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**Recognising Autistic women:
A minority within a minority**

A thesis

submitted in partial fulfilment

of the requirements for the degree

of

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by

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ABSTRACT

Evidence is emerging from the Western world that, when seeking assistance, Autistic women are remaining unrecognised, or are being misdiagnosed with mental illness by the clinical professionals they approach. However, as a result of their relative invisibility there is very limited academic literature on the occurrence of the mis(sed)diagnosis of Autistic women, as these women only draw statistical interest when they eventually become formally diagnosed. This thesis provides for an exploration of this usually hidden topic. As such it is an exploratory, inductive study that is guided by a transformative worldview. I use triangulation as a methodology in the corroboration of views found to be underpinned by opposing philosophical stances. I then consider the lived experience of unrecognised autism, the clinical context of mental healthcare, and the guiding documents and reports for the provision of autism services and support for Autistic adults in the government-funded New Zealand healthcare system. This information is supported by data collected from an online questionnaire of healthcare practitioners with a specialised knowledge of autism, specifically how it presents in females. I conclude that there is a longstanding and harmful relationship between Autistic women and madness in part driven by a negative interface between psychiatric services and women in general. Issues for Autistic women are exacerbated by a lack of understanding over time of neurodevelopmental conditions within the healthcare professions that I contend could be contributing to the ongoing, and harmful phenomenon of under-recognition of Autistic women.

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Haere i muri i te tuara o Te Hapuku; kia kai ai koe i te kai whakairo o te rangi xox

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PART ONE

CHAPTER ONE

INTRODUCTION

Autism does not discriminate, and Autistic individuals can be found across all ethnic populations. The World Health Organisation (WHO) (2018) describes poor health, education, social, and economic outcomes as a likely possibility for Autistic people, and sensationalist reporting of late has implied that we are in the grip of a global autism epidemic. Despite these claims it is believed that around 60% of Autistic adults who do not have co-occurring intellectual disability are going unrecognised; with Autistic women overtly represented in this group.

In 2011, New Zealander Hillary Stace's PhD thesis drew from her personal experiences as the parent of an Autistic son. Stace insisted that love and luck are key determinants in the likelihood of positive outcomes for Autistic people; the love of a supportive family, and luck that suitable services exist and are accessible. If her statements continue to be the reality for Autistic people in this country, those of us who are unaware of our place on the spectrum are left only with the possibility of luck; and for me it was 37 years before my luck came in.

No matter how hard I worked, how nice I tried to be; it didn't matter what I did or didn't do, I could never get ahead in life. I failed at every attempt to gain a suitable level of education. As I got older, I would get sick; seriously physically sick, and be unable to work. Social and interpersonal relationships would end terribly and hurtfully and for years I blamed myself. All the while I was oblivious to the fact that my experience of the world was different to that of most other people. Having been actively seeking answers for these problems most of my adult life, I was given all manner of reasons from the health and social support services I had engaged with. But the older I got, the less logic I could find in what they were telling me. It turns out that none of them had been remotely correct, until 'luck' intervened 2 and a half years ago.

In January 2017 it was suggested that I be assessed for autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). It was 4 months before I was diagnosed with ADHD, eleven months before I was sent to be assessed for ASD, and another 6 months before I was diagnosed as 'on the spectrum'. Although the idea that I might be autistic had been never even crossed my mind, it ended as a welcome relief. Akin to opening Pandora's Box, that was the beginning of my Masters journey.

*A NOTE ON TERMINOLOGY

At first it was easy to distance myself from the cloud of negativity emanating from this topic, having only recently become aware of my own place on the autistic spectrum. At the beginning of this journey I was tied up in the details of how I would explicitly describe the group of women I intended to represent. But over the last year or so I have found myself feeling anger and disappointment at the constant underlying tone of autistic inferiority, even from those who believe they are advocating for us. I know how it is to be picked a part as a person, labelled, categorised, and put in your place like the findings of a scientific experiment. Reflecting on my readings has led to disheartenment on realising that as an Autistic person the focus of such negative perceptions was personal.

The original title of my thesis was: Recognising adult women with high-functioning autism spectrum disorder; a minority within a minority. I was set on the idea that I address a very specific population which I believed myself to be a part of, which is expressed in the wording of my data collection information. Gaining a deeper understanding of what it means to be autistic, and interacting with other Autistic people since my diagnosis has led me to question the relevance of the 'high-functioning' label. The term 'high-functioning' discredits the social difficulties definitive of autism (Evans-Williams & Williams, 2016), belittling the experience of internal turmoil that has been stressed by so many Autistic people.

I have found that there are also a number of other interchangeable terms used in association with autism, dependant on the situatedness of individual, institutional, or

community voice. Simon Baron-Cohen is a clinical psychologist and well know authority in the field of autism research. Although some of his work has inadvertently influenced harmful autistic stereotypes, his following statement is a positive step towards changing deficit-based terminology within clinical professions:

Here and throughout we use the term "ASD" because this is what is used in DSM-5. However, in our publications over many years we have opted for the more neutral term "ASC" (Autism Spectrum Conditions) to signal that this is a biomedical diagnosis in which the individual needs support, and which leaves room for areas of strength as well as difficulty, without the somewhat negative overtones of the term "disorder," which implies something is "broken."

(Meng-Chuan, Lombardo, Chakrabarti, & Baron-Cohen, 2013)

Noting the authoritative standing of Baron-Cohen on this topic, I had hoped that this softening of terminology may have been incorporated into the works of other researchers. Unfortunately, the deficit terminology of medicalisation is hard to step away from, and most literature still uses 'disorder' as the main terminology associated with autism.

As this thesis is separated into three parts I have chosen to use a mix of terminology. In part one I write with heavy personal inflection and have chosen to use 'autism' or 'neurodevelopmental conditions' in place of autism spectrum disorder (ASD), autism spectrum conditions (ASC), or any other previously named neurodevelopmental condition that is now considered to be part of the autism spectrum. This is because there is still some variation in the terms used for diagnoses given, dependant on the diagnosing practitioner and the diagnostic manuals they adhere to. In Part two, where stating a point of importance from the literature I have kept the original terminology for impact and as a portrayal of the many differing views. The focus of chapters in part two is of the 'other' perspectives of autism and come from academic, and politically driven literature which draws from clinically based, medicalised information. Talking of my own referral for assessment and diagnostic story, as well as in chapter four, I have used ASD in some places. This is to reflect the predominant terminology used here, mirrored in the title of

the New Zealand Autism Spectrum Disorder Guideline (2016) (ASD Guideline). Part three uses a mix of terminology in the summary and returns to the use of autism and neurodevelopmental conditions for the conclusion and recommendations section. Where I use the term 'neurodiverse', I am referring to those with neurodevelopmental differences. The binary term for this is 'neurotypical' which gives equal balance between the two groups. This has become important to me after coming across the distasteful labelling of each in unequally balanced ways such as 'people with ASD' vs 'healthy volunteers' (Bishop-Fitzpatrick, Mazefsky, Minshew, & Eack, 2015), or 'normal population' (Lehnhardt et al., 2016).

POSITIONING THE RESEARCH

This thesis sets out to present information pertaining to the mis(sed)diagnosis of Autistic women, and how these women are currently perceived in relation to a diagnosis of autism within the context of the government-funded New Zealand healthcare system.

The thoughts behind this thesis come from my own journey and reflect an aspect of the contemporary re-considerations of traditional assumptions towards women and mental health, particularly how these assumptions may contribute to the mis(sed)diagnosis of Autistic women. Emerging research shows a high incidence of cases where Autistic women have previously been misdiagnosed as mentally unwell, leading to potentially harmful interventions, and an inability to access suitable support (Ministries of Health and Education, 2016).

My focus on unrecognised Autistic women has wide reaching implications when the prevalent expectations of women as mothers, caregivers, and homemakers are set against the negative lived experiences of these women (Corlett, 2017; Haney & Cullen, 2017; Kanfiszler, Davies, & Collins, 2017). I will argue that a Eurocentric worldview discriminates against women through the interactions of societal and medicalised perceptions of the 'normal' way of being female, leading to presumptions about the inability of females to maintain a healthy mental state. I attempt to show how patriarchal biased foundational

models of physical and mental wellbeing are built on the assumption of what constitutes a white male profile which can then lead to the discrediting of women's voices. I suggest that the meanings and methods of support offered for the Neurotypical women's experience that are driven by this assumption, in at least some cases, can be harmful to the unrecognised Autistic woman.

The framing of this study within one particular discipline has been difficult due my focus on a population that is not clearly defined within mainstream health and disability policy. Thus, I have drawn from aspects of Disability, Feminist, and Critical Autism studies in developing the groundwork for this thesis.

DISABILITY STUDIES

Broadly speaking, Disability Studies can be described as a measure of counterbalance to the pathologizing of difference from non-disabled medical professions and questions their right to defining an experience that is not belonging to them (Linton, 2005). Consecutively, the objectives of the disability rights movement are met by substantiating the voices of disabled people whilst actively engaging them with; and facilitating their participation in society.

The foundational principles for research in this field stem from the Social Model of disability which contests the deficit perspectives integral to the Medical or Individual Models. Where the Medical or Individual Model emphasises personal fault through an individual's impairment, the Social Model is broken into two mutually exclusive concepts. Firstly, impairment is seen to be a difference in functioning within the individual. Secondly, disability is the result of an environment that is unaccommodating of the individual who has an impairment (Tremain, 2013).

While the Social Model has proven to be instrumental as a social and political tool for change, it often presents disability as caused by physical barriers which create the lack of, for example; housing, employment, and transport being accessible to those with physical impairment (Shakespeare, 2013). From these statements one could be led to believe that

disability and its associated scholarship are exclusive to physical embodiment. There is a dire shortage of representation in the field of Disability Studies from those with neurological difference or other invisible disability, reinforcing assumptions of disability as physical when calling on the Social Model as an appropriate framework (Oliver, 2013). Disability Studies has also come under fire for its lack of attention towards the 'double disadvantage' faced by disabled women (Morris, 1998). I suggest that the absence of female specific concerns in Disability Studies may stem from longstanding perceptions of women's inferiority (Silvers, 2009), which crosses both societal and medical perspectives.

FEMINIST AND DISABILITY STUDIES

Contemporary Feminism collectively advocates for the emancipation of women through social change, regardless of race, ethnicity, social or economic status. However in traditional Western scholarship, historical constructions of women as inhabiting the binary opposite of wellbeing (Garland-Thomson, 2005) have helped to influence the ongoing marginalisation of the contemporary disabled woman (Fine & Asch, 1981; Mertens, Holmes, & Harris, 2009). The field of Disability Studies has faced criticisms for its seeming indifference to the manifestations of disability as specific to females (Sands, 2005), and conversely, the ignorance of feminism to the lived experiences of the disabled woman (Morris, 1998). As an example, advising on the role of feminist epistemologies in the research practice of community psychologists, Campbell and Wasco (2000) ascribe women's lived experience as legitimate knowledge, but neglect to mention the experiences of the disabled woman. Furthermore, positioned in Disability Studies and with a background in psychology, Simi Linton (2005) also draws attention to the absence of disabled women's perspectives in feminist psychology in particular.

CRITICAL AUTISM STUDIES

Emerging from the works of Davidson and Orsini in 2010, Critical Autism Studies is interested in the different conceptualisations of autism and the interactions between the

political, social, and medical constructions of autism within society (Davidson & Orsini, 2013; O'Dell, Bertilsdotter Rosqvist, Ortega, Brownlow, & Orsini, 2016). This emergent area of study is led by the following principles:

1. Careful attention to the ways in which power relations shape the field of autism
2. Concern to advance new, enabling narratives of autism that challenge the predominant (deficit- focused and degrading) constructions that influence public opinion, policy, and popular culture
3. Commitment to develop new analytical frameworks using inclusive and nonreductive methodological and theoretical approaches to study the nature and culture of autism. The interdisciplinary research required (particularly in the social sciences and humanities) demands sensitivity to the kaleidoscopic complexity of this highly individualized, relational (dis)order

(Davidson & Orsini, 2013, p. 12)

Speaking on their interdisciplinary collaboration of works from various perspectives towards autism, Davidson and Orsini see an opportunity to be influential to both policy makers, autistic self-advocacy organisations, as well as other stakeholder groups. Although their goal is to shift away from the lens of deficits, the Autistic individual is still predominantly seen to be an undefinable subject of political and medical confoundment. The Neurodiversity movement began in the 1990's, coined by Australians Judy Singer and Harvey Blume. Neurodiversity advocates argue that as a natural form of difference within the human race, the Neurodivergent community be accorded the same respect and rights as other populations differing from the expectations of societal norms. Ortega (2013) describes the 'cerebralization' of autism through the adoption of neuroscientific language which is used for a range of purposes. The highly individualised nature of the autistic experience and the variability of perspectives held by those who care for and support Autistic individuals is shown in the wide-ranging utilisation of neurocentric language, from cultural and self-identity formation to certain exemptions and allowances for financial supports and subsidised services.

Understandably, the multiple stakeholders situated in the autism arena make this a highly controversial topic, which has to some, become a 'thing'. This 'thing' is employed in certain fields as a moneymaking tool by organisations and individuals using scaremongering tactics (Solomon, 2008) to promote their 'revolutionary' treatments and therapies for autism's cure and/or prevention. Such fear is driven by deficit perspectives which in some cases sadly draws in the families and caregivers of Autistic people (Milton, 2014), academics from various fields and even Autistic people themselves. Within the field of Critical Autism Studies there is yet another group who questions the existence of autism as a neurological difference, claiming there is no substantiate evidence to the fact (O'Dell et al., 2016). This theory suggests autism is a psychological disorder for which the cure is yet to be found; a theory that ultimately undermines the credibility of the Neurodiversity movement.

MISMATCHES ACROSS THE DISCIPLINES

The academic fields of Disability, Feminist, and Critical Autism Studies all offer a number of grounding principles for my research. Yet it is difficult to situate myself cleanly in any particular one.

Whilst I do not advocate for the Medical or Individual models within a socio-cultural setting, they have their place in political and socio-economic contexts. Their current role is in the provision of access to the best available support for people who may be struggling as a consequence of autism related differences. Despite the great division between medical and social perspectives of autism, failure from one side to recognise any positive potential in the other can lead to a stalemate situation where Critical Autism Studies fails to meet its objectives of autistic emancipation (Davidson & Orsini, 2013).

Further, Disability Studies is mismatched with my work as the unrecognised Autistic woman does not hold any of the social, political, or legal rights accorded to disability. As for Feminist theory, I am a full advocate for equality between which-ever sex and/or gender people choose to identify with. But as an Autistic woman, I am personally wary of

connotations of an all-inclusive sisterhood and the ascribing of fixed gendered categories. Aside from my own experience of exclusion from any such sisterhood, socially gendered roles are a preoccupation of Western culture that seem of little relevance to the Autistic or wider Neurodiverse communities (Bejerot & Eriksson, 2014; Cheslack-Postava & Jordan-Young, 2012; Davidson & Tamas, 2016). Critical Autism Studies offers an openness to all types of literature and perspectives which becomes useful in presenting the intangible nature of autism. But as I came to find this field of study late in my research journey, to date I have not had the time to investigate this area sufficiently.

POSITIONING MYSELF

Entering tertiary education five years ago I have studied the impacts of oppression and marginalisation on minority populations through various means as well as the psychoanalytic interpretations of their possible behavioural manifestations. Social geography offered me a therapeutic form of explanation for my experiences. I worked my way back through my past, now viewed with an academic lens. My studies of patriarchy, colonisation, and Indigenous identity taught me that my experiences were 'a thing'. Not just in my head, but documented occurrences and themes within particular social and cultural structures. I held onto this as a means to offload some of the self-blame I had harboured for so long.

Throughout my life I have tried to understand the basis of my 'difficulties'. A lonely journey; I have been labelled as plain old 'crazy' by some, or 'bad' by others. Those who knew me best just made excuses, possibly out of a fondness for me. None of this was helpful and I felt I should be doing better, that I could achieve so much more. Unbeknown to me at the time, these are feelings that when voiced in the context of healthcare, are considered to be signs of mental illness (Haw, 2000). I did know one thing for certain though; that things would always go wrong, and life would fall apart. From a psychological lens, my background is complex. Cross-cultural adoption, limited education, living in an isolated area as a child, and having a sister with physical and intellectual disability were some of the reasons I was forced to believe as alluding to my 'perceived' difference. All

these things were further compounded by being female, all the negative connotations relating to gendered roles, ethnic minorities, and societal norms.

I had always known it to be 'a thing' whereby people who are adopted often feel like something is missing from their lives (Grotevant, 1997). Psychoanalytically speaking, this is a concept related to attachment theory. In the case of the adopted child, there is believed to be a deficient ability to form positive attachments in infancy which is then said to lead to impaired stress resilience and an inability to form emotional bonds (Haw, 2000)

In New Zealand, cross cultural adoption between Pākehā and Māori under the 1955 Adoption Act (Blake & Coombes, 2016) was based on unequal societal power relations and contentious understandings of what was socially acceptable within a hegemonic society (Mikaere, 1994; Newman, 2013). The Adoption Act provided a way to 'make right' the dirty secret of the illegitimate child (James, 2017a) as it was perceived by paternalistic colonial views (Haenga-Collins, 2011). Referred to as closed stranger adoption, and against the core principles of Māori culture, all genealogical connections were severed (Newman, 2013). The effects from the severing of genealogical ties is similar to that of the Autistic individual who remains unrecognised. Each finding themselves in an incompatible environment without any knowledge of why they are unable to meet expectations or feel any sense of belonging.

Although I didn't believe this to be the case for me, dominant discourse suggests adopted people are likely to be 'messed up' (Demick & Warner, 1988; Feeney, Passmore, & Peterson, 2007; Grotevant, 1997; Levy-Shiff, 2001). But as everything I felt, thought, and did had always turned out to be wrong, I assumed that I was probably wrong about this too. So in 2015, I decided to make contact with and meet my biological relatives.

Positioning myself as a detached observer, I analysed the behaviour of the people I shared a biological link with, seeking answers for myself and still feeling like an outsider. My initial thoughts had been right, nothing was missing from my life; I just felt different. Very recently I came across the online presence of Laura James, an Autistic woman with a successful career and a family who was diagnosed autistic at age 45 (Gillette, 2018).

Similarly, James also recalls the attribution for any difference or difficulty in her life to the fact of her adopted status.

Having worked through all other 'theories' I decided that it must be my cultural disconnection that was causing me such unrest. Being a 'half-caste', is also a theoretical cause for an inferiority complex (Meredith, 2000a), so I decided to undertake a year of full immersion te reo Māori. Seeing this as my final option, the high hopes I held of 'curing' myself caused a massive psychological drain. Despite the great sense of achievement on completion, my difficulties and differences were made crushingly clear during the process. Ahikāroa is literally translated as long burning fire, conceptualised as keeping the home fires going by regularly returning back home. Kanohi-ki-te-kanohi is literally face to face, or to be seen. Together these are intrinsic to Māori culture; to return regularly to your ancestral home, to be seen, to be known and familiar. Unrecognised autism and the associated sensory and social difficulties meant that without knowing why, I was also a failure at 'being Māori'.

The impact my education has had on me is similar to that encountered by Donna William (1992), herself an Autistic woman who saw her studies in psychology and sociology as a way to piece together her life using a theoretical framework (Dachez & Ndobu, 2018). She grasped education as a means to prove her sanity and intelligence by mastering the knowledge and understanding of Neurotypical humans and their behaviour. This is not to say that all Autistic people are alike and share the same experiences, but to point out that when we are unaware of the reasons for our differences there are many influences pointing us in the wrong direction. I can see how in the past my ideas were heavily persuaded by others on account of my dependability in always 'getting it wrong', consequently causing me further confusion. The overpowering negativity in statistical reporting of the Autistic population, and the horrific recollections of experience by other late diagnosed women give me a sense of amazement that I am still here, still positive and hopeful for change. There are a number of these women who have gone on to advocate for autistic rights and the better recognition of Autistic women. I share their reasoning and

purpose, knowing it would be wrong to stay silent when our actions have the potential to save the lives of other unrecognised Autistic females.

On a separate note, this account outlining my positioning as a researcher also serves another purpose. Within a Disability Studies framework, whilst it is important to outline our backgrounds in the research process, it is also important for me to show the great lengths needed in order to gain answers for myself and a sense of self-acceptance and identity. It had been my intention to include a chapter on the positive qualities of Autistic people as an additional justification for better autism recognition, but this was not possible for such a small study.

THE LAYOUT

PART ONE

Part one is greatly personalised and consists of my lived experience of unrecognised autism.

Chapter one introduces the topic of this thesis and the positioning of the research, and myself, for this study.

Chapter two describes the framework and methodology for this thesis, and how my past plays a large role in the development of thoughts and ideas for my topic of research.

Chapter three is an autobiographical account that shows some of the difficulties I have come up against. I have included this detail as it is in conflict with the ideas that are presented from a medicalised view. In this chapter I have referenced certain experiences with those of other women who have been diagnosed later in life. Whilst these may seem like circumstances that many women find themselves in, for those without knowledge of their underlying differences there is no way of learning from past mistakes as it is an inability to intuitively read and understand social situation that leads to these negative circumstances. The tone and style of part one is unapologetically in conflict with part two, as this is the reality we are presented with.

PART TWO

Part two is made up of chapters four and five. Having a medicalised tone, it is made up of literature from clinical practice, as well as publicly available government reports, guidelines and webpages from New Zealand.

Chapter four is a literature review giving insight into the formation of ideas towards autism and how these play out today. It also points at the ongoing imbalance of power between the sexes, how this leads to incorrect judgments, and subsequent inappropriate treatment and support for unrecognised Autistic women. I use this as a means of showing the context in which autism is generally viewed, both medically and in society.

Chapter five is a review of the ASD Guideline, relative Ministry of Health (MoH) webpages and recent reports on the New Zealand mental healthcare system. It looks at some of the issues affecting the provision of appropriate mental health and disability care and support in New Zealand. I look at the principles of care underlying this system and draw conclusions on the suitability of current practice in the recognition of Autistic women. From what is stated in the reports, and the side-stepping of certain questions, I am left to draw my own assumptions from some of the negative statistics on women that draw from the ongoing patriarchal ideas about the relationship between women and mental disorder.

PART THREE

Part three is a conclusion to the previous chapters, the findings of my field data, and final recommendations.

Chapter six is the conclusion of previous chapters and leading into chapter seven.

Chapter seven is the findings of my field data and the concluding statements and thoughts for this thesis.

CHAPTER TWO

RESEARCH FRAMEWORK

This chapter lays out the framework of my thesis and looks some of the conflicts involved in navigating the world of research methodology. In some ways the reviewing of my past has guided me in the search for a methodological framework. Although my thesis questions the reasons for the under recognition of Autistic women, part one is deeply researcher focused. By this inclusion of personal reflection, I hope to give some representation of the turmoil brought about by lifelong attempts to grasp a true sense of self. Therefore, I begin this chapter by detailing my journey to finding the right methodological fit. After describing my framework, I explain how my chosen methodology works in bringing the data together. I then present the methods I have chosen for the types of data I have used, stating why these have suited this particular research.

According to Creswell (2003, pp. 4-5) there are four main questions that underpin the development of knowledge as defined by Crotty (1998). I use the following insights to direct the layout of this chapter;

What epistemology- theory of knowledge embedded in the theoretical perspective- informs the research (e.g., objectivism, subjectivism, etc.)?

What theoretical perspective- philosophical stance- lies behind the methodology in questions (e.g., positivism and post-positivism, interpretivism, critical theory, etc.)?

What methodology- strategy or plan of action that links methods to outcomes- governs our choice and use of methods (e.g., experimental research, survey research, ethnography, etc.)?

What methods- techniques and procedures- do we propose to use (e.g., questionnaire, interview, focus group, etc.)?

FINDING THE RIGHT FIT

Now able to piece together a sense of identity, I have sought to find a guiding philosophical framework to support my research design, and that aligns with my thoughts and beliefs about the way things should be. The closest I had come to finding a framework where the 'researched becomes researcher' was that of Maria Haenga Collins. As a researcher herself, and being a Māori cross-cultural adoptee, Haenga-Collins' (2011) Masters thesis was on the narrative experiences of other Māori cross-cultural adoptees and their navigation of identity formation. The identity formation of cross-cultural adoptees is similar to that of Autistic people. Although Autistic people who are unaware of their place on the spectrum (as I was when I first came across Haenga-Collins' thesis) will be unable to pinpoint the cause of their sense of difference. As her study was themed on Indigenous experience, Haenga-Collins drew on the principles of kaupapa Māori in guiding her work.

KAUPAPA MĀORI

Kaupapa Māori was developed with the intention of creating a space by and for Māori where knowledge is shared and built upon, thereby validating Māori experiences and knowledge for the overall benefit of Māori (Mane, 2009; Smith, Puke, & Temara, 2016; Walker, Eketone, & Gibbs, 2006). A need was seen for Māori as oppressed minority populations to be able to share their knowledge in a way that is accessible to all. It is centred within te Ao Māori (the Māori worldview), emphasizing mutual respect and relationship building. Its utilization challenges eurocentrism by countering the many years of cultural suppression by colonial rule (Mead, 2003). Deeper meaning is offered by Taki (Pihama, Cram, & Walker, 2002, p. 32) in the following description:

"Kaupapa is derived from key words and their conceptual bases. Kau is often used to describe the process of "coming into view or appearing for the first time, to disclose." Taken further kau may be translated as "representing an inarticulate sound, breast of a female, bite, gnaw, reach, arrive, reach its limit, be firm, be fixed, strike home, place of arrival" (H.W. Williams c 1844-1985, p. 464). Papa is

used to mean "ground, foundation base." Together kaupapa encapsulates these concepts, and a basic foundation of it is "ground rules, customs, and the right of way of doing things."

Smith (1999) refers to historical defiance towards the idea of Māori being accepted as human, of the Indigenous fight in claiming the right to be acknowledged as a part of humanity under continued oppression. As a force against traditional Western methods of research that have monopolized academia, Kaupapa Māori stands apart as a form of resistance (Walker et al., 2006); emancipating those who had previously been silenced (Eketone, 2008).

Although ethnic culture as such is outside of the scope of this study, I make the comparison between the Autistic and Māori communities as being dictated to and told who and what we are while our voices continue to go largely unheard.

To refocus the views expressed by Smith into themes related to this research, I switch colonisation with medicalization, Indigenous with disabled and/or mentally disordered. In asking us if history is important, Smith (1999) offers me the chance to note synonymies in the historical incidence of institutionalization, oppression, and assimilation across both Māori and Autistic populations. Taki's translation of kaupapa as an emergence also fits well with the bringing to light of autistic narrative and meets with aspects of constructivism and grounded theory.

Being of Māori decent and sharing similar experiences with Haenga Collins I considered the primary use of kaupapa Māori to guide my work. Yet I didn't quite fit as Māori and felt a niggling unease about situating myself within a kaupapa Māori framework. Having suffered discrimination of various types myself, the defiance against oppression remained attractive to me. Speaking out as a member of an oppressed group was my desire. Nothing about us without us (Charlton, 1998) is a slogan that I lived by, although I was still unaware of where I was situated.

Despite the complexities of my background I have always faithfully returned to my 'privileged position'. This 'privileged position' is a place I am seen by others to hold; not

fully looking the part of either Māori or disabled. But this is not a comfortable place for me; more a hiding place from my inability to exclusively 'fit' anywhere. When one identity becomes too much, I can camouflage myself as a means of fitting into some other space or place. The concept of camouflage is tied to issues of self-identity, which is explained further in chapter 3.

