

Becoming Autistic: How do Late Diagnosed Autistic People
Assigned Female at Birth Understand, Discuss and Create their
Gender Identity through the Discourses of Autism?

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Abstract

The overarching concern of this thesis is discovering what it is that *autism does to gender*. This thesis argues that autism has come to constitute a form of gender trouble. Thus, the central question is how people assigned female at birth who have been formally diagnosed with autism as adults understand their gendered identity pre and post diagnosis. This thesis ascertains whether the diagnosis of autism holds any significance in how autistic individuals understand, think about and produce their gender. This thesis is interested in how an autistic identity is negotiated and how an autistic subjectivity emerges. It takes as its central proposition that autism is a masculinised diagnostic category and one which is produced and knowable through a masculinised discourse. Furthermore, autism is categorised as a neurodevelopmental disorder, thus, it becomes attached to the self or the 'I' of the person diagnosed through contemporary understandings of neurology and the self. This thesis determines if the gender trouble that is seemingly bound to autism plays out in the identity formation of those diagnosed and whether the diagnosis has any bearing on how they understand their gendered identity. Eight people assigned female at birth who reside in the United Kingdom and who have been diagnosed as autistic by services in the National Health Service at eighteen years old or over have been interviewed for this thesis.

The purpose of speaking with this particular group of individuals is to understand whether autism becomes a lens through which identity is constructed and whether this identity becomes framed by, or is resistant to, the gendered discourses which produce autism. And, indeed, whether these discourses which are so commented upon in the academic literature and popular discourse alike actually have any bearing on how individuals come to understand themselves as autistic subjects. Thus, this mode of investigation pays specific attention to how one *becomes* autistic; which resources and knowledges are drawn upon to understand the self and whether these are used to create an understanding of the self-post diagnosis.

Abbreviations

AFAB- Assigned female at birth

AMAB- Assigned male at birth

ASC- Autism spectrum condition

ASD- Autism spectrum disorder

BPD- Borderline personality disorder

DSM- Diagnostic Statistical Manual

ICD- International Classification of Diseases

Chapter One

Introduction

1.1 Research objectives

In this thesis I ask: *what does autism do to gender?* Much of the preceding work examining the connections between autism and gender has asked: *'what does gender do to autism'*. This latter question has in mind the overrepresentation of boys and men with autism, the presumed predisposition of autistic people to enjoy 'masculinised' pursuits such as maths and science over more 'feminised' interests, and the perceived autistic lack of sociality and appropriate empathic responses which are positioned as being on a spectrum with normative male skills and deficits. This observed phenomena of a connection between maleness and autism has been an entry point for understanding what autism is, where it can be found in the brain and what causes the condition (Baron-Cohen, 2002, 2010, 2018, Cahill, 2017). By asking the question from another direction I am positioning autism as less an ontological category which is biologically bound to gender but as a discursive construction which is understood and produced through normative gender assumptions. As such, this thesis explores what happens to gender when a person who was assigned female at birth (AFAB) receives a diagnosis in adulthood when autism is seemingly so closely tied to maleness and masculinity. This thesis will examine if- and how- the gendered discourses which 'make up' autism are interpreted, embodied and resisted by autistic AFAB individuals.

Autism circles around gender on multiple levels: from disputes over the accuracy of the gender ratio in autism diagnosis, to the ways in which autism is culturally portrayed and, consequently, discursively known as masculine, to the recent research into the over representation of autistic people accessing gender clinics (Murray, 2008, Jack, 2011, Nobili, et al., 2018, Loomes, et al., 2017, Mandy, et al., 2017).

In many ways, autism has come to constitute a form of gender trouble. Autism is considered to be a

neurodevelopmental condition and through this neurobiological understanding the possibility for finding some truth about the difference between the sexes has been explored. This has been discussed most explicitly through Simon Baron-Cohen's (2002, 2010, 2018) 'extreme male brain' hypothesis. Baron-Cohen's theory is perhaps the most well-known example of how normative gender ideals are mobilised as a complementary binary to hypothesise on autism's connection to gender. By positioning autism on an existing spectrum of essentialised gender categories from hyper feminine to hyper masculine Baron-Cohen is able to assert that autism functions as a 'extreme maleness'. Autism has been mobilised as a mirror for the normal for some time, as a condition it holds a strange place and one that is distinct from other neurodevelopmental conditions as it has been positioned as having access to the limits and potentials of the human being (Goodley in Timimi et al., 2016, Hacking, 2009). I argue, as others have, that currently autism is being mobilised as somehow having access to what gender and sex difference is and, in this way, autism has become a 'pathology of gender' (Gillis-Buck and Richardson, 2016).

That medical conditions are positioned as having access to the normal is nothing new, as Georges Canguilhem (2015) wrote in 1966: 'The identity of the normal and the pathological is asserted as a gain in knowledge of the normal' (p.43). Indeed, researchers have asked what is at stake for understandings of gender and our gendered regimes when autism is used as magnifying glass to better understand 'normal' or rather, normative, sex and gender differences (Gillis-Buck and Richardson, 2014, Jack, 2014, Jack, 2011). Where this thesis steps into this research is by thinking about these gendered understandings of autism as dominant discourses which function on the level of text but have material effects with regards to autistic people's experiences. In doing so, I position a diagnosis of autism in adulthood as a distinct moment – as a tentative discursive event- which brings into being an autistic subjectivity.

As will be shown throughout this thesis, the various connections of autism to gender cannot be fully explored without interrogating what happens to the individuals who are diagnosed with this already gendered neurological condition. When I began this project, I assumed that the masculinised discursive construction of autism would enforce AFAB individuals to enact this version of autism in order to receive a diagnosis, or, to legitimise to themselves and to others that they were, indeed, autistic. Furthermore, I considered that the diagnosis would produce a certain gendered unsurety in the participants. Autistic narratives such as those by Yergeau (2018) and James (2017) discuss how an autism diagnosis leads one to consider their brain as the sole controlling force of all aspects of their behaviour, their desires, their hopes, their fears and so on. It is as though the autistic person were simply a brain in a jar secluded from outside influence, exempt from neural plasticity and not impacted by the social, '[...] reducing being, body, selfhood, rationality, intentionality, rhetoricity, and symbolism to the domain of spatialised brains' (Yergeau, p.51). Consequently, I wondered how the gendered brain of autism would be related to after diagnosis by the participants; would it be as though a 'male brain' had been transplanted within them?

What I found through my conversations with the participants of this study was far more nuanced and spoke to wider concerns than what certain autism scientists, popular discourses, and lay people say about autism and its connection to gender. Specifically, the interviews presented a view onto the gendered regimes which affect us all, but which become clearer and more intensely felt by those who already do not fit into the ableist parameters of normativity. They demonstrate how gendered normativity is inextricable from the ableist structuring of legible subjectivities, whereby those with neurological differences (or other disabilities) are always-already gender deviants. In this sense, neurological difference functions as a 'neurological queerness' as Yergeau (2018) suggests. Consequently, for several of the participants after years of attempting to 'fit' into these gendered parameters the diagnosis did not produce a sense of gendered unsurety but, rather, a sense of gendered emancipation. The diagnosis was a distinct moment when those who had struggled to enact

gender in a normative sense were able to make sense of why they had never quite succeeded at this and to begin to be gendered differently. Thus, what came to the fore in the interviews was a sense that the autism diagnosis functioned as a 'coming out' to be gendered otherwise; to queer gendered expectations with impunity with a diagnosis of autism legitimising this. For those who did not consider the diagnosis in this way it still enabled a consideration of gender, if only by becoming aware of the gendered discussions that circulate around autism.

This enabled this research to depart from causal- or circular- relationships between autism and gender (i.e. crudely speaking, is autism the result of prenatal androgens? Does autism's connection to maths and science prove this? Does this account for the gender disparity in diagnosis? Are AFAB individuals more masculinised as a result of being autistic?) and instead allowed for a position whereby gender and autism have a co-constituent, or emergent, relationship. Importantly, whilst a certain 'freedom' from normative gendered modes of embodiment was anticipated or enacted by some of the participants through the diagnosis they were still beholden to their prior interpolations. Thus, this thesis highlights the temporal and relational aspects of 'coming out' as autistic. Or, to put it another way: it demonstrates the repetitive and reiterative nature of becoming autistic *and* of doing gender.

I came to this area of research from both an academic and a professional route. I had just finished a Bachelor's degree in Cultural Studies, and I had started working with young people who had recently left the care system. I was keen to keep my Cultural Studies way of thinking alive, so I was quietly analysing the bureaucratised system of care I now worked in, hoping I could put some of my University learnt skills to use. One of the young women I worked with received an autism diagnosis in place of a diagnosis of Borderline Personality Disorder (BPD) and after the autism diagnosis I saw how differently her behaviours and her vulnerability was viewed. She went from being viewed as troublesome and troubled to vulnerable, innocent and naïve. Though, of course, nothing about her behaviour and way of being had changed, the only difference was her BPD diagnosis became autism. At the time I had

vague knowledge of a connection between autism and masculinity, and of BPD and hysterical femininity (Appignanesi, 2008). However, this period during my employment really sparked an interest that would carry me through to the completion of this thesis. I wanted to know how the gendered formations of diagnoses interact with a person's sense of selfhood. In particular, I wanted to find out whether a diagnosis gained in adulthood enforces a new understanding of the gendered self in relation to the discourses that frame the diagnosis.

Consequently, as mentioned above, this thesis tentatively situates the diagnosis of autism as a discursive event in order to understand if, and how, a diagnosis in adulthood engenders a reconsideration of the gendered self through the new interpolation of autism. Thus, the approach of the analysis is one of *becoming*: what are the ways that one becomes autistic? How are the social, cultural and political modes through which autism has a reality mobilised by autistic individuals after diagnosis? This study is consequently an analysis of the gendered assemblages, that bring autisms reality into being and how these knowledges are enacted or resisted by those who are diagnosed. Taking into account the gendered regimes which affect us all, I argue that autism must be understood as constructed through these discourses. This makes the study of autism necessarily a feminist issue. Thus, this thesis will enter into a dialogue with feminist theory, critical disability studies and post structuralist social thought.

To conduct this research, I recruited eight people who were assigned female at birth (AFAB). Each participant was diagnosed at eighteen or over with what would have been called Asperger's Syndrome or high functioning autism prior to the shift to the umbrella diagnosis 'autistic spectrum disorder'. Semi structured interviews were conducted which ascertained information about the person's life course pre and post diagnosis. These were then analysed to determine how AFAB people experienced their

gendered embodiment pre diagnosis and whether the diagnosis had an effect on their understanding of their gendered identities.¹

The research questions which guide this project are as follows:

- 1) Does the diagnostic category of autism act as a discursive event and a gendered technology of power for late diagnosed autistic people?
- 2) How do autistic people assigned female at birth produce a sense of the autistic self through the existing discourses of autism?

I argue that understanding how autistic individuals relate to the diagnosis of autism has not played a role in much, if any, autism research. The scant qualitative research of autistic people's experience does not interrogate the diagnosis of autism and takes it as a pre discursive fact, whereby the diagnosis simply gives access to an authentic autistic self (for examples of qualitative research see: Kanfisz, et al., 2017, Kourti, et al., 2019, Webster and Garvis, 2017). As noted, much of the recent research into autism and gender has been conducted around the gender ratio in diagnosis which cites a higher rate of assigned male at birth individuals (AMAB) (Gould, 2017, Baron-Cohen, 2010). This latter area of

¹ I have chosen to only include people who were assigned female at birth due to the time and length constraints of this thesis. I acknowledge that autism's gender trouble may also affect AMAB individuals and this will be followed up in my forthcoming Ph.D research at the University of Bergen, Norway. AFAB refers to the sex that the medical team gave to a baby shortly after birth. This sex categorisation goes on to become the way that gender sticks to, and shapes, the body. The sexing of the body comes to bear on how a person understands themselves, how others understand them and even shapes the biology of the body as Anne Fausto-Sterling has noted (2012). I find this a useful mode of thinking as it incites an immediate demand to rethink our conception of biological sex being correlative with the gendered formations which work through the categories of 'man' and 'woman'. This terminology was not something I was aware of prior to a symposium where I gave a paper about my research. I was advised by a fellow presenter that it is important to know what sex/gender an individual has then AFAB and assigned male at birth (AMAB) are the preferable terms. This not only provides a conceptual interjection but this language sides with transgender and non-binary activism which seeks to remove the genitals as being the regulatory force which determines gender identification. Only one participant in this study doesn't identify with the sex assigned to them at birth. I considered simply omitting their data because I didn't want to erase their identity and position them as a woman. However, given their experiences of being read and interacted with as a girl in childhood I decided that their story was important to hear in the context of this research. Moreover, when I delved into my interviews it became less clear that the people that I interviewed had a strong connection to their sex and its correlation with their gender. Thus, using this terminology allows us to destabilise the notion of a 'common sense' biological determinism.

autism research positions sex/gender difference as an ontological fact of the individual and seeks to determine if sex/gender is the cause of higher rates of diagnosis in AMAB people.² Consequently, this research asks the question; what does gender do to autism? As I have argued here, an important avenue of research that needs to be taken up is understanding how these gendered discourses of autism affect those who are diagnosed. This thesis is examining if autism functions as a diagnostic event and through this naming consequently makes intelligible a temporally and spatially shifting set of distinct bodily and psychological manifestations and effects. Therefore, concepts and names, and how people come to construct their selfhood through these categories, are integral to the thesis. As such, it is now important to provide an exegesis of the language which will be used going forward in this thesis.

1.2 Terminology

When we claim to have been injured by language, what kind of claim do we make? We ascribe an agency to language, a power to injure, and position ourselves as the objects of its injurious trajectory. We claim that language acts, and acts against us, and the claim we make is a further instance of language, one which seeks to arrest the force of the prior instance.

(Butler, 1997, p,1)

Autism and gender, and the language used to describe and produce them as distinct categories are highly contested ground. As with other categories through which we come to know the other and ourselves, autism, gender and their effects are often produced and sustained at the level of language. As Dan Goodley and Katherine Runswick-Cole (2014) discuss in relation to disability, it would be preferable that we would not have to use labels such as ‘intellectual disability’, ‘autistic’ and the high

² I follow Anne Fausto-Sterling (2012) in the use the term sex/gender here. Sex/gender allows us to articulate the entanglement of the social production of sex and gender as they work on and through the biological body.

and low functioning categories that go along with them. However, these words, and the categories they sustain, have to be acknowledged both on a philosophical, *and*, an (inter) personal level.

