have to. I think we are forced to. We get bullied whereas with males its more acceptable to just do your own thing and its fine"*.

While not all females submit to gender stereotypes, existing research on gender socialisation suggests that even from a young age girls and women, have greater expectations placed upon them to be sociable (Cheslack-Postava & Jordan-Young, 2012). According to Saxe (2017), autistic females experience a specific set of challenges navigating the expectations of their gender due to the intersection between gender and disability. In this research, all the participants demonstrated an ability to understand the influence of gendered socialisation practices and wider societal expectations and shared awareness of the pressure to behave in accordance with the gendered expectations. As highlighted by Esther, autistic women are not immune to gender expectations as she infers that females with ASC are exposed to the same social practices as non-autistic females.

Kirsty and Sarah go on to describe the negative consequences of gender expectations for women with ASC, including the development of mental health conditions and lower rates of ASC diagnoses. There is an absence of literature exploring how autistic women experience

gender expectations and experiences of stigmatisation for deviating from 'feminine' norms. However, in this study, participants appeared to use gender stereotypes related to ASC as a reference. All of the women pulled on male autistic stereotypes and compared themselves to these. Interestingly, three of the participants discussed empathy as a feminine trait, however there were contrasting views on how females might experience empathy.

Karen said, *"I think my empathy is learned, empathy with Asperger's is not something you have naturally"*.

Likewise, Katie said, *"I think our empathy levels are higher um and that's true for non-autistic females as well"*.

Chloe also says, *"There's like a stereotype about like not having empathy… I'm the complete opposite, I'm like really emotional and I have a lot of empathy"*.

The reference to empathy implicitly references psychological theory related to the 'Empathising-Systemising' hypothesis, which proposes that ASC is the result of an *"extreme male brain"* (Baron-Cohen, 2009). Chloe is firmly rejecting this stereotype as she does not meet the criteria around empathy. However, these comparisons may reflect that the literature surrounding ASC remains predominantly male-focused.

Several participants reflected on how efforts to behave in adherence to societal expectations for female social behaviour such as acting 'compliant' or 'shy' led to their ASC being unnoticed for many years.

Belinda said, *"I think many females don't lash out as much. We can amuse ourselves and appear to be more adaptable... A female who is quiet and reads isn't considered a problem that needs fixing… I was quiet and didn't create trouble as I tended to retreat"*.

Likewise, Chloe states, *"Everyone always asked me why I was so quiet… I used to not talk and people just thought I was shy but it was more than that"*.

Similarly, Sophia said, *"I tried really hard to be a good girl"*.

These accounts infer that it is only the externalising or overt behavioural presentation of ASC that generates a diagnosis, and the symptoms typically associated with ASC in males is deemed to be problematic and therefore generates more attention. Research suggests that women are diagnosed with ASC only when behavioural or language difficulties become apparent, often in a school setting (Duvekot et al., 2017). The women in this study suggested their feminine behaviours of being passive and compliant were misinterpreted as being well behaved or shy and failed to warrant concern from teachers.

This main message from this theme is that the women compared themselves to male ASC stereotypes and suggested this was the main reason they were not diagnosed earlier. The pervasiveness of the male presentation of ASC around language challenges and disruption behaviours was seen as needing to be challenged as it did not capture their experiences.

Disinterest in Gendered Norms- "I just didn't get it"

Given the unavailability of female presentations of ASC, the participants pulled on feminine gendered norms as a reference to understand their differences. The participants described how they deviated from normative gendered behaviour, expectations, interests and explained how gendered rules and feminine norms did not come naturally to them. The implicit gender rules and pressures inherent in being a female were frequently referenced, including the personality traits and gender norms they are expected to conform to. The participants recalled struggling to share the same interests as their female peers and associated this with their difficulties connecting with female peers.

Kirsty who was 40 at the time of the interview and self-diagnosed ASC at 36 reflected back on how she did not understand certain practices but performed them anyway in an effort to fit in. Kirsty described a sense of confusion when female peers began hair removal practices at high school.

Kirsty said, *"I just didn't get it I was like what are you on about? Shaving your legs, why?" (laughs)*.

Despite disinterest in typical female activities, Kirsty described considerable efforts to conform to normative gendered expectations and *"trying to do what everyone else was doing"* to fit in and perform femininity. Kirsty added, *"I used to not leave the house without proper clothes on, full face of make-up, heels… I wanted to be like other people so they'd like me"*. The pressure to act 'normal' and conform to cultural representations of 'femininity' despite feeling *"uncomfortable"* appeared to create incongruence internal and external portrayals of gender. Therefore, external expressions of gender appeared to placate others and was not indicative of self-understanding (Craig & Lacroix, 2011). Kirsty seemed to struggle to challenge gender expectations. These findings are consistent with existing qualitative

research, which suggests that autistic females experience additional pressures to adhere to gendered expectations for 'feminine' social behaviour and felt that they deviated from 'normal' female gender stereotypes (Bargiela et al., 2016; Kanfiszer et al., 2017; Milner et al., 2019; Saxe, 2017).

While Kirsty appeared to conform to feminine presentation ideals, the other participants were disinterested in this aspect of being female. Despite this, the participants drew on feminine stereotypes and highlighted how they did not fit these. The participants explained how their disinterest and inability to adhere to gendered norms led to discrimination and social exclusion. The consequences of non-conformity were evident at school, workplaces, and in roles such as being a mother.

Belinda stated, *"I just didn't relate to like pop culture and pop music…I hated being forced into social activities such as school dances".* Belinda associated her indifference to topics that non-autistic females would typically enjoy as compounding difficulties with social assimilation, consequently leading to being *"badly bullied and ostracized"*.

Likewise, Sarah recalled how her disinterest in being *"that stereotypical female"* led to her being the 'outcast'.

Sarah said, *"All they wanted to do was you know that stereotypical female, stay at home, have children, sit around and talk about other people and I just didn't get it and I think I didn't react. I wasn't as emotionally invested as I should have been and they turned against me".*

Belinda and Sarah described the social consequences they encountered for failing to comply with hegemonic feminine ideals. They interpreted their social differences through a gendered lens and explained how women are expected to be more social and emotional. However, when failing to meet these expectations, they described experiencing

discrimination from their female peers, including bullying and social exclusion. These findings are consistent with accounts in the wider literature which suggest that autistic women encounter difficulties engaging in and understanding gender-typical activities, further exposing differences from female peers and create feelings of disconnect from non-autistic women (Bargiela et al., 2016; Davidson, 2007; Kanfiszer et al., 2017). As a result of difficulties in understanding and following social norms, autistic women are more susceptible to discrimination (Bumiller, 2008; Saxe, 2017).

The embedded nature of gendered norms within societal ideas of what a woman should behave like is evident as Sarah recalled being told by her friends that she was *"like a man"*.

Sarah said, *"A lot of friends have said that I am like a man and I'm like you mean I look like a man or I'm butch and they say no but you're like a man and it's because I don't do the drama, I don't react emotionally unless I'm really provoked but I'm not emotional about things um I'm more practical…because as a female you're supposed to be emotional"*.

In making sense of other people's perceptions, Sarah reinforced how aspects of her personality fit in with males and described her male-typical interests and traits as 'practical' and 'unemotional'. This extract alludes to identification with a 'tomboy' identity, which is defined through activity rather than appearance (Holland & Harpin, 2015). According to Craig and LaCroix (2011), identification as a 'tomboy' may prevent negative categorisation and enable the space to construct an identity that does not conform to a binary gender construction.

It is apparent that autistic women experience unique challenges as they navigate intersecting identities (female and ASC) while attempting to conform to societal expectations of gender and neurotypicality. It is important to note that this research demonstrates that the

participants have a high level of awareness of gender expectations, which may contribute to

the widespread use of compensatory behaviour such as social mimicry and masking. Autistic

women may absorb gender stereotypes through the process of 'camouflaging', which is

explored in the next theme.

Learning to Camouflage- "It just fully feels like an act"

This theme captures participants' experiences of using compensatory strategies in social environments. The participants described learning to camouflage, motivations for camouflaging, the impact of social expectations and gender roles, and the consequences of camouflaging. Camouflaging was a salient theme and was described as an adaptive coping strategy that was central to the women's social experiences. Participants shared significant awareness of the social and communication difficulties they experienced and sought to manage this by engaging in masking and social mimicry. Furthermore, participants identified camouflaging as a learnt strategy to hide their self-perceived social difficulties, conceal anxiety and develop friendships.

Kirsty and Chloe described a strong sense of confusion involved in understanding social behaviour.

Chloe said, *"I didn't know how to act as there seemed to be all these unwritten rules, so I was yeah, I was trying to imitate things"*.

Kirsty added that masking served a function and enabled her to conceal her anxiety.

Kirsty said, *"It's just mainly hiding the anxiety I think of trying to live in a world you don't understand and trying to be friends with people and you're trying to understand social cues"*.

Participants were self-aware of their differences compared to their non-autistic peers, with many women reporting that they consciously and learnt social skills to attempt to fit in. This self-awareness of social difficulties appeared to motivate camouflaging behaviour.

Kirsty and Chloe use the word *"trying"* to represent the effort involved in learning social skills such as eye contact, emphasising that these skills do not come naturally and therefore need to be learnt.

Chloe said, *"I had to really work on it, it doesn't come naturally… I have learnt to make eye contact and stuff… I didn't even know that you had to look at people like my mum had to show me a diagram"*.

Similarly, Kirsty added, *"I did a course on how to look people in the eyes you know (laughs)… I mean there's no class in school for social, you know how to be a social person, so your trying to learn that yourself and neurotypical do it naturally… I've spent 40 years learning to copy and learning to adapt"*.

For Kirsty, camouflaging was motivated by the desire to build friendships and fit in socially. Unsurprisingly, given the high level of social awareness and desire to belong to find belonging within a group, participants described explicit 'training' to learn social skills from family members, the media and by copying their peers (Bargiela et al., 2016; Webster & Garvis, 2017).

Esther described the pressure she felt to assimilate and conceal her autistic differences in childhood.

Esther said, *"I remember learning quite quickly what was expected of me um and this is what I should do, and I definitely watched what the others did and tried to do the same things to varying degrees of success"*.

Esther began camouflaging in childhood and described carefully observing her peers to learn social skills. Despite the process of camouflaging beginning in the women's school years, this also appears to extend into adulthood.

Edith described being *"very good at masking"* and explains how she adopts a 'persona' for socialising at work.

Edith said, *"I'll smile, make eye contact with them um and say they things I know that they will want to hear and then as soon as they walk out of the room my smile will just drop straight right off my face and like in my head I'm thinking I didn't care about that conversation at all kinda thing and it just fully feels like an act"*.

Edith's experience parallel findings from a recent study by Cage and Troxell-Whitman (2019b), which reported that women, particularly those diagnosed late in life, are more likely to camouflage for 'conventional reasons', which is described as serving a functional purpose in the workplace. They hypothesised that the lack of understanding and expectations placed on autistic women in the workplace might result in the perceived need to camouflage more in these social settings. Interestingly, they also found that individuals who intermittently camouflage and hide their identity across contexts experience higher levels of psychological distress than those who consistently mask and subsequently experience disconnection from their identity (Cage & Troxell-Whitman, 2019b). Therefore, despite outward success (e.g. maintaining employment and nearing completion of a degree), Edith's statements revealed an awareness of the consequences of camouflaging, namely her sense of identity. Edith goes on to express her struggle to reconcile who she really is and associated this with her masking.

