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An exploration of the lived experiences of women with a diagnosis of Autism Spectrum Disorder

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Abstract

Literature exploring autism in female populations is characterised by its predominant quantitative methodology and child participant focus. First-hand accounts of those whose lives are most impacted by ASD are limited to a number of small scale qualitative studies leaving much unknown as to how autistic women in particular experience their lives. Findings from these studies in conjunction with autistic life writings produced by women on the Autism Spectrum have begun to expand and deepen the narratives surrounding autism. A comprehensive general literature review followed by a state-of-the-art review of first person adult female perspectives aims to contextualise the lived experiences of women with ASD. A qualitative methodology was adopted using a constructionist Reflexive Thematic Analysis method and aims to add to the currently limited body of knowledge about female autism as a subjective and socially contextualised experience. Using on-line recruitment, semi-structured interviews with sixteen women who had a diagnosis of ASD were conducted. Two major themes, ‘male-centric view of autism’ and ‘gender-based role expectations’ were developed from discussion of women’s experiences. Combined, these themes served to contextualise the impact of intersecting cultural ideologies on women’s sense of self and psychological wellbeing. Findings are discussed in relation to dominant theoretical conceptualisations of autism, adult psychosocial outcomes and the emerging construction of autism in women in the guise of ‘the female phenotype’. Clinical implications of findings in terms of service provision, assessment and diagnosis are outlined alongside recommendations for further research and the limitations of the study.

Contents

Chapter 1: An exploration of the lived experiences of women with a diagnosis of Autism Spectrum Disorder

1.1 Thesis Overview

Females with Autism: under-recognised, under-researched and under-served (Chester, 2019)

This thesis analyses the lived experiences of sixteen women who received a diagnosis of ASD in their adulthood. As indicated by Chester's (2019) comment, autistic females represent a marginalised group within the autism research community and beyond with findings from predictive models suggesting approximately 39% more females should be diagnosed with ASD (Barnard-Brak et al., 2019). Knowing how to interpret a lower prevalence rate in females (recently suggested as 3:1 by Loomes et al. (2017) with little variability across the spectrum or intellectual ability) is problematic. Debate suggests autism may affect men more than women or it may imply autism manifests itself differently in females or in a way that society perceives differently (Hens et al., 2019). A lack of understanding of autism in females is suspected to have led to many women receiving a late or delayed diagnosis (Gould & Ashton-Smith, 2011). Anecdotal evidence suggests not receiving a diagnosis in childhood leaves women vulnerable and unsupported as has frequently been the experience of those diagnosed later in adulthood, often following earlier diagnoses of mental health conditions (e.g. Bargiela et al., 2016). Reflective of child focused research in autism in general, the limited female autism literature has largely focused on adolescent autistic girls creating a significant gap in the current understanding of how adult autistic women experience their lives prior to and following their diagnosis of Autism Spectrum Disorder.

1.1.2 Thesis structure

In order to contextualise the qualitative focus of this study, Chapter one outlines the contribution of the existing, largely positivist, autism literature in relation to: current constructions of autism, quality of life outcomes for people with autism and the 'female autism phenotype'. Chapter two highlights the additional contributions of the limited number of first-hand accounts of women with ASD to our understanding of the adult female experience. This is followed by the methodology chapter, which documents the researcher's positionality and theoretical framework providing a rationale for applying a constructionist Reflexive Thematic Analysis to women's accounts. Chapter Four is structured by respective analyses of developed themes, 'male-centric view of autism' and 'gender-based role expectations' with findings contextualised in related subthemes and participant quotation. In the final chapter, the significance of findings is discussed in relation to dominant theories of autism, how participants experiences sit within the existing literature related to both quality of life and the wider female population's experience of autism. The conclusion of the research is that greater gender sensitivity needs to be demonstrated in policy, clinical and research practice in relation to autism and women.

1.1.3 Terminology

The terms person with autism, person with ASD, autistic person and person on the autism spectrum are used interchangeably throughout this thesis. This is to reflect the researcher's efforts to be respectful of differences within the autism community on the use of such terminology (Kenny et al., 2015). It also represents the researcher's efforts to adhere to the American Psychological Association guidance (APA, 2020), regarding bias free language and the importance of recognising the dominance of group membership preferences regarding self-descriptive terminology. Additionally, the terms ‘autism’, ‘autism spectrum’ and ‘autism spectrum condition’ are used interchangeably.

1.2 Chapter Overview

The purpose of this current chapter is to interrogate the literature most relevant to the aim of this thesis; to explore the lived experiences of women with Autism Spectrum Disorder (ASD). The literature will be presented in two parts. To introduce the aims of this study, chapter one outlines the current context of autism in relation to definition, aetiology, assessment and diagnosis. Attention will be paid to the implications of gender differences in these discrete areas and, consequently, to how they impact the everyday lives of these women. Existing qualitative literature exploring the experiences of autistic women from a first person perspective will be discussed in the second chapter.

1.3 Defining Autism Spectrum Disorder

Throughout history, autism has been seen through a medicalised lens whereby autistic individuals are viewed from a deficit perspective, creating a research legacy with a continued focus on the aetiology of autism (Chown & Leatherland, 2018). Autism has been conceived as a ‘problem with communication’, a ‘problem with maintaining social relationships’ or a ‘cognitive problem’ (Hens et al., 2019). In replacing descriptive labels such as Aspergers Syndrome, Autism and Pervasive Developmental Disorder Not Otherwise Specified, with the umbrella term ‘spectrum’ the Diagnostic Statistical Manual-Fifth Edition (DSM-5 American Psychiatric Association, 2013), marked a significant revision of the autism diagnostic criteria which changed the nature of how autism is construed. As a spectrum condition it can ‘include individuals who are highly intelligent and verbally proficient but socially and emotionally helpless, or incapable of communicating effectively and in need of assistance of every daily personal need' (Ripamonti, 2016, p.58).

In an attempt not to 'whitewash the evident heterogeneity' (Lai et al., 2013) gradations of individual differences are specified in DSM-5 by three severity levels of social communication impairment and repetitive and stereotyped interests. Such alterations in diagnostic criteria has been controversial causing commentary within critical autism studies and elsewhere about the 'predominantly non-autistic medical community's…societal mismeasurement of autism almost at will' (Chown, 2014, p.1). Furthermore, despite explicit recommendations from autistic advocacy groups in relation to gender bias in females and adult needs in particular, changes in diagnostic criteria have provided limited guidance on working with either group (Kapp & Ne'eman, 2012 as cited in Saxe, 2017). The sheer heterogeneity of autism represented within the spectrum has led some to suggest that rather than one unique phenomenon, there may be different autisms with different biological processes and developmental pathways making unclear what exactly is meant by autism (Verhoeff, 2013).

1.4 Understanding Autism

Spath and Jongsman (2020) note that the apparent increase in the prevalence of autism has resulted in a simultaneous increase in the ways in which diverse sciences direct to different explanations concerning the causes of autism (Autism Research Foundation 2018). They observe that rather than adding clarity to its interpretation, autism remains under-studied and often poorly understood. In research terms, the autism construct is dominantly understood within a biomedical model with several influential cognitive theories such as theory of mind deficit (ToM: Baron-Cohen et al., 1985), executive dysfunction (Ozonoff, 1997) and weak central coherence theory (WCC: Happé & Frith, 1996) positioning autism as a neurodevelopmental disorder. For the purposes of this thesis, theories surrounding the aetiology of autism will be referenced to varying degrees. However, the researcher acknowledges that critiques of each theory in terms of validity and universality since their inception have led to a modern questioning of autism as a singular or multiple cognitive deficit, or, alternatively, a neurological ‘difference’ typified by Baron-Cohen’s comment ‘when we examine the cognition and biology of autism, arguably what we see is not evidence of dysfunction but rather evidence of difference’ (Baron-Cohen, 2017, p.744).

Happé and Frith (1996) sought to understand specific cognitive processes through the framework of Weak Central Coherence Theory, suggesting that individuals with ASD tend to process information in a detail-focused way, at the expense of global meaning. This theory seeks, among other things, to explain difficulties in making sense of a social situation and planning how to respond appropriately. Ozonoff’s (1997) theory of executive functioning links social communicative competence to mental operations such as working memory, inhibition, mental flexibility and planning (Taylor & Tager-Flusberg, 2004). Theory of Mind (ToM: Baron-Cohen et al., 1985) attempts to locate social difficulties at the core of autism, suggesting individuals with autism lack a fully functioning theory of mind and hence have difficulty taking on the perspectives of others. Accordingly, social difficulties arise from a failure to understand alternative motives thus making what others are doing and why and how to respond difficult to interpret.

Frith and Happé (1999) sought to extend the Theory of Mind hypothesis suggesting that people with autism exhibit deficits in attributing mental states not only to others but also to themselves. They suggest that while autistic people undoubtedly have mental states, their capacity to reflect upon them is diminished, thus self-reports by autistic individuals should not be assumed to be necessarily accurate accounts. As noted by Hens et al. (2019), this position is problematic not just because it presupposes the truth of the ToM hypothesis but the sheer existence of autistic self-reports (discussed in a later section) make it improbable that such a statement would apply to the entire spectrum of autistic people.

Additionally, autistic scholar, Damian Milton (2012), and others (Hacking, 2013; Sasson et al., 2017; Smukler, 2005) point to the lack of acknowledgement in such cognitive behavioural discourse of the 'universal issue of relationality and interaction in the formation of a contested and constantly reconstructed social reality, produced through the agency of its "actors" (Milton, 2012, p.883). Milton argues that positivist methodologies in cognitive psychology in particular, incorrectly assume there is a set of definable social norms and rules that exist for individuals to follow which has led to a 'wildly inaccurate measure' (Milton, 2012, p.884) of the mental states and the motives of individuals with ASD. Accordingly, ToM represents a 'double empathy problem' whereby individuals with ASD and neurotypical individuals alike, experience equal difficulty interpreting each other's mental states and motives. That social misunderstandings can occur in both directions is supported by research where family members were found to underestimate an autistic individual's perspective taking abilities (Heasman & Gillespie, 2017), and by Brewer et al. (2016) who found non-autistic individuals struggled to identify autistic person's emotional expression.

Sasson et al. (2017) argues such relational factors are emphasised in the social model of disability which posits that those with disabilities may be disadvantaged not only because of their own differences and challenges but also because of societal structures (e.g. systemic barriers, negative attitudes and lack of accommodation) that impede optimal functioning. To illustrate, Sasson et al.'s (2017) analysis of three studies investigating the impact of first impressions of children and adults with ASD by unfamiliar same-aged, non-autistic observers in ten-second video clips, indicated negative evaluations and reduced desire to meet in person. Findings were consistent across studies and stable over time leading Sasson and colleagues to suggest the social disability experienced by those with ASD may be in part impacted by the behaviours and perceptions of, and social decisions made by their neurotypical peers. This notion is further supported by Wood and Freeth (2016) who found non-autistic university students defined autism in terms of negative stereotypes (eight out of ten) which the authors, related to their autistic peers' reports of bullying and unsatisfactory university experience. Additionally, awareness of diagnosis is not necessarily protective as demonstrated by Cage et al. (2018), who found that non-autistic individuals (who are cognisant of a peers' diagnosis of ASD) can also dehumanise those on the autism spectrum.

Variation across key cognitive theories of autism in terms of how the condition is construed has led some critics to highlight the need to question the normative positionality of models of autism such as ToM, which Gernsbacher and Yergeau (2019) suggest has become the 'sacred cow' of psychology. Smukler (2005) argues such theories are inadequate in large part, as they fail to consider what autistic people think and feel, how they experience the condition making the theory in effect, 'mindblind' with regard to autistic perspectives. Accordingly, Smukler (2005) questions the objectivity of any science and argues all truth is created in social context. Instead, he argues, that alternative constructions of autism are only possible when autistic voices are made part of the discourse.

Duffy and Dorner (2011) argue a 'rhetoric of sadness' has ensued from ToM in particular in which 'autistic humanity is mourned even as the researchers seek to apparently explain and improve the lives of autistic people' (p. 213). They suggest ToM encourages a dehumanising narrative of autistic individuals with; 'evolutionary deficits' (such as the capacity to feel), deviant minds (that are impossible for 'normal' people to imagine) and, a 'tragic being' that results from the cumulative disorientation of both. The implications of such positions for people with autism is a continued overemphasis within the research community on finding cognitive and biological explanations and hence (it is assumed) a cure (Pellicano et al., 2014;2018). The real world implications involve various sections of the media, including autism charities such as Autism Speaks, a US based organisation founded by parents of autistic children which, despite the removal of the word ‘cure’ from its mission statement in 2016, (Stenson, 2019), continue to sometimes depict and speak about autism as a disorder that needs to be cured and steers large research budgets in this direction (Hens et al., 2019).

Similar to Smukler’s views, Duffy and Dorner (2011) encourage researchers to seek out stories that have been, for the most part absent from the autism research: the stories told by autistic people themselves. A realisation of their collective ambitions has arguably been captured in the neurodiversity movement that has since emerged through the work of Autistic self-advocates promoting the alternative argument that autism is the result of a difference in neurology which should be accepted as a form of human diversity (Autistic Self Advocacy Network, 2017). Individuals who are affected have come to consider autism as an intrinsic part of their identity, their sense of self and personhood (Silberman, 2015) and autism should be afforded equal respect alongside other forms of diversity such as race, gender, ethnicity or nationality (Roth, 2020). Viewing autism as an identity, as a ‘difference’ rather than a ‘disorder to be cured’, provides a more balanced view in that it removes the disproportionate focus on ‘deficit’. This position has been debated in the wider autism community often by parents of autistic children with significant behavioural difficulties who argue that those advocating for neurodiversity cannot speak for all those diagnosed with autism (Baron-Cohen, 2019). Debate in the autism research community suggests an ‘either/or’ position is unnecessary, as given the heterogeneity that exists within the autism diagnostic category, the neurodiversity model fits autism well and sometimes the disorder/medical model is a better explanation particularly in situations where functioning and wellbeing are impacted (Baron-Cohen, 2017).

1.5 Psychosocial adult outcomes

As illustrated above, research in ASD in general can be characterised by an overemphasis on biological/cognitive investigation (Pellicano et al., 2014; 2018) meaning research on the everyday lives of individuals with ASD is limited for either sex. A review of studies devoted to exploring autistic life in adulthood by Howlin and Lounds-Taylor (2015) indicates a worrying trend of high rates of: unemployment, comorbid physical and mental health problems, stressed carers, criminal offending and limited access to specialist services. Their observations suggest broadly similar findings to earlier reviews of large-scale longitudinal studies into the outcomes of 68 adults with an ASD (Howlin et al., 2004; Howlin, et al., 2013) where no participant in the 7-29 year groups with an IQ <70 (an IQ score of 100 is deemed average) had a ‘good outcome’ (defined by having some friends or acquaintances, being employed in the past or currently and requiring some support with daily living). Of those participants with an IQ>70, a minority were living independently and the majority were dependent upon the support of others.

The lack of progress in terms of improved outcomes for adults with autism over time has been related to poor service provision for individuals on the autism spectrum, exemplified by Camm-Crosbie’s (2019) study of autistic adults experiences (majority sample autistic women) of mental health services which were characterised in the main by a lack of accessibility, inappropriate treatments and poor understanding of autism. This want in progress is also related, in part, to a paucity of consensus within the research community on what constitutes ‘good’ outcomes (Lounds-Taylor, 2017). Researchers have begun to focus less on objective indicators such as employment, independent living or relationships and more on subjective indicators such as quality of life or happiness. A recent study (Griffiths et al., 2019) using the Vulnerability Experiences Quotient (VEQ), found intellectually-able autistic adults’ (n = 426) report lower life satisfaction and higher rates of depression and anxiety symptoms than their non-autistic peers (n = 268) and related this to their increased vulnerability to negative life events. Cross sectional analysis of online questionnaire responses indicated high rates of victimisation, bullying, and physical, verbal, emotional and sexual abuse by adults when they were children (Griffiths et al., 2019). They were also more likely to experience sexual, financial and physical abuse within a relationship than their non-autistic peers. Negative experiences related to mental health were common with 60% reported having made a suicide plan, 41% a suicide attempt and 64% self-harming. Additionally, four times as many adults in the ASD group reported having their parenting questioned by a professional compared to non-autistic peers.

A significant limitation of the Griffith’s et al. (2019) study in the context of this thesis, is that groups were not matched for gender, making it difficult to draw conclusions about what gender specific factors make ‘higher functioning’ adults more vulnerable to negative life experiences than their non-autistic peers. Oakley et al., (2021) caution against group level findings in relation to autistic quality of life research. Their review of wellbeing self-reports from autistic and non-autistic peers across the life span indicated significant subjective variability where between 33% - 71% percent of autistic individuals, did not report reduced quality of life across the quality of life domains. Where lower QOL was reported, and in line with Griffiths et al., (2019) study, depressive symptomology presented as a significant risk factor.

Importantly, Griffiths et al., (2019) highlight a number of previously unidentified areas related to life satisfaction (e.g. increased vulnerability to abuses within relationships) and adds context to a recent population-based study of intellectually able adolescent girls with ASD and ADHD which indicated they were three times more likely to experience sexual abuse than their neurotypical peers (Ohlsson-Gotby et al., 2018).

A qualitative meta-synthesis of the limited research on the lived experiences of autistic individuals from a first person perspective (DePape & Lindsay, 2016) suggests individuals with ASD struggle with disclosure of their diagnosis, particularly in the workplace because of fear of stigma. School experiences were influenced by a lack of understanding of ASD from teachers and peers which together impacted engagement with the curriculum and resulted in bullying experiences. Unemployment as well as underemployment and lack of opportunity for career advancement were also highlighted.

Importantly, in the context of this research, the paucity of studies focused on adult females (0.5% of studies are conducted on autism in women, Watkins, 2014) means that there is a dearth of understanding of how autistic women experience their lives across the lifespan. DePape and Lindsay's (2016) synthesis of studies indicates significant methodological concerns which arguably reflect the majority of research involving females with ASD. Sampling involves majority 'higher functioning' males, is child focused or relies on mixed aged sampling where women and girls are subsumed into the majority participant group. Additionally, some qualitative research (e.g. Milner et al., 2019; Mademtzi et al., 2018) also relies on the use of experiential data provided from third parties which make questionable to what extent findings can be generalised to adult women with ASD.

Considering the gender imbalance in sampling, it is understandable that there is very little research on the quality of life for autistic women specifically. Some research suggests that women with an ASD can achieve considerable success in their lives both on their own terms and by the standards of the neurotypical world (Webster & Garvis, 2017). That being said, themes of victimisation, isolation and of being misunderstood are common across the limited research that focuses on the lived experiences both of young girls and women with ASD (Bargiela et al., 2016; Cridland et al., 2014; Kanfiszer et al., 2017; Mademtzi et al., 2018). Australian research, examining quality of life outcomes for a relatively large scale population of males and females (n = 313), identified significantly worse broad psychosocial outcomes for women with ASD than for either non-autistic women or men with ASD in areas such as, employment, social relationships and mental health (Baldwin & Costley, 2016). Of note, a systematic review by Zimmerman et al., (2018) found the influence of gender on psychosocial outcomes of adults with higher functioning autism was inconsistent.

1.5.1 Case for female specific need

The issue of the specific needs of women with autism has garnered international attention as highlighted by United Nations Secretary, General Antonio Guterres, during the recent World Autism Awareness day (2018), when he recognised the increased marginalisation of females with ASD in their everyday lives. Reports have also focused on the multiple forms of vulnerability autistic women face. A special rapporteur report (Blakemore et al., 2017) containing first-hand accounts, clinician reports and audits of service usage, detailed the difficulties, abuses, assaults, mental health issues, eating disorders and social isolation experienced by women with ASD in Australia. Elements of all these problems have a major impact on the lives of these women. While several of these experiences are not necessarily exclusive to women with ASD, the potential impact of these difficulties on women compared to their impact on autistic men who face different social expectations is not currently known (Sedgewick, 2017) and further highlights a need to address the potentially double-disadvantaged status of women with ASD in autism research (Shefcyk, 2015; Skuse, 2016).

While research on women with ASD and mental health specifically is limited, a mental health disparity between autistic men and women is suggested in recent research (see Lai et al., 2019 for review). Population-based research (Kirby et al., 2019) highlights an alarming trend of increasing incidents of suicide in females with ASD without intellectual disability. In 2016, in an effort to raise public awareness on early deaths in autism, Autistica, the UK’s leading autism research charity published a report ‘Personal tragedies, public crisis’ to highlight suicide risk in this community and in women in particular. The report highlighted that women with ASD without an intellectual disability are at twice the risk of death from suicide than higher functioning males with ASD, suggesting that further study of potentially unique additional suicide risk factors in this specific group is necessary.

The eating disorder, anorexia, has also been linked to females and autism (see Westwood & Tchanturia (2017) for review). Findings from one study found almost three quarters of the women in an in-patient anorexia treatment facility displayed elevated autistic traits on the ADOS-2 (Mandy & Tchanturia, 2015), leading authors to suggest that anorexia may in some individuals represent a ‘female’ presentation of autism. As noted by Sedgewick et al., (2019) similarities between the two conditions include a preference for routine, obsessive behaviours and reduced sociability. However, conclusions should be cautionary, as eating disorders are not exclusively a female condition. Additionally, Westwood and Tchanturia (2017) cite studies largely focused on examining autistic traits in a population whose primary diagnosis is anorexia rather than investigating disordered eating behaviours in participants whose primary diagnosis is ASD, about which little is known (Happé, 2020).

Botha and Frost (2020) recently found that women with ASD are more vulnerable to experiencing poorer mental health than their male peers, because of their multiple minority statuses. Applying the minority stress model (Meyer, 2003) to both groups, they highlight the impact of everyday discrimination and internalised stigma in laying the groundwork for mental health difficulties, arguing that women with ASD are particularly vulnerable because their sex represents ‘a marginalised minority with minimised social standing’ (Cage & Whitman, p.1908). Relatedly, researchers (Cage & Whitman, 2019; Parish-Morris, 2019; Saxe, 2017) have suggested using intersectionality theory to further explore these experiences.

Intersectionality, a theory/framework originating from black feminist scholars and activists (Crenshaw, 1989, 1991) focuses on interlocking systems of oppression and the need to work towards structural level changes to promote social justice and equity. It highlights the importance of attending to multiple, intersecting identities and associated social positions such as gender, race, class and sexual identity as people are at the same time members of many different social groups and have unique experiences with privilege and disadvantage because of these intersections (Rosenthal, 2016). Accordingly, the intersection of multiple overlapping marginalised identities potentially creates unique pressures on women with ASD. Adopting an intersectional lens to the multiple barriers which women with ASD face, arguably challenges the dominant medical discourses by adding to discussion in the next section as to why women are misdiagnosed, experience elevated mental health difficulties or go unrecognised.

1.6 Gender Differences

Autism has historically been reported as more prevalent in males than in females (Whitely et al., 2010). Collectively the extant literature suggests females with ASD are both under-identified and/or misdiagnosed and the true extent of both is not currently known (Kreiser & White, 2014). This section examines the apparent gender disparity in groups with autism, theoretical and biological, before continuing to discuss a suggested female phenotype.

Gender ratios are traditionally reported to vary across the spectrum with a 4:1 ratio being the most widely cited (Baron-Cohen et al., 2009; Kim et al., 2011). The female: male ratio for high functioning ASD is much lower at approximately 1:10 (Dworzynski et al., 2012) with a considerable narrowing of the gender gap in low IQ samples (Fombonne, 2009; Mattila et al., 2011). While evidence suggests an overestimation in the diagnostic gender bias (Idring et al., 2015; Kreiser & White, 2014), research in the last two decades is showing a general trend of decreasing male predominance (Matilla et al., 2011; Kim et al., 2011). The collective ratios described above have recently been challenged by findings from epidemiological studies with active case ascertainment, which reveal smaller male to female ratios in autism within general population groups. A recent meta-analysis (Loomes et al., 2017) concluded that the ratio as estimated by methodologically rigorous studies, is likely to be 3:1, with little variability across the spectrum or intellectual ability.

Such diagnostic gender bias has created a research drive to uncover a ‘female profile’ to inform the design and use of diagnostic tools (Allely, 2019). However, as previously noted, the absence of females from ASD research sampling in general means current diagnostic criteria are derived from studies using predominantly males and are thus likely to be male specific. Women who do not present with male specific ASD symptoms are being overlooked entirely, as those who receive a clinical diagnosis of ASD are more likely to present with male specific ASD symptoms (Kok et al., 2016).

Recent reviews (Rynkiewicz et al., 2016; Tillmann et al., 2018) have found that ‘gold standard’ screening and diagnostic tools such as the Autism Diagnostic Interview-Revised (ADI-R), developed with 75% male samples (Lord et al.,1994), and Autism Diagnostic Observation Schedule – 2nd Edition (ADOS-2) developed with 87% male samples (Lord et al., 2012), are less sensitive in identifying ASD in females. Such reviews raise valid concerns over the legitimacy and accuracy of using such instruments with a female population and add context to findings from predictive models, which suggest that approximately 39% more girls should be diagnosed with ASD (Barnard-Brak et al., 2019). With poor validity of test instruments, the risk of misdiagnosis is amplified. This may be particularly the case for ‘high functioning’ women with ASD who may be better at masking their autistic features, perhaps because of better self-awareness and self-referential capabilities (Kirkovski et al., 2013). Additionally, as more females with ASD have co-occurring individual disabilities they may be more likely to be diagnosed with the other disability and the ASD element may go unnoticed (Lai et al., 2011).

These concerns also raise broader questions relating to the validity of the existing female autism literature base (Happé, 2020; Hull et al., 2020) and highlights the increased need to collect qualitative first person female perspectives to minimise the circularity of male autism research. Given the inclusion criteria of a diagnosis of ASD for this thesis, the author fully acknowledges a similar criticism could be applicable to this study.

1.6.1 Theoretical conceptions of gender differences

Hypotheses designed to explain variances in how autism is expressed and experienced are grounded in both biological and cultural theories based upon, or emphasised by, the male-dominance in diagnostic rates (Sedgewick, 2017). One prominent theory is the ‘Extreme Male Brain’ theory (EMB: Baron-Cohen, 2002). The EMB hypothesis of autism posits that autism expression and risk are associated with brain ‘masculisation’ due to high levels of prenatal testosterone. High prenatal testosterone, in turn, drives altered expression of a range of sex-differential phenotypes, especially those related to empathising (empathy towards people, which is female based in typical individuals) and systemising (interest in mechanistic, rule based systems, which is male-based in typical individuals) (Crespi et al., 2019). By the extreme male brain hypothesis, autism is thus typified by low empathising and high systemising, in both females and males. Accordingly, females will cognitively present as more ‘male like’ in their interests, thinking and behaviours.

Extreme Male Brain theory has been critiqued in several literatures sociological, feminist, neuroscientific, philosophical and psychological (Maynard & Turowetz, 2019). Joel and Fine (2018) and Fine, Joel and Rippon (2019) argue that gender-based essentialisms cannot be the answer to what autism is or how its presents. In their view, EMB is based upon a fundamental misconception that female and male brains or natures exist and cite large scale review studies of brain scans and hundreds of cognitive performances which show no evidence that men and women’s brains are wired differently, negating a male-female continuum. Instead, what is more typical of both sexes is a ‘mosaic’ (Joel & Fine, 2018) of feminine and masculine characteristics.

A related but separate critique of EMB theory involves the assumption that people with a diagnosis of autism have a defective capacity for empathy. This view is strongly contested by the autism community (Pentzell, 2013) and others, who distinguish between different kinds of empathy, cognitive and empathic (Lookwood et al., 2017) and question how to conceptualise empathy and interpersonal understanding as distinct constructs (Bloom, 2017). A recent response from Baron Cohen and colleagues (Greenberg et al., 2018) suggest that the lower scores of people with autism on empathy measures, such as the Empathy Quotient (EQ), likely represents difficulties with cognitive empathy or ToM rather than all components of empathy. Additionally, they stress EMB theory deals with averages and there is considerable variance in empathic ability in the autistic population.

Jack (2011; 2012) suggests hyper-systemising the brain of the autistic person deemphasises not only their disabilities but also their fundamental humanity, leading to the development of several stereotypes of autism built on the notion of the male ‘geek’, with interests in technical objects or machines, who lacks understanding of emotions and non-verbal communication. Additionally, EMB theory focuses on a binary model of sex/gender which forces individuals into two categories rather than accounting for a wider more fluid understanding of sex and gender (Jack, 2011). Some autistic women may find traditional categories inapplicable to their experience, with greater gender variance being reported in women with ASD than both their neurotypical peers and men with ASD (Cooper et al., 2018; Dewinter, 2017a).

1.6.2 A ‘female phenotype’

Interest is steadily emerging amongst some researchers in how autism may present differently between the sexes and this is reflected in the increasing numbers of studies focusing on girls and women (Mandy & Lai, 2017). Concerns have been expressed in the adult autism community in particular regarding the validity of such a construct (National Autistic Society, Adult Forum, 2020). Research is largely positivist in focus typified in the 2017 special edition of the academic journal Autism, entitled ‘Towards sex and gender informed autism research’ in which eight of ten papers focused on possible gender differences in behavioural, cognitive or neuroanatomical patterns within child and adult samples.

Literature examining gender differences in core ASD symptoms, as well as co-occurring symptoms, has been inconsistent thus far and reflects other areas of autism research with the majority focusing on children and adolescents (Schuck et al., 2019). To illustrate, some studies report more internalising symptoms in diagnosed females and more externalising symptoms in males (Mandy et al., 2012) but others reported no clear differences (Nasca, et al., 2019; Woodhouse et al., 2016). Research on gender differences in adults with ASD have resulted in similarly inconsistent findings. Using the ADIR, Wilson et al. (2016) found that high functioning adults did not differ by gender in socio-communicative symptoms, but males had more Restricted and Repetitive Behaviours (RRBS) than females and no sex differences were reported on the ADOS. Conversely, Lai et al. (2011) found females showed fewer socio-communicative deficits than males with ASD in clinician observations, though self-reported more autistic traits on the Autism Questionnaire (AQ). Sedgewick (2017) suggests differences in the type of measurement used (e.g. clinician observation, parent report or self-report) may account for different manifestations of ASD.

Research focused on the impact of sociocultural factors on biogenetics has enhanced understanding of difference in occurrence rates and symptom expression in females. Hiller et al. (2014) noted that the special interests females with ASD adopt, are similar to the interests of their neurotypical peers allowing the intensity, exclusivity and functional impact of these interests to be overlooked. The net effect is delayed/missed diagnosis due to lower measurements of RRBs on 'gold standard' testing instruments. Eye tracking studies suggest autistic girls show more social attention than autistic boys, close to typically developing boys and approaching typically developing girls (Harrop et al., 2019). Autistic girls show more social motivation in friendship than autistic boys (Sedgewick et al., 2019) and seem more able to engage in reciprocal conversation using higher linguistic abilities than boys which Parish-Morris et al. 2017 link to gender socialisation processes.

The impact of recognition biases because of gender stereotyping is emerging. Geelhand et al. (2019) found parents more likely to report autism as a concern for boys than girls. Similarly, teachers may not notice difficulties experienced by girls (Mandy et al., 2012) or are less likely to intervene when externalising behaviours and social skills difficulties are observed in girls (Hiller et al., 2014). Clinical expectation and gender socialised interpretation of behaviour may also contribute to underdiagnoses of ASD in females (Kreiser & White, 2014). A recent systematic review on psychiatric diagnoses in autism shows studies with more females tend to report more co-occurring depressive disorders (Lai et al., 2019). Hypotheses regarding an 'adolescent onset' of autism in individuals with mild autistic characteristics, particularly females, is also gaining traction (Geelhand et al., 2019; Jamison, et al., 2017; Lai et al., 2015; Mandy et al., 2018).

Finally, 'camouflaging' may be common in autistic females and is frequently cited as explanation for less salient symptomology in this population (Attwood, 2006; Hull et al., 2019; Lai et al., 2017; Schuck et al., 2019). Qualitatively, males and females with ASD report camouflage as a way to appear ‘normal’, where they consciously ‘mask’ the external diagnostic features of autism (Hull et al., 2017). Attempts to operationalise camouflage behaviours in both males and females with ASD showed imitation, gestures and conversation skills allowed both sexes to mask underlying difficulties associated with ASD, with women engaging in higher rates of this behaviour (Lai et al., 2017).

While camouflage behaviours may be thought of as a coping mechanism for both groups the use of camouflage behaviours has been linked to increased self-reported stress and anxiety in comparison to those who do not camouflage (Hull et al., 2019). Using Ragins’ (2008) Disconnect Theory, Cage and Whitman (2019) identified two contexts for camouflage (formal and interpersonal) and related usage to exhaustion, anxiety and depression.