As Goodley and Runswick-Cole (2014) state, for the people whom they reference these labels can function as both 'inclusion' and 'exclusion' (p.1). Inclusion can take the form of being granted access to a specific group of people where pride and resistance are key, such as LGBT groups or neurodiversity groups. Exclusion can mean that by inclusion in a specific community one is not considered a member of a majority group and is therefore not worthy of the same legal rights and protection. This exclusion can act on the level of symbolic violence, whereby one isn't endowed with the symbolic privilege to construct representations of themselves. Of course, exclusions can occur with inclusionary groups or politics; such as the exclusion of bisexuality from sexuality discourses, or the exclusion of individuals with so called 'low functioning' autism from academic research (Osteen, 2007).

I am fully of the belief that autism has a reality. There is 'something/s' present in certain neurobiologies that partially produces the traits and difficulties correspondent with autism.³ As a researcher who is not medically educated it matters less to me that we find 'proof' of autism than that we treat people with dignity, respect and afford them the right to a life full of the things we deem to be important, if not essential, for human life. Not only the essentials of bare life but the right to relationships, respect, desires, agency, safety and so on (Agamben, 1995, Kittay, 2009). It is here I believe language matters once again.

Acknowledging autism has a reality and it is experienced by individuals in differing ways, the terms in which we discuss autism and to categorise it as a specifiable disability have a philosophical genealogy.

³ I use the word 'partially' here to note that whilst certain ways of being can be attributed to a distinct neurobiological difference, the modes in which these come to be pathologised primarily occur through, and as part of, the regulation of social norms of human behaviour and conduct.

To be fully human is to be abled bodied and cognitively able and consequently granted access to the privileges of being endowed with rationality, reason, worthy of life and a liveable life at that. To be deemed to be less than human, or non-human offers up the other side of the binary of ability/disability; lives that are not worthy of human rights, to a dignified existence or to full life (Braidotti, 2018). This is what is at stake. As such, it is necessary to subject language, labels and categories to 'close readings' for the structures of power and possibilities which underpin them and, in turn, to understand how those categories come to highlight how bodies can be thought, what they can do and how they are politically constituted.

As Butler (1997) suggests, language has the power to injure. This is clearly not a property inherent to language but historically contingent upon structural, institutional and (inter)personal usage. Butler does not mean this solely in the sense that language can injure in a symbolic sense (which of course it can) but that it has material effects. In the case of autism, and referring back to Goodley and Runswick-Cole's (2014) notion of inclusion/exclusion, autistic can be used as a slur and, likewise, the naming of autism as it pertains to a stigmatised state of being can cause violence to be inflicted on the body.⁴ Conversely, the absence of language to categorise behaviours or motivations, can legitimise violence both by others and the self. In the case of autism; assigned female at birth individuals without a diagnosis are statistically more likely to have engaged in self harming or suicidal behaviours than their neurotypical counterparts (Gould and Ashton-Smith, 2011). We could argue that this was because there was no language to describe their feelings and struggles with their otherness. Without a name for their difficulties and, consequently, with no support from educators, social services, and carers, difficulties were compounded and led to a tendency for the individual to blame themselves for their

⁴ See the ongoing history of Applied Behavioural Analysis which utilises negative reinforcement behavioural techniques to change perceived maladaptive behaviours (Morris, 2013). Recently legal cases involving bleach enemas and injections administered by care givers to rid their child of autism have been given attention by the press (See: The Guardian, 2016, BBC, 2015).

perceived shortcomings. Indeed, this was a common articulation in the interviews for this project as will be discussed in the analysis chapters.

Language, the words we use and their absence, has the power to transform subjects in both negative and positive ways. They can be mobilised to foreclose entrance to certain modes of being and they can be reclaimed as a strategy of resistance and agency. A key example is the reclamation of crip and queer (McRuer, 2006, Rand, 2013).⁵ Language, during processes of interpellation, is also what brings subjects into being. The well-known example which Butler cites is the proclamation ‘it’s a girl!’ or ‘it’s a boy!’ given at the birth of a child (Butler, 1990). This naming simultaneously opens and forecloses the formation of the child’s experience and subjectivity. Though differing in its outcomes when someone is diagnosed as autistic as an adult, the newly diagnosed adult has also emerged into a different mode of being by being interpolated into a state of neurological otherness or difference. As is the nature of interpolation, this is not a singular event but will occur in a variety of spatial and temporally distinct times across a life course. Additionally, timelines may be (re)considered retrospectively through this new lens of autism. Thus, we see language has the power to bring into being certain ontological categories, and it has the power to foreclose or delimit access to support and to ‘liveable lives’ (Butler, 2004). Language, and the changes of, also opens a space where we can interrogate deeper questions around the ontologies and epistemologies of specific categories.

The process of coming to the language that I use in this thesis was not a linear process. In a phenomenological sense I would position this as a *coming to language* (Ahmed, 2006). In every discussion I had with an autistic person, and every text, autobiography or medical report I read, I encountered different ways of naming or discussing autism and gender, and in every encounter I found

⁵ The two terms of crip and queer have an interlinked epistemological development. The underlying principles of them as necessarily disruptive to the historical meanings which dehumanised disabled and LGBT people have gone on to guide activist goals and become an identity for many (Rand, 2013). There is not only epistemological interlinkage in the terminology but also in the shared pathologised historical status of LGBT and disabled people, whereby queerness was synonymous with pathology (Yergeau, 2018).

that I orientated myself slightly differently. I moved away or towards certain words, phrases and terminology. In the ways that I dis-guarded, or took on, certain words or ways of naming, the meaning and the impact of the terms I used shifted slightly and informed the overall trajectory and aims of this thesis.⁶ Thus, the ways in which I name and describe the categories in this thesis has been done so under the premise that language is powerful and that the act of naming is not merely descriptive, it brings into being material effects at the same time as it makes transparent the production of meaning and materiality. These material effects may be the shaping of a research project in one direction or another, or they might be the difference between allowing someone the right to a full and dignified existence, or not doing so. In time it may come to be with hindsight and the shifting of meaning that the language I have used is no longer working in service of those whom I have written this thesis about and for. Consequently, it is perhaps only at the time of writing that I believe these terms are working with the participants of this project and those for whom the contents of this thesis directly affect.

Autistic person or Person with Autism?

I use the terms autistic person rather than person with autism as this is used most often within the neurodiversity movement's disruptive and affirmative politics of difference (Houting, 2018). This position argues that a person *is* autistic, and autism forms their subjectivity. This enables autism to be viewed less of an encumbrance and something to be gotten rid of or cured but, rather, as forming the distinct subjectivity, individuality and ontology of the autistic person. Whilst I do have a resistance to certain identity categories being a stand in for true political group building, at present using autistic person overcomes the pathologising tones of person with autism. Pride and resistance may be more prevalent in the neurodiversity understanding of autism and being autistic (Yergeau, 2018).

⁶ For example, I initially began this project by looking solely at autistic women. Over the course of the thesis I realised that a lot of autistic people do not experience themselves within binary terms such as woman and man. I opened my criteria to include those were assigned female at birth. This terminology is important as it allowed for those who identify as transgender, non-binary, or agender to take part in the study.

There are of course those who do not wish autism to be viewed in this way and they prefer to consider autism as separate from their sense of self or identity (Autistic Self Advocacy Network, 2019). As Kenny et al (2013) state there is 'no single way of describing autism that is universally accepted and preferred by the U.K's autism community [...]' (p.20). Many of those who would not agree with the ways I have decided to name autism may feel burdened by being autistic, they may not be able to work, find friendships and create family relationships (Clements, 2017). Taking on autism as an identity for these individuals is to be essentialised into a fatalistic state of abject otherness and it is without a sense of pride and political resistance to social norms. Moreover, an important issue lies within the varying support needs that those autism have. Whilst pride and community building may be an option for those who would have been diagnosed with Asperger's syndrome, it may not be for those who require more support (Clements, 2017).

Due to these discrepancies in how autistic people consider autism, I ascertained each individual's preferred terminology in the interview. All of the participants stated they would prefer 'autistic person', with varying levels of importance attached to using this term. Furthermore, I found difficulty in demarcating autism into its higher or lower functioning categories without using this phrasing. Generally, autism is conceptualised as a 'spectrum' onto which high or low functioning labels are overlaid (Frith and Happe, 2005). I have engaged continuously with autistic people themselves and those affected by the issues in this thesis in order to determine which words bring about the least harm and which words are tied into residual historical narratives which dehumanise and discredit them (Stiker, 1999, p.3). For example, terms such as mental retardation and dumb have been pushed aside in favour of more specific conditions. Autism is one of these specific conditions that came to rename some of those classified as 'mentally retarded' (Eyal, 2013). Consequently, I utilised my networks on the social media site Twitter and started a discussion around what language to use instead of high and low functioning (see appendix iii). 'Varying support needs' was suggested by many as a way to discuss the temporal and relational nature of difficulties autistic people face. This way of communicating the

abilities and difficulties that are common to autism also brings into focus support as a human need and vulnerability as a political position (Beckett, 2006).

High and low functioning are descriptions of how much assistance and support a person needs to function and to reach their goals. It is hard to move away from this language, but I agree with a study conducted by Kenny et al (2015) who suggested that this distinction can be damaging to all autistic people. For those deemed 'low functioning' it can have dehumanising properties and for those who are 'high functioning' it can erase a variety of support needs. Furthermore, high and low functioning labels rely upon a distinctly political measurement of what it means to adequately function or to function productively within a neoliberal capitalist regime (Goodley, 2014). It places the onus onto the individual as lacking in particular areas, or it denigrates or disavows those 'high functioning people' whose support needs become a personal weakness or a failure. It also presents ethical and philosophical questions around where the boundary lines between low and high functioning lie and demands we consider what consequences occur when a permanent place on the 'spectrum' is defined for an individual (Kittay, 2019). Therefore, despite the difficulty of making this language 'fit' within the predetermined parameters of 'good writing', I will refer to this terminology by using the phrases higher support needs or lower support needs in relation to the particular people whom I speak about within this thesis where this is necessary. Support needs may change daily or may stay consistent for many years or a lifetime but by bringing into focus the temporal nature of support it will highlight the social structures and communal support which we all utilise and need.

Support and vulnerability should not be denigrated nor denied, and, we should remember as Lennard Davies (1995) highlights, we are all only able bodied (and able minded) temporarily. Whilst we should all be aware of our existence as mutually dependent on one another we should not simply mobilise disability to clarify this point. Davis' assertion is useful in thinking about the relationship between disability and ability and how these are constructed politically. Or, as Dan Goodley, we might think it

this continuous dialogue between disability and ability as dis/ability. Mobilising dis/ability enables us to both look for the boundaries of the human as she is structured within able bodied and gendered parameters and how power operates to sustain this. At the same time this allows for a critique of (linguistic or otherwise) practices which dehumanise disabled people. Thinking about dis/ability, as Campbell (2009) states, enables us to ‘stalk [ing] ableism while contesting disablism’ (p.10).

Autism Spectrum Condition/Autism

Autism has been subject to many changes in nosology and correspondent name changes over the last century or so. The name autism was coined by Eugen Bleuler in 1911 to describe ‘a symptom of the most severe cases of schizophrenia’ (Evans, 2013) Autism from the Greek auto meaning self, with its etiological roots in autoeroticism, stemmed from a sexological and Freudian understanding of pathology (Evans, 2017). In 1943, Leo Kanner, working at John Hopkins University, produced an article in which he described a condition he termed ‘infantile autism’. This use of the word autism was distinct from Bleuler’s early usage of it. Kanner presented a case study of eleven young children in his care who he describes as being ‘[...] without the social instinct to orient towards other people, who were mostly focused or even obsessed with objects, and who had a “need for sameness” or a “resistance to (unexpected) change”’ (Kanner cited in Baron-Cohen, 2015, p.1329). Just one year later in Vienna, Austria, Hans Asperger wrote an article entitled ‘Autistic Psychopathy in Childhood’. This article documents almost identical findings of this newly named condition (Asperger in Frith, 1991, pp.37-92). Whilst Kanner’s diagnosis went on to be known across the Western world, Asperger’s documentation of the children in his hospital was forgotten for many years.⁷

⁷ In his book *Neurotribes* Journalist Steve Silberman argues that despite the belief that the two conditions were named without prior contact between the two psychologists and their teams, it is likely that Kanner plagiarised Asperger’s work. This was possible because one of Asperger’s colleagues went on to work at John Hopkins University with Kanner prior to either paper being published (Silberman, 2015).

The rediscovery of Asperger's young patients who were considered to be of average to high intelligence would lead the way for the introduction of Asperger's syndrome to the diagnostic category in the mid 1990s. Enabling the re-emergence of Asperger's findings was the 1981 publication by Lorna Wing who was then a child psychologist at the Institute of Psychology, London. An article entitled; 'Asperger's Syndrome: A Clinical Account' argued the case for including this new taxonomical definition within the wider category of childhood autism (Wing, 1981). In the early 1990s Asperger's Syndrome was added to the International Classification of Diseases and the Diagnostic Statistical Manual (DSM IV). Where Asperger's and Kanner's definition of autism diverged was in the levels of impact that the condition had on the lives of the children. Whilst many of Kanner's patients needed daily assistance, Asperger's patients were considered intelligent, curious, verbose and eccentric (Sheffer, 2018). Psychologist Uta Frith suggests that those with Asperger's Syndrome 'shade into eccentric normality' (Frith, 1991, p.111).⁸ However, despite the traits of Asperger's being found within the entire human population there must be a distinction from 'normality' in order for Asperger's to be identified. Hans Asperger identified his condition as a 'stable personality trait' which affected 'far more boys than girls' (Wing, 1991, published online, no pagination).

Lorna Wing's (1981) article argued for the inclusion of Asperger's syndrome within the broader category of autism. Wing (1981) discusses the differences between so called Kanner's autism and

⁸ Historian Edith Sheffer's book *Asperger's Children: The Origins of Autism in Nazi Vienna* discusses the classification of Asperger's patients in Nazi occupied Austria and the emergence of the distinct syndrome. Sheffer argues that a historical approach is fundamental to understanding why Asperger's Syndrome became a definable condition. Children, much like adults, in Nazi Germany were organised by virtue of their adherence to desirable traits. A particularly important trait demanded from citizens in this project of nationalism was 'community spirit'. Roughly defined as an ability to create strong ties to others and thus to the collective state (Sheffer, p.19). Asperger's patients would be corrected in order to fix their deficits in *Gemüt* (originally meaning soul) a term Asperger's appropriated to capture the issues that these children had in respect to them playing a part in the new construction of the Nazi social order. These children were determined to have poor *Gemüt* and Asperger aimed to give them a rich and full *Gemüt* once again. A lack of full historical examination had led to Asperger being seen as a kind of saviour: a rebellious man who saved his patients from death or experimentation. As Sheffer notes, Asperger sent many children to their deaths, many of them girls and adolescents whose behaviour he did not see as part of autistic psychopathy but rather describing some of these girls as 'hateful', 'vulgar' and 'rude' (Sheffer, p.151). Asperger's Syndrome thus arose from the rigid norms which guided Nazi occupied countries and unavoidably intersected with existing gendered ideals for girls and boys.