Edith said, *"I wouldn't really know who I properly am to be honest like with how I would react to situations because I've been doing this like the whole sort of not fake personality but in some regards it is in terms of like most people around me would probably be like oh so you have autism oh that doesn't fit because you're usually quite bubbly and ok to talk to but if I actually acted how I wanted to then they'd be like yep ok (laughs)"*.

Similarly, Kirsty described forcing herself to maintain eye contact in social situations in adulthood.

Kirsty said, *"It freaks me out, it gives me anxiety but its socially acceptable to look people in the eyes so I look people in the eyes. So, I've trained myself to act like a neurotypical person whereas inside I'm going crazy".*

Edith compared her behaviour to an actress, suggesting that she struggles with a sense of confusion surrounding her identity. Identity confusion is widely reported across the literature as a negative consequence of camouflaging (Baldwin & Costley, 2016; Bargiela et al., 2016; Haney & Cullen, 2017; Webster & Garvis, 2017). For the women, there is tension between their public efforts to *"act like a neurotypical person"* and their personal efforts to embrace ASC as part of their identity. For example, Kirsty said, *"We hide it. We go home and scream in our pillows".* There is a strong sense that while camouflaging allows the participants to keep their ASC 'invisible', this comes at an emotional cost.

Part 2: Post-diagnosis

This section details the experience of the women reflecting on living with ASC as a female, processing of the diagnosis and coping and how they have made sense of their own identity. Despite knowing and being aware they were different, each participant had a unique and often long journey to diagnosis. This is discussed in the first theme, *"Misdiagnosis and Missed diagnosis"* which describes the challenges involved in receiving an accurate diagnosis and the impact of being mislabelled or overlooked. The next theme *"Reactions to Receiving the diagnosis"* details the initial reactions to receiving a diagnosis and the process of gaining a new identity. The third theme *"Who am I now? Living with ASC"*, describes developing adaptive coping strategies to manage the symptoms of ASC and outlines the value of forming connections with the Autism community through strategies such as researching. The last theme *"Disclosure"* refers to how the participants perceive reactions to their diagnosis, including stigma and misunderstandings.

Misdiagnosis and Missed diagnosis

This theme outlines the participants' reflections on how their presentation of ASC was missed by healthcare professionals and discusses the moments that led the participants to diagnosis.

Esther and Katie believed that their presentation of ASC was apparent as they both recalled how key features indicative of ASC (social problems, special interests, eye contact) were overlooked by clinicians. Esther described how her special interests were overlooked and related her misdiagnosis to gendered expectations.

Esther said, *"How on earth they missed my obsession with cats I have no idea…they were probably looking for very large stereotypies… obviously my special interest as a child was cats and it's perfectly normal for a little girl to be obsessed with cats. Um having a 13-*

year-old that understands why you get coat colours because of genetics is probably past a
typical obsession with cats but they didn't really question that".

The use of the word *"obviously"* emphasises that her special interest should have
been easily identified and inferred that the clinician was looking for male-typical interests.
Despite an increasing body of research suggesting there are gender differences within the
presentation of ASC, the formal diagnostic criteria fail to recognise these (Lai et al., 2015;
Kirkovski et al., 2013; Hull et al., 2019).

 Similarly, Katie described feeling *"kind of annoyed"* as she presented with
'stereotypical' ASC and did believe that she presented in a 'female way'.

Katie said, *"It's not that I was a female with autism displaying female autism traits*
that wouldn't be identified if you didn't specifically know that it could look different. I
displayed the traits of an autistic child when I was a kid. Like I didn't make eye contact. I
didn't like social situations and I had extreme special interests and had very little interest in
anything that wasn't them".

Katie challenges the dominant narrative that autistic females present in a way that is
harder to detect as being the reason for her late diagnosis. Rather, Katie suggests it was the
incompetence of the clinician to blame.

Katie said, *"I think a diagnosis was possible then…like if they had someone that knew*
what they were doing had a conversation they would have been like there you go!".

Both Esther and Katie associated their childhood misdiagnoses with gender bias and
the lack of knowledge surrounding ASC. Existing research suggests that some clinicians hold
damaging stereotypes, particularly surrounding the presentation of ASC in women (Bargiela
et al., 2016; Lewis, 2017; Tint & Weiss, 2018; Treweek et al., 2019; Zener, 2019). The
negative impact of mislabelling on women's mental health and sense of self has been widely

reported (Baldwin & Costley, 2016; Leedham et al., 2020; MacLeod et al., 2013), suggesting this is a common and concerning part of autistic womens' diagnostic journey.

Kirsty's story was unique as her journey was one of self-diagnosis through genetic testing, whereas the other participants received a formal diagnosis from a clinician. This process occurred when she took her son for a genetic test associated with identifying ASC and an associated heart condition. As Kirsty's husband and two sons are autistic, she was confident that the gene was linked to her husband.

Kirsty said, "*They said right we are going to test the parents. I said well it's through my husband definitely he's just like my youngest…if you don't have the gene you can still have autism so it's not a perfect test yet*".

The role of gendered stereotypes surrounding the presentation of ASC may play a role in Kirsty's unexpected diagnosis. Kirsty stated, *"You ask him to make a tea and you go you're autistic".* Kirsty described how her husband's presentation of ASC is markedly more obvious than her own, suggesting that her understanding of ASC was heavily mediated by the male presentation of ASC displayed in her two sons and husband.

It was not until their early twenties that Edith and Sophia described developing an awareness that their difficulties may potentially be attributed to ASC through their study and work. Edith described how she was introduced to the idea she may be autistic while studying Psychology at University.

Edith said, *"I kinda figured it out during then and just didn't think about it for quite a few years".*

Similarly, Sophia described her first encounter with ASC as a potential explanation when she was working as a teacher for children with special needs.

Sophia said, *"I found myself like looking at them and going that's me that's me I shouldn't be teaching them I should one of them learning about me because when I shut my eyes I lose my balance you know, when I get something wrong I get really upset um I need to bounce I need to stim like someone should be teaching me about me and so I knew then that probably I was on the spectrum but that was, that was the pivotal bit for me… it was pretty beautiful for me though because it meant that any little idea of ableism that might have been lurking from my high school days like immediately got thrown out"*.

This experience was a pivotal moment in Sophia's journey as it immediately made sense to her that she was autistic. In contrast to this Edith, Sophia and Belinda did not seek a diagnosis until the intensity of 'autistic meltdowns' and living with ASC became almost too much to cope with.

Edith said, *"My meltdowns started getting more intense, I was struggling a lot with some stuff, so my husband made me go and talk to somebody and the process sorta started from then"*.

Similarly, Sophia said, *"I was melting down and my melting down is just crying and crying so it's really disruptive. But um that's the point where I was like I'm not neurotypical. I feel fine after I meltdown, but I need to manage this better kind of thing"*.

Likewise, Belinda recalled reaching crisis point before receiving a diagnosis.

Belinda said, *"I was only diagnosed when I experienced autistic burnout due to a huge emotional event… this caused severe depression for which I received counselling for the first time in my life and my counsellor realised I thought and communicated differently and referred me on to a peer who had experience with autistics"*.

Despite navigating the autistic diagnostic process for her son, Belinda's ability to thrive in her job appeared to hide her ASC for many years as she appeared 'adept'. After

many years of trying to appear 'normal' and live in a neurotypical world, Belinda inferred that she reached a 'crisis point'. Autistic burnout is an informal term used to describe the chronic exhaustion associated to the accumulation of stress, barriers to support and inability to gain relief from these burdens (Raymand et al., 2020). In the exploratory study mentioned above, timely diagnosis was associated with the decreased need to camouflage, suggesting that an earlier diagnosis may mitigate autistic burnout and associated (Raymand et al., 2020).

Like Belinda, Sarah was referred for a diagnosis after struggling with mental health difficulties. Sarah described the arduous journey to her diagnosis after spending years *"on and off"* seeing a counsellor at University. Sarah was subsequently sent to a Psychologist after an inability to make progress over several years.

Sarah said, *"The GP sent me to a psychologist and I think I was with her for half an hour before she asked if I ever thought that I might be autistic…since I was 15 I have been trying to get help".*

Interestingly, even participants identified and assessed by professionals early in life due to parental concerns faced a long journey to diagnosis. Despite gaining a professional assessment in childhood, both Esther and Katie perceived their initial diagnosis and labels to be inaccurate and described a strong sense of frustration that early signs of their autism were miscategorised and overlooked. Esther recalled being *"incredibly unhappy"* after being diagnosed with PDD-NOS at the age of fourteen and explains the impact of living with a diagnosis that she did not identify with.

Esther said, *"It actually did more harm for my self-esteem because I sort of saw it as not only am I abnormal but I'm abnormal among abnormal people, like I don't actually fit into a nice little category".*

For Katie, being told she was *"highly gifted with difficulties in social situations"* at the age of nine held little value as she described it as *"something you can't do much with"*.

Esther implies that receiving the PDD-NOS diagnosis had greater negative consequences than remaining undiagnosed. These findings echo a theme found in a study by Powell and Acker (2016), which reported 'diagnostic disappointment' from individuals in a subclinical threshold group that did not receive a diagnosis despite presenting with significant autistic symptoms. It is evident that Esther's disappointment was born out of the desire to find a sense of belonging with an Asperger's diagnosis. The historical context has played a significant role in the development of Esther's identity as she recalls how the change in the diagnostic criteria in the DSM-5 in 2013 coincided with her self-identification with the Asperger's label. Despite feeling that her identity was closer attached to an Asperger's label, the use of the term Asperger's prior to a formal diagnosis was fraught with guilt.

Esther said, *"I felt that I had that but then I would feel bad because I felt like I was lying because I didn't officially have it on my paper. So, I would be torn a bit… it actually did probably more harm for my self-esteem because I sort of saw it as not only am I abnormal, but I'm abnormal among and abnormal people"*.

Esther's comments highlight the dominance of biomedical conceptions of diagnosis. Esther described a sense that self-diagnosis is insufficient and felt that a diagnosed was required to validate her symptoms. Despite personal identification with the Asperger's label, Esther described how the lack of a 'formal diagnosis' felt insufficient and 'fake', particularly when disclosing to others. According to Lewis (2016) managing self-doubt and feeling othered is indicative of the self-diagnosis experience. These findings suggest unique challenges involved in navigating a subclinical presentation, self-diagnosis, and the development of an autistic identity.

Many of the women were diagnosed with other conditions first, leading to ASC diagnostic delays. There were contrasting views from the participants, with some women reporting that the core characteristics of ASC were secondary to mental health services, however Chloe, Kirsty, and Sarah viewed mental health issues as secondary to the ASC. Regardless of what the participants perceived as being more important, all experienced mental health difficulties alongside their ASC.

Chloe said, *"They said I've got social anxiety, which is wrong but yeah, I have anxiety as well, definitely, but it's like because of my autism. Like I've always been anxious"*.

Similarly, Kirsty recounted receiving multiple diagnoses after having a *"complete nervous breakdown"*.

Kirsty said, *"I was diagnosed at 15 with anxiety, depression, borderline personality disorder…but it's not anxiety and depression it's the reaction to what your going through… I think it was an autism meltdown…that was caused by the autism not being noticed"*.

Likewise, Sarah recalled feeling misunderstood by the mental health system.

Sarah said, *"The doctor would always be like your depressed, take these pills and go to counselling… I got told that they might put in my notes that I have traits of Borderline Personality Disorder… Yeah it was quite scary and shocking…I mean when you're trying to get help and when you have something like that on your record well people just kind of dismiss you…They tried to tell me I had PTSD"*.