Ragin’s theory (as cited in Cage and Whitman, p.19) suggests that we use different contexts to inform the way we act. The energy we expend in concealing parts of who we are in different environments can cause identity fragmentation, stress and depression. For autistic individuals this may mean experiencing a type of ‘camouflage disconnect’ which reduces wellbeing. Cage and Whitman linked women’s greater use of camouflage for ‘conventional reasons’ (to get by in formal settings like work or education) than ‘relational reasons’ (to get by in relationships with others) when compared to men, to the increased barriers women with autism experience as a result of the male dominated narrative around autism. It may be that women need to camouflage more than men to ‘fit in’ in these settings. This observation is further supported by qualitative findings whereby autistic females and their mothers indicate that women with ASD feel more pressure than men to ‘mask’ their ASD because of increased expectancy of female sociability (Milner et al., 2019).

2.3 The voices of autistic women

Despite much larger numbers of diagnosed autistic males, a higher percentage of women (56%, Chamack, 2008, as cited in Webster & Garvis, 2017) publish their reflections of their life experiences which serves to simultaneously highlight a drive to be active agents in sharing their life stories and emphasises the importance of hearing autistic women’s perspectives to inform our understanding of the elements that most impact their lives. ‘Not fitting in’ appears to be a common narrative coming from the autobiographical literature which highlights the difficulties women with ASD face if they fail to fit a gender stereotype. Early reviews of female autistic life writings (Davidson, 2007, Davidson & Smith, 2009) suggest women’s accounts articulate the negative impact of other people’s gendered perceptions of them on their sense of self, wellbeing and confidence in navigating social situations. Davidson (2007) argues the barometer of normalcy against which these women compare themselves is fundamentally skewed. She posits that these women’s perceived unusual behaviours are quite appropriate given the descriptions of their lives, further highlighting the need to hear women’s lived experiences from their perspective.

More recent reviews (Van Goidsenhoven, 2017) suggest such themes are contextualised in shifting narratives involving: the quest for diagnosis, self-identification with ASD, communicating and concealing ASD, counter-medical urge and sociocultural disability perspectives. While it is beyond the scope of this thesis to review individual biographies, the author is mindful of how they have become a distinct literary genre (‘autie-biographies’, Van Goidsenhoven, 2017) with inherent strengths and shortcomings. Autistic autobiographer, Heather Stone Wodis (2018), recently commented on the need to interpret these works as part of the broader cannon of disability narratives. She cautions readers to be mindful of the capacity of these works to reaffirm negative stereotypes and negative constructions of disability and autism and/or reject traditional scripts of disability and transcend the narratives of overcoming. Similarly, Kanfiszer et al., (2017), questioned the representativeness of these narratives and suggest that the very nature of these autobiographical works is indicative of a particular perspective; typically a woman with a higher intellect with access to significant resources and support that allow her story to be told.

Nonetheless, the contribution of these works lies in their potential to form a conception of autism and women that extends beyond the ways in which the condition is labelled in medical and other institutional contexts (Van Goidsenhoven, 2017). Given the relative neglect of women in the literature, these works play a critical role in shaping others understanding of autism and offer a legitimate avenue for women to demythologise autism stereotypes. In personal correspondence with Barnbaum in 2007, autistic biographer Wendy Lawson noted that her writing ‘allows [her] to shed light on much of [her] autistic world. This is my passion. I love teaching and helping others to ‘see’ something that, perhaps, they had been blind to before’ (Barnbaum, 2008, p. 68). Chapter Two will demonstrate how researchers have started using qualitative methodologies to ‘shed light’ on these gaps in the adult female autism literature.

Chapter 2: First Person Perspective Literature

2.1 Chapter overview

This chapter will review existing qualitative literature exploring the lived experiences of adult women with ASD from a first person perspective. The overriding aim of this state -of -the -art review is to provide an examination of recent literature on the life experiences of women with ASD from their perspective, a much neglected area of research.

2.2 The literature search

In line with state-of-the-art literature review writing guidance (University of Southern Denmark, 2020), a systematic approach to the literature search was adopted. A search across several databases (PsychINFO, PubMED/Medline, CINHAL Plus, EMBASE, ERIC and Academic Search Complete) produced 5 published papers which explored a first person perspective of the lived experiences of women on the autism spectrum using a qualitative methodology (see Appendix A for search strategy, terms and inclusion/exclusion criteria). An additional three studies were identified through exploration of the grey literature. One study exploring the childbearing experiences of women with Asperger Syndrome was published (Gardner et al., 2016). The remaining two were redacted theses from educational and clinical doctorate studies and had been sourced as published studies through original searches of the named databases (Bargiela, 2016; Kanfiszer, 2015).

Published and grey literature is combined in discussion of study characteristics which are detailed in Table 1. The studies represent the lived experiences of women with autism from the Western world (America, UK, Australia and Canada). The vast majority focused upon the experiences of women at the high functioning end of the autism spectrum with diagnoses of ‘high-functioning autism’ or Asperger’s syndrome listed in their inclusion criteria. Participant age ranges spanned almost five decades (18-69 years) and the vast majority of participants reported co-morbid mental health difficulties. A mixture of data collection methods were used; questionnaire, focus group and interview.

Table 1

Characteristics of reviewed literature

Author(s)/Year, Country	Title	Sample Characteristics	Method	Analysis	Themes/subthemes
Bargiela, Steward and Mandy (2016), UK	The experience of late-diagnosed women with Autism Spectrum Conditions; An investigation of the female autism phenotype	14 women with a diagnosis of ASD, without an intellectual disability, 18-35 years	Interview	Framework analysis	Missed/inaccurate diagnosis Camouflage Victimisation Assertiveness Gender stereotypes & identity formation Mental Health
Kanfiszer, Davies and Collins (2017), UK	'I was just so different': The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships	7 women with a diagnosis of ASD, varied intellectual ability, 20-59 years	Interview	Narrative inquiry	Gender identity Social relationships Diagnosis Absence of camouflage Mental Health
Baldwin and Costley (2016), Australia	The experiences and needs of female adults with high functioning autism spectrum disorder	N =313, 82 were women with a diagnosis of ASD without an intellectual disability,18-64 years	Questionnaire	Mixed methods – thematic analysis applied to 'open comment' data	Delayed Diagnosis Executive functioning Social Understanding Support needs: Health, Education, Employment
Tint and Weiss (2017), Canada	A qualitative study of the service experience of women with autism spectrum disorder	20 women with a diagnosis of ASD, without an intellectual disability, 19-69 years	Focus Groups	Thematic analysis	Dismissed needs Camouflage Service needs (Mis)Communication with service providers Suitability of services
Gardner, Suplee, Bloch and Lecks, (2016), America	Exploratory study of Childbearing Experiences of women with Asperger Syndrome	8 women with a diagnosis of ASD, 27-52 years	Questionnaire	Thematic analysis of secondary data	Sensory Processing Control Mother stereotype
Webster and Garvis, (2017), Australia	The importance of critical life moments: An explorative study of successful women with autism spectrum disorder	10 women with a diagnosis of Asperger Syndrome, 28-55 years	Interview	Narrative themed analysis	Agency Advocacy Identity formation Mentoring

Data was examined using thematic analysis in the majority of studies. Where appropriate, comparisons will be drawn between studies.

2.3 Review of qualitative studies

The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype (Bargiela, Steward & Mandy, 2016)

This study explored the female autism phenotype and its impact on 14 women with ASD without a learning disability. It identified a number of themes relating to the female phenotype including being misunderstood, camouflaging needs and identity formation as a woman with autism.

The majority of these women (8 out of 14) described the detrimental impact of a delayed diagnosis to their sense of wellbeing and various opportunities in life, ‘if I had known, and if people had helped me from earlier on, then life would have been a whole lot easier’(P07). Pre-diagnosis, they recalled being misunderstood, with their autistic difficulties often labelled in very negative terms by peers and adults. These same women experienced the eventual confirmation of their diagnosis as a positive. Some stated that it fostered a sense of belonging in a group of like-minded people and that it promoted a more positive sense of self, ‘something that I really appreciate about having the diagnosis is actually being in this club now where people talk about their experiences and having so many echoes of my own experience’(P03).

While the experience of receiving the diagnosis of ASD was reassuring for many of these women, the difficulties they faced up until that point are significant. Bargiela and colleagues found nine out of the 14 participants were victims of sexual abuse, often within the context of relationships or what they thought were friendships. The comment ‘We don’t see danger and we can’t’ (P07) underlies participants’ thinking as to why the abuse occurred. Women’s accounts of the abuse highlighted: an unconscious mimicry of the flirtatious behaviours of others (camouflage technique), the struggle to understand the intentions of others towards them, the lack of feedback of neurotypical peers regarding what ‘normal behaviour’ in relationships should be, the impact of previous social rejection on the desire to be accepted, not knowing how to say ‘no’ to unknown men and not having ‘no’ as a legitimate option within their social understanding. Despite the accounts of abuse, many of these women talked about learning from these experiences and described an increase in their assertiveness over time which allowed them increased control in uncomfortable situations.

Participants’ views of gendered stereotypical roles ranged from outright rejection to a loss of identity when they attempted to fulfil these roles. Women reported ‘…not being me’ when trying to play ‘the wife’, ‘or girlfriend’ with some feeling equally ‘unauthentic’ in their friendships with female peers, whom they commonly perceived as judgemental and friendships were less enjoyable as a result. They detailed deliberate efforts to ‘put on a mask’ in their daily lives to develop neurotypical personas through observation, trial and error, reading novels, psychology books and imitating fictional characters. The pressure of wearing the mask led some participants to develop a preference for male friends. Authors surmised that this was not due to any biological difference but to society allowing men to be more straightforward and communicating in a way that was easier for participants to interpret, ‘You can take them at face value. They kind of say things straight’. While none of the women in this study reported being at odds with their birth gender, authors suggest that the above commentary indicates some participants experienced a conflict between a feminine and an autistic identity. They argue this conflict may influence reported elevated rates of gender dysphoria and non-binary gender amongst natal females with ASD, about which very little is known.

One of the comparative strengths of this study is the recognition paid to the wide degree of heterogeneity between and within individuals, specifically women, on the autism spectrum. Rather than compare these women's stories with narratives of females without ASD or males with ASD, age, cognitive ability and age of diagnosis limits were set to limit group heterogeneity allowing authors to focus on understanding the meaning of individual and subgroup differences of higher functioning, late-diagnosed women on the spectrum. In recruiting women who received their diagnosis within ten years of the study, they recognised the likely variability of these women's lives when compared to those who received their diagnosis in childhood where timely identification and supports may have been available. Similarly, in limiting the age rage to 18-35 years, authors recognised the implications of historic changes in diagnostic criteria which would have meant that older women with ASD would have been more severely impacted by their autism in areas such as intellectual disability or communication difficulties.

Unlike other studies yet to be discussed, authors also used a number of formal assessments to ensure sample homogeneity. While they did not retrieve clinical records to double check the veracity of self-reported diagnoses, the Autism Quotient-10 (AQ-10) (Alison et al., 2012) was used to respectively verify autistic symptomology and severity. The Weschler Test of Adult Reading (WTAR: Wechsler, 2001) was used to estimate verbal cognitive ability. Both measures have been found to be reliable and valid measures, (Booth et al., 2013; Van der Linde & Bright, 2018). Additionally, women with ASD were involved in interview design and authors detailed a number of credibility checks such as the consensus approach used to develop themes and subthemes and provided participants with the coding framework for their feedback to ensure it accurately reflected their experiences.

The authors stated that, in using these formal measures, they would be better able to 'situate' participants and give the reader a sense of who the participants were, to inform thinking about transferability of findings. Using well established measures of adult mental health the General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1998) and the

Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), researchers identified that the majority of participants were experiencing significant mental health difficulties. Of note, three participants scored in the 'distressed range' and a further two in the 'severe range' on the GHQ-12, indicating severe psychological difficulties at the time of the interviews. Three participants scored in the clinical range for depression and all but one scored in the clinical range for anxiety. Authors linked internalising difficulties to two main risk factors, the first one associated with non-detection of ASD in women particularly in childhood, where if not disruptive, girls are not referred for clinical help and, secondly, to diagnostic overshadowing of an underlying ASD diagnosis. The current thesis recognises that the measures used to 'situate the sample' in terms of their mental health are self-report screeners, not clinical diagnoses and are validated with an ASD population without intellectual disability (Mayhew et al., 2020). However, the severity of scores reported by participants suggests that discussion could have been enhanced by the authors' reflection on the potential impact of such conditions on individuals' relationships and behaviours as they may have complicated the extent to which autism was the focus of participant stories and thus in some way may have confounded findings.

'I was just so different': The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships (Kanfiszer, Davies & Collins, 2017).

Kanfiszer and colleagues carried out a narrative study examining seven women's stories about their lives. They identified two main themes, gender identity and social relationships.

All of the women regardless of whether or not they had an intellectual disability discussed having difficulties with their gender identity. Participants with lower intellectual ability focused on the physiological representations of being a woman and viewed the time involved in attending to their physical care needs involving menstruation as burdensome and anxiety provoking. For one participant, her physiological discomfort was so intense that it seemed to impact her sense of self, ‘I personally don’t think I am in the right body… I just don’t like the fact that I’m female’. In contrast, women with higher intellectual ability reported struggling more with societal pressure to adhere to gender stereotypes, a difference authors linked to cognitive maturity. Similarly to the women in the previous study, this was particularly clear in their discussions of trying to meet the gendered expectations of others to be both maternal and feminine, ‘It became apparent I wasn’t really a girly girl… [I] didn’t get on with the other girls’.

Like the women in Bargiela’s study, the presence of an ASD diagnosis seemed to provide a lens with which the women could make sense of these experiences and having the diagnosis also provided a frame of reference to enable them to develop specific skills, such as enabling the identification of future triggers of stress (such as parenting), ‘I don’t think I could have coped with a child, I would never have been able to organise it or cope with the noise or sleep disturbance, I could have probably been ill’. Authors posit that the fear of becoming unwell and not coping acted as a deterrent to experiencing motherhood and seemed to override the cultural expectation to have children.

As in Bargiela’s study, participants’ difficulties in interpreting social cues in relationships and friendships were suggested as the context that led to experiences of bullying, isolation and for some, sexual assault, across the life span. Some participants linked their autistic traits to a lack of ‘social flexibility’, making ‘meeting new people’ or managing ‘a change in the environment’ a real barrier to social engagement. Participants also linked their ASD traits to ‘conversation going dead’ and others not wanting to be in their company; ‘people don’t want to know me’. As noted by Sedgewick (2017), while the women in

Bargelia’s study also reported struggling to make and maintain friendships and relationships, this was not necessarily because others rejected them. Instead, it was a consequence of how they functioned within those relationships.

In contrast to participants in Bargelia’s study, these women do not reference ‘camouflage’ as a mask to their social needs. Instead these women were labelled as ‘odd’ by others from a young age, by professionals and peers alike. For one participant, this ‘oddness’ was directly linked to her very ‘untypical’ special interest in windmills. While it served a central purpose in relation to her identity and feelings of being secure, it also acted as the barrier to relationships and caused her painful feelings of difference, ‘I remember that, ‘cos of this…loneliness, actually having suicidal thoughts at 7’.

A key strength in the Kanfiszer et al. (2017) study is the ethical structure applied to the methodology to ensure less privileged women and those with intellectual limitations could participate in the research. To ensure meaningful inclusion of these ‘unheard voices’ in the research, authors sought the advice of a focus group of women with ASD and intellectual disability and a specialist Speech and Language therapist to support communications. Flexibility regarding participant choice of setting for interview was provided, being accompanied and the use of 3D objects to encourage recall were welcomed. Details regarding risk management were provided. Furthermore, the completion of respondent validation by each participant ensured an ethical underpinning.

A separate strength to the study is the author’s questioning of the previously referenced female autism phenotype. Despite the infancy in evidence to support this phenomenon (Allely, 2019), the capacity to ‘camouflage’ need is identified as a core feature of the female ASD presentation (e.g. Kenyon, 2014). In contrast to the vast majority of female participants in the six studies reviewed here, women in Kanfiszer’s study did not report masking their needs in either childhood or adulthood. While higher intellectual ability has been associated with greater use of camouflage (Attwood, 2006; Sedgewick, 2017), this does not explain the lack of ‘masking’ by some women in this study, as over half did not present with an intellectual disability.

Findings were not contextualised within participant characteristics and need to be referenced as a potential contributing factor to differences within Bargelia’s research. Authors did not provide the age of ASD diagnosis for participants, nor did they provide the diagnostic timeline of their mental health diagnoses. This information was available to researchers and would have created an important time line in terms of history of supports. As some respondents stated their ‘oddness’ was recognised from a young age, it may be that their ‘oddness’ led to mental health diagnoses in childhood and subsequent involvement in specialist mental health services from a young age. In this scenario, the mental health diagnosis would become the primary lens through which both medical professionals and the women themselves viewed their difficulties, perhaps reducing awareness of conscious masking behaviours.

Additionally, the majority of participants in Bargelia’s study were ‘high functioning’ in that they had above average IQ, were employed or in full time education. In contrast, about half the women in this research had co-occurring intellectual disability and were living in supported or secure accommodation or living with parents. As previously mentioned, age limits were also set in Bargelia’s study to limit group heterogeneity. The age range in Kanfiszer’s study was 20-59, and although all had received their diagnosis in adulthood, the age of their diagnosis varied greatly. The life experience and needs of a participant being diagnosed in late teens would, one could reasonably assume, be quite different to those of a 56 year old participant. Collectively this means that the accounts of women included in this study were to some degree representative of the range of experiences of women on the autism spectrum, however, it also means they are likely to have quite different life experiences to younger, more cognitively able women with ASD.

‘The experience and needs of female adults with high functioning autism spectrum disorder’ (Baldwin & Costley, 2016).

Baldwin and Costley (2016) used an online survey to capture responses from 313 adults as part of a large scale study entitled ‘We Belong’ which examined what life is like as an Australian adult, either male or female, with autism spectrum disorder without an intellectual disability in the 21st century. A mix of statistical, descriptive and thematic analysis methods were applied to different aspects of the data. This study was included in this review due to the relatively large female sample size (n=82) and the study’s disaggregation of male and female data. This review examines the self-report data from the female participants of this study in relation to their health, education, employment and social and community activities.

Commentary on ASD symptomatology indicated two main themes: challenges with social understanding and challenges with executive functioning, which provided the backdrop to contextualise the difficulties these women experienced in their education, social and work lives. Close to half of participants were undertaking some form of education or study at the time of the survey, indicating a strong interest in, and aptitude for learning. Nonetheless, non-directed commentary from participants indicated that their educational experiences (primary, secondary and third level) were characterised by social isolation, failure to meet learning support criteria, harassment and bullying, which resulted in years of struggle particularly because of ongoing mental health needs.

Participants struggled with the executive functioning aspects of formal learning. Experiences of learning support were identified by a third of participants as one of the best things about their school experience, whether it was formal as in support classes or informal as having an understanding teacher. Conversely, almost half of respondents cited a lack of learning support as one of the worst things about their educational experience, which related to the dissatisfaction that participants' experienced with the inconsistency in support delivery across ages and settings, 'There were very clear signs that I needed significant support throughout education, but I got none because my marks were very good'. As observed by Baldwin and Costley, the absence of intellectual disability did not equate to an absence of learning support needs. The reverse of the situation was true for some participants who believed that their skills went unrecognised and they were not intellectually stimulated, 'I remember being accused of cheating when handing up complete, original and pristine projects'.

Half of participants explicitly named bullying and social isolation (37%) as particularly common experiences in the secondary school years and peer relationships were identified as one of three worst things about their time in education (leading authors to suggest a higher rate of perceived bullying amongst females with ASD than more broadly amongst Australian school students). Social aspects of work also presented a significant challenge for these women, with two-thirds reporting social interaction to be one of the three worst things about their employment experience. Daily communications, both formal, such as managing group work or client-facing tasks, and informal interactions, such as exchanging pleasantries with colleagues, could be equally overwhelming experiences. 'I stress about missing body language cues from clients and staff and making a stuff up'. Bullying was less prevalent in the work place when compared to education settings but was mentioned by almost a quarter of participants as one of the top three worst things about their work lives. 'The boss/owner told me nobody else would hire me because I have Aspergers'.

A recurrent theme in commentary about work lives in general was a perceived mismatch between these women's qualifications and skills and the demands of their current role. This is unsurprising given that over half the participants held qualifications that exceeded the skill requirements of their current job, an 'over education' rate that greatly exceeds the corresponding figure of 24% calculated for employed Australian women as a whole (Black, 2013), as cited in Baldwin & Costley, 2016). Over half the participants reported being 'pinned back' from fulfilling their career potential. Similar to their time in education, they perceived that their skills and abilities were frequently under recognised or devalued in the workplace. 'One of the worst things was having to follow rules when I came up with ways that got the job done quicker'. Executive functioning difficulties underpinned expressed challenges in the workplace and manifested in various ways: difficulties in task comprehension and following instruction as well as cognitive overload in some circumstances. 'I experience cognitive shut down and often meltdowns as the days goes on and just have to keep working'.

While a third of participants noted supports at work such as adjustments to the work environment and work tasks, understanding colleagues and links with external agencies, a similar number of women would like additional assistance. Flexibility in work tasks and communication skills were highlighted as common areas of need. The vast majority of women wanted part-time work but sourcing this was difficult: 'It's hard to find jobs that let me work few enough hours so that I can manage'. Responses indicate that despite the challenges and negative experiences in their work lives, many women remained positive and ambitious about their future plans for further study and career changes. Creative interests such as writing and visual and performance arts were mentioned by some women who made it clear that they needed support from others to achieve these life/career goals. 'I plan to run my own business from home, but even joining an agency wasn't helpful, there aren't enough specialised services to provide support'.

As in the previous studies discussed, women in this study commented that having timely confirmation of a diagnosis of ASD would have allowed them access to appropriate supports which would have eased their day-to-day lives. 'I have had lifelong problems with eating (due to sensory issues) misdiagnosed and was therefore wrongly treated for 25 years prior to ASD diagnosis'. While thematic analysis of commentary on participant mental health was not provided, as in previous studies, mental health issues were identified as a significant concern for the participants. Descriptive statistics indicated the vast majority of women reported ongoing feelings of worry and stress that seriously impacted their everyday functioning. In addition to this, three quarters of participants reported needing ongoing professional help to support their mental health and wellbeing.

A range of unsolicited comments provided by participants suggested a common belief that the support needs of women with high functioning ASD in particular were overlooked or dismissed, because they do not fit the conventional social constructions of disability and are belied by a normal or above average level of intelligence. 'It seems that if you have a job and live alone, no one thinks you might still need help until you reach rock bottom'.

As illustrated above, the strength of Baldwin and Costley's research lies in its investigation of a broad range of lived experiences. In an attempt to capture the complexity of such breath of experience, the authors applied a hybrid structure to their survey applying a mixture of multiple choice and a series of open-ended questions to give respondents the room to reflect upon their personal experiences. A methodological assumption underlying triangulation of findings from both qualitative and quantitative data sets would be to increase the reader's confidence in the study's outcomes. However, the study's distinct lack of detail concerning the data analysis process for both sets of data makes this difficult. Of particular concern in the context of the present review is the lack of detail concerning the derivation of themes and subthemes from the referenced coding frame. What is equally absent is information regarding the credibility checks involved in the thematic analysis process.

One possible explanation for the omission of such detail lies in the author's statement that open comments used in the study 'are intended to be illustrative rather than 'scientific', and intended to augment the quantitative data presented in the report' (p.5). Considering the title of the study, using participants' commentary to enhance the 'optics' of quantitative data seems contradictory and somewhat tokenistic. Without a 'scientific' integration of both sets of data, the reader's opportunity to explore the context and situational complexities of participants' lived experiences is diminished.

The lack of information provided regarding the analysis process feeds into a second concern which equally impacts the reader's confidence in the study findings and involves the overrepresentation of participants' negative commentary throughout the study. While the author of this review appreciates detailing the needs of these women was a main objective of the study, implicit in the use of the word 'experiences' is that the breath of experiences both positive and negative will be represented. Of the 54 quotes used in the study, only three could be interpreted as indicative of a positive response. This is despite the fact that open comments were typically structured within a 'three best things and three worst things' format in relation to different life experiences. While the researcher acknowledges that the sample were self-selecting and participants may not have experienced and/or wanted to detail their positive experiences, the question structure makes this difficult to envisage. Additionally details on participant non-responses were not reported.

As 58% of the participants were diagnosed after the age of 18 with age of diagnosis ranging from 2-63, the overwhelming negative commentary may be reflective of a lack of timely access to appropriate supports. However, 42% of the sample were diagnosed in childhood which, it is reasonable to assume, would result in more positive life experiences. While authors noted that age of diagnosis made no difference to perceptions of support for learning and behaviour, similar analysis was not reported for any other life experience, either negative or positive, making it difficult to draw any conclusions in relation to age of diagnosis and life outcomes. In addition to this, no commentary outside of a desire for more help was provided in relation to participant mental health despite the fact that 85% self-reported a mental health condition. The poor ‘audit trail’ and resulting apparent imbalance in quotation usage limits interpretation. In not detailing ‘success stories’, the authors prevent dissemination of possible indicators of good professional practice in the health, vocational and educational lives of these women.

A qualitative study of the service experiences of women with autism spectrum disorder (Tint & Weiss, 2018).

Using focus groups, 20 adult women with ASD discussed diverse, unmet service needs and barriers to supports in the adult service sector. Dominant themes underpinning their experiences involved: masking service need, (mis)communication with services and the appropriateness of available services.

Similar to the previous study, women’s service needs were either dismissed or minimised because of service gatekeeper preconceptions of ASD where ‘not looking the part’ meant participants did not fit the conventional social construction of disability, making them ineligible to access supports. Participants linked the professional disregard of their service needs to their masking behaviours. ‘....turning on [their] normal’ had a deleterious short-term and long-term impact on their mental health, causing feelings of exhaustion, depression and anxiety to the point of ‘breakdown’. The ostensibly unobservable precursors to these ‘breakdowns’ were perceived to further perplex service providers. Repeated denial of their support needs led to feelings of shame amongst several women, who internalised the belief they ‘should be able to handle it like everyone else’, which in turn stopped them from accessing supports to which they were legitimately entitled.

‘Not being heard’ or a miscommunication when interacting with service providers was a common experience. Being ‘rushed’ by medical practitioners, in particular, to the point that processing and clarifying medical information was not possible, was reported by the majority of participants. Participants also described a ‘neurotypical obsession with pain’, which dominated medical assessment and treatment, but which was frequently secondary to the distress they were experiencing because of being sensorily overwhelmed in the medical environment. A combination of a high pain threshold and blunted physical presentation translated to perceptions of lower priority of care. One participant described experiencing extreme pain and thinking that she would ‘die’, but because she was not ‘screaming’ or ‘crying’, staff were less responsive. Relatedly, participants most valued others’ willingness ‘to understand’ their needs. Positive service communications typically involved experienced practitioners.

Access, engagement and suitability of services posed separate, but related, challenges to participants. Service exclusionary criteria such as age posed particular difficulties for women diagnosed in adulthood, who found themselves above cut-off points for funding for various supports. Diagnoses such as intellectual disability ruled out residential supports for participants who lived with parents (50%) ‘... but I would also really like to live on my own with my own space’. As detailed by participants in the previous study, executive functioning difficulties made negotiation of service applications (which were frequently multiple due to multiple discreet needs) and associated paperwork a significant barrier to accessing support, ‘... just trying to keep track of the bazillion people who aren’t talking to each other... I have given up at times just because I’ve had to conserve energy for life’.

Insensitivity and inflexibility regarding service delivery described the majority of participants' experiences when in services, medical, educational and vocational. A mismatch between need and support characterised therapeutic experiences for many '...it was always just do the exercises ...but I'm different and .....don't really need to the exercise'. Reflective of Baldwin and Costley's findings, women in this study reported variability in educational supports and identified a lack of personalised support, particularly at postgraduate level. In a related vein, these participants were identified as being 'overqualified' for vocational and employment programmes. Maintaining steady employment was a significant challenge which women related to the unpredictable nature of their mental health. Participants reported that work place support did not focus on on-site maintenance support.

In the absence of effective formal supports, women in this study utilised online media fora for support. Like women in Bargiela's study, participants highlighted the importance of receiving support from other women with ASD and the convenience and accessibility it offers them '...it's international. If I'm having a crisis at 2 Am., there's somebody online I can talk to who gets it'.

While some similarities have been drawn to previous research findings (mainly to aspects of Baldwin and Costley's study), the strength of the Tint and Weiss study lies in its unique focus on the service experiences of women with ASD. To the author's knowledge, no other study has specifically addressed how women with autism experience the myriad services they access or attempt to access across the lifespan, highlighting the important contribution the Tint and Weiss study makes to the research.

This contribution is however not without its limitations. In their efforts to support meaningful participation in the research, authors note their rationale for using focus groups to gather data. They state that focus groups are used extensively in health service research to examine individuals' service experiences and that they are the preferred method of research participation among individuals with ASD. The authors quote the Hass' et al. (2016) study of participatory research within the ASD community to support this claim. Further reading of this particular study indicates their assertion may be a misreading of Hass et al., (2016) conclusions, as equal percentages of adults with ASD and intellectual disability preferred face to face interviews and online surveys while a much higher percentage (76.8%) of individuals with HFA autism preferred face to face interviews, with focus groups being their third least favourite. Additionally, the Hass et al., study data was not disaggregated by gender and included non-autistic participants suggesting that generalisations regarding research methodology preferences of females with ASD may not be appropriate. Furthermore, details of facilitator numbers were not provided. As the focus group sizes ranged from 2 – 6 participants, it may be that in some instances facilitator numbers exceeded participants which may have impacted participant responses. Relatedly, the 'snowballing' recruitment process used by researchers was not described in any detail and so any attempts to encourage diversity within this participant group are not known.

Collectively the above suggests that generalisation of findings is a concern. Tint and Weiss report a lack of generalisation as a significant limitation of their research but not for the identified reasons, instead quoting broader participant characteristics such as race, lack of intellectual disability and education as contributing factors. The author of this review does not view generalisation as the end goal of qualitative research but, instead, to develop an in-depth and contextualised exploration of a central phenomenon (Creswell & Creswell, 2017).

With this in mind, this author asserts that in stating 'natal females' in the study's inclusion criteria, Tint and Weiss (2017) potentially lost an opportunity to capture first-hand accounts of a further marginalised group within the female autistic population. Quantitative research findings suggest that there could be higher rates of gender dysphoria, and transsexuality, in autistic women than in neurotypical controls (Pohl et al.,2014), which is supported by Butler et al. (2018) who found that 35% of children and adolescents assessed at a UK gender dysphoria clinic present with moderate to severe autistic traits (versus an estimated 1% prevalence of ASD in the general population). While debate exists regarding an ASD and gender dysphoria link (Nordahl-Hansen et al., 2019), capturing the discrete service needs of individuals who question their gender identity would have enhanced the study findings and uncovered this subgroup's potentially unique experiences, with a view, if necessary, to providing direction in relation to appropriate supports.

Exploratory study of childbearing experiences of women with Asperger Syndrome (Gardner, Bloch, Suplee & Lecks, 2016)

Researchers conducted a secondary analysis of qualitative data provided by eight women with Asperger syndrome which was gathered during the process of developing a questionnaire to assess childbearing experiences of women with Asperger syndrome. Dominant themes across stages of pregnancy (prenatal, intrapartum and postpartum) involved sensory processing, the need for control and motherhood.

While childbearing represents a significant life event, physiologically, emotionally and socially for all mothers, authors Gardner et al.,(2016) argue that ASD symptomology such as sensory modulation and social communication difficulties, combined with possible comorbid mental health diagnoses means women with Asperger's face particular challenges during this time.

As in the previous study, the majority of women found the medical environments they attended for care as sensorily overwhelming. Not unexpectedly, pre-existing sensory sensitivities were heightened during hospital and clinic visits, and when combined with new pregnancy-induced sensory challenges, caused feelings of general 'disorientation'. Participants reported noises from equipment, crowds, heat, touch during physical examination, and lights to be particularly heightened. Exposure to this environment had a deleterious cumulative effect on the majority of participants, even after a relatively short amount of time. One participant hospitalised three days prior to delivery stated ‘I was in complete overload, in a meltdown, terrified, I have lingering PTSD’. Despite the reported sensory-related difficulties, the vast majority of women breastfed their infants which authors related to women’s knowledge of its benefits to the baby. Authors suggest that participants’ information on breastfeeding overrode the physical discomfort they experienced when feeding their babies.

A serious secondary effect of sensory overload is the negative impact on communication which left participants feeling particularly vulnerable. Not unlike the experiences described in the Tint and Weiss study, sensory discomfort made ‘it difficult to figure out what the person in front of me is saying’ and made discrimination of voices in consultations involving more than one person ‘very difficult’. Communication needs were intertwined with a second theme of ‘Needing to have control’, which was particularly apparent during the birth itself. Participants linked an absence of a birth plan to feelings of disempowerment ‘…a birth plan would have been helpful for self-advocacy, I wasn’t able to convey how much discomfort I was in’.