While the beginning of my postgraduate journey was filled with methodological uncertainty, I frequently found mention of constructivist grounded theory, transformative research, and the transformative paradigm. These all seemed somewhat related to my understanding of kaupapa Māori but lacked in central cohesion. Where I found certain aspects of social constructivism and grounded theory to be useful in validating the technicalities behind theory generation, attempts at deeper understanding of each methodology uncovered conflicts of ontology with the use of the transformative paradigm. Constructivists consider multiple realities that are socially constructed, with the privileging of participant views in creating realities (Mackenzie & Knipe, 2006). While similar to transformative research, the crucial point of separation was missing.

I kept returning to the works of Mertens and found similarities in our ethical beliefs and cultural backgrounds. Moving deeper into the field of research methodology I found Mertens' references to the oppression of Māori populations and Indigenous academic Linda Tuhiwai Smith, the founder of kaupapa Māori. Reading more about transformative research under the transformative paradigm relieved my sense of appropriation and at the same time allowed for my philosophical comparisons to kaupapa Māori.

Regardless of this I was still confused about the deeper conflicts between the constructivist and transformative paradigms; only finding clarification on the matter at the end of my research journey.

PARADIGMS AS A WORLDVIEW

Similar to how I am perceived within certain circles, Mertens is critically aware of her 'privileged position' as a white American researcher. Reflecting on her early career she recalls feeling frustration around the legislative constraints dictating whose realities were

voiced when addressing the longstanding societal issues affecting marginalized populations (Mertens, 2010). In the early 1980's Mertens took a position as assistant professor of research and evaluation methods at Gallaudet University. As the only university in the world which catered specifically to Deaf students, she saw this as an opportunity to develop a research framework derived from the explicit intent to pursue social justice and human rights.

Heavily aware of the tendency towards deficit perspectives within the research community, and the lethargic connections between the philosophical values of the researcher and their guiding processes (Mertens, 2007) Mertens expanded on the ontological assumptions of constructivism in the development of the transformative paradigm.

The transformative ontological assumption recognizes that there are many versions of what is considered to be real and is cognizant of the constructivists' discussion of the social construction of multiple realities. Yet it diverges from this belief in that it holds that there is one reality about which there are multiple opinions. And here, it leads to epistemological implications. The transformative ontological assumption that there is one reality leads us to delve deeply into understanding factors that lead us to accept one version of reality over another. We are led to ask questions such as, "Whose reality is privileged in this context?" "What is the mechanism for challenging perceived realities that sustain an oppressive system?" "What are the consequences in terms of who is hurt if we accept multiple versions of reality or if we accept the 'wrong/privileged' version?"

(Mertens, 2010)

Citing the work of Denzin and Lincoln (2005), and Guba and Lincoln (2005), Mertens defines paradigms as a researcher's worldview on reality and methodology encompassing their ethical, epistemological stance (Mertens, 2012). Creswell (2014) frames transformative research as possessing an overarching perspective of social justice and the incorporation of mixed methods. It is acknowledged that there are multiple knowledge's

and understandings which are shaped over time and are influenced by individual factors such as dis/ability, sex/gender, culture, race, and ethnicity which are then affected by socio-political context that are fluid throughout time and space (as cited in Mertens, 2007).

While qualitative data is a necessity of transformative research, recognition of the multiple layers of power and oppression allows for flexibility in the methods of data collection and analysis (Mertens et al., 2009). The methodology and methods selected for use as fitting with a transformative worldview must be in line with the facilitation of social justice and the uplifting of minority groups (Mertens, 2007).

The demand for the researcher's conscious awareness of how the realities of power and privilege predominantly hold weight over those in marginalised positions is well fitting my intent. I have therefore used a transformative worldview as the guiding framework in structuring my research.

METHODOLOGY

EXPLORING WICKED PROBLEMS

Being diagnosed with autism after years of psychiatric misdiagnosis was troubling in itself, but has proven to be more so when opened up to questioning. In 2011, Stace described autism as a 'wicked' policy problem, finding that despite her background in policy and health research alongside her lived experience as an 'autism parent' and advocate, a substantiated understanding of this 'wicked problem' proved elusive. Wicked problems are defined as social issues, intensified through complex interactions between multiple stakeholders that are further burdened by limited and uncertain knowledge (Mertens, 2015; Romm, 2015). Stated bluntly, social problems are resolvable, but ill-defined, and unsolvable.

Rittel and Webber (1973) use the example of poverty and low socioeconomic status as a wicked problem. Is this a result of economies or individual capabilities? How do we improve the job market? How do we improve individual capabilities? Do we look at the individual's mental health, or a systemic failure in the education sector? There is an inexhaustible supply of variables involved in the making of these wicked problems.

Although my supervisor had insisted from the start that my story had a key role in this research, I spent months looking for ways to avoid it. After years of having my difficulties dismissed, I found it hard to see why they would be important now. Influenced by the dominance of traditional empirical research and its demands for total objectivity, I felt that any personal inflection would somehow discredit my work.

I have tried always to remain conscious of the strong critical bias I hold towards certain ideas. As a result, I had often found myself unable to move forward while I question the credibility of my theories in consideration of my own personal experiences. Coming across Patton's (1980) conceptualisation of inductive research only added weight to my concerns. "Inductive analysis means that the patterns, themes, and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis" (Bowen, 2006, p. 13)

But finding myself as a researcher who was also the researched, it became apparent that traditional methods were not compatible with this type of inquiry. In the back of my mind I knew this was an exploratory study derived from personal experience, and involving a multifaceted problem; but what exactly was I investigating?

Concluding to the previously foreseen wickedness of this topic and my methodological difficulties, "not only do conventional processes fail to tackle wicked problems, but they may exacerbate situations by generating undesirable consequences" (Camillus, 2008, p. 1). Alongside this I realised that my philosophical worldview and the justification for my line of questioning required my personal centrality to the research process.

EXPLORATORY INDUCTIVE RESEARCH

“The research questions we ask and the initial hypotheses we formulate are not only influenced by who we are; they are constituted by our very being in the world, our culture, context, biography, sexual, gender, and racial backgrounds, and oftentimes, by the sort of funding we receive”

(Reiter, 2017, p. 133).

Originally, the purpose of my research had been to find answers surrounding my late diagnosis of autism. My intent had been to question mental healthcare practitioners about how and why it was possible for me to have been constantly misdiagnosed, why autism had not previously been considered, and why was their resistance to the idea despite it being the main reason for my referral? But even if I gained answers for myself, I realised my research would hold less weight if I excluded all insight into how important a correct diagnosis can be, and the harm and distress that can occur without knowledge of the underlying reasons for one’s differences and difficulties. Looking at my concerns there are three main perspectives at play. These being the medical in clinical research and practice, the socio-political stance on the topic of autism, and the lived experience of late diagnosed Autistic women.

In contrast to Patton’s description (Bowen, 2006) implying the need for objectivity in inductive processes, I cite Srivastava and Hopwood (2009, p. 77), who question the ability of inductive analysis to provide unbiased theory:

From our experience, however, patterns, themes, and categories do not emerge on their own. They are driven by what the inquirer wants to know and how the inquirer interprets what the data are telling her or him according to subscribed theoretical frameworks, subjective perspectives, ontological and epistemological positions, and intuitive field understandings. In short, rather than being an objectivist application of analysis procedures, the process is highly reflexive.

I came to realise the impossibility of excluding my personal voice as the reliability of inductive exploratory research demands reflexivity, honesty, and the transparency of

intent behind research (Barnett-Page & Thomas, 2009) As the formation of ideas is never unbiased, the addressing of personal experience as is relative to the research topic can act as a measure of counterbalance (Reiter, 2017). This understanding of the place that personal bias has for my research is what influenced the heavy personal tone for part one of this thesis. Of course, this account has been included with a strategic purpose (Plummer, 2001) and is tailored as a backdrop to the direction and formation of ideas around this study.

The reflexive aspects of data analysis and exploration of theory are summed up by up by Berkowitz's 1997 (Srivastava & Hopwood, 2009, p. 77) conceptualisation of qualitative analysis:

a loop-like pattern of multiple rounds of revisiting the data as additional questions emerge, new connections are unearthed, and more complex formulations develop along with a deepening understanding of the material. Qualitative analysis is fundamentally an iterative set of processes.

WHAT?

Thinking about what had driven me to undertake this research I came up with three points of significance:

1. The problems arising from the processes that adults need to go through, and the experience of assessment, to be formally recognised as autistic.
2. The aversion of mental healthcare practitioners in considering the existence of Autistic women, showing a preference to diagnosing mental illness.
3. The unnecessary trauma that can be experienced by Autistic women who remain unrecognised.

WHY?

Why are Autistic women remaining unrecognised? Pondering the possible answers to this question left me reflecting on the factors that had led to my own misdiagnosis. Firstly, to address point one, I was eventually referred to mental health services with the intention that I would be assessed for autism. Secondly, to address point two, once I was engaged with mental health services, I encountered a great resistance to the idea that women could be autistic. Not only was I openly laughed at, all options I was offered as an explanation to my difficulties were the contemporary equivalents of neuroticism. Thirdly, point three is shown throughout this thesis by way of my personal inflection, While I have no medical or mental health related educational background, I have developed a distaste for psychoanalytic theory and its use in the over-pathologizing of every-day life (Rosenhan, 1973). Psychoanalytic judgements are not only confined to clinical settings but are also a favourite 'go-to' for use in social assertions of power, or what is more commonly known as bullying behaviour.

It was not possible to use literature from a localised context as New Zealand draws its autism knowledge mainly from international sources (Ministries of Health and Education, 2016) Although there has been recent media interest in the dangerous under recognition of Autistic females (Corlett, 2017), there is a noted absence of autism research carried out in the southern hemisphere (O'Dell et al., 2016).

HOW?

How have I presented my case in the verifying that the three points above are linked not only problematic, but are all closely linked? The relative invisibility of Autistic women and the lack of definitive literature on the topic are what make this an exploratory study. I have attempted to collate different perspectives with the aim of corroborating my ideas and hypotheses. I have used mixed qualitative methods for data collection. As it would have been impossible to collect enough substantiated field data to validate my claims in the time available for a Masters project, I have used secondary data alongside the collection of original field data from a New Zealand sample population. Close to the

conclusion of my Masters journey I have realised that my methodology is the corroboration of conflicting perspectives in validating the theory that the invisibility of Autistic women is problematic. The validity of hypotheses or theory building cannot stand without an explanation of how they developed if we have any intention of addressing the issues proposed.

TRIANGULATION

As an iterative and inductive process, I have needed to present the three opposing perspectives (Torrance, 2012) which are jarring in contrast and amount to difficult reading. If I were to adjust the style or terminology to flow easily between chapters, the multiplicity of context would be hidden and ultimately defeat the purpose of my investigation. In further defence of this choice, I ask you, as the reader, to imagine that your existence requires a constant navigation of, and attempts to understand the multiple perspectives in which you are viewed. By exposing the contents of my life, I show that this is not just a story contained in a book; it cannot be closed and put away. Autistic women cannot safely return to a simplified world, as for us such a world does not exist.

The methodology I will use to justify this rough reading journey and validate my conclusions is triangulation. A navigational term, it involves the utilisation of existing reference points in order to locate the unknown (Jonsen & Jehn, 2009). Framed as a qualitative research methodology it works to corroborate or give deeper depth and meaning to the understanding of the phenomenon under investigation (Bowen, 2009). Triangulation used for my purposes is best described by Patton (1999), who equates it to the locating of the researcher at the intersecting point of two known perspectives which in this case is the triangulation of data sources in showing a picture that was previously undocumented.

METHODS

For this thesis I term methods to mean the modes of data collection, such as questionnaires and interviews, over the common usage denoting types of data, such as qualitative or quantitative as does Biesta (Mertens, 2012). Predominant thoughts towards the meaning of transformative mixed methods is of the inclusion of both qualitative and quantitative data types (Howe, 2012). While a transformative framework suited my research, it would not have been practical for me to collect first-hand quantitative data as fitting with the mixed data types required of transformative research. Detailed statistical information on the Autistic population is not routinely collected in New Zealand. Having only very recently becoming aware of my place on the spectrum, I have not made enough connections within the Autism community that would provide a suitable sample population matched to this study. The unique nature of autism means that often the people who are unrecognized or misdiagnosed are themselves unaware of their place on the spectrum. Subsequently, the majority of this population is literally invisible. Although I have not collected first-hand quantitative data, the peer-reviewed literature, institutional and organizational documents that have been part of my reading are built on quantitative statistical information which is what has helped in bringing this issue to light (Sweetman, Badiee, & Creswell, 2010).

Excluding the data I have collected first-hand, I wanted to figuratively paint a picture of the space that unrecognized Autistic women exist in. This required the difficult decision on what perspectives and from what sources, would best illustrate the whole. For this reason, I have separated into chapters, the perspective of lived experience, themes from clinical settings and the influence these hold on societal perceptions, and the socio-political picture of the New Zealand mental healthcare system where I believe many of these women could be hidden.

My selection of data collection methods and the inclusion of each different perspective ties in with exploratory research and triangulation as the methodology for inductive analysis, and the corroboration of ideas (Creswell, 2003).

AUTOETHNOGRAPHY

In chapter two I situate myself as a member of the population at the centre of my study by introducing the context of this population through my own auto ethnographic account. Autoethnography is a qualitative research method consisting of data about the positioning of self, and the relationships between self and others within the same context. As a research method autoethnography can be defined as a self-narrative that critiques the situatedness of self with others in social contexts (Spry, 2001). One of the leading criticisms of autoethnography as a method is its inability to claim generalisability (McIlveen, 2008). For this reason, I felt the need to further justify myself and have referenced my personal story with the autobiographies of late diagnosed Autistic women who have had similar experiences. These references have come from women in New Zealand, America, and the United Kingdom, showing that the under recognition of Autistic women is potentially a global issue. Whilst autoethnography is viewed sceptically by the scientific community, it offers deep insights into sensitive issues where the researcher has intimate awareness. Autoethnography enables me to present insider knowledge to the topic under investigation (McIlveen, 2008; Ngunjiri, 2010), and provides justification for the ideas and intent behind this research.

Finally, (Ngunjiri) state that “various auto ethnographers have explored their own identity and its development within given socio-cultural contexts,” and the introductory positioning of myself as the researcher is just one example of a lifelong quest for answers and identity.

LITERATURE REVIEW

In order to create valuable research, investigators must first have an understanding of their topic area and knowledge of previous works in their relative fields. By reviewing the available literature in the area of interest Hart (1998) suggests that the researcher is then able to build on any existing theories or evidence. But as this is an exploratory study on a somewhat invisible population that has yet to gain mainstream acknowledgment, I have

been left to draw assumptions around the large gaps in what information was available to me.

A literature review was first undertaken to gauge the topic of Autistic women, which divulged studies about 'women' and 'autism'; not women who are autistic. These initial searches resulted in articles around parental experiences of Autistic children, and cause and effect type studies investigating maternal testosterone levels or environmental factors during pregnancy. Although these types of studies show one extreme of how Autistic people are viewed, it was incompatible with the focus of this study. The literature I eventually decided to include outlines the history of ideas in the field of autism. It is information that most parents of/or Autistic people would need to know in order to advocate for themselves in the often hostile and uneducated environments we face when attempting to access suitable support.

Unable to find solid confirmation of the how's and whys pertaining to the mis(sed)diagnosis of Autistic women, I wanted to understand why women in general tend to be viewed as inferior in Westernised healthcare systems. Additionally, academic literature from disciplines relating to my questions around health-related policy and services held very little information on Autistic women as a population that was specifically catered for. Widening the scope of my literature review showed that the interdisciplinary interest in autism presents contentions between the ethical assumptions and vocabularies underlying the different fields of knowledge (Boote & Beile, 2005).

My reading in this area led me to include a brief introduction to the development of typical health modelling which sets the scene for viewing females as innately flawed. This addition was a natural progression of discovery in what is a topic of limited information. It fitted with the ways I felt I had been perceived within healthcare settings and expanded on my existing review by covering the references listed for my initial readings. By outlining a brief history of the main points in autism research and knowledge this literature review provides the reader with a theoretical understanding of how the issues of an invisible population have arisen. Whilst the topic of autism is interdisciplinary, it is emergent, and I have found that specific ideas or concepts are closely tied and cross-referenced to others.

DOCUMENT REVIEW

Document analysis as a qualitative method involves the reviewing or evaluating of electronic and /or printed documents. It requires the same interpretation and meaning making as other qualitative methods; working well in the process of triangulation when combined with other qualitative data in the study of a specific phenomenon (Bowen, 2009). The analysis of content within selected documents uncovers certain themes or ideas that are directed by the philosophical worldview under which the research is being carried out (Milner, McIntosh, Colvert, & Happé, 2019).

In Chapter four I have reviewed and included excerpts from the recent reporting on the New Zealand mental health system as well as publications pertaining to disability where they include the word 'autism' or 'ASD'. As autism is said to be assessed for, diagnosed, and 'treated' in the mental healthcare system, I felt it necessary to investigate the suitability of mental healthcare services to carry out these duties in light of my own engagement with them. My own experiences were terrible, and I wondered if they were just a 'one off', or a common occurrence that had impacted on the outcomes of other Autistic women. My interest in the way's women are still negatively perceived within Westernised healthcare and societal settings is something that inadvertently came up again in the reviewing of these documents.

The inclusion of certain excerpts and key themes from these documents exposes a different side of the difficulties for unrecognised Autistic women, more so in what information is missing than what is explicitly stated. As Patton (1999) points out, it is important to address any inconsistencies that may be found through triangulation of different data sources, leading to a deeper understanding of the relationship between various approaches to inquiry and the findings they yield.

In order to find where autism is sits within the context of the New Zealand healthcare system, I undertook a keyword search of documents from the MoH website. This simple method also allowed me to navigate the MoH website to find out what services were available to Autistic individuals. As this thesis is directed from the perspective of an Autistic adult, the accessibility and ease of navigating this information is seen in the same

way as someone who would be seeking support. During this process I came across conflicts in the statements which outline the available services for adults which I have also included in this chapter.

In regard to finding publications related to autism, I searched under the publication categories for 'disability' and 'mental health'. Under these categories I then looked for documents that made a distinct reference autism. My main tool for this task was a basic key-word search using the search terms 'ASD' and 'autism'.

Determining the relevance of documents involved a simple key-word search for 'autism' within each document. This narrowed the results down to two publications relating to mental health services, and two under the category of disability. To begin with though it was important to introduce the founding guidelines that direct the current provision of mental healthcare services.

MENTAL HEALTH

- Blueprint for Mental Health Services in New Zealand How Things Need to Be, 1998.
- Blueprint II Improving mental health and wellbeing for all New Zealanders, 2012.

As suggested in the titles, these two documents provide the guiding principles behind the 'recovery approach' which underpins the provision of mental health and wellbeing services in New Zealand. Blueprint 1 states itself as a National Mental Health Service Development Plan.

- The Office of the Director of Mental Health Annual Report 2016 (2017c).
- The Office of the Director of Mental Health and Addiction Services Annual Report 2017 (2019).

These documents contain information collected from district health boards and non-government organisations across New Zealand through the Program for the Integration of Mental Health Data (PRIMHD). Their purpose is to monitor and inform on the progress made towards implementing new initiatives as well as meeting the legal requirements of reporting on certain clinical practices under the 1992 Mental Health Act (MHA) (Ministry

of Health, 2012). Within the public health sector, I have found very few references to autism and these two documents are no exception. In my search of the 2016 annual report, autism was mentioned only once but envisions significant progress for the Autistic community. Although my key-word search for autism did not return any results in the 2017 annual report, it is certain statistics pertaining to women and mental illness, as well as the exclusion of the Autistic population that make it a relevant inclusion.

- New Zealand's mental health and addiction services The monitoring and advocacy report of the mental health commissioner (2018).

This report was carried out by the Office of the Health and Disability Commissioner, an independent monitoring agency who is responsible for the promotion and protection of rights of health and disability service users. Aligning with the office's role of monitoring and advocacy, this report includes the voices of service users and their family and whānau, service providers, as well as information relating to performance indicators.

The word 'autism' was not found in this report, but again it is the contention between what is stated and what is missing when considering those on the margins of access to appropriate disability and mental health related supports. The voices of dissatisfied service-users provide useful insights into how the current system may be unsuitable for Autistic adults.

- He ara Oranga Report of the Government Inquiry into Mental Health and Addiction (2018).

As a consequence of widespread concern about the performance of the mental health sector this report was commissioned by the New Zealand government. It incorporates input from a range of stakeholders, including service users and their family and whānau, iwi, as well as community and district health board (DHB) service providers. Recognising the wide range of needs across New Zealand, He ara Oranga makes recommendations for policy and legislative change to the current system with a note to the health and disability sector review which is currently under way. References to autism in this report are again limited, but highlight key areas where the current system is failing the Autistic community.

DISABILITY

- Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services as at September 2016 (Ministry of Health, 2017b)

As it suggests this report provides demographic statistics on the population who are allocated funding to access disability support related services in 2016. Throughout my research journey this report is the only evidence I have come across that gives a quantitative account of the Autistic population in New Zealand. The importance of this document is that it aligns with the international statistics and widely held beliefs of who Autistic people are. While these statistics are problematic for my focus, they offer hard evidence of an issue which can be laid against other sources of information that show a different picture.

- The New Zealand Autism Spectrum Disorder Guideline (2016)

This document claims to be a guideline built on evidence-based best practice for the assessment, diagnosis and support of Autistic people across the whole lifespan. The target audience of this guideline are professionals in education, primary healthcare, policy developers, specialists, family, whanau and support people, and any other group or individual involved with the Autistic community.

FIELD DATA

To make sense of my life experiences I felt the need to question those I had seen as having had control over my situation. I had originally wanted to question clinical mental health practitioners working in public mental healthcare settings, but with these intentions I could not gain approval for my draft research proposal.

Instead, it was suggested that I engage with tertiary education providers to future healthcare practitioners in nursing, counselling, and social work. Despite this new focus in participant recruitment, my mind was still set on gaining answers from healthcare practitioners tasked with the assessment and diagnosis of autism in adults. I had

previously written an assignment on snowball sampling as a method of participant recruitment and remembered its benefits in gaining access to populations that are traditionally hard to engage with. All paperwork and details pertaining to the collection of field data are attached in the appendices section.

THE QUESTIONS

Main question:

- How might misconceptions about the spectrum nature of autism impact on the recognition of high-functioning adult women with this condition?

Sub-questions:

- What categorisation is given to ASD within the New Zealand healthcare system (mental health disorder, neurodevelopmental disorder, or disability), and how might discrepancies in ideas about where this condition 'sits' impact on the possibility of diagnosis for adult-women at the high-functioning end of the autistic spectrum?
- How do healthcare practitioners who interact with this group of women navigate the interface between mental health and disability services when referring to ASD-related Ministry of Health or other related professional guidelines in the assistance of these women?
- How might past views of women's mental health, and a lack of informed awareness around autism spectrum disorder contribute to difficulties in recognising high-functioning autism spectrum disorder in adult-women who engage with mental health related support services?

Through the use of snowball sampling I was also able to reach out to a wider range of professions. Whilst this method allowed me greater access to potential participants, there have been unforeseen outcomes relating to the healthcare sectors my participants are employed in. My recruitment did not attract participants from either the education or

government funded healthcare sectors, and as a result it is difficult to match my findings cleanly against my original questions. This is an aspect covered further in the findings chapter.

SNOWBALL SAMPLING

A technique often used in qualitative research; snowball sampling relies on the passing of information within groups defined by the researcher to aid the identification of potential participants. Described by Patton as;

... an approach for locating information-rich key informants or critical cases. The process begins by asking well-situated people “Who knows a lot about ...? Who should I talk to?” By asking a number of people who else to talk with the snowball gets bigger and bigger ...,

Patton, 1990, p. 176 in Brace-Govan (2004).

Snowball sampling is therefore highly effective in engaging with the small and otherwise closed population I seek as participants in this study (Noy, 2008; Woodley & Lockard, 2016).

Some critics of snowball sampling cite an inability to maintain participant anonymity, which has been a key feature of ethical practice in Eurocentric research. van den Hoonaard (2003) attempts to discredit snowball sampling methods in suggesting that maintenance of ‘collective anonymity’ involving the locale of the research, becomes very difficult within small and/or marginalised communities where close-knit relationships are held. Other researchers have questioned the validity of information collected through snowball sampling, considering the non-randomised selection of participants within a closed network.

For my purposes this method offers a practical solution to issues of access arising from the sensitive nature of my topic (Cohen & Arieli, 2011), and the difficulties involved with

accessing members across the various professions from which information is sought (Atkinson & Flint, 2001).

THE PARTICIPANTS

As it was not possible to follow my original plans for the recruitment of diagnosing practitioners employed in the government funded healthcare sector, my target population was the education providers to future healthcare practitioners in the fields of nursing, counselling, and social work. I chose to recruit participants from healthcare professions who at some stage in their career will/have potentially interact/ed with unrecognised Autistic women. These target recruits are part of a larger group of professionals identified in the ASD Guideline as requiring access to education and knowledge of autism to successfully fulfil their professional duties. This group of professionals hold insider knowledge of the policies and procedures for directing these women through the health care system, and therefore could offer information on their experiences, what is working, and areas that may need improvement.

I had intended for my participants to include up to four academic staff from tertiary institutions providing training for future healthcare professionals working in the professions of social work, counselling, and nursing. In the event of difficulty recruiting participants of the above specifications, healthcare professionals who had worked in such positions within the last three years would also be considered.

As Snowball Sampling does not consider geographical constraints participation in my research involved the completion of an online, open-ended questionnaire (*see appendix D and E). This allowed for the engagement of suitable participants who may not have been located within the areas of initial recruitment.

My questions were around their professional experiences of interactions with women who are or may be on the autistic spectrum, as well as gaining information on current curriculums of study for future healthcare professionals with regards to how recognition

and engagement of women with possible autistic symptomology are explored in the context of education for these professions.

Thinking of the possibilities opening up through the use of snowball sampling I realised that the criteria I had stated for participation could be too narrow. I then decided to include a second participant group on the provision that I could gain insight of a different perspective again by widening the criteria. The questionnaire for this group was based on the same guiding questions as for group one, but differed slightly according to the duties and knowledge of their professions.

A ONE-STEP PROCESSES

Preparing to initiate the recruitment process I considered factors that were likely to limit participation. Noting the timing of my data collection to be over the Christmas holiday period, I wanted to make the process as quick and easy as possible. One way to do this was to limit the need for back-and-forth contact between myself and any potential recruits. I also wanted the participants to have the opportunity to contribute at a time that was suitable to them.

I decided that the most convenient way to do this was to send out all the relevant information and links at once. This included the original introduction letter, sent by email as a call for participants (*see appendix B) which stated my position as a Master's student carrying out a 120-point thesis and introducing the topic of my research. Furthermore, it outlined who my target participant groups were, the title of my thesis, the guiding questions for this study, and my contact details.

For those who were interested in further details of my research, attached to this email was a participant information sheet (*see appendix C). This included evidence of ethical approval to carry out this research, further details on the purpose of my study, and the participant recruitment information, timeframes, and obligations. At the end of the participant information sheet was a consent form be emailed back to me or given in person for those wishing to participate in a face-to-face interview after the completion of

the online questionnaire. Deadlines are stated for the acceptance and recognition of consent, the arrangement and siting of interviews (should this option be chosen), as well as an option to review the transcribed data (from interviews), and the option to withdraw from the project.

Hyperlinks to the online questionnaires were embedded in the participant information sheet. One for each participant group (*see appendices D and E.) was accessible under the coinciding recruitment criteria. The giving of consent for the online questionnaires was built into the online process. Participants were unable to access the questionnaire without first granting consent.