The women perceived that earlier mental health diagnoses were inaccurate, and the result of their ASC being overshadowed and therefore overlooked. Existing research suggests that autistic women diagnosed in adulthood are particularly vulnerable to being mislabelled, with an estimated 42% of females misdiagnosed (Bargiela et al., 2016; Gould, 2011). Sarah's experience of being mislabelled mirrors the findings in Leedham et al. (2020) which found

that mislabelling is associated with overarching generalisations and consequent feelings of disempowerment. A recent online survey (Au-Yeung et al., 2019) interviewed autistic adults and found that participants perceive their ASC characteristics to be misattributed to mental health conditions by clinicians and perceived their mental health difficulties to associated to their ASC.

While co-occurring mental health difficulties in the female autistic population are prevalent and many diagnoses are 'accurate' (Zener, 2019), the core features associated with ASC are likely misinterpreted (Au-Yeung et al., 2019; Kirkovski et al., 2013). The misinterpretation of the symptoms of ASC is commonly reported within the research as women described how their social difficulties were understood as social anxiety, repetitive behaviour interpreted to be obsessive compulsive disorder and lack of eye contact attributed to schizophrenia (Bargiela et al., 2016; Leedham et al., 2020; Milner et al., 2019; Zener, 2019). Consequently, women are disadvantaged as they lose opportunities for early intervention and diagnosis that they may have benefitted from.

"I wasn't coping"

All the participants reported difficulty coping with the neurotypical world. The women shared various problems and discussed the strategies they used to try and cope with the symptoms of their undiagnosed ASC. Many of the strategies used involved internalising their difficulties, which had negative emotional consequences.

Katie and Sarah described using alcohol to cope with the autism-related difficulties they were struggling to make sense of. For Sarah, *"binge drinking"* provided temporary relief from the anticipated sensory overload she would experience.

Sarah said, "*I would binge until there was nothing left in the house or I passed out and it's not because I couldn't actually deal with, it's not so much the talking its more the sensory overload. I just started drinking and wouldn't stop until there was nothing left, and I passed out... I actually don't like alcohol I actually don't like drinking I don't like how it makes me feel*".

Similarly, Katie used alcohol as a tool to overcome the social difficulties she faced.

Katie said, "*When I drink I am suddenly the person that I always wanted to be, people don't make me anxious, I smile all the time, I make small talk, I um am social and happy and smiley and start conversations with people and I am confident and like its all of these things that I have desperately been trying to make myself be because that's what I thought I should be for years and years and so I drink to the point of helplessness and terribleness*".

For Katie, alcohol allowed social situations to be easier and enabled reprieve from the ongoing social challenges she faced. The word *"desperate"* emphasises a sense of helplessness managing the social demands of living as an autistic female in a neurotypical world. After feeling different like 'outsiders' for so many years, Sarah and Katie felt pressured to comply and act in a way they thought they *"should"*. Therefore, alcohol served

as a tool to conceal ASC difficulties and meet the gender expectations that women should be bubbly and confident. Attempts to cope by self-medicating with alcohol is widely reported in biographical accounts of experiences living with ASC (Davidson, 2007) and may be a consequence of the lack of self-awareness associated with receiving a diagnosis.

Sophia, Edith, and Kirsty described the difficulty involved in coping with ASC from managing meltdowns, to eating disorders and depression.

Sophia described the difficulties she experienced while learning a new job and coping with change.

Sophia said, *"The main one was that I wasn't coping. I was learning about the job that I do now and there were a lot of like why am I really upset about learning a new bit of information and it occurred to be that I was spending my days trying to predict a million different things and then masking for everyone including Ben so that I could get through and if something happened that was unexpected I felt like my processing got all messed up and it meant that I was melting down and my melting down is just crying and crying so it's really disruptive. But um that's the point where I was like I'm not neurotypical. I feel fine after I meltdown, but I need to manage this better kind of thing"*.

Katie explained how she developed an eating disorder as a *"coping mechanism"* to regulate emotions.

Katie said, *"I definitely think that eating disorders and everything has been a coping mechanism for dealing with how I'm feeling and that's like autism and the way that the brain works… I think autism really gives you that willpower"*.

Sarah described how her mental health regressed, and she was no longer able to cope with the daily demands of her life.

Sarah said, *"It got to the stage where I couldn't go into uni and I'd have to work from home. I imagine that was kind of like a depression… People talk about autistic burn out and one of my friends was like oh my god that's what happens to you. For me, I have cycles, like three years would be the maximum um because I've never given up"*.

Sarah had no way of comprehending her inability to cope with University and described struggling with depression. Despite encountering difficulties and taking a break from University at one-point Sarah attributed her resilience as a determining feature in her story.

ASC is often misdiagnosed as other mental health conditions or missed completely and found accidentally, such as in the case of Kirsty. Irrespective of the age the participants received a diagnosis, diagnostic delays led to mental distress, autistic burnout, meltdowns, and poor coping strategies. The participants in this study attributed delayed diagnosis and the associated consequences to clinicians' lack of awareness and gendered ASC stereotypes.

Reactions to Receiving the diagnosis- "I feel I'm longer an alien"

Participants reported mixed reactions to receiving a diagnosis of ASC, highlighting the diversity involved in each women's experience and the meaning the diagnosis had at a personal level. The relationship between an individual and their diagnosis was complex, with feelings being unclear or a mix of positive and negative emotions. For some participants, the diagnosis was surprising and took time to process, while for others, it was a positive experience and considered a fundamental part of who they are.

Belinda and Kirsty described the sense of shock associated with the unexpected nature of their diagnosis. Belinda recalled experiencing her emotions when she received her diagnosis.

Belinda said, *"I felt shaky, relieved, sad and happy one after the other. I was surprised I didn't feel anger. I think I was way past anger or maybe felt anger would achieve nothing, change nothing"*.

Kirsty said, *"I was like WHAT I've never no one's every said that to me"*.

Belinda infers that anger is a warranted emotion due to her difficulties not being understood sooner and delays in getting diagnosed. Feelings of anger are common in autistic adults, often associated with receiving a delayed diagnosis (Leedham et al., 2020; Lewis, 2016; Powell & Acker, 2016). The diagnostic process was often perceived as challenging and an 'emotional rollercoaster' which may raise difficult personal and emotional experiences from the past (Crane et al., 2018; Lewis, 2016; Stagg & Belcher, 2019). Consistent with this, Sophia described the diagnostic process as *"confronting"* as this involved revisiting difficult past life experiences.

Sophia said, *"I found the process a little hard. It was pretty tricky going through traumatic stuff and pretty exhausting. I was glad it was split between different sessions and it can be hard because like a lot of this stuff is really personally felt and it was really hard"*.

Similarly, Sarah described a sense of anticipation as she feared that she may not receive any answers.

Sarah said, *"At the time it was really distressing because of the issues I've been having I just wanted answers, I felt like I was so close to having something… I was kinda shocked (laugh) I was like I had never thought about that… It was just a really weird, a weird feeling"*.

Sarah explained that she has been looking for answers since she was 15 and has spent a long time considering what the outcome may be. The importance of the diagnosis is evident as Sarah stated that she *"would not have known what to do"* if she had been told she wasn't autistic. Sarah explained how her feelings of shock were influenced by the stereotyped assumptions and limited knowledge of ASC.

Sarah said, *"I didn't know what autism was, well same as everyone else, you know the typical the male banging his head against the wall"*.

Sarah reflected on how she differed from dominant stereotypes of ASC, referencing behaviour seen in media representations of ASC, which perpetuated negative perceptions of ASC. The influence of the media representation of ASC, or lack thereof for women, appeared to play an influential role in how Sarah reacted to her diagnosis.

In contrast, Esther, Chloe, and Katie reported neutral reactions to their new diagnosis.

Esther said, *"I had thought I had a diagnosis in all fairness like it wasn't out of the blue. We were going there to reassess and reaffirm as opposed to get a diagnosis… it*

probably just confirmed that very last bit of me that was like yeah I can officially say I'm autistic yeah, I have a little bit of paperwork now that officially says ASD".

For Esther, the neutrality of her reaction was linked to her diagnosis not being a surprise, and perhaps not unexpected.

Similarly, Chloe recalled her initial emotional ambivalence to the diagnosis, however attributed this to being *"selectively mute"* at the time of her diagnosis.

Chloe said, *"I don't really know how I was feeling because I kinda lacked awareness then, like I was in my own little world and I didn't know what was going on…apparently after I got diagnosed, we got back into the car and my mum burst into tears and I was completely oblivious, I was just like where are we going next, what are we doing now?".*

Chloe contrasts her indifferent reaction to her diagnosis with her mother's highly emotional reaction to emphasise the ambivalence she felt at the time. While this reaction could be related to difficulties with emotional recognition associated with ASC (Lai et al., 2015), it also highlights that Chloe has reflected back and acknowledges her lack of emotion at the time. However, she was also aware of the impact that her diagnosis had on her mother who had sought a diagnosis for her daughter for years.

Similarly, Katie described how the diagnosis occurred during difficult a time in her life and therefore did not have the capacity at the time to meaningfully process the diagnosis. Katie explained how she received her diagnosis during her second inpatient stay in a mental health ward.

Katie said, *"My diagnosis was a very chaotic time in my life. I was given a bit of paper that had a list of diagnoses they had given me and one of them was autism…I was basically given a discharge sheet and it had a list of diagnoses obsessive compulsive*

disorder, anxiety, depression um borderline personality disorder um and then one of the bullet points was autism… I didn't absorb it for a few months".

Chloe and Katie's accounts suggest that personal feelings concerning their diagnosis may change over time, with neutral feelings developing into more positive emotions. Consistent with this, Esther described how she developed an increased acceptance of her autistic identity as an adult.

Esther said, *"There were plenty of times as a teenager where I said I hated having autism, but I think as a teenager you just hate everything, and you probably reach twenty-five and be thankful. I have not met many in their early twenties and in adulthood who hate being autistic. Sometimes I can hate odd bits about it but not the whole thing".*

Even though Chloe was ambivalent at the immediate time of getting a diagnosis, Chloe recounted the transformative impact the diagnosis had once she had processed what it meant for her.

Chloe said, *"It was honestly one of the best things that happened to me. Getting diagnosed is so important".*

Similarly, Katie said, *"a few months later when I actually processed it, it was helpful".*

It appears that the timing and unexpected nature of the diagnosis impacted their ability to process and identify with the ASC diagnosis meaningfully. For both Katie and Chloe, their diagnoses were not individually sought and therefore were unexpected which may influence subsequent feelings and reactions to receiving the diagnosis.

Edith had her assessment for diagnosis online via video and while she had reservations surrounding the online format being *"awkward"* Edith described a sense of validation after having her concerns met.

Edith said, *"I enjoyed the process because she seemed to understand a lot about what I was talking about were normally I'd say stuff and people would be like oh that's weird, I don't do that but she would be like oh yeah, yeah of course that was quite good, validating I would say".*

Similarly, Karen described a sense of relief when she received her diagnosis.

Karen said, *"I don't know - all I remember was one minute I thought I was just weird and then the next it was a kind of relief".*

Sophia said, "*Yeah, it was pretty confronting. And I'm like, since then, I've found it really empowering. And it's, it's really helped me. I knew that getting an answer in the form of a diagnosis can be really empowering and so it's actually turned out to be that for me*".