The theme ‘Motherhood on my own terms’ encapsulates a number of conflicts, which participants experienced internally and externally regarding their ability to parent. Several participants were frustrated by others’ expectations of how new mothers should behave ‘I didn’t love being a mother…for spectrum women it’s a nightmare. You are made to feel ashamed’. Those who sit outside of the boundaries of what ‘new motherhood’ looks like may incur unwanted interventions and being seen as at risk, ‘…it’s not that we don’t want to be seen as good parents, it’s just that we want to do it on our own terms’. Connecting emotionally with new-borns was a source of concern for many participants following the birth and bonding was reported as delayed for all women, '…he seemed like a ball of rags'. Reading their babies' cues was difficult for some women and one woman reported being more in tune with her child's 'grunts' and 'coos' than reading their facial expressions.

There are several noteworthy features of the Gardner et al., (2016) study that suggest the research was shaped through meaningful participant involvement at the planning, data gathering and analysis stage, which collectively separates it from the majority of studies reviewed here. In their efforts to assess the validity of a questionnaire, authors sought out an expert review with key stakeholders in the Asperger's syndrome community. The 'richness' of data compiled during this process directly shaped the focus of the study. The authors acknowledged that the unsolicited commentary provided regarding childbearing experiences represented a more authentic account of their experiences than a questionnaire could. An additional feature, unique to this study, is that the women's views of what might be helpful to them to address their needs was highlighted at each stage of the pregnancy and birth journey, and directly informed discussion of the clinical implications of the study.

While the use of secondary data can be problematic for a variety of reasons, including the distance of the researcher from the original data, in this instance, the original data was self-collected by two of the authors. Credibility checks, the expertise of the authors in qualitative analysis, the use of an honest broker to de-identify data and steps taken to further protect anonymity within the data, are well described allowing for reader confidence in the study's findings. What is not detailed, however, is the ethical considerations involved in obtaining consent when using data for an unintended purpose. While authors sought approval to analyse the gathered data in a new way from the institutional review board, they do not reference any efforts to secure participants' consent for same. While these women may have been happy to share their views on childbearing to inform the use of a questionnaire, they may not have been as happy to have their 'spontaneous commentary' used as data in a qualitative research study. Had they known, they may have chosen not to participate and, as respondent credibility checks were not referenced, it is impossible to know whether or not those who participated would have added contexts to their commentary. Most likely, if fully informed, they would have done so and in that process may have given a greater depth to the study's findings.

Additionally, while participant details were limited to protect anonymity, pertinent details in several quotes suggest that findings need to be interpreted within the context of maternal and infant health, as well as the ASD diagnosis. Details such as ICU, three month hospital stays - pre and post birth, mental health medication, and social services, suggest that some participants and their infants may have been deemed 'at risk' for a number of reasons. Authors do not reflect on how these factors may have impacted the study findings. Nor do they reflect upon the fact that a quarter of the sample self-diagnosed their ASD. On the one hand, this could be argued to be a step in the right direction as research reviewed here has highlighted the potential for missed or misdiagnosed 'higher functioning' females in particular. On the other hand, the use of a measure to formally characterise the ASD symptomology would have added to the study's rigour.

A final observation relates to assumptions made by the authors in relation to the specificity of findings in relation to the ASD diagnosis. To illustrate, authors surmised that the participants' decision to breastfeed their babies was linked to their cognitive understanding of the benefits to the baby and this overrode the physical and sensory discomfort they experienced when feeding. Authors' discussions lacked consideration of other pertinent factors related to the likely high uptake of breastfeeding in this group. Individual lactation support in a non-medical setting was available to these women. In addition to this, cultural factors in relation to the uptake of breastfeeding were not referenced and the women's knowledge of the benefits of mother-child bonding during feeding was not considered. Relatedly, the types of needs these women presented with and the suggestions they made to address same, were not considered in relation to the childbearing experiences of women who are not on the spectrum. This is not to suggest that there are no differences in how childbearing is experienced by all women or in any way minimising participant experience, but points to the need to consider conclusions in broader contexts.

The importance of critical life moments: An explorative study of successful women with autism spectrum disorder (Webster & Garvis, 2017)

Webster and Garvis interviewed 10 women with ASD who viewed themselves as successful in their lives in order to identify the factors that had enabled them to achieve such success. Using self-efficacy theory (Bandura, 1997) to frame examination of these factors (both internal and external), they signalled out the following as critical to these women’s perceptions of success: being agents of change, understanding their diagnosis, the belief of an influential person and the role of a mentor.

Unlike participants in previously discussed studies, none of the women in this study viewed themselves as victims or limited by the challenges they faced in their lives. Despite experiencing similar difficulties in their lives as women in previous studies, such as abusive relationships, difficulties in work or education settings and traumas of a sexual nature, they viewed themselves as efficacious females, who at pivotal moments in their lives made decisions that allowed them to remove themselves from current risk and future risky situations, ‘…I saved the money and I took the kids and got out of there…I was very proud of that’.

Some women spoke of the powerful influence of others’ beliefs in their ability to achieve and be successful across different aspects of their lives. This transference of belief from trusted others allowed them to develop a sense of agency for current and future action.

One participant recounted how collectively she and her employer addressed a specific behaviour of hers that 'really bothered him' in meetings. Together they sensitively differentiated tasks so that '…he knew the bigger picture, I knew all the details and we became a brilliant team'.

As noted in previous studies, the diagnosis contributed to the development of a new identity. All participants recalled undergoing an initial period of reflection, readjustment and even depression, '…I was depressed because everything said it was a lifelong condition and there's nothing you can do about it'. Reading about ASD and about other individuals who have ASD helped participants to see that the diagnosis could be a positive in their lives, and following this period of readjustment, spoke of feelings of purpose and hope.

All participants identified inner qualities that allowed them to persist at difficult times and ultimately to succeed in some way. Several women related this to compartmentalising their diagnosis in that 'not blaming the diagnosis' was important, 'If I had gone through this life without holding myself to the same standards as everybody else, I would have achieved less'. The women felt that their ability to focus on a goal was one of the things that helped most when encountering problems and viewed having 'drive [and] focus…' as a particular area of strength, '… go with your strengths, don't worry about conforming with society…'. In a related vein, women suggested a 'reimaging' of the roles of women and girls with ASD. Comments such as '…what if these roles were recast into something that better fit with the way women with ASD see the world...where the different roles were considered just as much the norm as the norm itself…' perhaps suggest a more philosophical approach to the identity conflict, which overwhelmed some women in previous studies to the point of outright rejection.

The main strength of Webster and Garvis' study lies in its retelling of stories where women with ASD experience success in many forms and find their lives purposeful, rewarding and satisfying. In stark contrast to other studies reviewed above, messages of hope and positivity underlie these women's life experiences. This research shows how, as women mature, grow and increase their sense of their own competence, they build problem-solving skills and create happy lives.

Compared to those who have additional intellectual or behavioural difficulties sufficient to obtain a diagnosis in childhood, those with a later diagnosis appear to have developed and displayed a certain capacity, and level of resilience, to mask their difficulties into adulthood. However, with the exception of Kanfiszer's study, participants from the remaining studies reviewed were also considered to be 'higher functioning' and had average or above average cognitive ability. The absence of an intellectual disability did not seem to act as a protective factor in their life experiences.

In Wester and Garvis' (2017) research, participants defined their successes in 'non-traditional' ways. This conclusion was made in spite of the fact that the vast majority of participants viewed themselves as successful in their work, studies and personal lives. Eight of the ten women had been in long-term relationships. Each participant had a third level educational qualification, each was employed and each reported profession involved a high level of face-to-face client interaction, suggesting adequate social communication skills. Additionally, sensitive and timely supports appeared available to these women when/if they struggled in any of these areas, suggesting that the high sense of self efficacy and positive self-concept reported may well be attributed to their achievements in these traditional measures of successful life outcomes for individuals with and without ASD.

On a separate but related point, mental health difficulties have been a pronounced feature in the life experiences of the majority of women with ASD in studies reviewed here and in the general literature. Nine of the ten participants in this study did not report a co-morbid mental health difficulty. This may have been the participants' choice or their difficulties may have been undiagnosed. Regardless, mental health difficulties were little discussed. The majority of participants were recruited from a local psychologists' social media platform which specialises in supporting women with a diagnosis of ASD, suggesting these women at a minimum had the resources to access appropriate information and source appropriate supports. It is reasonable to suggest that findings from previous studies may be in some way confounded by participants' mental health difficulties and that, in their absence, women with ASD with the right supports are able to achieve successes across 'typical' life experiences.

2.4 Summary

Although there are key areas of the methodological designs that require further consideration (as well as the ethics of excluding certain groups and consent regarding use of data) these papers provide significant insight into the challenges women experience across the life span. Broad themes of being misunderstood, misdiagnosed and victimisation in various contexts were common across the six studies echoing previously referenced literature. Although not the primary aim of some papers, when contextualised in women's narratives, the collective experiences lend some support to a 'female autism phenotype' whereby some autistic females express their autism through subtle variations in behaviour compared to males, which are not captured in current diagnostic tools.

Despite research indicating that females are more socially motivated and have less social impairments to males, women in these studies struggled in their social interactions with others suggesting there may be other factors impacting particular aspects of their socialising. Difficulties interpreting social cues in relationships and friendships in conjunction with societal pressures to adhere to gender stereotypes provided a context for bullying, isolation and, in some instances sexual assault. Communication difficulties with service providers (medical, educational and occupational), while exacerbated by sensory and executive functioning difficulties, largely stemmed from professionals' lack of recognition of need which translated to prevention or restriction of access to supports.

The cumulative impact of a lack of support in relation to women's wellbeing was highlighted across studies in the high prevalence of mental health difficulties reported. Internalising problems frequently present as part of typical clinical presentation but do not represent core features of autism (Hull et al., 2020). In line with this observation, women's internalisation of distress served in some instances to diagnostic overshadowing of their ASD characteristics and was a factor in the delay of their diagnosis. For others, internalising difficulties may have unwittingly enabled the gender bias in autism recognition and referral, particularly in health and education settings.

Women also related delayed diagnosis to their use of camouflage or masking to fit into social situations. With higher social motivation than men, women may experience greater pressure to fit in socially, especially as the social environment becomes more demanding during adolescence and, for some women during motherhood. Variation in presentation across social contexts may account for discrepancies in the perceived extent of women's autistic social communication difficulties (Hull et al., 2020). The use of camouflage was also related to poor mental health caused by the physical and emotional exhaustion of not being able to present their authentic selves.

The reviewed studies have been interpreted in terms of their contribution to the existence of a female autism phenotype from a first person perspective adding to discussion about potential gender differences in social difficulties, the co-occurrence of internalising disorders and increased camouflage behaviours. Additionally, these studies highlight the fact that the challenges that women face are not all directly attributable to their autism but also reflect how these difficulties interface with gendered sociocultural contexts.

2.5 The Current Study

As previously referenced, people with autism and those within the autism research community have called for the prioritisation of research that focuses on adults and females with ASD and their life experiences (Pellicano et al., 2014; 2018). The above key pieces of research and introduction to the broader literature in Chapter One highlight the ‘budding interest’ (Gould, 2017) in this area and the intrinsic research challenges this call presents. Contextualised within this literature, the current study seeks to give voice to those who have been neglected, to those marginalised adult women diagnosed with an ASD.

Chapter 3: Methodology

3.1 Chapter Overview

This chapter will introduce the research paradigm and rationale for the qualitative approach taken in this study. The selected methodology and mode of analysis will be discussed within the context of the ontological and epistemological stance. The research procedure is also considered, including factors related to the participants, data collection and analysis, and relevant ethical considerations.

3.2 Qualitative paradigm

The literature review in Chapter One highlighted the largely reductionist focus of research in relation to the potentially unique experiences of women with an ASD. Quantitative analysis of neurophysiological processes and mechanisms has thus far dominated the literature. Exceptions lie in autistic life writing and studies reviewed in Chapter Two which collectively indicate the need for further holistic understandings of women's experiences of living with ASD.

Qualitative methodology seeks to enable an individuals' world to become visible (Denzin & Lincoln, 2005). This in turn enhances an understanding of how individuals describe their own experiences, how they construct their worlds and what meaning they attribute to their experiences (Merriam & Tisdale, 2016). As noted by Darlaston-Jones (2007) exploration of the nuances of experiences is simply not available through quantification. Therefore, a qualitative methodology was identified as the most appropriate way to explore the perspectives of autistic women on their lives.

3.3 Ontology and Epistemology

Ontology determines whether or not we think reality exists entirely sperate from, or is entirely dependent on, human interpretation and practices. A relativist ontology assumes there are multiple constructed realities, ‘what is ‘real’ and ‘true’ differs across time and context, so that what we can know reflects where and how knowledge is generated’(Braun & Clarke, 2013, p. 27). This assumption influenced discussion of the construction of autism in chapters one and two. Epistemology refers to the philosophical assumptions underpinning a piece of research focusing on how knowledge is obtained and investigating the most valid ways to reach the truth. Epistemological positions determine a perspective upon what is possible to know and thus what counts as knowledge (Braun & Clarke, 2013). The epistemological position of this research is social constructionism which views reality as ‘subjective and need not be something that can be shared by anyone else but at the same time is independent of the person living it’ (Darlaston-Jones, 2007, p.19). The influence of a constructionist worldview on research methodology will be discussed with some consideration of feminist assumptions.

3.3.1 Theoretical frameworks

Social constructionism asserts that our understanding of reality is a social and historical construction, that there is no independent and separate ‘objective truth’ that can be discovered. Rejecting the broad metanarratives previously created to understand the world, the postmodern era facilitated social constructionism by considering a panoply of ways that individual realities might coexist (Burr, 2015).

Social constructionism directly contrasts positivist and empiricist orientations that assume reality exists ‘out there’ and that it is observable, static and measurable (Merriam & Tisdale, 2016). Not unlike other epistemologies, it stems from, and is influenced by, diverse disciplines and intellectual traditions. It’s multidisciplinary nature makes inappropriate a single definition of the approach and relatedly no coherent and identifiable types of social constructionism exist (Burr, 2015; Gergen, 2015). Despite the variability in approaches, in its essence, social constructionism argues that the concepts and categories we use to think and communicate with are socially constructed rather than natural features of the world, making our ‘knowledge’ of the world relative rather than absolute rendering the idea of ‘truth’ ‘problematic’ (Burr & Dick, 2017, p.70).

Burr (2015) and Gergen (2015) suggests the following key assumptions commonly underpin the variety of social constructionist approaches: a critical stance towards taken for granted knowledge; that knowledge is socially and historically specific; that knowledge is both produced and maintained by social processes; and that knowledge and social action are intertwined. Relevant to this study is Burr’s (2015) use of the example of gender and sex to highlight how social constructionism encourages questioning of the status quo, whether constructs of ‘man’ or ‘woman’ are the product of social forces rather than an inevitability. The critical and yet catholic embrace of social constructionism is often lauded. Instead of a singular or hegemonic view of reality, social constructionism is an invitation to creativity as it opens the door to multiple ways of seeing the world (Gergen, 2015).

Gergen (2015) acknowledges the centrality of social processes in the formation of a perception of reality. The impact of the relationships and daily interactions between individuals and the societal norms, ideologies and practices make it difficult to separate a sense of one’s self from our cultural surrounds (Gergen, 2015). Furthermore, Gough et al., (2013) identify four key related components in the role of social processes: ‘the individual is (always, already) located in society, the individual is (at least partially) positioned within systems of difference/inequity, power is linked to language and representation (discourses) and research should aim to challenge oppression and promote social change’ (p.17). Social constructionism asserts that language, for all its semantics and complex semiotics, is fundamental to these social processes. ‘When people talk to each other, the world gets constructed’ (Burr, 2015, p.5). In placing centre stage the everyday interactions, the ‘goings on' between people in the production of knowledge, language is not conceived of as describing and representing the world but as a social action, a way of collaboratively constructing knowledge.

When social constructionism is applied to research, the researcher is an active participant in the construction of new ways of knowledge (Mac Namee & Hosking, 2012). As such, the role of the researcher needs to be transparent in both data collection and subsequent analysis to ensure that findings are not presented independently and objectively, but as a result of 'the subjective construction which is a unique result of the moments of interaction between the researcher and the participant' (Tuckett, 2015, p.75). This will be referenced in more detail later in this chapter.

The key components of social processes referenced above dovetail with the socio-political aims of this study and the prospect of facilitating co-constructions of, as well as building a critical literacy around, autism in women through researcher – participant interaction. Burr & Dick (2017) note that what we think of as 'knowledge' is underpinned by power relations, where some sections in society have more power than others. They decide what counts as legitimate knowledge and some ways of speaking (or discourses) frame experiences and identities in ways that can be oppressive. Aside from the exceptions already noted, the broader literature on women with ASD has arguably been reductive, it has diminished the actuality of their experiences to a limiting collection of numerical/biological data or observations almost devoid of context and the subtleties of individuality. A qualitative method of investigation is thus apposite within the social constructionist epistemology, endeavouring as it does to garner linguistic data that enables the contextualisation of the women's experiences and facilitates the vocalisation of the multiple standpoints of those most impacted by ASD.

Feminist theory as a separate but complimentary theoretical framework emerged as the research progressed, most notably during the data collection phase. Women's accounts of successive interactive inequalities sat outside of the 'dominant discourse', the patriarchal framework of understanding (Smith, 1998) and in doing so presented the conditions of possibility for a feminist understanding. A feminist approach acknowledges the pervasive influence of gender relations. It is because of differences in the social position and power of women and men that gender relations are held to pervade social life (Haig, 1999). To make women's lives and experiences visible and to fight against oppressive structures is a priority. Feminist research offers a clear political direction – what oppresses women should be criticised (Smith, 1998).

Gergen (2015) cautions a negative consequence of critique is the creation of a 'binary ontology' which silences opposing parties and shuts down debate. Instead, differences in discourse should (gradually) create a complex picture allowing for the possibility of ongoing democratic debate. Jorgensen and Phillips (2002) suggest that implicit in this is the notion that all arguments/ discourses are of equal validity rendering social constructionism (a) scientifically unusable as what is 'true' can never be determined and (b) politically meaningless where social conditions fit for change can be identified but what is positive or negative about them cannot be determined. This pessimistic view of social constructionism negates the common sense understanding that in 'unmasking naturalised taken-for-granted knowledge'(Jorgensen & Phillips, 2002, p. 205), social constructionist researchers make it the subject of critique and discussion and thus open to change. Feminist theory with its clear political agenda extends the critique process in providing greater understanding and an explanatory framework for inequality.

3.4 Choice of method

This section will explore the rationale for the qualitive framework of choice. Reflexive Thematic Analysis (RTA), a Thematic Analysis (TA) subtype, will be considered against other methods.

3.4.1 Reflexive Thematic Analysis

Unlike other well established methods of pattern-based qualitative analysis, such as Interpretative Phenomenological Analysis (IPA), Grounded Theory (GT) and Discourse Analysis (DA), Thematic Analysis (TA), has a less coherent developmental history. Braun and Clarke (2018) chart its original reference as a method in the 1970's, to procedural guidance by Boyatzis in 1998, to its' 'launch' as a method within social and health sciences as a result of the publication of their 2006 paper 'Using Thematic Analysis in Psychology'. Similar to qualitative analytic approaches, such as those referenced above, Braun and Clarke's thinking about TA has evolved since 2006. TA is not a single analytic approach but better understood as an 'umbrella term' designating sometimes quite different approaches aimed at identifying patterns (themes) across data sets (Terry et al., 2019). Three major types of TA are identified by Braun and Clarke (2013): Codebook, Coding Reliability and Reflexive TA. The main difference between types lies in their understanding of theme, how the coding process is conducted and 'in a priori or a posteriori nature of the resulting themes' (Cisek & Krakowska, 2019, p.5).

In Reflexive Thematic Analysis (RTA), Braun (2019) and co-authors (Terry, Hayfield & Clarke) emphasise:

> Themes are conceptualized as meaning-based patterns, evident in explicit (semantic) or conceptual (latent) ways, and as the output of coding – themes result from considerable analytic work on the part of the researcher to explore and develop an

> understanding of patterned meaning across the dataset. Coding (and theme development) is an organic and open iterative process; it is not "fixed" at the start of the process (e.g., through the use of a codebook or coding frame) (p. 848)

Setting the scene in terms of differing qualitative philosophies will further make clear the rationale for the researcher's method of choice, RTA. Qualitative analytic approaches can be divided into two 'broad schools'; 'Big Q' and 'small q' (Kidder & Fine. (1987), as cited in Braun & Clarke, 2013, p.224). 'Big Q' approaches refer to qualitative research conducted within a qualitative paradigm. RTA, to use Braun and Clarke's (2019) terminology is an 'organic', 'fully qualitative', 'Big Q' approach to TA. Being a 'Big Q ' approach, it prioritises: the importance of reflexivity, the contextual nature of meaning and researcher subjectivity as a resource, all assumptions which align with a social constructionist epistemology.

RTA as a 'Big Q' approach is contrasted with the second school of qualitative analytic approaches, 'small q' approaches which retain a foothold in positivist research and are concerned with establishing coding reliability. 'Small q' approaches involving the use of coding frames facilitate the generation of measures like inter-rater reliability which equate to 'a thoroughly positivist conceptualisation of reliability' (Braun & Clarke 2018, p.108). In contrast to 'Big Q' assumptions, Braun and co-authors (2019) contend that coding using a code book approach suggests that: findings already exist in the data waiting to be discovered, researcher subjectivity is flawed, it is possible and desirable for coding to be accurate and objective, and implies that minimising the influence of the researcher's subjectivity leads to better analysis. Using RTA, coding (and theme development) and analysis is viewed as something created by the researcher 'at the intersection of the data, their theoretical knowledge, research skills and experiences, not something to be found waiting 'in the data' (Terry et al., 2017, p.19).

Other pattern-based approaches to qualitative analysis, namely Grounded Theory, IPA and Discursive Analysis could be considered in the context of this research. Critics of RTA (Herzog et al., 2019) argue its variations make it difficult to establish clear distinctions from other methods of qualitative analysis and posit that approaches such as those referenced above can be seen as ‘special cases’ or ‘extensions’ of Thematic Analysis. Braun and Clarke in their refinement of thinking about RTA in particular (Braun & Clarke, 2013, 2014, 2017, 2018, 2019) make clear that distinct procedural and theoretical philosophies separate each approach.

Grounded Theory and IPA in particular are better thought of as methodologies as well as distinct methods compared to RTA which ‘is just an analytic method’ (Braun & Clarke (2017) as cited in Jankowski, 2017, p. 6). Each approach has inbuilt theoretical frameworks (ontological/epistemological assumptions), advocates the use of particular research questions, and the use of particular methods of data collection, as well as the use of a particular set of analytic procedures. In contrast, RTA ‘is characterised by its flexible procedures applicable to various methodological frameworks or epistemological positions’ (Braun & Clarke, 2006, p.76). Common criticisms of RTA involve comparison to the analytic sophistication of approaches such as IPA and Grounded Theory, suggesting RTA is a simplistic method that simply aims to describe or summarise patterns in data and equating theoretical flexibility to an absence of theory (Braun et al., 2014). However, RTA demands a clear and transparent declaration of: epistemological stance, influencing theories and analytic choices such as the approach to the data (inductive or deductive), and semantic or latent level coding. (Braun & Clarke, 2019).

Methodologies evolve and are adapted to fit a changing history of philosophical milieu (Ralph et al., 2015). This is particularly true of Grounded Theory which sets out to discover or construct theory from data. Approaches to theory generation can broadly be divided into ‘Grounded Theory Lite’ and ‘Full Grounded Theory’ (Braun & Clarke, 2013), both of which share similarities and differences with RTA. Grounded Theory Lite involves using the specific techniques of Grounded Theory (coding, memo writing, diagrams, constant comparison and relationship to the literature) for the development of categories and concepts and an understanding of the relationships between them. Similarly, RTA involves coding, theme generation and interpretation of broader patterns in data, leading Braun and Clarke to suggest there may be little difference in the results of a contextualist Grounded Theory and contextualist RTA (Braun & Clarke, 2013). Full Grounded Theory involves the full range of GT procedures, including theoretical sampling with the aim of producing a theory grounded in data. While RTA can produce conceptually informed interpretation of data, it does not attempt to develop theory. The aims of this study do not seek to generate a theory but to understand the experiences of women with ASD.

An alternative method is Discourse Analysis (DA) which seeks to understand how reality is produced and how this is reliant on patterns of language used (Reissman, 2008). While a constructionist RTA recognises the constitutive nature of language, it does not involve a micro analysis of language use which is a feature of some forms of DA.

Like Grounded Theory, IPA as a methodology (as well as a method) comes with a different theoretical lens and procedures in relation to pattern-based analysis. Being grounded in phenomenology, exploring people’s lived experience and the meanings people attach to those experiences is its overriding concern. RTA has long been used within phenomenological research and its theoretical flexibility makes it equally compatible with social poststructuralist, social constructionist and critical application to qualitative research (Braun et al., 2014). Its theoretical flexibility may help explain that while a rise in IPA studies in the autism field has been observed, only 3 of 33 studies in DePape and Lindsay’s (2016) meta-synthesis of the lived experience of autistic people employed IPA as their analytical framework. By contrast, the majority of studies employed thematic analysis, which indicates that IPA is perhaps not yet recognised as a primary qualitative approach for research with the autistic community (Howard et al., 2019).

Relatedly, IPA relies on language to be a valid representation of experience. A constructionist RTA such as this study, views language not simply as mirroring a world ‘out there’, it does not seek to know or understand objectively ‘real’ experiences but is more interested in how women’s stories construct realities and queries taken-for-granted knowledge about their lives. Additionally, knowledge about ASD communication features and information processing is crucial for the understanding and interpretation of data. For example, Dewinter et al. (2017b) highlight that limited expressive language and overly formal language of some participants restrict the richness of data, suggesting IPA may not appropriate for all people with autism.

Important procedural differences between IPA and RTA also make IPA a less suitable approach for this study. In RTA, because the techniques are separate from the theoretical orientation of the research, the question of what level patterns are sought at, and at what level interpretations are made of those patterns, are left to the researcher. In contrast, IPA takes a dual focus on the unique character of individual participants and on patterning of meaning across participants. Codes and themes are developed on the actual data item and focus on the unique character of individual participants because the researcher codes and develops themes for each data item in turn. This is not to say that RTA does not capture difference and divergence of meaning (Braun et al., 2014). As a constructionist RTA study, this research captures such variation through the use of latent coding which goes beyond participant meaning to understand the patterns/stories in the data (Braun & Clarke, 2006). Of note, in practice, both latent and semantic coding are frequently applied to the same data item (Braun & Clarke, 2006). Additionally, in contrast to IPA’s idiographic focus, RTA focuses on patterns of meaning across participants. The in-depth analytical focus of IPA typically demands a small number of participants (4-10, Braun & Clarke, 2013) which was at odds with the researcher's aim to engage with as many women with autism as possible.

A critique of IPA lies in its tendency to emphasise psychological rather than critical socio-cultural interpretations (Larkin, 2006). Braun and Clark reference the social justice orientation of RTA, although little has been written on this subject (Terry et al., 2017). In choosing latent level coding and theme development, this researcher attempts to engage with the feminist 'give voice' agenda at differing levels. As referenced in Chapter 1, women with ASD are marginalised not only within society at large but also within the ASD community (Saxe, 2017). In response, this study emphasises the centrality of the participant voice and experience in order to inform how healthcare providers and others may better understand, and more fully meet, these individual women's needs.

In summary, a RTA conducted within a constructionist framework emphasising latent and semantic themes was the preferred method, because of its flexibility, non-idiographic focus and 'pure' qualitative nature, which means that both data collection and analysis were underpinned by the Big 'Q' qualitative paradigm.

3.5 Reflexivity and Positionality

A social constructionist epistemology recognises that we all encounter the world from our particular location in the social world; our questions, theories and hypotheses stem from the assumptions embedded in our experiences (Burr & Dick, 2017). The task of the researcher, therefore, becomes to acknowledge the influence of their own background and involvement in the research process reflecting on the part that this may play in the findings (Burr & Dick, 2017). Additionally, the researcher's awareness of their subjective experiences may be especially important in the field of autism (Howard et al., 2019), where, as previously referenced, a double empathy problem describes the difficulties of achieving mutual understanding between neurodiverse and neurotypical representations of the world (Milton, 2012). The researcher maintained reflexive capacity via research supervision and completion of a research log and memos during each stage of the research process (see Appendix B: Sample Memo).

Braun and Clarke (2013) and others (Finlay, 2002) emphasise the importance for the researcher as a positioned subjective person to consider their ‘insider’ and ‘outsider’ positions. We have ‘insider’ status when we share some group identity with our participants, with the converse representing our ‘outsider’ status. Occupying multiple ‘insider’ and ‘outsider’ statuses is commonplace and this is the case in this study: the researcher is a middle aged, middle class woman of white Irish origin. She is a mother, a feminist and a qualified educational psychologist in practice for ten years. She has had significant opportunities in her life to engage in education and is supported by those around her in her professional roles. Her interest in autism and autism in women in particular stems from her time working in a professional capacity with both children and adults in various settings, an autism specific service, child and adult intellectual disability services and special and mainstream schools. The researcher also has familial experience of autism.

Some of these individual details were made explicit to participants at the earliest stages of the research and may have acted to reduce potential power imbalances in the researcher-participant relationship, increasing comfort in sharing sensitive experiences. It may, equally, have triggered pre-conceptions or previous experiences of working with health care providers, which may or may not have been positive.

3.5.1 Feminist assumptions

Additionally, there is no one singular ‘feminist theory’ but rather a wide range of perspectives underpinned by a steady concern with politics and social action (Osmond &

Thorne, 1993). A social constructionist feminist approach suggests ‘nature’ is a contingent social and cultural construct that should not be taken for granted (Fiaccadori, 2006) and advocates a broadening of discourses that contribute to identity formation processes. In prioritising a first person perspective the researcher aims to widen the narratives around autism and women. However, in her privileged status as a white middle class woman, the researcher was also sensitised to academic debate (Fine, 1992, 1994, as cited in Jankowski, 2017) about the appropriateness of white middle class female researchers giving ‘voice’ to women from a marginalised group, such as autistic women. To this end, the researcher recognises that her ‘inner status’ is potentially problematic, as it can ‘often re-inscribe existing power relationships’ (Jankowski, 2017, p.8). Thus, while it is the women’s experiences that the researcher aimed to bring forth, she recognises that she brings her own perspectives (practices, ideologies and discourses) to bear on the data and the end result is her interpretation of their lived experience.

3.6 Procedure

3.6.1 Participants and recruitment

A self-selecting sampling technique was adopted. Women aged over 18 years who had a diagnosis of autism were invited to contact the researcher via online adverts to take part in semi-structured interviews. Broad based questions explored the experiences of being a woman on the autism spectrum (see Appendix C: Interview/prompt sheet). Leaders of two Irish founded autism-specific online social media fora (one specifically for women, the other with separate facilities for men/women-only contributors), were initially approached regarding the research topic. Following receipt of further information regarding the study, and pending ethical approval, both agreed to advertise the research on the respective forums. (see Appendix D: Letter to Gatekeeper).

Due to unforeseen circumstances beyond the researcher's control, the advertisement of research on these fora did not go ahead as planned. The researcher then advertised the research on a long established Irish founded autism-specific service website for people with autism. Following the first interview, the interviewee offered to retweet the research advert across a number of national and international social media fora frequented by women with autism. The advert detailed the aims of the study, inclusion criteria and expectancies regarding participant and researcher role, it confirmed ethical approval and provided contact details for the researcher and the study supervisor. (see Appendix E: Research advert)

Women aged over 18 years who had a diagnosis of autism and who were interested in the study were invited to contact the researcher directly. Once contacted, the researcher discussed the purpose of study, the interview procedure and confirmed that the individual met the study inclusion's criteria. With an exploratory focus on obtaining varied perspectives, no exclusion criteria was set with regard to cognitive ability and/or comorbid diagnoses. Eighteen women contacted the researcher asking to participate in the study. Two did not meet eligibility criteria; one woman did not yet have a diagnosis and the other was self-diagnosed. Of the sample of 16 participants, twelve were resident in Ireland and received their diagnosis here. Two participants resided in the UK, one in the US and one in Denmark. The mean age of participants was 38.7 years and the mean age of diagnosis of ASD was 35.9 years. The majority of women reported longstanding mental health difficulties that included clinical diagnoses of depression, anorexia nervosa, generalised anxiety disorder, bi-polar disorder, postpartum depression and personality disorder. No participant reported a diagnosis of intellectual disability. Once interviews were analysed, several elements of the data strongly indicated the study sample should be considered 'high functioning', in that 100 percent of women had attended and/or were currently attending third level education and all lived independently.