Asperger's but nevertheless argues that the struggles that many face with the latter condition would benefit from the widening of the category of autism to include people who have less support needs on a daily basis. As Wing (1981) writes:

[...] is there any justification for identifying Asperger syndrome as a separate entity? Until the aetiologies of such conditions [autism and Asperger's syndrome] are known, the term is helpful when explaining the problems of children and adults who have autistic features, but who talk grammatically and who are not socially aloof. Such people are perplexing to parents, teachers and work supervisors, who often cannot believe in a diagnosis of autism, which they equate with muteness and total social withdrawal. The use of a diagnostic term and reference to Asperger's clinical descriptions help to convince the people concerned that there is a real problem involving subtle, but important, intellectual impairments, and needing careful management and education.

(Published online, no pagination)⁹

From the reintroduction of Asperger's mid-century documentations of his young patients in the early 1980s to the present day many more changes have occurred in how autism is understood and, how it is named. Autism has shifted from being considered to be a debilitating disorder of the psyche or a type of schizoid personality which only affected infants and children to a pervasive developmental disorder rooted in neurobiology. Autism is increasingly recognised in adults who go on to receive a diagnosis many years after childhood (Mandy et al 2009). Asperger's syndrome was included in the DSM as a distinct diagnosis in the mid 1990s. In 2013 it was removed again and now the umbrella term 'autistic spectrum disorder' will be given in its place. This encompasses autistic disorder, Asperger's syndrome and pervasive developmental disorder (not otherwise specified) (National Institute of Mental Health, 2018). Throughout these changes in the nomenclature, autism has consequently

⁹ When we come to discussing the ways that autism presents in AFAB people in the first analysis chapter the idea of belief in autism comes to play a major role in whether AFAB people receive a timely diagnosis or not.

transformed from being solely considered as a profound and debilitating psychiatric disorder to being conceptualised as a 'spectrum' with people with a variety of support needs falling into its catchment criteria.

Despite Asperger's Syndrome being removed from the diagnostic manual it is still often used by those who have been diagnosed with it, and a pride as emerged around the identity (see, for example, Aspies for Freedom, 2019).¹⁰ However, I have chosen to only use the terms autism and autism spectrum condition because following discussions with autistic people it seems that these are the preferred terms as it removes some the complicated and often incorrect assumptions around sectioning off autism into 'low' and 'high' functioning subsets (Kenny, et al, 2016). I have likewise decided against using the term autism spectrum disorder in favour of autism spectrum condition (ASC). This is to limit the pathologising effects of the term disorder whilst in the same time acknowledging the difficulties which may arise from being autistic. However, there is a certain value in viewing autism as a disorder in terms of the disruptions and openings it creates to the social order. This is much like the reclaimed terms queer or crip. Yet, we are not at a point of reclaiming disorder as a political position since we have only just begun to leave it behind, and therefore ASC will be the language I utilise throughout this thesis.

Cisgender

The participants of this research are people who were assigned female at birth. Seven participants identify as the sex/gender they were assigned at birth. It was ascertained in the initial questionnaire which gender identity the participants feel most comfortable using. Cisgender refers to people who feel that their gender identity matches the sex assigned to them at birth. This terminology has come from trans activist groups and communities. Cis is counterposed with those who are transgender. As

¹⁰ Since Sheffer's research on Asperger's involvement in the Nazi eugenic projects of nation cleansing became widespread many autistic people have rejected the term on these grounds (de Hooge, 2019).

Vincent (2016) writes: '[T]he construction of this word was made in reference to the Latin etymology of 'trans', meaning 'across' or 'on the other side' – with cis correspondingly meaning 'on the same side' (p.6). Using the term cis or cisgender is a way of destabilising the ways we position people whose gender identity does not match the cultural and social designation of their assigned sex as pathological or other.

Non-Binary

One participant of this study identifies as non-binary. Non-binary is a term in use by those who do not feel that using the binary terms of man or woman fully describes their gendered experience (Richards, et al., 2015). Non-binary can also be described as gender queer (Richards, et al., 2015). Importantly non-binary gender is not connected to sexuality. A non-binary person can be heterosexual, homosexual, bisexual, asexual and so on. It is also important to note that being non-binary can be used by people who do not feel any sense of gender and do not see gender as an important identity. Non-binary individuals often make use of different pronouns than she/he in order to state their gender positioning. For example, the non-binary participant in this study asked to be referred to as they/them.

Neurotypical/Neurodivergent

Neurotypical, a convergence of the two words neurological and typical, generally refers to people who do not have autism or other developmental conditions such as attention deficit hyperactivity disorder, dyspraxia and dyslexia (Silberman, 2015).¹¹ In contrast, neurodivergent, from neurologically divergent, refers to those who do have autism or some other developmental condition. Both terms emerged in autistic led activist communities, though neurotypical is a newer term (Singer, 1999).¹² Neurotypical

¹¹ Importantly there is a large overlap between these conditions, many autistic people will be diagnosed with some combination of these conditions not just solely autism (The National Autistic society, 2019).

¹² Some autistic people prefer the term allistic to refer to those who don't have autism. Allistic further destabilises those without neurological conditions as the norm as it works to position those who don't have autism as allies to those who are autistic rather than creating further boundaries. However, I am using the term neurotypical in order to highlight the social world as being one which works along neurotypical regimes and not just something one /s.

functions in much the same way as cisgender does. It challenges the belief that those who do not have any neurological or mental health conditions should be positioned as the norm. In this way we can destabilise the normalcy of not being autistic and attempt to break down the hierarchies that structure those with neurological conditions and those without. From its roots in autistic led activism, neurotypical and neurodivergent are now commonly used in academic research (Brewer, 2016, Sasson, 2017, Jakab, 2013). I will use neurotypical in this thesis to highlight the norms which govern our societies rather than to refer to any particular individual/s. This is in part because we cannot determine whether someone is or is not neurotypical without prior knowledge, but we can state that certain behaviours or ways of being in the world fit within neurotypical parameters. For example, an autistic person can behave in neurotypical ways in order to fit in to some environments.

Queer

I use the term queer at certain points in the analysis and I have considered certain individuals as engaging in, or embodying, queering practices. Queer can be taken on as an identity, but more importantly for this thesis it 'also describes a certain critical relationship to heteronormativity' (McRuer, 2006, p.13). This relationship with heteronormativity is where I utilise the word queer in order to highlight the destabilising effects some participants produce through their gender identity and interactions in the social world.

1.3 Outline of Chapters

The structure of this thesis is organised into seven chapters. Chapter one has formed the introduction. Chapter two provides a brief overview of what autism is, or, at least what we know about autism. This chapter will also include a landscaping of key sociological interventions into autism research. The specificity of diagnosis and how sociology has approached diagnosis as a window onto a wider scene of ability/disability and health/illness will be addressed here. Thus, this section will engage with those

works of sociology which think about autism in the ways most useful to the project at hand; those which think about how autism has been able to emerge as a distinct category of diagnosis of the twentieth and twenty first century and how the diagnosis itself functions in creating both the condition and distinct autistic subjectivities. This literature has been chosen as the most relevant from the social sciences because it shows how autisms materialisation, in individuals and as a diagnostic category, is contingent upon the contemporaneous knowledge of the condition.

Chapter three continues the analysis of literature from chapter two in order to highlight the key areas of research which addresses gender and its connection to autism. This literature has been selected as relevant because it speaks directly to the question of what role gender plays in autism research and discourses. In presenting this literature I will show the gap in the current research that this thesis has taken up: namely, the subjective experience of autistic people's relation to their diagnosis as it exists as a gendered discursive formation.

Chapter four is the methodology chapter. Particular attention is paid to rethinking traditional qualitative interview techniques which presumes normative interlocuters. Conducting qualitative research with autistic participants demands considerable discussion. The social and communication difficulties common to many with autism makes interviews the least likely option to utilise. However, adaptations such as changes to the interview environment and the option of online or paper communication gave choice to participants so that lack of ease of verbal communication was not presumed.

Chapter five is the first of two analysis chapters. This chapter outlines the life prior to diagnosis as remembered for the autistic adults interviewed in this study. This chapter adds to existing research which has predominantly focussed on experiences of AFAB individuals as autistic children and adolescents (Little, et al., 2017, Pisula,2017, Sutherland, et al., 2017). A distinct empirical finding of

thesis is that the participants self-perceived difference was centred around the sexed body. Many of the participants mobilised intensive disciplinary techniques to deal with bodily development in order to manage to their un/known difference, in the process demonstrating both the building of bodies and the building of worlds. Furthermore, many participants discussed using 'masking' techniques in order to fit into a neurotypical world. This will be discussed with reference to the politics of passing, similarities and key divergences will be noted.

Chapter six is the second analysis chapter and it examines how the participants came to their diagnosis and their experiences of coming to understand themselves as autistic. A significant focus is placed on what happens to perceptions and understandings of gender identity after the diagnosis. A key theme emerged which suggested that the diagnosis, for many of the participants, opened a space for different gendered expressions. Counterposed with the first analysis chapter which suggested that gender and the sexed body became a site of intense management and control, I argue that for some participants the diagnosis of autism acted as a 'coming out'. This meant that a sense of negative difference which had been centred on the body and its gendered constructions began to become a positive difference through the autism diagnosis which legitimised, or gave name to, issues which had been tied to sex/gender. This is problematised through a consideration of the prior interpolations which, I argue, prevent the full 'becoming' of an autistic subjectivity.

Chapter seven is the conclusion which ends the thesis. It provides an overview of the research questions which guided the thesis and the key findings. I present a narrative of the qualitative findings of this project. I discuss the contributions this thesis has made to the field of sociology of autism and I close the chapter with key areas that can be taken up in future research both by myself and other researchers in the field. Appendices close the thesis. I have included recruitment and interview material to make transparent the modes through which I gathered my interview data.

Chapter Two

What is Autism?

We know more about autism now than at any other point in history ... yet, at the same time, if we're honest, the foundational observation that we might make, 'the central fact' about autism with which we should probably start, is that we don't know very much about it at all.

(Stuart Murray, 2011, p.1, as cited in Des Fitzgerald, 2017, p.28)

2.1 What is autism?

If one were to ask someone what autism is, a number of terms, perceived facts or identifiers would most likely be presented as markers of autism. It might be suggested that autistic people require round the clock support, or, on the other hand, they could be high achieving, but aloof and eccentric, professors at the top Universities. It will probably be stated that they are more likely to be men and boys. It might be stated that autism is a series of perceived masculine traits (collecting, esoteric interests, inability to empathise appropriately) and that they are more likely to struggle with social interaction and that they struggle making friends or romantic partnerships, and that they might prefer computers or technology over people or animals. It might also be suggested that if a parent is autistic, they are more likely to have autistic children due to hereditary autism genes. However, despite what we know, or what we think we know, about autism there is still so much more that is not known. Furthermore, autism, what it is and what it feels like or looks like, is different across all those who are autistic. Autism is a slippery and changeable concept and though mentions of autism may bring to mind certain signifiers, these are not all that autism is, nor are they always accurate.

In the majority of contemporary Western societies, the medical understanding of autism is that it is a neurodevelopmental condition which, whilst it may not be present from birth, must be recognisable from a child's early years of life usually between two to three (International Classification of Diseases-10, 2019). In the biomedical understanding of the condition a dyad of impairment must be present for a diagnosis to be made. As the Diagnostic Statistical Manual V (DSM V) determines it, the two fundamental categories of impairment must present 'persistent difficulties' within: social communication and social interaction, and restrictive and repetitive patterns of behaviour (Diagnostic Statistical Manual V, 2013, The National Autistic Society, 2017). As mentioned, in 2013 the category of Asperger Syndrome was removed from the DSM 5 and now autistic spectrum disorder will be given as a primary diagnosis. Asperger Syndrome is unlikely to be given as a formal diagnosis in the United Kingdom, though it may be mentioned informally to an individual who has just been diagnosed as a clarification term. Autism is not degenerative and is not a mental illness or a mental health condition. As Uta Frith (2003) suggests, autism will manifest differently over the course of someone's life with periods of 'adaptation and compensation' but, it is important to note that the condition will always be present (p.16).

Whilst the differentiating categories of autism no longer exist in the DSM V, they are still useful categories for understanding the varying abilities and difficulties which people with autism may have. The main distinction between the previous categories of autism and Asperger's syndrome is that to receive a diagnosis of the former there had to be considerable delay in the child's acquisition of language, and they may not have acquired speech at all, there may also be other learning or intellectual disabilities present (National Autism Society, 2019). Those who would have been given an Asperger's diagnosis will have had no delay in speech acquisition. Some people with Asperger's Syndrome may develop an understanding of complex written language far surpassing their peers and consequently gain a diagnosis of hyperlexia (The National Autistic Society, 2019). Hyperlexia may be given when

reading and written language is developed precociously yet spoken language does not develop to the same degree and abnormal patterns of speech or an inability to engage socially with peers is present..

Neither autism nor Asperger's syndrome are considered a learning disability; however, this may be given as a co-occurring diagnosis. Secondary impairment categories such as intellectual impairment, language impairment and catatonia can be given alongside the ASD diagnosis (The National Autistic Society, 2017). As mentioned, the decision to combine the subcategories of autism has come after many years of considering whether Asperger's Syndrome can be considered autism (Frith, 1991 p.11). However, a shared set of deviations from the norm differentiated by the extent to which they effect the individual meant that autism could be conceived of as a spectrum (Wing, 1981). For those diagnosed with what would have been termed Asperger's Syndrome, despite being considered to present with lower support needs, it can still present great difficulties across a person's life course. For some individuals it can be difficult to fit in at school or work, they can struggle to make friends and relationships and they can fail to achieve their goals which can be the cause of distress. Indeed, The National Autism Society (2019) suggests that only 16% of autistic adults are in full time work. Individuals may also have periods of being non-verbal or of crisis. For this reason, as noted, I want to argue for a move away from thinking about autism as a spectrum and toward a conception of an autistic space. By thinking of autism as a space rather than spectrum we have a further conceptual tool to disrupt the high or low functioning model and can therefore situate difficulties, and indeed strengths, as temporal and relational.

What is common to autism, regardless of where it falls within the autistic space, are the medically defined impairments of 'social interaction and imagination, and restricted and repetitive actions' (DSM V, 2013). What this means for the autistic individual can vary widely. Restricted and repetitive actions may encompass ritualised behaviours which are directed toward objects in the world; lining toys up as a child instead of playing with them or being distressed when plans change even slightly are generally

cited as key markers. Restricted and repetitive actions may also include certain embodied behaviours such as arm flapping, curling hands and fingers and spinning or rocking. These behaviours are known as stimming by many in the autism community (Runswick-Cole, 2019). Some of these actions are said to be a way of coping with sensory overload which has now been added as a subheading in the DSM V where previously it was not considered as a core part of autism (Diagnostic Statistical Manual V, 2013).