I saw this method of engagement as non-intrusive and giving any interested parties the opportunity to offer their input, in their own time, without the inconvenience of needing to contact me for further information. There was also a personal reason for setting up my data collection process in this manner. I am aware that my verbal abilities are not always the best when meeting new people for the first time. I felt that in this case I was especially susceptible to difficulties with my verbal communication in light of the power-imbalances I have encountered when dealing with these particular professions in the past.

MOVING ON...

This chapter has shown the interconnectivity between my experiences, the development of my research framework and the ideas for this thesis. Moving into chapter three, I offer a highly personal account of the experience of unrecognized autism, and how this lack of awareness and understanding of self has led to negative consequences across all areas of my life.

CHAPTER THREE

LIVED EXPERIENCE

THE ISSUE

Although some of it is anecdotal, a growing body of evidence suggests the existence of an unrecognised population of Autistic women (Bargiela, Steward, & Mandy, 2016). Such speculations have been strengthened by the growing collection of narratives which offer insight into the experiences of women who have lived unrecognised on the autistic spectrum. Whilst numerous examples of these experiences are available in the form of autobiographies as well as social and traditional news media, there is very little available in the form of peer-reviewed academic literature.

WHY IS THIS AN ISSUE?

Unrecognised:

- not recognised as valuable or valid (Oxford dictionary, 2010)
- not given a formal acknowledgement of legal status (Collins dictionary, 2014)

This single word both describes the status and compounds the severity of difficulty that can be encountered by the Autistic women that I wish to represent in this thesis. As implied by the meaning of unrecognised, the unnecessary distress imposed on these women will only ever gain validation if at some stage they manage to obtain an official diagnosis of autism. Without official recognition by either a clinical psychologist or psychiatrist, it is likely that their distress will continue to be labelled as mental disorder. This chapter contains a brief account of my life so far.

As a personal account, my story is not remarkable and could appear to be consistent with any woman who has had bad luck or made seemingly poor choices. This may be the case, but I believe that if I had been aware of my place on the spectrum much earlier, my life

may have taken a different path. At least then I could have avoided what now seems to have been unnecessary distress and abuse, and perhaps have met my potential much earlier. As an effort towards 'authentication', I have referenced autobiographic accounts or narratives from peer-reviewed literature of other late-diagnosed Autistic women where their experiences have paralleled my own.

MY STORY

When I was at primary school I can remember wondering how and why other children thought and did the things they did (James, 2017b). I also wondered if inside their heads they all were questioning these same things.

Somewhere around this time one of the kids at school told me I was adopted, and that my parents weren't my 'real' parents. I went home and asked about this, and my parents explained adoption to me, as well as the reasons behind my adoption (Haenga-Collins & Gibbs, 2015). It didn't make any difference to how I felt (James, 2017b). They are my parents and the who, what, and why thing was irrelevant to me. But throughout my life my adopted status has been cited as a reason for any of my troubles which were seen to originate within the mind (Gillette, 2018; James, 2017b).

Around the age of eight I was moved ahead a year because I was doing so well academically. I knew I was smart because other people told me (Birch, 2002). But I never could understand how I knew things, I just did (Holliday, 1999; James, 2017b). I remember looking at the word 'because'. I knew how to spell it and I knew what it meant but I was still confused (Baldwin & Costley, 2016). How did I know how to spell that word and know what it means? How did it mean 'because'? What made it what it was?

I had to play netball, because I am a girl. Mum played netball with all the other mums, so I guessed it to be something we must do as females. I hated it, I never knew where I was supposed to be, rolled my ankles constantly, told I was 'scared of the ball' (Williams, 1992) and consequently I was always in the wrong (Holliday, 1999). I remember one day our class went out to play soccer. I really wanted to do this, even though it was 'for boys'. My

dad likes soccer, so to me that meant it must be good (Kanfischer et al., 2017). But in reality, it was all crazy, fast, running around with no purpose while trying to avoid being hit by a flying ball. I was scared and confused and wanted to get away from the chaos (Birch, 2002). I was trying to reach my teacher to tell her I had had enough. She happened to be kicking the ball as I got close to her and her shoe came flying off, hitting me in the face. I took this as another sign that team sports were bad; invented to hurt and humiliate me.

Although many experiences were hard, I was lucky in the fact that I went to a small country school with 34 pupils at its fullest (Birch, 2002). Having been a part of this community for as long as I could remember I suppose I was somewhat protected by the familiarity of everyone around me. As I grew older this was another fact that became problematic; another reason given by psychologists for my inability to engage normally in social relationships and activities.

With one of my close friends, I once talked about how I felt different (Williams, 1992). We were probably about six years old and he asked me if that meant I thought I must be an alien. We ascertained that I didn't believe I was an alien, and also that other people don't feel such things. He seemed to be ok with the conversation, and most importantly, he still liked me and didn't think I was weird.

My memory of everyday events isn't too great, but I remember being happiest when playing by myself in one of the rivers or streams by our house. It was even better if the horses were near me. As part of the process for my autism diagnosis my parents confirmed in a psychological assessment that although I could engage with and play with other children, I had preferred to play alone.

When I was nine, we moved into town. Going to a larger school where I did not know anyone was scary (James, 2017b; Birch 2002). Apparently, I was popular and well-liked by the other children. But I only remember having a few friends. It was always loud and busy (Birch, 2002). I recall it as a scary experience, finding it hard to keep track of what was happening, and to recognise and remember all the new faces (Bargiela et al., 2016). Maths

was really hard; we were learning times tables and the numbers were just a big mess in my head. My parents separated from each other temporarily which possibly didn't help matters. I got sick often, but the doctors could never find anything wrong with me.

Despite this, my school reports still showed that I was above average in most subjects.

Around this time my parents sent me to see a psychologist. The teacher and my parents had lied to me, telling me that dad was coming to take me out to lunch. I ended up in some lady's office where I was offered chocolate biscuits and asked to draw pictures of my family. Having seen this kind of thing on television before, I was extremely upset and betrayed about being sent to the place the crazy and naughty kids go. I went along with it though as I was too shocked to react otherwise. To my knowledge nothing ever came of this appointment and I am still not clear on the reasons for sending me there.

We moved to Auckland when I was 10 and I continued to struggle. One day at Intermediate school the teachers said that anyone who did not do their homework was going to be put on detention. Of course, I didn't do my homework. But it wasn't like I didn't want to do it; I just didn't know how to. When our homework was due, I hid in the toilets all day, even though it was freezing; all just to avoid getting a detention (Williams, 1995) and having to try and explain why I hadn't done the work. Somehow the teachers found out, so I had to go to a meeting with my parents and the school principle. Being an otherwise well-behaved student, no one could figure out why I did it. Subsequently nothing happened to change anything for me. No one seemed to understand that I didn't understand (James, 2017b) and therefore couldn't do the work without guidance. I started to feel stupid and lazy; a longstanding belief that was re-enforced by the words of those around me. Why else wasn't I doing what I was supposed to?

High-school was a nightmare (Grandin, 1996). Apparently I was popular and well-liked there too. Not such a good student though. I was always confused and never knew what was going on in class (James, 2017b). My homework was never done, and I would wonder how other people did theirs. I just didn't know what to do about anything! Once I discovered the school counsellor's office, I spent as much time as I could there. I tried to make appointments to co-attend with the classes or activities I found most difficult or

distressing. Despite the large amounts of time I spent there, no-one ever noticed that I was seriously struggling.

I hated P.E. even though I was fitter and stronger than most of the other girls. When classes were in the gym where it was noisy and bright, I battled to figure out what was going on and what I was supposed to be doing (Williams, 1992; Williams, 1995). I dreaded having to play any games as I could never grasp the rules or keep track of what was happening.

Although I was good at art, I grew to hate it (Williams, 1992) because of the illogical restrictions the teachers put on us. The last art class I attended, I used different coloured crayons than what the teacher had allowed. She yelled at me not to come back to her class if I wasn't going to use the correct crayons, so I didn't.

There were strange and unexpected times though where I would get extremely high marks in an assessment (Williams, 1992). I didn't know how this happened as my grades were always a complete surprise to me. I once missed the first two weeks of term after getting my tonsils out. On my first day back, I was told there was a test the next day based on a book the class had been reading. My teacher told me to have a look at the book that night, but to not worry too much about the test as I had been away. When we received our results back, I had achieved the highest marks of all the students in my year (Williams, 1992; Holliday, 1999).

Socialising with my peers outside of school was something I rarely did, and I was never invited out by the other kids (James, 2017b). I had one 'friend' (James, 2017b) who tried to exclude me from her life. But as I was unaware of this fact at the time, I just invited myself along to any social things she was doing (Kanfischer et al., 2017). A funny coincidence is that this girl went on to get the highest girls mark in New Zealand for school certificate English. I sometimes wonder how I would have done if I had known what my difficulties were (Holliday, 1999) and managed to stay in school, or had I been on the same playing ground as everyone-else.

More than hate, I was fearful of maths. I was terrified of being asked a question in class because numbers make no sense to me (Birch 2002; Williams, 1992). I chose to take New Zealand maths, which we called 'vege' maths. It was easier than school certificate maths. The last time I attended a maths class, the teacher told us that if we achieve higher than 93% in the next test, we would be moved into school certificate maths. Somehow, I had consistently achieved higher than this and my fear of numbers meant I never attended another math class. During high school some of my teachers just gave up on me. They would leave me when I fell asleep at the back of the class, knowing there was no chance of me engaging or doing any work.

As a teenager I used to write, but shame and limited self-worth made me destroy anything personal. I had grown to believe that any indications of suffering and struggle were shameful and demeaning. Readily believing I was crazy after being told it was all in my head. Ironically so true. The communication aspects of autism, rendering my troubles invisible, meaning it was all trapped inside my head. On top listening to music and writing as a form of dissociation (Williams, 1992; James, 2017b), I discovered substance abuse and self-harm as a way to stop feeling trapped and frustrated all the time.

After an overdose at 15 when I was sent for appointments with community mental health services at the local DHB. Nothing came of this for me. Apparently, my parents were told that I was just a 'spoilt brat' (James, 2017b; Holliday, 1999). Our family doctor put me on Prozac, but they made me feel yuck, so I stopped taking them. My parents feared for my safety and withdrew me from mainstream schooling. I was then enrolled with the correspondence school. This was short lived as I decided it was much easier to go to work and earn money than attempt to learn.

Soon after leaving school I became very thin (James, 2017b); refusing to eat meals with the rest of the family which caused massive arguments (Williams, 1992). I don't know why, but I just didn't feel like eating. Sometimes it was a game for me to see how long I could go without eating, or how much I could restrict my food intake; meaning I could be in control of something at least. There were days when my frustrations at everything would result in my bingeing on junk-food. Then I would think about my problems which

made me feel physically sick and cause me to vomit. Other times when I was extremely stressed, I knew that eating would make me vomit so just decided it was best not to eat in the first place (James, 2017b). I never considered this to be an eating disorder as I didn't force myself to be sick. Besides, my refusing to eat was not a result of any wish to lose weight.

From the ages of 15-23 I worked in supermarkets. I started out at the checkouts and then moved into the bakery. At 15 I was raped by a friend of my department manager (Gillette, 2018; Sedgewick, Crane, Hill, & Pellicano, 2018). The manager saw this as an opportunity to be used against me. He and his friends attempted to blackmail me (James, 2017b) into spending time drinking with them at their houses or the local pub. It was not the assault that affected me, but the subsequent stress of the attempted blackmail (Williams, 1992); the unexplained written warnings, threats that I would lose my job for reasons that made no sense, and the implied feelings that I was letting everyone down by refusing to comply with their demands (Birch, 2002; Williams, 1995). This manager would refer to me as 'legs' when speaking about me amongst male colleagues, sometimes shouting it out when I arrived at work in the mornings (Gillette, 2018).

On one occasion I was unsure of how to answer a customer's question, so I asked them to wait while I checked with one of the other ladies. The manager heard this exchange and rushed over to address the customer with "oh excuse her, she's uneducated", followed by his raucous laughter. I don't know what the point of this was, or why he thought it was funny. I didn't know at the time that none of this was my fault, or how to explain the situation (Grandin, 1996) to anyone who could have helped me. No one would take anything I said seriously anyway (Birch, 2002), I believed it would just be seen as me seeking attention and causing trouble as was the usual assumption (Williams, 1992).

My first serious relationship started around this time and lasted on-and-off for six years. By this stage I held no respect for myself as a person, I was nobody and nothing ((Prince, 2013; Williams, 1992). There were no positive qualities I could recall about myself, except that people thought I was pretty. My boyfriend both loved me and hated me for this. He was the type of guy who is attracted to the type of girl I was (Birch 2002). Why wouldn't

he be? I was easily manipulated, put up with his psychological abuse, and only occasionally reacted with short, but violent outbursts of anger and frustration (Tint & Weiss, 2018). I made him look good, he introduced me as his girlfriend; a model, an attractive object, not a person with a name.

I clung to him as I did other questionable partners over the years, and most of my hurt and bewilderment was trapped inside (Tint & Weiss, 2018; Williams, 1995) Because as a female I had been taught to believe that I am nothing without a man (Birch, 2002; James, 2017b). Besides, all the hurt and abuse was my fault, everything that went wrong was always my fault (James, 2017b). Not to say that I didn't snap because I did (Tint & Weiss, 2018; James, 2017b). I cannot stand to be lied to, as he often did. There were so many lies from so many people (James, 2017b) that I began to doubt my version of reality (Williams, 1995). I was losing sleep and the ability to tell what was real and what I had imagined (James, 2017b). As I was so used to being told I was wrong, stupid, mental, horrible, nasty (Williams, 1992; Williams, 1995) alongside other horrible and derogatory terms. I didn't have any way to judge what was true and real. I actually believed whatever I was told because I had so often had my reality undermined.

The end of our relationship involved me up against the wall, his hands tightening around my throat, dead eyes, and blank expression as he told me he would kill me. It happened so suddenly but as I came to realise what was happening, I smiled and began to laugh. As I started to laugh, he seemed to come to his senses and let me go. He then left, and that was the end of that.

Despite the bad start to working life, I went on to become a bakery manager and ended up developing severe seasonal, environmental, and food allergies. When I was twenty-two, I bought a house with my parents as guarantors. No one took seriously my concerns about being unable to maintain mortgage payments due to my rapidly deteriorating health. First, I sought advice from the specialist I saw for my allergies who was adamant that my job had nothing to do with my illness (James, 2017b). Nothing ever came of all my expensive scans, x-rays, doctors and specialist appointments so I just stopped making the appointments and tried to ignore how sick I had become.

Less than a year later I fell asleep on the couch while visiting my parents. Mum panicked when she saw that I had stopped breathing and dragged me off to the doctors. I didn't understand what all the fuss was about. My flatmates had told me that I stopped breathing in my sleep every night. Sometimes they even had to drag me out of bed by my feet to wake me up if my breathing stopped for too long. My doctor informed me I would soon be dead if I continued to work as a baker. She also ordered complete rest for three months before I even considered looking for new employment. I didn't know how to talk to my insurance company, and Work and Income (WINZ) gave me a 6-week stand-down period before they would offer any financial assistance. The assistance I eventually got was not enough to pay my bills. They were asking for too many forms and I never seemed to have the right information. Without a job, an education, transferable skills, or the ability to reach out for help and advice, I lost my house. Any thoughts or hope for my future diminished to nothing.

Seeing no future for myself (James, 2017b) I used the money I got from the house sale to travel to the U.K and Europe. In Paris I was mugged and woke up in a gutter covered in blood; my blood. My mistake was to go for a walk with a group of people I mistook as belonging to my travel group (Williams, 1995; Birch 2002). I never told anyone the truth about this because I knew how I would be ridiculed. How could I be so stupid as to go off with people I didn't know (Bargiela et al., 2016). Only in 2017 did I become aware of the fact that I don't recognise people's faces or voices unless I have a certain level of familiarity with them. Obviously, this would leave me vulnerable to such an attack (Birch, 2002). This inability to recognise people was something I had just written off as poor eyesight. To this day I can struggle to identify members of my own family members when outside of a familiar context.

Between the ages of 15-25 I was frequently at the doctors for sleep and stress related issues; always being told I was suffering depression (Bargiela et al., 2016) and given various medications (James, 2017b). Even though this felt a bit wrong to me, I forced myself to believe them as they are medical professionals (Birch 2002). And what would I know? Nothing if what everyone else had told me was true. Nothing ever worked for me

(Grandin, 1996), but also no one had ever really listened to my concerns. Life and relationships continued to be messy (James, 2017b).

After recovering from my allergies, I started working in print finishing where I stayed on and off for 7 years. While I often worked over 50 hours a week, my boss was flexible in the times I did the work. As long as the deadlines were met, I could usually work whatever hours suited me. This was great but eventually the physical labour and ongoing issues with allergies wore me down.

Attempting to get out of manual labour roles, at 25 I decided to enrol in a degree at Auckland University of Technology (AUT). I had always secretly dreamed of 'being intelligent' and lauding my superior knowledge over everyone who had ever discredited or hurt me. I associated education with power and respect (Williams, 1992); finally, people would listen to me! But I wasn't smart anymore, just stupid and lazy. Deep down I knew that getting an education was an impossible dream.

At first, I loved the work and the learning experience of being in a tertiary environment (James, 2017b). But then I couldn't do the assignments. I would get drunk before attempting my weekly online tests and did so well that my classmates would ask me to help them. Again having no idea how this was happening as I felt like I knew absolutely nothing. Some of my classmates got angry when I got good grades while seemingly doing no work. It wasn't that I wanted to be lazy; I just didn't know what to do or how to go about doing it. Although I made two close friends who I stuck with in my time there, the others eventually stopped acknowledging or including me in their social plans (Holliday, 1999).

In my second semester I stopped going to classes (Webster & Garvis, 2017). One of my assessments was to give a 10-minute presentation in front of the class. The thought of it stressed me out so much I began having nightmares and was unable to sleep properly (Holliday, 1999). Every time I slept, I was woken by the thunder of shouting inside my head. Another assessment involved finding a group of children to coach for a term. Children terrified me with their unpredictability, and this stress further affected my

health. I was constantly at the councillors who told me that I didn't have a problem that they could help me with and to go and speak with student learning services. But I didn't know what my problem was either, so I couldn't communicate to anyone what was going on (Birch, 2002). I knew it all sounded irrational, but it was real for me (James, 2017b).

My doctor put me on a mix of sleep and anxiety medication, saying that I had depression. I believed her and took the pills (Birch, 2002) which made me even more confused and withdrawn (Grandin, 1996). The last day I took these medications was the day I suddenly found myself driving through central Auckland with no memory of what I was doing or how I had gotten there (Birch, 2002; James, 2017b). Dropping out of uni completely, I returned to work in print finishing for another year.

Quickly growing restless again, I decided to move to Whitianga which is where I met the father of my son. From the start, life in Whitianga was bad. I was earning terrible money working in a cafe and felt trapped and isolated from reality. My partner never seemed to have any money so never contributed to rent or household bills. Most of the people I met had serious problems of some sort or other and everything seemed to be spinning out of control. I needed to get back to Auckland and took the first job that was available.

Stupidly I thought that as I had been working in a cafe, I would be ok to return to work as a baker. Within 3 weeks I was so sick that I couldn't breathe properly, and my back was so painful I couldn't lie down to sleep at night. This was around the time of the global recession and it was 7 months before I managed to get another job. While my partner had work, he contributed very little. He would spend his money on good times and weekend trips back to Whitianga, not worried that I was stuck at home, unable to buy groceries or pay the bills.

Luckily my old job in print finishing eventually became available, and I was happy to return to the familiarity. By that stage I was suffering re-occurring tendonitis in my wrists that kept me awake most nights and caused my arms to go numb. At one stage I had a cast put on my right arm but ended up with worse trouble than before I went to physio. Because I attempted to carry on as usual with the cast on, I had caused further damage. I couldn't

take time off work as Accident Compensation Corporation wouldn't cover my pay (Birch, 2002) and I couldn't afford to be without an income for any longer. My partner had just taken out a loan under my name and to avoid heavy interest penalties, I needed to pay it back within 2 months.

My partner had always made a big deal about how he wanted a family and couldn't wait to be a dad. The day I told him I was pregnant he said he was so excited he had to go and spend the weekend sharing the good news with his family and friends. Our relationship had always been pretty rocky, but from here it rapidly became unbearable for me. He was constantly lying to me and would take off for days at a time ignoring any attempts I made to contact him. Past experiences had made me suspicious and distrustful of most people in my life and by the time I was 4 months pregnant I had had enough. His latest lies sending me over the edge; yelling and screaming I kicked him out of our flat. For nearly a week he refused to come and remove the rest of his stuff from the flat; telling me he would do it in a few weeks. I couldn't stand to have any of his belongings in my space any longer. That evening I packed them all up, drove to his workplace, and dumped it all on the curb side.

I was 31 when my son was born and became further socially withdrawn (Birch, 2002). The terrible state of my life and being a solo mother caused me great shame. Fortunately, the birth of my son was a natural deterrent to all the self-destructive habits I had previously been using as coping mechanisms. I realised I was happiest and that my life was easier and calmer when I was alone (Baldwin & Costley, 2016; Birch, 2002; Holliday, 1999; James, 2017b).

When my son was nearly one, I found myself in a relationship with someone who portrayed themselves as having similar morals and beliefs to myself. He lived in a small rural town, and because he had an established life there with school aged children, we decided it would be easiest for us to relocate there. A few days after relocating I was offered an office job. But my partner convinced me not to take it, insisting that he wanted to look after us and that I needed be with my son while he was still so young. I didn't click (Birch, 2002; James 2017b) to the implications of him always 'helping out' at the local pub

or connect this with the copious amounts of alcohol he drank each night. It seemed to me we had mutual experience of being manipulated and abused by the people closest to us, and I made the mistake (Birch, 2002; James 2017b) of confiding in him about my past difficulties and how poorly my family thought of me.

We got married after two years together, despite ongoing issues within the relationship (Birch, 2002). There were warning signs in his displays of mental instability; the breaking-down in tears, telling me I should leave him now because he wasn't good enough. Other times he would scream at me in rage, telling me I was just a stupid solo mum without him, that I had nothing and was nothing (Birch, 2002).

But of course, all of this was my fault! No-one else saw this side of him, and even when I began to suggest things were not ok, I was met with disbelief. Attempting to ask friends and family for advice on what to do, I was told that I was exaggerating, and things weren't really that bad. Everyone kept telling me how much he loved me, and what a great dad he was. I took it all on as I somehow felt I had a responsibility to make a stable family life for the kids. I thought that to stay and be part of a family would make me 'normal' (Williams, 1995).

Getting married was what was expected (Birch, 2002). I believed it would stop people nagging me about being a solo mother. My husband had his life that I was mostly excluded from, and I assumed this meant that I could have my own life under the protective title of 'married woman'. By being a 'married woman' I would become a 'real person' (James, 2017b). I wondered if this was love, if this is what everyone went through (James, 2017b; Grandin, 1996). Well, if everyone else could do it, I didn't see why I couldn't. And from the way I was being disregarded, I was the obviously the cause of the problems, not him.

From the day of our wedding he became increasingly psychologically abusive. Even though it was a mutually agreed plan, the fact that I was starting a course at the local tertiary institute seemed to be angering him disproportionately. I was sleeping less and less, shocked and confused by the overwhelming nastiness directed at me day-after-day.

Sometimes in the middle of the night he would attempt to force himself on me (Birch, 2002). He claimed never to remember these events and I believed him because he had been so drunk. But I never slept properly, always conscious of where he was and what he was doing. On one occasion he became enraged when I had taken my son into the lounge to sleep by me and barricaded us behind the couch and some chairs. He accused me of not trusting him, calling me all sorts of names for even daring to suggest that he would hurt a child.

He was drinking more than usual. One night he got up to go to the toilet, but he didn't come back. I found him asleep in one of his son's beds. His sons were with their mothers at the time, but I recalled his sister's claims of their father being a disgusting drunk who had been sexually abusive when she was a child.

You can imagine the screaming and yelling when I reminded him of her claims, the fact I had found him in one of his children's beds (with him having no recollection or understanding of how or why he was there), together with the occurrences of him unknowingly forcing himself on me in the night. I was called a nasty, evil, manipulative bitch. I was disgusting and crazy. How dare I try to say such a thing; what kind of person did I think he was? I guess I had instinctively never trusted him with my child anyway. I spent hours trying to calm him down. But the take-away message here was that I was the bad guy (James, 2017b; Grandin, 1996).

After 5 weeks of marriage, I left him. Without being able to explain what was happening, I lost the support of my family and all but one of the people who were in my life at that time (James, 2017b; Williams, 1995). Everyone in town who I had come to consider as friends had instantly cut me from their lives, which I eventually realised when none of them ever again answered my texts or calls.

Until I could figure out what to do, I was staying at a friend's house, the only person in town who was still in acknowledgement of my existence.

My husband and a woman who had posed as a friend (Bargiela et al., 2016) rang members of my family with claims that I was neglecting my son. These claims were that I had left

him at the mall by himself for over an hour (my son was 3 at the time), that I locked him in a shed at night, and left him in freezing cold baths. Instead of contacting me to ask if everything was ok, my family chose to contact the woman I was staying with to see if these claims were true. To me they denied that any of these phone calls ever took place.

I cannot describe the fear this situation caused me. I couldn't think straight and felt constantly on the verge of vomiting. The next day when I dropped my son at childcare the centre manager asked where his lunch was. In all my panic and fear I had forgotten his lunch! This just proved what a terrible and neglectful mother I was, and I burst into tears. Sensing that something was seriously wrong, the centre manager took me to her office and kindly asked what was going on. Through my sobbing I told her everything of my relationship up to the latest phone calls about my 'neglect'. After calming me down she gave me forms to fill ensuring that no-one but me could collect my child from the centre. She told me that one look at him would inform anyone in authority that he was in no way neglected. I was told that he was one of the most well-rounded children at the centre and the staff would fully support me in any matters relating to him. I found security in this and am now sadly and acutely aware of the importance of aligning myself with 'professionals' and people in 'authority'. This has become my safety net, my source of validation and protection as a substitute for my lacking family and social supports. I don't think I have ever faced a greater fear or betrayal than that imposed on me by the people involved in that situation. These were people whom I had thought I could trust (Holliday, 1999).

On another occasion my husband rang the friend I was staying with to inform her I had a drug and alcohol problem. He went on about how upset he was that I had become so hormonal and irrational (Russell 1995), saying he didn't know who I was anymore. All he managed to achieve was confirmation of how desperate he had become in trying to gain control over me. My friend could clearly see there was no truth in anything he was saying. As much as I wanted to leave town, we had to stay until I completed my course.

Moving to Hamilton in mid-2014 we needed to start a new life (Birch, 2002; Webster & Garvis, 2017). This was the eighth 'home' my boy had been moved to in his three years of life. I enrolled in a Bachelor of Environmental Planning, something I had dreamed of since

my time at AUT. I saw this as the only option left for me to ever get myself into a position where I could keep us safe (Holliday, 1999). Life had shown me that there are very few people who could be trusted to do right by us. At this stage I trusted no-one, so had to make it work, no matter what. Compounded by my extremely distressing personal circumstances, university was scary and daunting (Holliday, 1999). I ended up with school-sores 3 times in my first semester (James, 2017b).

People say that going to university is hard work. I love reading, learning, and putting my new knowledge into assignments; these things are not hard work for me (James, 2017b). But I just didn't know what to do. On asking for help I was most often told to just follow the instructions. To me, instructions produce more questions, but no one ever understood this. I had no idea of the boundaries within those instructions! For reasons that are beyond me now, I took an economics paper, which I was constantly (literally) sick with dread over (Williams, 1995; James, 2017b). I would go visit my lecturer and he would ask me what the problem was. I felt like screaming "how would I know!!!" The diagrams and formula confused me so much that I was constantly on the verge of tears (James, 2017b). This was made worse by his insistence that I was doing well and was on track for a final grade of B. How could this be true when I could never grasp what he was saying in class?