Table 2

Participant Details

Participant Pseudonym	Country of Residence	Formal Education	Occupation	Age at time of interview	Age at time of diagnosis	Relationship status	Other demographics
Linda	Ireland	Third Level	Technology consultant, Artist	56	55	Married	Mother
Amanda	UK	Second Level	Freelance writer	40	39	Partnership	
Emma	USA	Third Level	Post-doctoral position	26	24	Married	
Annemarie	UK	Third Level	Teacher	48	44	Married	
Sarah	Denmark	Third Level	Biologist, Geographer	44	40	Partnership	Mother
Jean	Ireland	Third Level	Full-time student	28	24	Single	
Amy	Ireland	Third Level	Full-time student	35	32	Single	
Sheena	Ireland	Third Level	Social care worker, childminder	31	24	Dating	
Deirdre	Ireland	Third Level	Artist, writer	40	39	Married	Mother
Mary	Ireland	Third Level	Part-time student	45	43	Single	
Dorothy	Ireland	Third Level	Volunteer, Supports children with additional needs	42	42	Partnership	Mother
Sally	Ireland	Third Level	Teacher	30	24	Partnership	
Shauna	Ireland	Third Level	Psychologist	40	39	Single	
Aoife	Ireland	Second Level	Childminder	48	42	Single	Mother
Amira	Ireland	Third Level	Full-time student	33	31	Married	Mother
Jenny	Ireland	Third Level	Part-time student	33	32	Married	Mother

3.6.2 Interviews

Participants were interviewed using a semi-structured interview developed specifically for the study. Semi-structured interviews give a much-needed voice to autistic individuals (Humphrey & Lewis, 2008), facilitate rapport-building between the researcher and participant (Cridland et al., 2014) and confer agency on the participant with regard to the pace and direction of the interview (Huws & Jones, 2015). The interview questions were broad in their focus and open ended to allow women to tell their own stories. A prompt sheet based on topics taken from previous research findings discussed in the literature review was also developed and included questions about diagnosis, friendships and relationships. The interview was piloted with a woman in her 40's who met the study's inclusion criteria. Her observations regarding the flexibility of the schedule and the prompt sheet indicated a semi-structured interview method was appropriate. Her recommendation of the creation of a time-line in terms of childhood, adolescence and adulthood to help structure discussion was incorporated into the interviews.

3.6.3 Sharing of experience

As there is no conclusive evidence for the most appropriate method for interviewing people with autism (Nind & Vinha, 2013; Nind, 2017), the researcher considered the individual needs of participants when conducting the interviews. Based on her clinical experience working with individuals who have autism, the researcher was cognisant of participants' potential communication, social interaction and sensory capabilities and needs, and made the appropriate adjustments. Depending on participant choice, interviews were conducted in various ways. For women resident in Ireland, the option of interview location was offered. Eight women, at their choice of location, were seen in a face to face interview, one of which was completed over two sessions. Three were carried out over the phone and five women were interviewed using Skype or Zoom video call services. Three women followed up their interviews with emails providing further details on their experiences which, with their consent (see Appendix F: Consent form) were incorporated into their individual interview transcripts. The researcher was cognisant of the burdensome demands talking for extended time periods placed on some autistic people and so formulated the interview to be of one hour's duration. With this in mind, timing preferences, break options and the opportunity to split the interview into two parts was also offered. One participant chose this option. The researcher was equally mindful of the variability in time involved in processing and responding, thus no limits were placed in terms of the researcher's time availability. Interview duration times ranged from one hour to two hours twenty five minutes. Demographic data was collected in the context of the interviews to obtain additional contextual information.

Information sheets were provided in the first instance to women who requested to take part in the research (see Appendix G: Information sheet). These were posted or emailed at least 24 hours before consent was requested, in order to allow participants time to read the relevant information and to consider whether they wanted to take part in the study (Nind, 2017). Participants who decided to participate then arranged a time to be interviewed. Interviews were conducted and audio recorded in a setting such as the university base, a hotel conference room and a community resource centre depending on the participant's wishes. The researcher's home office was the setting for those interviewed by video online or by phone.

Before each interview commenced, the researcher reviewed the participant information sheet with each participant to remind them of the requirements of the study, the recording of the interview and gave them an opportunity to ask any final questions. Participants were required to sign a consent form stating they had read and understood all the requirements of the study and wished to participate. Participants were reminded of the explicit safeguarding procedures outlined in the consent form. The participants' right to decline to answer and cease participations in the research was reiterated before the interview began. No participants chose to withdraw from this study. All but one interview transcript were transcribed by a paid professional transcription service, bound by a confidentiality agreement (see Appendix H: Confidentiality Agreement). Some authors advocate that researchers should transcribe interviews themselves, so as to facilitate immersion in the data (Braun & Clarke, 2013), however, this was not possible for the researcher. Her confidence in being 'immersed' in the data comes from carrying out the interviews in person, reviewing each transcript against the corresponding audio recording to ensure accuracy and, as described below, the phased analytic process of RTA itself.

3.7 Analysis

Reflexive Thematic Analysis was chosen as an analytic approach, as it allows for the analysis of a large amount of data from multiple participants to be synthesised into a meaningful account using a systematic process that facilitates researcher transparency at each phase of the analytic procedure (Braun & Clarke, 2013). The six phases of the RTA are outlined in chronological order below. The term 'phase' is deemed a critical descriptor for Braun and Clarke (2006), who stress the 'iterative' and 'recursive' analytic process of RTA, meaning the researcher moves back and forth between the individual phases.

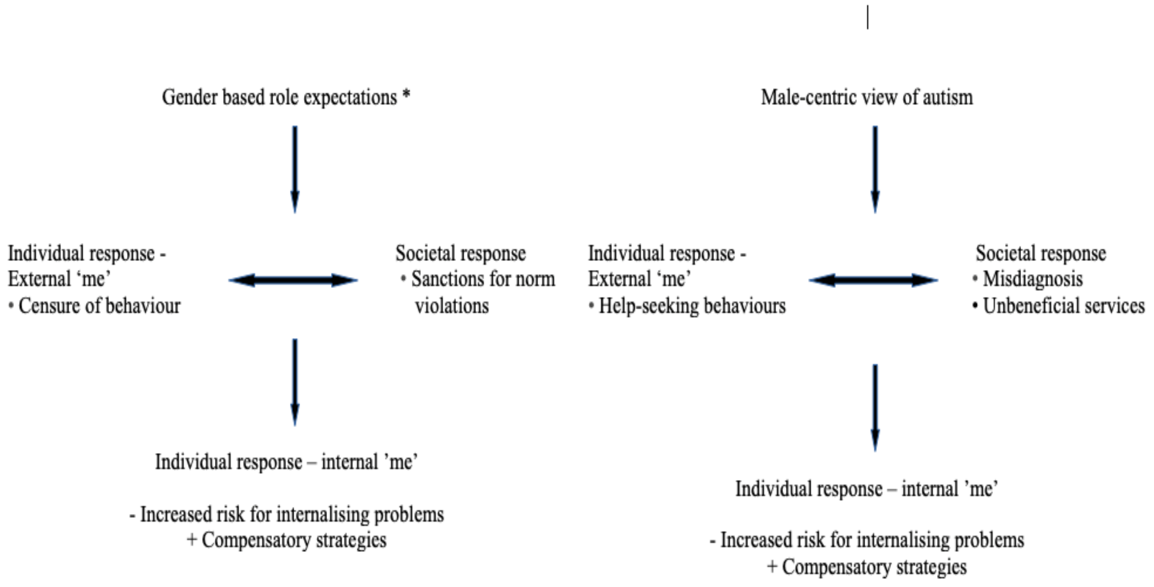
Familiarisation (1) : This involves intimately knowing the data set. The researcher engaged in several readings of transcripts and re-listened to interview audio to ensure accuracy. During this phase, Clarke & Braun (2019) advise documenting initial 'noticing's' of trends, exceptions, quirks and observations across the data, while keeping the general research question in mind. (see Appendix I: Sample 'noticing's)

Generating Codes (2) : This involves identifying and labelling all segments of interest and relevance within the data set and everything that is of relevance within these segments. The researcher hand-coded transcripts (see Appendix J: Coding extracts) and codes were selectively transferred to word documents during later phases. In line with the RTA process demands, the researcher declared her epistemological and theoretical influences which directly informed how the researcher approached the data and the coding process itself. In practice, it is common for data to be treated inductively and deductively allowing both latent and sematic coding within the one dataset (Clarke & Braun, 2014). Data was approached with such flexibility in mind and coding moved from a semantic level to a more interpretative level (latent coding) built around concepts that help explain the data.

Theme development (3) : This is an active process of pattern formation and identification, based on the earlier engagement with the data to shape a first version of salient patterning in the data (Terry et al., 2019). Here, themes were constructed as the researcher made choices about what data segments were relevant and what was important about them, ensuring themes told a coherent and relevant story about the data. Clarke & Braun (2014) reiterate the importance of developing a central organising concept at this phase, ‘a clear core idea or concept that underpins a theme’ that is shared across a number of codes. In viewing gender as the central organising concept at this stage, it allowed the researcher to assess whether or not any particular codes fitted within it.

Theme development was influenced by Kreiser and White’s (2014) model of gender based sociocultural and psychological influences impacting phenotype expression and interpretation of symptoms of females with ASD over the course of development. Using Bussey and Bandura’s (1999) social cognitive theory of gender role development, Kreiser and White outline how manifestation and identification influences are moderated by gender as an alternative explanation to the gender discrepancy in ASD diagnosis. A conceptual guide to the author’s adaptation of the outlined model makes clear the connections between themes, Gender based role expectations and Male-centric view of autism. It conceptualises the reciprocal nature of impacting factors (both at the individual and societal level) on the women in terms of their external behaviour and internal thought processes (respectively labelled ‘external me’ and ‘internal me’) which are highlighted as compensatory strategies, both positive and negative.

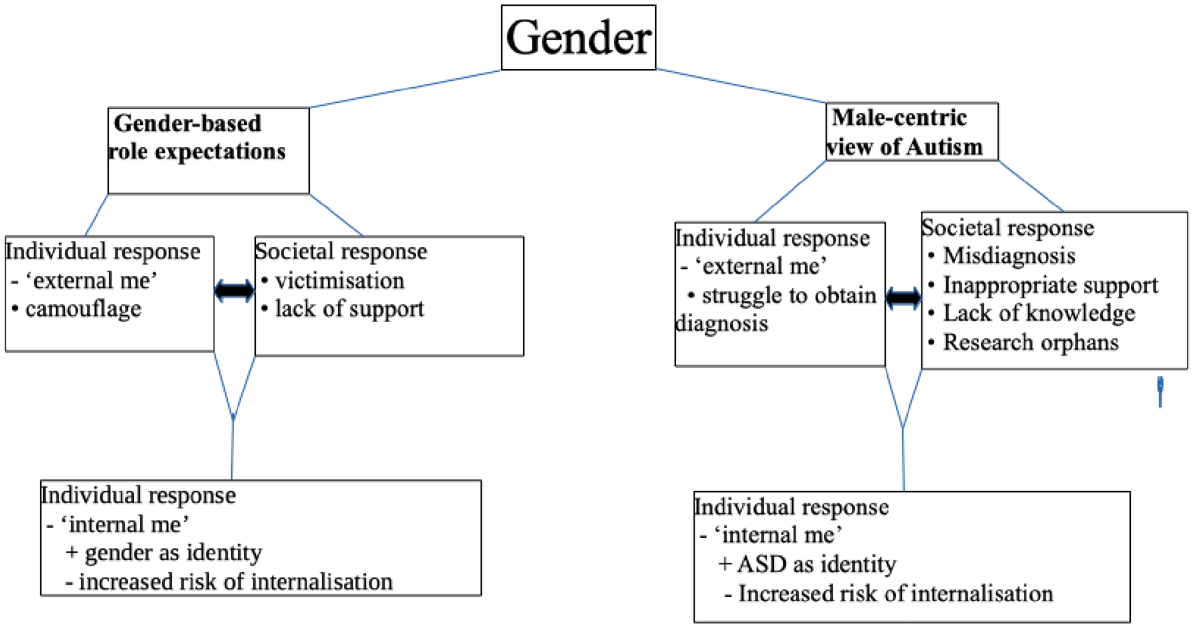
Conceptual Guide



* (Kreiser & White, 2014)

Subthemes have been incorporated into the model under broad headings illustrated overleaf in the Thematic Map.

Thematic Map



Braun and Clarke's (2006) and Buetow's (2010) thoughts on saliency analysis, where codes and themes do not have to be present in every transcript to be meaningful, also influenced work at this phase. While frequency is an important factor in theme development, 'the researcher's role is about telling a story which involves capturing the different elements that most meaningfully answer the research question' (Buetow, 2010, p.124). Work at this phase involved multiple levels of repeated cutting and pasting data extracts under broad headings to organise the data, followed by the use of visual aids to capture the researcher's ability to identify and understand potential themes in relation to each other (Braun & Clarke, 2013).

Reviewing and defining themes (4 & 5) : These phases involve further shaping, clarifying and even rejection of some themes. Terry et al. (2017) suggest this process demands a reflection on whether or not all the data extracts that chosen themes represent relate to the central organising concept of the theme and the diversity of meaning around this central organising concept. Defining and naming themes was also part of this process. Theme definitions were provided for the two main themes, ‘male-centric view of autism’ and ‘gender stereotyped roles’ and captured a short summary of the scope, core idea and meaning of each theme (Braun & Clarke, 2013).

Report Writing (6) : This is a distinct final period of refinement where the researcher weaves together the data and analysis and connections to scholarly and other literature into a singular output that answers the research questions (Braun et al., 2019). The researcher chose to use data extracts both illustratively and analytically in the Findings Section, with reference to the literature made in the Discussion section of the thesis.

3.8 Qualitative validity

According to Burr and Dick (2017), rigour is achieved when research outcomes can be replicated and ‘objective reality’ mirrors what is observable. However, within social constructionist research, an objective truth is absent and the knowledge produced is ‘already partial and situated;[where] findings actively construct the social world which is itself an interpretation and in need of interpretation’(Aguinaldo, 2004, p.128). Therefore, the criteria currently used to assess validity in quantitative research is not fit for a qualitative purpose. Attempts have been made to engineer more appropriate criteria, but there is no universal application as yet (Braun & Clarke, 2013).

Lincoln & Guba (1985) attempted to engineer such appropriate criteria in order to establish trustworthiness with qualitative research in mind. Trustworthiness was refined by introducing the criteria of credibility, transferability, dependability and conformability. Although widely referenced, these criteria have been critiqued as a parallel of more conventional positivist criteria of reliability and validity and thus may remain inadequate for qualitative research (Sparkes, 1998, as cited in Kanfiszer, 2015). An attempt to apply trustworthiness criteria to the individual six phases of TA by Nowell et al., (2017) was reported as successful. However, their use of approaches such as member checking and triangulation were not deemed appropriate for the current study. As noted by Braun and Clarke (2013), ontologically, member-checking is situated within a realist framework; and they advocate ‘understanding results from a critical position, where they are an interpretation, underpinned by theory (and subjectivity), the participants cannot ‘prove’ or ‘disprove’ the analysis, because it is not intended as a reflection of their experience as they understand it’(Braun & Clarke, 2013, p.285). Similarly, triangulation in its varied forms (method, investigation, theory and data sources (Carter et al., 2014), is arguably inappropriate for a ‘BIG Q’ study such as this, which views meaning as fundamentally tied to the context in which it is produced rather than an observable ‘truth’ that can be affirmed by others in some way (Braun & Clarke, 2013). However, the researcher’s study supervisor reviewed and provided guidance on each stage of the thesis development. Additionally, the researcher had dismissed member checking from her reading at the study’s outset due to potential risks in asking women to revisit traumas they may have disclosed during interview.

Within the context of a constructionist RTA and a social constructionist epistemology, Aguinaldo (2004) proposes social constructionist validity prioritises researcher reflexivity where explicit declaration of ontological, epistemological and methodological commitments address their construction of the world and hence, their own practice and power. The active researcher voice is present in this study’s explicit delineation of the above criteria as evidenced in a declaration of epistemology, ontology, foregrounding the construction of autism in Chapter 1 and referencing literature related to the social and cultural ideology surrounding autism and women.

Additionally, Yardley’s (2008) four theoretically ‘neutral’ qualitative validity criteria were also adhered to: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Firstly, the researcher must be cautious and not impose preconceived categories onto data but demonstrate careful consideration of the many meanings generated by participants. Women's experiences were contextualised within a broad literature to demonstrate the complexity and exceptions in the data. Secondly, the research should demonstrate commitment and rigour through in-depth engagement with the topic, including data collection and level and breath of analysis. Using a constructionist RTA facilitated in-depth engagement in each of these areas. Thirdly, Yardley (2008) highlighted transparency and coherence which were demonstrated in the inclusion of a thematic map and contextualised quotes following the six phase approach to RTA as previously outlined. Lastly, Yardley (2008) argued that research must have pragmatic use, generate hypotheses or even influence how we think about the world. It is hoped that through dissemination within the research field the current study can influence future research and professional practice.

Clarke and Braun (2019) recently incorporated their original 15 point TA quality checklist into a more detailed (20 point) specific guidance document: Guidelines for reviewers and editors evaluating thematic analysis manuscripts (April, 2019). The researcher faithfully applied these guidelines (outlined below) throughout the research process.

Evaluating the methods and methodology

1. Is the use of TA explained (even if only briefly)?
2. Do the authors clearly specify and justify which type of TA they are using?
3. Is the use and justification of the specific type of TA consistent with the research questions or aims?
4. Is there a good 'fit' between the theoretical and conceptual underpinnings of the research and the specific type of TA (conceptual coherence)?
5. Is there a good 'fit' between the methods of data collection and the specific type of TA?

6. Is the specified type of TA consistently enacted throughout the paper?
7. Is there evidence of problematic assumptions about TA? These commonly include:
    - Treating TA as one, homogenous, entity, with one set of – widely agreed on – procedures.
    - Assuming grounded theory concepts and procedures (e.g. saturation, constant comparative analysis, line-by-line coding) apply to TA without any explanation or justification.
    - Assuming TA is essentialist or realist, or atheoretical.
    - Assuming TA is only a data reduction or descriptive approach and thus has to be supplemented with other methods and procedures to achieve other ends.
8. Are any supplementary procedures or methods justified and necessary or could the same results have been achieved simply by using TA more effectively?
9. Are the theoretical underpinnings of the use of TA clearly specified (e.g. ontological, epistemological assumptions, guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?
10. Do the researchers strive to ‘own their perspectives’ (even if only very briefly); their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the ‘voices’ of marginal and vulnerable groups, and groups to which the researcher does not belong.)
11. Are the analytic procedures used clearly outlined?
12. Is there evidence of conceptual and procedural confusion? For example, reflexive TA (Braun & Clarke, 2006) is the claimed approach but different procedures are outlined such as the use of a codebook or coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as

analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development).

13. Have the authors fully understood their claimed approach to TA?

Evaluating the analysis

14. Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map?
15. Are themes reported domain summaries rather than fully realised themes?
    - Have the data collection questions been used as themes?
    - Are domain summaries appropriate to the purpose of the research? (If so, if the authors are using reflexive TA, is this modification in the conceptualisation of themes explained and justified?)
    - Would the manuscript benefit from further analysis being undertaken and the reporting of fully realised themes?
    - Or, if the authors are claiming to use reflexive TA, would the manuscript benefit from claiming to use a different type of TA (e.g. coding reliability or codebook)?
16. Is non-thematic contextualising information presented as a theme? (e.g. the first theme is a domain summary providing contextualising information, but the rest of the themes reported are fully realised themes) Would the manuscript benefit from this being presented as non-thematic contextualising information?
17. In applied research, do the reported themes give rise to actionable outcomes?
18. Are there conceptual clashes and confusion in the paper? (e.g. claiming a social constructionist approach while also expressing concern for positivist notions of

coding reliability, or claiming a constructionist approach while treating participants' language as a transparent reflection of their experiences and behaviours)

19. Is there evidence of weak or unconvincing analysis?
    - Too many or two few themes?
    - Too many theme levels?
    - Confusion between codes and themes?
    - Mismatch between data extracts and analytic claims?
    - Too few or too many data extracts?
    - Overlap between themes?
20. Do authors make problematic statements about the lack of generalisability of their results, and implicitly conceptualise generalisability as statistical-generalisability?

3.9 Ethical Considerations

Ethical approval for this study was sought and obtained from the University College Dublin Ethics Committee, Reference code: HS-19-30-Kinsella-Condon. (see Appendix K: Letter of ethical approval).

Continency was built into the design of the study to allow for the potential for participants to become distressed during the interview. All participants were made aware of their right to stop the interview at any point, to take a break and resume should they feel able to do so. The researcher's role of Educational Psychologist equipped her with the experience of responding to distress and knowledge of safeguarding issues. To support this process, a distress protocol to address these eventualities and information regarding helpful support agencies was developed (see Appendix L: Distress protocol). Any contact with a support agency would have been discussed in advance with the participant whenever possible. Post interview, participants were offered the opportunity to debrief, discuss their experience of the interview and ask any questions. They were also offered the opportunity to receive a summary report.

Interviews were recorded on an encrypted and password protected audio recorder and electronic files were stored on secure electronic storage. These will be deleted following thesis examination. Paper copies of the anonymised transcripts and identifiable data were originally stored in separate sealed envelopes in a locked filing cabinet in the researcher's locked work office which is accessible only to the researcher. Due to changes in work circumstances due to COVID-19, paper copies of anonymised transcripts and identifiable data were safely transferred and securely stored in the researcher's home office, accessible only to her. Paper copies of all data will be destroyed following a period of seven years (in line with the Psychological Society of Ireland (PSI) data retention guidelines).

3.10 Summary

This study is framed by a social constructionist epistemology, with constructionist Reflexive Thematic Analysis deemed to be the most appropriate method of data analysis. The process of RTA has been explored alongside procedure, trustworthiness and ethical considerations. The next section will explore the findings of the multi-phase RTA analysis.

Chapter Four: Findings

4.1 Chapter Overview

This chapter documents the lived experiences of sixteen women with an ASD diagnosis. The findings are based on 31.2 hours of interview data. The audio was transcribed, prior to being analysed using Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2013) as detailed in the previous chapter.

While each woman conceptualised their experiences and the meaning of their diagnostic label at an individual level, patterns across their stories were identified, extracted, themed and are illustrated in direct quotes. The analytic process generated a number of themes and subthemes which collectively contextualise the meaning attached to experiences in women's perceptions of themselves, the influence of others, the impact of services and support and dominant cultural ideologies.

From broad-based questioning around women's life experiences, gender was highlighted as an overarching theme that played a dominant role in the individual differences in their lives, both pre and post their diagnosis of ASD. Women's stories illustrated how cultural expectations of gender and discourses of ability influenced how they navigated their lives across the lifespan. In making sense of these experiences, the women repeatedly drew upon notions of 'normalcy' and how this impacted their understanding of themselves and others' (mis)understanding of them as individuals. Two main themes were developed from discussion: 'male-centric view of autism' and 'gender-based role expectations' which are delineated by twelve subthemes. 'Male-centric view of autism' includes six subthemes; '(mis)diagnosis', 'inappropriate support', 'lack of professional knowledge', 'struggle to obtain ASD diagnosis', 'ASD as identity' and 'research orphans'. 'Gender-based role expectations' also includes six subthemes; 'feeling different', 'victimisation', 'camouflage', 'lack of support', 'motherhood', 'gender conflict' and 'gender as identity' (Table 3).

To increase the inclusivity of voices from this study, additional quotations to those used in Table 3 are sometimes utilised to further illustrate subthemes. Pseudonyms are used to maintain participants' anonymity. Some quotes have been edited to support clarity for the reader and missing data are represented by the use of '…'. Additional explanations of points are included within '[ ]'. Frequency counts are sometimes reported, mostly as general descriptors of frequency around a theme or meaning, not as a measure of prevalence but to help gauge the extent of shared experience (Braun & Clarke, 2013). The terms *majority* or *most* are used when almost all participants reported the meaning; *frequently* refers to meaning described by more than half; *some*, to less than half the participants and *minority,* to three or less.

4.1.1 Terminology

According to the WHO (2013), the term 'disability' is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal). Central to this definition of disability is the relationship between the individual (with a health condition) and environmental factors (physical, social and attitudinal). It is the interaction of the person's health characteristics and their contextual factors (environment, personal) that produces disability.

According to the World Health Organization (WHO, 2015), the term 'sex' refers to the biological determinants that define men and women, and 'gender' refers to socially constructed characteristics such as roles, behaviours, activities, and attributes that a given society considers appropriate for men and women.

Table 3
Reflexive Thematic Analysis Themes and subthemes

Theme	Subtheme	Example
Male-centric view of autism	(Mis) Diagnosis of mental health	'My bipolar, which I now know is really common for women on the spectrum, that's the default wrong diagnosis' (Deirdre)
	Inappropriate support	'I realise that for years he was trying to use CBT and I just didn't get it, and we know that some people with autism just don't respond to CBT' (Amy)
	Lack of professional knowledge	'So I arrived to my GP with my observations, he looked at me like I was an alien…his jaw dropped , "what's this? I don't have time for this" (Linda)
	Struggle to obtain diagnosis	'…they make you feel like you have Munchausen by Proxy like, they were like we don't think there's anything wrong with you' (Jenny)
	ASD as identity	'Hearing it was like "ah this is great, thank god I have a label" and then it was like "oh no", you don't want anyone to know have a label now' (Sheena)
	*Research orphans	'…well autism is just like little boys who play with trains isn't it ?' (Annemarie)
Gender-based role expectations	Feeling different	'There was great hope for me that I would be a real girl' (Jean)
	Victimisation	'It was an all girls' school and girls can be bitches to each other. It was dog-eat-dog in there' (Aoife)
	Camouflage	'I should have got an Oscar, I'm the worlds' best actor' (Dorothy)
	Lack of support	'Quiet ones don't get the attention' (Aoife)
	Motherhood	'…they were the swans drifting along, I was the legs kind of paddling underneath…' (Linda)
	Gender as identity	'I don't try to be either but I slip into the male side of thinking a bit more easily' (Sheena)

*(Bazelon, 2007)

4.2 'Male-centric view of autism'

This theme reflects women's experiences of their wellbeing without knowledge of autism and as an adult with a diagnosis of ASD. Their identification with gender played a central role in the (mis)understanding of their mental distress by health care providers. Being misunderstood led to a number of interactive inequalities in women's lives related to sex stereotyping which served to increase their psychological distress. Analyses will be structured under subtheme headings.

4.2.1 (Mis)Diagnosis of mental health

'I am so used in this life to being disrespected, told I'm crazy, ignored, spoken over, told I'm imagining things, dismissed….as a woman, any woman dealing with medical professionals, you're going to have more of that'. (Amanda)

Poor mental health, both historic and current, was a dominant shared experience for the women and for those whose teen daughters who also had a diagnosis of ASD. Most women reported having experienced one or more mental health difficulties prior to their ASD diagnosis. Their distress typically manifested in middle childhood/early adolescence with depression, anxiety and eating disorders being the most commonly reported. Mental health difficulties were associated with a range of factors, including dysfunctional family relationships, traumas and bullying at school. While the women's individual stories were varied the influence of their gender underlined discussion of healthcare providers' (mis)understanding of their distress, inappropriate treatments and delayed diagnosis of ASD.

Women's interactions with medical professionals highlighted gender stereotypes regarding a proclivity to emotional problems amongst women. This frequently led to an initial diagnosis of depression with pharmaceutical treatment being the typical response. For some, this gendering of emotions led to outright dismissal of their difficulties and poor consideration of the severity of their needs. Not being believed or listened to when seeking help, left women feeling they were being dismissed and their symptoms discarded.

> I was asked to move to another room and I just wasn't able to move my body, and I was rocking and I was kind of crying, wailing. They said, 'You'll need to leave by the back door, you're scaring the other patients'. The next time I go to the doctor, he started our thing by telling me off for having a 'hissy fit', his words (Deirdre)

Relatedly, misreading the severity of women's distress directly impacted the women's access to much needed supports. Linda recalled her GP's response when she first articulated her belief she may be depressed '…you are too young to be depressed, there's no problem, go home'. Amy's experience was somewhat similar, 'My [GP] told me she doesn't think depression exists, so that was great [laughs], I just needed to buckle down really, that's what she told me'. Both women had a history of suicidal ideation and self-harm at the time they first sought help from their GPs and neither was referred to support services.

The majority of participants recounted inaccurate interpretation of their difficulties which sometimes resulted in inaccurate mental health misdiagnoses. Their reflections suggested that health care providers' gender recognition bias prevented a more rigorous examination of symptomology frequently related to ASD. For example, difficulties with change, feeling socially overwhelmed and for each of the women interviewed, sensory challenges of some kind. '…[the anorexia] was never body image related, it didn't come from that place, I always had digestion sensitivity and issues with the physical…the sensory piece' (Amy); '…on my bad days on campus I would literally shout at buses because I'd be like 'why are you doing this to me?'. It was my auditory sensitivity. I was in constant pain' (Emma); 'It's not a panic attack, I didn't feel scared a lot of the time, it was my brain shutting down because of complete overload and sensory overload' (Aoife). Women experienced their (mis)diagnosis of Borderline Personality Disorder as particularly stigmatising and this added to their sense of hopelessness and isolation:

> You go to a new mental health professional and you tell them that, they're immediately thinking 'Oh this is a problem person' no medication will help, no therapy, that's just the way you are…maybe not even wanting to work with you, that sort of thing (Amy)

4.2.2 Inappropriate supports

'…emotion regulation [therapies] are the virus of the mental health system' (Deirdre)

Women who accessed support services did so typically after a crisis or breakdown of some kind. Women used the lens of their ASD diagnosis to interpret these experiences as the cumulative cost of being misunderstood and undiagnosed. Women referred to crisis experiences as the end point on a type of stress continuum that moves from 'autistic shut down' to 'autistic burnout'. Similar characteristics were disclosed for both and included bouts of extreme fatigue, impaired mobility and poor communication skills, 'when I'm distressed I cannot talk…so when I would most need to speak up, I can't speak…if you don't, you immediately become, in a sense, the victim' (Linda); '…it's like analogue having to consciously command your body to do what you want it to do' (Deirdre).

> My GP is trying to convince me that I have chronic fatigue but actually what I'm experiencing periodically is autistic burnout. I'm trying so hard during the day to hold it all together and be what I need to be but it's literally, physically flooring me' (Amira)

Misdiagnosis translated in some instances to years of largely unbeneficial involvement with public (and some private) services which served to further perpetuate women's sense of distress. Women spoke of waiting lists, service related administrative pressures, lack of practical accommodations and inappropriate therapeutic approaches. Without consideration of their unique communication and social interaction needs women's engagement with intervention was intermittent and frustrating in nature as summarised by Amanda:

> I didn't want to go to do group and told them…by the time I got to see someone individually, it was the wrong kind of therapy, she tried to frame everything I experienced in grief and told me 'for grief therapy to work you have to come when the grief is fresh and the person's just died. I was like, 'I tried'.

Deirdre described a contrasting experience where she was listened to and where she received the practical supports she needed at that time to help her engage with the service. This was the exception across women's experiences and described as a 'lotto' in terms of its impact and the rarity of occurrence. In the absence of appropriate treatment and support, most women prioritised and accessed support in a private capacity both online and in person. Those who could not afford to do so, did without.

4.2.3 Lack of professional knowledge

'So I asked my GP first and he had not a clue of what I was talking about'. (Mary)

The majority of women thought that the lack of professional consideration given to an ASD diagnosis for themselves (and in two incidences their daughters) was partially due to a lack of professional knowledge of how autism presents specifically in females. Women had done a great deal of reading and research on ASD and women, some were reading for years, and some considered it their special interest. This led to problematic relationships with health care providers with women complaining they had more knowledge about autism and women than, for example, their GP. Women suggested that recognition bias may have impeded health providers' consideration of ASD diagnosis in females, who showed 'surface level' social ability as they may have operated with a preconceived generic notion of 'people with ASD' who have very severe and overt social and communication problems.

> …the old-fashioned view of autism equals male, non-verbal, completely incapable of functioning. And you're just like, 'Nope, I'm afraid not'. My doctor wouldn't believe that I was autistic. He didn't think my daughter was…. because we're capable of looking somebody in the eye without spontaneously combusting, we're not going to do it for large amounts of time but we can do it. We're not sitting, rocking in a corner. He doesn't see when we're rocking in corners, that's the thing, he sees when we're masking and functional (Deirdre)

Some women also felt that these unhelpful stereotypes were perpetuated in the wider media and identified well-established autism charities and popular biographies written by parents of children with ASD in particular as complicit in this practice. For a minority of women across jurisdictions, stereotyping within the autism community was something they personally struggled with, as it added to the women's delay in seeking support to explore a diagnosis. Emma explained:

> I was really worried about being [1]gas-lighted, because I had already kind of found some of the autistic community online. I was worried they wouldn't think I was really autistic because I'm verbal and can look at people and that kind of stuff… all of these stereotypes…it was really hard to think, like, oh I could be autistic and I have needs. I was like, am I really autistic? I was still like 'Oh that's not enough.'

The impact of gender recognition bias was pronounced in this study. The majority of women (fourteen) independently sought their diagnosis of ASD not on the recommendation of a healthcare provider, but following suggestions from friends or family members or as a result of personal research related to their children's diagnosis of ASD. This process was costly in terms of personal finance (with no public assessment referral route available to the majority) and also in terms of difficulties finding practitioners specialised in ASD who also specialised in recognising ASD in women. This lack of specialism was noted by women across jurisdictions.