‘Impairments of social interaction and imagination’ encompasses difficulties in verbal and nonverbal communication (DSM, V, 2013). Autistic people may struggle to learn how to socialise and behave in different situations, they may also understand language literally and have trouble working out other people’s intentions (Baron-Cohen, 1997). Autistic people may struggle to express ‘appropriate’ emotions and may have difficulty in making and maintaining meaningful relationships. It is important to note that contra to the prior belief that autistic people lack empathy, or inner emotions or desires, autistic people do, of course, have a full and rich inner life; it is the communication aspect of articulating appropriate responses which presents difficulty (Happé, 1991). This short summary is, however, not all autism is composed of, and these, and other, traits will be manifested differently in each individual who has autism and at different stages in life and in different relational spaces. It is a complex condition which encompasses a wide range of abilities and difficulties and as such each person ought to be understood as an individual whose difficulties and strengths will manifest to a greater or lesser degree in differing areas.

This heterogeneity of how autistic people experience their embodiment and their engagement in the social world is also mirrored in the search for autism as a discrete biological entity. Like many researchers of autism working within the social sciences or medical humanities this thesis does not situate autism as a homogenous entity, which emanates from a discreet neurological and genetic makeup of a person. Indeed, there has not been any ‘breakthrough’ in determining the neurological aetiology of autism (Runswick-Cole, 2012, Mallet and Timini, 2016, Nadesan, 2005). Rather, autism is

increasingly considered to be related to multiple genetic differences from the norm. Even these recent genetic developments cannot be definitive due the lack of the genetic database needed, and the heterogeneity of the genomic make-up found within each individual (Miles, 2011, Nadesan, 2005).

This seems to present the impossibility of determining autism as a discreet genetic pathology and it is more likely to emerge as a mixture of multiple genetic vulnerabilities and their interaction with environmental factors (Cheslack-Postava and Jordan-Young, 2011, Hollin, 2016). Even so, the lack of certain empirical data to position autism categorically as a biological and neurological condition has not stopped it being conceptualised as such in scientific, medical, legal and lay understandings of autism. Thus, heterogeneity is perhaps a key word to hold in one's mind when thinking about autism, as slippery and as definitively undefinable that may be. For, as Fitzgerald (2016), citing Ian Hacking, states, when we talk about autism, we have to be aware that we are discussing a 'moving target' (p.28). Thus, we must be aware of how autism is framed, where the boundary markers are drawn of normative and pathological, for what ends and, ultimately, how this subsequently impacts on people's lived experiences.

2.2 The Sociology of Autism

Autism is a particularly fruitful object of research for those working in sociology because of its positioning as a social and interactional impairment, a neurological condition and a diagnostic category which is increasingly represented in popular culture. This positioning enables sociological research to be undertaken in numerous ways and for varying aspects of autism to be interrogated. The two main areas which research into autism focuses upon are the increase in autism diagnoses and whether there is indeed an 'autism epidemic' and, secondly, the gender disparity of diagnosis rates (Eyal et al, 2010, Evans, 2013, Nadesan, 2005, Hollin, 2016, p.210).

Real increase or diagnostic substitution?

Over the last few decades rates of autism diagnosis have increased dramatically leading to what has been cited by many as an 'autism epidemic' (Eyal et al, 2010, p.2). As Bonnie Evans (2013) suggests rates of autism diagnosis have increased dramatically from Victor Lotter's first epidemiological study on autism which cited 4.5 cases of autism to every 10,000 children, to a 2006 *Lancet* article which suggests those figures are around 116.1 cases of autism to every 10,000 children (p.4). This dramatic increase in rates of diagnosis from what was once considered a rare disorder of childhood has sparked interest in numerous fields including medicine, neuroscience, literary analysis and the social sciences (Evans, 2013, p.4). The increase of autism rates has been a major focus from which research seeks to find a theory which will enable some understanding of why autism has become so widely diagnosed in the last half of the twentieth century and the beginning of the twenty first.

These debates centre around whether autism has had a 'real' (i.e. biologically situated) increase in actual cases or whether autism has become a diagnostic substitution for previously homogenously defined intellectual disability or 'mental retardation' (Eyal, 2010). Theories of those who advocate for the former position range from arguments that autism is caused by MMR vaccines or environmental influence, or that the increase in the tech industries labour force are causing babies to be born with autism due to the pairing of couples with cognitive profiles that are highly technologically proficient, Baron-Cohen (2006) has discussed the latter as a 'assortive mating of two systematising cognitive profiles' (Silberman, 2015, Donovan and Zucker, 2016). Theories from the diagnostic substitution position suggest that the category of autism has expanded and that closures of state institutions meant a more defined diagnosis than retardation, for example, had to be created in order to successfully implement community care (Eyal, 2010). Within the diagnostic substitution position there are some who maintain that we have to consider autism as first and foremost a socially constructed category and thus only understandable through an analysis of the social world (Runswick-Cole, 2016). All these

differing positionalities demonstrate just how much the study and the history of autism needs to be considered sociologically. Autism is a condition of social impairment and it is shaped and formed through the social and political histories which its current configuration is contingent upon. As Jutel (2015) argues, to consider something sociologically and to 'do sociology' means to seek to find wider understandings, meanings and methods from the object of knowledge with which you work. Thus, autism can never be taken as an object in isolation, it speaks to, or illuminates, wider concerns at the same time as it is produced by them (p.845).

Bonnie Evans (2013) takes up the question of the dramatic increase in diagnosis rates and suggests that autism has a central positioning in the history of child psychology and psychiatry in the U.K and that the shifts in the historical modes of understanding autism in child development psychology have widened the categories, not only of autism, but of many related cognitive categories of impairment. To make this argument Evans traces the history of autism back to the inception of the term coined in 1911 by Eugen Bleuler. Bleuler's work was heavily influenced by Sigmund Freud and the sexologist Havelock Ellis (Evans, 2013, p.6). Freud's work on childhood psychopathy argued that the cause of certain mental disorders was within a disordered splitting of the self from the environment, with a specific interest on how the self sees itself as autonomous and distinct from both its environment and its primary caregiver (Freud, 2005). This led Freud to infer and then interpret the psychic symbolic life of a child prior to all language and prior to the child being able to give an account of itself. This understanding of the working of subjectivity, the psyche and the self and its relations with others, at the turn of the twentieth century influenced Bleuler to state that autism was a condition wherein the child could not come to experience itself and its environment coherently. Instead, the child had a rich symbolic life and experienced fantasy and hallucinations as a result of infantile wishes to 'avoid unsatisfactory realities and replace them with fantasies and hallucinations' (Evans, 2013, p.4).

The main deficit of the autistic child not being able to form reciprocal human relationships was understood theoretically as an inability of the child to properly engage with reality (Evans, 2013, p.17). Importantly as Evans (2013) suggests, these earlier theories and ideas about autism were based upon individual cases, and causes for autistic behaviour were inferred and interpreted through the early psychological knowledges which sought to understand how subjectivity is formed and not through the observable and empirical behavioural tests which would emerge (p.7).

As Evans cites it, a major change came in the conceptualisation of autism when instead of being a condition understood through excessive fantasy and hallucinatory experience it became, conversely, categorised as a 'complete lack of unconscious symbolic life (p.4).' As Michael Rutter, head of the first genetic study of autism in 1972 writes: 'the autistic child has a deficiency of fantasy rather than an excess' (Rutter in Evans, 2013, p.4). With the removal of the psychoanalytic techniques to interpret the symbolic life of a child and the reasons for the deficits in his or her relationships with others, the study of autism could be opened up to standardised tests and empiricism through the observation of visible behaviour. With the creation of a standardised diagnostic criteria autism could be understood as a delimited set of behavioural impairments (p.14). This allowed for many more children to be counted under the diagnosis of autism as it became distinguished from a rare form of childhood schizophrenia. The standardisation of autism as a diagnostic category could then be used for epidemiological studies not only to determine prevalence but to determine causation as separate from the psychoanalytic theories of affective disturbance and the inability of the ego to develop a differentiation of fantasy and reality (Evan, 2013, p.15).

The shift in understanding from that of autism being a condition categorised by a retreat into the self into fantasy and to the consequent positivist methods that were deployed after allowed speech to come to hold an important place in autism. Not only must a child account his or her own psychic life and only then could hallucination, or lack of, in childhood be verified, but language became a central

category in identifying the cognitive deficit of autism (Evans, 2013, p.19). As Evans (2013) writes '[those researching autism] did not know the exact form of the central sensory disorder which caused autism, they were all united in the view that the condition was not caused by emotional reactions or hallucinations but what instead characterised by a deficit in certain aspects of linguistic thought' (p.19). Furthermore, as Evans (2013) writes '[T]hese changes were contemporaneous with a wider interest in the 'communication' problems of children as opposed to their emotional problems' (p.19).

Autism psychologists Lorna Wing and Judith Gould (1979) suggested that autism needed to be re-categorised as a condition of social impairment. Wing and Gould (1979) devised a triad of observable behavioural phenomena: impairment in social interaction, communication and imagination (p.27). These were positioned as against the norm of childhood development and were mapped against the impairments of associated conditions and this allowed for autism to be positioned as a central problem through which to understand other conditions. Removed from its association to psychosis and hallucinatory states and positioned as a behavioural and communication disorder autism could be mapped epidemiologically and statistically against the norm of childhood behaviour, likewise it could be observed through behaviours rather than psychological theoretical inference. In this new framework of 'cognitive deficits', the scope of who could be given an autism diagnosis was widened dramatically (Evans, 2013, p. 23).

Gil Eyal et al's (2010) book *The Autism Matrix* also begins with the increase of autism rates. Eyal et al, suggest that the question of whether there is a so called 'autism epidemic' has led to a huge increase in research and money being given over to the area. If the cause of the epidemic can be found, then this would suggest autism can be contained as would be similar to the outcome of other so-called health epidemics. As Eyal et al argue there are two positions which are taken in the argument of whether or not there is an autism epidemic. On the one side, there is position that autism is a disease entity which is spreading (cause unknown) and this must be identified and brought under control and

the other side of the argument that autism is a solely socially constructed discourse which has been enacted and materialised by the increase in the focus on the condition. From the latter position questions are asked which think about how could we better think about autism in such a way that provides a more holistic knowledge which takes into the account the conditions of its emergence. Would we be better placed to understand autism if we look at conditions of society rather than brain imaging and genetics? Can the increase in diagnoses be found within the political and social world rather than environmental or biological mutations caused by vaccinations or dietary changes?

Critical autism studies positions autism as a social category to argue that autism is socially constructed and bound up in political power and big pharma. Thus, questions emerge around whether autism as a diagnosis is 'scientifically valid' and whether this diagnosis is indeed helpful for those diagnosed (Runswick-Cole, et al., 2016, p.7). *Re-thinking Autism*, an edited collection of articles, cites itself as being the first such book in the new field of critical autism studies. However, as Damien Milton (2016) states, critical autism studies has been around as an intervention into traditional ways of thinking about autism for many years before the publication of this book and that this collection of essays repeats past mistakes of autism, in Milton's terms, of misunderstanding the biomedical model of autism and of failing to engage with autistic scholars. Furthermore, Milton suggests that many authors of the chapters in the collection seem to agree that autism is only scientifically valid as a 'natural kind' and systematically ignore the history of autism in the U.K as being diagnosed and identifiable based on behavioural observations (p.1414).

Taking what they cite as a 'radical position', Katherine Runswick-Cole et al (2016) argue that by assuming autism to have a biological aetiology, even if we consider the social nature of it as interacting with a certain biological reality, we can never fully understand what autism is. To understand autism, they argue, we must relinquish the idea that autism has a singular biological basis which can be found in 'nature' and that it may one day become visible and thus located as a discreet observable entity. As

Runswick-Cole et al state: '[T]he recurrent failures of any visible progress in academic attempts at discovering what autism is serve to obscure a simpler and more likely possibility – that the reason that science is not uncovering what autism is, because it doesn't exist at the biological level' (2016, p.9). The position they advocate is to fully explicate autism from scientific expertise and knowledge and firmly place it in the social world. As they write: '[...] autism can only be understood through examining 'it' as a socially/culturally produced phenomena' (p.9). What is more likely to be true is that a discrete aetiology for autism hasn't been found because autism is not one thing but that it is multiple and that autism spectrum conditions are so heterogeneous as to be pinned down to a shared biological or social cause common to all individuals who come under the category of the autistic spectrum disorders (Hollin, 2016, Timmi and McCabe, 2016).

Eyal et al (2010), suggest that the question of whether there is an autism epidemic and of the opposition of those who believe in the biological and disease origin of autism to those who have faith that autism is constructed solely in the social world is not the correct place to understand what autism is (p.3). Rather Eyal et al (2010) suggests that we think about how categories of disorder and impairment are formed. As these debates endlessly circle around trying to define the 'real' of autism Eyal et al (2010) suggests that sociologists are in a good position to think about what autism is and how we understand it because '[sociologists] can take as our object the total population of actual autism diagnoses, treating it as a real phenomenon in need of an explanation (p.20)'

Eyal et al's (2010) main argument which runs throughout *The Autism Matrix* is that increased autism rates are the direct result of the deinstitutionalisation in the 1960s which placed many who had previously been categorised under the homogenous title of 'mentally retarded' into community care. Specialised care and support was needed for individuals, thus the unhelpful and generalised category of 'mental retardation' was broken up into various categories of atypical conditions. As Eyal et al (2010) write: '[T]he current rise in autism diagnoses, we argue, should be understood as an aftershock of the

real earthquake, which was the deinstitutionalization of mental retardation that began in the late 1960s. The deinstitutionalization of mental retardation was a massive change, not only materially [...] but symbolically' (p.3). That meant that autism became brought into public visibility as a distinct diagnosis and one could be sought by parents, or imposed upon parents, to give a name to their children's problems. It is the specificity of the diagnosis, or 'giving the name', and the sociological understanding of diagnosis which I will turn to next (Brown 1990).

2.3 The Sociology of Diagnosis

A diagnosis exists on multiple levels. It is a conceptual tool for making sense of someone's complaints or 'suffering' when they are encountered in a medical setting. It is a social tool that demarcates normality from pathology, and it can function as a form of social control. It re-produces the hierarchical position of the doctor and it produces subjectivities; the sick person, the dying person, the autistic person (Nussbaum, 2013, Brown, 1990, Jutel, 2009). As Annemarie Jutel (2015) suggests, diagnosis is an important object for study from a sociological perspective because a diagnosis is never simply just a diagnosis. As Jutel (2015) writes:

['doing' sociology on diagnosis] is unearthing and revealing an object as a way of adumbrating an even broader scene [...] sociology should shine light on concepts, processes, and practices, which are otherwise not seen or not recognized for the impact they have on more general issues such as, in this case, health, illness and disease.