Enrolling myself in a heavy workload for 2015, my grades were the best they had ever been. My lecturers seemed to think it was this heavy workload that led to me always being run-down and needing extensions for my assignments. It felt like I was always asking for extensions when there wasn't really a suitable reason. The story of my life, I was unable to do what was expected within the given timeframe, and there was absolutely no reason for it (Birch 2002).

In 2016 I completed te Tohu Paetahi, a year-long, full-immersion te reo Māori program. The alternating fortnightly presentations and written assessments eventually wore me down so that I would not be able to sleep for days afterwards. Te reo is a spoken language, but I struggle to communicate verbally at the best of times (Grandin, 1996). In class I could feel my mind trying to escape out the top of my head as I spoke, while not having any connection to what I was physically doing or saying (Williams, 1995).

Everyone said public speaking gets easier, but it never did. I suffered memory loss (Birch 2002), losing whole days of class at a time. In spite of the fact that I could write very well, we only had a short time to prepare our assessments, so I couldn't actually figure out what we had to do, and then make sure it was correct (James, 2017b). Sometimes I couldn't understand anything that was happening because of the noise of everyone talking, or the smell of someone's perfume (Grandin, 1996; James, 2017b). No-one could understand why these things bothered me (Williams, 1995). As a result of my classmates finding amusement in my distress, I spent a fair amount of time crying by myself in the toilets. I hated the forced interactions with people day after day (Grandin, 1996; Holliday, 1999; James, 2017b), and I was 'feeling' the emotions of the people around me (James, 2017b; Birch 2002) But I had no idea that this was not something that others experience and could never explain why I always felt so excluded, so fearful, and so stupid.

Most of my classmates treated me as though I was a child, thinking that by speaking very slowly and behaving as they would in teaching a toddler, I would somehow understand. I would be so angry inside; I knew more than most of these people, but I couldn't seem to prove it (Baldwin & Costley, 2016; James 2017b). Often, I would look at someone's written work, or hear them speak and know it was wrong (Holliday, 1999; Williams, 1992). I would want to correct them. But mostly my input was disregarded as I struggled so much with the presentations, and my marks were always on the verge of a fail. I couldn't explain how I knew the 'correct' way to say or write things. But I knew when it was right, because it 'felt' right (Holliday, 1999).

We ended te Tohu Paetahi with a two day stay at a marae, where we would do our final oral assessments. We were unable to prepare for these as we had to draw our topic out of a hat when we got up to speak. Afterwards we all went for drinks to celebrate making it through the year. I didn't intend to drink, but as always in social situations; I ended up drinking as it enables me to cope (James, 2017b). We were supposed to be speaking in te reo. The more I drank, the more fluently I spoke while correcting everyone else's grammatical errors. Despite their shock, they all thought it was hilarious.

The day we left, we all had to take turns to stand up and talk about our journey that year. Getting up to speak at my turn, I instantly forgot everything I wanted to say. All I got out before I started crying and was unable to speak was “he tino uaua te tau nei ki ahau”, “this year was extremely difficult for me”. No-one acknowledged me as I went to sit down, but I already knew that no-one understood.

While continuing with my degree I was accessing disability support services at the university. Unfortunately, there was little they could do to help without actually knowing what the problem was (Birch, 2002). Again, I was continually at the doctors, who would refer me to the counsellors (another one of those common themes). At the end of 2016 my counsellor told me to go back to the doctor as she could not solve my problems and believed they were medical.

Out of pure luck, in January 2017 I was referred to a clinical psychologist who had done training with children on the autistic spectrum (Birch 2002). She suggested that I could have ADHD and ASD. No-one had ever suggested anything like that before, and from my own lack of knowledge of these conditions I was shocked (James 2017b). I had no understanding of autism; I didn't even know it was a spectrum. And ADHD? I had always believed this to be associated with extreme and intentional bad behaviour! I went home and started reading about autism and ADHD. Mostly ADHD. Because from my own limited understandings at that time, I couldn't possibly be autistic. Learning about these conditions became an obsession for me (James, 2017b; Holliday, 199).

Because of suspected ADHD I needed to see a psychiatrist as they are the only ones able to prescribe the appropriate pharmaceutical treatments. But first I had to undergo triage assessment by a psychiatric nurse. She told me I had depression, but not to worry because they would get me on some medication right away. Again with the fear and confusion. How had I ended up back here with all control ripped away!! On meeting with the psychiatrist, I was told not to listen to the nurses; that I was not depressed or needing medication. But it was a constant and nearly year-long fight for an ASD assessment.

The psychiatrists refused to consider that I might be autistic (James, 2017b); because I can talk, I have a sense of humour, I am female, and did I know that Autistic children who undergo therapy are no longer autistic (Williams, 1995) In April 2018 I was formally diagnosed with ADHD. I clung to this diagnosis, wanting to believe I had found the answer to my problems. I waited another two months for approval on a prescription for Ritalin, which is the first choice of treatment for ADHD. When I questioned them about an assessment for autism, which was the main reason for my referral, I was also told things like “it's just social anxiety” or “oh, those are just traits of obsessive-compulsive disorder (OCD)”; “females don't get autism”; “you are talking, laughing, and making eye contact, you cannot be autistic”. The most ridiculous and possibly most harmful was; “you don't have a personality disorder (BPD), but let's just put ‘traits of BPD’ in your notes and see what happens” (James, 2017b). I was also asked questions such as “are you like Sheldon Cooper?”, and “do you think you are better than everyone else?” But the more I read about other women’s experiences of autism, the more it made sense to me. The ADHD medication was having little effect and I suggested that I didn't need it. The psychiatrist insisted I continue taking it, even though I felt it wasn’t really doing what it was supposed to. Eventually he admitted that sometimes 'they just don't know'.

My engagement with mental health services affected me badly. My studies went downhill, and I was withdrawn on medical grounds at the advice of my head lecturer. I had felt so close to getting answers for my issues, but as none of the mental health staff showed even a basic level of autism knowledge, I was reduced to feeling crazy and stupid again. The changes to my study plans meant that I was again at the mercy of WINZ for financial support. The same as my other interactions with WINZ, I could never provide the right documentation at the right times. On more than one occasion I was told that I was not eligible for any financial assistance and just had to get a job. Adding salt to my wounds, one psychiatrist asked me if WINZ would “give me more money” if I was diagnosed with ASD. I asked him why I was wasting my time and money on an education if my career aspirations were to live off WINZ. He laughed my questions off, but I later found a note in my file saying that I wanted more ‘financial resources’.

Eleven months after my first meeting with community mental health I was begrudgingly referred to an outside agency to assess my intellectual ability. I filled out countless forms, all pointed to a high presence of autistic traits. But not enough to formally access any support for social, educational, or vocational difficulties. I saw one psychologist who translated my words “I have a sister who couldn't walk or talk, I don't think my parents were bothered by me walking on my tiptoes” into “Kyle feels she didn't receive enough attention as a child”.

Recently I found an article called ‘being sane in insane places’ by David Rosenhan (1973). His experiment involved 8 pseudo-patients presenting at psychiatric hospitals and explaining that they were hearing voices in their heads. Of the eight pseudo-patients there were four psychologists and one psychiatrist. All of them were admitted, and despite immediately resuming their normal behaviour, all were diagnosed with schizophrenia. It was up to themselves to facilitate discharge and stays ranged from 7-52 days. The pseudo patients all admitted under false names for the experiment as it was acknowledged that there was a lifelong stigma attached to diagnoses of mental disorder. Rosenhan concluded to the over pathologizing of every-day life that turns uneventful accounts into mental disorder. Despite most of us wanting to believe that we have come a long way since then, personal experience tells me otherwise. It is often impossible to get past an incorrect diagnosis, simply from the psychopathological translations of our stories by the people who are supposed to be helping us (Birch 2002). It leaves us little or no control over our own self-determination, being stuck with incorrect and unhelpful labels.

Every counsellor, psychiatrist, and educational support person I had ever met spoke of the importance of planning, organisation, and strategies. Yet I have always written lists and planned everything out carefully (James, 2017b). Obviously, I wasn't trying hard enough, or was doing it wrong, because every single one of them kept insisting on the same thing, despite my insistence that I was doing them (James, 2017b). Regardless of leaving home at a reasonable time, timetable and associated room numbers in hand, I was unable get to the right building or class at the right time (Birch 2002; Holliday, 1999). After 3 years at the university I was still encountering the same problems. I often thought this a

good sign that something was going seriously wrong for me, but no-one else seemed to notice (Birch, 2002; James, 2017b). Luckily my lecturers realised I was hardworking and knew it was not down to insolence.

At the beginning of 2018 I could not imagine a scenario that would ever lead me to complete a tertiary degree. I began to again feel trapped and fearful for my future and how I would manage to support my son. Two weeks before the start of A semester I was advised to cut my degree short, and graduate with a Bachelor of Social Science. It was believed the pressure of public speaking needed for my chosen would be damaging to my health. Still having no medical explanation for my difficulties, I had no credibility for any allowances that my lecturers could offer (James, 2017b; Birch 2002). I panicked at suddenly having to go out into 'the real world'; I had expected another year to prepare myself for that! Sheer terror found me enrolling in postgraduate study, with absolutely no idea of what I would do, or where it would lead.

I have never spent long without having to interact with healthcare practitioners or some form of support agency (James, 2017b). People who have known me have never been able to comprehend the terrible bad luck I have had when attempting to get help (James, 2017b). There were times I have gone without basic necessities because of my inability to communicate my needs clearly (Williams, 1995; Tint & Weiss, 2018; Birch 2002). Family and friends would laugh or tell me I was exaggerating, "its' just not that hard Kyle, just tell them!" It became that I would rather just go without. I have neglected my health needs on many occasions after being told that "that isn't possible", "no, things like that don't happen" (James, 2017b), or the treatments that were prescribed for me had no effect or made the problems worse (James, 2017b). This year I have become aware that I have an issue with receptive and expressive verbal language, and it explains a lot about the contents of this chapter. Although I am grateful to now be able to understand myself, it's too late for me to develop the types of supportive relationships that Stace (2014) declares a requirement in gaining the best possible outcomes for Autistic people.

MOVING ON...

Chapters one and two and three have offered some insight into my lived experience of unrecognized autism which I have supplemented by referencing similar accounts from other late diagnosed Autistic women. Part one of this thesis is to give context to the reality of autistic experience which often fails to show in the medicalized accounts of the clinical professions who are deemed to be 'experts' in autism knowledge.

PART TWO

Part two shifts the tone from personal experience to clinical perspectives. The literature used in the writing of this section comes from medicalised settings of international scope, as well as guidelines, reports, and webpages made accessible by the New Zealand government. The web pages and documents provided by the New Zealand government represent the local context of services and support available to Autistic people. My objective for part two is to offer a different perspective on autism to the lived experience of part one. Part two gives some insight into how these issues have come to be, and how autism is placed within the New Zealand healthcare system.

CHAPTER FOUR

LITERATURE REVIEW

This chapter consists of a literature review that has grown and evolved throughout the research process. It considers the interplay between socio-cultural and medicalised perceptions of autism and how these play into the political directions of authoritative systems. The development of knowledge and understanding on the topic of autism has undergone many changes over the past 100 years. In exploring some of the key contributions to the field over the last century, I attempt to show how Autistic women, have come to the place we find ourselves in today. During the process of this review I have encountered conflicts and inconsistencies in researcher perspectives, statistical reporting and the retelling of historical accounts.

Before beginning my Masters thesis, I had undertaken a literature review in order to refine my research topic. One theme that came through strongly was a connection between women and mental disorder. The shortage of information on Autistic females coupled with my own negative experience of the health care system led me to consider possible facilitators to the ongoing relationship between women and madness.

Connecting the assumptions between women and madness, to the frequently evidenced misdiagnosis of psychiatric disorder in unrecognised Autistic women seemed a natural progression in my literature search of this phenomenon. I suggest this connection as a noteworthy factor which, to my knowledge, remains absent from studies addressing the socio-political context in which unrecognised Autistic women sit.

As this chapter involves literature mainly from clinical settings of psychology and psychiatry, the style of writing and terminology used is in stark contrast to the previous chapter. In an effort to show inequities of power and marginalisation in action, I have chosen to retain the deficit terms which would now be considered disrespectful and ignorant in everyday contemporary conversations. Although I have tried to logically order the different ideas and concepts into sections for ease of reading this has proven impossible.

HISTORY AND EVOLVING IDEAS

During the first half of the 20th century there were various streams of psychiatric thought as to the categorisation and labelling of what was more generally termed 'childhood psychoses'.

In 1911 Eugen Bleuler described autism as a symptom which he saw to be indicative of schizophrenia in the severest form. It involved one's psychological withdrawal from an undesirable reality to an internal world of fantasy (Wing & Wing, 1976). The term 'autism' was used in this manner by practitioners of psychology, psychiatry, and psychoanalysis until the late 1950's (Evans, 2013).

Strongly influenced by the work of Bruno (Bettelheim, 1956), it became widely accepted that all psychotic children had been subjected to 'extreme conditions of living'. Through the lens of psychoanalytic theory, signs of such disturbance in infants and young children naturally raised questions about the quality of their home life. Bettelheim went on to cite other psychoanalytic practitioners as sharing his insistence that autistic behaviour was a direct result of severe emotional neglect. These implications had devastating effects for the families of children who were deemed psychotic as a consequence of their mother's disturbed psychology (Bettelheim, 1967; Volkmar, 2000; Wing, 1997b).

Some studies seem to view the schizophrenic child, or at least his pathology, as not much more than a negligible appendage of maternal pathology. Though never explicitly stated, such an attitude has led some students of this disturbance to concentrate mainly on the mother, not only for understanding, but also for helping, the schizophrenic child. Thus, the child, who suffers most of all from not having acquired an autonomous existence as a person, is again not regarded as an autonomous being even in treatment efforts designed to help him become a human being in his own right. As if in culmination of an all-too-subtle irony, treatment methods are advocated which rely on efforts to understand and help

the schizophrenic child through the very person who, it is assumed, destroyed his humanity in the first place-his mother.

(Bettelheim, 1956, p. 508)

Declarations such as the ones above ensured that the followers of psychoanalytic theory failed to recognise any associated biological factors, choosing only to focus on certain aspects of the condition. Alongside these ideas, Evans (2013) presents a timeline suggesting psychosis, autism, and schizophrenia as somewhat interchangeable labels during the 1940s and 1950s. In general, to some degree autism was perceived in this manner until the 1970s when considerable evidence refuting the emotional aetiology of autism brought about a complete switch in ideas. Attention then moved to childhood development due to a new interest in the area of cognition. As such, the theory of a mother's pathological transference no longer held weight by the late 1960s (Frith, 1991).

Meanwhile, the 1940's saw Leo Kanner (1943) share his observations of 11 children who he described as having a condition of 'fascinating peculiarities'. Kanner noted that although some of the children had been diagnosed with schizophrenia, which to his observations had many similarities, there were also numerous differentiating features (Mesibov, Adams, & Schopler, 2000). He evidently termed the condition 'infantile autism'.

Independent of Kanner's work, in 1944 Hans Asperger (Frith, 1991) documented accounts of children fitting a similar profile which he named 'autistic psychopathy' (Haney, 2016). Early on Asperger expressed his belief in the organic nature of autism; observing similarities between the children he studied and their parents. He noted one crucial difference to common understandings in that 'autistic aloneness' is present from birth, whereas schizophrenia involved a gradual but progressive withdrawal. Therefore, these children were not psychotic, leading him to declare psychoanalysis as inappropriate for working with children (Frith, 1991). Although Asperger's work is closely aligned to contemporary ideas, publications of his findings were in German and subsequently absent from international literature until their English translation by Uta Frith in 1991.

Whilst Wing (1997) felt the confusion between schizophrenia and autism in children was dispelled in the 1970's, problems continue for the unrecognised population of Autistic adults. Schizophrenia as a diagnostic term draws harsh and ongoing criticisms from many on account of its wide-scoping symptomology (Barlow, Durand, & Hofmann, 2018) rendering it vague (Rosenhan, 1973; Russell, 1995; Wong, 2014). Unfortunately, today many of these 'symptoms' overlap with diagnostic criteria for autism (Ghaziuddin, 2005), which has shown to be a potentially dangerous connection for both practitioners and clients alike.

MISINTERPRETATIONS

Wing (1997a) addresses the 'autistic spectrum' as encompassing a much broader picture than the original observations and statements of Kanner and Asperger. Suggesting that definitions of pervasive developmental disorders within the DSM-4 (current at that time) and the ICD-10 are unhelpful and of little clinical relevance, Frith (1991) went further in concluding the impossibility of defining the borders between Asperger's syndrome and other neurodevelopmental disorders. The characteristics we now associate with the autistic spectrum have presumably always existed, but the historical terms used for such were psychosis, schizophrenia, madness, and mental retardation (Strauss, 2013).

Consideration should be given to the unfortunate timing of Kanner's terming 'infantile autism' and the possible influence this has had on assumed links to Bleuler's childhood schizophrenia and psychosis. Over time the characteristics described in Kanner's syndrome have been misconstrued, leading to the inclusion of irrelevant behavioural characteristics and the exclusion of potentially key criteria for diagnosis. These inclusions and omissions thus influencing the formation of autistic stereotypes, as is indicated below:

Schain and Yannet (1960) omitted preservation of sameness from their diagnostic criteria. Tinbergen and Tinbergen (1972) went further in placing their main emphasis on avoidance of eye-to-eye gaze, which not only ignored all the other clinical features described by Kanner but also took just one social feature out of

context and without cognizance of the other developmental and behavioural characteristics of the Autistic child's "aloneness" (as described by Kanner) which differentiated it from the many, many other types of social difficulty shown by children and adults.

(Rutter & Schopler, 1978, p. 3)

Also, in the case of Asperger's syndrome, there were prodigious references to autistic presentations that require careful contextual consideration. Mis(sed)diagnosis becomes a highly plausible outcome where practitioners are unable to account for the situational context in which the individual's difficulties arise.

As previously indicated, the early development of ideas on autism concentrated on the observations of children. This continues to be problematic for unrecognised Autistic adults with much of the literature still describing it as a childhood condition (Williams and Williams 2016). The scarcity of research covering the full lifespan of Autistic individuals means there is too little evidence available to suggest a weighted need for the continuation of supports past adolescence. Mainstream healthcare for adults has yet to acknowledge and support the notion of the spectrum, despite the knowledge that autistic presentations are highly evolving, owing to factors such as age, gender, intellectual ability, as well as social, health, and economic circumstances (Lai & Baron-Cohen, 2015; Wing, 1997b).

REVISITING THE PAST

Driven by the birth of her daughter who showed early signs of socio-communicative differences, the work of Lorna Wing has been invaluable in her dedication to advancing the field of autism research (Watts, 2014). Of particular note is her influence on the recognition of Autistic females, and more generally, her awareness of ASD without co-occurring intellectual disability.

Wing's (1996) work describes characteristic 'groups' of atypical social presentations, while also cautioning that these are not strictly defined and can merge into each other. These include:

1. The aloof group

This group is most relatable to stereotypical ideas of autism, who in early life (and some throughout) appear totally oblivious to other people. They are non-responsive to attempts at communication directed at them. Some children in this group do seek out rough and tumble play and show joy during these activities. Emotion is only shown at the extremes of anger or happiness.

2. The passive group

Recognised as the least common group, these children will not initiate social interactions themselves, but will engage when contact is initiated by someone-else. They are likely to make eye-contact when reminded by others to do so. Compliant and agreeable as children, they will be included and accepted by other children. Wing describes this group as the least troublesome in terms of behaviour but recognises adolescence can bring drastic change for some who end up being extremely disturbed.

3. The active but odd group

This group makes active but strange and often intense contact with others, predominantly seeking out those in charge rather than children their own age. They make eye-contact, but it is poorly timed, sometimes coming across as too intense. They are also unable to adapt behaviour to that which is acceptable across different situations.

4. The overly formal, stilted group

These individuals have well developed language skill and in late adolescence and adulthood this group displays extreme politeness and formality. They adhere strictly to rules they know about social interactions but are unable to fully understand what is seen as acceptable behaviour in the Neurotypical population.

Other key characteristics and presentations from her book include:

- Issues with the use of language, particularly one associated with Autistic children who confuse the words they use by verbalising the exact opposite in meaning to their intention. Or using one word to describe something similar, sock=shoe, spoon=knife/fork.
- Regardless of age, most Autistic individuals have significant difficulty with games and physical education. This is thought to be due to difficulties in managing to coordinate with other team members and remembering the rules.
- Hypo or hyper reactions to sensory stimuli (sight, touch, smell), suggesting that food limitations are related to insistence on sameness, and a basic connection between sensory stimulation and repetitive stereotyped behaviours.
- Wing dismisses the notion of anxiety as integral part of autism, having observed that most Autistic individuals are generally not anxious people. She believes anxiety within the Autistic population to be caused by situations that they do not understand.
- Uneven levels of intelligence are extremely common in this population Wing suggests skill of a visual-spatial nature or involving rote-memory are displayed by the majority of those who tend to excel.
- Kanner's group showed 1/3 with low average or higher, 1/3 with mild learning difficulties, and 1/3 with severe to moderate learning difficulties. Asperger's group was mostly in the range of low average or higher.
- Diagnosing practitioners need to be aware of autistic presentations in adolescents and adults, as autism is neurodevelopmental and lifelong, psychiatric disorder, noting that those without intellectual disability have been misdiagnosed with 'any and every' psychiatric disorder.
- Behavioural therapy is inept for this population and do not fundamentally change the individual, with any results usually only being temporary. Wing declares the best way to go about eliminating 'inappropriate' or 'bad' behaviour is to first understand the underlying cause.

In the first English translation and review of Asperger's works, Uta Frith (1991) also raised some key points that seem to have become lost from mainstream ideas over the course of time:

- There may be no developmental delay in the meeting of expected milestones during the early developmental stages, and attempts at social inclusion are not uncommon.
- Bleuler describes 'schizophrenic patient' as unengaged and distracted while exhibiting bizarre and impulsive behaviour; 'whimsical obstinacy' as wanting one thing and the opposite at the same time. Frith refutes this, citing Asperger's note of schizophrenia as a progressive move towards internalisation, while 'autistic aloneness' is obvious from the outset. This is interesting when considering the reference to whimsical obstinacy in light of Wings description of language issues seen in Autistic children.
- Deficits in attention and learning ability were seen despite high levels of intelligence.
- Frith clarifies the differences between the repetitive behaviours seen in obsessive compulsive disorder (OCD) and autism. Repetition in autism is a source of enjoyment, whereas in OCD it is a cause of severe distress.
- Alongside a strong attachment towards certain individuals from some of his studied subjects Asperger saw their 'sense' of others, often unwittingly knowing of invisible differences in other, which goes against the belief of Autistic individuals being incapable of empathy.
- In addressing his never being in the presence of an Autistic female, Asperger recognised similar traits in the mothers of some of his subjects, accounting this to different presentations in females which he thought may not be apparent until adolescence.
- The observed sensory hypo and/or hyper reactivity within Asperger's subjects.

Although contemporary diagnostic manuals acknowledge some of these characteristics, contemporary research shows that there are a limited number of healthcare practitioners

with an appropriate knowledge of neurodevelopmental disorders (Takara, Kondo, & Kuba, 2015). In addition, there are a number of criticisms for the pathologically informed dialogue contained within such manuals. These criticisms hold relevance in that the interpretation of autistic symptoms by practitioners in a mental health setting are unlikely to associate such behaviours to diagnostic descriptors for autism or to consider the importance of context in differentiating ASD symptomology from those of mental disorder.

CONTEMPORARY

Today autism is clinically described as a pervasive neurodevelopmental disorder causing persistent deficits in social communication and interaction, together with behaviours, activities and interests of a restricted and repetitive nature (Barlow et al., 2018). The assessment for and diagnosis of autism is tasked to the clinical professions of psychology and psychiatry and carried out with the guidance of diagnostic manuals. Most notable are the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, and DSM-5) (American Psychiatric Association, 2000, 2013) and the ICD-10 Classification of Mental and Behavioural Disorders (ICD-10) (World Health Organization, 1992).

Fundamental changes to the DSM-5 (2013) potentially confuse assessment and diagnostic practice with the introduction of autism spectrum disorder (ASD) as an umbrella term for neurodevelopmental disorders previously of their own standing. A diagnosis of ASD now encompasses autistic disorder, Asperger's disorder (Asperger syndrome), childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS).

In the DSM-IV-TR acknowledgement was given to the frequent diagnosis of attention-deficit/hyperactivity disorder (ADHD) in individuals who are later diagnosed with Asperger's disorder, and associations with other (mainly mood) disorders. Limited evidence was also suggestive of a familial link in prevalence. It was thought that

individuals diagnosed with ADHD are likely to have relatives suffering a wide range of mental disorders, including anxiety, mood, personality and substance abuse.

Genetic components are addressed where the DSM-5 suggests a variable scope of hereditary links in autism, from 37% to around 90%. Sex related differences in statistical reporting backs what considerable evidence now shows; females diagnosed with ASD are more likely to have co-occurring intellectual disability on account of Autistic females without co-occurring intellectual disability being capable of 'camouflaging' their social deficits. It is believed that around 70% of those with ASD have at least one co-occurring mental disorder.

The ICD-10 lists a number of what it terms 'pervasive developmental disorders' including childhood autism, atypical autism, Rett syndrome, other childhood disintegrative disorder, overactive disorder associated with mental retardation, Asperger syndrome, other pervasive developmental disorders, and finally, pervasive developmental disorder unspecified. Opening the section on disorders of psychological development, it is stated that the delays and impairment associated with these disorders diminish rapidly with age.

It is important to remember that while we are immersed in the realm of mental disorder, autism is developmental, not psychiatric (Cage, Di Monaco, & Newell, 2017; Frith, 1991; Wing, 1996).

MENTAL DISORDER

Mental disorder is said by some to be a socially constructed concept enabling the oppression and marginalisation of those who are seen by the dominant group to fall outside the borders of perceived normality. Deviation from this perceived normality becomes mental disorder when it is brought to the attention of the general public or instigates judicial and/or psychiatric interventions (Holmshaw & Hillier, 2000). Individuals seeking assistance for mental distress are viewed through the lens of the medical model. Within the field of Disability Studies, Linton (2006) describes how emphasis on the

Medical Model leads to societal stigmatisation of anyone exhibiting behaviours seen to be outside the narrow confines of medically defined normality.

In 1995, Russell noted the DSM definitions current at that time had moved from the term 'mental illness' to that of the largely undefinable 'mental disorder' (Rogers & Pilgrim, 2014). Criticising the absence of clarity in what exactly constitutes as disorder, Russell believes that as a medical term, it is wide open to value-based judgements. In lacking clear definition, the decision of whether mental disorder truly exists is subject to the discretion of the diagnosing practitioner (Rosenhan, 1973).

In keeping with arguments to the contested meaning of 'disorder', the DSM-5 and the ICD-10 have outlined their use of such terminology below:

A mental disorder is a syndrome characterised by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behaviour (e.g., political, religious, or sexual) and conflicts of that are primarily between the individual and society are not mental disorder unless the deviance or conflict results from a dysfunction in the individual, as described above.

(American Psychiatric Association, 2013, p. 20)

The term 'disorder' is used throughout the classification, so to avoid even greater problems inherent in the use of terms such as 'disease' and 'illness'. 'Disorder' is not an exact term, but it is used here to imply the existence of a clinically recognizable set of symptoms or behaviour associated in most cases with distress and with interference with personal functions. Social deviance or conflict alone, without personal dysfunction, should not be included in mental disorder as defined here.