4.2.4 Struggle to obtain ASD diagnosis

'…they make you feel like you have Munchausen by Proxy like, they were like "I don't think there's anything wrong with you"' (Jenny). Women who had discussed their initial thoughts about autism with their family doctor were frequently disbelieved and dismissed which negatively influenced their pursuit of the diagnosis. Women storied paternalistic attitudes when seeking to assert their rights to have the diagnosis explored as a possibility. Their motives were questioned and contextualised in broader discussion of 'the current obsession with labelling' (Jenny) and/or related to broad external indicators of

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[1] *Gaslight*: to manipulate another into doubting their perceptions, experiences or understandings (APA, nd).

'coping' such as having a job, attending university, being a parent or having a partner, all of which can be summarised in Annemarie's experience:

> My GP told me not to bother because she said, 'You're doing alright, you're married and you're working, so why do you want to bother?' And I said, 'Well, I really think I might be autistic.' I had to insist**…** she said I'd be taking resources away from children, which is ridiculous, yeah I suppose she just thought I didn't need it. If my wife hadn't insisted that I keep pressing her, maybe I would've left it at that.

In contrast, there were two exceptional cases of a speedy diagnosis and both occurred in a jurisdiction that had an ASD adult public assessment service. In both instances, the health professionals involved (GP and a Health Psychologist) recognised the women's signs of autism, in their behaviours and supported them from the point of referral until the women were diagnosed. Amanda was one of these exceptions, and although she suspected she had autism for some time, the diagnosis would not have happened in any other way, 'I would never have the confidence…I just didn't believe that anybody would take me seriously.. so it was really astonishing for the psychologist to bring it up independently'.

4.2.5 ASD as identity

'Hearing it was like "ah this is great, thank god I have a label" and then it was like "oh no", you don't want anyone to know you have a label now'. (Sheena)

A separate but related experience for some of the women, involved their family doctor's explicit disregard for their independently sourced diagnoses which served to undermine their efforts to integrate their ASD diagnosis as part of their identity. Although untrained in assessing neurodevelopemental disorders, GPs passed negative judgements regarding the professional competence of other health practitioners specialised in the area, causing women to query the validity of their diagnosis. '[GP] is dismissive of it because of who I got it from.. I would like another diagnosis because I do feel that her diagnosis isn't recognised… I think a lot of people dilute the assessment because of who it's from sadly' (Jenny). 'She kind of laughed when I said it, she said 'we'll just park that for now'. I immediately thought I won't be saying that again… if I'm not believed [autism and women] is not believed' (Aoife). Unsurprisingly, these experiences led to loss of trust towards their GPs and led a minority of women to assert themselves by accessing healthcare elsewhere. However, being under the care of the same family doctor for significant periods of time made leaving a difficult decision for others.

Despite these unhelpful experiences, the vast majority of women experienced their diagnosis of ASD as largely positive. It served to bring important practical benefits such as financial allowances and educational accommodations for some and equally important psychological benefits related to a sense of agency in understanding themselves. Processing the diagnosis was not a neutral experience and took time for most. But, in the main, women spoke of experiencing feelings such as validation, vindication and relief. For Sally, '…my life is significantly happier and an easier one to navigate'. Aoife (and others) described making personal financial sacrifices to fund the assessment and viewed it as an indulgence, as a kind of 'birthday present to [her]self'. The ASD diagnosis allowed women to challenge the internalised 'social norm' and associated negative self-beliefs that they were fundamentally 'wrong', 'different' and 'weird'. 'That's when the world became clearer to me, that I wasn't the weird person I'd always felt. The world was just weird and I was a triangle trying to fit into a square' (Jenny). It also provided women with a sense of self compassion, women repeatedly spoke of being kinder to themselves. It represented a source of resilience to others, '…it was like, there's nothing wrong with me, I'm just different…it went from 'No I'm not weak' to 'I'm really strong' because I deal with more than other people and I'm incredibly strong' (Jean). For many, it provided opportunities to relate and connect with other females with ASD, providing a sense of belonging to 'a community' (Dorothy) through reading, online ASD forums and/or through support groups; '…I only have to live for 13 days… [until the bi-monthly group meeting], it gives me that grounding, I never miss it, even if I don't say anything, something happens to charge me' (Sheena).

A minority of women queried the impact of the timing of the ASD diagnosis on their lives suggesting that a childhood diagnosis may not have been that helpful. For Deirdre, 'I think I would've limited myself out of fear. I probably wouldn't be married. I probably wouldn't have had children. I probably wouldn't have gone to university'. For Shauna, 'I feel a bit like, while emotionally I might sometimes look back and cry and think 'I wish I hadn't had to fight every step of the way to feel like I was understood', I wouldn't be the person I am today'.

> I think in a way I was blessed not to know I was 24…. until I had achieved all the non-stereotypical things …like tying my shoelaces, eye contact, going to college, living independently, having my own job, would I have achieved those things? Possibly not because it might have stopped me. I believe I was in the best place possible to find my diagnosis when I was 24. I had all this achieved, failed but achieved (Sheena).

Despite the myriad benefits the diagnosis of ASD bought to most, women were reluctant to share their diagnosis outside of close relationships and spoke of the difficulty in integrating autism as a part of their identity. The combined fear of being on the outside of the expected norm of neurotypicality and association with stereotypes correlated with a male-centric understanding of autism, made most women keep their diagnosis 'secret'.

Varying perspectives were given around the disabling nature of a diagnosis of ASD. Most women experienced a related internalised ableist conflict that prevented the majority from sharing their diagnosis with others. 'As a woman, as a disabled person or a minority of any kind, there is a lot of stuff in the media to tell you about all the ways that you were wrong' (Mary). Fears of negative evaluation from an ableist society with a specific male oriented view of autism were juxtaposed with the positive attributes women specifically associated with their diagnosis. Valued attributes included discrete cognitive skills, academic aptitude, work ethic and personal traits, such as loyalty, honesty, kindness and acceptance. Women expressed the challenge of keeping self-acceptance separate from negative attitudes and autism stereotypes in their personal and work lives. ‘For me I feel that autism is actually my superpower. It is what makes me fantastic at a lot of what I do. But other people don’t see it that way’ (Amira). For Sheena, this conflict prevented her from progressing an important relationship in her life: ‘…I’m not giving him the skills to know me…the fear is he walks away…all that effort getting to some sort of acceptance space and you’re like ‘have to go and fuck this up now’…no I can’t’ (Sheena).

Fear of disclosure in the workplace, in particular, was a commonly expressed fear and largely grounded in anecdotal stories of women known to them who were disadvantaged following disclosure of their diagnosis of ASD. The only woman interviewed who disclosed her diagnosis in her workplace had done so recently and this had significantly compromised her sense of wellbeing. In an attempt to progress the inclusiveness of her workplace (which was within her professional remit), Shauna’s disclosure was met with an organisational culture at odds with its advertised commitment to diversity. The conversation about paradigm shifts from a medical model to a social model of disability she had hoped her disclosure would begin, triggered an ironic reaction whereby organisational policy mandated a medical assessment of her needs:

> …HR said ‘we’re sending you to a doctor to make sure we don’t discriminate against you’’. I’m saying ‘I kind of feel discriminated against by being sent to a doctor’. He actually said ‘you won’t know what you need, the way a doctor will’.

Unsurprisingly the majority of women wanted to distance themselves from the view of autism as a disease or disorder, viewing their autism as a form of diversity among other diversities that requires understanding: ‘They think we’re disordered… I don’t like that term at all, I prefer difference’ (Annemarie): ‘So I would love it to become that my type of brain is different but celebrated…like you are just on a different frequency but we’re still all people’ (Dorothy).

4.2.6 Research Orphans

'You can't ask a [non] intercounty hurler what it's like to be an intercounty hurler … he's never been an intercounty hurler' (Sheena) Most women commented on the lack of visibility of females in general in autism literature which increased their sense of alienation from the autism community: '… I felt all the things I found described a man who we know was a trainspotter, who couldn't make eye contact, who didn't have any friends. I just kept thinking 'Good god, that's not me, no',' (Dorothy). Others linked their sense of estrangement to the literature's theoretical focus:

> I was reading, but it wasn't voice, it wasn't a case study…a professional in the ASD world and they don't have it, they don't live with it, they don't experience it. I feel removed from that world… I wasn't reading voices…I'm living it (Sheena).

Being aligned with Extreme Male Brain theory of ASD (Baron-Cohen, 2002) was particularly stigmatising for some who evidenced their interest in, and, in some cases, life-long dedication to, advocacy work as a clear demonstration of their empathic nature: '…the no empathy thing… nonsense but you internalise it and it's dehumanising' (Amanda). Women working in caring professions in particular articulated how their capacity to empathise was both a strength and a challenge in that they tended to over-empathise with others in need and how this left them emotionally vulnerable:

> '…[empathising] makes me very responsive and discrete in how I work but I carry a lot of guilt if I can't get through to them, if I can't help them get to where they need to, I'll take it very personally… I need to learn to let go, to detach' (Sally).

Others experienced struggles to have their communication of empathy correctly interpreted by others, noting it may look 'different' and not 'socially appropriate' because of their autism, for example, a delay in processing, and this should not be equated with not feeling for others.

> I may not have the words…or any words…or give a 'comforting' physical response…but I will feel another person's pain deeply, I will go home and cry for them in private and ..try to figure out practical ways to help… their pain will sit with me for a very long time (Deirdre)

A minority of women spoke of ‘budding shoots’ of a wider awareness of women in the research community evidenced by their attendance at conferences with a ‘female focus’ or their role as panellists and presenters at similar events.

4.3 ‘Gender-based role expectations’

Historically, the women developed a sense of self within the confines of this theme, absent a knowledge of autism. As adults, a diagnosis further broadened this sense. Their identification with gender seemed central to this and to be constructed from their perceptions of ideological constructs of femininity and the cultural expectations of women. Analyses will be structured under subtheme headings.

4.3.1 Feeling different

‘There was great hope for me that I would be a real girl’.(Jean) A repeated experience across all interviews and one that began in early childhood was that of feeling different. Most of the women used the word ‘different’ specifically to describe how they felt about themselves and everyone talked about feeling like an ‘outsider’, a ‘blacksheep’ ‘weird’ and ‘out of sync’ in some way. ‘I just always felt different, people were on certain wavelengths and I was never on those wavelengths and I can see, it’s almost like I’m observing it and analysing it, but I can’t ever bridge that gap’ (Mary).

In childhood, the women’s feelings of difference and ‘not belonging’ were consistently represented as a socially mediated experience, as a failure to conform to their perceptions of what their peers, ‘normal’ girls, are like and what it means to be a ‘normal’ girl. For the majority, falling short of these gendered societal expectations encouraged negative self-beliefs to develop early in their lives: ‘…as a result of that label ‘girl’…this is how I’m expected to behave, these are the things that I’m interested in….and just never being able to meet that standard; not smiley enough, polite enough…' (Sally). For some, the pressure to conform to gender-linked behaviour was explicitly expressed within the family. 'I often got… "why are you so angry, why don't you be softer"… they wanted to turn me into this little girl and play a really feminine role, be submissive, like that's how girls behave'(Dorothy).

Feeling dissimilar to their female peers was also related to the women's awareness that their interests were not necessarily aligned with stereotypical female interests and this continued to be the case across the life span. As children, play interests would have differed for the majority of women. 'I suppose I was never really interested in playing in the same way as the girls that would have been on my road…and I never really liked to play with dolls, doll houses or anything like that …far more engrossed in computer games'(Amira). In adolescence, Sheena recalled '… if [female teen peers] were going shopping on a Saturday, I was going to the farm with my dad. If they were going to the cinema, I was going to a hurling match'. In adulthood, women chose female company more judiciously and actively avoided 'overtly feminine' peers; 'I know a lot of women more 'girly' than I am …just can't do it…I'm the one who goes to the hairdresser every three years and can't remember or care where I bought my clothes' (Linda).

Most women commented that not relating to stereotypical female interests led them to identify more with the males in their lives, typified by Jenny's comment, 'Like I would've been normal to boys, this kind of quirky unusual girl with loads of interests that would have been interesting to a boy, but weird to a girl, so I've never related to girls'. For Dorothy, 'I'd be off with the lads in the corner with a beer watching sports rather than standing with the girls looking pretty...I just couldn't'. However, a minority of women described enjoyment of activities considered to be typically both masculine and feminine. Feeling connected to boys for most women was related to a combination of males' lack of judgement and easy-to-interpret style of communication:‘Boys are easier, they just get on with it. If they like each other, they like each other and they hang out’ (Amira).

> [boys] didn’t expect anything of me. You could come in by yourself, sit in the middle of them, they didn’t ask you a million questions, they didn’t judge you on...if I came in in a pair of combats or a dress with makeup, they didn’t judge either way (Dorothy)

In contrast, female company was experienced by the majority as both ‘confusing territory’(Sally) at best, and at worst ‘a nasty place to be’ (Sheena).

4.3.2 Victimisation

‘…[girls] back bite, bitch or ostracise…’.(Sarah) Adolescence was identified as a distinct period of rapidly increasing complex social demands during which women’s sense of difference from their female peers was magnified. Peers became ‘adults overnight’ (Jenny) and the ‘game changed’ (Amira). ‘I don’t know how [teen girls] even learnt to talk in the new way they talked. I didn’t know how they knew where they got their information…it was just a world I couldn’t break into’ (Sally). Sanctions for being on the ‘outside’ during these formative years resulted in severe long lasting consequences with the majority of women recounting painful memories of social rejection, victimisation, isolation and distress.

While social motivation and interest in friendships was strong for most women, their teen friendships were characterised as limited in number, intermittent in nature and typically short lived. Women recounted painful memories of being bullied both within their existing female relationships and by those unknown to them. A minority of women experienced overt bullying, including physical aggression from both sexes, but relational aggression typified by rumour spreading, manipulation, exclusion and indirect nonverbal behaviour like giggling and eyerolling was common place. ‘…I was always like the third wheel, girls are awful, when there were ‘best friends’, I always seemed to be the third one that they’d allow in or out on their whim' (Shauna); '…like my best friend who I had for years actually treated me so badly. It was one of those friendships girls sometimes have where one of them runs rings around the other psychologically, it was so unhealthy'(Amanda). Emma recalled being victimised in person and online:

> She found me online, she pretended to be someone else and kind of tricked me… at school she['d] like yell words at me …it was subtle because it would only happen during passing periods. I was just frightened to walk down the hallway.

Women drew upon their deviation from female stereotypes as the basis for their peers' behaviour and considered this, in combination with a belief that their lack of social skills, had caused other female peers to react so negatively: '…finding myself in a circle of girls my age and not understanding how I was suddenly in trouble, how I had somehow said the wrong thing…had broken a rule that was never made clear in the first instance' (Sally). For Deirdre, '… it felt so unfair…I hadn't changed but a whole cohort of people turned against me… I'd be like "they were my friends last week"'. Even when negative reactions from others were retrospectively clear, some women recalled being unaware that they were violating gender normative standards or acting oddly: 'I'd go to school and the cuffs of my jumper would be all shredded from the mice. It's not like I didn't have hygiene, I was just weird' (Shauna). In discussion of how her safety was threatened by a particular group of girls, Jenny noted, 'I got bullied because I stared…they were waiting for me outside the [school] gate… I would stare at them, I wouldn't realise and they'd just think I was weird'.

A sperate but related experience shared by half the women involved their vulnerability in adolescence in particular to sexual exploitation including: sexual harassment, grooming, abuse and rape. While women's individual stories varied, in the main their vulnerability to these traumas was connected in one way or another to being socially isolated from their female peers. Previous rejections, when combined with a perceived delay in not adhering to stereotyped gendered narratives about sexualised teen behaviour, left Shauna vulnerable to risky behaviours: ‘So at 15, I realised oh *this* [being sexually active] is how you get in and you drink and smoke and do drugs and… now I realise how many stories get told at school by girls about what they’ve done and they might not have done any of it’. Being excluded from their peers translated to a lack of feedback about what a healthy relationship should be for a number of women: ‘I just had no way to realise what’s healthy and what’s not’ (Jean);‘I wasn’t in the gang… I missed cues and conversations, I don’t know like even how to navigate a boyfriend’ (Aoife). Not being part of the ‘gang’ left Amira particularly vulnerable to predatory adult behaviour, ‘ I [didn’t] know what is normal…I was 16 they’d be 26, I’ve always been quite articulate, adults feel comfortable talking to me, like ‘she’s not a typical 16 year old’, maybe that’s just me justifying their abhorrent behaviour, when I look back now I’m disgusted’. For Jenny, being in an abusive relationship in her teens acted as a buffer to the painful social interaction challenges she faced:

> I was in a relationship from 14 to 19 that got me through a lot of social things …he would manipulate me to do whatever he wanted…I was with him a lot so that’s kind of what got me through those years

4.3.3 Camouflage

‘I should have got an Oscar, I’m the world’s best actor’. (Dorothy) Women’s diagnosis of ASD seemed to help them to interpret their experience of rejection, exploitation and isolation. Most recalled unsuccessful attempts to understand and ‘mask’ their social interaction difficulties, both at a cognitive and behavioural level during this time. The majority of women understood their social deficits as a fundamental skill gap. This led them to adopt a social anthropologist-type role where they observed, recorded and, in some instances, imitated others, assimilating social information from a variety of sources such as parents, books and T.V. Sally recounted hours of soap opera and sitcom viewing ‘constantly storing up the data …until I reached a point when it was internalised …I could just reach for the right thing to say or hold back on something I would say that was wrong’. Dorothy spoke about profiling people, ‘I was trying to figure out a way to be interesting and literally took notes about how they behaved and talked’.

However, compensatory efforts to emulate peer behaviour and adopt gendered social scripts commonly proved unsuccessful and costly in terms of women’s wellbeing, and involved sacrificing some sense of self: ‘if you want to have friends, if you want teachers to like you, the overall message [is] that you can’t really be who you want to be’(Sally). Deciding to ‘mask’ was a conscious effort for most women and was evident in their descriptions of weighing up the costs of bullying and non-acceptance when not masking. As poignantly summarised by Deirdre:

> …being me would come at an enormous cost. So for me, to be able to show and express myself as I am was an act of extreme courage because when I tried doing that without knowing what the cost was, as a child, it resulted in bullying and rejection and not understanding people’s responses. So to keep myself safe, I tried really hard to be ‘normal’, but I wasn’t very good at it…the choice… I’ll have to shut down what I am in order to pass, or do I risk being me, knowing what the cost might be out in the world?

Some women developed distressing fixed beliefs about the act of masking itself. It led to intrusive thoughts about ‘mindreading’ for Emma, evidenced ‘a faulty personality type’ for Jean, indicated to Dorothy that she had been born in the ‘wrong era’ as social interaction was perceived as more interpretable in earlier decades, and evidenced ‘sociopathic’ tendencies in Sally: ‘I was one person with people and another person by myself. I was aware of jumping from one personality back to my own and my own was the more ‘secret’ one, the one I wasn’t comfortable expressing’.

4.3.4 Lack of support

‘Quiet ones don’t get the attention’ (Aoife) Masking their difficulties did not help the women achieve their desired ‘normalcy’. Women’s repeated experiences of social rejection and victimisation led to a devalued sense of self and unhelpful but strongly held beliefs about being essentially ‘wrong’, ‘stupid’ and somehow ‘lesser’. This damaging comparison to a traditional gendered stereotype of what makes a ‘normal girl’ was internalised and became the source of much distress. ‘I always thought I was wrong and secondary school really enforced that…everyone else could do it, even people who weren’t that popular, they always find their groups, their niche. I couldn’t even find that’ (Dorothy).

Unsurprisingly most women recalled experiencing a significant decline in their wellbeing during their secondary school years in particular. Women rarely disclosed their struggles to others for a number of reasons; not having the know-how to seek support, concern about potential financial costs for guardians and the risk of further isolation. As a result, women internalised their difficulties and typically, social withdrawal increased. Possible indicators of distress such as periodic mutism, uncharacteristic absenteeism and prolonged illness were observed by teachers and some parents, but rarely resulted in intervention. Social expectations of passivity and compliance typically attributed to, and expected of, girls’ temperament in conjunction with academic ability seemed to facilitate their distress to go ‘under the radar’. It is noteworthy that the majority of women attended all-girls schools, either primary, secondary or both, possibly suggesting an increased value in such feminine attributes for both home and school.

In the context of discussion of her persistent anxiety-related school absenteeism, Aoife noted ‘…well ‘quiet ones’ don’t get attention. I was ‘the good girl’. I was quiet. I didn’t cause any trouble. I did my work and handed it up on time’. In the context of Emma’s experience of teen suicidal ideation, she recalled ‘[Teachers] would say “oh she’s the perfect student” but I was doing so much masking….I would try to stay away from other people…I would read a book with my head on my desk so I couldn’t see them’. In relation to Annemarie’s experience of overt bullying, she noted, ‘I was quiet, no trouble, doing well academically so anything else wasn’t picked up’. Similarly for Amy, ‘…I loved academics…

ready with the hands up and teachers would have seen [non-verbal bullying] and then did nothing, I was very quiet and I was just overlooked'.

Three of the women whose daughters also have autism, reported a similar pattern in school's gendered interpretation of their daughters' behaviours which seemed to actively prevent intervention. Despite high rates of absenteeism and parental concern regarding their daughters' wellbeing, schools reported little concern: 'School basically denied there was anything wrong, they just had her down as the 'shy girl' and yet we were having massive meltdowns [before and after] school' (Deirdre). ' [daughter's name] was away from school and with me 20% of the time and the school never noticed. They just told me 'oh …such a nice girl, she's so clever' but they didn't miss her, they never noticed she was away'(Sarah).

A minority of women who struggled academically reported similar experiences of a lack of response to their needs; 'All my school reports seem like they're written by the same person'(Jenny). School reports outlining consistent academic underachievement in contrast to over-achievement in distinct areas of learning relative to their peers were interpreted as indicators of personal failings. The women's learning needs did not prompt additional attention or referral to external agencies for further investigation, but instead were documented as signs of 'laziness', 'lacking in focus' and 'poor motivation' in school reports.

A contrasting experience was described by Jean where identification of her learning needs (Dyslexia and DCD) allowed her to access the 'amazing support' of an 'intuitive proactive' classroom assistant in secondary school. However, this support was temporary and the subsequent feelings of failure when that support was removed culminated in a series of negative beliefs that prevented her from returning to education for a significant number of years ' …that was a big knock. I was like, I can't do education, it's just not for me'.

Some women were able to advocate for themselves in third level education settings and were proactive in seeking what additional accommodations were available to them.

However, accessing support came notably later in adulthood, typically followed a pattern of failed attempts at course completion and was not always satisfactory. For Amy, securing a reduced workload was complicated by her failure to meet the gendered autism stereotype:

> First of all, you have to melt and they'll kind of notice and help and they're like "ah you're grand, you're well capable". I suspect they think I'm a bit of a snowflake, that I'm just being precious, and the fact that I'm able to make okay eye contact and am able to talk, I don't seem like an autistic person necessarily but certainly, I'm not being treated as someone who has quite severe issues…I'm really struggling with that

Women recounted feelings of sadness and anger at the lack of intervention and understanding of their needs across their lives. For Sally, 'It makes me so sad to think about it, it didn't occur to me that there was an actual struggle there, it just seemed like my own fault'. 'When I look back on [school report], I feel like contacting him and saying, 'You have no idea what was going on for me there. How dare you assume it was laziness'. I was really struggling then' (Amira).

> For years, I was so angry that no one helped me, they just left me die slowly inside. I was so angry because I was so hurt. They just left me, from first year. It was talked about but no one helped me do anything about it or asked me what would help me (Dorothy).

The serious consequences women faced as young girls when the attention and perception of their behaviour was influenced by their gender marked a trend that continued into their adult life.

4.3.5 Motherhood

'…they were the swans drifting along, I was the legs kind of paddling underneath…'(Linda). Similar to adolescence, motherhood represented a second distinct period in some women's lives where the women's sense of difference to their female peers was magnified. The majority of mothers planned their families, were positive about their mother identity and related a sense of confidence in their mothering skills to their in-depth research and knowledge in the area typified by Jenny's comment: 'I was excited and obsessed by this, I excelled…the best form of the most proven form of parenting, attachment, positive reinforcement, you name it’. However reading, researching, and, in one instance, publishing on the subject of motherhood was not sufficient to protect the women from the normative pressure for women to be ‘perfect mothers’ and the associated idealised mother stereotypes.

> I was reading about it, I was an expert about it…but I’m lacking somehow, to not be natural, as good a mother as I’ve felt I should be able to be…I’d been trying to be the perfect earth mother and yet it wasn’t me (Deirdre).

The stay-at-home mother stereotype was also problematic for others. ‘I always knew that being a stay-at-home mother wouldn’t suit me and I was disappointed to have it confirmed… I hoped that I’d be a little more like that’ (Amira). Women acknowledged that other women experienced similar difficulties with the concept of motherhood but commonly commented that their unique challenges set them apart from ‘normal mothers’. They viewed mothering with a diagnosis of ASD as different and harder because of increased sensory and social demands both pre and post-delivery.

Motherhood represented one of the most socially demanding times in most of the women’s lives and mothering difficulties were contextualised in their failure to meet these demands:‘ …mother and toddler group…the chit-chat…a social nightmare…’(Amira). In many instances, the women’s expert knowledge acted as an initial buffer and helped mask their difficulties in situations such as play dates and breast feeding groups to such an extent that some women took lead roles in parenting related group interests. However, sustained engagement proved too much and typically resulted in abrupt exiting from these groups which evoked a shame response in some women in terms of their views of their identity as a mother.

> I had to be completely put on hold…it wasn’t me at all… I became a mother and a mother who wasn’t even a good mother because I couldn’t host coffee mornings or I couldn’t...I have no interest in having the most fashionable stroller or all of that…whatever the latest trend is (Deirdre)

The minority of mothers who rejected the perfect mother stereotype to 'mother on their own terms' were met with judgement within and outside of their immediate families. Fear of judgement of alternative parenting approaches made them reluctant to seek support from others as summarised by Sarah's comments:

> …these stories children been taken away and questioning over parenting practices …so I've been very afraid of the system unfortunately…seeking out support for me has always been terrifying because, am I going to be hospitalised? Am I going to have my children taken away? (Sarah).

In contrast to this focus on parenting, almost half the women expressed little sense of future motherhood and any reference to a cultural expectation to have children because of their sex was absent. Practical concerns ran alongside ideological and existential conflicts when deciding not to start a family. 'Motherhood was simply not a priority… I thought of it, but I've always been more interested in my career and doing other things' (Annemarie). For others, overpopulation and the potential negative impact on the environment underlined decision making.

The diagnosis of, and experience of living with, ASD influenced some women's choice not to have children. The women were able to predict and manage or avoid potentially stressful experiences such as parenting: 'Having a baby was medically more risk than I was comfortable with and I wouldn't have coped…I can barely look after myself' (Amanda); '…the fear of the physical transition [in pregnancy]… I've gone so far down before' (Emma).

4.3.6 Gender as identity

'I have always rejected gender typing always' (Amira) The internalisation of stereotypical gender constructs led women to question their gender identity at different points in their lives. Degrees of expression varied. A minority of women detailed developing early childhood beliefs that they were male, but were being raised female to explain their feelings of difference. For some, this involved the comfort they felt in their own bodies and, at a young age, led to outright rejection of overt signs of femininity related to birth name, hair and clothing. For a sperate minority of women, pubertal changes such as menstruation triggered questioning about how gender should feel.

> I remember thinking this is uncomfortable, this doesn't feel right, I thought 'I don't feel like I'm a girl. Am I girl, am I boy? Am I not a girl or a boy? I don't feel on the inside that I'm a boy. I feel different but I don't think it's that (Amira)

Regardless of whether women queried or temporarily rejected their female gender identity, all were adamant that such thoughts and actions were unrelated to their physicality and more about an inability to 'meet the standards' of the female stereotype. As explained by Sally, her exploration of gender identity represented a rejection of an inaccessible female world making identifying as male the only other option, '… it really wasn't about being a boy as much as it was about not being a girl and boy was the only other thing to reach for' (Sally).

In adulthood, rejection of female gender identity evolved into acceptance of both masculine and feminine traits, 'somewhere in a cloudy middle space'(Jean)**,** perhaps suggesting a fluidity in women's sense of gender identity. Women linked their acceptance of male/female traits to cognitive styles. 'It's not a gender dysphoria thing, I actually quite like a lot of aspects of being a girl … within me, my brain just works like a boy's' (Dorothy). '…I don't try to be either but slip into the male side of thinking a bit more easily' (Sheena). Annmarie, a gay woman in her late forties, had just recently become more comfortable as identifying as nonbinary and made similar distinctions in relation to her cognitive style, 'I am not [transsexual] because I'm quite happy in my body but I do feel in my head, I'm kind of in between the genders'. Further exploration of these comments indicated feelings of inferiority related to the women's interests and social interaction skills.

4.4 Summary

The themes ‘male-centric view of autism’ and ‘gender-based role expectations’ highlight the multiple, multilevel sociocultural influences upon the lived experiences of women with an ASD. Collectively they compound the distress societal constructs of gender and ability can engender in women with an ASD in reinforcing both a sense of difference and disorder. Short a diagnosis of ASD, their sense of difference was labelled, both internally and externally, as odd and ‘weird’, making it harder to define a sense of self. The receipt of a diagnosis seemed to offer an ameliorative lens for self-perception, providing a sense of much needed agency.

Chapter 5: Discussion

5.1 Chapter Overview

To the author's knowledge, this is the first time the lived experiences of autistic women has been investigated using Reflexive Thematic Analysis within a constructionist framework. In the process, through a conversation between the themes of 'gender role expectations' and 'male-centric view of autism', alternative narratives to a deficit focused view of ASD were developed as the impact of social context and cultural factors on autistic women's lives were revealed. Findings highlight the significant psychosocial and emotional impact of the intersection of their gender and disability experiences across the life span. In challenging taken for granted norms, both themes combined, identify the complexity of these influencing factors which have multilevel implications for theory, research and clinical practice. Additionally, to the author's knowledge, this is the first time a study of this kind has represented a majority Irish adult autistic female sample adding a particular local context to some of the women's experiences.

In its interrogation of the existing research, the findings of this study both concur with and contest elements of existing literature related to a 'female profile' or a female population's experience of autism. Women's lived experiences will firstly be contextualised in discussion of cognitive theories of autism. They will then be explored in relation to existing literature on adult psychosocial outcomes, and finally in the presentation and experience of autism within a female population.

5.2 Cognitive theories

As previously discussed in Chapter 1, a significant critique of existing autism related theories such as theory of mind (ToM: Baron-Cohen et al., 1985), weak central coherence theory (CCC: Happé & Frith, 1996) and extreme male brain theory (EMB: Baron-Cohen,

2002) is that personal experiences, voiced by those with autism, has been poorly considered (Hens et al., 2019; Chown, 2014; Chown & Leatherland, 2018; Jack, 2011, 2012; Duffy & Dorner, 2011; Milton, 2012; Silberman, 2015). Subsequently, a deficit focused narrative has emerged denying those diagnosed the benefit of a positive self-identity (Chown & Leatherland, 2018).

Hull et al., (2020) suggest women's apparent difficulties with ToM manifest themselves in their struggles to manage social situations and to navigate the expectations, beliefs and communications of others. Women in this study repeatedly spoke of their 'confusion' and difficulties in being 'misunderstood' as children and as adults by peers and health practitioners in particular. However, considering the previous critique of ToM as a bidirectional phenomenon in Chapter 1, an alternative consideration is that some of their communication difficulties were shared. Women were aware that their non-autistic peers did not generally have the necessary information to understand them, which runs counter to the hypothesis that the women were unable to attribute mental states to others and by extension to themselves. This observation builds on the work of Milton (2012) and Sasson et al. (2017) which suggests the social difficulties individuals with ASD experience are due to societal structures inhibiting optimal functioning. Thus the social interaction difficulties the women experienced may not just be an individual impairment but a relational one in which the perspectives of others affected the quantity and quality of their social experiences. As noted by Sasson and colleagues, consideration of the potential contribution of both parties makes for a fuller understanding of social interaction difficulties.

The frustration experienced by women in adhering to a stereotypical construct of femininity and associated female gendered behaviours and roles has been suggested to align with both Weak Central Coherence Theory (CCT: Happé & Frith, 1996) and Theory of Mind (ToM: Baron-Cohen et al., 1985) (Kanfiszer, 2015). In line with the ToM model, women in this study may be less likely to instinctively understand social (including gender) norms, and consequently less likely to understand gender conceptualisations or to conceptualise gender in terms of the traditional male/female dichotomy. Similar to women in Kanfiszer's study, women reported feelings of confusion in relation to their gender identity mainly in childhood and adolescence to the point of temporary deidentification in some instances.

Women's struggle to identify with their female peers, may in some way echo previous research indicating greater gender variance in gender expression and lower social affiliation to gender group (Cooper et al., 2018). Of note, women in this study were adamant that the confusion they experienced should not be pathologised as a nonconforming gender presentation: their confusion or rejection of the female stereotype did not necessarily mean they identified with the opposite sex. Indeed, some participants felt 'dehumanised' by the assumption that they were 'male brained' (Extreme Male Brain, (EMB: Baron-Cohen, 2002) and depending on one's perspective, their passions in life (which were related to their occupations in some way) could be seen as examples of empathising interests (Jack, 2011).