Participants described how knowledge of their ASC enabled them to retrospectively reflect and develop an understanding of previous life experiences, which often involved re-attributing and explaining negative experiences in the past to their ASC. The participants reported that the diagnosis reduced their feeling of personal responsibility as they were able to attribute previous experiences and difficulties to the ASC label. Consistent with existing research, these findings suggest that the ASC diagnosis provided an explanation for the prevailing sense of difference and the difficulties they experience (Bargiela et al., 2016; Leedham et al., 2020; Stagg & Belcher, 2019). This process appeared to have positive impacts on their self-concept, including increased self-acceptance and reduced self-blame. These findings are consistent with existing literature, which indicates that the diagnosis is a

relief and provides an opportunity to begin a meaning-making process (Baldwin & Costley, 2016; Leedham et al., 2020).

Sophia said, *"You think of your whole life up until diagnosis being like neurotypical and that you know that retrospective looking back at your memories and going oh like actually in some ways I've known along and like different things make sense looking back… little lonely Sophia… like conversations with my parents really insisting "look me in the eye" and how hard I found it to make eye contact. Things like that where I was just like oh wow that's huge actually and just things like I could be in a room full of people and feel really alone or not really knowing how to keep friendships and things like that".*

Sarah said, *"It used to make me really angry when my flatmates and son would be talking or singing and the TV was going, now I understand what it is, um it's like I know because I get it, oh this is happening and this is why I'm feeling like this".*

Kirsty said, *"I just felt weird and stupid and like I was an alien my whole life and I hated myself. If someone said its ok you just have autism your brain thinks a little bit differently I would have gone oh ok… it would have changed my life".*

Katie said, *"Ever since then I've been on a streak kind of like oh well now this makes sense, this makes sense and this makes sense and um telling my friends and family being like did you know that this was an autism thing and they were like what! No that's a you thing and I was like I know!".*

Sophia said, *"I hit these peaks of ridiculousness and I can just call that autism because I know that something sensory weird has gone on or there's been some kind of information that's thrown me and I have that to refer to now".*

For adults, who have a plethora of life experiences prior to receiving the diagnosis, it is unsurprising that the diagnosis led them to reconceptualise past life experiences in the

context of their diagnosis. According to Punshon and colleagues (2009) receiving a diagnosis provides a framework for participants to explain difficult past experiences and reduce self-blame. Consistent with this, Katie described how the diagnosis reduced self-blame for previous 'mistakes'.

Katie said, *"It wasn't defining but it was explanatory. I was able to kind of look back and rather than kind of beating myself up and wanting myself to look back at all the things I've done wrong it was more of a like oh that's just how my brain does things, like an acceptance and so it was just kind of like a calm that kind of just like settled... it's made it really easy to accept the way that my brain does things".*

Similarly, Esther said, *"For all that autism has sometimes made my life incredibly hard I don't know who I would be without it. Autism is just a label for how my brain works and how my brain works isn't that by very definition the definition of me... I would never choose not to be autistic".*

The use of the term *"brain"* suggests an understanding of ASC as a difference in biology. Affiliation with brain-based neurodiversity terminology provides a means of resisting biomedical discourses surrounding ASC and align with the neurodiversity model of ASC (Silberman, 2015). For individuals diagnosed more recently, in a time where the neurodiversity movement is growing, the participants perceptions of themselves and ability to make sense of their diagnosis may be more favourable. This conceptualisation may play a role in greater self-acceptance as highlighted in Katie and Esther's extracts.

Similarly, Katie described how acceptance of her 'differences' led to reduced self-blame.

Katie said, *"It's made me more forgiving towards myself whereas before I'd be like god I'm too tired to socialise what's wrong with me I just need to get over myself like other*

people don't act like this why can't you just be normal that was before like an attack and now it's just like a fact".

Similarly, Chloe said, *"When I got the diagnosis I realised that there's nothing wrong with me I was just different… and I finally like, everyone always asked me why I was so quiet and I didn't know either because I used to not talk and people just thought it was shy but it was more than that… then people knew why I was a bit different like they knew I wasn't being rude or anything".*

For Chloe, the diagnosis's explanatory ability is evident as she described an awareness and concern that people form negative perceptions of her being 'rude'. Therefore, the ASC diagnosis provides a means to explain her differences to people to avoid the negative attribution of her ASC-related difficulties being attributed to inherent personality traits. However, Chloe highlighted that her relationship and feelings towards her ASC diagnosis had changed over time, identifying her teenage years as a particularly difficult period.

Likewise, Belinda said, *"I understand myself better I have a lot more self-acceptance. I'm kinder on myself instead of berating myself for not fitting in, for not doing better, for not being what I can never be…it explains why I struggled so much to fit in… I understand why I get frustrated by people breaking rules. I understand why there are things I can't stand (food, noises etc.). I understand my struggles, past and present better. I understand my strengths and challenges… it is useful for me in terms of better understanding and accepting myself. The right label matters… I realised that I didn't understand myself and that was impacting on how others understood me".*

Belinda repetitive use of the term *"understand"* emphasises that the diagnosis has enabled her to develop a new self-concept and understanding of past difficulties. Increased

self-awareness associated with the diagnosis enabled the participants to understand their own behaviour as they were happening, draw on their knowledge of ASC, and develop appropriate autism-informed coping strategies.

Likewise, Edith said, *"I think it was really positive because it provided a lot of clarity and like validation for things and then a lot of understanding and identity too because I had done, there were all these sorts of things that I've done like I should hide that I should hide that and now I'm just like nope this is me, this is cool, like it's an actual thing I can name so its fine. That was really great after so long".*

Sophia follows on and said, *"I've loved being autistic now officially it's super helpful and like I really like that now I feel I'm no longer an alien".*

Sophia reflected on her life following her diagnosis saying, *"Yeah, it was pretty confronting. And I'm like, since then, I've found it really empowering. And it's, it's really helped me. I knew that getting an answer in the form of a diagnosis can be really empowering and so it's actually turned out to be that for me".*

Sophia alluded to her previous experiences of gaining an endometriosis and fibromyalgia diagnoses, which she described as *"two very complex paths"* after years of being disbelieved. Despite difficult experiences within the healthcare system and ongoing *"vigilance"* Sophia's previous diagnostic experiences appeared to impact her positive reaction to the ASC diagnosis, despite an initial sense of shock. Sophia described a sense that past experiences of coming to terms with health diagnoses enabled her to develop a positive conceptualisation of her ASC diagnosis.

However, not all aspects of receiving the diagnosis were positive for the participants. Edith described how an increased awareness of ASC traits led to hypervigilance in social situations.

Edith said, *"I always used to pick up on things that I felt were different but I never picked up on them quite as much as I do not which I guess is kinda like an ok thing but its somewhat distressing because I just come out of a conversation now and I'm like wow I'm really awkward with all those things…I wasn't so aware of it so now I understand it more and its almost more taxing because it's more in my consciousness of all the sorta processes that my brain is doing throughout a simple conversation with someone".*

For many of the participants, reactions to the diagnosis were mixed and ranged from relief and distress. However, over time all of the participants accepted the diagnosis as something that made sense to them and described a largely positive reaction which was characterised by a prevailing sense of relief. This strong sense of relief appeared to be associated to the of reduction self-blame for past difficulties. Irrespective of the age of diagnosis or the initial reactions to receiving an ASC diagnosis, the diagnosis prompted reflection on past life experiences and initiated a meaning-making process. Participants were able to reframe past experiences, largely negative experiences, as an inevitable consequence of their ASC-related difficulties.

Who am I now? Living with ASC- "This makes sense"

This section discusses the sense making the participants used to integrate their ASC diagnosis into their identity. Much like the reactions to diagnosis, the participants stories were mixed about what it is like to live with an ASC diagnosis. The participants used a number of strategies to make sense and cope with the ASC despite ongoing difficulties surrounding the social representations of female ASC.

Many participants described how researching online helped them to make sense of the diagnosis and develop greater understanding of who they are now they have a diagnosis of ASC.

Kirsty said *"I started researching because that's what I do, I'm, I live on google and girls with autism, women with autism and every single article I read, every test I took was yes you have autism 9/10 on every test was autism and reading these article about these women and girls I'm like wow that's me! That's what I went through! That's what people said to me!"*.

Kirsty's exclamations represented her surprise when she understood that her differences could be explained by ASC. After many years of being unable to make sense of difficulties, the new information provided the opportunity to make sense of her past experiences.

Similarly, Katie said, *"I read Tony Attwood's book on Asperger's it was really helpful and then a couple of other books on female autism… ever since then I've been on a streak kind of like oh wow this makes sense, this makes sense and this makes sense"*.

In contrast, Sophia bemoans that there is not that much information for women with ASC which is an unmet need.

Sophia said, *"I've been trying to find a book that will help me and there's like no handbook that will help you if you're an autistic female adult (laughs). It seems like too much to ask apparently, like a lot of the stuff that's out there is really anecdotal. As someone who's like really hungry for information as soon as I find out something about myself like this, I'm like okay give me all the books (laughs)"*.

Karen described wondering who she would be without ASC and imagined what life would be like without ASC.

Karen said, *"I think about what I'd be like if I didn't have it. I'm sure I'd be very different… I think in some ways being on the spectrum is a good thing because it gives me compassion for others. I think there are pros and cons either way I think if I didn't have it life would be easier in some ways"*.

The diagnosis was also positive for the participants allowing them to identify as autistic as integral to their sense of self. Kirsty described that she no longer feels the pressure to comply with gender norms and 'fit in' and questions women's motivations for their compliance.

Kirsty said, *"I dress this way because I'm comfortable. I will wear sneakers over high heels. Why the hell are you wearing high heels? (laughs)… don't your feet hurt? I had a whole row of heels and now I just want to be comfortable… I used to not leave the house without proper clothes on, full face of make-up, heels… I wanted to be like other people so they'd like me and now I'm like well that's uncomfortable. I'm autistic I'm wearing my jeans and sneakers"*.

Kirsty has a strong sense of freedom and self-acceptance to live as her authentic self and compares her current perspective to her pre-diagnosis conformity behaviours. In addition

to this personal acceptance of self, the diagnosis influenced her social self as well. Belinda described how her relationships with people have changed following her diagnosis.

Belinda said, *"Since my diagnosis I no longer accept being treated as a doormat. I was willing to lose those relationships because I was allowed to value me and my autistic son. I tend to seek out people who accept me and encourage my personal growth"*.

For Belinda, receiving an ASC diagnosis has given her the confidence to be assertive and overcome the passivity that defined her past. Belinda implies that she had been taken advantage of in the past and highlighted how the diagnosis had led her to develop personal values that has been pivotal to positive development. These findings mirror existing research, which suggests that women making life-changing relational decisions in response to a diagnosis, feel more assertive in their identity and confident advocating their needs (Leedham et al., 2020).

However, social difficulties remained a key concern as the participants' expressed a high level of awareness surrounding the ongoing challenges involved in understanding social cues and social interactions. Despite an awareness of their social difficulties' participants described the importance of friendships.

Karen said, "*I love being social I love it but I consider myself awkward (laughs) and I often say things wrong...it's tricky when you don't hear the persons voice and their inflection and body language. I don't understand it well I try but um different expressions mean different things to different people so I get very confused"*.

Similarly, Chloe said, *"I've had a lot of problems making and maintaining friendships because well I'll not respect their boundaries but it's because I didn't know what the boundary was like in the first place and there's like all these rules like how often you have to talk to them and its really confusing and I still don't get it"*.