(p.843)

Jutel (2009) states: 'diagnoses are the classification tools of medicine' (p.285). These tools do the work of ordering bodies into categories of sickness, health and disease. Or, in the case of neurological conditions, such as autism, dyslexia, attention deficit disorders, they classify a certain abnormality of behaviour or ability as being a medical concern (Hollin and Pilnick, 2015, Conrad, 2007). Diagnoses

really *matter*; they shape social structures such as medical and care institutions, social security structures and wider support and educational policies. They provide the recipient of a diagnosis with access to care or support pathways designated as being 'useful' to them (Nussbaum, 2013). They are also cultural and social tools which not only demarcate people into sickness and health, but they do social boundary making work. The power of the diagnosis extends far beyond the individual patient.

The patrolling function of diagnosis

In the psychiatric branch of diagnosis, a commonly discussed, or critiqued, area is the important role this institution has, and has had historically, in wider process of social control (Brown, 1990). As Nikolas Rose and Joelle Abi-Rached (2013) discuss, in particular the sociological study of deviance has focussed on the controlling and patrolling functions of pathology as legitimised by the authority of psychiatry (p.113). Phil Brown (1990) in his foundational paper *The Name Game: Towards a Sociology of Diagnosis* noted that much of the historical work that criticises the social control aspect of psychiatry had not taken into account the importance of the diagnosis as 'central component of this social control' (p.387).

Brown (1990) discusses several historical examples which are notable for the ease of their analysis as diagnoses given specifically for a societal and political function, for example: witchcraft, sexual immorality and absconding slaves (p.386). These categories, with the benefit of hindsight, allow a clear insight into the hegemonic goals and aims of the society in which these behaviours were deemed to be deviant and undesirable. Yet, as Brown (1990) states what has not been so clearly understood, nor analysed is that; '[G]iving the name has been the starting point for social labellers. The power to give the name has been a core element in the social control nature of the mental health professionals and institutions' (p.387).

Discussing the perceived social control aims of psychiatry Nikolas Rose and Joelle Abi-Rached (2013) cite the infamous experiment by David Rosenhan where 'pseudopatients' (students without any history of mental illness) were admitted to a psychiatric ward by stating that they heard voices (p.113). This particular exercise focussed attention on the diagnosis as a social tool that defines normality and pathology imprecisely and according to the social norms and codes of conduct in existence. In the process it demonstrated how difficult it is to 'diagnose normality' and points to the instability of both sides of the binary of illness and health (p.113). Importantly, Rosenhan's study also points to the importance of shared narratives in the process of diagnosing. All the participants in the experiment were instructed to make use of words understandable in a wider framework of mental illness, as it itself made use of existential philosophical understandings of selfhood. It is of particular interest to this project to understand if the participants engaged with the narratives – or the discourses- which allow autism to be diagnosable in a clinical setting, much like Sandy Stone's (1991) argument that trans people must tell the dominant trans origin story to access healthcare and be recognised as trans.

is important to note, that whilst critiques of psychological normalisation are valid in many ways, they are also overly general and uniformly present medical professionals as malevolent handmaidens for the hegemonic political social order. As Brown (1990) and Rose and Abi-Rached (2013) note, many psychiatrists and other front-line health care professionals are also 'troubled' by psychiatric diagnosis and uphold an ethics of care (Brown, p.387, Rose and Abi- Rached, p.113). As Abraham Nassbaum, writes in the introduction to a guidebook for young clinicians *The Pocket Guide to the DSM-5 Diagnostic Exam*: [...] even if a person endorses all the symptoms of a particular disorder, if the disorder does not *usefully inform* that person's treatment process, or prognosis, then the diagnosis is considered inappropriate' (p.10, own italics). However, Nassbaum's (2013) focus here is solely on clinical usefulness, and a diagnosis always exceeds its usefulness within the clinic.

Brown (1990) also notes that many professionals with diagnosing authority will work around some of the rigidity found in standardised diagnostic manuals in order to enable an individual to access things of 'use' (p.387). Gould and Ashton-Smith (2011) likewise argue that the autism diagnostic tools are not designed to diagnosis assigned female at birth individuals, as such they suggest that adaptations in diagnostic techniques should be made to account for gender differences in autism presentation (p.34). Brown (1990) refers to the official standardised framework for diagnosis (as found in the ICD or the DSM, for example) as 'diagnostic technique' and the actual process of diagnosis within the clinic by individual actors as 'diagnostic work' (p.391).

The interactional and interpretative work of diagnosis

Though Brown (1990) did not explicitly refer to the interactional space of the clinic with his phrase 'diagnostic work', it calls for an exploration of the work that is actually being done in diagnostic examinations. I will focus on autism diagnosis here. Maynard and Turowetz's (2019) critical analysis of how clinicians determine diagnosis in local encounters uses historical case data to ask how 'the interaction order of the clinic articulates with a larger-scale historical forces affecting the definition and distribution of ASD' (p.89). Maynard and Turowetz (2019) wish to develop an understanding of abstraction to complicate the tendency, as they see it, to a Foucauldian analysis of the production of categories of people through diagnosing and medicalising practices acting on passive subjects, or what could otherwise be called 'institutional determinism' (Hollin and Pilnick, 2018, p.1216).

Abstraction refers to the interpretation of patient-doctor interactions as removing the holistic individual from their environment, their other social identities and simply looking 'beneath the skin' with a medical gaze, to borrow Barbara Duden's (1998) phrase. This perceived power relation between the clinician/s and the patient has been addressed critically as being common to medical interactions and as constitutive of medical power in much scholarly work, especially that which is critical to

medicalisation processes and the social labelling of constructed deviance, as discussed above (Foucault, 1994, Foucault, 1988). These criticisms have often focused on gender relations and address the already hierarchical power dynamic between the woman patient and the (male) doctor (Duden, 1998, Cross, 2010, Ehrenreich and English, 2005). These criticisms are relevant to understanding how the male phenotype of autism has come to be understood as the normative presentation of autism and consequently the one that is looked for in diagnostic examinations (Murray et al, 2016). Across their body of work on autism diagnosis Maynard and Turowetz (2019, 2017, 2015) suggest that rather we should recognise the interactional aspect of, what they cite as, ““doing” autism diagnosis’. Whereby, social encounters, speech and ways of narrating are co-produced in the clinic itself in relation to social structures such as ‘changing diagnostic terminology and criteria, altered networks of expertise, and services for handling disease, illness and disability’ (Maynard and Turowetz, 2019, p.92, p.109). Thus, the process of diagnosing is always relational.

Hollin and Pilnick (2018) also argue for an understanding of how the interaction between the ‘patient’ and the professional in the clinic actively produces a distinct profile that becomes named as autism. This naming is done through interpretations of social behaviours as measured against standardised tests. Building a coherent framework out of a patchwork of multiple behaviours into a singular category of pathology ‘reifies’ disparate and apparently disconnected behaviours by producing a nameable entity into which they fit. As Hayes, et al, (2020) writes: ‘[F]or autism, this process of reification transforms what is sometimes an inconsistent or intangible set of social behaviours into a concrete condition, perceived as an inherent attribute of an individual’ (Hayes, et al, 2020, p.3)’. Hollin (2017) argues that autism is best understood as an ‘ontological uncertainty’ which is ‘determined by its indeterminacy’ (p.214). Though autism is especially indeterminate, (it has no biological or genetic markers, no direct identifiable cause from the social or the biological) if not indeterminacy but multiplicity can be attributed to a broader range of diagnoses. In her work on atherosclerosis, (an obstruction of the arteries), Annemarie Mol (2002) asserts that the disease entity itself is ‘not one, but

multiple'. Obstructed veins under a microscope are distinct from the pain that a patient signals to their doctor and this is again distinct from the readings on a blood pressure monitor. The disease atherosclerosis is concretised through the various interactions between patient, clinicians, researchers and wider institutional interests, through this 'reality [is] enacted' (p.44)

Producing Affects

As Hayes, et al (2020) note the transformation of multiple social behaviors into the singular condition of autism becomes figured then as an 'inherent attribute of an individual', thus, a person who enters a diagnostic clinic leaves as an autistic person (or a cancer patient, or an AIDS patient, and so on). This diagnosis of autism can provoke affective responses by the patient herself or those who interact with her. These affects range from sympathy, shame, paternalism, grief to indifference and anything in between. These emotive reactions can potentially produce negative effects; loss of employment, family breakdown, societal ostracization. Affective reactions to a diagnosis are always culturally and socially specific (Jutel, 2009, p.279). It is not necessarily the condition, or its prognosis, itself which produces these affects but often it is the metaphorical construction of the condition, illness or disease which one is diagnosed with. Susan Sontag (1989) in her seminal work *Illness and Metaphor* describes the impact that the metaphoric constructions of cancer have on the experience of the cancer patient in relation to wider social conceptualisations of the disease. As Sontag writes (1989), '[I]t is not the naming as such that is pejorative or damning, but the name "cancer". As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people will indeed be demoralised by learning what disease they have' (p.7).

Melanie Yergeau (2018) also states that it matters *when* one is diagnosed, not only with *what*. Once believed to be solely a childhood condition, rates of diagnosis of autism in adulthood are increasing (Murray, 2008, p.139, Murphy et al, 2016). Despite this phenomenon of adult diagnosis, popular perceptions of autism as a condition of childhood persist. These perceptions persist not only in the idea of autism as delayed development which leaves those diagnosed as forever in a childlike state

but, through a disbelief that one can truly be autistic if diagnosed in adulthood. Melanie Yergeau (2018) writes: '[C]laiming, for instance, that one was diagnosed with autism as an adult is often read as misdiagnosis – one's autism must not be real enough or terrible enough if it hadn't been cataloged during early childhood' (p.156).

Then discussing the tendency for autistic adults to have received autism in the place of another diagnosis Yergeau (2018) writes, echoing Eyal et al (2010):

Of course, these stereotypes ignore, for instance, that many autistic adult diagnoses take shape as reclassifications, replacing and/or complementing prior diagnoses such as intellectual disability, verbal apraxia, schizophrenia, ADHD, borderline personality disorder, selective mutism, cerebral palsy, Tourette's and beyond. Deinstitutionalization brought as many diagnostic shifts as did revisions to the *DSM*

(p.156)

This tendency to not quite believe an adult can be autistic if diagnosed in adulthood can shape how the individual relates to their autism diagnosis and the ways they feel compelled to prove their autism, as will be discussed in the 'masking and passing' section of the next chapter. At the same time that a diagnosis of autism can produce a sense of great relief, a sense of disbelief can be present within the individual (Stagg and Belcher, 2019). In autism diagnoses a commonly discussed reason for the 'misdiagnosis or missed diagnosis', as Ashton-Smith and Gould (2011) cite it, in those who were assigned female at birth is that gendered biases shapes access to diagnosis and to the construction of the diagnosis itself. Ashton-Smith and Gould (2011), as noted earlier, have proposed the creation of a new model for diagnosis based on a 'female phenotype' of autism. However, as Brown (1990) notes:

‘[...] race, sex, and class bias- which have long been central features of psychiatric diagnosis- are much more value-laden- and will undoubtedly be even harder to eradicate with technical classification. These biases are part of the overall culture and will invariably show up in major social institutions.

(p.391).

Self-diagnosis

In part due, no doubt, to a history of gendered bias at play in diagnosis processes, self-diagnosis among assigned female at birth individuals appears to be common (Lewis, 2016). The authoritative stamp of diagnosis can be hard to come by and self-diagnosis is a chosen path for some. Reasons for self-diagnosis may include; previously being misdiagnosed, not being diagnosed in childhood, fear of workplace discrimination, class, race or gender barriers in place, or not considering autism a disease which needs to be diagnosed (Sarrett, 2015). As Jutel (2015) notes, whilst diagnosis still relies on the doctor to make the final call on whether a name can be given, diagnoses are not the sole preserve of the medical sphere. Brown (1990) stated that ‘diagnoses are the language of psychiatry’ and, as language is never the sole property of an individual or an institution it is always subject to appropriation and adaptation from the officiating medical sphere. As Jutel (2015) writes:

Diagnoses are no longer (if they ever were) something you get uniquely from the doctor and apply in medical conversation alone. They spill into daily life, batted back and forth between friends, discussed on radio and newspapers [...] diagnoses are also something one might now bring to the doctor, rather than request of her: realms of papers with suggestions from Dr Google, patient advocacy groups, and big pharma.

(p.846)

Like many other diagnoses that come under the broad areas of interest to psychology and psychiatry, autism has become a diagnosis that many lay claim to without any medical assistance. There are

numerous self-test frameworks and interactive tests online which anyone can take, and it will score them on a points system that is similar- if not the identical- to the one used in preliminary tests used by gatekeepers to the specialist diagnostic services. For many people these tests can be the first steps to going to a general practitioner to ask to be referred to specialist services, for others the tests are enough in their own right (Sarrett, 2016). This, I believe, makes the diagnosis of autism especially interesting. Since a self-diagnosis cannot open pathways to services or support, we must ask what the specific desire to have a diagnosis of autism is. Even gaining a medical diagnosis of autism is not a guarantee that structural provisions can be accessed. As the authors of the current National Institute for Health and Care Excellence guidelines (2012) state, though assistive provisions ought to follow the diagnosis, these cannot always be implemented. As the authors (2012) write: '[C]urrently, widespread inconsistency in access to and provision of care and effective interventions (for autism and for physical and mental health problems) are potential challenges to guideline implementation'. Crane et al (2018) have also noted a lack of resources for autistic adults and services which were cited as inadequate by adults who received a diagnosis and wanted access to aftercare or support.

The Transformative Power of Diagnosis

For many adults who are diagnosed with what we could call autism with lower support needs there is a common story being told; that the diagnosis helps them understand who they are. It makes sense of signs, traits, and of feelings that something is not quite right (The Guardian, 2016, Hickey et al 2017, The BBC, 2018). In many instances when individuals discuss receiving an autism diagnosis it is framed as though the diagnosis gives access to a self that was always there but not quite knowable (Williams, 1999). Or a self that had been covered up through years of self-imposed, not-quite conscious attempts of neurotypicality, this will also be discussed in the 'masking and passing' section of the literature

review (Holliday-Wiley,1999, Wylie, 2014, Mandy, 2019). There are numerous self-help books, autobiographies and personal accounts by autistic people which cite this as a common trope.¹³

This demonstrates what Jutel (2015), describes as the ‘transformative power of diagnosis’:

[...] the diagnostic moment imposes an indelible division of “before” and “after” onto an individual’s life story despite the absence of any material change in condition (Blaxter 2009; Bury 1982; Fleishmann 1999; Frank 1995). The impact of the diagnostic pronouncement is as important as the disease itself, altering the sense of identity and, of future potential.