Women's experience of a profound sense of difference to their female peers is echoed in previous research (Bargelia et al., 2016; Kanfiszer et al., 2017; Leedham et al., 2019; Milner et al., 2019). Feelings of such difference may be connected to women's retention of an unfortunately rigid notion of what it is to be female and feminine, thereby deeming themselves the only ones to be 'not normal' (Kanfiszer et al., 2017). In line with both ToM and CCT, it may be that rather than incorporate gendered norms reflexively or automatically into their identities (Jack, 2012) the women had to carefully study gender as a set of codes or signals exemplified in their adoption of a 'social anthropologist' role, which, over time, allowed them to learn about the social expectations tied up with femaleness and femininity. As described by the women, they may primarily have focused on minor details (the circumscribed interests, style of clothing, personal grooming, the tone of voice, the fashionable stroller) rather than broader categories of male and female, preventing them from fully participating in the ‘social conversation’ that produces (and often mandates) gender roles (Jack, 2012). It is unlikely that all of their peers firmly aligned with stereotypical views of how girls/women should present themselves, however, similar to women in Kanfiszer’s study, this was the women’s understanding, indicating a rigid perception of self and others. While such cognitive inflexibility aligns with CCT theory in particular, the potential impact of contributory factors such as low self-esteem and social anxiety (which were not uncommon reflection points for women in discussion of their relationships) on thinking styles also needs consideration (Kanfiszer, 2015; Sedgewick 2017).

Alternatively it may be that identifying gender experiences as socially constructed roles provides an explanatory framework that helps the women interpret their difficulties in identifying with a gender (Jack, 2012). Examining gender from this perspective supports women’s adult understanding of gender as fluid and multidimensional. In adulthood, women in this thesis spoke of coming to a ‘cloudy middle space’, no longer viewing their gender ambiguity as a negative and found alternative positions from which to understand themselves. Women also found points of ambiguity between the culturally constructed identity of an autistic person, stereotypically males, and their own interests and identities. The ‘cloudy middle space’ perhaps provides a resource for some women who struggle with feelings of difference from dominant depictions (autistic male and neurotypical female) to help assimilate an alternative identity. The finding that some women experience a conflict between a feminine and autistic identity specifically aligns with findings from previous research (Bargelia et al., 2016; Kanfiszer et al., 2017; Milner et al., 2019).

Kanfiszer et al. (2017) linked higher intellectual ability to women’s reluctance in identifying with conventional ideological female gender norms. It may be that this reluctance reflects a similar discomfort seen in non-autistic females. Steinem (2015) notes that as women age, they become ‘more rebellious’ and actively critique the politics of their current lives and childhoods. The age range of this study’s participants, the multiple barriers they faced in accessing an ASD diagnosis (mean age of diagnosis 35.9 years) and the subsequent application of an ‘ASD lens’ to their experiences, most likely sensitised women to the ‘politics’ of their lives. This suggests women’s perceptions of ‘difference’ to their peers may have, over time, become related to increasingly complex factors such as gendered contexts. Albeit an intuitive argument, this developing consciousness may also suggest potential limitations of retrospective accounts – the application of a later lens to an earlier experience.

Alternatively, and in line with Chown (2014); Chown & Leatherman (2018) and others’ view, it may be that mainstream cognitive theories do not decisively account for the heterogeneity and complexity of ASD as presented in these women. Perhaps, cognitive theories of autism such as ToM, CCT and to a certain extent EMB, can only explain the male-centric view of ASD. Considering the previously referenced critique of placing male and female brains on a continuum in Chapter 1, this suggestion seems conceptually problematic, at least in the case of EMB theory. As noted by Jack (2012), just because autistic males may exhibit certain characteristics more often, this does not mean that they are in and of themselves ‘male characteristics’. This implies a gendered focused construction of autism such as EMB may not be a particularly useful explanatory model for a ‘male’ or a ‘female’ autism and may partially explain why the majority of women in this study, like women in previous research (Webster & Garvis, 2017; Milner et al., 2019) actively sought alternative explanatory models beyond autism, such as neurodiversity which views their cognitive ‘deficits’ as ‘difference’.

However, the concept of neurodiversity is also arguably an ‘incomplete fit’. The concept of neurodiversity was not a universal choice for the women. A minority of women (notably those significantly impacted by physical health and specific learning difficulties) in this study view their autism as both a difference and a disability adding to the wider debate regarding the appropriateness of a blanket neurodiversity label within both the autism community (Silberman, 2015) and the autism research community (Baron-Cohen, 2019; Lai et al., 2014).

In a recent interview, Baron Cohen (2019) noted that while, collectively, cognitive theories have certainly increased general awareness of autism, they have not necessarily translated into improvements in the lives of people with autism. Adult outcomes are the focus of the next section.

5.3 Psychosocial adult outcomes

In contrast to much previous work on adult outcomes in autism (Howlin et al., 2004; 2013) the autistic women in this study were mostly in employment or education, and many were dating, married, and mothers. In this sense their outcomes, as previously defined in Chapter 1, were in the ‘very good’ range. Furthermore, all participants were living independently which contrasts with cohort studies which found that more than 50% of autistic adults live with their parents (e.g. Arnold et al., 2019), and are dependent on them for support with daily living skills (Bishop et al., 2016; Henninger et al., 2013; Howlin et al. 2004; 2013). As noted by Sedgewick (2017), such studies tend to be longitudinal, focusing on individuals who were diagnosed in their childhood over the 60’s, 70’s and 80’s when diagnostic criteria were dramatically different and only corralled those individuals at an extreme end, for example those with a co-occurring intellectual disability or limited spoken communication. To illustrate the point, none of the women in this study attended special schools unlike the majority of participants studied by Howlin and colleagues (2004, 2013).

In line with this observation, the ‘very good’ range outcomes of women in this study reflect, in part, more recent research across a number of adult outcomes which places greater emphasis on quality of life (Baldwin & Costley, 2016; DePape & Lindsay, 2016; Griffiths et al., 2019) and where participants were deemed to be ‘higher functioning’ as are the women in this study. A noteworthy finding in this study and replicated in referenced research is that individuals are considered to be ‘higher functioning’ despite experiencing a range of needs.

5.3.1 Employment

Unlike previous findings in relation to work experiences and women with ASD (Baldwin & Costley, 2016; Tint & Weiss 2018), women in this study did not report significant recurring occupational difficulties in relation to executive function, mis-communication or being unemployed or ‘overemployed’, relative to their education training. In the main, commentary in relation to their work lives was limited to discussion regarding non-disclosure of their ASD diagnosis at work, a finding also noted in DePape and Lindsay’s (2016) study.

However, not discussing their work lives in other contexts does not necessarily mean the women were immune to these difficulties. In fact, characteristics of their current work lives implicitly suggested some women experienced these same difficulties and made adaptations to avoid their reoccurrence. To illustrate, the majority of women were currently self-employed and were working in areas related to either their academic training, personal interests or both. The majority worked alone and worked part-time, regardless of whether or not they had family commitments. Additionally, many women also worked from their homes. These adaptations collectively suggest that some of the women were successful in creating careers where they were largely autonomous, working to their own schedule and intrinsically rewarded in their work roles, in potentially less demanding social and physical environments. Of the two women in full time employment, one was on a study sabbatical and the other worked three jobs, by choice, again perhaps allowing for finite demands in terms of communications, work tasks and the physical environment. These flexible work arrangements echo what women in previous research (Baldwin & Costley, 2016;Tint &Weiss, 2018) name as the most desirable supports in women's work lives. Thus, the agency the women demonstrated in making these adaptations were perhaps indicative of the 'high functioning' status of interview participants who had learned from previous experience and were personally resourced to create optimal working conditions for themselves. Additionally, the lack of agency women experienced in other areas of their lives was notable and perhaps suggests that those concerns were currently more of a priority for the women to share.

5.3.2 School experience

Similar to women in previous outcomes research (Baldwin & Costley, 2016), women in this study demonstrated a strong aptitude for learning (the majority of women in this study were third level educated or currently studying at this level). Similar to women in previous research, their academic ability was overshadowed by negative school experiences which were characterised by victimisation, being bullied and/or exploited by peers and their needs being overlooked and/or misunderstood (Baldwin & Costley, 2016; Bargeila et al., 2016; Crindland et al., 2014; Kanfiszer et al., 2017; Sedgewick, 2017; Tint & Weiss, 2018)

5.3.2.1 Victimisation

Difficulties with developing and maintaining relationships are central to the diagnostic criteria of autism (APA, 2013). Women in this study experienced significant problems in their relationships, in adolescent years in particular, with the majority reporting relational aggression and relationship breakdown. They related their difficulties with peer relationships, and especially with managing conflict within those relationships, to a combination of wider social issues, such as not conforming to female gender stereotypes and innate social skill deficits. These findings add to current debate (Geelhand et al., 2018; Jamison et al., 2017; Lai & Szatmari, 2020) about whether social interaction difficulties have a later onset in girls with autism or whether pre-existing milder difficulties are brought out due to the increasing complexity of girls' social development during adolescence. In line with these expectations, as teens, women in this study repeatedly spoke of the 'inaccessibility' of the female teen social world and experienced harsh social sanctions, isolation and rejection, when displaying atypical behaviours such as social withdrawal or 'odd behaviours', which contrasted with the gender role and age-specific expectations of teenage girls around them. In line with previous observations made by Jamison et al. (2017), these findings may further explain why male: female ratio in referral for autism assessment drops to 2:1 in teenage and adulthood from the childhood ratio of 5.5:1 (Rutherford et al., 2016).

Poor social problem solving skills, involving conflict avoidance combined with passive presentations such as the 'quiet girl' persona adopted by the majority, may have also made women vulnerable to the attention of bullies. These findings extend clinical observations by Attwood (2006) who suggested that females with ASD are more likely to exhibit 'passive personalities' thus avoiding social faux pas and notice for social blunders. Indeed, almost all of the women reported wanting to have friends but being unable to attain such 'normalcy'.

Women's inability to appear 'normal' also drew upon their deviation from gendered norms and echoes the perspectives of other females on the spectrum (Bargeila et al., 2016; Kanfiszer et al., 2017; Milner et al., 2019; Sedgewick et al., 2019). There is evidence to suggest that women with ASD are more aware of their symptoms and, therefore, more likely to be affected by rejection and isolation from peers (Gould & Ashton-Smith, 2011). Additionally, the majority of participants attended same-sex schools which may have served to intensify their feelings of 'difference' from their peers. Women reported that 'trying to be someone they were not' entailed a sacrifice of self, a loss of authenticity, and attempts to comply with predominant stereotypical female roles were to their own psychological detriment. Previous findings support the observation here that socialisation processes and pressure to adhere to gender stereotypes contribute to internalising problems frequently reported by autistic females (Davidson, 2007; Jack, 2012).

Similar to participants in the Bargelia's et al. (2016) study, women reported that their passive and compliant behaviours were commonly misconstrued as being 'shy' or 'good'. In school these behaviours, combined with academic success, helped to ensure they remained 'under the radar'. Their observations build on previous findings where girls were reported to be 'coping reasonably well' where their passivity was, once again, misinterpreted as shyness and therefore ignored (Attwood, 2006). The women hypothesized that because they were often well-behaved and performed well academically, adults failed to act even at times when it felt quite obvious (selective mutism, uncharacteristic absenteeism and recurring illness) that things were not going well in their lives. Regardless of need, it appears the 'quiet ones' did not receive help and this served to further perpetuate their distress. This finding aligns with previous research (Hiller et al., 2014; Mandy et al., 2012), where teachers raised fewer concerns about girls' behaviours compared to boys. It also adds to the broader discussion of ASD behaviours being overlooked or misinterpreted in girls due the influence of sociocultural factors on assumptions about gendered behaviour (Kreiser & White, 2014; Lai et al., 2015).

Participants in Baldwin and Costley's (2016) study did not explicitly name gender as an influence on their education experiences (or other outcomes) or the misidentification of their needs. Executive functioning in combination with social interaction difficulties were most frequently cited as contributing factors. Executive functioning difficulties may have been less salient for women in this study. Additionally, this difference in findings may reflect the limits of questionnaires in comparison to the strength of in-depth qualitative, anecdotal and autobiographical data approaches in capturing holistic accounts of individuals' experiences.

Half the participants also talked about being victims of sexual abuse. Risk of sexual victimisation and autism is largely undiscussed in the literature. To the researcher's knowledge, it has only been reported in seven previous studies (Bargelia et al., 2016; Garvis & Wester, 2017; Griffiths et al., 2019; Kanfiszer et al., 2017; Kreiser & White, 2014; Milner et al., 2019; Ohlsson et al., 2018). In line with previous research (e.g. Bargelia et al., 2016), women in this study understood their vulnerability in varying ways; they were not necessarily aware of the risk to themselves at those times; were desperate for acceptance; felt they had no choice as abusive relationships were a lesser pain than social exclusion, and because of isolation, they had no reference point to develop strategies to stay safe. Risk to women and girls with ASD is also echoed in autistic life writing and has prompted the publication of materials aimed specifically at educating women with ASD on sexual safety in relationships (Brown, 2012; Steward, 2013). Even with these publications, greater intervention is required to meet what is a necessity as, unlike women in Garvis and Webster's (2017) research, women who reported sexual abuse and assault in this study did not report pivotal moments in their lives when they made decisions that allowed them to remove themselves from current risks. Differences in findings may in some way be attributed to the lack of co-occurring mental health difficulties reported by participants in Garvis and Webster's (2017) research. Women in this study were struggling with their mental health from a young age which most likely (along with other external factors) increased their vulnerability and prevented them from being their own 'agents of change' in these situations.

5.4 Diagnosis – stigmatising or empowering

The average age of ASD diagnosis in women in this study was 35.9 years and their diagnostic experiences align with recent studies of ‘high-functioning females’ with ASD, which confirm they are more likely to have a delayed diagnosis, be misdiagnosed or remain unidentified compared to males (Baldwin & Costley, 2016; Bargelia et al., 2016; Kanfiszer et al., 2017; Kreiser & White, 2014; Lai et al., 2015; Milner et al., 2019). The limited research available on women’s perspectives of the impact of a delayed diagnosis (Baldwin & Costely’s (2016); Bargelia et al., 2016; Stagg & Belcher, 2019; Webster & Garvis, 2017) reveals a recurrent belief that life would have been much easier if the ASD diagnosis had been confirmed and more support provided at an earlier age. As described in autobiographical works (Davidson, 2007; Van Goidsenhoven, 2017) delayed diagnosis resulted in painful identity issues for the majority of women in this study, sometimes involving a recurrence of previous feelings of poor self-concept, rejection and the perception of being ‘different’. Women in this study indicated that their adolescent years in particular would have been easier had their needs been recognised and supported.

The process of coming to terms with a new ‘lens’ to re-evaluate past and present identities was demonstrated by some of the women in this study who questioned the value of an early diagnosis on the direction of their lives. Similar to women in previous research (Kanfiszer et al., 2017) women wondered if a notion of disability would have hindered their options or influenced their choices – wondered, in short, if diagnosis itself was not a potential roadblock. This thought process demonstrates the complexity of identity formation post ASD diagnosis (Stagg & Belcher, 2019). Women queried whether they would have attended mainstream school, become parents and followed particular career paths. While their emotional wellbeing had been compromised as a result of some of these experiences, they expressed few regrets. In the absence of diagnosis and as a ‘consequence of being autistic in a world created by and for the non-autistic majority' (Pearse, 2020, p.1) they knowingly or not demonstrated strength, resilience and resourcefulness. Importantly, many of the women in this study also have partners who provide them with a welcome dovecote, with support and security.

The divergence in narratives about being abled or disabled by a childhood diagnosis of ASD may reflect differences in participant ages and thus exposure to life experiences. The mean age of diagnosis of women in Baldwin and Costley's research (2016) was 25 years and 21 years in Bargelia et al.'s (2016) work, versus 35.9 years in the current study, suggesting a younger cohort of women not yet fully immersed into the world of work or parenthood may not necessarily share the same reflections as women who were mothers and more than a decade older. However, it is more likely that the enabling or disabling nature of a diagnosis is mediated by other factors. An alternative view is that the women in this study were speaking as a generation who found it hard to conceptualise what supports (if any) could have been helpful, as historically so little was known about autism and girls during their youth. This observation is supported by commentary from mothers who indicated that they valued their daughters' childhood diagnosis of ASD (albeit also delayed), as it led to self-knowledge which was a key factor in women's self-understanding and management of wellbeing. The women's commentary is also likely to reflect the conflicting thoughts they have about the stigma associated with the diagnosis itself and the personal relief, validation and vindication it has brought to their lives.

The internalised ableist conflict the women expressed simultaneously adds to debate regarding the benefits and risks of disclosure of an ASD diagnosis and to thinking about the processes that underlie assimilation of a diagnosis into one's identity (Botha & Frost, 2020; Cage et al., 2018; Stagg & Belcher, 2019). Stagg & Belcher (2019) suggest that knowledge and self-awareness of the diagnosis reduces the shock of the diagnosis, allowing a primary experience of relief and a decrease in the negative impact of labelling. The vast majority of women in this study sourced their diagnosis through private practitioners. Their diagnostic journey involved reading other people’s stories, research to the point of autism becoming a special interest, learning about the profile of the condition over a number of years and relating it to themselves. These steps were taken prior to ASD even being assumed in order to make a strong case to their G.P.’s and, when unheard or dismissed, to other health practitioners. The process of gathering evidence and of earnest self-reflection on the journey to diagnosis was a cathartic experience for most and the diagnosis itself was reported as a validation for many of the women, as ‘a birthday present to myself’. Notably, most women in this study began the interview with discussion of their diagnosis before moving to talk about their childhood. The meaning of the diagnostic label in adulthood functions as a plausible and acceptable explanation for women’s difficulties and strengths. The recency of their ASD diagnosis (six months to four years for the majority), combined with the aetiology of their condition, may have served to further enhance the meaning it held in their identity formation, allowing them to (re)frame past and current experiences, rewrite negative self-concept narratives and live life more on their own terms. Experiencing the diagnosis in this way echoes previous research (Baldwin & Costley, 2016; Bargelia et al., 2016; Stagg & Belcher, 2019; Webster & Garvis, 2017).

Cage et al. (2018) posit that assimilation of diagnosis is influenced by the feedback from those around the individual. Women’s decision to keep their diagnosis of ASD largely private in their personal and professional lives was predicated on their fears of negative judgement against a male-centric stereotyped version of ASD, with which they struggled to identify. Some women also struggled to have their diagnosis accepted by health care practitioners. Considering previously referenced research regarding the negative stereotypes afforded to autism (Wood & Freath, 2016), the high probability of exposure to stigma suggests women’s non-disclosure may represent an act of self-protection. The majority of women received mental health diagnoses prior to their diagnosis of ASD and may already have experienced stigma related to these difficulties just as they had experienced stigma for being ‘different’.

Non-disclosure as an act of self-protection potentially supports the hypothesis that the stigma attached to an ASD diagnosis and its potential to impact wellbeing represents the effect of ‘social punishment for being outside of the expected norm of neurotypicality’ (Botha & Frost, 2020,p.18; Griffiths et al., 2019). The dual minority identity (Saxe, 2017) of women with ASD who are outside the norm of both neurotypical women and the ASD community suggests the wellbeing detriment associated with disclosure may be heightened for women with ASD. This finding provides further context to the women’s preference for the label ‘neurodiversity’, as it signifies their consciousness of stigma as much as their desire for society to move to a place where difference is valued and ‘celebrated’. The potential connection between such stigma and wellbeing is contextualised in discussion of a ‘female phenotype’ in the next section.

5.5 A ‘female phenotype’

The findings of this study align with observational, qualitative and quantitative data suggesting that female populations demonstrate the ability to ‘camouflage’ their needs and learn social scripts with appropriate social behaviours (Attwood, 2006; Bargeila et al., 2016; Camm-Crosbie et al., 2019; Lai et al., 2017; Sedgewick et al., 2019). Camouflage or ‘masking’ was the predominant coping strategy used in social situations by all participants. As indicated in recent research (Cage & Whitman, 2019), ‘masking’ aided women’s attempts to ‘pass’ in the neurotypical world and to manage others’ interpretations of them. Arguably, their attempts were highly successful in that autism went unrecognised by parents, teachers and health care practitioners in all but two women. For the majority, ‘masking’ was an active process characterised by taking, as previously referenced, a social anthropologist role, learning to mask by studying others’ behaviours or characters in various media to guide their behaviour.

This finding also extends Cage and Whitman’s (2019) hypothesis regarding Disconnect Theory (Reissman, 2008) and the impact of the varying contexts in which women with autism camouflage. While not explicitly questioned on the reasons why they camouflage, women in this study reported largely ‘relational’ reasons (to get by in relationships with others) in contrast to participants in Cage and Whitman’s (2019) study, who named ‘conventional reasons’(to get by in formal settings like work or education). The difference in findings may be reflective of a difference in age of diagnosis whereby women’s recollections pre-diagnosis were largely focused on adolescence when social demands tended to peak. Equally, the difference in findings could be interpreted as a reflection of their academic strengths and work-life satisfaction, meaning they were more comfortable in managing these demands and thus more able to be themselves in these situations.

Regardless of the contexts in which women ‘masked’, what is clear from this study is that a deterioration in their wellbeing seemed to be inextricably linked to the act itself. Previous research has suggested that females with an ASD may demonstrate a greater propensity to develop more severe mental health difficulties and suicidal ideation, due to the exhaustion caused by persistent imitation of peers (Bargelia et al., 2016; Gould & Ashton-Smith, 2011; Hull et al., 2017; Lai et al., 2019; Mandy et al., 2012; Rynkiewicz & Lucka, 2015).

Indeed, mental health was a recurring theme across women’s experiences, with the women accessing varying degrees of support regarding their mental health. The majority of women had received a mental health diagnosis (depression, anorexia, anxiety, bi-polar, postpartum depression and personality disorder) prior to putting themselves forward for autism assessment. Post ASD diagnosis, most women attributed their subsequent mental health difficulties to earlier misdiagnoses, which were complicated by their ability to mask their ASD symptoms and the fact that symptoms such as social and sensory overload went unrecognised. Gauging whether the ascribed mental health labels represent a lack of awareness of autism in women (which the women frequently reported) or the development of serious mental health difficulties as a result of being unsupported is problematic. These findings add to discussion regarding the complexity involved in assessing mental health difficulties in women with ASD and co-occurring mental health difficulties (Camm-Crosbie et al., 2019; Lai et al., 2019). Due to masking behaviours, without a comprehensive individual assessment, it is difficult to determine whether mental health symptoms are in fact part of the presentation of autism (e.g. sensory and avoidant behaviours being interpreted as social anxiety; ‘repetitive behaviours’ being construed as symptoms of OCD, (Kreiser & White, 2014). This option was largely unavailable to the women of this study.

Additionally, recognition biases because of gender stereotyping may be at play. Limited understanding of the more subtle female type presentations or more egregious assumptions by health practitioners that women could not have autism compounded women’s difficulties. This adds to discussion regarding the role of general expectancy biases and gender-stereotyped assumptions in awareness, assessment and formulation of autism. Similar to their needs being misunderstood and unaddressed in an education context, recognition and measurement error in health practitioners may originate from prevailing gender stereotypes in society (that women are more emotional, for example) and general expectancy biases (i.e., autism being more prevalent in males may mean that associated characteristics are less likely to signpost autism when shown in females) (Lai & Szatmari, 2020).

Furthermore, given that adult mental health professionals and psychiatrists are generally not trained in recognising and understanding adult ASD (Raja, 2014), it is not perhaps surprising that the majority of women experienced a lack of GP knowledge of the different ways in which autism presents itself in general, indicating a specific vulnerability in securing accurate diagnosis in women. Similar to participants service experiences in previous research (Camm-Crosbie et al., 2019; Tint & Weiss, 2017), women's experiences of treatment and support negatively impacted their wellbeing. Women recounted not being 'believed', having their symptoms dismissed, being exposed to treatments not suited to their needs and, for some, the validity of their co-occurring diagnosis of ASD questioned. Limited professional knowledge may also be, in part, symptomatic of jurisdictions that do not have an effective adult autism referral pathway. Lack of professional knowledge, combined with women's largely unhelpful experiences with various health practitioners, explains why those who could afford to access mental health supports did so in a private capacity. Similar to women in previous qualitative studies (Bargeila et al., 2016; Webster & Garvis, 2017), the majority of women used virtual and non-virtual ASD communities as a support.

5.5.1 An alternative view

An alternative view of a 'female profile' may lie in examination of the multiple overlapping marginalised identities which women with ASD inhabit. The findings in relation to women's lived experiences in this study add to the discussion (Booth & Frost, 2020; Cage & Whitman, 2019; Mandy & Lai, 2017; Saxe, 2017) regarding intersectionality theory and contextualisation of the lives of 'twice excluded' autistic women, who potentially experience specific and unique barriers due to their intersecting identities. The external assignation of traditional stereotypical gendered views (interests, personas, roles and physicality) and the internalisation of such views led to significant distress and was a recurring experience across women’s lives. Women’s exclusion from the autism community is further demonstrated in their ‘invisibility’ in the research literature. Although women invested significant time reading and researching the autism literature, they were not ‘hearing [their own] voices’. The absence in media of any significant representation of the female experience of autism misdirected and underinformed broader messages regarding ‘what autism looks like’. This, in turn, served to compound women’s self-doubt regarding the assumption of a diagnosis, encouraged self-gaslighting behaviours and consequently delayed their diagnosis.

In line with questions raised regarding the generalisability of autism research to autistic females, highlighted in Chapter 1, being underrepresented or absent highlights the inherent barriers women face in research studies and consequently the barriers they face in theories driving the research agenda. Poor representation has meant autistic women have been excluded from the process of the production of knowledge about autism (Pearse, 2020). Women in this study struggled with Extreme Male Brain (EMB) theory in particular which served to ‘dehumanise’ their person. For them, EMB theory perpetuated a damaging, inherently male-biased stereotype of the autistic brain that further distanced them from the ASD research community. Saxe (2017) notes that theories such as EMB takes attention away from the needs of women on the spectrum and the research it influences likely exacerbates the barriers experienced by autistic women. Intersectionality theory thus provides an alternate lens through which to understand the added stress burden women with autism experience. As outlined in this thesis, women experienced defined unique minority stressors (Botha & Frost, 2020) such as experiences of victimisation, discrimination, an expectation of rejection, internalised stigma and the camouflaging of their autism which resulted in reduced wellbeing and magnified psychological distress suggesting that a more profound and arguably more complex vulnerability is possible.

5.6 Clinical and policy implications

5.6.1 Identification and diagnosis

The findings highlight that autism was unidentified by health care practitioners for the majority of women in this study. Their journey to privately sourced assessment indicated numerous barriers that made accessing, identifying and living with their diagnosis a complex, challenging, and, at times, a devastating process. This reinforces key recommendations in the international (Think Autism, Autism Strategy, UK, 2019; Persons within the Autism Spectrum Empowerment Act, Malta, 2015) and national context (Health Service Executive, 2019; National Disability Authority, 2017) for ASD-specific training for professionals and service providers, including gatekeepers such as GP's, schools and managers of autism services, to ensure they are alert to the potential differences in how autism presents in women and the potential individuality of their needs. Given the critical roles both GP's and schools, in particular, play in referral for ASD assessment, prioritisation of targeted training for both groups in the recognition of autism in females seems appropriate.

To make the case, findings from this study echo patterns in women's help-seeking behaviour and treatment in relation to their mental health as women nationally and internationally (National Women's Council of Ireland, (2018); WHO, (2002). Women were more likely to seek help from their GP and, in turn, GPs were more likely to prescribe women with medication rather than refer them to psychiatric or other relevant community services thus delaying the women's access to potentially more specialised services including ASD assessment. Under the current model of support for children with additional needs operating in Irish schools, severity of presenting need rather than a clinical diagnosis should trigger access to a staged approach to intervention which, if necessary, includes referral to external services, such as the National Education Psychological Service and the Child and Adolescent Mental Health services. Findings in this study identified 'masking' behaviours and potential gender recognition biases in the school context, in particular, suggesting some girls with ASD may miss out on these supports. Thus, consideration of severity of difficulties in the context of what is socially normative in peers of similar ages and gender should form part of the training content to support GP and school decision-making regarding onward referral for supports, including ASD assessment.

Findings also suggest consideration of sociocultural and interpersonal influences in the diagnosis and screening of ASD in females is warranted. A critical view of ‘gold standard’ instruments and being mindful of potential differences in presentation of autism in females is recommended. As advised above, comparison of skills and deficits to the behaviour of a female peer group is suggested. Findings from this study suggest information gathering regarding history of functioning across multiple social contexts with specific attention to self-report of social deficits, such as social confusion, an enduring sense of difference, relational bullying by peers, risk of sexual abuse and persistent attempts to compensate for social deficits through the use of a variety of strategies, is appropriate. In terms of problem solving a differential diagnosis, this study’s findings align with Kreiser and White’s (2014) position that a thorough consideration of the developmental history of the observed deficits is key to deciphering whether current problems are better explained by the social deficits and co-occurring problems frequently associated with ASD (e.g. sensory sensitivities) or are better accounted for by a different diagnosis. Adopting an intersectional lens to women’s self-reports can only enhance this process.

In the main, women’s reports indicate the onset of mental health difficulties during middle childhood and their adolescent years. Given that the likelihood of developing these difficulties increases substantially during youth and transition stages clinical attention is required. The majority of women had been unable, for a variety of reasons, to access appropriate supports in these years, accessing ill-fitting adult crisis services instead. It may therefore be reasonably suggested that, with appropriate, contemporary and timely mental health support, girls with ASD might not experience the same extreme lattitudes of difficulty the women in this study have. Additionally, the likelihood of relational bullying and sexual trauma in women's lives requires immediate clinical attention. Findings from this study suggest that, alongside traditional biological sex education, a programme specifically exploring the nature and norms of 'healthy' relationships would be most useful for autistic girls. Such a programme would focus on areas of consent and the management of potentially risky situations (including conflict and bullying) but also, more generally, provide a safe space for detailed and honest conversations on relationship management as well as an objective 'sounding board' for the girls' queries.

5.6.2 Service Provision

A clear finding from this study is that women with ASD considered to be 'high functioning' were vulnerable to negative events across their lifespans. To assuage the impact of these events and the corollary potential mental health deterioration they may entail, the provision of supports for this specific group of adults is vital. Such mental health deterioration and social vulnerability were both recently identified as priorities by Irish autistic adults without intellectual disability (ID), in a recent consultation process with the HSE around autism service provision (HSE, 2019). Some women in this study were resourceful in accessing ASD support groups, on-line or in person, but to varying degrees. In a national context, despite the known prevalence of mental health difficulties in this group, the mental health care policy 'Sharing the Vision' (2020), mentions children and adults with ASD and intellectual disability but not adults with ASD without ID. Additionally recent efforts to push forward the creation of Ireland's first National Autism Plan falls short of meeting these adults needs. The ten key recommendations to progress autism services (HSE,

2019) do not include adult autism specialist teams such as those in operation in other jurisdictions, instead placing a heavy emphasises on early intervention suggesting that as ASD becomes increasingly diagnosed in childhood, the issue of adult services such as specialist adult diagnostic and support services will resolve itself overtime. Findings of this study in relation to missed and misdiagnoses in women suggest this approach is based on a single assumption of autism (specifically a male-centric view of autism) that has, arguably, perpetuated a systemic gender-based bias that marginalises both girls and women with ASD. This study's findings suggest the HSE should consider specific recommendations in relation to the recognition of a potential gender vulnerability and a translation of those differences into flexible gender-sensitive service provision.

6.1 Methodological Considerations

6.1.1 Strengths

As recommended by Pellicano et al., (2014; 2018) the adult female autistic voice is expressly involved and heard in this study. A social constructionist epistemology paired with reflexive thematic analysis supported the socio-political aims of this study. Using latent and some sematic level analysis allowed for a focus on not just what the women spoke of but how they interpreted their experiences, enabling them to be contextualised in broader contexts. The developed themes 'gender role expectations', 'male-centric view of autism' and respective subthemes, highlighted the complex context within which a delayed diagnosis of ASD exists. They allowed for the identification of multiple barriers in women's lives that make it difficult for their strengths and needs to be visible and focused attention on the influence of cultural weltanschauung on our understanding of the autism construct. Similar to previous studies that prioritised first-hand accounts of their lived experiences (e.g. Bargelia et al., 2016; Kanfiszer et al., 2017; Webster & Garvis, 2017) the variation in experiences when contrasted with theoretical literature, allowed for new narratives to emerge which go some way to challenge the dominant biomedical autism discourse, whereby autistic individuals are viewed from a deficit perspective (Chown & Leatherland, 2018).

Yardley's (2000, 2008) four quality principles were used in conjunction with Braun and Clarke's (2019) guidelines for evaluating thematic analysis manuscripts, to ensure trustworthiness throughout this study. Firstly, the researcher has endeavoured to demonstrate sensitivity to context through data collection in exploring what was important for the women to share through the use of semi structured interview and, in the analysis, by exploring how the women's sociocultural contexts have shaped their experiences. Transparency and coherence are supported in the six phases of the RTA method and the use of participant quotes to support analysis. The researcher has maintained reflexivity throughout the research process by journaling and utilising research supervision where the co-construction of themes and subthemes was considered. Lastly, the study has pragmatic use. It adds to the limited body of literature regarding women's experiences of ASD, has implications for practitioners and policy makers alike (such as the Health Service Executive (HSE) referenced by participants in this study) and raises new questions related to specific facets of women's experience that warrant future exploration.