Likewise, Sophia said, *"I don't know if I've gone too far or disobeyed some kind of social norm without me knowing about it or being like too friendly or too interested or too intense or something so I think a lot of people have dropped off all of a sudden in terms of friendships because of that, because I've just done something and I haven't known what I've done (laughs)".*

Analogously, Belinda said, *"I don't fit in socially and it gets awkward".*

Kirsty said, "*I don't understand people, I really don't".*

While the ASC diagnosis provided an explanation for their social difficulties, the participants described that social interaction remains challenging and an area of ongoing uncertainty. Perhaps experiences of discrimination, bullying and social exclusion which characterised the participants early lives contributes the ongoing uncertainty the participants experience navigating social situations in adulthood. Despite these challenges, the participants highlighted the value they placed on friendships, which appeared to make the challenges associated to developing and maintaining friendships particularly distressing.

Adapting to life with ASC

Participants reported that the new understanding in the form of a diagnosis increased their self-understanding and encouraged the implementation of strategies to manage their social and sensory needs. As previously highlighted in the *"I wasn't coping"* theme, the women described the development of maladaptive coping strategies prior to receiving a diagnosis. However, for many women, the diagnosis provided the opportunity to accommodate their social and sensory needs, which involved implementing lifestyle changes and communication strategies to reduce becoming overwhelmed. The women demonstrated resourcefulness in adapting and coping with the challenges associated with living in a 'neurotypical' world.

The first element of coping involved building self-awareness of their unique needs and what the diagnosis means for them. The participants described this as something that could be learnt over time.

Kirsty said, *"A lot of the times you can go oh I'm just being autistic and shrug it back off again. I'm learning to do that"*.

Kirsty described how she is now able to use her ASC diagnosis to explain difficult experiences. This newfound understanding enables her to shift the blame off herself and enhances her ability to cope with the challenges that may arise. Sophia, Edith, and Kirsty described how their ASC diagnosis helped them recognise the triggers for their meltdowns and manage their stress more effectively. For Sophia, this involved implementing *"sensory snacks"* to manage her stress and create a sensory-friendly home environment.

Sophia said, *"Now that I kind of understand that a lot of my stress can actually be managed with sensory techniques I'm feeling a bit more confident…I have a weighted blanked to sleep under at night (laughs)…my balance board um and I have a massage balls*

that's just like spikey that I can hold and I've trying to get into a regular habit of doing that. I've got a little smell tube um I've been trying lots of things. I've got noise cancelling headphones… we've got a third layer of windows to try to buffer the noise… we spent like 17 grand on the windows, we're really lucky we can afford to do this".

The importance of managing sensory needs is apparent with Sophia's account as she describes consulting with an Occupational Therapist to ensure that she is employing the correct strategies. Furthermore, the emphasis on creating an autistic friendly environment is evident as she described the difficulties of living right next to a motorway and the difficulties she encounters with the noise while working from home.

For Edith, the diagnosis confirmed that the sensory difficulties she experienced at work could be explained by her ASC and described *"stimming"* to manage these difficulties.

Edith said, *"I find sound I can go throughout the whole day and I would get home and feel tired but now I know about the ASC I can actually recognise that I'm close to a meltdown at that point it's not just normal tiredness for me…which has actually been a really good thing…also in terms of like stimming and things like that and actually finding ways to calm myself down because I've become more aware of what that means for me".*

Kirsty explained that the diagnosis has improved her self-awareness of sensory challenges and enabled her to communicate her autistic needs to her husband who is now better able to accommodate them.

Kirsty said, *"When I got the autism diagnosis I realised that going to the supermarket has triggered everything in my whole body and I need to go and lie down for an hour and so that is what I do now… you can tell your partner and he can understand".*

The ASC diagnosis has given the women in this research the knowledge to identify and understand the early triggers of sensory overload within the social environment. This not

only had practical value by enabling the women to utilise coping strategies prior to reaching a meltdown but removed self-blame. Sophia described how this has made her more *"confident"* as she has greater control over her behaviour. These findings echo the 'Agents of change' theme found in a recent study (Webster & Garvis, 2017) which found that the participants saw themselves as efficacious women who could bring about change and take positive action for their future needs. Similarly, Lewis (2016) found that diagnosis prompted autistic adults to accommodate their individual needs, with many participants strategising to improve their lives.

It is important to note that the coping strategies reflect the participants increased understanding of themselves, which in turn led to the development of more effective coping strategies. It was not that they were actually being better supported because of their diagnosis. All of the participants in this study did not feel supported by the structures in NZ aimed at support and care for ASC. Despite the lack of support and provision of practical coping strategies from professionals following diagnosis, the participants demonstrated resourcefulness as they proactively developed coping mechanisms to benefit their lives.

Katie, Sarah, Kirsty, and Belinda described recognising that they needed time alone to cope with the demands of daily life and used strategies that worked to help them.

Katie said, *"My biggest one has just been like my cell phone is a good one, headphones and music and audiobooks, just like plugging in some headphones and sitting in a corner and being like don't talk to me"*.

Similarly, Sarah said, *"For me the withdrawn, self-isolation type thing is more yeah, and people go you are depressed bla bla bla but for me it's to keep me happy and to keep me well"*.

Analogously, Kirsty said, *"I come home and say right I'm gonna go lie down for a nana, destress and he takes the kids away…he gets that I need to destress and so I'm not yelling and screaming at him (laughs), you know because I don't know because I don't know what's going on in my head… I've gotta go to my bed pull my covers up and either play a game or watch something on Youtube and just completely distract my brain enough to calm it down"*.

Belinda said, *"I use strategies to mitigate things I might struggle with (e.g. I don't socialise a lot, I rarely go to movies, I prefer to eat at home. I've adapted my life to suit me…I work to my strengths and often push myself though the challenges"*.

The need for time alone to de-stress and cope is consistent with Attwood's (2007) suggestion that solitude can serve as emotional restoration for autistic individuals. Kirsty gives an account of feeling overwhelmed and out of control which she now able to connect to her ASC rather than her abilities or personality, and contrasts this to feelings pre-diagnosis which she describes feeling like a failure, stating that she used to believed that she was a *"bad wife"*. It appears the women used to associate their difficulty coping with their own internal flaws, however they all developed an understanding of the profound role the environment had on their ability to cope in different situations.

The participants viewed the diagnosis as a positive step forward, which allowed an appreciation of individual needs and improvements in daily functioning (Stagg & Belcher, 2019). The findings indicate that prior to the diagnosis, the women were unable to have their support needs met; however, the diagnosis provided the understanding required to initiate and implement coping mechanisms that enabled the women to enhance their potential. The adaptions the women made in response to their diagnosis appeared to improve their daily functioning while simultaneously reducing the self-blame.

Connection

An important part of adapting and coping with a diagnosis was connection: connection with other women with ASC, connection with groups that were accepting of them, and connection with the wider Autism community. Many participants felt that the diagnosis generated a sense of social connection with the ASC support community (online or in person) which was important for them to access. The desire to belong to a social group and the acceptance within the newfound social identity of being 'autistic' was important for the participants. Tajfel & Turner's (1979) Social Identity Theory (SIT) is a lens used to examine this theme, as SIT considers the influence of group memberships in helping us define our sense of self. Furthermore, SIT recognises the role of societal stigma in shaping identity, which is relevant considering that autistic females occupy two minority identities and experience specific challenges associated with this.

In previous research, women reported a sense of belonging associated with forming connections with autistic female peers (Bargiela et al., 2016; Kanfiszer et al., 2017; Leedham et al., 2020; Milner et al., 2019; Webster & Garvis, 2017). According to Webster and Garvis (2017), building connections is important during the 'readjustment phase' following diagnosis as women reported reading literature about other individuals with ASC and attempting to access the Autism community. They suggested that forming these connections had positive impacts on women's feelings of self-efficacy and autistic identity. Despite limited post-diagnostic support information and resources, participants described how they initiated and accessed their own support by searching for online or in-person support groups, both within NZ and internationally. Many participants outlined the barriers they encountered as they attempted to build social connections with their local Autism community.

Edith said, *"I like to join in with discussions and things like that on Reddit so like autism pages but it's mostly American people on there so it would be cool to have something*

like that in New Zealand and actually find people who are close to you like in the same city or whatever that might be experiencing the same things…we don't really have groups in New Zealand".

Similarly, Sophia said, *"I've really been searching for one um and then online hasn't really been helpful cus like Reddit and stuff seems to be full of autistic guys um and just their experience and their interests are so like different…I'll keep searching but I haven't found anything so far unfortunately. I think if there was a group in Auckland I would make a big effort to come to that cus I really (pause), I just want to be a part of that community like I think I am but like with anyone you know in that community".*

Participants also expressed the difficulty involved in accessing cultural and gender relevant information and support groups via online forums. Edith described her preference for gender-specific support groups.

Edith said, *"I think potentially like female only groups or something like that to share aspects of what you are going through… I would be more comfortable if something like that was online like a forum or something like that because I enjoy having discussions with people just not face to face".*

Reminiscent of the women's experiences of having to be persistent and struggling to be 'seen' diagnosed (Baldwin & Costley, 2016; Bargiela et al., 2016), the participants described the need to be proactive when attempting to access and connect with the Autism community. In NZ, autistic adults are often overlooked by support mechanisms, reporting dissatisfaction with post-diagnostic support services and resources, noting delays and lack of support adjusting to the diagnosis (van der Meer et al., 2021). Despite these barriers, Edith and Sophia were motivated to connect with the Autism community and engaged in online forums. Consistent with the collective strategies theorised in the SIT, an individual may

affirm one's stigmatised identity (e.g. autistic identity) by seeking group contact (Nario-Redmond et al., 2013).

Many of the women reported the benefits of connecting with autistic peers for both friendship and understanding their own identities. Katie described how developing a friendship with another autistic woman enabled her to feel supported in her new ASC identity.

Katie said, *"We really bonded over liked shared experiences and being able to name that shared experience has been nice… kind of like her being so sure in her diagnosis and having it help her understand so much more of her life really centered me and made me go well maybe this is something that I want to identify with rather than it just be like a point on the list maybe this is something that I want to actually look a little bit more in depth and see if I can understand my brain a little bit more".*

Forming a friendship with another autistic woman allowed Katie to safely explore her autistic identity, see the value in learning more about her ASC diagnosis and understand the difficulties associated with adjusting to the diagnosis. This friendship appeared to foster a sense of belonging and acceptance.

Similarly, Esther described the sense of belonging she felt when she attended a group for youth with ASC for the first time.

Esther said, *"I vividly remember (pause) I mean don't get me wrong we were all very different and there were definitely more boys there not many girls but I remember being like I don't feel so strange in here it definitely felt like hey there are other people like me which was really quite nice".*

Despite highlighting that her gender was a minority within the group, Esther describes a sense of belonging and connectedness by participating in ASC groups. Burgeoning research

suggests that autistic adults who have high social identification with the autistic community are more likely to develop a "positive autism identity" (Cooper et al., 2017, p. 844). Consistent with this, a recent qualitative study by Crompton et al., (2020) (n=12, with 10 autistic females) found that there are various benefits of connecting with an Autism community, suggesting that autistic-autistic friendships and access to social support may have a protective role for psychological wellbeing. They found participants reported greater ease socialising together than with non-autistic individuals (Crompton et al., 2020).