(p.848)

After an autism diagnosis in adulthood, for those who with lower support needs, it is quite often that the act of receiving the diagnosis terminates interactions with different social structures. This is not always by choice but, as noted, because of the lack of support provisions (National Institute for Health and Care Excellence, 2012). The diagnosis for those with lower support needs, whether self or medically diagnosed, often marks the end point rather than the beginning of treatment plans, care pathways and other institutional encounters. A diagnosis can also act as a safety net which can be brought out in relation to specific needs when required, such as in the workplace or educational institutions. This makes the diagnosis a highly individualised event as in many ways it is left to the individual to work out their own coping strategies and ways of being in the world. The diagnosis of autism is the tool to do this with.

¹³ Autistic writer Donna Williams (1999) describes the period before diagnosis as a ‘war’ and describing the experience of discovering a different version of the self through diagnosis writes; ‘[W]ithin each of us there is a stranger (or strangers) lurking in the shadows of our subconscious minds. They know of us but do not know us. And the only thing that keeps them ‘back there’ is a sense of self (self-possession). Not all of us are born aware we have this’ (p.6). Phillip Wylie (2014) is even more explicit, he compiles a list of bullet points that document the periods of time leading up to, and beyond diagnosis. The list cites; ‘knowing we are different’ [...] clues we have ASD [...] pretending to be normal [...] reaching tipping point of self-identification (acknowledgment of ASD) [...], receiving a diagnosis of ASD [...] ‘coming out’ [...], finding self-acceptance’ (p.29).

The autism diagnosis (self or medical) may lend itself to forms of community building and to building an autism politics. As Chong (2001) notes, diagnosis may 'confer collective identity on patients, removing them from the isolation of their own suffering and providing them with new networks of support' (cited in Jutel, 2009, p.288). Since the medical or social assistance that is in existence has little to offer to a lower support needs autistic adult then other autistic adults often become a support system. Online resources, self-help books, Twitter, Reddit, Facebook or Wrong Planet conversations can often be some of the only materials that autistic adults have to work with (Benford, 2008, Bagatell, 2010). This is, in part, why neurodiversity and other autistic-led political movements have taken off in the way that they have. Autism-led politics take place predominantly in online spaces where the individual who received a diagnosis has to take it on themselves to discover what exactly autism is and what it means to be an autistic person. If we view an autism diagnosis (self or medical) in this way then interaction with medical services or with medical tools, such as diagnosis, functions less obviously as a categorising regime of normativity and pathology and, instead, as *a tool for emancipation* and a potential gateway to a political project aimed at liberation for autistic people through the creation of a distinct autistic subjectivity.¹⁴ However, it is important to note, as Jutel (2009) has, that these autism-led narratives and the identity politics that have emerged around the autism diagnosis cannot be divorced from the ordering 'regime' of the diagnosis and continuously refer back to the 'cultural, spatial and historical practices associated with a diagnosis' (Jutel, 2009, p.288).

2.4 The introduction of Asperger's syndrome and neurodivergent identities

Nadesan (2005) argues that the increase of autism diagnoses is correlative with the opening of the autism category to 'the eccentric shades of normality' which are found within Asperger's syndrome

¹⁴ There is a clear difference here between those with low support needs and those with higher support needs. For some autistic people and their families, neurodiversity politics are not accepted as a useful way to approach autism. Indeed, the neurodiversity movement has been framed as producing an accepted version of autism (namely what was called Asperger's Syndrome) and neglecting or wilfully ignoring autistic people who are non-verbal and requiring round the clock care (Clements, 2017). This highlights the internal struggles of diagnostic definition within the autism community.

(Frith, 2003, p.11). Nadesan's (2005) interest is specifically toward Asperger's syndrome and as she argues the widening of the criteria of autism and increasing paediatric care in the very early years of life allows for more children to be identified as autistic. Nadesan (2005) does not engage with the circular arguments around whether autism is biological or constructed, she rather suggests that autism has a biological aetiology. However, the best place to understand autism as it is lived, experienced and understood is through examining conditions of the social world. As she argues, to understand autism we must recognise that it is contingent upon historical and contemporaneous configurations of the social world and our conceptualisations of ourselves as social beings. As Nadesan (2005) writes:

[...] autism, or more specifically, the idea of autism is fundamentally socially constructed. [This claim] is not to reject a biological basis for the condition or symptoms that come to be labelled as "autistic". Rather, I use the phrase socially constructed to point to the social conditions of possibility for the naming of autism as a distinct disorder and to the social conditions of possibility for our methods of interpreting the disorder, representing it, remediating it, and even for performing it

(p.2)

Nadesan (2005) suggests that autism is fundamentally a condition of the twentieth century, and Asperger's syndrome is fundamentally a condition of the late twentieth and early twenty first century. Furthermore, Nadesan argues that the emergence of Asperger's syndrome and the so-called autism epidemic has led to autism being simultaneously a fascination and a threat (p.108). This fascination/fear of autism comes from the idea of the 'autism epidemic' and from narratives of lost children stolen by the condition. It also stems from the idea of the so called 'higher functioning' autistic person or person with Asperger's syndrome as somehow being temporally displaced through their connection to the machine in their perceived technological and computing superiority.

Elizabeth Grosz (1994) has written on how some conceptions of the human being are only possible because of the prevailing technological advancements (p.9). The conception of the autistic person as rational, logical and systematic with deficits in emotion, empathy and reciprocal engagement in the social world configures autistic people at one and the same time more than human and less than human through their connection to the prevailing technological modes of the last forty years. This is, too, a gendered framing of co-existing patterns of male genius and pathological maleness. This will be returned to in the third chapter of this thesis.

This conception of autism as, if not superior in certain areas, then certainly 'different' has also been taken up by certain demographics of the autistic community who identify, as a group, as neurodiverse and individually as neurodivergent (Singer, 2016, Meyerding, 1998, Blume, 1998, Bumiller, 2008). Indeed, the very language which configures the autistic subject as closer to the machine than the human is taken up by some sections of the autistic community. The neurodiversity model suggests that those with autism should not be categorised as pathological but rather that they are neurologically different and this is '*hardwired*' into their genetic and neurological make-up from birth (Brownlow and O'Dell in Ortega, 2009, p.439). The neurodiversity movement is formulated upon the knowledge of the self as what Vidal (2009) cites as a 'cerebral subject'.

It is partially through this knowledge of the neurological aetiology of autism that it could move away from its historical categorisation as psychopathy as framed within psychological and psychoanalytic discourses (Bettelheim, 1972, Asperger in Frith, 1991). Rather than being a condition of the mind, autism becomes a condition of the body through its attachment to the brain. Thus, it is argued that there is no person underneath the autism, *having autism is their subjectivity*. Through this ontological positionality blame and responsibility can potentially be removed from all parties involved with the autistic person and the autistic person themselves (this is especially the case for caregivers of those with autism who were previously blamed for their child's autism (Bettelheim, 1960)). Autism can be

positioned as morally innocent and can be reframed as a difference rather than a pathology (Lurhmann, 2012, p.37).

To say that we understand ourselves and our consciousness as the product of biological processes of our brains is not to say that this is an ontological fact or a pre-existing reality, nor does it mean that this is truly the case with all individuals (Latimer, 2013). Rather, it makes sense to think about this emergent subjectification as Ortega does, as 'an anthropological figure' and one which is constituted by performative enactments. As Ortega writes: '[...] to analyse the cerebral subject, one should focus on its formation and the practices of self-constitution through which individual's fashion themselves in cerebral terms' (p.426). Neurodiversity is one of the ways that a cerebral ontology is constituted through performative enactments of this discourse.

Rather than suggesting that neurodiversity and the neurodivergent subjectivities it enables are a direct consequence of the neurosciences it makes more sense to think of the two as influencing one another, in a form of what Ian Hacking (2006) cites as 'looping'. As Ortega has suggested it is not that neuroscientific 'discoveries' have created the 'cerebral subject' which has in turn enabled the neurodivergent subject but that increasing visibility, in which we can include numerous autobiographical works, and the work of activists and self-advocates that have built new possible categories of human identity which then the various fields of the neurosciences engage with. This connectivity continues to 'loop' within complex institutional and interpersonal networks (Ortega, p.426, Hacking, 1999, pp.103-104). As Chloe Silverman (2008) states, if the neurodiversity model positions itself as a biosocial culture then social science research ought to be thinking about how it is conceptualised and put into practise through using resources from externally produced medical understandings, guides and information by those with autism and popular representations of autism.

2.5 Conclusion

This chapter began with a discussion of what we know about autism, and, by doing so it is clearer all that we do not know. A presentation of some of the relevant literature from the sociology of autism and related fields followed. This literature primarily discussed one of the key areas of inquiry in autism research: are rates of diagnosis going up or has there been a diagnostic substitution? The answer to this question is most likely that this is not an either/or question. Due to the changes in the ways in which autism is understood and consequently diagnosed we can infer that diagnoses of individuals are more likely to occur. Terms such as mental retardation became broken up into more specific diagnoses and child psychology became more prevalent which enabled autism to become subject to epidemiological studies and consequently tested for more precisely. The historical and social practices of diagnosing autism demonstrate its entanglement within the social. Sociologists such as Nadesan (2005) and Runswick-Cole (2016) argue that we must approach autism through this lens in order to aid understanding its complexity.

A specific focus was placed on the literature which determines the specificity of a diagnosis as 'giving the name' (Brown, 1990). A diagnosis is never as simple as it seems and examining the effects of a diagnosis allow a unique vantage point onto other areas. A key area that is of interest to certain social theory is that a diagnosis is placed on passive bodies and functions as a device to aid social order. In this sense the diagnosis produces the disease or condition it claims to simply be naming (Brown, 1990, Duden, 1998). This labelling theory is often how autism – especially Asperger's Syndrome- has been discussed (Conrad, 2007). I argued in this section that this must be complicated to understand how autism diagnosis are 'done' and to discuss how they are always relational. I argued that the diagnosis of autism is interesting specifically because the diagnosis itself is often the end point of support and care, therefore the diagnosis is creating autistic people, but that this has a certain political and communal potential distinct from the negative understanding of medical power acting on passive bodies. Consequently, the final section of the chapter discussed how these knowledges of autism do

not only exist at the level of diagnosis or sociological analysis but come to create subject positionings and identity formations through the idea of neurological difference. These subject positionings are reliant upon the formations of diagnosis and of wider conceptions of the human.

The next chapter 'Autism and Gender' will address the key literature around the second big question in autism research: is the gender diagnostic ratio the correct picture? As I will discuss in this chapter, many AFAB people engage in processes of normalisation through 'masking' or 'camouflaging'. This presents a key challenge to what the category of autism is if it can no longer be observed in behavioural diagnostic settings. This privileging of visibility being the key to both the identity one assumes and is presumed to have will be discussed in detail in chapter four, the first analysis chapter (Samuels, 2002).

Chapter Three

Autism and Gender

3.1 The gender disparity in diagnosis rates: Is it the correct picture?

The history of autism has always cited a gender ratio which documents higher rates of boys and men (Frith, 2003, p.59, pp.65-66). Understanding this disparity in the gender ratio is the second main area in autism research (Hollin, 2016, p.210). The National Autistic Society cites a speculative gender ratio of anywhere between 2:1/15:1 male/female split (The National Autistic Society, 2017). These figures have led to numerous debates around whether they are an accurate representation of the gender division in the UK's autistic population (Atwood, 2006, Hurley, 2014, Gould and Ashton-Smith, 2011, Wing, 1981). These considerations centre around two ideas: is autism simply less prevalent in women and girls, or does autism occur to the same, or similar rates, to men and boys but it is simply being missed.

Questions consequently arise around the following areas: have those assigned female at birth (AFAB) have always been autistic and now the category has widened once again through increasing knowledge to be able to include them? Do AFAB individuals, through socialisation or biological differences, display autism differently so they are not visible as autistic? Is autism framed through its connection to maleness which in turn makes autism in AFAB people unthinkable and unidentifiable? Or, is there something inherently and biologically male about autism? Suggestions as to whether autism is being missed in AFAB individuals often cite a failure of the medical community who are the first point of referral for an autism diagnosis (usually from primary care such as a GP or possibly from secondary care such as a Community Mental Health Nurse) to consider the gender norms which may force girls to mimic other girls without autism to escape stigma (Gould and Ashton-Smith, 2011, Giralli, et al, 2010).

That autistic AFAB individuals mask their autism by mimicking other AFAB individuals is a prominent emerging argument in research from psychology and neurology which has recently gained traction (Belcher, 2016, Gould and Ashton-Smith, 2011, Attwood, 2000, Livingston, 2020, Mandy, 2019, Hull et al, 2017, Lai et al, 2017, Cage and Troxell-Whitman, 2019). Gould and Ashton-Smith (2011) argue that autistic girls and women watch other women and girls and learn how to copy the social norms common to their gender so that suspicion that they may have the condition does not arise. The suggestion that AFAB individuals with autism must perform their genders to mask their autistic traits is also presented in high profile autobiographical accounts by women on the autistic spectrum, for example, Liane Holliday-Wiley's (2014) influential autobiography *Pretending to be Normal*. This discussion on masking will be continued at the end of this chapter when it is considered in relation to theories around passing and 'coming out'.

There are also discussions around whether autism as experienced by AFAB individuals has differing manifestations and, whether bias in the diagnostic category itself is producing the gender disparity due to the diagnostic criteria being based on a male model of autism (Gould and Ashton-Smith, 2011, Belcher, 2016). Bargiela et al (2016) has suggested that there that may be a female phenotype of autism which the diagnostic tests do not account for. Thus, we must think about whether the tests devised to identify autism enact gender as a fundamental part, or even the aetiology, of autism. As Bargiela et al (2016) discuss, the tests to diagnose autism are highly standardised but that because these tests have been implemented through overwhelming male samples they do not allow for the possibility of a female phenotype when testing women and girls, and thus this may account for a greater gender disparity (Bargiela et al, 2016, p.3282). I would argue that not only do the diagnostic tools miss the specificity of AFAB individual's manifestation of autism, but that a masculine phenotype of gender is enacted through certain diagnostic tests. The ways autism is diagnosed is deeply embedded within existing frameworks of gendered norms.