6.1.2 Limitations

As noted in Chapter 2, the focus of this study is to provide an in-depth understanding of contextualised human experiences. Reference to issues of generalisability made below should be interpreted as reflections of inherent difficulties in achieving sample heterogeneity in the autistic population.

Sample characteristics such as diversity and education status is a limitation as participants were mostly white women from a single jurisdiction who had received higher education and none reported a diagnosis of intellectual disability, thus restricting transferability. Unfortunately, much of autism research is limited in its generalisability /transferability in these ways (Pellicano et al., 2014). With an exploratory focus on obtaining varied perspectives, no exclusion criteria were set with regard to cognitive ability and/or co-morbid diagnoses. Readability age was factored into the development of both participant information sheets and consent forms and the research advert was posted on an autism service website which offers various supports for families and individuals with autism. However, posting the advert online possibly represented an intrinsic feature of the study's methodology that could have presented challenges for an individual with ID seeking to participate, as their usage of technology and contribution to online forums where the advert was retweeted is unknown. While this has resulted in helpful information about an under-researched cohort (late-diagnosed women with autism), no participant reported an ID leaving the voices of those with additional cognitive impairments underrepresented. Additionally, while it is not possible to predict the influence of online recruitment on findings, it is possible that individuals who volunteered were not representative of autistic women who did not respond. It is also important to consider that all participants recalled historic life events and may have been affected by recall difficulties, particularly when disclosing traumatic events.

To increase the robustness of findings, only women who reported a formal diagnosis of ASD were included in the study. The researcher had no direct means to verify the accuracy of self-reports which is similar to previous research (Baldwin & Costley, 2016; Bargelia et al., 2016; Milner et al., 2019). To ensure the integrity of the sample, women were asked to state the age at which they had received the diagnosis and 100% of participants were able to share this information. However, as discussed in Chapter 1, the validity of diagnostic tools for the female population is debated, with stereotypical male constructs only considered in their validity testing. Therefore, as previously acknowledged, it is possible that the women recruited were more male-like in their presentation and perhaps not representative of the female autism population. However, integrity of the sample may be interpreted from the women’s self-identification with the autism spectrum diagnosis prior to their formal diagnosis. Previous research found no differences in responses of samples including women with a formal diagnosis versus those self-diagnosed (Milner et al., 2019) suggesting risk to sample integrity was reduced.

The inclusion of individuals with co-occurring diagnoses (rather than just those with so-called ‘pure’ autism) may have had an impact on the findings of this study. However, the range of co-occurring diagnoses reflects the reality for women diagnosed later in life. Separately, although there is growing evidence of heightened gender (and sexual) diversity in autistic individuals (Dewinter et al., 2017b), which may confound gender definitions in research, the majority of autistic people still identify with the sex they were assigned at birth, meaning that splitting participants by gender may still be a useful exercise (Sedgewick, 2017).

6.3 Future Research

Being exploratory in nature, this study addressed broad life-span experiences. Subsequent research could begin to investigate specific experiences highlighted by the women in more depth. Gender was identified as a particularly important individual difference impacting both access to supports and the efficacy of these support. This study suggests that providing equitable access to such supports goes beyond a revision of diagnostic criteria and involves a reflection on the influences of prevailing gender norms and gendered socio-cultural contexts on shaping an individual’s development and behaviour. To further assess the potential impact, future research could focus on identifying the connections between broader sociocultural factors such as gender, race, socioeconomic status and the recognition of measurement errors in service gatekeepers’ and clinicians’ screening for autism. In terms of gender, Lai and Szatmari (2020) suggest such work should begin by taking a longitudinal focus involving close follow up of children with older siblings with autism from birth and/or involve investigation of the causes parents (and others) attribute to their child's behaviour and whether these vary as a function of their child's gender.

Relatedly, more research is needed in order to determine how to address the unique barriers women face in other areas of their lives. Such research would highlight the need for a more holistic approach to understanding the individual in the context of their sex and gender, to ensure timely and accurate diagnosis and supports that are relevant and helpful to these women. That the women in this study had very much co-opted as their own the stereotypical gender norms of their enclosing peer groups and evinced an unquestioning belief in and rigid adherence to these norms suggests that it may be beneficial to explore women's perceptions of their own and other people's gender development much further. Such beliefs seemed to alienate their own developing person and deepen their sense of difference to their peers. As privilege is given to information that matches stereotypical expectations (Ellemers, 2018) the devaluing of those who disconfirm these expectations also requires attention.

This study focused on women only meaning that comparisons cannot be made to autistic males or neurotypical men or women. It is possible that a sample of 'high functioning' males diagnosed in adulthood would produce similar findings to those of autistic women who received late diagnosis, and this would be a topic for future research, as these men may have faced similar challenges and developed similar coping strategies. Thus, the current study may provide a foundation for further investigations, making direct formal gender comparisons in order to assess how much this group of men camouflage and thus have their needs unrecognised and/or misinterpreted especially in relation to their autistic identity and adherence to gender norms. Furthermore, this research provides a foundation for comparison with neurotypical women who often face similar gendered expectations to see what differences, if any, might emerge and possible causation for those differences. An intersectional lens would optimise the usefulness of such research for both sexes.

6.4 Conclusion

In conclusion, this study sought to explore the lived experiences of women with ASD. In line with calls from the ASD community, autistic scholars (Chown, 2014; Chown & Leatherland, 2018; Milton, 2012), the autism research community (Pellicano, et al., 2014; 2018) and governmental bodies (Interagency Autism Coordinating Committee, 2017) for 'a paradigm shift in how we approach autism research and acknowledgement of the need to address the everyday realities of autism' (IACC, 2017, p. iv), this study applied a constructionist RTA framework to 16 women's life stories, prioritising the voice of those most underserved in autism research, namely, women with ASD.

Using a constructionist RTA framework allowed for an in-depth exploration of the complex factors that influence the everyday realities of these women's lives. It facilitated the development of two major themes 'gender role expectations' and 'male-centric view of autism', which served to contextualise discussion of how women make sense of their ASD diagnosis. The women's experiences pre and post ASD diagnosis were interpreted within the context of existing literature, cognitive theories of autism and the researcher's perspective, which collectively suggested there may be distinct experiences associated with being female and autistic that warrant specific attention.

The women's stories and life paths indicated a more complex and 'richly faceted portrayal of autism' (Barnbaum, 2008, p.5) than the deficit focused model, as evidenced in their 'adult outcomes', ownership of positive attributes associated with ASD and active engagement with alternative explanatory theoretical models of difference. Feminist approaches added to the neurodiversity debate by offering critique of discourses of 'not fitting in' that encourages stereotyped behaviours and pathologises gender presentation (Jack, 2011). It offers another explanation as to why women in this study feel so ‘different’. In this way this thesis has highlighted, to quote Parish-Morris (2019), that the traditional definition of autism via observational behaviours needs to move on to consider the unseen aspects of the female autistic experience. Adopting an intersectional lens to examine the influence of bisecting identities on women’s experiences is suggested as a starting point. Proctor et al. (2017) note that if we focus only on one aspect of marginalisation and ignore the intersection of identities and their additive effects we miss the mark. The women in this thesis have described the serious fallout from such omissions, highlighting the adverse effects of both interpersonal and structural oppression and stigma across the spectrum of their experiences and behaviours. Misunderstanding and misdiagnosis related to sex stereotyping set against a backdrop of ableist and androcentric discourse created a cluster of disadvantaging conditions for their lives, seriously impacting individual wellbeing.

The lodestones of this research are understanding the lived experience of women with ASD and appreciating the wider context in which this experience happens. These lodestones should drive the development of autism services. That this process of further developing and improving services should take its lead from autistic women is a sine qua non.

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Appendices

Appendix A

Search Strategy

Gould’s (2017) phrase ‘budding interest’ in this area as illustrated in the recency of the research discussed, implies a paucity of studies, most likely mixed methodologies and gaps in the emerging literature. The Campbell and Cochrane review libraries and the Prospero protocol register were searched in February 2019 for completed and ongoing reviews relevant to the area. This search found no completed reviews and three proposed reviews which are outlined below.

- A protocol for a review of the barriers to diagnoses for women and girls with autism spectrum disorder (Estrin, Milner, Colvert, Happe & Spain, 2018). This mixed methods review focuses on the reported gendered ASD symptomatology and collating perspectives (adults with ASD, parents, family members, teachers and health care workers) of the diagnostic process. Participants are aged less than 21 years and present with autism diagnosis or autism symptoms/behaviours, including if co-morbid with other mental or physical health disorders (e.g. anxiety, OCD, depression, ADHD).
- A protocol for a review of the lived experiences of women diagnosed with Asperger Syndrome (Kelly, Sharma & Ramon, 2018). This mixed methods review focuses solely on the diagnostic experiences of women with Aspergers Syndrome before, during and after their diagnosis of Aspergers Syndrome.

- A protocol for a review of the current knowledge on the sexual health literacy of autistic young women (Thomas, Gunson & Thirumanickam, 2018). This review restricts its focus to identifying the barriers autistic young women face in accessing sexuality education. Participants are aged 16-25 and have a functional impact of ASD/Asperger's syndrome that requires low-medium levels of support. They do not have a coexisting intellectual disability.

In a wider search of the literature two systematic reviews were sourced, one which focused on the experiences of women with High Functioning Autism (HFA) in the workplace (Hayward, Mc Villy & Stokes, 2016) and the other, a mini-review which explores self-reported empathy in females with ASDs (Kok et al., 2016).

- Hayward's et al. review aimed to synthesise what is known about the labour market experiences of women with HFA. No study included in the review had systemically investigated the challenges specifically relating to females with HFA at work thus no differences in work experiences could be accurately ascertained. Of the 11 studies included in the review only one differentiated female data in analyses. Evidence of external validity of a third of the included studies was absent and no information regarding how or if saturation had been assessed, suggesting that maybe not all challenges or issues unique to this population were captured in the review.
- Kok's et al. systematic mini-review examined the empathy construct in women with ASD and compared this to men with ASD and men and women without ASD. Five of the six studies in the review did not present data on women separately, and over 75% of total participants were taken from two publications from the Baron-Cohen workgroup and associated scientists.

The ProQuest platform was then used to obtain literature based on the research question from the following electronic bibliographic databases: PsychINFO, PubMED/Medline, CINHAL Plus, EMBASE, ERIC and Academic Search Complete. Titles and abstracts were searched for relevant published and unpublished literature from their inception until the date of the running search using the following terms: [women OR females] And [Autism Spectrum Disorder OR High Functioning Autism OR Autism OR ASD OR Asperger Syndrome] And [lived experience OR perceptions OR narratives OR self-report OR views] AND [qualitative research]. In addition to electronic searching, a manual search of the author’s own files was examined for additional relevant literature, followed by review of reference lists of both included full text studies and potentially relevant systematic reviews. Grey literature was searched using Opengrey and Google Scholar for literature including conference abstracts and theses.

Inclusion/exclusion criteria

Studies were included if they satisfied the following criteria: (a) are empirical studies (b) use a qualitative design for data collection and analysis (c) women are aged 18 and over and have received a diagnosis of an autism spectrum disorder (d) participants provide first person accounts (f) their diagnosis can include co-morbid symptoms (e.g. cognitive impairment) (g) are published in a peer reviewed journal and (h) are written in English. Studies containing only quantitative data, opinions, editorials, content analysis and male or females under 18 years or third party perspectives were excluded.

Appendix B

Sample Memo

13/7/219

Received call from Gatekeeper x.x., re cessation of women's ASD support group. She reported continued existence of group as a 'women's group' would be discriminatory towards individuals who did not identify as women. Thus, accessing a sample of women via this group was no longer tenable. Contacted associate who sources support through this group and discussed its' planned closure and the issue of discrimination. Her view was that this was not a perspective she personally shared as her sense of the group was that it was already welcoming to those who identified as female and that the name of the group was perhaps a separate issue. Discussed the possibility of my research, considering its' focus, to be discriminatory in some way at supervision. I felt uncomfortable reading previous research that named participants 'natal' females and felt this may be more discriminatory than the term woman. I am equally sensitive to the individuality of language use by individuals in terms of how they choose to identify. BPS article Autism in Women, by autistic scholar Eloise Stark asks the question 'should we be found?', reaffirms my thinking re the legitimacy of exploring how life is experienced by women with ASD. Separately, I will need to access sample via alternate route asap.

Appendix C

Interview/Prompt Sheet

This schedule will serve purely as a guide for the interviewer. The interviewer’s language and communication style will be tailored to the needs of each participant.

Introduction:

-Introduce interviewer and remind participant as to why they are being interviewed – there are no right or wrong answers.

-Remind the participant of the length of the interview.

-Remind the participant of confidentiality and their right to leave the interview at any point.

-Remind them of times when confidentiality may be breached (if at risk of harm to self or other).

1. Adulthood

Could you tell me a little about your life now?

Prompts – employment, friendships, relationships, hobbies, family, health, successes, positive and negative experiences

2. Diagnosis

What led to you being diagnosed with ASD?

Prompts – importance of diagnosis, impact upon life, meaning for self/others

3. Childhood

Can you tell me a little bit about what life was like as a child?

Prompts – school, family, friends, relationships, adolescence, hobbies, sense of difference, positive and negative experiences

4. Future

What do you look forward to in the future?

Prompts – employment, friendships, relationships, hobbies, family

Conclusion

Is there anything else you would like to talk about or add that you have not had a chance to?

- Enquire as to how participant is feeling post interview

Appendix D

Letter to Gatekeeper

Scoil an Oideachais UCD

An Coláiste Ollscoile
Baile Átha Cliath, Belfield, Baile
Átha Cliath 4, Éire

education@ucd.ie
www.ucd.ie/education

9/07/2019

Research title: An exploration of the lived experiences of women who have a diagnosis of Autism Spectrum Disorder.

Dear X,

I would like to invite you to assist me in conducting a research study. Before you decide you need to understand why the research is being done and what it would involve for you and for the participants. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to facilitate this research.

Who I am and what this study is about?

My name is Louise Condon and I am an educational psychologist. I currently work with the Department of Education and Skills National Educational Psychological Service. Previous to this, I worked for a number of years as a psychologist working with the Health Service Executive in various services, Autism specific and disability services, both child and adult.

I am interested in learning more about women's experiences of living with a diagnosis of autism spectrum disorder. By asking the broad question 'what are the lived experiences of females with ASD?' this research aims to connect with, and understand, the varied aspects of the human experiences of these women. This study is being carried out as part of my studies on the Doctoral programme in Educational Psychology at University College Dublin.

What I need your assistance with

It is my understanding that you are a founder of the online group 'Women's Autism Social Group Dublin'. I hope to interview up to 8 participants and believe that some of the women who contribute to this group may meet the study's inclusion criteria. Women who are interested in participating in the study must have a diagnosis of ASD and must be over 18 years of age. Interested participants are advised to contact me directly should they want further information on the study. I would be most appreciative if you would post a flyer that advertises this research to the ‘Women’s Autism Social Group Dublin’ facebook page. The flyer is attached.

What taking part in the research will involve?

If interested and happy to be part of the study, participants will be interviewed, at a time, day and location of their choice. The interview can be carried out face to face, online or by phone, in whatever way the participant feels most comfortable. The interview will last from approximately 45 minutes to one hour. Participants will be asked ‘what is it like to be a woman with ASD’ and prompts, if needed, may cover a number of areas, such as, interests and hobbies, successes, the experience of getting a diagnosis of ASD, sensory sensitivities, educational experiences, friendships, employment, partnerships, parenting and health. Participation in the study is voluntary and participants are free to cease participation at any stage without any risk of disadvantage. Some questions may elicit emotional distress for some participants. Should this be the case the researcher will adhere to a predesigned distress protocol.

Who will have access to the data from this study?

Participants will not be identified in the study. A pseudonym will be used throughout the research process. This means that I will be the only person who will know participants’ names. My research supervisor will know only pseudonyms. The interview will be audio recorded. The recording will be encrypted and kept on a password protected computer until it is transcribed. The audio recording will be deleted following examination of the thesis. The hard copy of the interview will be stored in a locked filing cabinet in a room which is locked when not in use and accessible only to the researcher. All information will be treated as confidential and identifiers from participants’ lives will be anonymised. The exception to confidentiality arises should a participant indicate that they or someone else is at risk of harm. The researcher may have to report this to the relevant authorities. This will be discussed with the participant first. In this instance, the researcher may be required to make a report with or without the participant’s permission.

What will happen to results of this study?

Results of this study will be submitted as the thesis component of the Doctorate in Educational Psychology at University College Dublin. The findings may also be published in scientific journals and used at conferences.

Who should you contact for further information?

Please feel free to contact me, the primary researcher, Louise Condon on xxx xxxxxxx, louise.condon@ucdconnect.ie and/or my research supervisor, Dr. William Kinsella, School of Education, Roebuck Buildings, University College Dublin, Belfield, Dublin 4.

Many thanks for your time and assistance,
Kindest regards,

Louise Condon

Appendix E

Research Advert

University College Dublin researchers want to learn more about women's experiences of the Autism Spectrum.

Can you help?

Are you a woman on the Autism Spectrum?

Are you over 18 years of age?

Who are we looking for?
Women aged 18 and over who have received a diagnosis of Autism Spectrum Disorder (A.S.D., including high-functioning autism and Asperger Syndrome).

What would happen if I took part in the study?
You would be asked by a female researcher to tell your story of your autism. Your answers will be made anonymous.

The benefits of taking part in the study include?
Contributing to the research community and others' understanding of women's lived experiences of the Autism Spectrum.

To take part or find out more:
Please contact the principal researcher Louise Condon on 087-1381124 or email louise.condon@ucdconnect.ie

The research supervisor for this study is Dr. William Kinsella, UCD. This study has been approved by the U.C.D. Ethics Committee.

Appendix F

Consent Form

UCD School of Education

Roebuck Castle

University College Dublin

Belfield, Dublin 4

T +353 1 7167965/7968/7967

F +353 1 716 1143

Title of research: An exploration of the lived experiences of women with a diagnosis of Autism Spectrum Disorder.

Consent form for taking part in the research.

By signing and returning this consent form you are indicating your agreement with the following statements:

I am a woman with a diagnosis of ASD and I am over eighteen years of age.

I have read and understand the information leaflet for this study.

I have asked any question I needed to and I am happy with the answers.

I understand I am free to leave the study at any time that I want to. This is my choice.

I understand that I will be asked to talk about some of my life experiences and that the conversation will be recorded using a dictaphone.

I understand that following examination of this study as part of the UCD Doctorate in Educational Psychology, the audio recording of my interview will be deleted.

I understand that some of the things I say will be written into a report. I understand that my name will not be written anywhere in the report and so anyone reading the report will not know I said them.

I understand that the information I give will be kept for seven years in a locked filing cabinet, in a locked office that is used by the researcher only. After this time, it will be destroyed.

I understand that under freedom of information legislation, I have the right to access the information I have provided at any time while it is in storage as described above.

I understand that if during the interview, the researcher becomes concerned that I am at risk of harm or someone close to me is, she may have to tell the relevant authorities to make sure I am safe. Should this happen, she will discuss this with me first.

I understand that should I need more information about this study, I am free to contact Dr. William Kinsella. His contact details are detailed below.

Signature of participant

I believe the participant is giving informed consent to participate in this study.

Signature of researcher

Date __________

Contact details of Research Supervisor: Dr. William Kinsella, School of Education, Roebuck Offices, University College Dublin, Belfield, Dublin 4, Ireland. Email: william.kinsella@ucd.ie

Appendix G
Participant Information Leaflet

An exploration of the lived experiences of women with a diagnosis of Autism Spectrum Disorder.

You have been asked to take part in a research project that is being carried out by Louise Condon as part of an educational psychology doctoral training course. Louise is an educational psychologist who works with the Department of Education and Skills, National Educational Psychological Service (NEPS). She has spent the majority of her career to date working as a psychologist with the HSE in various services, autism specific and child and adult disability services.

Before you take part in this research it is really important that you understand why the research is being done and what it will involve. If something is unclear, you can ask Louise a question by calling, emailing or writing to her. Her contact details are at the end of this sheet.

What is this research about?

There has been little opportunity for women with a diagnosis of autism, Aspergers Syndrome or an Autism Spectrum Disorder to share their stories and experiences. This study aims to extend existing research that discusses what are the lived experiences of these women by offering them an opportunity to tell their life stories in their own words. This study also hopes to inform services that support women who have a diagnosis of autism, Aspergers Syndrome or an Autism Spectrum Disorder.

Why is this research being carried out?

There is not a lot of research that focuses on the lives of women who have a diagnosis of autism, Aspergers Syndrome or an Autism Spectrum Disorder. Also, other people have given their views of what these women's life experiences are. This study aims to directly address these research gaps by exploring the specific experiences that make up the reality of the lives of these women by asking them to tell their life stories in their own words.

Why have I been invited to take part?

You have been invited to take part because you have been given a diagnosis of Autism Spectrum Disorder and you are an adult woman.

Do I have to take part?

You can decide whether or not you would like to take part in the research. This is your choice.

What will happen if I take part in the study?

If you are interested in taking part, you can contact me by email, phone or writing and we can discuss any questions you have. If you then decide that you would like to be a part of the study, we will arrange an interview at a date and time that is easiest for you. The interview can be done in person, over the phone or using online video. The interview will last for up to one hour in duration.

I will ask you to tell your story about having autism, Aspergers Syndrome or an Autism Spectrum Disorder. Some areas I may ask about include: interests and hobbies, diagnosis of

ASD, education, sensory sensitivities, relationships including friendships, work life, parenting, health and what makes you feel successful in your life. There are no right or wrong answers and you are free to talk about what is meaningful for you. I will record our interview using a dictaphone so that I can type it up afterwards.

When the interview is over, I will ask you if you would like to do a second interview with me in the near future. If you say yes, when I have all of the interviews typed up, I will contact you to see if you are still interested in doing a second interview. If you are, I will ask you to sign another consent form. During the second interview, you can help me make sure I have correctly understood the things that you and other women in the study have said about their life experiences.

How will the information collected be used?

If you decide you would like to be part of this research study, you will be asked to take part in an interview with me. I will ask you to tell your story about having autism, Aspergers Syndrome or Autism Spectrum Disorder. I may use short extracts from the interview to support the study's findings. Should this happen, I will ensure any quotes used are anonymous and will remove any information that may identify you. Your name will not be linked to any information. The study will be submitted to UCD for examination as part of the Doctorate in Educational Psychology. There is a possibility that at some stage in the future, the findings will be shared at conferences or published in academic journals.

Will my privacy be protected?

You will not be identified in the study. A pseudonym will be used throughout the research process. This means that I will be the only person who will know your name. The interview will be audio recorded. The recording will be encrypted and kept on a password protected computer until it is typed up. Then audio recording will then be deleted. The hard copy transcript of the interview will be stored in a locked filing cabinet in a room which is locked and accessible only to me.

If during the interview, I become concerned that you are at risk of harm or someone close to you is, I may have to tell the relevant authorities to make sure you are safe. Should this happen, I will discuss this with you first.

Are there any benefits in taking part in this study?

While there will be no direct benefit to you from taking part in this study, talking about your experiences will help others understand how they can understand and help women with autism, Aspergers Syndrome and an Autism Spectrum Disorder.

Are there any risks to me being part of this research?

There are no known risks associated with being part of this study. When talking to me about difficult experiences, you might feel angry or sad. This is ok. If this happens, we can talk about this and in my role as the interviewer, I will be there to help you.

If I agree to take part can I change my mind?

Yes. At any stage of the study, if you decide that you no longer want to be a part of the study, you can leave the study. However, once your information has been made anonymous, it cannot be withdrawn from the study.

If I take part can I find out the outcome of the study?

Yes. If you like, when the study is finished, I will contact you and send you a summary copy of the findings of the study.

I would like to take part in the study - what do I do now?

If you decide that you would like to take part in this study you can contact me by phoning me on: xxx xxxxxxx. I will then give you more information about the study and answer any questions that you may have. After, our discussion, if you still want to be part of the study, we will arrange an interview at a day and time and location that is easiest for you. The interview can be by phone, on-line video or in person. I will also ask you to read and sign the enclosed consent form. Depending on your choice of interview (by phone, in person or on-line video) you can return this form to me by email (scanned signature) or by post (stamped envelope enclosed) or you can give it to me in person prior to our interview.

Who has checked to make sure this research is safe?

The University College Dublin ethics committee has agreed that this research is safe.

Thank you for reading this information leaflet. Please hold onto it.

Contact: Louise Condon, c/o Dr. William Kinsella, School of Education, Roebuck Offices, University College Dublin, Belfield, Dublin 4. Phone: xxx xxxxxxx. Email: Louise.condon@ucdconnect.ie

This information leaflet was printed on the School of Education headed paper.

Appendix H

Non – Disclosure Agreement for Transcription Services

I hereby agree that any recorded information I obtain as a transcriber during Louise Condon's research titled 'An exploration of the lived experiences of women with autism spectrum disorder', will be kept confidential on a permanent basis.

I am not to inform anyone else about any of the content of the interviews. I also refrain from making any copies of the recordings of the interviews. The recorded interviews will be kept safe on a password-protected computer.

Moreover, the recorded material will be deleted immediately upon the completion of the transcription. None of the content will be forwarded to any third party under any circumstances.

Date	Signature
9th September 2019	The picture can't be displayed.

Appendix I

Sample ‘Noticings’ across dataset

Neurodiversity more attractive label ....less stigmatising

HFA misleading

Stereotype of ASD – harmful, can’t relate to this, barrier

‘they’ never mean what they say - trusting neurotypicals is an issue…repeated experiences of victimisation

Inclusiveness of ASD community – some find their ‘tribe’ group identity, need to belong is strong

Love of learning = resilience = self help

Love of learning able to channel into a career, working part time on own terms

Careers self-made in the main

Diagnosis – helpful, validating, accepted by others, empowering or debilitating?

Physical health – some linked to a unique female ASD profile?

Health and medical professional reactions....wider issue, women not being listened to

Advocacy so N.B. in medical setting…sensory overloads, communication suffers

Fleeting moments across school lives of happiness

Bullying common…observed by adults in their lives, abuse continued for some into adulthood

Ignore bullying because grades were good? ‘quiet girls’

Help seeking challenging – perfectionism part of the picture, can’t be anything wrong

Sexuality/identity

Societal expectation of women – mother, wife, girlfriend, life trajectory, ‘good daughter’

Dx – mixed positives and negatives, resilience – ASD dx protects – black and white about what is good and what is not, DX means to be assertive, to fight for self and others, legitimising, provides a role, an identity, good for daughters- still need help, still not being picked up, fear of judgement, society reinforces message that you are ‘wrong’- afraid of children being taken away

Search for self is ongoing- society/family tells you are wrong, vulnerable in your child/adult life

Transition points – the reinventing, the change, vulnerability at these times

Cost of conforming - devastating

Society not ready to accept differences…ableist

Physical symptoms of ASD? – vague symptoms doctor may not pick up but are ongoing

Executive functioning difficulty in education - viewed as lack of interest

Children – the costs, instinct, environmental considerations, adoption

Mental health – suicide in the community, suicidal ideation in childhood

Misdiagnosis – ‘not looking’ for ASD, looking for answers

Vulnerable families – need for family support, discord in families – parents on the spectrum, intergenerational difficulties, impacted mental health, impacted work, family incomes

Unhealthy organisations – focus on individual issues not the systemic issues, strength of ASD is that ‘it calls this out’

Risks of advocacy – personal impact on wellbeing

Appendix J

Coding Excerpts

I Interviewer: Louise Condon
R Respondent: 1- 5

Dorothy	
I: So thanks again for making the time this morning to speak with me and share your experiences. I'm going to start off by asking you to tell me a little bit about what your life is like right now.	
R: At the minute, it's actually alright besides my mental health, the reason being I've found an autistic community very recently, probably since January. What I mean by that is that I've found the adult autistic community. There's a lot of confusion in that community as well because there's people coming from different angles and sometimes I actually find autistic people hard work, just from a sensory perspective. Some of them are quite loud and some of them are very narrow-minded. I'd be a lot more...there are some people who are autistic and I don't feel disabled. I know I am disabled by society but I don't feel like a disabled individual. I've only been formally diagnosed since July at 42 years old. It wasn't that it was a surprise. I knew I was self-diagnosed and both of my children have been diagnosed. It wasn't a big deal, you can see it in my family but for me, I just knew I wanted that validation for my own personal reasons, and to be able to explain to other people because you know, people are very dismissive of certain things. So yeah, within the community, it's usually the kind of thing between autism mums, as they're called, parents trying to help or fix their child or whatever, and autistic adults screaming "no" that's actually not helpful. That happened to me when I was a child, and with autistic parents having a different view of things because they want to best for their child but they're so narrow-minded. I'm very much...when I talk about parents who have newly diagnosed children I'm like, "Sure let them do what they want, they'll come to it when they're ready." I used to work with children with special needs, and everyone will	Mental health Group identity (ASD community) NB resource ASD community not homogenous group Engagement impacted by sensory demands Divide in community perspective on disability Recent diagnosis – confidence in self-diagnosis Children on the spectrum Dx = validation, provides a context for others to understand difference Divide in community -Parents of children with ASD – looking for the cure/fix versus accepting difference Childhood experience of 'fixing' Working in childcare Advocacy role

reach their potential whenever they feel like they're ready to. This societal "Oh you must do this you must do this"...and I've always kind of thought that way, I couldn't really understand what the problem was but I got sucked in, culturally, and then society and what was expected of me and I was miserable.	Confusion-impact of cultural/societal demands re behaviour
I: In what way were you sucked in?	
R: I did the whole thing like you get a job, you earn money, you find someone, you settle down and all within certain time frames. I thought I needed to behave in a certain way, especially in relationships. Long-term relationships. Having my mum and other family members kind of going, "Oh you have to compromise" and this, I literally gave up myself. I didn't have the clarity so of course control was very easy for other people. And then other people would judge me for that, going like "Why don't you stand up for yourself?" I just didn't understand. I always felt untrue to myself like I wasn't going in the way I had envisioned when I was younger. And I considered myself a strong person, so for me to be sucked into that kind of world, to go against everything I felt and believed in, was really difficult and I ended up hating myself, and I took it out on myself. I would have done the anorexia thing, I was bipolar at one stage, general anxiety disorder	Traditional life plan - not aware of choice Lack of power in relationships - abuse Confusion re how to be in a relationships Familial expectations re behaviour Judgement of others is strong Sacrificing of self in relationships Inner conflict re authenticity and adhering to societal expectations re relationships Self - poor fit with societal expectations - internalising distress
I: So you said quite a lot in that now, can I unpick particular pieces? Some of the words you used 'miserable', being sucked into the social expectations around marriage, being in relationships and hearing that you had to compromise in relationships and yet also being told you had to be assertive. You were getting these mixed messages and in the process you were losing yourself. Can I ask, in terms of the vision you had of what your life would be ...what was your vision?	
R: Honestly, I wanted to be a single mum with my own job and do my own thing. I didn't really want to...I wanted to do things on my own terms. I didn't feel the need to be in a relationship. I thought, "Yeah, that'll be cool, that'll be lovely" but I actually wanted to do	Always wanted to be a mother Independence NB Benefits of relationship surface level

everything by myself. I wanted to be a mother but I didn't want to compromise on my own ideals and my own thing. I felt very strongly about that for a long time, and it's great when you meet someone and you're in love...that's all wonderful but I felt that people were telling me to...I often got, from being a teenager, like "Why are you so angry? Why don't you be a bit softer?" and I felt that they wanted to turn me into this little girl and played a really feminine role and be submissive. That was expected of me, like that's how girls behave. But I thought my brain was like a boy's, I'd be off with the lads in the corner with a beer watching sports rather than standing with the girls looking pretty...I just couldn't, I wanted to hang out with the boys.	Relationships = sacrifice of self - authenticity Enjoyed love in relationships Family expectations re stereotyped gendered behaviour Identified more with males – cognitive connection Stereotyped male interests – sports/beer Feminine aesthetics too demanding Sense of exclusion from girls world