These findings echo participant reports from a study evaluating an 10-week autistic-led support programme 'Exploring Being Autistic', which found that by exploring their experiences as autistic individuals and feeling 'normal', participants developed a positive outlook on their ASC (Crane et al., 2020). Therefore, the impact of belonging and the sense of unity associated with gaining a social identity may contribute towards enhanced psychological wellbeing. Altogether these findings suggest that social identification within a stigmatised group may foster the development of a 'positive autism identity'.

Esther explicitly stated that a benefit of having an ASC diagnosis was the ability to access the Autism community.

Esther said, *"I personally would rather have the autism label because that at least gives me a community of other people like me who have similar experiences, not the same experience but similar"*.

Likewise, Sophia said, *"I'm like proud of a community because there's always other people that are also autistic in this, or they shared common things about us"*.

Esther and Sophia described positive feelings of belonging to the group.

Participants reflected on the differences between neurotypical individuals and engaged in in-group and out-group categorisation consistent with the intergroup processes

outlined in SIT (Tajfel & Turner, 1979). Kirsty and Chloe described feeling misunderstood by neurotypical individuals.

Kirsty said, *"I find that a lot of neurotypical people don't get it you know… they have no idea what's going on in our brains".*

Similarly, Chloe said, *"I get kind of annoyed because I'm studying psychology and I feel like the lecturers get it wrong and I get real frustrated when they talk about autism which is kind of shit really".*

The participants engaged in a comparative process that cultivated a sense of affiliation and connection with the Autism community. However, self-categorisation appeared to be defined narrowly or broadly as Esther described her involvement in a group for disabled students at the University she attended while Katie described her involvement in a physics group at school. Esther explicitly described bonding with individuals who shared a minority social status and explained how this involvement was formative in developing her autistic identity.

Esther said, *"I met a bunch of people who I am still friends with now today… I was introduced the idea of actually a disability can be positive and being different can be a positive thing… and met a whole bunch of other people who we all have different impairments and different disabilities or we all had some commonality in how we related to the world in a different way".*

Similarly, Katie said, *"We just tested and did projects all day, we came in on weekends, we were there after and then you go to a competition. It was just SO fun and SO like my brain and we were known as like the physics kids and it was the first time I had proper friends who understood my brain".*

Shared identity of being *"different"* allowed the women to understand their ASC in a more positive way. This appears to mirror the collective strategy processes described in SIT which suggests that the promotion of favourable in-group comparisons cultivate a shared social identity and positively impact identity formation.

For Esther and Belinda, connecting with likeminded individuals provided a safe space to be themselves, gain self-esteem and reduce concern about making social faux paus.

Esther said, *"I can make social… say something terrible or make a big mistake and one really bats an eye at that because we are all just different"*.

Similarly, Belinda said, *"I have socialised with Autism NZ staff but there is less stress and less worry"*.

Previously mentioned in the *'I knew I was different'* theme, many women shared experiences of belonging to a negatively stereotyped group and reported the negative impact this has on self-esteem. Interestingly, a recent study (Botha, 2019) examined the importance of Autistic community connectedness (ACC) in mitigating negative effects of minority stress and mental health vulnerabilities. They found that ACC was associated to an improved psychological wellbeing, suggesting shared social identity may be protective against the negative consequences of marginalisation.

These findings are consistent with existing research which suggests that being active in the Autism community may help to cultivate a sense of pride and comfort in an autistic identity, contributing towards self-acceptance (Bargiela et al., 2016; MacLeod et al., 2013). Coherent with SIT (Tajfel & Turner, 1979) which argues that our identity is mediated by how we view ourselves as an individual and how we position ourselves as a member of a group. All of the participants in this study reported psychological benefits of group membership,

including a sense of belonging, meaning and purpose (Bargiela et al., 2016; Milner et al., 2019; Leedham et al., 2020; Webster & Garvis, 2017).

This is an important finding showing firstly the complexity of presentation of ASC for females and secondly, how self and identity as formed as much by personal and social factors for women with ASC. These findings challenge dominant understandings of women with ASC being lost in their own worlds, not seeking friendship or groups, or the lack of desire to form connection with others. The importance of connection is also reflected in the last section on disclosure which describes the public aspect of an invisible diagnosis.

Disclosure- "I am very careful who I tell"

Disclosure was a salient theme throughout all the participant's transcripts. This was surprising as I did not specifically ask the women how and if they told people about their ASC diagnosis, however, the disclosure process appeared to be important to the participants and embedded in their experiences of receiving an ASC diagnosis. This theme explores participants' decisions navigating the disclosure of their new autistic identity to others and the consequences of different disclosures. Some participants disclosed their ASC diagnosis immediately while others took their time and were selective about who they disclosed to, demonstrating a sense of apprehension about the potential reaction from others. The complexity of living with a stigmatised condition is apparent as the participants recounted experiences of dismissal because they did not fit the male ASC stereotype and perceived the broader cultural representations of ASC contributed to the stigma. Therefore, disclosure of diagnosis occurred in the context of low awareness, lack of understanding and the stigmatisation of female ASC in society.

While most women described receiving a diagnosis as a relief for themselves, many women described the duality of the experience, which was associated with mixed reactions from family, friends, and health professionals. The necessity to conceal and withhold information about their diagnosis was directly associated with the stigma imposed on autistic females and the concern that people would not accept them if they disclosed their autistic identity. A review by Davidson and Henderson (2010) examined the disclosure of individuals autistic identity by conducting a discourse analysis of forty-five autistic autobiographies and personal narratives and found that the process of self-disclosure involves the careful consideration of the potential reaction from others and an awareness of societal stigma. Therefore, it appeared that how others perceive ASC and the anticipated stigma associated influenced the participants' comfortability to disclose their diagnosis. Consistent with this,

Karen described being highly selective and cautious with whom she disclosed her diagnosis to.

Karen said, *"These days I'm very careful who I tell because I don't want it to be used against me…people underestimate me a lot and I hate that. They think I'm stupid or something".*

Karen expressed a sense of vulnerability and fear of being treated differently, explaining that as a result of disclosing her diagnosis, her cognitive abilities were often underestimated. ASC stereotypes left the participants feelings of vulnerable and at risk of being treated differently following disclosure, leading to concerns or hesitations around sharing their diagnosis (Haney & Cullen, 2017; Mogensen & Mason, 2015).

For Karen, perceived stereotypes posed as a barrier to disclosure and influenced her decision to conceal her autistic identity from certain audiences. Karen added that her fear of negative stereotypes is warranted as she recounted the impact this had on her self-esteem.

Karen said, *"I remember growing up I'd get called handicapped a lot. That hurts".*

In contrast, Chloe and Kirsty described openly disclosing their ASC, however Chloe remained cognisant of potential stigmatisation.

Chloe said, *"I'm very honest, so I just tell people (laughs), probably too open sometimes…I just tell people (laughs), …I don't have to like pretend to be normal or whatever…I don't know I'm just not ashamed or anything".*

Similarly, Kirsty said, *"I'm very open about you know I'll out on Facebook I had an autism day because I did this, this and this. I want people to (pause) it's gotta be known, especially for women".*

Chloe and Kirsty's extracts represent a voice of resistance against the deficit-based interpretations of ASC. Chloe strongly asserts her Asperger's identity by countering the stereotype that she should be *"ashamed"* of her diagnosis. Similarly, Kirsty highlights the importance of countering stigmatic beliefs by disclosing her ASC to normalise and educate others about ASC. Despite being 'open' with disclosure, Chloe remains aware of the stigma associated with ASC, which is reflected in her questioning if she shares too much information about her diagnosis and appears to doubt the acceptability of her approach. Interestingly, Chloe described personal benefits to disclosing her diagnosis, including relieving her of the pressure to camouflage and assimilate, suggesting that disclosure offers benefits as it enables her to 'drop the mask'.

Participants generally found disclosing their diagnosis to friends and family challenging as several women reported having their diagnosis dismissed. This disbelief is challenging to their sense of self as it challenges their identity.

Chloe said, *"You get some ignorant people or people that don't really know what it is. Like one of my friends has recently told me that like she doesn't think that I have it which kind of annoyed me…*she's *like oh I just think your anxious and she told me like I'm good at reading social situations, I'm like yeah maybe but I had to really work on it, it doesn't come naturally…people don't really understand it they just assume stuff"*.

Likewise, Kirsty said, *"I'm sure some people don't believe me. I've had a therapist who said no you're not, but she hasn't sat down and spoken to me about why I think that"*.

Analogously, Edith described being dismissed by her parents.

Edith said, *"They were like nooo and then like cus girls tend to mask so much more and people just don't even know and other people that'll talk to about it they will be like*

that's not you but it's like people just don't know because it's your own life your completely different to how you act with people".

For Chloe and Kirsty, experiences of dismissal created self-doubt around their autistic identity and caused them to question their diagnosis.

Chloe said, "*I've sometimes questioned myself with like that friend, whether I have it*".

Similarly, Kirsty said, *"I've wondered and I've said to my mum am I really autistic, am I just fooling myself…you know you do doubt yourself which is why I would love to talk to a professional about it"*.

In situations where participants did decide to disclose, the women described how people found the idea of being female and autistic as incongruent with their knowledge of ASC and strongly associated disbelief and dismissal of their diagnoses with the 'invisible' presentation of their ASC. For Sophia, one negative experience with disclosure shaped her reluctance to share her diagnosis with other people as she felt rejected by her friend.

Sophia said, *"She tried to psychoanalyse me in like…it was a tone that like I could tell that she'd like changed her mind on me in a bad way… she was demanding to know what my experience was and it felt like a real intrusion… it really felt like she had rejected me from her life because of my diagnosis, like it was that was the one thing that changed their mind"*.

For Sophia, the decision to share her diagnosis was driven by the desire to create connection and openness. However, following this experience, Sophia described a dramatic shift in her plans to disclose with others as she described questioning her initial plan for online disclosure. Sophia described the sense of apprehension about the consequences of disclosing her diagnosis in the future and explained that she will *"test the waters"* to gauge who will accept her diagnosis.

Sophia said, *"Originally I was like, cool, I'll just let people know online, and now, I'm questioning whether I should do that"*.

A stigmatised identity is characterised by uncertainty as to how they would be perceived (Goffman, 1963). According to Goffman (1963) external stigma leads to tension between an individual's personal identity and social identity, leading to a 'spoiled identity' that negatively impacts the stigmatised individual. For many participants, a diagnosis of ASC categorised them with unfavourable stereotypes that increased their risk of bullying or discrimination. The participants appeared to internalise the stigma they encountered which negatively impacted the participants sense of identity and psychological wellbeing. As a result, the participants employed 'impression management strategies' described by Goffman (1963) to manage stigma by withholding their diagnoses from certain family members or friends.

Goffman (1963) suggested that people's motivations for managing their impressions are influenced by roles and social norms. In addition, there is a social identity which is based on the public part of our everyday lives or a collective representation. For people with ASC there is a sense of difference from the collective "discrediting" them (Schneid & Raz, 2020, p. 42) based on the associated private and public stigma. Goffman suggests a tension arises from stigma through interactions with others. Impression management for females with ASC was concerned with mitigating public discrimination. These findings demonstrate an awareness of occupying a marginalised position and the associated stigma through masking and performing in a non-autistic manner.

Edith was also wary of disclosing her diagnosis and described her decision to withhold her diagnosis from certain family members, also using impression management to

manage her public and private self. The online environment appears to pose different problems for impression management as your personal self is much more visible to all.