(World Health Organization, 1992, p. 5)

According to Barlow et al. (2018), the most commonly diagnosed mental disorders in the general adult population are associated with psychosis, depression or mood, sleeping, eating, and anxiety. Naming but a few are: OCD, phobias, post-traumatic stress disorder (PTSD), anorexia, bulimia, and insomnia. Of importance to the topic of this thesis being women and ideas around mental health are the specific references that link to eating, personality, mood, and anxiety disorders.

CORE CHARACTERISTICS AND MENTAL DISORDER

Acknowledging the misrepresentation of the core autistic characteristics over time offers some explanation as to the occurrence of misdiagnosis with mental disorder. When considering that typically diagnosed mental disorders in the Neurotypical population relate mostly to psychosis, mood, depression, and anxiety, it is interesting to note that schizophrenia, bipolar, psychotic, and depressive disorders are the most frequently misdiagnosed, or hinder the recognition of underlying ASD (Barlow et al., 2018; Takara et al., 2015). Aiding the general lack of awareness and knowledge of pervasive neurodevelopmental disorders within the healthcare sector are conflicting ideas around ASD in clinical academic literature. These mixed messages further blur the boundaries between autistic presentations, and those of commonly diagnosed psychiatric disorder. Takara et al. (2015) note that underlying and unrecognised ASD can both cause the appearance of and aggravate any co-morbid psychiatric disorder.

As an example, sensory processing difficulties and an aversion to contextual uncertainty are now included as ASD symptomology in the DSM-5. As these difficulties are affected by stimuli within an individual's environment, there is a need for consideration of context. On the other hand, we have anxiety disorders and specific phobias. These are said to include irrational fears of, for instance: public transport, enclosed spaces, storms, and animals, which are clinically significant in their disturbance of normal daily functioning (Barlow et al., 2018). The suggestion of irrationality around these disorders and phobias exposes the

paternalistic nature of the Medical Model, rendering any contextual rationale for the distress to be invalid.

Illustrating the potential harms arising from the possibility of clinical malpractice, Alexander and Farrelly (2019) present an example from Ireland of the horrific life trajectory for one misdiagnosed adult. In this case a young man was diagnosed with multiple psychiatric disorders throughout adolescence and early adulthood, including psychosis, personality disorder, anxiety disorders, and dysthymia. The prescription of various pharmaceutical treatments failed to result in recovery, and the young man was subjected to multiple involuntary admissions for psychiatric treatment. The eventual diagnosis of ASD led to the recognition of how environmental factors had impacted on his sensory processing. Previous to this his hypersensitivity to certain stimuli had been read as irrationality, resulting in overtly emotional outbursts. There was also a marked reduction in prescribed pharmacology and a stabilising in wellbeing once he was correctly diagnosed with ASD.

From another angle, it is hypothesised that depression is also underreported in those with ASD due to an inability to clearly express one's self (Lai & Baron-Cohen, 2015; Lewis, 2017). Taking this this stance, assumptions could be made toward other situations where ineffective communication causes a breakdown in the Autistic persons positive daily functioning.

In this respect, Cage et al. (2017) adopted the Social Model of disability (Shakespeare, 2013) as a basis for understanding the high occurrence of mental distress in the Autistic population, which then locates the cause of distress within the individual's surrounding environment. Unsurprisingly the negative perspectives around autism and the experience of poor self-acceptance from others were found to be leading facilitators in the development of any subsequent mental distress. Possessing a sense of acceptance and belonging is known to be intrinsically linked to outcomes of positive wellbeing (Werner-Seidler, Afzali, Chapman, Sunderland, & Slade, 2017), a point that also holds relevance to the Autistic population.

MIS(SED)DIAGNOSIS

There are a number of reasons that the assessment and diagnosis of ASD in adults is seen to be a challenging task. Aside from the superficial similarities between ASD and some psychiatric conditions, early research and the development of ideas on autism focused on the paediatric population. This is a preoccupation that continues to cloud contemporary practice (Giuliani, 2018; Tan, 2018), with leading diagnostic manuals still requiring accounts of childhood presentations. Evolving societal perceptions over time create difficulty in the recollection of relevant information by caregivers who are now of advanced age.

As an example of the previous point, one study from the United Kingdom reporting on the experiences of adults accessing diagnostic services notes an average of two years between the initial seeking of help, to the conclusion of the diagnostic process. Although 86% of participants were relieved on obtaining their diagnosis, 40% were dissatisfied with the process, and 42% were not offered any form of post diagnosis support (Jones, Goddard, Hill, Henry, & Crane, 2014). The course of diagnostic practice was often complicated by healthcare practitioner's lack of relevant knowledge about ASD, with the number of referrals to different physicians per person ranging from one to six.

In recent times we have seen sensationalist reporting of an autism epidemic. While this link is unfortunate, it follows on from an already extensive list of misunderstandings towards autism (Evans-Williams & Williams, 2016). This 'autism epidemic' could more accurately be described as the slow but increasing awareness of ASD and its evolving presentations across sex/gender, and life stages (Lai & Baron-Cohen, 2015). Yet increasing awareness of mis(sed)diagnosis in the adult population has not resulted in emancipation for those Autistic adults who are seeking help. Unrecognised adults with average or above intellectual function are unlikely to have raised suspicions in childhood where the majority interest in ASD is heavily focused. Emerging evidence suggests that between 50-60 % of Autistic individuals without concurrent intellectual disability remain unrecognised (Lewis, 2016).

As mentioned earlier in this chapter, there is a common assumption that substance abuse and addiction issues are uncommon in the Autistic population. Addiction is associated instead with a diagnosis of ADHD, leading to the misdiagnosis of Autistic individuals presenting with these types of issues. Doubts are cast on this theory in a health-related database review of a Swedish population by (Butwicka et al., 2017). Their findings showed an elevated level of substance abuse within the Autistic population when aligned with the Neurotypical population.

Also problematic for those who missed out on childhood identification of their ASD is a strong belief that Autistic individuals become 'normal' over time (Bennett, Webster, Goodall, & Rowland, 2018; World Health Organization, 1992), further supplementing ideas such as Geschwind and Levitt (2007, p. 103); "Autism is a common and heterogeneous childhood neurodevelopmental disorder". From these ideas it could be assumed that any individuals being diagnosed in adulthood have suddenly, and without warning become affected. Contrasting with this, Barlow et al. (2018) affirm that there is no treatment for ASD, and all attempts to eliminate social difficulties have proven unsuccessful to date. With a softening of terminology and more accurate description, Cage et al. (2017) describe autism as a lifelong neurodevelopmental condition.

There are numerous accounts from Autistic individuals who share feelings of being ignored by healthcare practitioners when attempting to describe their difficulties. Rogers and Pilgrim (2014) believe that the views of clients are seen to be invalid, and that any disagreement with 'professional opinion' is then seen as a symptom of mental illness and resisting assistance to 'recover'. These beliefs are sadly shown in many narratives of lived experience. In a similar vein are the findings which suggest a resistance to pharmaceutical treatments in some Autistic individuals (Alexander & Farrelly; Crucitti et al., 2018; Ministries of Health and Education, 2016). At best this could be seen as a refusal to become well, at worst it could result in untimely and preventable death at the hands of healthcare practitioners without the specialised skills and knowledge needed to work with the Autistic population.

While investigating the barriers faced by individuals in their attempts to access diagnostic services, Lewis (2017) found the biggest issue to be the disbelief and subsequent dismissal of client concerns from across the healthcare professions. One individual suggested that the main goal of the healthcare practitioner was to fit their clients into a particular box with no consideration for what they were attempting to communicate. This study also found a general mistrust of mental health practitioners for a variety of reasons, including a history of misdiagnosis and of Autistic individuals repeatedly having their concerns ignored. These historical misdiagnoses occurred before the individual had an awareness of ASD as a possible reason for their difficulties. Another significant barrier to autism assessment, diagnosis, and support was the cost of the services offered by suitably knowledgeable practitioners. Lewis's study sheds light on the widespread nature of these issues by inclusion of data from Australia, Canada, America and the United Kingdom.

PSYCHOANALYSIS

In its broadest sense, psychoanalysis is a model of human development, psychological function, psychopathology, and a framework for psychological treatment which is made up of multiple theories and treatment formulations (Safran & Kriss, 2014, p. 19). Directed by their beliefs towards a pre-conceived outcome, there is a risk of practitioners missing the visible evidence in front of them.

Shown in the early literature on childhood psychosis, psychoanalysis played an influential role in shaping the ideas of both psychology and psychiatry in the first half of the 20th century. As a theoretical concept, psychoanalysis involves the uncovering of the unconscious mind; providing meaning to one's reactions of thought, emotion and behaviour.

Although the brainchild of Sigmund Freud, and therefore associated with psychology, the use of pathologizing terminology in psychoanalysis shows the dominance of psychiatry and the medical model over the mental health sector.

The goals of psychiatry and psychology are to assess the patient, and then diagnose the disorder(s) matching the patient's symptomology to the best of the practitioner's knowledge. From this it is inferred that the individual is mentally disordered, and appropriate treatments are prescribed (Rogers & Pilgrim 2014). Assessment can involve the investigation of social, biological, and psychological factors (Barlow et al., 2018); all of which are recommended when assessing for ASD. Yet many mental health practitioners carrying out this duty are failing to collect comprehensive information and subsequently missing key indicators (Office of the Health and Disability Commissioner, 2018).

In 1954, Stone endorsed the practice of psychoanalysis in disorders of an emotional aetiology as a potentially suitable procedure of treatment in cases where distress was within a clinically significant range. Treatment is achieved by facilitating awareness of the patient's past traumas as affective on the present, thereby enabling the patient to move on without further burden from trauma-associated thoughts. Stone dismisses the naming of psychoanalytic therapy to situations where regard is not totally immersed in the contextual nature of the patient's distress, consequently resulting in the failure of 'illness cure'. Recalling the 'irrationality' associated with many mental disorders (Barlow et al., 2018) and the high incidence of misdiagnosis where ASD goes unrecognised suggests that the contexts in which mental distress occurs are of little relevance to mental health related professions.

Dumont (2014, p. 8) cites Pinker's (2002) belief of a fundamental nature shared by all human beings. Forgetting the tiny minority who possess some form of 'abnormal gene mutation', Pinker holds faith in psychoanalysis and its theories. This faith stems from the idea that all human behaviour can be explained by the theoretical concepts of psychoanalysis through investigation of the patient's life. From this it is clear that traditional groundings in the field of mental health are incompatible with the recognition of neurodevelopmental conditions.

Still holding its grip on clinical diagnostic practice, psychoanalysis continues to disregard any biological aetiology and neurological difference that is the underlying 'condition' of autism. This is in conflict with contemporary causal research which presently focuses on

neurobiology and genetics (Werling & Geschwind, 2013). With psychoanalytic principles having little relevance to biology and genetics, it is unfortunate that the assessment, diagnosis, and 'treatment' of ASD is still carried out on the interpretations of behavioural presentations (Grandin, 1996; Kreiser & White, 2014) where the possibility of neurological difference is closed to investigation.

GENDER BIAS

Autism has traditionally been recognised as a condition affecting males. Although male/female ratios of 4:1 are widely reported (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015), the difference is suspected to be as high as 10:1 in those without concurrent intellectual disability (Baron-Cohen, 2002). Coming to light are examples of how gender bias throughout the history of autism research has impacted on today's diagnostic assessment and screening tools.

Kanner's (1971) famous study of 11 children included 3 girls, while Asperger only referred to male subjects in his work (Haney, 2016). More recently, Happé, Briskman, and Frith (2001) carried out a study said to involve the parents and siblings of children with autism, when in fact this study only involved Autistic boys and their male siblings. Rynkiewicz et al. (2016) suggests that male-biased understandings of autism are influential in the sex/gender disparities seen in statistical reporting.

Suspicious by Baron-Cohen of male/female ratios of 10:1 at the so called 'high-functioning' end of the spectrum coincides with studies showing that Autistic females displaying positive intellectual and social function, despite equal presentation of clinically significant traits as seen in their male counterparts, are likely to avoid an ASD diagnosis (Baldwin & Costley, 2016; Bargiela et al., 2016). Similarly, the findings of Mademtzi, Singh, Shic, and Koenig (2018) in a review of historical literature noted a consistently higher occurrence of male diagnosis. These findings suggest that females with ASD were more likely to be labelled with intellectual disability and misdiagnosed with learning disorders.

understandably then, the building of standardised diagnostic screening tools stems from the collective understanding of male presentations (Hull et al., 2017), with diagnostic observations left open to stereotypical bias and interpretations of the often-unskilled observer. The Autism Diagnostic Observation Schedule (ADOS) is considered by many to be the gold standard in observational screening tools yet does not account for subtleties in social difficulties that are known to occur in Autistic females (Duvekot et al., 2017; Lai et al., 2017). Reviewing the accuracy of standardised diagnostic tools, Gould (2017) found limitations in their ability to diagnose Autistic females. The inability of diagnosing practitioners to recognise Autistic females could also be owing to superficial knowledge of Baron-Cohens (2002) widely cited 'extreme male brain' theory influencing beliefs that females cannot be on the autistic spectrum. Repetitive accounts from Autistic women overwhelmingly evidence the ignorance of health care practitioners to the existence of ASD in females (Tint & Weiss 2017; Bargiela et al., 2016). An emerging area of interest into this particular phenomenon is the suggestion that females are able to 'camouflage' differences.

CAMOUFLAGE

Among others (Frith, 1991; Ghaziuddin, 2005; Wing, 1996) Asperger recognised that the difficulties encountered by this population are increasingly pressing as life's demands become more reliant on one's ability to build and sustain complex social relationships. For Autistic individuals without concurrent intellectual disability, camouflaging is seen as a way to get by in a neurotypical world (Cage & Troxell-Whitman, 2019). Camouflaging is better recognised as 'passing'; the ability of those on the edge of marginalised groups to 'pass' as 'normal', a tool/phenomenon well established in literature on ethnic minorities, and more recently within disability studies (Siebers, 2004).

Identified by both clinical observations and the narratives of Autistic women is the propensity of Autistic females to use camouflaging behaviours, said to be a result of high levels of social motivation. Yet evidence suggests that the practice of camouflage can be detrimental to mental wellbeing, with researchers noting the exhausting emotional and

psychological toll it takes to successfully enact 'normality' (Hull et al., 2017; Lai et al., 2017).

Remembering the disturbingly high number of misdiagnosed females, diagnostic practitioners need to become more aware of the potential impacts of camouflaging in influencing the presentation or development of mental disorder in females who may be autistic. Initial findings of research focused on camouflaging behaviours have pointed to the attenuation of typical autistic traits in Autistic females (Lehnhardt et al., 2016), aided by gender typicality's that are observable in the general population. In short, males are more likely to externally express their distress through visible actions whereas females are assumed to internalise problems; then appearing as emotionally disturbed. Whilst Gould (2017) argues that not all males or females submit to gendered stereotypes, there is undoubtedly a greater pressure on females to conform to these expectations, which is also assumed as factoring in the dominance of females camouflaging (Lai et al., 2017; Gould 2017)

Adding to the conflict and confusion of knowledge surrounding the autism spectrum, Filipek et al. (1999) further suggest that commonly cited statistic and prevalence rates often fail to consider the differences in symptom presentation across gender, life-stage, and intellectual ability; refuting the popular opinion that autism and all the conditions falling within this spectrum are of rare occurrence. The many instances of female misdiagnosis with mental disorder appears to be underpinned by the ongoing connection between women and madness.

WOMEN AND MADNESS

The labelling and stigmatisation of women throughout history goes hand in hand with the long and intimate relationship held by women and mental disorder. From 16th century witches, 19th century hysterics, to contemporary neuroticism in the form of mood and personality disorders; Russell (1995) proposes that the transference of sexism through religion, and now medicine, has enforced the labelling of women as unwell.

Hemmed in by the social expectations of a patriarchal society, Western women have long been confined to positions of oppression. In the 19th century the socially acceptable role of a woman was defined by duties believed to mitigate the severity of hysteria caused by the functions of her reproductive system. The laws of matrimony were intended to curb any immoral sexuality on the part of the woman, while her sexual obligations to her husband eliminated the possibility of celibacy-induced insanity (Russell, 1995). Deviation from 'correct' displays of femininity brought about the threat of institutionalisation. Crimes such as showing signs of independence, or any intellectual interest outside of the home were deemed to be 'madness'.

More recently, Russell (1995, p. 30) cites research from the 1970's where gender-unbiased indicators of wellbeing were founded on the white male profile, considered to be humanity in its purest form (Young, 1995, in Meredith, 2000b). Without comparative markers, their female counterpart becomes unhealthy by default. The Broverman studies (1970; 1972) provide a comparative psychological profile of the 'healthy' female, including socially undesirable traits such as submissiveness, vanity, overt displays of emotion, a lack of independence, and a disinterest towards science and mathematics. Whilst women who do not possess these traits are seen as mentally disordered, those modelling a 'healthy' female profile (weak, emotional, submissive) are more likely to be labelled with disorders relating to hysteria.

During the 1980's institutionalisation still posed a threat for women seen to be behaving in 'masculine' ways. Lest any women escape the historical bonds of madness, a contemporary reconfiguration of hysteria has led to the inclusion of masculine traits in criteria meeting the diagnosis of borderline personality disorder (Ussher, 2011; Waisberg & Page, 1988). In the 21st century women continue to be subjected to harsh judgement in measuring the adequacy of their feminine conduct; often expressed through superficial, non-verbal mannerisms. Yet femininity is intrinsically tied to excessive emotionality and dependency (Haw, 2000), therefore binding it to illness as demonstrated in the clinical descriptors of disorder where women make a distinctive feature.

It is widely known that women in general are disproportionately victim to violence (Holmshaw & Hillier, 2000), causing not only physical and mental trauma to the abused, but wider social and economic detriments (Bosch, Weaver, Arnold, & Clark, 2017). Inevitably, the natural and reasonable responses of women to particular situations or events such as sexual, physical, and psychological abuse, are consistently pathologized (Schur, 1984) to the point where 'treatment' is not only encouraged (Haw, 2000) but seen as the only logical solution to any socially perceived dysfunction.

Presenting such an example is 'battered woman syndrome'. In pleading a case of self-defence, a woman must be mentally 'disordered' in order to justify her violent retaliation, whilst men behaving in the same manner are considered to be reacting logically towards negative environmental factors. Continuing her decline in self-confidence is the re-enforcement of stigmatisation through her association with psychiatric services (Russell, 1995). For some mothers, an understandable and pervasive anxiety exists on the basis that mere perceptions of deviance in the act of her parenting could see a mother torn from her children (Bettelheim, 1967; Schur, 1984).

This ongoing marginalisation and oppression of women flowing from authoritative ideas acts to fuel the positive correlation between women and depression (Ussher, 2011). While patriarchal dominated societies offer men greater control over their lives, social circumstance often creates barriers for women needing an escape from negative situations, causing them greater psychological burden (Nolen-Hoeksema, Larson, & Grayson, 1999).

Questioning the validity of the medical model in characterising sex-related differences in depression statistic, Janet Stoppard (1988) draws from the comparative evaluation between mainstream and feminist perspectives on the causation of depression in females. Stoppard insightfully reports that despite the substantial evidence backing feministic reasoning for the statistical disparities, these ideas were unlikely to ever be influential in policy or mental health practice accounting for psychiatric dominance in defining mental disorder. Again, these dominant ideas from within the healthcare professions leaves little room for the consideration of an underlying neurodevelopmental condition.

WOMEN AND AUTISM

Under-recognition of Autistic individuals without concurrent intellectual disability is said to be an extensively occurring phenomenon (Tebartz van Elst, Pick, Biscaldi, Fangmeier, & Riedel, 2013), specifically for women (Evans-Williams & Williams, 2016). There are those who argue against the need for 'formal' diagnosis, citing the stigma associated with labels. Yet these same people often trivialise the difficulties of the Autistic person as being relevant to the general population (Giuliani, 2018). This is especially true for unrecognised Autistic women whose hardships can be invisible to the casual observer. In clarifying this matter, Wing (1996) emphasises the notion that the individual who is not suffering distress and in need of support would not also be seeking answers from services with a diagnostic focus.

Tying in with the occurrence of misdiagnosis with mental disorder, the Autistic female's understanding of how positively or negatively she is perceived by others in her social circles is believed to play a role in the severity of her autistic symptomology (Kreiser & White, 2014). Parallel to this, Kanfischer et al. (2017) found that all women represented in their study testify to the negative manner they were viewed in by both their families and health care practitioners. Self-acknowledgement of one's failure in the eyes of others can then elicit camouflaging behaviours, inducing psychological distress (Lai et al., 2017) whilst distancing them from the possibility of correct diagnosis and support. These women then continue to be labelled with and treated for mental illnesses which they are unlikely to have and are unable to 'recover' from. All too often they encounter a form of victim-blame (Lewis, 2017) proceeded by their apparent failure to become well (Leedham, Thompson, Smith, & Freeth, 2019). Autism as a neurodevelopmental condition is not something that can be recovered from, and once recognised it is primarily categorised as disability, not mental disorder.

Again, statistical variance in male/female ratios in the range of 2:1 to 10:1 dependable on intellectual ability add evidence to the dire under recognition of Autistic females (Milner et al., 2019). A question first raised by Asperger (Frith, 1991), but largely absent from predominant knowledge, is the likelihood of Autistic females presenting differently to the

autistic norms drawn from male-biased understandings (Lehnhardt et al., 2016).

Unfortunately, these women also fail to meet their peer's expectations of gendered norms (Bargiela et al., 2016), and despite their social motivation are often left feeling an overwhelming sense of rejection (Cage & Troxell-Whitman, 2019). Deviating from the idea of the Autistic female's inability to 'fit' gendered norms, Tierney, Burns, and Kilbey (2016) propose that superficial observations of Autistic females presents them as fitting in with typical gendered expectations.

Deeper investigation shows that Autistic women diagnosed in adulthood are of a high likelihood to report a lack of social support during their school years, recalling bullying and persecution from both students and teachers (Baldwin & Costley, 2016). Continuing into the work environment, these women are habitually victimized and discriminated against (Hayward, McVilly, & Stokes, 2018). Recurrently expressed are incidents of mistreatment and social failings, indicating the possibility that depressive disorders in Autistic adults without a childhood diagnosis of ASD are a consequence of living with unrecognised autistic traits. Accounts from lived experience show that Autistic women find friendships with other women to be difficult, commonly perceiving Neurotypical women as neurotic, unpredictable, and the leading instigators of bullying (Haney & Cullen, 2017).

On a different topic, Baldwin, Costley, and Warren (2014) highlight the disconnect between the superficial knowledge of an individual drawn by healthcare practitioners and their actual functional ability where impaired by socio-communicative difficulties. Through investigating the employment activities of Autistic adults without concurrent intellectual disability Baldwin et al. (2014) show that almost half of this population are over-educated for the positions of employment they hold. When accounting only for Autistic women, this percentage increases to 55% (Baldwin & Costley, 2016).

Looking at other areas of concern Holmshaw and Hillier (2000, p. 55) reference high levels of domestic violence, rape and/or attempted rape in the Neurotypical female population. Suspected to be much higher due to under-reporting, we must spare thought for Autistic women in light of the core socio-communicative difficulties associated with autism.

There are parents who have expressed concerns about the possibility of their Autistic daughters being subject to sexual exploitation (Mademtzi et al., 2018) which are validated through the accounts of Autistic women themselves. With a vulnerability to predatory individuals (Zener, 2019a, 2019b) Autistic women are known to fall victim to sexual abuse (Ghaziuddin, 2005) and generally negative social experiences at much higher rates than Neurotypical women (Bargiela et al., 2016; Sedgewick et al., 2018). Links have been made between sexual violence and the occurrence of mental illness, where disordered behaviour is recognised as a reaction to the encountered abuse. Attuned to the inherent pathologizing of women's experience, the disclosure of abuse within a health care setting is then seen to override any other cause of distress. It is this pre-determined theorising of a psychoanalytical basis that again distances the possibility of recognising underlying ASD. An inherent misreading of social situations which placed these women in harm's way to begin with is something now buried deeper under the compounding weight of adversity.

While there is a lack of consensus on the impact of gendered expectations for Autistic women, one consideration is the variability of intellectual function within research samples. One study of 'high-functioning' females found 50% to be co-habiting in intimate relationships, which is said to be more than twice as many Autistic males (Lehnhardt et al., 2016). In contrast to this Baldwin and Costley (2016) found Autistic females to be significantly happier in their own company, being less likely than their male counterparts to see marriage and interpersonal relationships as key life aspirations. However, another study by Sedgewick et al. (2018) found that some Autistic women will persevere in unhealthy relationships. Reasoning from these women shows their fear of losing their established social networks; being all too aware of the additional isolation that would come from ending the relationship.

Naturally, the unescapable erosion of self-worth drives the tendency towards depression and suicidal ideation seen in Autistic women who are confoundingly rejected by most everyone they encounter (Zener, 2019a). Maddox, Trubanova, and White (2017) report that Autistic women are overrepresented in non-suicidal self-injury compared to men with ASD, and both sexes in the Neurotypical population. Suicide statistics widely report on

high male prevalence, yet a female dominated population researched by Richards et al. (2019) suggests that although unsuccessful, attempted suicides are more common in women.

THE IMPORTANCE OF DIAGNOSIS

Schur (1984) relates the severity of psychological harm to the individual as effective of their stores of personal resources (social, psychological, and economic). For example, fewer resources equals' greater harm and sadly for the unrecognised Autistic woman, there resources are shown to be in dire shortage.

Looking at the coping strategies of Autistic adults Dachez and Ndobu (2018) offer two examples of such strategies from Folkman and Lazarus; firstly, to solving the problem that is causing stress, and second is the management of negative emotions that result from the stress. Dachez and Ndobu (2018) propose another which is the search for meaning. For those whose stressor is unrecognised autism, there is no hope for them to ever develop effective coping strategies that would enable them to live without distress. Dachez and Ndobu (2018) found autism diagnosis to have ameliorative effects on mental distress through the formation of self-awareness and the subsequent ability to build an identity. There are multiple other studies (Lewis2016 realising diagnosis adulthood) which have found that throughout their lives', Autistic adults have faced substantial difficulties before being diagnosed. Additionally, many of these adults attest to the reconciliatory effects of diagnosis in the formation self-identity (Lewis, 2017).

BRIDGING THE GAPS BETWEEN THEORY AND REALITY

Over twenty years ago Frith (1991) and Wing (1996, 1997) addressed the diversity of the autistic spectrum as a lifelong condition, noting the ineptitudes of the DSM and ICD manuals in their descriptions of neurodevelopmental conditions.

As is evident in chapters two and three, there are many instances where women have been misdiagnosed with, and treated for any and every psychiatric disorder which they in fact never had; instances that only come to light when they are later correctly diagnosed. This chapter has shown that from early research into what we now know as autism, women have been implicated with madness and mental disorder; from early mother blame, to contemporary assumptions of women's natural tendency towards mental disorder.

A CHILDHOOD CONDITION

Early researchers in the field of autism described what they assumed to be symptoms of psychiatric disorder that were present during infancy and childhood. Historic diagnostic terms such as infantile autism, childhood psychosis, and childhood schizophrenia have helped set the foundations for many of the misunderstandings that remain today. Following on from this is a wide-held misconception amongst healthcare practitioners who are uneducated in the area of neurodevelopmental conditions that suggest autism is a childhood condition. Many healthcare practitioners are of the belief that the Autistic individual magically 'recovers', becoming 'normal' somewhere in late adolescence. Unfortunately, the recognition of symptoms during childhood is still a requirement for diagnosis in the DSM-5 and causes problems where there is a lack of appropriate knowledge in mental healthcare settings. Somehow this delusion of autism as a childhood condition has remained, despite its classification as a lifelong disability.