Emma	
I: And then when you move into your adolescence, how do you remember that time in your life in terms of how you were doing in general in your school life, in your friendships?	
R: School life was always fine, I was always doing homework and getting stuff done but I think that was when...my auditory sensitivity got worse. Either that or I was so stressed in school that, when I'm stressed out, my auditory sensitivity gets worse. So I have like auditory sensitivity and hyperacusis. So having those multiple voices everywhere is really overwhelming. In Junior High, people are constantly talking, I don't know why they do that. I did end up getting bullied by an 8th grade girl when I was in 7th grade, who made my life hell for a year. I just didn't talk in school, I stopped talking.	Academics came easy Sensory difficulties increase with stress response Environment fit – schools too loud Confusion re social interaction – social demands increase in adolescence Bullying experience Mutism – one year
I: To teachers, friends?	
R: I think I had two friends but they weren't after school friends, we'd just talk about books and stuff during lunch and after lunch. We were basically...we called ourselves weird, we	Uncertain if friends were friends – separated into in-school and after-school groups

took on that label like it didn't matter anyway. It was nice I had that but I pretty much just didn't talk. During classes, I just kept my head down most of the time.	Ownerships of ‘Weird’ label – protective in school at breaktimes Mute within friendship group No friends in class Stayed Under the radar
I: And that bullying experience...again, I'm just wondering, were you able to share that with anyone?	
R: The only thing that helped me, honestly, was that I had a journal I would write poetry in. I was really worried my parents would find it because it was very dark. I just wrote very dark things because...I wasn't suicidal but I probably had some suicidal thoughts at the time, like I needed to get some emotion out. I definitely wrote a lot but I didn't tell my parents because it was really hard to explain.	Self-help in teens - journaling Suicidal ideation in teens Poor help seeking related to fear of judgement Subtlety of bullying hard to explain?
I: And what happened to end that really difficult year?	
R: I think that girl just started getting tired of bullying me? I don't actually know what happened. I just know eventually it got less bad. I don't think she moved out of the class, I'm not sure what happened to be honest. She was in my gifted and talented class.	Poor problem solving/conflict resolution Lack of agency in relationship Gifted class – like minded peers/smaller numbers in class did not prevent bullying
I: I appreciate this is difficult to think back on...you said it was hard to explain what was happening, could you try?	
R: She found me online, it was kind of like a cyber bullying thing, like pretending to be someone else and kind of tricked me. That was the issue and at school she would like yell words about me. It was very subtle because it would only happen during passing periods. I was just frightened to walk down the hallway.	Online bullying and in school – didn’t suspect fake profile Female bullying – relational aggression
I: So difficult, and not on an adult's radar?	
R: The only person who actually knew was the teacher herself, and I didn't know about this but she actually told them to stop bullying me. The only reason I knew is because, for some reason, we were at some competition and literally there was a group of people coming up to me and making fun of me. She was leaving it and I got so upset that I actually	Adult aware of bullying Group involved in bullying – more observable to teacher, had to act

scratched someone with my fingernails because I didn't know what to do. The teacher said to them "We talked about this" and basically let me off the hook. She asked what happened and I explained it, and she was like "Okay don't do that again but they need to stop bullying you."	Acting out – poor conflict resolution
I: So it had been seen by an adult, you just weren't aware of that?	Socially unaware - adult had previously intervened
R: Yeah until then.	
I: And that year, what age would you have been?	Transition - 13 years
R: 13 years old.	
I: Okay. The rest of your time in secondary school, as you move into later adolescence, what's the defining memory of that time in your life?	
R: Trying to help people...that might sound weird but there were a lot of other people who were self-harming and I didn't traditionally self-harm. I masked…I did have intrusive thoughts because I thought people were reading minds. I couldn't figure out why I couldn't understand non-verbal signals. So when I had intrusive thoughts, I'd put my fingernail in my neck to try and stop them. Eventually, they went away, after a year or two. I think I just convinced myself I was making it all up.	Empathy for others Drawn to marginalised peers – acceptance? Camouflage Distressed by social interaction difficulties Seeking explanations for social interaction difficulties Suffering – two years internalised distress
I: So it sounds like you almost explained it away to yourself?	Impact self-concept – self gaslighting
R: Yeah, it was strange	
I: You mentioned when you first entered grad school, that you felt you were experiencing a lot of generalised anxiety or maybe social anxiety. Do you think you were experiencing that in your younger years?	Mental health – constant state of anxiousness Didn't recognise physical symptoms
R: I had anxiety the entire time, I just didn't recognise it. I didn't know what relaxed feels like. In high school, I actually started having shoulder pain and I was literally doing this all the time (hunches shoulders). I didn't actually	

understand that you were supposed to be able to relax your shoulders, as weird as that sounds. I went to a physical therapist and he physically pushed my shoulders down because I wasn't using my shoulder muscles at all and I didn't know I could do that. I was definitely stressed out. I also have TMJ so I clench my teeth at night and I think I was definitely clenching my jaw in elementary school when I was overwhelmed and I didn't realise it the whole time. Like I didn't realise how stressed out I was until I found out I was autistic and I was like, "Oh I actually don't need to put myself in these terrible situations without sensory support."	Dx = knowledge, self-understanding, permission to prepare/ avoid sensory challenges in the future

Sheena (Part II of interview) **I:** Okay. I'm going to go back to your childhood. I remember you telling me in the first meeting that if you saw school friends outside of school you'd wave and greet them but you may not necessarily have a chat with them, small talk's always been difficult for you. You were contrasting that to your sibling's experiences. I remember you telling me you didn't get any support from the teachers, extra support, you don't remember that happening. You said that you always had a feeling that there was something different about you but you didn't know what that was. Tell me more about what school was like for you? What were your school days like?	
R: Difficult. Looking back, hard every day because life was an effort. Not invited to parties or only invited because my brother was...you know, not wanted. I remember just not being wanted by friends. I was never the cool girl and I was okay with that. I was never asked what I'd be doing at the weekend. I always felt like a burden if I was with people.	Survival in school Pain of social rejection – feeling unwanted from a young age Outsider role Rejection = Poor self-concept
I: Is that in primary school? **R:** Yeah. **I:** What would you do in primary school, there's two or three break times?	

R: I'd often be found playing by myself or else in detention because I wasn't conforming in class. I was fighting with people and just...I remember one particular incident where I took off a girl with an English accent in my class and I got detention for a week. I remember thinking "Everyone else does this it's just because I got caught." Things like that.	Friendless Not conforming to quietly behaved role Sanction - detention
I: When you were fighting...?	
R: It would just be petty girly fights, stuff I don't remember now, I just remember always being treated differently.	Poor conflict resolution Difference
I: Do you think those girly fights and even the imitating the English accent, do you think your Asperger's had anything to do with that?	
R: I definitely do think I was misunderstood. I don't know who could have understood me. They're the early 90s, you know...I was sent to school a year early to start with. I was always younger. It is an Asperger's trait that you don't mix with your peers anyway, that you don't get on with people your own age. So probably the Asperger's was always there but because it was misunderstood and because I was misunderstood, I think that's why they were so difficult.	Misunderstood by others Historical, societal lack of knowledge of ASD Self-knowledge of ASD – social immaturity Peers don't understand me
I: So if you were found fighting or playing by yourself, was that ever picked up by teachers?	
R: That's something that really upsets me. It's funny, like X would say to me "Are you not pissed off that your friends didn't see it?" I'm like "No, how were they supposed to understand if I couldn't understand myself?" It didn't happen in the x school, it was survival, just 100% survival for me. It does piss me off because they were good primary schools, they're good women, they're good at what they do but I would love to go and speak to my principal now but I don't know how relevant it would be for her because of how much ASD has come on and... But I would have had a better chance.	Post dx reflection - lack of adult intervention upsetting, sadness, angry Contextualises adult misunderstanding in historical lack of knowledge Dx = support, empathy Easier life earlier dx
I: You mentioned bullying during our least meeting……	

R: 100% primary, secondary, college. I let myself succumb to the bullies as well. It was easier to just let it happen. It was the cop out, it was easier just to let it happen.	Bullying experiences across education settings Self-blame – not strong enough
I: Can you tell me about that?	
R: Being left out...exclusion is a massive one. That could be mixed in with females but definitely exclusion and the fact that I was in an all-girls, so I was in that cauldron all the time and it's a nasty place to be. I can see that even now with work, an all-female environment, nasty. I've been asked to move to a different side of work for a few months and I'm like, no thanks. I work with two males every so often and by god, do they cut up the atmosphere. It's great. Is that because I get along better with males or because I have brothers I get on with? I don't know. I do know that an all-female environment is not a healthy place for me to be in because I don't think like a female.	Exclusion- relational aggression All female company – destructive in school and now in work – toxic? Males = positive change in social dynamics Exposure to males in family makes male interactions easier All female environment – unhealthy Male/female differing cognitive styles
I: Tell me about that.	
R: I don't feel like a male but I think more like a male than I do a female. So this, again, could be skewed because of interests but the girls yesterday at work were going on about something to do with Love Island and I was there like "How long is this going to go on for?" And one of them said to me "Oh you don't watch it?" and I was like no and she threw out a few series and I was like "I don't watch telly." I don't, like. They found it hard to find a subject to talk to me about and they were like "What do you do?"	Dissimilar interests to females Social interaction difficulties -struggling to find common ground Power in social interaction – others lead the discussion- reciprocity
I: Are you saying your interests are more traditionally male?	
R: Oh yeah. The best thing about living with the boys is sky sports. Like, Kardashians, who are they? That's why going shopping today by myself is hard because I don't know how to shop.	Male interests versus female Doing ‘female’ things is hard
I: Do you see that as a female interest?	
R: Oh 100%	

I: And you don't share that? **R:** No. At work now again the other day, we got into a situation where we had four hours to do what we wanted so my male co-worker said "Come on we'll throw on the USB and see if there's a movie." I'm like, why would you sit down all day and watch a movie? But it was pissing rain, I was getting paid, I was like alright then. And he asked what I want to watch and I said "Just pick a true story or something sporty" so we watched *The Hurricane*. I didn't know what was coming and at the end of it he was like "What did you think?" and I said "Class show" and he was like "Yeah, it's good alright, there's a few more there" so we watched something about Alcatraz...I was interested in it because it was factual, it happened, it was real but it was male. My coworker came in and was like "What did you do, watch *The Notebook?*" and I was like "I'm not watching that shit" and she was like "Have you not got an emotional bone in your body?" *The Notebook* wouldn't make me cry. *Marley and Me* wouldn't make me cry, I don't like dogs. I don't get emotional by these kind of "female" things.	Internalised gender roles Appeal of stereotyped male interest – sport, fiction Fiction- tangible ‘real’ ‘male’ Reactive to judgement of female colleague re interests Male interests = concrete, ‘real’ Female interests = emotion focused

Amanda **I:** You've mentioned a couple of times about your concern that others would not believe you, that they just wouldn't believe you have autism. So where's that coming from? Tell me more about that. **R:** I think maybe it's because I'm kind of...I just seem to expect that people won't believe me about stuff and I don't know if it's because I have trouble believing my own insights about myself or if it's...but if you have any kind of mental health issue, and if you're a woman especially, because I have a lot of depression and anxiety, people around you are so used to you freaking out about something you're worried about that I feel like they kind of go into this default mode of reassuring you that such and such probably won't happen. So I think that maybe I've had a bit too much of	Not being believed Hx of mental health difficulties question self-judgement – cannot trust self Self-gaslighting Response to female concerns – placation

that, and I kind of expect that...it's like if I have news about anything like that...I remember how carefully I told him in the first place what the psychologist suggested. I really felt like I had to control the way that news came out so that he wouldn't make assumptions about what assumptions I might be making.	Risk of disclosure of ASD – not being believed Risk of disclosure – how will ASD be perceived
I: Is the ASD diagnosis something that you feel comfortable sharing with others now?	
R: If anything, I'm open about it and I think it's useful to be able to be open about it in certain situations, like I went through an assessment for PIP, which is one of the disability benefits here, and I actually said to the assessor at the start, and I'd also brought in the documentation that the psychologist had made because I didn't want to...if I was having trouble with eye contact or anything else that day, I didn't want that to be seen as a sign of dishonesty. The one time I haven't...I was in hospital from last Wednesday until Monday and while I was in there, I was in one of those wards where there's three other beds, and at one point the other woman in there started talking about how people with Asperger's have no empathy. The conversation had just whipped from one subject to that, and it turned out two of them had kids with autism. It was horrible because they all started confidently agreeing this thing which is untrue, which has been debunked by autistic people ourselves. I was thinking, "You know, I'm right here, and I rescued your inhaler from the bed, so clearly I do care." After one of them had gone home, I kind of found an excuse to mention it because they were talking about the gastro psychologist we'd all seen, so that became an opportunity to mention it. But there's situations where disclosing it is weird, and I'm starting to realise that it feels a bit like disclosing that you're on disability benefits because that's also something that's highly stigmatised and highly misunderstood.	Exception - happy to disclose in certain situations DX = practical support (financial aid) DX documentation NB to communicate need Social interaction difficulty Poor eye contact perceived by others as dishonesty – disability assessment context Parents of ASD perpetuating negative stereotypes e.g. no empathy ASD Knowledge Group identity Evidence of empathy Dx = offers opportunity to educate others, broaden understanding Risk of disclosure: stigma and lack of understanding
I: And that's your fear, that would be a concern for you, how it would be perceived?	Disclosure to few

R: Yeah and there's also...most of my family don't know about it yet. My mother does, and she was really surprised but fine about it. My mother's reaction was basically, "Wow I always wondered about myself." Other than that, I'm not really in touch with most of my family. The family on her side, I don't really speak to. There's a couple of elderly relatives on my dad's side, I'm close to them and I told them right away and they were fine with it. So basically, even though it's been a few months, the news is still leaking out in some cases, and what I've said to my mother is, "You are welcome to tell your family if it comes up. It's not a secret or something I'm ashamed of but be prepared for the fact that they won't understand it and only know the stereotypical stuff." **I:** Conversations like, "People on the spectrum don't have empathy", what thoughts or feelings does that evoke for you? **R:** I find it very dehumanising, and it's very ignorant. It's difficult because the conclusion I came to with those women in hospital was that this was a buzz word that they...it felt like a mantra they had as a way of dealing with the fact that they didn't understand the emotional lives of their kids, and they fear their kids don't understand their emotional lives. One of the things they talked about was like, if someone in the extended family died and their child didn't react...I was kind of thinking like, it's not my place to say what's going on in the kid's head, I don't know the kid. But at the same time, I've heard so many autistic people say, "Actually, I feel a staggering amount of empathy." I'm willing to bet that there's more going on than is being expressed, and it's not...this is the first time that anything like this has really happened to me. Who would want to be associated with this?	Positive parent reaction Risk of disclosure – stigma and poor understanding No empathy stereotype Stereotypes = dehumanising Parents of children with ASD -perpetuating stereotype Double empathy theory Difference in grief expression Community discussion re inaccuracy of theory Desire to distance from ASD stereotype

Sally **I:** And then, can I ask about your childhood? You mentioned that difficulties were always there and the diagnosis allowed you to see that in hindsight. Can you tell me a little bit about what your childhood was like?	

R: Yeah. I'm one of four, I'm the only girl, which I think is also interesting because there are kind of unconscious expectations that I would be better at certain things compared to boys, it's possibly another reason why I didn't stand out in some ways. As a three-year-old, four-year-old, I identified very strongly as a boy. I changed my name, I looked like a boy, I had deliberately short hair and wore only boy's clothing, and distanced myself quite a lot from anything to do with girls, and befriending them and keeping their company, playing with them. It was always something that I found very confusing, and still sometimes find difficult to navigate. **I:** Why do you think that was? Why do you think you were identifying more with boys and the boys in your life and feeling uncomfortable and confused by female company? **R:** I think it was distancing myself from a label that had been put onto me, being told that I was a girl, being told that as a result of that, this is how I'm expected to behave, these are the things that I'm interested in. And just never being able to meet that standard; not being smiley enough, polite enough, I don't know, various things like that. Then also not having any interest in dolls or playhouses, any of those things. But I think more than anything kind of finding myself in a circle of girls my age and not understanding how I was suddenly in trouble, how I had somehow said the wrong thing, how I had broken a rule that was never made clear in the first instance. It was just always confusing territory for me. And boys, by comparison, played games with rules, and you either understood the rules and went along with them, or you didn't play fair, in which case you were out. Those were the stakes. **I:** You mentioned you felt you wanted to reject that label and the expectations of the label of "girl". Where do you think that was coming from? **R:** It wasn't a family thing because I have very easygoing, open parents who were happy	Unconscious expectations re daughters behaviour v sons Behaved like brothers and as a result did not stand out? Acceptance in family? Rejected girl identity – name, hair, clothes Kept physically distant from girls Being with girls is confusing/hard and remains a challenge in adulthood Label of girl forced onto self Assumptions of label -sterotyped ways of behaving, of 'being' Being a girl is 'hard' – failing standards Dissimilar play interest Social interaction difficulties – unable to access girls social world Female company – confusing landscape Male company – rule bound, structured, predictable – less 'grey' Family accepting of outward expressions of rejection of label girl

to put me in boys' clothing if that's what made me happy. I was never told that I needed to dress a certain way or behave a certain way. It's just a series of cues that I picked up on, I suppose. My only true memory is that feeling of just stress when I was in a situation where I had to be a girl, to play with girls and wear girls' clothes. Just really uncomfortable.	Rejection of societal cues re girls behaviour Girl label experienced as stressful
I: You were so young to be aware of such feelings	
R: I know, yeah, and to reject it so strongly. I don't have a memory of everything but I know that it wasn't simply a case of "I have a big brother and I want to be like him." It wasn't to do with him at all. I suppose the fact that he was there, and I could play with him and his friends, meant that I had access to the company of boys but it didn't stem from a place of wanting to be like my older brother. It was more not wanting to be something else.	Rejection of label girl unrelated to greater exposure to boys Rejection of label related to wanting to being anything but girl
I: How long did that feeling last for you? You said you still find it difficult to be in female company at times.	
R: It depends. The women I'm friends with, and I do have some very close female friends, they tend to be slightly different in ways. They are the more open and non-judgmental and generally accepting of others type of people. I don't feel like I need to keep up with any kind of illusion with them or something. They're not overtly feminine, they don't necessarily talk about their relationships all the time. I don't mean to generalise but it's just company I find easier to keep. And then I can feel it instantly when I'm in company that I know whatever I say will be perceived as odd, or won't be met with every action that's positive.	Enjoys close female friendships Selective about female company Overtly feminine = difficult to relate to Steroytyped female conversation - emotion focused/ relationship focused = difficult to relate to As adult aware of being perceived as ‘odd’ by women
I: So you have a sensitivity as to how you'd be interpreted by others?	
R: Yeah, definitely. I can feel it quite instantly if I'm in a group.	Self awareness

I: What do you do in those situations? You mentioned masking earlier on. Is it something that you consciously do?	
R: I think I'm aware of when I'm doing it. Generally it's something I try not to do anymore, to almost win back time that I've previously lost in trying to do it all the time. I'm aware when I'm doing it. I know the things that I should say that'll get me through a situation, I know the reactions I should have. Generally, I think in tune enough to be able to play the part that I need to play but I'm aware that it is that, that I'm not really bonding with a person, that I'm not really bonding with a group or contributing in any meaningful way, that I'm just keeping up an appearance to get through it.	Dx = agency, reclaiming lost time, being more authentic Masking =conscious act Masking = social survival Masking = allows for surface level connections
I: Is there any particular time in your life where you would have been heavily invested in using masking as a coping strategy?	
R: Usually any of the occasions where I had bigger downfalls as a teenager, hugely. As a teenager in an all-girls school constantly surrounded by the same kind of conversation, same expectations, the same culture. Then in college, not so much trying to keep up appearance with peers but trying to keep up the pretence that I know how to get from one lecture room to the other without getting lost, I know how to submit an essay online without getting confused. It was trying to keep up in other ways, a different form of it I suppose.	Masking intensifies in teen years Cost - mental health suffers All female environments = identity suffocating Masking not only social needs - executive functioning difficulties
I: Those very difficult times in your life where that masking intensified, what do you think was the cost of it, or the side effects of it?	
R: I remember as a 9-year-old hearing a story on the news about a sociopath and not knowing what that word was, knowing what the story was. I looked up what it meant and thought I was one. That I was one person with people and another person by myself. I was aware of the fact that I was constantly changing myself as soon as I was interacting with another person. I was aware of jumping from one personality back to my own, and my own being the more "secret" one, the one I	Seeking explanations for difference: Believed she was a sociopath for years Seeking identity: self not good enough

wasn't comfortable expressing, whether that was small talk, eye contact, just generally body language maybe being out of sync...I was aware of these things that I wasn't doing right and so much of my interactions with others was me trying to make sure I was doing these things. And being aware that it was an effort to sustain eye contact, that it was an effort to hold myself or carried myself in a way that mirrored what they were doing. I was always aware that it was never a natural thing for me, that I was conscious at all times where my hand was, how often I was looking, how often I was nodding...counting in my head, sometimes, like, I'd nod every five seconds. That's how unnatural it was. It had been that way from the time I was 8 or 9 and then onwards. I was very self-aware as a child. Trying not to do it so much now means I allow myself not to make eye contact sometimes, not because it makes me uncomfortable but because it's distracting for me, I do find it hard to process thoughts and put them into words, in real time as it is, and if there's a distraction on top of that, I can see someone's expression and they're looking at me with that strange, confused, "Is she going to make a point?" Like that will throw me and I won't make a point in the end. So allowing myself to be in a conversation on my own terms and not be constantly trying to make it look like I'm doing it another way or something.	Social interaction difficulties – body language Mental and physical exhaustion of masking Adopted social anthropologist role: controlled imitation ASD self-knowledge – social interaction difficulties Dx= living life on own terms…reducing masking, reducing eye contact to allow her to be more comfortable/present in conversations

Shauna **I:** And the impact of having the diagnosis confirmed for you, what difference has it made for you, would you say? If any?	
R: I gather these are not uncommon steps because I have talked to others and read into it. Massive relief, mainly. I knew I actually wanted it...well actually, the reason I'm interrupting myself is that I had a funny one.	Dx = relief Dx= sharing in the community
I'd been working in mental health and campaigning against the medical model; in other words, if people are depressed I believe it's a state. It may be a deeply ingrained state from childhood trauma but I don't believe people have chemical problems in their brain in that way. So I had been staunchly	Actively campaigning against medical model of disability
against...not against people having a diagnosis of being depressed but really against someone saying "You have depression" like "You have to take drugs for the rest of your life." I was	Campaigning against not seeing people's mental health problems in the contexts of their lives
really campaigning to say, let's see humans as generally healthy and reactive to our environment. Obviously I do see autism	Medication as only treatment option
differently because I see it as neurodiversity. What I was up against was, I used to say to people who would maybe seek out a diagnosis of maybe PTSD wanting a diagnosis of	Views autism as neurodiversity
something and me saying - aren't you playing into very patriarchal parental culture here, that somebody tells you you have a disorder and then you get to say, "Oh good it's not my fault" and then you don't get to be empowered, you don't get to say, "I'm deeply	Occupation – challenging mental health diagnoses process
depressed or traumatised and I'm going to find out why and fix it." You just go to a doctor because you have a condition called this,	Diagnostic process disempowers?
"Here's the medicine." So even though I see neurodiversity differently, I had a really big issue with it, going, why do I want this diagnosis? Because if I already feel like I identify as someone on the spectrum, why	Identifying with social model of disability/neurodiversity creates inner conflict when seeking dx
don't I just self-identity? I thought no one was listening and this is the culture we live in, that	Self-identification not enough
some psychologist somewhere has to say, "Yes you're right about yourself." And I felt like I also do over-analyse everything and I thought, I could have taken myself down a total rabbit hole and I want an objective	DX = recognition from others
opinion because it might be that I go for the assessment and he sort of says, "Do you know what? I get why you've come here. I	DX = unanswered questions answered

genuinely don't think this is what it is that's going on for you. Maybe it's X, Y or Z." And I kind of went in there knowing I wanted to be right because I'd researched it so carefully and it made so much sense. Bearing in mind I'd looked into a zillion things in my time about, have I got some personality disorder, even though I said I don't think they exist? Every time I'd read into it, I'd come away going, no that's just not me, that doesn't fit. So this fit and I wanted it to be validated. Of course, what's happened since, I got the clinical psychologist throw a stamp on it but the way it works, it gets sent to my GP which immediately medicalises it. So my doctor now holds my diagnosis on record as a medical thing. I was really torn about that because it was like, I've just played into the way the system is.	DX = explanation ASD self-knowledge Mental health – queried personality disorder Mental health dx poor fit Dx= validation Medical model deeply entrenched across systems Conflict over lack of agency re sharing of dx
I: A lot of the women I've spoken say that diagnosis was a personal validation and also a systems piece, it was needed for other supports, for you, you still needed to follow this particular...	
R: I thought what would happen would be is that instead of me saying...the way I played it out in my head was...when I was at the X I said I had a feeling I was on the spectrum and ADHD. Don't know, have mixed feelings about ADHD, I think it's up in the trauma, anxiety...anyway, doesn't matter. They just couldn't give a shit because it was my opinion. It wasn't a formal disclosure but it was me trying to say, there are things going on for me that are impacting. It was really funny, my boss at the x is the X's occupational health physician. So when I was trying to discuss it with him, almost as a friend and a manager, I recall him very clearly saying "I wouldn't have the first clue. I'm an occupational health physician, I wouldn't have the first clue about autism spectrum." And when I was in that job, we had a couple of managers come to us as health and wellbeing occupational health team saying, "Someone's identified being on the autism spectrum, can they come to you?" And my boss immediately said "No, it's nothing to do with us."	Self-identification not enough to access support Safety behaviour -testing reactions of colleagues to dx Professionals lack of knowledge of ASD Lack of expertise in ASD in occupational health system Thought 'official' dx would lead to support at work

I thought in [redacted] being a [redacted] company, what I thought would happen is, that instead of me saying "I'm pretty sure I'm on the spectrum" and them saying "Based on what?" and being invalidated, I sort of naively made the mistake of saying I was on the spectrum and that it had been clinically validated, I thought they'd just say "Oh right, brilliant, tell us what you need", that's what I thought. The way I put it, like "This is both a big deal and not - it's a big deal to me but so long as the environment's inclusive, it doesn't really matter." I said to my manager, "I've been told this is a	
strengths-based organisation, so it shouldn't matter why my strengths are the way they are. As it happens, my strengths are a lot to do with being autistic. I have got crazy amounts of information in here and very high recall	Strengths of ASD
and nearly photographic memory but I struggle with politics and some other stuff and sensory but I'll manage that. I might sometimes come to you and say that one too	Self-knowledge ASD – sensory, interaction demands
many group meeting has been booked in, I think I might just ask if I can go..." and she started out fine. It was when I was raising	Employer supportive on an individual basis
problems with the general workplace environment that she suddenly switched it back to being something to do with me.	Organisational level gaps reflected as individual's problems
I: So I would like to unpick some of this if that is ok? You mentioned neurodiversity at the start and before….	
R: I have thoughts that are currently under formation. I instinctively prefer neurodiversity because, both intellectually and...I don't know whether to call it moral or ethical but that's me being very precise about language, it doesn't matter...to me the whole thing makes more sense to work towards neurodiversity like	Neurodiversity makes most 'sense'
sexuality, where it doesn't have to necessarily be about being gay, straight, bisexual. I mean those things are what they are but it's more about going...like "My sexuality is under an umbrella of sexuality" everybody's got	Neurodiversity – umbrella term
something under the umbrella. Probably not the best example. But I'm definitely against	'Disorder' – diagnostic language offensive
"disorder", 100% against "ASD". The clinical psychologist I saw was explaining about how the whole Asperger's thing, so he said to me, "Look I would've said Asperger's, some	Late dx- missed opportunity to identify with Asperger's label

people identify with that." I never really had a chance to identify. I feel that if I'd been diagnosed earlier, I might've quite liked being able to be an "Aspie", to feel like that's a community, it's not autism per se. I do have my doubts about autism as an umbrella because it does run up against more trouble with misunderstandings when I say I'm autistic rather than Asperger's. I've run into trouble with parents of children who are non-verbal or whatever, so I've had that insulting like "How could you dare call yourself autistic when..." so I'm somewhere in the whole...my clinical psychologist called it "autism spectrum condition" because he's bound by the diagnostic manual to an extent but he said he was happy to...this wasn't at my request, he also feels the same. He said he doesn't tend to call it a disorder, that he doesn't think that's fair. What he was saying, as a clinical psychologist, he said what he's trying to do is he was operating within the diagnostic criteria he's bound by...in X, you don't have to use a DSM, it's the international classification of diseases, so he was just saying that if I want a diagnosis that's considered legally recognised, it has to be autism spectrum but he called it a condition not a disorder. I want it to become neurodiversity because I want it to be...you know the way that left-handed people used to be burned at the stake...if you're right-handed it's dextral, if you're sinister like a witch, you're left-handed. So I realise I'm talking hundreds of years ago but I just want it to become more like that, where neurodiversity, you can just go "Yeah, my brain's not really in the middle norm, it's a bit off." So dyslexia, autism, any of those, I wish it could all be seen as a normal...you're a researcher, so you know why I'm tripping myself up here. The point is that we're divergent from the "norm"...I mean normal like "healthy". They reckon that even early cave paintings might have been people who would be described as being autistic because we're likely to bring innovation forward and not stick with comfort zone. That, to me, has to be neurodiversity. Even if I say, "Oh I'm the neurodivergent that people call autism or used to call autism or call Asperger's"...because I think people need to understand. I know that, meanwhile, dyslexic people have been fighting for a long	Preference for 'Aspie' label – more appealing, select sub group in the community Lack of inclusion within the ASD community Judgement of parents of children with ASD – HFA V LFA Professionals' conflict with language of labels Professional conflict working within system that operates based on medical model Desire for difference to be accepted as the 'norm' 'Norm' = healthy Strengths of ASD Label has power – misunderstood vs understood

time for it to be a learning difference not a learning disability or disorder. So it's that, where I fall. There's something about Asperger's that I like as an identity, I suppose, because it means that I can find the right people via that term, like other people who have been able to work, have been able to get educational qualifications, have been able to live independently but still have the struggles. So I think Asperger's is one that...I understand why people have been angry that they did away with it as a diagnostic criteria because I think I would've rather, given the choice of autism or Asperger's...in that binary choice, I'd have rather Asperger's.	Group identity Assumptions of Asperger's profile - distance from LFA? Autism spectrum label unhelpful for HFA individuals

Appendix K
Ethical Approval

An UCD Office of Research Ethics
Oifig Eitic Thaighde UCD

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June 17th, 2019
Ms Louise Condon c/o Professor William Kinsella UCD School of Education Building Belfield Dublin 4

Re: HS-19-30-Condon-Kinsella: *An exploration of the lived experiences of women with a diagnosis of Autism Spectrum Disorder.*

Dear Ms Condon,
Thank you for your response to the Human Research Ethics Committee – Humanities (03/05/19). The Decision of the Committee is that **approval is granted** for this application which is subject to the conditions set out below.
Please note that **public liability insurance for this study has been confirmed** in accordance with our guidelines.[i]
Please note that approval is for the work and the time period specified in the above protocol and is subject to the following:
- Any amendments or requests to extend the original approved study will need to be approved by the Committee. Therefore you will need to submit by email the *Request to Amend/Extend Form* (HR4);
- Any unexpected adverse events that occur during the conduct of your research should be notified to the Committee. Therefore you will need to Submit, by email, an *Unexpected Adverse Events Report* (HR5);
- You or your supervisor (if applicable) are required to submit a signed *End of Study Report Form* (HR6) to the Committee upon the completion of your study;
- This approval is granted on condition that you ensure that, in compliance with the Data Protection Acts 1988 and 2003, all data will be managed in accordance with your application and that you will confirm this in your *End of Study Report* (HR6);
- Please note that further **new** submissions from you may not be reviewed until any **End of Study Reports due** have been submitted to the Office of Research Ethics. That is, any earlier study that you received ethical approval for from the UCD HRECs;
- You may require copies of submitted documentation relating to this approved application and therefore we advise that you retain copies for your own records;

.../.

- Please note that the granting of this ethical approval is premised on the assumption that the research will be carried out within the limits of the law;

- Please also note that approved applications and any subsequent amendments are subject to a Research Ethics Compliance Review.

The Committee wishes you well with your research and look forward to receiving your End of Study Report. All forms are available on the website www.ucd.ie/researchethics please ensure that you submit the latest version of the relevant form. If you have any queries regarding the above please contact the Office of Research Ethics and please quote your reference in all correspondence.

Yours sincerely,

Dr Joan Tiernan
Chair Human
Research Ethics
Committee -
Humanities

Appendix L

Distress Protocol (adapted from Dempsey et al., 2016)

The interview will be terminated if:

- The participant decides to terminate the interview.
- The participant decides to participate in the interview at another place or time.

The researcher will intervene if the participant is:

- Experiencing anxiety or distress during the interview. The participant will be asked if they would like to take a break and if they wish for the audio recorder to be turned off.
- Continuing to show signs of upset. The participant will be asked if they would like the interview to end and if they would like the researcher to call someone to spend time with them, such as family member or friend.
- Unduly distressed. The researcher will remain with the participant until they are calm and composed. The participant may then decide to continue with the interview or not.

The researcher will, with the participant's consent

- Refer to others if they request
- Secure permission to call them later in the day or the following day to ensure they are no longer distressed. Alternatively, the researcher may ask if they would prefer someone else, a family member or friend to call them to offer support.
- Contact details of useful numbers and support groups will be offered if participants require them.
- Should the participant indicate that they or someone else is at risk of harm the researcher may have to report this to the relevant authorities. This will be discussed with the participant first. In this instance, the researcher may be required to report with or without the participant's permission.