Edith said, *"Not everyone in my life knows that I've been diagnosed only like my family and stuff because my grandparents and stuff are not in the right frame of mind to understand things so at the moment I couldn't like go join groups on there (Facebook) without feeling like oh what they might see (whispers) kind of thing so accessing stuff on general social media I can't do".*

Edith who was recently diagnosed at the time of the interview, describes the challenges involved in navigating her largely private ASC identity. The use of the term *"can't"* emphasises the restrictions involved in sharing her new autistic identity online as she is not fully 'out'. Consequently, Edith's describes how her partial disclosure poses as a barrier for accessing certain online support groups as she fears that her grandparents may see. This suggests that partial disclosure may influence the ability to benefit from the psychological benefits associated with shared social identity, highlighted in the *"Connection"* sub-theme.

The experience of navigating the tension between personal acceptance and the external stigma of ASC was poignant for Sophia and Sarah. They described the contrasting experiences of the labelling themselves for personal and public disclosure.

Sophia said, *"So far it's been amazing at home. Then when it comes time to disclose to people it felt really sad… the hard part I think a lot of people have like a real set idea of what autism is and I think a lot of people are afraid of it for some reason".*

For Sarah, disclosure to her mother did not go as planned and she did not receive the response she was hoping for.

Sarah said, *"When I found out I could be autistic it was like oh my god I can tell my family, here's an answer and now we can understand and get past everything but no".*

Sarah assumed that the diagnosis would be explanatory to her family and repair past relationship issues, however, there is a sense of disappointment that the diagnosis did not improve their relationship. According to Davidson and Henderson (2010), even when people consider their ASC diagnosis helpful at the personal level, there can be challenges involved with disclosing the diagnosis at a public level.

The participants' processes of disclosure, navigating their identity and processes of disclosure, parallel theories of sexual identity development as sexuality and ASC are pieces of identity that can remain hidden or concealable to the outside world. Consequently, issues around disclosure, concealment and "outness" (a term used the Autism community has adopted to describe disclosure) are key factors as ASC is an 'invisible' label (Cage et al., 2018a; Davidson & Henderson, 2010). For autistic women, invisible disability presents unique considerations for disclosures as they were unidentified for many years and occupy a unique position as they can choose to make the identity known to others.

Existing research supports the possibility of increased discrimination after 'coming out' as a recent study examining autistic adults' perceptions on ASC stereotypes found that misunderstandings of ASC by others had negative consequences for them (Treweek et al., 2019). A recent study by Botha and Frost (2020), including a predominantly female sample, found that 'outness' was also associated with higher psychological distress, suggesting that anticipated discrimination or bullying may be associated with ASC disclosure. Consistent with these findings, many participants in this study feared that being 'out' would increase the likelihood they would be compared to prevailing, negative ASC stereotypes. Many participants reported experiences of stigma when disclosing their ASC in the past and

anticipated negative reactions and comparisons to stereotypes would occur again, consequently undermining their individuality and sense of identity.

The 'gendered' knowledge surrounding ASC and stereotypical expectations in females appears to have implications on the participants' experiences of disclosure and appeared to worsen the stigma they experienced. The women described being largely misunderstood and expressed a sense of frustration that non-autistic individuals denied and questioned their autistic identity, thus minimising the challenges and experiences they encounter. Some of the participants attempted to manage the anticipated stigma associated with self-disclosure by employing 'impression management strategies'.

CHAPTER FIVE

Conclusion

Sarah said, "*You're not autistic because you know, you're a woman and you have a sense of humour and you laugh and what was it, asking me if I was like Sheldon Cooper*".

From the outset, it was clear that the female experience of receiving and living with ASC diagnosis has been severely neglected in the research. With current estimates suggesting a growing number of adults seeking a diagnosis of ASC in NZ (van der Meer et al., 2021), it is critical to gain an in-depth, detailed understanding of what these lived experiences involve to understand how to best support a late-diagnosis of ASC. At present, diagnosis and support are largely based on men's needs and experiences, although existing research highlights that these differ considerably for women. IPA was an appropriate methodology for addressing the research aim as it enabled the researcher to gain in-depth 'insider' knowledge, deriving rich and detailed knowledge whilst acknowledging the influence of the sociocultural context on individual experience. This chapter discusses the findings in relation to the main theories, the practical implications and finally outlines future research directions.

The participants' experiences were split into two time periods: prior to and post-diagnosis. The time prior to diagnosis was primarily about the awareness of difference which was formed through comparison to others, primarily other girls and women. Many participants reported the difficulties associated with understanding social norms or gendered expectations in terms of appearance, puberty, and social behaviours. Gendered understandings and expectations played a critical role in how the women made sense of their early experiences. The participants associated diagnostic delays, misdiagnosis and the experiences of bullying, difficulties at school and maintaining social relations to the influence of gendered expectations within society. Similar findings have been highlighted in existing

research (e.g. Bargiela et al., 2016; Treweek et al., 2019), indicating that autistic women perceive the societal stereotypes of ASC impact their subjective experiences of diagnosis. This study adds to these findings and suggests that gender expectations and comparisons negatively impact self-esteem.

Alongside a high level of self-awareness reported concerning gender expectations, the women reported detailed insights into the motivations and consequences of camouflaging and masking. Many participants described using a range of compensatory strategies prior to diagnosis in an attempt to fit in and conceal social difficulties, with many women attributing these behaviours to diagnostic delays. While women reported less camouflaging after diagnosis, the use of these strategies did not dissipate completely, suggesting self-stigma and impression management both prior and post-diagnosis. Given the negative consequences of masking reported by women in this study, including identity confusion and cognitive exhaustion, further research examining how masking changes over time, particularly following diagnosis, would be beneficial.

Many women described the difficulties of coping with the demands of the neurotypical world. The difficulty associated with managing their undiagnosed ASC resulted in maladaptive coping strategies such as binge drinking, disordered eating, and depression. The women associated the development of beneficial coping strategies with their diagnosis, suggesting that the maladaptive coping strategies may result from remaining undiagnosed for a significant period of time. Difficulty coping may be a consequence of the demands placed on women to comply with gendered and social expectations, suggesting the ability to 'cope' and mask in may be associated with managing stigma. Experiences of stigma are heightened for autistic women as they occupy two marginalised and intersecting identities, being both autistic and female (Cage & Troxell-Whitman, 2019b; Saxe, 2017). Consistent with this,

Botha and Frost (2020) found a strong association between stigma and masking behaviour, indicating that females may be subject to more stigma than males with ASC.

The barriers to diagnosis found in this research were consistent with existing research (e.g. Green et al., 2019; Lewis, 2017; Tint & Weiss, 2018). Participants described the practical barriers they encountered when attempting to access a diagnosis of ASC in NZ. Common barriers include the financial cost, time, long waitlists, and lack of knowledge about ASC from clinicians, particularly surrounding the female presentation of ASC. Of the eight women who received a formal diagnosis of ASC in this study, six pursued a private diagnosis. Financial barriers posed as a significant obstacle for many of the participants, with Kirsty, who was self-diagnosed, stated that the cost prevented her from accessing a diagnosis and other women who suspect they may be autistic. Participants reported long waitlists and associated this with the need to go private to receive a timely diagnosis.

These findings add to concerning reports which suggest that gender stereotypes within clinical practice remain a significant issue. Across various studies, women report a lack of awareness of the female presentation of ASC among clinicians, resulting in dismissal and misunderstood needs (Baldwin & Costley, 2016; Bargiela et al., 2016). In *The autism diagnostic process in New Zealand*, clinicians reported the complexities of making ASC diagnosis in adults and females, suggesting the need for updated and continuous professional support (van der Meer et al., 2021). They also found that autistic adults indicated that clinicians needed to be more aware of ASC presentation in females and that assessment tools may be less appropriate for females and suggested that "females may be slipping through the cracks" (van der Meer et al., 2021, p.27). This study builds on the existing evidence which suggests that autistic women encounter various practical barriers associated with obtaining a diagnosis, contributing to diagnostic delays.

All the participants went through a period of adjustment when they received their diagnosis. They all reported relief (some immediately, some overtime), but the diagnosis also disrupted their identity. All of the participants reported that they made changes in their lives following the diagnosis. These changes were primarily positive for their wellbeing and were unique to each individual, including forming connections, adapting to accommodate social challenges and sensory sensitivities, and conducting research on ASC. Receiving an ASC diagnosis had a significant impact on the participants' lives, albeit to varying degrees, with many participants describing a largely positive effect on developing an autistic identity and overall wellbeing.

The reactions to receiving a diagnosis and subsequent impacts are important to acknowledge as research suggests that a positive autistic identity can act as a protective factor for psychological distress. This research did not directly explore the period of adjustment; however, it was evident that a shift in identity occurred once diagnosed, which was viewed positively by the women over time. However, it should be noted that having a positive autistic identity is not fully protective as the women face ongoing challenges associated with living in a neurotypical world, masking, experiencing autistic burnout and meltdowns to cope in a world that does not accommodate neurodiversity.

Another key finding for all of the participants was increased self-acceptance associated with receiving a diagnosis of ASC. Katie described how identifying as 'autistic' has made her "more forgiving" towards herself and lessened comparison to neurotypical ideals, for being too tired to socialise and not fitting in with social expectations. Similarly, Belinda stated that she is "kinder" on herself and no longer berates herself for not 'fitting in' while Sophia described how she found the diagnosis "really empowering". The increased self-acceptance associated with the diagnosis appeared to reduce self-comparison to non-autistic female peers and embrace their difference. A byproduct of the diagnosis was the

ability to engage in support groups which accommodate diversity, further fostering self-acceptance.

There is no doubt that females with ASC in this study struggled with socialisation, friendships, understanding social norms in relationships following diagnosis. However, an important finding in the study is the high level of self-awareness and sociality. Participants described significant awareness of the social and communication challenges they encounter and clearly expressed the impact of gender expectations and the pressures placed upon them. Many participants described the impact of struggling to navigate social norms, behaviours and gendered behaviours for females and described the negative consequences associated with the inability to conform. These findings are consistent with existing research, which suggests that autistic females experience unique challenges as they struggle to fit with the social representations of being both autistic and female (Bargiela et al., 2016; Saxe, 2017). Importantly, these findings challenge prevailing stereotypes of ASC, which represent autistic individuals as socially disengaged and unaware.

Despite finding socialisation difficult, the participants described the desire to form social connections (online or in person), particularly with autistic women or individuals, highlighting the importance the women placed on finding belonging in social groups. It appeared that after feeling different and misunderstood for a significant period of their lives, many of the participants described the importance of feeling understood through building these connections. Esther and Belinda described less concern about making social faux pas around autistic peers, suggesting greater ease when socialising with their autistic peers, highlighted by Crompton and colleagues (2020). In accordance with Social Identity Theory (SIT), group belonging, and the development of shared social identity allows the women to positively reconceptualise their diagnosis' and accommodate ASC into their identity. This study also suggests that the shared social identity the women developed from engaging in

online forums and social groups influence the development of a positive autism identity. These findings add to existing evidence to suggest that social identification within a stigmatised group may foster the development of a 'positive autism identity' (Cooper et al., 2017; Crompton et al., 2020).

Despite the personal level of acceptance upon getting a diagnosis, the participants reported experiences of stigma. Further highlighting the participants high levels of self-awareness, the participants were very aware of the stigma they experience. Feeling different from social and gender norms resulted in many participants experiencing internalised stigma (Goffman, 1963). To manage anticipated stigma many women engaged in 'impression management strategies' that involved selectively disclosing or concealing their ASC diagnosis altogether. Goffman (1963) suggests that humans are interactional and social, and much of our life is involved in managing our view of ourselves to others. For these participants, disclosure of their autistic identity to family and friends was an area where the participants were engaging in impression management. For Chloe, disclosure resulted in her 'dropping her mask', while for many others, disclosure was a negative experience due to disbelief or other bad experiences.