A SEVERE CONDITION

Autism is now described as a pervasive neurodevelopmental disorder leading to assumptions that it can only present as a severely debilitating condition where the afflicted is unable to perform the basics of day-to-day living. This belief is in conflict with early observations where only 1/3 of Kanner's children had severe to moderate intellectual impairment, and Asperger's were all of average and above intellectual ability.

Today it is believed that around 60% of Autistic adults without concurrent intellectual disability still remain unrecognised, and Autistic women have shown to be disproportionately represented in this group. As is evident from previous accounts, autism is not intellectual disability, but in another discrepancy of reporting, intellectual disability is said to be common amongst the Autistic population.

A MALE CONDITION

Influenced by the disproportionate sex representations in historical research and reporting, autism is widely considered a disorder affecting young males. Asperger suggested the possibility that Autistic females may present differently than males and that their difficulties may not be apparent until puberty as he noted there were similar traits in the mothers of his subjects. Additionally, Kanner had three females in his group but this knowledge seems to be little known. Male biased measures of health have also carried over into the field of autism. This male dominance in research focus has led to the development of screening and diagnostic tools and criteria that are unsuitable for the recognition of autism in females.

MENTAL DISORDER?

The assessment and diagnosis of autism in adults is carried out in mental healthcare settings and guided by the diagnostic criteria set out in manuals such as the DSM-5 and ICD-10. Associations with mental healthcare for autism assessment and diagnosis do not allow for the consideration of disability as mental healthcare insists on illness, and recovery through treatment.

Although autism is not mental disorder it can appear to be so, especially in cases where the Autistic individual is lacking the appropriate supports and understanding. Disorder is seen to be a loosely defined and highly subjective term, and in light of the above proves highly problematic for the unrecognised Autistic population.

As set out in the currently operative DSM-5, autism spectrum disorder incorporates all previous diagnostic terms for neurodevelopmental disorders and now includes sensory processing issues and difficulties with contextual uncertainty as diagnostic criteria. To look at the unsuitability of the mental healthcare system in recognising autism; there is a reference to irrationality for anxiety disorders such as specific phobias. From this we can see the domination of the medical model over mental health practice through the pathologically interpreted reporting of client narrative. Reliant on the existence of illness, it is suggesting that the problem lies within the individual, leaving no room for contextual considerations or a recognition of environmental instigators. This tendency to pathologize behaviours is so deep that any disagreement with healthcare practitioners is seen to be mental disorder, a resistance to treatment, and the refusal to become well.

WOMEN ARE MAD, NOT AUTISTIC

Females face discrimination against across all areas of healthcare as the standardised models of health derive from a white male profile and are used as measures of wellbeing regardless of sex. Relatively recent studies show that depictions of women as 'unwell' match societal perceptions of the 'healthy' woman as being in possession of socially undesirable traits amounting to irrationality and weakness. These ideas disturbingly aligned with the clinical model of a psychologically healthy female.

Consequently, psychoanalysis and pathologizing behaviour appears to be heavily persuasive in any interactions between women and the field of mental health, automatically dismissing the possibility of anything in conflict with ideas of women as innately defective. Of interest when remembering that depression is often attributed to the distress of women who are yet to be diagnosed as autistic, statistical data suggests that women in general have a much higher likelihood than men to suffer from mood and anxiety related disorders.

Unfortunate for the unrecognised Autistic female is the underpinning assumption of psychoanalytic theory that all humans are fundamentally driven by the same neurological

makeup. Autistic women have reported on the frequent dismissal of their concerns by health practitioners. This discriminatory and derogatory behaviour stems from poorly educated views of autism. There is evidence that typically prescribed pharmaceutical treatments do not always work for Autistic individuals and can have unusual and sometimes harmful side-effects. For unrecognised Autistic women this is seen to be a purposeful defiance to become well, and often results in a form of victim-blame.

From the limited literature available it is evident that Autistic women have a higher representation across all negative aspects of life as well as gender specific troubles that are complicated further by autism. Building on the perspective of lived experience from chapters one and two, here I have presented a similar story from peer-reviewed clinical accounts. Much of what has been stated in this chapter echoes the lived reality but from a deficit driven, objective view. The difference is shown through the lens of which the observer chooses to look.

Gaining a better understanding of my topic through reviewing the available peer-reviewed literature showed that here in New Zealand we do not produce knowledge or localized data pertaining specifically to autism (O'Dell et al., 2016). To understand what was happening within the context of the New Zealand healthcare system I needed to search and review what relevant information was available.

CHAPTER FIVE

THE NEW ZEALAND SYSTEM

The Diagnostic and Statistical Manuals are the leading influences for mental health assessment and diagnostic services in New Zealand. My concerns being specific to females are evidenced by Mertens et al. (2009) on finding a significant number of girls in America, across all ethnic groups, have unrecognised disabilities resultant of differences in their displays of difficulty when compared to disabled males. Whilst Mertens et al. address an American population, I draw relevance to this through New Zealand's predominant use of the American Psychiatric Associations DSM manuals in public health settings (The New Zealand Psychological Society Te Rōpū Mātai Hinengaro o Aotearoa, 2014). Attending to the obligatory requirements of the New Zealand health care workforce in adhering to the guidance of the DSM manuals, the New Zealand Psychological Society (NZPS) (2014) released a statement outlining their concerns on the pathologically driven amendments to the latest manual. Their feelings were of the DSM-5 as incompatible with the recovery approach our system aims to work on, acknowledging the power of such a manual in shaping clinical practice. The statement outlines the importance of social and cultural contexts in addressing mental distress, which underpins the New Zealand model of mental health care.

The NZPS acknowledges that the influence of pathological language shapes the ideas and clinical practice of practitioners who may lack an appropriate understanding of mental health issues, and the flow-on effect this can have in the development of stigmatising perspectives towards mental distress within the wider social context.

Described by Mental Health Foundation of New Zealand (2002) as a social disorder affecting language, ASD does not primarily require medical treatment and most importantly is not a disease. Guidelines for diagnosis ASD in the United Kingdom exemplify this in declaring the assessment process need to consider not only psychiatric criteria, but the contextual diversity in which social difficulties arise, and the impact these difficulties have on one's life (Lai & Baron-Cohen, 2015). While there is no note to the specific

changes in the classification and diagnosis of neurodevelopmental conditions, it does suggest a need to step back from the clinical dehumanisation of mental distress that is operative in the DSM-5.

In this chapter I include key points from the documents and reports that I see to be relative in the under recognition and misdiagnosis of Autistic women here in New Zealand. Where local evidence is lacking, I have referenced international studies in corroborating my assumptions. I start with the foundations of our current mental health system, and then work between the documents that mention, or should mention the Autistic population, and have hidden implications for Autistic women who are yet to be recognised. Further filling in some of the gaps, I have included information from relevant pages of the MoH website.

THE VISION

The Blueprint for mental health services in New Zealand (Blueprint) (1998), built on the 1997 Blueprint Working Document, was a national mental health service development plan attempting to drive the mental health sector towards a people centred provision of service. Perhaps momentarily forgetting the purpose and principles they were advocating for is the inclusion of WHO data stating that in 1990 mental illness was accountable for around 11% of the “global burden of human disease” p. 6.

The adoption of a ‘recovery approach’ came from an admission that historically, those suffering mental distress had been isolated and discriminated against, often denied their basic human rights, and forcibly treated against their will. The Blueprint looked to incorporate ‘recovery principles’ into the provision of mental health services.

The Ministry of Health supports a 'recovery' approach to mental distress and mental illness, which means working towards supporting an individual in a way which minimises the level of distress and impact on their day-to-day lives as much as possible.

(Ministry of Health - Manatū Hauora, 2018)

Although mental health services have been directed by a 'recovery' approach for over 20 years now (Blueprint, 1998; Blueprint II, 2012), recent reports into the effectiveness of the mental health system evidence ongoing failings towards the enactment of recovery principles.

At present there are no clearly defined pathways for adults seeking assessment for autism in the New Zealand public healthcare system. Those who do manage to access services available in the government-funded healthcare system find themselves within a mental health system focused on recovery approaches. As established in the previous chapter, autism is classified as a lifelong disability, not a mental disorder, and therefore not something that one is able to recover from. Subsequently, the services available through the New Zealand healthcare system are under-resourced to deal with the specialised nature of recognising or diagnosing neurodevelopmental conditions. These services are unlikely to be useful in the amelioration of symptoms which could be undiagnosed ASD, where these women continue to be misdiagnosed with mood, anxiety, and personality related disorders (Ministries of Health and Education, 2016)

In keeping with the focus on a recovery approach, mental disorders are considered to be short-term illnesses. As such, they do not enable access to disability support services, unless there is also a diagnosis of ASD. This point is significant in that an ASD diagnosis allows for access to government-funded disability support services, where needs assessments are carried out to create targeted support plans which are tailored to the individual.

Much of the literature on ASD centres on the early diagnosis and early intervention of young children with ASD. However, there are also undiagnosed young people and adults with ASD. Some seem to manage well while other undiagnosed people and their families endure great stress, and they can be misunderstood, blamed, teased, bullied, poorly supported and miss out on effective treatment options, or receive inappropriate medical, psychiatric and educational interventions. Some receive psychiatric or intellectual disability services or both, yet without the

recognition of their ASD, services are not appropriately tailored to their individual needs.

(Ministries of Health and Education, 2016, p. 30)

The Autistic population are known to have disparities across all areas of well-being which often necessitates specialist knowledge and health care services that are either unavailable in New Zealand or come at a high financial cost. Associated physical health is often ignored or little understood due to the rarity of conditions associated with autism, and without recognition, labels such as factitious, bipolar, personality, depression, anxiety are known to have been thrown around (Birch, 2002; James, 2017b). Noting the paucity of information detailing the general health status of Autistic adults (Croen et al., 2015) were driven to investigate. Compiling data focused on physical functioning, these authors found that adults on the autistic spectrum are overrepresented across almost the full range of major and chronic medical conditions. Those of note were sleep, gastro-intestinal, and immune conditions, diabetes, epilepsy, hypertension, dyslipidaemia, obesity strokes and Parkinson's disease.

Further compounding the difficulties faced by Autistic adults is the knowledge that individuals suffering severity of autistic traits are often not in a position to finance these services themselves (Ghaziuddin, 2005). This proves troublesome in light of findings by Barr et al. (2016) where the stresses associated with re-assessment applications for healthcare related supports hold accountability for higher rates in suicide, self-harm, and depressive conditions.

WELFARE SUPPORTS AND MENTAL DISTRESS

Although Barr et al.'s findings are based on statistics collected in England, a similar restructuring of social welfare supports was undertaken in New Zealand in 2013. Welfare reforms here led to changes in accessibility and criteria enabling access to welfare supports (Ministry of Social Development, 2013), aimed at reducing 'welfare dependence' incidentally impacting heavily on those with mental health and disability related

conditions (Mattheys, Warren, & Bamba, 2018). Of main importance is the disestablishment of the sickness benefit where people who are unable to work due to what are considered to be temporary illnesses are subject to regular reassessment for their ability to return to work. Reassessment processes require the provision of medical certification in backing one's application to access welfare assistance. This becomes an impossibility for unrecognised Autistic women when healthcare practitioners fail to correctly diagnose. There are then additional pressures arising from the misdiagnosis of mental illness and a subsequent 'failure' to become well and/ or respond positively to treatments.

Emphasising the predicament of the unrecognised Autistic women and the likelihood that they are affected by any social welfare reform is the knowledge that they are already statistically overrepresented in suicidal ideation and self-harm (Au-Yeung et al., 2019). Socio-communicative differences a core feature across the autism spectrum (Lord, Cook, Leventhal, & Amaral, 2000) means that the successful navigation and coordination of this complex system can be somewhat hit and miss. Considering suggestions by Lai and Baron-Cohen (2015) that depression is under-reported due to communication issues, it could be assumed that depressive presentations and anxiety are also induced by the inability to express needs and be understood by the agencies whose purpose is to provide support. This then leads to a vicious cycle of further misdiagnosis, the provision of ineffective supports, and the stresses of reapplication alongside the pressures of also engaging in employment seeking whilst core difficulties are left unaddressed. It is often that the individual is unaware of ASD as an underlying cause for their distress (Zener, 2019a, 2019b) and therefore they would not be asking the right questions when seeking assistance from either mental or primary healthcare services.

Lacking local information on the effects of welfare reform on mental wellbeing I draw comparisons to the English system accounting for the New Zealand government's tendency to use international data in the drawing of health-related conclusions. The complexities of support access are difficult and confusing (Barnes et al., 2017); requiring a

dogged determination and incessant multi-agency interactions in order to elicit even the most basic levels of support.

FUNDED DISABILITY SUPPORT

The Ministry of Health offers a range of funded support services for people with disabilities. Their website outlines the following eligibility criteria for who is eligible for disability support:

These are available to people who have a physical, intellectual or sensory disability (or a combination of these) which:

- is likely to continue for at least 6 months
- limits their ability to function independently, to the extent that ongoing support is required.

These are mainly younger people under the age of 65 years.

The Ministry will also fund DSS for people with:

- some neurological conditions that result in permanent disabilities
- some developmental disabilities in children and young people, such as autism
- physical, intellectual or sensory disability that co-exists with a health condition and/or injury.

Who can't get Ministry-funded support services?

The Ministry of Health does not generally fund disability support services for people with:

- personal health conditions such as diabetes or asthma
- mental health and addiction conditions such as schizophrenia, severe depression or long-term addiction to alcohol and drugs
- conditions more commonly associated with ageing such as Alzheimer's disease.

(Ministry of Health, 2016).

Yet another page on the MoH website provides the following information on what support is available to Autistic individuals

Disability Support Services (DSS) has developed a clear, nationally consistent approach to accessing disability support services for people with ASD. From 2 April 2014:

- people with a sole diagnosis of ASD as well as people with ASD and another co-existing physical, intellectual or sensory disability can access disability supports through DSS
- people who currently access disability support services will have no change to their level of support.

(Ministry of Health, 2018)

With the underpinning 'core deficits in social communication' (Barlowetal2018) associated with ASD, the findings of these studies are undoubtedly transferable to at least some in the New Zealand context.

LACK OF CLARITY

Across the board, New Zealand reports and guidelines focusing on mental health have yet to consider the implications of ASD for unrecognised Autistic individuals who are accessing mental health related services. There are very few references to ASD, with those noted highlighting it as a condition where the needs of this population are complex; involving interagency engagement where cohesion is evidenced to be lacking. Crucial to the wellbeing of all Autistic people regardless of their level of functioning, is an understanding of the condition and its presentations by all personnel in authoritative or support systems who may come into contact with them. Yet Autistic individuals are still being unjustly imprisoned under the MHA, and the 2003 Intellectual Disability Act (IDA) (Ministry of Health, 2003) resulting from the systemic ignorance of autistic presentations and the reasoning behind them (Stace, 2016). Such systemic ignorance is described by Stace in the unjustifiable and inhumane incarceration of Autistic man Ashley Peacock here in New Zealand. This echoes a similar example from a Swedish study where the so called

‘treatments’ enforced on some Autistic people to be inductive in aggravating autistic symptomology (O’Dell et al., 2016).

Within the New Zealand context there is no definition or classification of ASD that clearly and practically provides access to support for the adult Autistic population. This is backed by New Zealand statistical information stating that in 2016, those accessing disability support services for ASD were 81% male, and predominantly children and young people (Ministry of Health, 2017b). This is of great concern as women on the autistic spectrum who do not have co-occurring intellectual disability are shown to be at greater risk of missing out on an autism diagnosis or being incorrectly diagnosed with mental disorder (Lai & Baron-Cohen, 2015).

NEW ZEALAND AUTISM SPECTRUM DISORDER GUIDELINE

In 2018 Penner, Anagnostou, Andoni, and Ungar (2018) declared ASD Guideline to be an international leader in government led directives for Autistic children under the age of 6, showing that Autistic adults are still generally of little research interest. The ASD Guidelines are a living guideline where an annual review and recommendations are made with direction from significant international research findings. Although it is said to have a focus on autism spectrum disorders across the lifespan, the guidelines have neglected to suitably address both the spectrum and the lifespan aspects. The stated input of Autistic individuals into the development of the guidelines fails to hold any weight, with evidence-based recommendations influenced by clinically detached research. Lack of lived experience incorporated into the knowledge and best practice guidelines does not account for the reality of autistic lives (Fletcher-Watson et al., 2019).

Stressing the paediatric focus, the ASD Guideline suggests that children with ASD aged 1-8 are likely to present with significant delays in language and/ or behavioural issues. The severity of these presentations is comparable to the age of the child at the time of referral to paediatric services, with older children displaying milder issues. Echoing the thoughts of Asperger, Frith, and Wing (Frith, 1991; Wing, 1996) there is a recognition that ‘more able

children' may not raise suspicions until placed in environments where they are subject to the increasing social demands of every-day life. Early recognition and intervention have been found to have mitigating effects towards the development of other psychiatric conditions (Aggarwal & Angus, 2015), but contentions are still apparent in the following statement which is both relevant and troublesome for unrecognised Autistic adults:

There is debate about whether the behavioural, emotional and mental health issues of people with ASD should be considered co-morbid disorders (i.e., completely separate disorders that occur at the same time as ASD) or underlying symptoms of ASD itself.

(Ministries of Health and Education, 2016, p. 134)

Despite a recognition that individuals with ASD face a high risk of negative life outcomes, disparities exist between what supports are needed, and what is available. As an afterthought to identifying the dire shortage of health care practitioners competent in the assessment and diagnosis of neurodevelopmental conditions in adults, a pathway is offered through the services of local district health boards (DHB). How viable this pathway is in reality remains questionable.

Although recommendations have been made for multidisciplinary and/or multiagency involvement in the assessment and diagnosis of adults with suspected ASD, there has been no move to implement this. Furthermore, the continuity and cohesion of appropriate supports for those who managed to obtain a diagnosis but do not have intellectual disability or mental health issues are non-existent. The guidelines have the potential to be a very powerful tool for the Autistic community, but awareness of this resource seems to be lacking outside of the knowledge of all but a few healthcare practitioners.

HE ARA ORANGA

He ara Oranga (2018) reports on the government inquiry into the mental health system which came about after recent highly publicised complaints. This report is strongly

directed by the voices of affected individuals, including those suffering mental distress, their families and whanau, as well as support people within the community, and those working in roles associated with mental health. The report outlines some major failings within the health sector as to how we address matters of mental distress. Yet the current system remains centred in the biomedical approach, where paternalistic systems focus on disorder, illness, and the coercion and medicating of those who are viewed as unwell.

Within this approach, primary healthcare as the first point of contact for initial mental health and addiction concerns has come under fire for the lack of comprehensive understanding of mental health issues. Evidence points to the preference amongst general practitioners to prescribe medication for depression without sufficient understanding of the complexities of mental distress. It is therefore suggested that a greater emphasis on mental health is required during the process of educating the health care workforce.

Of the many influences towards mental distress are a lack of education, unemployment and poverty. Within this complex web there are issues of substance-abuse and addiction, social isolation and discrimination, trauma, violence and crime. All too often the resulting outcomes include suicide attempts and untimely death, all of which the Autistic population are known to be at a heightened risk of. Despite the government directed drive to create awareness and acceptance of mental distress, the topic is still highly stigmatised.

An inherent lack of cohesion between services has been seen as leading people to fall through the gaps due to their needs not meeting the specific criteria for support. As mentioned in the previous chapter, meeting specific diagnostic criteria is often dependant on the interpretations of the assigned diagnosing practitioner. People are required to navigate the system by their own means, which is extremely difficult under the current healthcare system. These concerns are echoed in the voices of healthcare practitioners who are also feeling the pressures of an under-resourced system.

A reoccurring theme in the criticism of the current mental health system is the detrimental effects of the MHA, and its conflict with New Zealand's obligations to the

United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2011), and the Convention on the Rights of Persons with Disabilities (United Nations, 2006) . This act is enforceable on anyone meeting the description of mentally disordered; which comes down to the discretion of practitioners who are often lacking a comprehensive understanding of the complexities of mental distress. The MHA is described by many as inhumane, and too often brought into effect without first considering other, less harmful options. One service-user provides an account of being unjustly subject to the MHA:

Psychiatrist number four was time pressured and we didn't click and he couldn't quite figure me out, so he sectioned me. Because if you're time pressured its 'safer' to section someone with chronic suicidality than to actually spend some time getting a better handle on their situation.

(Service user, New Zealand Government, 2018, p. 58)

The MHA is a large driver in the treatment of those who are seen to be severely mentally disordered. A section of the MHA on compulsory detainment is presently given overriding status to the Convention on the rights of people with Disabilities. New Zealand has increasingly high instances of people being detained under the MHA, drawing high criticisms that this is in breach of basic human rights. To a lesser degree, concerns have risen from the narratives of service-users and the feeling that medications are overly prescribed as a measure of control. Disturbingly, there are no accessible records kept on the prescribing of medications within inpatient settings; obscuring the experiences of those detained under the compulsory care acts for mental health or disability.

Below is a definition of mental disorder as it is stated in the MHA. As was suggested earlier, it has questionable credibility in this context on account of vagueness in definition where making such decisions as the involuntary detainment of individuals. These decisions are carried out at the discretion of practitioners who often do not have adequate training in or understanding of neurodevelopmental conditions and their presentations.

mental disorder, in relation to any person, means an abnormal state of mind (whether of a continuous or an intermittent nature), characterised by delusions, or

by disorders of mood or perception or volition or cognition, of such a degree that it—

(a) poses a serious danger to the health or safety of that person or of others; or

(b) seriously diminishes the capacity of that person to take care of himself or herself;—

and **mentally disordered**, in relation to any such person, has a corresponding meaning.-

section 2(1) of the Mental Health Act

(Ministry of Health, 2012)

The MHA goes against all principles of the recovery approach, and in most cases causes even greater harm and distress to those sectioned under it. As it stands, many people are reportedly fearful of seeking help in times of distress, owing to the stigma and associated consequences of being labelled as ‘mentally ill’. Such fears are noted above as part of the complex web of factors relating to mental health, which could also involve the loss of employment, friends, family and whānau, and the possibility of forced separation from their children.

THE MONITORING AND ADVOCACY REPORT OF THE MENTAL HEALTH COMMISSIONER

The monitoring and advocacy report of the Mental Health Commissioner was published in February 2018 providing an independent overview of the mental health and addiction services within the wider network of healthcare provision.

Encompassing the wider picture is a recognition of poorer overall health in the population who suffer mental distress and/or addiction problems, in part owing to wider socio-economic factors associated with mental distress which lack consideration in the current medically focused system. It is recognised that in addressing issues of mental distress

there are wider social and economic benefits. The belief that the New Zealand healthcare system is moving towards a recovery and wellness social system is somewhat hindered by the over-riding predominance of the healthcare workforce in resorting to a medicalised treatment approach. This is a common complaint seen throughout reports voicing the opinions of service users and their supporters. There is a serious need for transparency amongst all health care professionals involved in the provision of an individual's care to be fully engaged in the monitoring of adverse effects to treatment and especially the potential for life threatening side -effects of medications prescribed in amelioration of mental distress.

Echoing He ara Oranga, is recognition of major gaps in the cohesion of services, leading to an inability to address the wider issues that influence wellbeing and recovery. Factors affecting the continuity of care have been noted as the insufficient documentation process and a failure of healthcare practitioners to read notes, poor referral processes and management, as well as the undefined borders of responsibility and duty within the mental health system. These leadership and coordination issues have had an ongoing and negative impact on the mental health sector with a lack of uniformity throughout the system which involves over 20 DHBs and untold other agencies. Rectification of this is immediately required if we are to see the effective delivery of services and consumer outcomes.

Another focal point for consumer complaints is the dissatisfaction of those who have co-occurring mental health and addiction needs, and/or co-occurring mental health and disability needs due to the noted discontinuity in the provision of care between these services. Although these issues have been highlighted previously, little has been done to remedy the matter. One service user's input bluntly describes their feelings on mental health services and the inability of these services to provide ongoing support and/or treatment for people needing service provision outside that requiring intensive intervention:

“DHB services are *\$@# at getting people better, good at getting people stably unwell.”

(Adult consumer feedback session, service user, Office of the Health and Disability Commissioner, 2018, p. 41).

“No clear pathway for where need to go to get help that you need. If start with GP and they don’t really know where to go then can bounce around.”

(Youth consumer feedback session, service user, Office of the Health and Disability Commissioner, 2018, p. 41)

“feels like to get help you need to be ‘sick’ and then once receiving help you have to get ‘better’. Where is the ongoing support for people who are ‘well’ but still needing support?”

(Youth consumer feedback session, service user, Office of the Health and Disability Commissioner, 2018, p. 41)

There are heavy consequences for both service-users and their families and whanau thorough the multiple inadequacies of the system where the end result has been premature and completely avoidable death.

From the gathering of statistical information carried out using the Health of the Nation Outcome Scale (HoNOS) indicator tool, He ara Oranga is of the opinion that the majority of people experience improved well-being through interaction with mental health services. This tool (HoNOS) has been criticised for its medicalised nature, noting that what can be seen as wellness and recovery in a clinical setting does not equate to the same in every-day life. Prevalence data that has been collected using this tool is said to be outdated by over 15 years and does not account for less common conditions such as ASD.

OFFICE OF THE DIRECTOR OF MENTAL HEALTH SERVICES

The 2016 annual report for the Office of the Director of Mental Health (ODMH) refers to the half-century transformation of mental health care provision in New Zealand and suggests that we have moved from forced institutionalisation to a recovery model of voluntary engagement. The ODMH is responsible for encouraging good clinical practice

across the mental health sector, reporting that in 2016 the office worked on “implementing the Autism Spectrum Guidelines and resolving mental health/disability support interface issues” (Ministry of Health, 2017c, p. 9), with acknowledgement that mental distress is statistically significant in the Disability community.

Early this year the 2017 (Ministry of Health, 2019) annual report was released. Follow-up data on successful implementation and remediation of interface issues for the Autism Spectrum Guidelines does not feature, in fact there is not one mention of autism in the report.

The issues of practitioner transparency flowing through the mental health sector appear to contrast directly with grandiose claims of service provision guided by a recovery approach. Efforts by the ODMH to improve the reporting of non-consented ECT are given as justification for the increase in ECT treatments between 2016 and 2017. As with the findings of other mental health reports, the lack of accountability within this sector provides little faith for the care and protection of our most vulnerable people.

ECT is a therapeutic procedure in which a brief pulse of electricity is delivered to a person’s brain in order to produce a seizure. It can be an effective treatment for various types of mental illness, including depressive illness, mania, catatonia and other serious neuropsychiatric conditions. It is often effective as a last resort in cases where medication is contraindicated or is not relieving symptoms sufficiently. It can only be given with the consent of the person receiving it, other than in certain carefully defined circumstances.

(Ministry of Health, 2019, p. 76)

During 2017, six people were treated with ECT who retained decision-making capacity and refused consent. The total number of ECT treatments not able to be consented increased from 954 in 2016 to 1,137 in 2017, which may be attributable to focused efforts by the Office during 2015 to improve reporting on non-consensual ECT.

(Ministry of Health, 2019, p. 81)

In 2017, of the 265 people who received ECT treatment, 168 (almost 63 percent) were female and 97 (almost 37 percent) were male. The main reason for the sex difference is that more females present to mental health services with depressive disorders. This ratio is similar to that reported in other countries.

(Ministry of Health, 2019, p. 83)

DISABILITY CONNECTION AND CONFUSION

He Ara Oranga (2018) addresses the ties between the disability and mental health sectors, suspecting a prevalence of ASD to be one in one hundred New Zealanders. Admitting to the confusion between the roles of disability and mental health services, there are some cases where mental health issues are overlooked as symptoms of disability, and then conflictingly citing statistics where disability is resultant of psychological and/or psychiatric conditions. Recognition is given to the overarching topic of this thesis in the following statement:

There are few suitable services for, and poor responses to, people with complex or multiple needs (for example, people with an intellectual disability and/or autism as well as a mental health need). Age and life stage transitions are not well supported. The lack of integration between and within the health and social sectors and for high-need population groups is a barrier to improving people's experience and outcomes.