For all the reasons mentioned above there is a large temporal disparity between the ages that boys and girls are diagnosed (Bargiela, 2016). On the so-called 'higher functioning' end of the autism spectrum when AFAB individuals are diagnosed with autism it is far more likely to take place in adulthood or in adolescence than in early childhood as is often the case for those assigned male at birth (AMAB) (Giarelli, et al, 2010). Bargiela et al, (2010) suggest that there is also an increased likelihood of AFAB individuals being misdiagnosed with a number of a variety of mental health diagnoses (for example, Bipolar Affective Disorder, Borderline Personality Disorder, Obsessive Compulsive Disorder) before the autism diagnosis is assigned. This alerts us to how gender disrupts and confounds the normative and prevalent understanding of autism and potentially to come some way to understanding that overrepresentation in AMAB individuals is not the correct picture. It also highlights that AFAB individuals may experience higher rates of mental distress and have concurrent disorders or previous mental health difficulties as a result of a temporal lag in diagnosis as opposed to their male peers. It is clear that being identified as autistic when one is AFAB is contingent upon various factors which rely heavily upon what we already understand autism to be. It demands that those closest to them have sufficient knowledge of autism to recognise the condition as it manifests in AFAB individuals and that the individual has adequate support to advise on seeking diagnosis. This is particularly important as many with autism do not recognise the condition in themselves, especially as younger children and teenagers.

This lack of self-knowledge prior to diagnosis is referenced in the numerous autobiographies or self-help texts which document the sense of clarity that arises when a person who knew they was different or struggled but never considered autism finds out they have the condition (Dunne, 2016, James, 2017). As Bargiela et al (2016) states from findings in her qualitative research project on late diagnosis in AFAB individuals, many with autism simply do not recognise it in themselves because it is assumed to be a male condition. Likewise, GPs, parents and educators are unlikely to assume autism in AFAB

individuals (although this is changing slowly) thus leaving the individual to the fate of chancing upon somebody with knowledge of the condition as it presents in AFAB people.

Therefore, it is also important that the AFAB individual has access to knowledges about the condition to, in the first instance, think they may have autism and in the second instance, have access to knowledges about their condition to better understand themselves as an autistic person. These interpersonal, educational and institutional factors connect together to allow autism to be diagnosed in AFAB individuals. Thus, understanding the gender disparity is only possible by understanding the contingencies which lead to diagnosis. This bares similarities to what Goffman wrote of the mental patients he worked with: '[O]ne could say that mental patients suffer not from mental illnesses, but from contingencies' (Goffman cited in Eyal et al, 2010, p.21). Though this is not to state that autism is not a 'real' entity and one that only arises through linguistic nomenclature, but rather, that these factors must be addressed to understand how autism is knowable, and consequently diagnosable, in AFAB individuals.

3.2 Simon Baron-Cohen and the Extreme Male Brain

Simon Baron-Cohen takes up the position that there is something inherently male common to autism. Baron-Cohen is currently the director of Cambridge's autism research centre and a professor of neurodevelopmental psychopathy. Baron-Cohen (1997) took up Hans Asperger's theories of autism being an extreme variant of male intelligence to suggest that aetiology of autism is to be found in the male brain. To do this Baron-Cohen proposed a theory of essential sex difference. Baron-Cohen's starting point is the over representation of boys and men with autism. Taking this as the problem to be solved, Baron-Cohen (2002) suggests that the reason for this over representation is that those who are male are predisposed genetically and biologically to having autism. Baron-Cohen argues this from the starting hypothesis that the non-autistic male population have lowered empathic and higher

systematising traits and consequently the autistic brain is an exaggerated version of this (p. 249, 1997, p.8). Baron-Cohen argues that these traits are the result of exposure to excess pre-natal testosterone (2005, p.9). These heightened levels of exposure, states Baron-Cohen: '[...] may be pushing the autistic brain to develop beyond the typical male [...]' (p.90). Thus, it is not a great leap for boys to have autism, but it is much harder for girls to have autism. There may be certain biological and genetic 'protective' factors for girls which may offer partial reasons for the gender disparity in autism diagnosis, but Baron-Cohen problematically suggests that gender differences should be understood as biological sex differences and that the two are one and the same.

To make his claims that autism is a version of the 'extreme male brain', McCabe and Timmini (2016) suggest that Baron-Cohen took up ideas from his influential work on the Theory of Mind Module (ToMM) (Baron-Cohen, 2002). Baron-Cohen theorised that those with autism lack an ability to understand what is going on in the mind of another person and that understanding why this deficit exists would be the key to understanding where autism emanates from (McCabe and Timmini, 2016). However, used as a tool to uncover a biological aetiology of autism, ToMM was not successful so Baron-Cohen turned to thinking about what motivates and allows for human beings to have a theory of another's mind. Baron-Cohen suggested that what we ought to be thinking about is whether autistic people lack empathy and that this is the reason for a lack of ToMM. Baron-Cohen hypothesised that the focus on objects over people and the impaired sociality of the autistic mind suggested a highly systematic, logical and rational way of thinking and perceiving, much like the non-autistic man. Women, in his opinion, are much more likely to be empathic and have highly developed social skills. As Baron-Cohen (2002) writes: '[T]he male brain is defined psychometrically as those individuals in whom systematising is significantly better than empathising, and the female brain is defined as the opposite cognitive profile. Using these definitions, *autism can be considered an extreme of the normal male profile*' (p.248, italics in original).

Baron-Cohen does not suggest that all those assigned female at birth have a female brain, or all assigned male at birth have a male brain, but rather in his triad of asocial free floating brains there is the female, the male and the autistic brain (1997, p.3, 2002, p.249). Thus, an assigned female can have a male brain and vice versa. This of course makes a very simple way for Baron-Cohen to account for autism in women whilst still maintaining autism's connection to essential maleness. This also, as Evans (2013) suggests, allows for Baron-Cohen to engage with some of the earlier theories of autism as a disorder of ego but it does not attempt to infer or speculate on the psychic processes (p.24). Through this conflation of gender differences and sex differences, Baron-Cohen enacts gender as a part of what autism is and gender becomes an observable set of behaviours which can be assessed for autism.

As Baron-Cohen (2005) writes: '[T]he EMB [extreme male brain] theory was first formulated by Hans Asperger as a clinical anecdote more than sixty years ago. In the last decade it has been reformulated to be *psychologically testable*. Using psychometric definitions of typical male and female brain, people with autistic spectrum conditions show an exaggeration of the male profile' (p.13, own emphasis). This enables Baron-Cohen's research to be implemented in standardised behavioural tests such as the Sally-Anne test and the Empathy Quotient (EQ) which also have the potential to be utilised for epidemiological and statistical data collection.

The EQ is one of the initial questionnaires that is given to individuals who may have autism and is implemented as standard in the NHS.¹⁵ If there is a high score on the EQ further assessment may be considered (Asperger's in Frith, 1999, Baron-Cohen, 2002). If we agree with the arguments that autism may manifest differently in women or that women mask their autistic traits, then Baron-Cohen's EQ test based around his hypothesis on an extreme male brain may gather results of a higher male to

¹⁵ This test and variants of it can be found online for self-diagnosis. See: <https://psychology-tools.com/empathy-quotient/>

female split. The EQ test may not allow for AFAB manifestations of autism to be picked up upon if they exist outside of this framework of maleness.

More recently in 2018, Baron-Cohen made the headlines again when he suggested that a new and larger study confirmed the extreme male brain hypothesis (The Conversation, 2018). From findings devised from 7,000 online survey participants hosted by the website for the U.K TV channel '4', Baron-Cohen argues that being autistic does not make one 'more male' but that the traits map onto shared masculine traits and a lack of empathy. Baron-Cohen and his team do not situate these masculine traits as purely social or biological but as an entanglement with the social and biological. Although again, Baron-Cohen fails to note the inclusion of the bias of the medical professionals in the construction and materialisation of autism. Baron-Cohen notes that AFAB people have been overlooked and concedes that many AFAB people are likely to be undiagnosed, but he holds fast to the idea that sex difference is partially responsible for diagnostic rates citing more men than women.

It has been historically difficult to notice women and girls with autism as they operate outside of this framework of maleness. In Hans Asperger's (1991) case notes it is evident that he could not see autism in women even when he was confronted with a mother who manifested the same behaviours and affect as her autistic son who was in his care (p.51). Edith Sheffer's (2018) historical study discusses Asperger's apparent contempt for the girls in his care who displayed ASC tendencies. Asperger described them as 'disruptive, manipulative and untreatable' (Sheffer, 2018). Stuart Murray (2008) has further stated '[A]utism, it appears, can be understood best when seems in terms of the male character, and while its presence in females cannot be denied, it seems more difficult to map an idea of the condition on to the generalised sense of what we believe women and girls to be' (p.140). Giarelli et al (2010) suggest that this reliance on autism being manifested in typical masculine patterns of behaviour is partially to be held accountable for diagnosis disparity between boys and girls. Giarelli et al (2010) also suggest, as have others, that there is sometimes an unwillingness for those in close

professional capacity (such as teachers, nurses, social workers and sports coaches) to suggest that an AFAB person begin the referral process for diagnosis due to an ignorance about the occurrence of autism in girls or an inability to see certain behaviours manifested by girls as autistic traits (Posserud et al, 2006).

3.3 Sociological Responses

Gillis-Buck and Richardson (2014) have argued autism shows a gender ratio disparity as equal to other cognitive disabilities when we reach the so called 'lower functioning' end of the spectrum (around 2:1 male to female) (p.2). So, we must ask, why the specific interest in gender and sex difference and its relation to autism? Autism holds a strange place both medically and in our cultural and social understanding of the condition. It seems to offer a window onto something uniquely human, our ability to socialise and form connections and bonds with other human beings. Gillis-Buck and Richardson (2014) argue that the inclusion of Asperger Syndrome into the autistic spectrum in the 1990s allowed for autism's specific connection to maleness to be formalised (p.3). At present, the Asperger Syndrome gender ratio is anywhere from 16:1 to 3:1 and there are no accurate figures due to there being no studies done on a large enough scale to validate or invalidate this disparity (National Autistic Society, 2019). Asperger's Syndrome is tied to cultural understandings of genius, of rationality, of overachievement in the educational and vocational areas of science, technology, engineering and maths, and the over representation of boys and men with the condition is taken up to suggest there is something inherently male about autism. Due to the inability of many with autism to engage easily in normative identifiers of social behaviour and coupled with the excellent and diverse skills many have; autism is positioned as allowing an insight into both the excess and the limits of our existence as human beings. Specifically, as Dan Goodley (2016) argues, it offers an insight into the excess and limits of normative, European rational man born in Enlightenment (no pagination, Kindle edition).

Goodley (2016) suggests that the connection of maleness that Baron-Cohen gives to autism through his work at Cambridge University lends autism a level of 'prestige and recognition' which has been little afforded to other learning disability and related conditions (no pagination, Kindle edition). Yet, of course this prestige and recognition doesn't necessarily extend to improving the lives of those who are autistic. Autism is said to speak to the human condition, but if the universal human is *a priori* man, then it can only be in dialogue with a very narrow idea of the human. Goodley suggests Baron-Cohen's research depoliticises gender as it individualises and essentialises maleness, with femaleness as its binary opposite (no pagination, Kindle edition). Goodley's critical engagement with autism and masculinity in modernity states that to understand what autism is, we must also interrogate our current configurations of what a man and women are and how autism comes to represent the limitations and the potential of maleness within the gender binary.

Cheslack-Postava and Jordan-Young (2012) take up the overrepresentation of boys and men with autism to argue in their paper *Autism Spectrum Disorders: Towards a Gendered Embodiment Model* that the scientific methods and empiricism used to identify the sex differences often believed to be the aetiology of autism conflate sex with gender in an unproblematised way. They begin by giving a breakdown why being assigned female at birth may have protective factors. Namely, that when a co-morbid intellectual disability is diagnosed (an IQ below 70) then the gender disparity goes as low as 1:2 male/female divide, this could account for the overrepresentation of men and boys with what was called Asperger's Syndrome because the disparity levels out significantly when diagnosing classic/Kanner's autism (p.1668). Likewise, two X chromosomes are cited as a protective factor in girls not developing certain disorders which are X-linked. Fragile X disorder is cited as an example because it is far more often diagnosed in boys and if it occurs in girls it is far less severe, but when it does occur up to 30% of them are cited to have a co-occurring autism diagnosis (p.1668).

Although Cheslack-Postava and Jordan-Young cite these as potential protective factors in select assigned female cases, they suggest this is not sufficient to suggest that there is a fundamental biological male/female difference which can be said to cause autism. They argue that the behaviours of autism which are commonly discussed as though they were innate biological sex differences, such as in Baron-Cohen's research, cannot be separated from the social gendered environment. Engaging with Fausto-Sterling's (2005) feminist work on the intraconnectivity of biology and the social on bone density across different social and cultural demographics, Cheslack-Postava and Jordan-Young argue that autism needs a detailed consideration of the gendered social world as it interacts with the biological matter of the body, as this may be at least partially accountable for the gender disparity in autism diagnosis rates.

Sex based biological and genetic differences are generally distinguished from socially (re)produced gender roles. Yet, Cheslack-Postava and Jordan-Young suggest that in many research projects around autism sex and gender become one, and gender ceases to exist. As they suggest: '[T]hough sex and gender may be conceptually distinct they are often in practice inseparable' (p.1668). Baron-Cohen's research that suggests that the systematising brain is a mainstay of the male brain is one example. Baron-Cohen's evidence to back up his claims that male and female brains are solely genetic and hormonally constituted relies upon socially and culturally normative understandings of men and women. Baron-Cohen (2002) suggests that the fact that more women work in care jobs or educating roles and more men in the STEM subjects forms objective evidence that men and women have different brains with different aptitudes and limitations. It is as though the social world and social oppression and sex/gender/class/race-based privilege did not exist for Baron-Cohen (though he may slowly be coming around to the idea in his later research (The Conversation, 2018)).

Cheslack-Postava and Jordan-Young suggest that rather than rehashing the sex is biological and gender is socially constructed argument we ought to consider the possibility that there is an impossibility of

separating the two into distinct spheres of influence. Rather we should refer to sex and gender as sex/gender to highlight the inseparability of the two as they interact in and on the locus of the body. As they state: '... it is not possible to separate the individual's gendered biography from their biology – in fact from the moment of birth, gendered processes literally *become* biological' (p.1668). Thus, a framework better suited for understanding autism would be one which looked to more complex social interactions on infants which pay attention to neuroplasticity and the effects that gendered interactions have on the developing mind. Indeed, it is strange to consider that whilst our brains are considered to be plastic, in these essentialised sex-based configurations neurosex/gender is not affected by the social world. Gillis-Buck and Richardson (2014) follow on from this argument to suggest that the conflation of sex and gender within autism research suggests that autism is becoming a lens through which to identify the aetiology of essential sex difference. In this way *autism becomes a disorder of gender* (p.2, own emphasis).