The other important finding is social representations across time and place. This was evident in the terminology the participants used to refer to ASC (e.g. Asperger's, Autism or ASD). This was also influenced by their age and reflected growing up in a time when knowledge of ASC was limited, where there was DSM changes to the diagnostic criteria, and the inconsistencies of how ASC is diagnosed, treated, or positioned in society (e.g. either as a disability or, mental illness). While there is increased diagnosis of ASC for females in NZ, very little support is offered alongside the diagnosis. Consequently, the ability or inability to cope with ASC is dependent on the individual's willingness and ability to seek post-diagnostic support.

Directions for Future Research

This study highlighted several areas where future research would be beneficial. This study suggests that autistic women may benefit from engagement with an Autism community, such as online forums and social group when exploring their newfound autistic identity. In support of the social identity perspective, women's perceptions of their ASC diagnosis extended beyond their personal identity to their association with group membership within the ASC community. This study suggests that there are psychological benefits to a women's ASC identity associated with social identification and connection with the ASC community. Further research examining the impact of connection to the Autism community and sense of identity would be productive to understand the type of social supports would benefit autistic women following diagnosis.

The participants reported a lack of following up support in NZ and expressed high levels of interest for post-diagnostic support. Therefore, future research aimed at developing post-diagnostic support programs, online or in person would be constructive. Furthermore, some participants reported difficulty accessing cultural and gender-appropriate post-diagnostic resources within NZ, suggesting that future research needs to consider the role cultural and gender-specific educational information to support the women adjust to their ASC diagnosis.

It is also clear that theoretical constructions of ASC need revisiting. The participants in this study strongly rejected the assumptions made by the assumptions perpetuated by theories such as the EMB theory. The notion that ASC is rarer in women perpetuates the gendered stereotypes of ASC and creates further barriers for autistic women, especially those who are cognitively able.

Furthermore, this study found that the participants encountered various barriers when attempting to access an ASC diagnosis, with concerning numbers of participants being misdiagnosed or missed altogether. Future research should examine the perspectives of important gatekeepers in the diagnostic process, including teachers and healthcare professionals. Consistent with the recommendations highlighted in *The autism diagnostic process in New Zealand*, it would be constructive to explore clinicians' experiences diagnosing female ASC to determine what factors contribute to the difficulty autistic women encounter when attempting to access a diagnosis to mitigate delayed diagnosis.

Finally, all of the women in this study reported experiences of stigmatisation related to their ASC, with many participants attributing stereotyped understandings of ASC to the representation in the media. It appears that gendered assumptions of ASC disadvantage females and present as a significant barrier to diagnosis. The participants acknowledged improvements in recent years, indicating the stigma associated with ASC and mental health conditions has decreased alongside increased education and acceptance of ASC. However, there is a long way to go to educate professionals, families, and society about what ASC is, and how it presents quite uniquely across genders, ages, and life stages. These findings highlight the importance of accurately representing autistic females within the media and educating the public about ASC in females to develop greater inclusivity and acceptance within New Zealand society.

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Appendices

Appendix A: Project Advertisement

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Are you a female that has received a late diagnosis of Aspergers or Autism?

Please consider taking part in a research study that would like to know more about your experiences of a female living with ASD/Aspergers.

In New Zealand there is a lack of understanding and support services for females who receive a late diagnosis of Aspergers or Autism. Research suggests that diagnosis for females typically occurs later than males, often leaving females' needs unmet and a lack of understanding of the challenges facing females. This research would help us understand what the process of what diagnosis meant, explore coping mechanisms and how you have adjusted to the diagnosis.

As part of my Masters research, I would like to know more about this group.

Your participation will help us gather information about the experience of receiving a late diagnosis of autism for females so that we can increase understanding and improve support services.

If you are interested in taking part in the study a full information sheet and consent form will be provided.

If you feel the above description fits your experience, please consider taking part.

In order to participate you must:

- Be a female living in New Zealand
- Speak fluent English
- Be at least 18 years old
- Have Asperger's or Autism Spectrum Disorder (ASD)
- Diagnosed within the last 10 years

We would greatly appreciate your participation. Please contact me (Stacey) for more information.

Researcher: Stacey Dukes   Research Supervisor: Dr Kathryn McGuigan

Email: ███████████████   School of Psychology- Albany Campus

                                                    Email: k.mcguigan@massey.ac.nz

Appendix B: Information sheet

Exploring the experiences of females who receive a late diagnosis of Autism Spectrum Disorder (ASD) in New Zealand

Information sheet

Researcher Introduction

My name is Stacey Dukes, a Master's student at Massey University. This research is being conducted for the fulfilment of the requirements for the degree of Master of Arts in Psychology. The academic supervisor involved is Dr. Kathryn McGuigan from the School of Psychology.

Project description and invitation

This project aims to explore the experiences of females who receive a diagnosis of Autism Spectrum Disorder (ASD) or Asperger's any time after the age of 11 years. Currently little is known about this topic, particularly in New Zealand. This research would contribute towards a greater understanding of what the experiences of females who are diagnosed late in life. It is hoped that greater understanding of the experiences of autistic females may lead to improved awareness, diagnosis and support to improve overall wellbeing for women and girls.

Participant identification and recruitment

I am inviting females who received a diagnosis of ASD and Asperger's any time after the age of 11 years to take part in the project.

You may be eligible to participate if you are:

- A self-identified female living in New Zealand

- Speak fluent English

- At least 18 years old

- Have Asperger's or Autism Spectrum Disorder (ASD)

- Diagnosed within the last 10 years

This project will involve a small sample of between five and eight participants to enable me to gain a rich understanding of each participants experience. These participants will be recruited through snowball sampling, which will involve participants referring other potential participants and through appropriate social media sites.

You will be given a $30 Westfield voucher to thank you for your time.

Project procedures

If you choose to participate in this research, it will involve a relatively casual 1-hour interview about your experiences. This can be conducted face-to-face or on-line via Zoom or Skype. Face to face meetings will be safely managed using social distancing measures. The interview will be conducted at a time that suits you and will be audio-recorded using Otter Voice Notes, a transcription application. This information will be transferred to a secure hard drive after the interview and will be deleted off the application.

I will send you the interview questions with the information sheet before the interview. You are welcome to prepare answers before the interview. You are welcome to prepare answers before the interview that we can discuss. I want you to be as comfortable as possible for the interview so feel free to bring any support people with you that will help or you can also bring any objects (e.g. stim objects, weighted blankets or special interest items).

You will be emailed a consent form as well and this will need to be completed prior to the scheduled interview. Please contact the researcher with any questions you have.

At the end of the interview you will be asked if you know any females that may be eligible to participate in the research. If you do, then I will ask you if you would like to pass an information sheet on to them, however you are under no obligation to do so. You will also be asked if you would like to be emailed a summary of the project findings upon completion of the project.

Data Management

The information from the data will be interpreted to find themes in participants' experiences. The findings will be published in my master's thesis, and potentially an academic journal. If you chose, you will be emailed a summary of the project findings. You will be given 2 weeks to review this and if there is no response, the researcher will assume this is fine.

All participant information will be carefully managed to ensure that privacy and confidentiality is maintained. The interview audio-recording will be typed up in written form and you will be given a pseudonym (fake name). Any other identifying information will be changed or removed. There will be no identifying information in any reports or publications. Audio-recordings, transcriptions and any other associated information will be securely stored, only myself and my supervisor will have access to these. The information collected will only be used for purposes of this project. Upon completion of the project, all data will be destroyed, except for the sign informed consent forms which will be kept by the supervisor for five years, as per Massey University requirements.

Participants' rights

You are under no obligation to accept this invitation. If you decide to participate you have the right to:

- decline to answer any particular question

- withdraw from the study up to three weeks after the interview

- ask any questions about the study at any time during participation

- provide information on the understanding that your name will not be used unless you give permission

- be given access to a summary of the project findings when it is concluded

- ask for the recorder to be turned off at any time during the interview

Project contacts

If you are interested in participating in this project or have any questions, please feel free to contact me (Stacey Dukes) using the email or phone details provided below. You may also use the contact details below to contact myself or my supervisor any time throughput the research if you have questions, concerns or wish to provide feedback.

Researcher: Stacey Dukes

Email: ▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮

Phone: ▮▮▮▮▮▮▮

Supervisor: Dr Kathryn McGuigan

Email: k.mcguigan@massey.ac.nz

If you need support, feel free to contact:

- Lifeline- 0800 543 354

- Samaritans- 0800 726 666

- Depression helpline- 0800 111 757

- Anxiety phone line- 0800 269 4389

- 1737, need to talk? - Call or text 1737

- Autism New Zealand- Call 0800 288 476 or Email: info@autismnz.org.nz.

- Altogether Autism- Call 0800 273 463

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 20/19. If you have any concerns about the conduct of this research, please contact Dr Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43347, email humanethicsnorth@massey.ac.nz.

Appendix C: Interview Schedule

Interview Schedule

Demographic questions:

- How old are you?
- What is your current occupation?
- What was the diagnosis you were given?
- What age were you diagnosed?
  Main questions:

- What was your experience of receiving the diagnosis? Can you tell me about that day?
  - Who diagnosed you? Psychologist, psychiatrist, doctor, other professional?
- How do you feel receiving the diagnosis has affected your life?
  - Do you agree with the diagnosis, what does it explain to you?
  - School must have been difficult
  - Being alone would be useful to you
  - What aids do you use e.g. stim tools, weighted blankets, music?
- What does the diagnosis mean to you now? Tell me about how autism has impacted your life?
  - Job
  - Relationships
  - Study
  - Difficult situationships for them
- Has the diagnosis influenced the way you see yourself now?
  - What does it mean to have autism to you?
- Has the diagnosis affected your relationships with other people?
  - Are your parents/family supportive and understanding?
  - Friendships can be hard
- Why do you think you were diagnosed late?
  - Is the label of this condition useful?
  - Females have it easier with autism as they can speak and look people in the eye.
- Why do you think females with autism are generally diagnosed later than males?
  - Have you been teased because of your autism? E.g. flapping or rocking.
- Have you been diagnosed with other mental health conditions such as anxiety or depression?
- What kind of follow up support have you received after diagnosis?
- What additional support do you think would benefit females with autism?
- Is there anything that we haven't talked about that you would like to add?

Housekeeping questions:

- Do you know of any other females that may be suitable for this study? If so, would you be able to get consent from them to pass on their contact details to me?
- Would you like to be sent a summary of the research findings?

Appendix D: Informed Consent Form

Exploring the lived experiences of females who receive a late diagnosis of Autism Spectrum Disorder (ASD).

Participant consent form- Individual

I have read and I understand the Information Sheet attached. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study up to 3 weeks after the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

I _____ hereby consent to take part in this study.

Signature: _____ **Date:** _____

Appendix E: Abbreviations

Autism Community Connectedness (ACC)

Attention Deficit Hyperactivity Disorder (ADHD)

Autism Spectrum Condition- ASC

Autism Spectrum Disorder- ASD

Diagnostic Statistical Manual- DSM

Intellectual Disability- ID

International Classification of Diseases- ICD

New Zealand- NZ

Social Identity Theory- SIT

United Kingdom- UK

Pervasive Developmental Disorder – Not Otherwise Specified- PDD-NOS