(New Zealand Government, 2018, p. 78).

Commendations can be offered for mentioning the recognised Autistic population, but there is a failure to account for other perspectives. Firstly, to address the incidence of individuals suffering mental distress due to their unrecognised ASD. Secondly is the failure to acknowledge that there is an issue of unrecognised ASD in at least a small number of individuals engaging with mental health services. This is not to say that Autistic individuals do not suffer mental distress, but more to point out that 'recovery' is not possible for any individual without first recognising and understanding all contributors to mental distress.

There is a variability seen in statistical reporting which is supported by an aversion towards the collection of comprehensive data across a range of organisations. Accordingly, Russell et al. (2016) suggest that a shortage of directed investigation by governing bodies works to cloud any appropriate awareness of the service needs for Autistic people. Although glaringly evident with respect to the paucity of appropriate autism related knowledge and support available in New Zealand, O'Dell et al. (2016) highlight the absence of input from the southern hemisphere into the global autism knowledgebase, hence our need to utilize offshore data.

WHAT IS AUTISM?

The Ministry of Health website provides information on ASD under the disability section with the suggestion to contact a health professional for advice should you have suspicions that you or your child may have ASD.

Autism spectrum disorder (ASD) describes a range of conditions that includes autism and Asperger syndrome.

People with ASD have a delay or difficulty in three areas of development:

- 1. Language skills** – they have trouble understanding and using spoken language and non-verbal communication such as facial expressions and body language.
- 2. Social behaviour** – they have trouble understanding social interactions, which affects their ability to play or interact with others.
- 3. Cognitive and thinking skills** – they have trouble thinking and behaving flexibly, and may engage in restricted, obsessive or repetitive behaviours.

(Ministry of Health, 2017a)

DISABILITY

The World Health Organisation (2019) defines disability as below:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.

People with disabilities have the same health needs as non-disabled people – for immunization, cancer screening etc. They also may experience a narrower margin of health, both because of poverty and social exclusion, and also because they may be vulnerable to secondary conditions, such as pressure sores or urinary tract infections. Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings.

Both this description and predominant disability studies literature embodies disability as a tangible thing, adding to the marginalisation of those living with invisible disability. While the social model of disability invokes consideration of difference and the location of barriers outside of the individual, the shortage of representation from those with lived experience of invisible disability has done nothing to help their plight. Here visible physical disability sits as the privileged version, comparative to the wealthy, white, non-disabled woman of early feminist theory (Mertens, 2010; Morris, 1998).

SUMMARY

Quite clearly there are problems in respect to autism within the New Zealand Healthcare system. Sporadic mention of these failings seems to be little more than an attempt to appease those who are affected. Recalling Stace (2011) earlier difficulties in accessing

relevant information; nowhere is there mention of what is being done or what could or will be done to improve the situation.

While classified as a disability that enables access to government funded disability support services, the diagnostic process for adults as well as much of the support provision comes under the jurisdiction of mental health services. Difficulty in clarifying the positioning of autism within the New Zealand healthcare system becomes apparent when those seeking help are actively attempting to navigate their way through the healthcare system. As my attention is on a somewhat invisible population, I have had to make assumptions from the un-said and tentatively suggest previously unformed links between all sources of information reviewed in this thesis.

PART THREE

Part three consist of a summary of ideas from parts one and two. The reason for this being included in at the beginning of part three is that it ties the previous chapters into the findings. This acts to bring the whole thesis together and clarifies some of the main points that need consideration when looking to address my recommendations.

CHAPTER SIX

BRIDGING LIVED EXPERIENCE, THE LITERATURE, AND THE NEW ZEALAND SYSTEM

To understand the circumstances of my past in light of an autism diagnosis I needed to know about the history and evolution of ideas on autism. Obviously, this wasn't as simple as it sounds here, and I was directed to further investigate the positioning of women in Western culture, and their longstanding relationship with madness. As a spectrum, autism can exist in any variation between opposing extremes, but from the start I noticed that women were 'othered', which signalled the start of their exclusion. The politics of autism had been labelled a 'wicked problem' before I came to this area of study, and given more time and a larger word count, there are so many more variables waiting to be investigated. During my literature review I came across an article noting the absence of autism research and ideas coming from the global south, further highlighting the minority status of the Autistic population. In 2011 Stace reported on the inaccessibility of knowledge to ongoing work by the MoH into the development of services and support for Autistic individuals. I have found this to still be true, and from my review of the New Zealand documents, have seen a gradual decline in the addressing of autism specific support services in both the mental health and disability sectors. My own collection of data on what is happening for Autistic adults in New Zealand comes from a search of the MoH website.

Although the ASD guidelines are rated as one of the best in the world, this only accounts for children under the age of 6, and there appears to be no imminent move to accommodate the needs of Autistic adults. Despite the ODMH 2016 report claiming work towards the implementation and cohesion of services under the guidelines, there are no evident changes in what services and supports are available.

From my literature review we see how globally, the ideas and knowledge of autism has evolved over the last century; and like Chinese whispers, how early observations and research have come to be distorted.

The dominance of psychoanalytic theory during the first half of the 20th century led to a belief in autism's emotional aetiology. Leading theorists of the time believed that the supposed psychosis they were witnessing was a direct result of parental malpractice. During an era where women were expected to take sole responsibility for parenting, severe scrutiny of the mother-child relationship ensued. It was then that the pathologizing nature of psychoanalysis concluded to her feministic deviance by the expression of gendered roles in the literature; being the good/innocent male child, and disordered/evil woman.

This relationship between women and madness was already well established in the times of early autism research; having invaded all areas of the society. Sadly, patriarchy is still going strong, and still causing problems for females today. It is potentially these early works that led to commonly held contemporary beliefs that females cannot be autistic. Whilst these problems are not explicitly stated in any of the literature I have reviewed, they are hinted at in part one, and strengthened in subtle ways throughout the ongoing chapters.

Lorna Wing and Uta Frith long ago declared the attempts within psychiatric circles to divide, categorise, and label neurodevelopmental disorders as problematic, and of little clinical relevance. Both Frith and Wing reference the historical observations of Leo Kanner and Hans Asperger which seem to have little input into current mainstream knowledge, and have either been eliminated from, or misinterpreted and reconstructed in the literature over time. Despite the lack of Autistic females in early observations, Asperger's explanations for this suggested that Autistic females do exist, and most likely present differently to their male counterparts. Somehow these acknowledgements failed to generate further investigation

Autism has been idealised as a male condition, a childhood condition, and a severe condition. But never one that fit the perceptions of what constitutes the being of women. Modelled on a white, male profile, wellbeing has been seen as something naturally unattainable by females; which has perhaps led to their exclusion from health research, more specifically in this case autism related studies.

Males, specifically youth seem to be a strong feature in the New Zealand publications relating to mental health and disability, as was the case in my peer-reviewed literature searches. Within various fields of knowledge, it is offered as explanation that males are more likely to externalise their issues in visible behavioural disturbance. In contrast, females are said to show their distress in extremes of emotionality. Suicide prevention measures take this into account by targeting young males, in accordance with their higher rates of completed suicides (Cassidy et al., 2014; Ministry of Health, 2017c).

I would hypothesise here that the higher rates in males are due to their tendency towards violent attempts at suicide, comparative to females. Tying together the concepts of women and madness, and the male domination over autism and suicide statistics is evidence of women with autistic traits having the highest representation in self-harm and attempted suicides. Questioning the positive correlation between elevated autistic traits and both completed and attempted suicide, Richards et al. (2019) suggest that mis(di)agnosis contributes to the probability of suicide attempts by disabling access to relevant and appropriate supports. Taking a bidirectional approach, Richards et al. (2019) also believe that a considerable proportion of adults who attempt suicide need urgent assessment for the possibility of autism.

Recent changes to the DSM-5 heeds recognition of a neurodevelopmental spectrum, and contemporary researchers specialising in this area are aware of the evolving presentations of autism accounting for intellectual function, gender and lifespan. Yet this knowledge is slow in gaining traction within mainstream health circles.

Neglecting to consider autism as a lifelong condition results in the failure to address the specific health needs of this population. There are considerable poorer outcomes across all areas of wellbeing, for example; employment, social, psychological, economic, educational, and physical. The Communication difficulties intrinsic to autism are therefore not recognised and further impact negatively on the individual's capacity to clearly state their support and care needs.

A unique feature of autism is that the individual is often unaware of their differences. As we have seen from criticisms towards the deficit based, pathologizing terminology used in diagnostic manuals, these do not align with the reality of lived experience. For the unrecognised Autistic women seeking help and stuck in mental health system, it is unlikely she, or the practitioners she is engaging with will come to the conclusion of autism.

Those women who have been lucky enough to gain recognition in adulthood recall instances of dismissal and disrespect from health care practitioners as a result of uneducated views towards who can, and who can't be autistic. Among other reasons, this disrespectful treatment from within health professions has led to a general mistrust of the healthcare sector. While the overrepresentation of the Autistic population in chronic health issues is not gender specific, remember that gender-ratios in autism-specific reporting point to women as worse off. Autistic women have higher representation in all negative areas as well as gender specific troubles that are influenced by autism. Failure to recognise this provides circumstances for greater harms.

Whether diagnosed or not, Autistic women are likely to have had interactions with some form of psychiatric service. Widespread beliefs that autism is inherently a lack of empathy are conflicting with the statements of Evans-Williams and Williams (2016) that Autistic females exhibit a form of 'hyper-empathy'. Aligning with the thoughts of Tony Attwood (James, 2017b), Autistic women are known to be susceptible to absorbing the distress of those around them. Where these women seeking assistance from providers of welfare and mental healthcare, there is a forced engagement in environments of a distressing nature. Therefore, the contexts in which these supports are situated are of a high likelihood to lead to the downfall of women who are often highly skilled and capable in the right environment,

Looking at the absence of autism research and data collecting in New Zealand, The ODMHAR 2016 reports that there are a number of women still being subjected to ECT. This treatment is seen to be a last resort for those who are failing to 'become well', yet there is no questioning of why this is the case. Poor offerings for explanation state that the higher incidence of women subjected to ECT is accounted for by their higher rates of

mood disorders; apparently excusable by their consistency with internationally reported findings.

I suggest this is again a poor attempt to side-step serious questions around the reasons for women's distress, their unresponsiveness to other forms of treatment, and crucially, the lack of accountability from practitioners who are privileged with a duty of care to these women. As stated in chapter three and acknowledged in the ASD guidelines, those with knowledge in the autism community are aware that there can be instances of contravened treatment within the Autistic population. The New Zealand autism spectrum disorder guidelines also acknowledges the possibility of ineffective treatments, which in females, tends to be pathologized into a 'refusal to become well'.

Offering excuses instead of questioning these phenomenon increases the likelihood of unrecognised Autistic women being forgotten within the mental healthcare system. With autism classified by the New Zealand government as a disability, refusing to acknowledge the existence of Autistic women is automatically debilitating; adding to any existing mental distress, and barring access to appropriate supports. Government funded services catering to Autistic people are unavailable without an officially obtained diagnosis, which is a near impossibility to receive under the current mental healthcare system. Privately funded assessment and diagnostic services come at a high cost, requiring financial means that are often beyond most Autistic people. These women are increasingly psychologically drained on account of the efforts needed to advocate for themselves in a system that does not acknowledge their existence.

It is not uncommon for late diagnosed Autistic women to be estranged from their families, or lack their support and understanding. Throughout this thesis it has been made clear that Autistic women are unlikely to have a strong and supportive social network and are more likely to be bullied and poorly perceived by those around them. Referring again to Stace's (2011) declaration that love, and luck are a requirement for positive outcomes in the Autistic population, I feel that at this stage there is little hope to be had.

In part one and two, there have been references to the fear that people have of their children being taken from them. In these cases, these fears are often unnecessary and could be classed as a form of patriarchal control, with there being no real evidence to suggest poor parenting practice. But the threat is real when combining societal and ill-informed medical views on what constitutes the correct display of femininity. These seemingly trivial matters have the power to be extremely damaging where there is no knowledge or understanding of the presentations of neurodevelopmental conditions. As this this thesis suggests, these women as a minority within a minority, and one at extremely high risk of harm. There is evidence that is unacceptable to ignore, stating that suicide is a leading cause of death in the Autistic population, and that late diagnosed Autistic women are the population most at risk of premature death by suicide (Cassidy & Rodgers, 2017).

The ASD guidelines talk about evidence based best practice, but again, where are the voices of those in the know? I ask how we can claim best practice when the voices of those who are affected are missing from the table. Clinical evidence has been criticised for its limitations; the failure to account for real life, and how real life is where evidence is the most irrefutable.

Part one of this thesis looked at the lived reality of unrecognised autism. It showed that, for me, a lack of understanding of my socio-communicative differences led to physical, sexual, and psychological harms, as well as educational, vocational, and financial disadvantage. Despite a love of learning, a desire to succeed, and always putting in my best efforts, a basic level of education had been out of reach. Subsequently I was only able to gain low-skilled and low-paid employment. As these roles involved heavy and repetitive labour, my body eventually refused to carry on in this manner. The contents of chapter one and two resulted in a life lived under constant and extreme pressure, without ever seeing a way out. The following chapters offered some background into how my experiences came to be as they were.

Although substantial evidence of neurobiological differences came about in the late 1960's it is unfortunate that the recognition of ASD is still carried out under systems

where the assumption is of illness and disorder in need of a cure. It is my thoughts that for at least some of these women, the distress from a lack of self-identity, victim blame, and an unexplained inability to achieve, could all be alleviated with a correct diagnosis. Traits which were stigmatized and pathologized as mental disorder become useful and understandable within the frame of ASD. The switch is from negative assumptions of 'illness' where the individual is forced to recover if they are seeking help, to a place where positive identity building can begin.

CHAPTER SEVEN

FIELD DATA

COMPLICATIONS

At the formative stages of my research application I had hoped to engage with diagnosing practitioners active in government-funded mental healthcare settings. From this I wished to gain an understanding of how Autistic women were perceived in the context of government-funded mental healthcare services. This was not to be, and it was suggested that I instead engage with institutes providing tertiary education to future nurses, social workers, and counsellors. Approval for this research was gained allowing for two participant groups, the first being educators to the professions noted above, or healthcare practitioners from these professions who have extensive experience working in the mental healthcare system in New Zealand. The second group targeted any healthcare practitioners with autism expertise. This research did not attract engagement from either the education or public healthcare sectors, and reasons for this are still unknown. Interest instead came from healthcare practitioners with specialised knowledge of, and experience in working with the Autistic community. My collected data comes from five of these practitioners, through their responses to an online questionnaire and one informal interview.

As a consequence of the difference between my target participants and the ones who engaged with this research, the data I have collected does not align smoothly with the main questions I had originally put forward. This has meant that I was unable to gather any information that directly relates to one of my original sub-questions. The questions my collected data now relates to, and which form the basis for my recommendations are:

- How might misconceptions about the spectrum nature of autism impact on the recognition of high-functioning adult women with this condition?

Sub-questions:

- What categorisation is given to ASD within the New Zealand healthcare system (mental health disorder, neurodevelopmental disorder, or disability), and how might discrepancies in ideas about where this condition 'sits' impact on the possibility of diagnosis for adult-women at the high-functioning end of the autistic spectrum?
- How might past views of women's mental health, and a lack of informed awareness around autism spectrum disorder contribute to difficulties in recognising high-functioning autism spectrum disorder in adult-women who engage with mental health related support services?

The full questionnaires are attached in the appendix section'

Although I did not manage to gain information from the public healthcare or education sectors, I have gathered some evidence suggesting that the under recognition of Autistic females is a serious matter which calls for further investigation. Below I have presented the data as key points that have come from my findings. This chapter contains quotes from the participants, with the style change making for ease of reading after the intensity of previous chapters. There were many important points made which I have included in some places as they were offered.

NAVIGATING THE VARIOUS 'LABELLING' OF ASD AND THE CHALLENGES OF NUMEROUS PERSPECTIVES

In New Zealand autism is classified as a disability but the specific autism services and supports for adults are accessed through mental healthcare services. My findings suggest that this setup is not productive for either the recognition of autism or the provision of support services for Autistic adults who do not have concurrent intellectual disability.

"I agree with Autistic people who dislike autism being seen as a mental health condition. When working with Autistic people who have low IQ, I may refer to

autism as a disability. With clients, there is an understanding that whilst current systems classify autism as a disability to mental health condition, there are actually numerous autism strengths, and the classification reflects an ableist society view.” (Participant A).

Participant A is in the practice of using ‘autism’ or ‘Autistic people’ where possible. While participant A only using ‘autism spectrum disorder’ where making a reference to the DSM-5, participant C. uses the ASD Guidelines as their standardized approach, not the DSM or ICD manuals. It would seem from these participants, there is no ‘person centred framework for working with Autistic people in a way that is influential to wellbeing and focuses on the many autistic strengths.

Participant D. stresses the male domination of literature and research on Autistic people. Furthermore, participant B. notes that Autistic women without intellectual disability are unlikely to be diagnosed correctly, especially where there is no co-existing mental illness, as there is still a prevailing belief that women cannot be autistic...

“Mental Health services under my local DHB refuse to offer diagnosis if there is no accompanying mental illness.” (Participant B)

Participant E. found that the separation between Asperger's and autism was helpful for treatment purposes, but there are a large number of variables that need to be taken into consideration.

“Challenges: reading the research within its context and appreciating that diagnoses may change, for example; autism plus depression (perhaps developed at adolescence). Appreciating that diagnoses may be complex, for example; autism, ADHD, plus/minus intellectual disability etc.... Research always needs to be read within the context of its criteria used for diagnosis.” (Participant E.)

The responses to this question show that there are a number of issues that relate to gender and clinical practice, which seem to be further complicated by the lack of a suitable clinical framework here in New Zealand that is applicable across both the spectrum and lifespan of autism.

WHY ARE AUTISTIC WOMEN REMAINING UNRECOGNISED (LACK OF AWARENESS? SHORTAGE OF RESOURCES? COMMUNICATION DIFFICULTIES?)

The answers to this question show a number of underlying issues in which clinical and gendered issues are tightly interwoven. Participants indicated that overall there is a lack of awareness of female presentation of ASD, influenced by the history of gender-blindness related to autism in females.

It was indicated that a lack of practitioner awareness, limited resources, and communication difficulties were all factors that contribute to the issue of mis(sed)diagnosis of Autistic women. Some of the key points are as follows:

Lack of awareness:

- Lack of awareness of the female presentations of ASD
- Female internalisation appears as mental illness
- General lack of awareness of neurodevelopmental disorders and ASD
- Resemblances to ADHD, PTSD, borderline personality disorder, and attachment disorder
- Practitioners are unaware of the need to assess for neurodevelopmental conditions

Shortage of resources:

- Diagnostic guidelines are based on the characteristics of severely disabled males
- Not enough Autistic practitioners carrying out assessment and diagnostic processes
- Lack of appropriate resources and guidelines
- Time pressures

Communication difficulties:

- Failure of healthcare practitioners to ask the right questions
- Women unable to express themselves due to autistic communication difficulties.

The responses to this question are in line with the literature on the misdiagnosis of Autistic women. Underlying issues relating to gender and clinical practice are tightly interwoven. Similar to the answers from the previous question, autism is thought to be a condition of severity that only affects males.

” Too many colleagues in mental health can't recognise autism when they see it (even in males). If they suspect autism, they are often poorly trained in diagnosis. When the diagnostic guidelines were developed, they drew on research on people who were clearly autistic, which was mostly males (because males tend to externalise problems, so get seen, whilst females tend to be internalisers and overlooked). Furthermore, few researchers actually networked with the Autistic community.” (Participant A.)

The association of autism with mental disorder acts to further hinder the diagnostic processes.

“Unfortunately, Autistic women and girls tend to be diagnosed as having personality disorders instead of autism”. (Participant A).

Participant D. notes that the limited awareness of neurodevelopmental conditions stems from the lack of resources and guidelines in this area. Which then contributes to instances where there is “difficulty with asking the right questions & with clients being able to express their needs”. (Participant E).

These points reiterate what has been shown from the narratives of lived experience as well as the findings of international literature on the topic. It is also apparent that the tendency to consider mental illness and dismiss the possibility of females with autism is present here in New Zealand healthcare practice. BPD, PTSD and attachment disorders all have links to the pathologizing of women, showing the ongoing tendency to presume women as mentally unstable without considering other possibilities.

AUTISM, NEURODEVELOPMENTAL CONDITIONS, AND A RECOVERY APPROACH

Participants were asked for their thoughts on the suitability of a 'recovery approach' to autism, as this is the approach that underpins the delivery of mental healthcare services here in New Zealand.

There were no positive points raised from these responses, which again raises questions about the suitability of the current mental healthcare system to work with Autistic people when the assumption of engagement with these services is of recovery from illness.

Whilst none of my participants work in the government-funded healthcare system, all of their responses were strongly against the idea of autism being connected to a 'recovery approach' which Participant C. summed up by stating that "the very notion of 'recovery' to me, invalidates any practitioners who use that term".

The main points from this are:

- Autism cannot (and does not need to) be 'recovered' from
- Therapies and treatment do not result in 'cure'
- 'Passing' or attempting to 'act normal' is very stressful, causing the appearance of mental illness
- An ableist approach suggesting autism is a problem or disorder
- Reinforces the stigmatisation of difference

Participant E. suggests "neurodevelopmental as a term poorly reflects treatment approaches. It assumes a 'rehab' or 'recovery' model. It does not semantically allow for 'living with and managing' a disorder or problem; 'living with' high functioning Autism is a more helpful framework." It is difficult for this way of thinking to be present in practitioners who are governed by recovery principles. As noted from the previous question around the lack of awareness owing to limited resources, women are automatically assumed to be suffering mental disorder.

Where there is knowledge and awareness of neurodevelopmental conditions, healthcare practitioners have a different perspective on approaches to care and support. Participant

A believes that “the recovery model is an ableist framework, reinforcing the notion that autism is a problem, and that autistic thinking and behaviour is wrong/weak/impaired. Those messages do not help people become strong human beings.” (Participant A.)

As neurodevelopmental conditions are lifelong, there is a conflict in the outcomes expected between those with mental illness and those who are living with lifelong conditions. Participant A. draws attention to the fact that “‘fitting’ in, or ‘passing for normal’ is immensely stressful, and fails to address the most important issue - that we have an ableist society that marginalises Autistic people.”

This shows the difference in understanding of neurodevelopmental conditions by those with expertise in this area and those without specialised training. The following statements are in stark contrast to the ideas which are formed within the context of a recovery approach that considers only short-term illness:

“I don't think of autism as something that can or should be recovered from. Autism is a way of thinking and being. It does not change. Autistic people can often learn strategies that help them fit in better with Neurotypicals, but that does not stop them from being autistic.” (Participant A).

“A what? One does not ‘recover’ from a neurological condition. What a ridiculous notion! One can learn how to ‘work around’ one's own particular issues with the help of others on the spectrum.” (Participant C).

INDICATOR TOOLS (INCLUDING THOSE FOR ASD) AT THE INITIAL SCREENING STAGES OF MENTAL HEALTHCARE PROVISION

Overall my participants expressed concerns about the use of indicator tools for the following reasons:

- Lack of female-specific screening tools
- Most screening tools are only suitable for use on children
- Questionnaires do not consider the context of experience

- Usually designed for males, not for females.
- Indicator questionnaires assume communication skills & engagement.
- Screening tools are contextually bound.
- They do not work well in a cross-cultural context

These points are brought together in the words of Participant A:

“I think that would be good, but my worry is about whether there are good enough screening instruments. My understanding is that screening instruments for autism in the general population are not particularly robust, and I do not know of any female-specific autism screening tools.”

Participant B. queried the possibility of using indicators within current mental healthcare practices, having concerns that echo the main findings throughout this thesis:

“I am not in a mental health service but I would be interested in how an indicator questionnaire would target ASD; as this is not necessarily part of mental healthcare services criteria - they are focused more on Mad and sad who will harm self and others.” (Participant B.)

Furthermore, Participant E. draws attention to the communication difficulties that are intrinsic to autism, suggesting that “language needs to be very considered e.g. literal & concrete interpretations of questions, use of metaphors, idioms etc... may be complex to navigate for some.” Participant E. additionally suggests that; “personally, a face-to -face interview gathers richer data.”

MANDATORY TRAINING IN NEURODEVELOPMENTAL CONDITIONS FOR HEALTHCARE PRACTITIONERS

When investigating ideas around the inclusion of the ASD guidelines and ASD specific education for healthcare practitioners, Participant E. stated that; “Yes-training in ASD should be part of all MH services training programs -There is no reason why ‘clear ‘ diagnoses through to ‘high functioning’ cannot be managed in training programs.”

Whilst the overall theme was that there needs to be ASD-specific education for healthcare practitioners, some showed concerns about the quality of material available for educational purposes, such as the fact that “there is nothing that specifically related to Autistic women and girls in the NZ ASD Guideline.” (Participant A).

My participants all felt that; “Absolutely - ASD should be a part of all training of health professionals as should other disabilities” (Participant B), with participant A insisting that; “There should be mandatory training on autism in all aspects of professional training for mental health, disability, education and legal practitioners.” (Participant A).

The sad reality of the situation as it stands is that; “It is by chance rather than design that Autistic women find their true autistic identity!” (Participant C.)

SPECIALISED KNOWLEDGE DEVELOPMENT

Asking how participants gained and maintained their specialised knowledge in this area showed that at present, this is an area of ‘special interest’. The knowledge these practitioners have gained is not available from mainstream education programs. Some of the ways their knowledge has been obtained are:

- Graduate and postgraduate education
- Attending conferences
- Keeping up to date with current literature
- Networking within the Autistic community
- Practical experience through employment
- Networking and being part of groups with other autism experts
- Reading, reading, reading!!

“There are numerous books being written by people on the spectrum, especially in Australia. Jessica Kingsley Publisher has many books which are very useful to read.” (Participant C.)

'RED FLAG' SYMPTOMS NEEDING REFERRAL TO OTHER SERVICES/ PRACTITIONERS

This question related to instances where clients presented with specific issues that would require referral to other services, for whatever reason. What is of interest from the responses is the total separation of autism from other conditions that are shown in the literature to hide autism from healthcare practitioners without specialised knowledge.

This is shown by Participant A. who states:

“I believe that all professionals should be adequately trained in autism to be able to diagnose and work with Autistic people. All support services should be available to Autistic people. Autism should never be an exclusion criterion (but too often that is exactly what happens).”

Following are some of the main reasons that my participants would refer their clients on to other services:

- Psychosis
- Personality disorder
- Depression and anxiety
- Hormone regulation issues
- Interpersonal relationship issues
- Eating disorders
- Gender identity

Some participants have indicated that they will refer a client on to other services where the client's issues are outside of their expertise. In an example of this, Participant E. “sees high functioning women with ASD as experiencing anything that any person can, so referral is required if helpful for that person to reach their full potential. For example, OCD through to issues with their sibling's acceptance of ASD.” To name but a few of the services that these participants may refer their clients on to are:

- Educational psychologist

- Psychiatrist
- Occupational therapist
- General practitioner

THE ASSOCIATION BETWEEN MENTAL HEALTH SERVICES AND AUTISM DIAGNOSIS AND SUPPORT PROVISION

The responses to this question shed some light on the interconnectivity of factors relating to the mis(sed)diagnosis of Autistic women, as we can see from the following points which are factoring features in most of the issues facing Autistic women:

- mental healthcare services provide poor service to Autistic girls and women
- ASD services are under resourced
- Stigma of mental disorder may stop people seeking assistance
- Focus on mental disorder, not ASD
- The context of ASD is not considered
- Symptoms of ASD are seen as mental disorder
- Autistic women are not taken seriously
- Lack of awareness of neurodevelopmental conditions

The stigma attributed to engagement with mental health services is an underlying matter that hardly needs voicing. This is seen in a different light where Participant B recognises that “ASD is under-provided for. Should it be a part of mental health or whereas mental health labels can be stigmatising / marginalising and thus people may not seek assistance”.

Reiterating the stigma that can be twofold for Autistic women, Participant A. talks of the ways in which Autistic women are treated by mental healthcare services:

“They are misdiagnosed, provided (inappropriately) with medication, expected to engage in therapy that has not been adapted for autism, and blamed when these things fail to make a difference. On top of that, they are taught that they are a

problem, that their views are invalid, and that there is something about themselves that they need to change.”

From my literature review it became clear how these occurrences came about in mainstream mental healthcare practice. Participant E. tells that this is commonplace in mental healthcare practice locally too by noting that; “It's easier for mental health practitioners to see the mental disorder rather than the full picture of ASD as well. Symptoms can be pooled into the mental disorder and not viewed in light of the context of ASD.” Here it is also the case that these women “have a tendency to be labelled with a personality disorder and their ASD to be discounted.” (Participant D.)

AWARENESS OF AUTISTIC WOMEN ACROSS THE HEALTHCARE SYSTEM

Again, the responses to this question act to compound the previous answers. My participants believe that there is generally a very limited awareness of Autistic women amongst the healthcare professions as a whole.

- There is poor awareness of Autistic females
- Autistic women are not taken seriously

Participant E. notes that “clients are often missed as having ASD. The communication elements of ASD are poorly understood”, which has been suggested throughout peer-reviewed literature as a major barrier to accessing an appropriate level of healthcare. While Autistic adults continue to have their concerns dismissed, or are misunderstood, it is likely this population will remain as statistically dominant in negative health outcomes.

A short but sharp quote from Participant C. is telling of the general dismissal of Autistic females in their communications with one psychiatrist: “He laughed at me and said, “only boys have that””.

RECOMMENDATIONS FOR RECOGNISING AUTISTIC WOMEN

At the conclusion of the online questionnaire, I asked the participants to state any recommendations they may have for the improvement of mental healthcare services in relation to the recognition of Autistic women. Here I have directly relayed their suggestions:

1. Train all of your staff in autism in general. Train them in how autism can present differently in women and girls (Participant A.)
2. Always consider autism as a potential co-occurring or alternative diagnosis when considering diagnoses like borderline personality disorder, OCD, eating disorders, and bipolar disorder (Participant A.)
3. Diagnose properly (include/ exclude) and provide follow through to appropriate services, or provide a separate service (Participant B.)
4. Look at the client's history, such as issues growing up, self-awareness (or not) (Participant C.)
5. Establish a good rapport & trust, then the assessment is more likely to be collaboratively managed (Participant E.)
6. Learn about the verbal & non-verbal elements of ASD, as psychology interventions rely heavily on only what is said and what is not (Participant E.)
7. Assess ALL contexts of a person's world. This often reveals the areas of difficulty. For example, they may function extremely well in one setting but be unable to socialise in another (Participant E.)

DISCUSSION

As can be seen from the findings above, the information gathered from my field data links directly to international peer-reviewed literature and the lived experiences of Autistic women which is summarised in chapter six. The lack of support experienced by Autistic women within the current mental healthcare system is exacerbated by the limited knowledge and understanding of neurodevelopmental conditions across the whole healthcare system.

The compatibility of autism assessment, diagnosis and support within mental healthcare services as it stands is brought into question. This is not only for the conflict between the principles of recovery, and autism as a lifelong condition, but also in the stigma associated with 'mental disorder' that engagement with such a system brings.

Mental illness and autism are not the same and addressing autism under the principles of a recovery focused system are evidenced to be causing more harm than good. There is a notable and understandable fear of the connection to mental disorder that is driven by the misdiagnosis, inappropriate and sometimes harmful treatments that are mistakenly given to Autistic women who are engaging with these services. While this is a phenomenon occurring in publicly funded healthcare, there are indications that this is a widespread problem stemming from the initial educating of healthcare practitioners in general, as is shown in a statement from Participant C.;

“Two of our clients consulted the same psychiatrist in a private clinic who did not use a template, consulted a dictionary and declared both 'not autistic', and charged \$400 for the privilege. They were subsequently diagnosed by the University Psychology Centre.”

As is shown from the ways that the participants of this study have gained their expertise, autism is an area where knowledge is obtained outside of the existing and compulsory education offered to healthcare practitioners. This is more so the case when the knowledge is focused on Autistic females.

The mental healthcare system is specifically driven to focus on mental disorder, and under the theoretical framework and principles guiding mental healthcare there is not the consideration for context and disability related difficulties that would indicate the presence of underlying autism. While screening tools and indicator questionnaires may be helpful, there are currently none that are suitable for this population. The second issue with this is that healthcare practitioners would not be considering autism to begin with, as it is not a condition that they are trained to look for. Therefore, these tools are unlikely to

be utilized where circumstances see a need, even if there were appropriately tailored ones available.

Looking at the relationship between women and madness and the contemporary relabelling of neuroticism, such as BPD and anxiety, these are the conditions that Autistic women are most likely to be labelled with.

The issue with this is that there is no place in the healthcare professions that considers an unrecognized and invisible disability in the adult population. With the paediatric population still holding most of the focus, practitioners would not be considering an undiagnosed neurodevelopmental condition in adults. And again, this raises the question of the suitability of mental healthcare services for addressing these issues.

The main body of this thesis has provided greater detail into how harmful these misunderstandings can be for Autistic women and how such misunderstandings can lead to their lack of familial, social, and professional supports.

While these women have a better chance of recognition in the private healthcare sector, this is not always a given, and there is a high financial cost related to private healthcare. The longer women remain unrecognized the more likely they are to have a collection of diagnoses of mental disorder. These labels can have the harmful effects of stigmatization and on further seeking assistance these women are judged on account of these incorrect labels. In turn this can influence the possibility that future practitioners engaged in their care will dismiss their concerns as being attributable to their 'mental disorder' which in reality they are unlikely to have.

Participant responses have provided a troubling local picture of what Autistic women can experience when attempting to engage with healthcare services in the hope of resolving the difficulties they face. Giuliani (2018) soberingly states that in light of the positive relationship between ASD and suicide, the best outcome for adults who live with unrecognised ASD is that they will seek help. Yet my findings declare this a near fruitless task, with a very limited knowledge of the complexities of autism across the healthcare professions.

INTERVIEW

After the initial data collection period, I was able to obtain one face-to-face interview with Participant E. This was an informal interview with the intention of gaining a localised, clinical perspective using the Social Model as the lens of observation. In my literature review I had come across clinical accounts that relay the narrative of lived experience from Autistic women, but here in New Zealand this information is very difficult to obtain. The interview verified the overall themes that come from part one of this thesis.

What I was interested in is how the sometimes-ill-matching ways that Autistic people are viewed in different circumstances and environments can, from an early age, aid mis(sed)diagnosis. The transcription from my interview offers insight into how, at different life-stages, there are indicators of autism that, for any number of reasons I have foretold previously, tend to be missed. I reiterate that my findings are suggestive of Autistic females who do not have concurrent intellectual disability.

From early on there is a tendency for the concerns of parents to be brushed off if their child is not drawing attention to themselves in learning environment.

“A lot of the experiences have been that the child is fantastic at school, but they have complete meltdowns at home. I think that again, they are just keeping it together, because they think “I've got to keep it together coz it's school, and this is what you gotta do at school”, and that's just a release mechanism of all the stress that built up when they get home.”

For many unrecognised Autistic females there is an overwhelming feeling that we must fit in, conform, and appear to be the same as everyone else. The findings from my field data attest to the psychological stress of keeping up these pretences, resulting in the aforementioned meltdowns when in the safety of one's own home.

“And then, the poor parents are just told that they need to be better parents really, or “have you tried the incredible years?”. They are just not getting heard. I find that, especially with young girls, they tend to be diagnosed later than boys”.

There is also mention in my findings of the internalisation of problems by females, which leads to their relative invisibility in an educational context. For mothers who ask for help and are struggling to understand what is happening for their child, they are potentially viewed as neurotic in light of the way their child behaves outside of the home.

“So, talking about whānau, you know it's not unusual for mothers to be particularly stressed; exhausted and stressed. And I believe that it's not just about whānau support, I believe there needs to be a lot more external resources and support.”

Where there has been no prior addressing of the Autistic persons difficulties, moving into adolescence, the problems only become worse, sometimes spiralling out of control.

“So, for some, they needed a mentor. Some young people got so overwhelmed, especially if they were disorganised. From the disorganised side of things, they just don't know where to start; everything is just too much and they can't even start their day. They're just sitting there, they're just overwhelmed, because everything is a mess.”

Remembering the invisibility of autism and the presence of average or above intelligence, it becomes probable that others have, or will begin to lose patience with the seeming laziness of the Autistic person. Sometimes bullying is the consequence of misunderstanding and frustration at the Autistic person for their inability to carry out the simplest of tasks.

“The presentation is of high intelligence. They are highly intelligent but there is incongruence. And that's probably quite hard for some people to comprehend; why should that be if you are an academic or if you've got a degree or whatever. Like, why are you struggling to catch a bus?”

The incompatibility between the Autistic person's apparent capabilities and their actual functioning is evident from early on. The frustrations arising from these and strengthened along the way from the absence of explanation to these issues can instigate irreparable conflict for family and other interpersonal relationships. This all subsequently leading to

difficulties in forming trusting and supportive networks, which then opens up the potential for any or all of the undesirable outcomes that are discussed in this thesis.

“I think it's the lack of whānau support. I think that because the diagnosis is often much later for women, in my experience, it's too little too late. The dynamics in that relationship are so set, and it's so far antagonistic between, say for example the mother and the daughter, or the parents and the daughter that they need outside help. I find that the women don't want the help from parents usually. The relationships are broken down too much really. They are feeling let down; the Autistic person feels let down by their parents.”

Without social, familial, or professional support, the stress of enacting normality becomes even greater. This is a vicious cycle that really does at this stage come down to luck for the possibility of positive outcomes.

“A lot of women, especially the ones I see in their sixties or seventies, they've got it very well masked. You know it's been only over years and years that they've just kept developing more and more skills in how to copy and how to imitate, to learn how to fit into society. Often what happens is that these women do have, and I'll put in inverted commas 'a breakdown' because the stress levels have just become too much, given they're trying to keep up appearances all the time, it's just too much”.

RECOMMENDATIONS

RESEARCH AND REPORTING

While there is questionability of the capacity of mental healthcare services to correctly diagnoses and support Autistic women, there are deeper issues. The fixation on mental disorder in women is ongoing and will continue to be so when there is no authoritative

questioning of this. It is continued by the research and reporting that employs previous notions of women as mentally disordered. In light of my findings

1. I suggest there instead there needs to be a reconsideration of how we look at women's distress, starting with research and stringent reporting guidelines from within the New Zealand context.
2. The carrying out of research into autism across the spectrum of gender and lifespan to gauge the specific needs of the Autistic population in the New Zealand context. As a multi-cultural nation there is a need to address the cultural diversity of how neurodevelopmental conditions present and are supported.

Furthermore, a reframing of mental healthcare perspectives on women and mental distress, could lead to an overall improvement in the holistic wellbeing of both Autistic and Neurotypical women.

EDUCATION

There is an urgent need to set up autism specific departments within all DHBs that are exclusively for the recognition of neurodevelopmental conditions by appropriately trained practitioners. Which leads to my second recommendation addressing the deeper issue.

Without the adequate education in neurodevelopmental conditions by all healthcare practitioners and those working in healthcare support roles, it is still unlikely that mainstream pathways and referrals will be able to address the issue of mis(sed)diagnosis, as there is not the knowledge of neurodevelopmental conditions within the existing healthcare workforce. Following are some suggestions:

1. An investigation into and enforcement of implementation of the ASD Guideline within all professions who may come into contact with Autistic people. By this I am referring to the specific professions that are already noted by the ASD guidelines as needing to be alert to how the Autistic population can be of a higher vulnerability to misunderstandings, leading to mental health or judicial interventions.

2. A review of the current guidelines with an emphasis on autism across the lifespan, and crucially, greater attention to the gendered differences in presentation across the lifespan.

A reconsideration of the undergraduate education that is undertaken by all healthcare practitioners in the recognition and support of people with neurodevelopmental conditions. This training should follow autistic presentations across the spectrum, and include factors affected by gender and life-stage.

Where practitioners are all suitably trained it may then be possible for autism to be situated under mental healthcare services. This would require a restructure of the entire healthcare and funding framework, and a complex investigation into the support and care needs of people with lifelong conditions and those with what are considered to be short-term mental illness.

CONCLUSION

This study has not only raised questions around the way women are perceived in relation to autism and more generally, mental health, but how deeper investigation into this topic holds potential for the improvement of wellbeing across many other populations who are portrayed negatively in statistical reporting. Sporadic mention of familial mental distress in relatives of those diagnosed with autism could also be an important factor concerning mis(ed)diagnosis. The New Zealand reports recognise the occurrence of intergenerational patterns of mental distress and the wider impact this has on education, employment, and social isolation which can lead on to addiction issues, violence and crime, or even suicide. Autism is known to be tied closely to genetics, and as has been shown in previous chapters it is also tied to the negative outcomes seen in those suffering mental distress as outlined in the government commissioned reports.

With an absence of research and reporting into autism here in New Zealand, my study has shown that there are a substantial number of connections between the outcomes for those suffering mental distress, and the Autistic population. While autism remains outside

the focus of localised investigation, I believe we will continue to see these same issues repeatedly. I believe that a reconsideration of the way's women are perceived within the healthcare professions in relation to mental illness, and their absence from autism research would be a good starting point.

Being limited by a small word count in the scope of this research, I hope that my work will contribute to the body of work showing that this is a matter of grave importance, and that by considering the concerns raised in this thesis, that our healthcare system may be changed for the better.

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Appendices

Appendix A

The University of Waikato
Private Bag 3106
Gate 1, Knighton Road
Hamilton, New Zealand

Human Research Ethics Committee
Karsten Zegwaard
Telephone: +64 7 838 4802
Email: humanethics@waikato.ac.nz



18-12-2018

Kyle Hefferon
kah@hotmail.co.nz

Dear Kyle

UoW HREC(Health)2018#77: Recognising adult women with high-functioning autism spectrum disorder: A minority within a minority

Thank you for submitting your amended application HREC(Health)2018#77 for ethical approval.

We are now pleased to provide formal approval for your project within the parameters outlined within your application.

Please contact the committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you all the best with your research.

Regards,



Karsten Zegwaard PhD
Acting Chairperson
University of Waikato Human Research Ethics Committee

Appendix B

Te Oranga: School of Human Development
and Movement Studies
The University of Waikato
Private Bag 3105
Hamilton, New Zealand
www.waikato.ac.nz



4 February 2019

To Whom It May Concern,

I am currently working on a four-paper thesis towards a Master of Disability and Inclusion Studies at the University of Waikato.

I am seeking health-care practitioners and educators from the fields of counselling, nursing, and social work who have experience within the mental-health sector to participate in my research. I also seek participants from any health-care profession who have specialised knowledge relating to autism.

The title of my thesis is:

Recognising adult women with high-functioning autism spectrum disorder: a minority within a minority.

Main question:

- How might misconceptions about the spectrum nature of autism impact on the recognition of high-functioning adult women with this condition?

Sub-questions:

- What categorisation is given to ASD within the New Zealand health-care system (mental-health disorder, neurodevelopmental disorder, or disability), and how might discrepancies in ideas about where this condition 'sits' impact on the possibility of diagnosis for adult-women at the high-functioning end of the autistic spectrum?
- How do health-care practitioners who interact with this group of women navigate the interface between mental-health and disability services when referring to ASD-related Ministry of Health or other related professional guidelines in the assistance of these women?
- How might past views of women's mental-health, and a lack of informed awareness around autism spectrum disorder contribute to difficulties in

recognising high-functioning autism spectrum disorder in adult-women who engage with mental health related support services?

Attached to this email is an information sheet providing the requirements of recruitment, participation and granting of informed consent.

Please also forward this email on to anyone you believe may be interested in participating in this research.

Yours sincerely,
Kyle Hefferon

Mobile: +64 272535250

Email: kah36@students.waikato.ac.nz

Appendix C

PARTICIPANT INFORMATION SHEET	
Study title:	Recognising adult women with high-functioning autism spectrum disorder: a minority within a minority
Ethics committee ref.:	2018#77
Lead investigator:	Kyle Hefferon
Email:	kah36@students.waikato.ac.nz

You are invited to take part in this research which focuses on the positioning of autism spectrum disorder (ASD) within health-care professions, and how women are currently perceived in relation to the diagnosis of high-functioning autism spectrum disorder (HFASD) within the context of the New Zealand health-care system.

This Participant Information Sheet will help you decide if you would like to take part. It sets out the purpose of the study, and what your participation would involve.

If you agree to take part in this research, you will be required to indicate your informed consent at the beginning of the online questionnaire.

This document is five pages long. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this small study is to present information on the positioning of ASD within health-care professions, and how women are currently perceived in relation to the diagnosis of HFASD within the context of the New Zealand health-care system. It will also offer some key points for consideration within the health-care professions from health-care practitioners with expertise in this area.

The topic arises from contemporary re-considerations of traditional assumptions regarding women and mental-health, particularly how these assumptions may contribute to the mis(sed)diagnosis of women at the high-functioning end of the autistic spectrum. Emerging research indicates a troubling incidence of women having previously been misdiagnosed as mentally unwell, leading to an inability to access effective support.

While there is limited peer-reviewed literature on this topic, anecdotal evidence suggests that health-care practitioners across a range of services are meeting women who may have undiagnosed HFASD in their roles as practitioners and support people. How these interactions are handled, and how the possibility of undiagnosed HFASD are explored are matters requiring further investigation. It is hoped that the outcomes of this small

research project will lead to the development of a larger survey of health-care practitioners, providing data to inform the development of future policy and practice.

There is a possibility that the findings of this research, aside from thesis publication, may be used in conference papers, or published in academic and professional journals.

This study is a requirement of a 120-point thesis towards a Master of Disability and Inclusion Studies from the University of Waikato.

Ethical approval for this study was granted from the University of Waikato Human Research Ethics Committee on 18th December 2018.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

Requirements of participation:

You will be required to complete an online-questionnaire which is centred on the three sub-questions for this study:

- What categorisation is given to ASD within the New Zealand health-care system (mental-health disorder, neurodevelopmental disorder, or disability), and how might discrepancies in ideas about where this condition ‘sits’ impact on the possibility of diagnosis for adult-women at the high-functioning end of the autistic spectrum?
- How do health-care practitioners who interact with this group of women navigate the interface between mental-health and disability services when referring to ASD-related Ministry of Health or other professional guidelines in the assistance of these women?
- How might past views of women’s mental-health, and a lack of informed awareness around autism spectrum disorder contribute to difficulties in recognising high-functioning autism spectrum disorder in adult-women who engage with mental health related support services?

WHAT ARE MY RIGHTS?

- Participation is voluntary, you are free to decline participation, or to withdraw* from the research at any practicable time, without experiencing any disadvantage.
- This research is carried out in accordance with the Ethical Conduct in Human Research and Related Activities Regulations 2019 which are available for viewing on the [university website](#).
- You have the right to access information collected from you as part of the study*
- All collected digital data will be stored on a password protected computer.

- Paper copies of any data will be stored in a locked cabinet at the University of Waikato.
- No identifying information, such as names or workplaces, will be included in the reporting of data that has been collected from you.

*As data from the online-questionnaire is collected anonymously, you will only be able to gain access to, or withdraw contributions that can be recognised by the researcher through your inclusion of identifiable information in the first section of the questionnaire.

WHAT ARE THE TIMEFRAMES FOR PARTICIPATION?

Informed consent and submission of contribution

If you fully meet the recruitment criteria for either Participant Group One or Participant Group Two and wish to contribute to this study, the deadline for completion of the online-questionnaire is Monday 4th March 2019. You will be required to indicate your informed consent at the beginning of the online-questionnaire.

Interview arrangements

On completion of the online-questionnaire you are offered the opportunity to meet with the researcher should you wish to contribute additional information to this study. In this instance you will be required to sign the Consent Form on the last page of this document and return to the email-address listed on page one of this document.

You will have until Monday 4th March 2019 to initiate contact for the arrangement of suitable methods and times.

The final date for the commencement of meetings is Friday 22nd March 2019.

Withdrawal of contribution

Should you choose to withdraw your contribution to this study, you will then have until Monday 11th March 2019 for the online-questionnaire. As information for the online-questionnaire is collected anonymously, you will only be able to gain access to, or withdraw your contribution if it can be recognised by the researcher through your inclusion of identifiable information.

For withdrawal of contribution by meeting, you will have one calendar week from the date of your meeting.

RECRUITMENT CRITERIA

There are two sets of recruitment criteria. In order for you to participate in this study you must fully meet the criteria of at least one group. Please read the recruitment criteria for both groups to help you decide which **one** set of criteria you may participate under.

Recruitment criteria Participant Group One:

- Background including practice experience in nursing, social work, or counselling.
- Currently (or within the last five years) employed by a New Zealand tertiary institute and involved with the development and/or implementation of curriculum directed at future health-care professionals in nursing, social work, and/or counselling.

Or:

- Background including practice experience in nursing, social work, or counselling.
- Extensive experience of employment within the public mental-health system in New Zealand (currently or within the last five years).

[Link to Participant Group One questionnaire](#)

Recruitment criteria Participant Group Two:

- Have expertise in the recognition and diagnosis of women at the high-functioning end of the autistic spectrum.
- Have worked in New Zealand as a health-care practitioner or in an advisory role in relation to autism or have current understanding of the New Zealand health-care system.

[Link to Participant Group Two questionnaire](#)

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, please contact:

Dr. Carol Hamilton – academic supervisor

+64 21415678

carol.hamilton@waikato.ac.nz

CONSENT FORM

Please indicate you consent to the following:

I have read, and I understand the Participant Information Sheet.

I am satisfied with the information I have been given regarding this study, and I have a copy of this consent form and information sheet.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time.

I consent to the research staff collecting and processing data that I have provided to them for the purpose of this study.

If I decide to withdraw from the study, I understand the set deadlines for which the data collected from me may be included in the research (from meetings or questionnaire data that can be identified as your contribution).

I understand that my participation in this study is confidential and that no material which could identify me personally, will be used in this study.

I know who to contact if I have any questions about the study in general.

I understand my responsibilities as a study participant.

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Participant group:

Signature:

Date:

Appendix D

Questionnaire Participant Group 1

I have read, and I understand the Participant Information Sheet

I am satisfied with the information I have been given regarding this study, and I have a copy of this consent form and information sheet

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time

I consent to the research staff collecting and processing data that I have provided to them for the purpose of this study

If I decide to withdraw from the study, I understand the set deadlines for which the data collected from me may be included in the research (from meetings or questionnaire data that can be identified as your contribution)

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in this study

I know who to contact if I have any questions about the study in general

I understand my responsibilities as a study participant

Headings are indicative of the over-arching theme for the following questions

What categorisation is given to ASD within the New Zealand health system – eg: mental health condition, developmental disorder, disability - and how might discrepancies in ideas about where this condition ‘sits’ impact the possibility of diagnosis for women at the high-functioning end of the autistic spectrum?

Where does ASD ‘sit’ within your profession (mental health, disability, or something else?), does this fit with the concept of autism as a spectrum?

What could be some of the reasons for women being misdiagnosed or undetected at the high-functioning end of the spectrum? Main barriers for these women in accessing correct diagnosis and effective support?

What are your thoughts on individuals with neurodevelopmental conditions being treated using a recovery approach? (How does this work? Positives and negatives? Areas of improvement?)

What are your thoughts on the use of indicator questionnaires (including those for ASD) at the screening process for women entering mental-health services?

How do health practitioners who interact with this group of women navigate the interface between mental health and disability services when referring to ASD related Ministry of Health guidelines in the assistance of these women?

Are documents or guidelines with reference to ASD incorporated into training programmes? (How detailed/specific are these? At what level of education are these documents incorporated?)

What autism-related training have you undertaken, such as the recognition of symptoms, or specialised aspects of client treatment? (Professional, postgraduate, informal, part of undergraduate study? Other ways you may have gained autism knowledge?)

What has influenced the development of your professional perspectives in relation to women and the issues they present with (training, personal experience, professional experience, cultural understandings, other)?

What are some 'red flag' symptoms you would see as needing referral to other/specialised services, and what services would these be?

How might past views of women and mental health contribute to difficulties in the recognition of HFASD in women who engage with mental health related support services?

When considering the possibility of high-functioning ASD in women's mental health, what processes or guidelines are in place for health practitioners in your field?

What are your thoughts on the awareness of ASD and the presentations of adult women within the mental health system or even across the health system as a whole?

When assessing women seeking mental health support, do you take into consideration their strengths/ability comparative to their challenges and the ways this could be impacting their mental health?

What consideration is given to previous engagement with mental health services (and other services?) for adult women expressing an extensive history of unsuccessful outcomes?

Appendix E

Questionnaire Participant Group 2

I have read, and I understand the Participant Information Sheet.

I am satisfied with the information I have been given regarding this study, and I have a copy of this consent form and information sheet.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time.

I consent to the research staff collecting and processing data that I have provided to them for the purpose of this study.

If I decide to withdraw from the study, I understand the set deadlines for which the data collected from me may be included in the research (from meetings or questionnaire data that can be identified as your contribution).

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in this study.

I know who to contact if I have any questions about the study in general.

I understand my responsibilities as a study participant.

How did you come to be working in this field?

Headings are indicative of the over-arching theme for the following questions.

What categorisation is given to ASD within the New Zealand health system – eg: mental health condition, developmental disorder, disability - and how might discrepancies in ideas about where this condition 'sits' impact the possibility of diagnosis for women at the high-functioning end of the autistic spectrum?

For the purpose of research and consultation; how do you navigate the multiple categorisations of ASD in the context of internationally published literature, and what are some of the challenges of multiple perspectives?

What could be some of the reasons for women being misdiagnosed or undetected at the high-functioning end of the spectrum? Main barriers for these women in accessing correct diagnosis and effective support?

What are your thoughts on individuals with neurodevelopmental conditions being treated using a 'recovery approach'? (How does this work? Positives and negatives? Areas of improvement?)

What are your thoughts on the use of indicator questionnaires (including those for ASD indicators) at the screening process for women entering mental-health services? (Positives and negatives?)

How do health practitioners who interact with this group of women navigate the interface between mental health and disability services when referring to ASD related Ministry of Health guidelines in the assistance of these women?

Should there be documents or guidelines with reference to ASD that are mandatory for training programs? How detailed/specific should these be for health practitioners across professions requiring professional registration?

How have you developed your specialised knowledge of ASD (research, personal, professional, postgraduate, informal, part of undergraduate study)? Other ways you have gained knowledge?

What are some 'red flag' symptoms that you would consider as needing referral to other/specialised services, and what services would these be?

How might past views of women and mental health contribute to difficulties in the recognition of HFASD in women who engage with mental health related support services?

What are your thoughts on the association between mental-health services and ASD diagnosis/ ongoing support? (Positives and negatives?)

What are your thoughts on the awareness of ASD and its presentations in adult women within the mental-health system or even across the health-care system as a whole?

What are three key points would you recommend to mental health services for recognising undiagnosed ASD in adult women?