3.4 Gender Trouble in Autism

Taking up the suggestion that gender is given far too much importance in autism research and that this interest in gender and sex differences does not match how autistic people think about their gendered identities, Davidson and Tamas (2016) present an interesting argument about the performative nature of gender in autism. They argue that because autism is a condition of social impairment and gender is a social construct which is produced and reproduced through the repetition of gendered acts that the performative nature of gender is made visible most clearly through those with autism. As they suggest, for autistic people gender is performance rather than performative. Davidson and Tamas (2016) suggest that this central positioning of gender as it relates to autism should be reconsidered through the gendered experiences of those within the autistic space. They argue that for autistic individuals, gender never becomes reified in a normative form. This they suggest, offers both an argument against the pathological connection of gender to autism and simultaneously offers a critical tool for feminist

theory. As they argue: '[C]learly, the approach makes something strange not just out of autism, but of gender itself, drawing the phenomena out of the social ether to give it an oddly prominent form and place in autistic lives, that [...] it doesn't quite deserve to have' (p.61). They draw attention to the ways that autism people experience their gender highlights the way that gender becomes reified and naturalised.

Indeed, through my research I have discovered that there is something about autism that troubles gender and that many on the autistic spectrum do not identify solely as cis gendered women or within the gender binary. Recent figures from the Tavistock Gender Identity Development Services, suggest that there is a doubling of young people accessing the services each year since 2010, and within this group there is an overrepresentation of those with autism or those who are clinically observed to have autistic traits (unpublished, own correspondence). Those accessing gender clinics with autism have been placed as high as 19% in the years 2015-2016 by the Tavistock (unpublished figures, own correspondence). Historically there have always been greater numbers of AMAB individuals accessing gender identity services, however in the last five years there has been an increase in assigned females accessing gender clinics and figures currently cite around 30 percent assigned male and 70 percent assigned female accessing these services. Of those assigned female, Tavistock research suggests, as high as 19 percent present with co-occurring GD and ASD. Of course, these figures only identify those who attend gender clinics and are known to clinical teams and many others may never come to the attention of gender clinics for a variety of reasons.¹⁶ This overrepresentation of people with ASD and gender identity is taken up by Davidson and Tamas (2016). Through their usage of online social media sites as researchers they found autistic people to be representing themselves and their gendered identity online as far more likely to be gender queer, non-binary or trans.

¹⁶ I discovered that certain gender clinics give the EQ test as part of the referral process. Anecdotally, this highlights the prominence that this correlation has and how gender identity and autism are being considered as potentially related.

Drawing on Judith Butler, Davidson and Tamas (2016) suggest that thinking about gender through and with people who have autism the ‘incessant enactment’ or the performative nature of gender becomes transparent (p.62). As the authors argue, there is ‘[...] no more articulate and radical account of the entirely fictional thing that gender is, than that which emerges from people who don’t have to unlearn its rules’ (p.63). By this they mean that for autistic people *doing* gender, assumed to be learnt naturally and unthinkingly by non-autistic people, is a conscious effort. People with autism must learn to perform normative genders in a way which is a great ‘emotional labour’ for them (p.59). The unquestioned assumption that gender is unconsciously performed by those without autism could, of course, be challenged by thinking about lesbian or gay subjectivities. Some of whom may trouble gender in non-normative performances which subvert the heterosexual matrix either by choice or not (Butler, 1993, p.313). Yet, Davidson and Tamas (2016) argue that it is precisely because autism is a fundamental condition of social impairment that the social nature of gender becomes apparent. They argue that the overrepresentation of autistic individuals who cite some form of gender trouble affirms this position (p.60-61).

Davidson and Tamas (2016) suggest feminist and gender theory could engage with gender as it is experienced through those with autism in a way through which the naturalised modes of doing gender can be undone and thus the fictive nature of gender can be shown. Thus, the figure of the gender queer autistic could be used to further certain sections of feminism’s assertion that gender is linguistically and socially determined. However, there is a theoretical contradiction in terms at work within this paper. Whilst, on the one hand, gender is set up as being purely imaginary and fictive, on the other they position reification as the process in which gender becomes separated from reality. They name gender as experienced by autistic people a ghost or a spectre. This naming as it is used pertaining to reification cannot help but to position the autistic individual as some kind of historical prophet, one who in dialectical fashion opens the way to a new genderless world. This, as I shall show briefly, is what the rhetorician Jordynn Jack (2012) does in her figuration of a gender copia.

Consequently, Davidson and Tamas (2016), perhaps uncritically (unwittingly?), engage with the idea of reification in a way which rather than undoing and untangling the institutional and ideological modes in which gender becomes both materialised and naturalised, they reiterate the idea of some essentialness to gender, having something pre-social and individualised which through the autistic individual we may have access to the *truth* about gender, even if that truth is that there is no such thing outside of the social. This perhaps fetishises autism and its connection to gender by using it for the aims of gender theory and could also be said to be suggesting that autistic individual's gender trouble is a result of their autism. The idea that autism causes confusion to one's gender identity is seen by many as a reduction of their identity to pathology once more. This argument has also featured in several problematic medical case studies which reduce trans identities to being caused solely by the patient being autistic (Landen and Rasmussen, 1997).

A similar position to Davidson and Tamas (2016) is taken by Jordynn Jack (2011). Jack also focuses on the overrepresentation of non-binary identities in the autistic community. The people who Jordynn Jack chooses to reference from online blogs do, indeed, overwhelmingly confound binary understandings of gender. Jack suggests that the social character of gender is not intuitively understood by autistic people and has to be learnt and repeated consciously. As Jack (2011) writes:

Due both to their ability to denaturalise social norms and to their neurological differences, autistic individuals can offer novel insights into gender as a social process. Examining gender from an autistic perspective highlights some elements as socially constructed which may otherwise seem natural and supports an understanding of gender as fluid and multidimensional.

(p.24)

Jack takes a position similar to Davison and Tamas (2016) in that she suggests that feminist and gender studies scholars can mobilise an autistic perspective of gender to understand how gender is formed, created and understood through utilising a range of available discourses. Jack (2011), also using Butler's terms, suggests that gender is a performance for autistic people rather than it being performative. Jack (2011) seems to position a utopic space of gender whereby one can choose their gendered identity. However, there is something missing in Jack's (2011) analysis in that whilst she explicitly highlights that her sample of autobiographical writings has been selected from online forums and blogs, she neglects to discuss this particular medium as being important in the freedom to express one's chosen gender. It is unlikely that this utopic space of gendered multiplicities (what Jack terms as a 'copia') could exist offline. In Jack's (2011) discussion a radical gender trouble is positioned within the individual autistic. Jack ignores the social norms and restrictions that are at play in the offline world which may, and most likely do, restrict the offline autistic embodiment of gender queer identities.

3.5 Masking, Passing and Coming Out

Medical understandings of masking

Where gender makes another appearance in autism research from the fields of psychology and neurology is in discussions of 'masking', otherwise known as 'camouflaging' or 'compensation' (Hull et al, 2019, Livingston et al, 2020). As discussed briefly in the beginning of this chapter, in recent years the purely observational diagnostic techniques for diagnosing autism have been challenged by an emerging understanding that many autistic people do not always demonstrate their autism visually and that they may 'mask' their autistic traits by copying learned neurotypical behaviours (Atwood, 2006, Cassidy, 2018). This has specifically been related to AFAB individuals and it is argued that AFAB people are said to mask more and to cover their autism through exerted efforts of gendered normalisation (Mandy, 2016, Lai et al, 2017).

A recent study suggests up to 70% of autistic adults mask their perceived differences (Cage and Troxell-Whitman, 2019). Masking has been documented as being more prevalent in AFAB individuals (Hull, et al, 2019, Atwood, 2007). Leading autism psychologists Judith Gould and Jacqui Ashton-Smith (2011), Tony Attwood (2006, 2007) and Simon Baron-Cohen (2019) have all suggested that some autistic people- predominantly AFAB individuals- may 'mask' their autistic traits through performing normative gendered behaviours and roles to avoid being seen as strange or not normal (Holliday-Wiley, 1999) . As Gould and Ashton-Smith (2011) have argued, this leads to predominantly AFAB individuals being 'missed' from diagnosis or 'misdiagnosed'. A different phenotype of autism as it manifests in AFAB individuals has been proposed by some as needed to understand this phenomenon and that, as such, diagnostic materials are needed to change accordingly (Kopp and Gilberg, 2011, Milner, et al, 2019).

A recent comparative study by autism psychologists Livingston et al (2020) examines what they cite as 'compensatory strategies in adults with and without autism'. The authors suggest that the compensatory theory may be relevant to understanding why many autistic individuals are not diagnosed until adulthood due to the diagnostic focus on observable behaviour. Compensation theory acts as an umbrella term which encompasses masking alongside several other categories which address the processes of hiding difference or working around perceived problematic behaviours for the individual. A key finding from Livingston et al (2020) suggests that compensation techniques are not strongly related to the diagnosis of autism. As the authors (2020) write: 'is it not diagnosis *per se* that prompts compensatory strategies' and that '[T]his novel finding indicates that it is more autistic traits (or insight into these), rather than a feature of diagnosable autism (e.g. knowing you have a diagnosis that makes you different from others) that is linked with greater compensation' (p.14, p.13).

This suggests that autistic people feel compelled to 'mask' much more consistently and intensively prior to the diagnosis. This is significant for this present thesis because it suggests a potential for the

diagnosis itself to alleviate some of the pressure of trying to fit in. If it is more prevalent for assigned female at birth individuals to mask then we can presume a gender component to this imperative, this will be examined in the analysis chapters. The idea that prior to diagnosis masking is more prevalent is further suggested by discourses around masking emerging from the autistic online community, as will be discussed shortly. This also relates to the discussion from the sociology of diagnosis section of the literature review in that the diagnosis functions as an emancipatory tool.

These cited medical explorations do not ask why undiagnosed autistic people feel they must mask, camouflage or compensate, why AFAB individuals might mask more, nor why the diagnosis may engender a feeling that masking is no longer so important. In not critiquing the governing norms of the social as producing normative bodies, these studies could be argued to be reproducing the ableist hegemonic norm and can be arguably a site of the reproduction of stigma. In this sense, Erving Goffman's (1990) work on stigma from 1963 still bears relevance in thinking about how the individual comes to experience themselves as non-normative or in some way stigmatised. As Goffman writes: '[...] the stigmatised individual is likely to feel like he is 'on', having to be self-conscious and calculating about the impression he is making, to a degree and in areas of conduct which he assumes others are not' (p.25). Stigma is mapped onto certain embodiments (e.g. burns victims, amputees, cancer patients) and identities (e.g. race, sexuality, class) through ongoing productions of hierarchised identities and this, of course, impacts on the individual's understanding of the self. Thus, masking or camouflaging can, then, be understood as the 'management of a spoiled identity' (Goffman, 1990). What is different to much of Goffman's understanding of stigma is that what the stigmatised difference *is* is not fully known by those who mask because prior to diagnosis – or self-recognition of autism- the difference is not visible nor has it yet been named. There is a sense that what is being masked is an as yet unnamed difference from normality. Attempts to enact normativity often focus on enacting a gendered normativity because of the foundational importance gender has to subject formation. As

Judith Roof (2016) has noted: '[...] to gender is to signal, mask, obscure, suggest, mislead, misrecognize [...] Gender's job is to make the subject fit' (p.1).

Taking the mask off

Understanding masking techniques and strategies as engaging with, and reproducing, discourses that inadvertently or explicitly present non-normativity as a 'spoiled identity' has been taken up by autistic campaigners as a form of political resistance through online activism. A recent campaign on the social networking site Twitter called for autistic individuals 'to take the mask off'. A hashtag (#TakeTheMaskoff) was used for several weeks intensely over the Summer of 2018 and has continued to be used, albeit more sporadically (Mandy, 2019). The intention of the six week long campaign was to encourage individuals to share their experiences of masking via Tweets and to also begin to enact some autistic behaviours in their everyday lives. Much of the discourse centred around how AFAB individuals were seen as bearing the brunt of the pressures of masking. The political resistance strategies that underpinned this campaign were aimed both at the psychiatric professions who many saw as enforcing masking through a diagnostic denial of alternative presentations of autism (e.g. racialised, gendered, lower support needs) and at wider society that stigmatised visible autistic embodiment. A diagnosis (self or medical) was positioned as the point where an autistic person should relieve some of the pressures of conscious normalisation, this speaks to Livingston et al's (2020) findings.

The call on Twitter to 'take the mask off', whilst aimed at enabling autistic people to liberate themselves from enforcing a normative bodily regime on themselves, conversely engenders a sense that autism politics is only able to arise from a visible (to others) difference and thus creates another normative regime. The paradox of constructing another normative regime in response to the hegemonic normative regime is summed up by Lisa Walker in her discussion on lesbian femme identities, cited in Martindale, (1997):

The impulse to privilege the visible often arises out of the need to reclaim signifiers of difference which dominant ideologies have used to define minority identities negatively. But while this strategy of reclamation is often affirming, it can also replicate the practices of the dominant ideologies which use visibility to create social categories on the basis of exclusion [...] members of a given population who do not bear that signifier of difference or who bear visible signs of another identity are rendered invisible and are marginalized within an already marginalized community.

(p.158)

In the above quotation Walker (cited in Martindale, 1997) is discussing femme lesbian identities when one confounds what a lesbian is supposed to look like and therefore faces being made invisible and excluded from both outside and within the LGBT community. To find entry and acceptance into LGBT or queer spaces one must often demonstrate their queerness through visual signifiers. This generally takes the form of some kind of gender deconstruction or subversion (Samuels, 2003, p.240). Ellen Samuels notes that one can wear pins and patches with queer insignia on them if one's gender identity is not understood to be subversive (p.240). Melanie Yergeau (2018) notes a correlation between signifying her queerness and her autism through the use of pin badges; an autistic pride badge adorns her backpack (p.135-137). Later in her book, Yergeau (2018) briefly mentions that autistic people recognise one another instinctually and makes an analogy with gaydar (a belief one can sense that another is queer): '[R]esonance is a crip-pity feeling. In autistic communities, this gut feeling- this "lust born of recognition" – is at times called *A-dar* or *aut-dar*, terms that are clever plays on gaydar. We encounter one another, and we know' (p.193). Gaydar is often formulated as something that queer people feel in relation to each other where they 'just know' instinctually that the other is also queer. The underlying – often very subtle - signifiers which enable this 'knowing' are not commonly identified. However, it is by sharing a culture that shared signifiers become known and it is therefore a distinctly

social and cultural phenomenon which privileges the visual field and the body as the site of identity. When this analogy becomes overlaid on to autism politics, we must ask what are the signs of autistic visibility and what does it mean to enforce visual signs as markers of belonging and does this position some as more justified in claiming an autistic identity?

Masking as a form of passing

In the sense that we can understand autistic masking as a series of temporally and relationally deployed embodied techniques which aim at passing as neurotypical, it points to similarities with theories of passing and, 'the flip side', coming out (Samuels, 2003, p.239). Notably, the embodied techniques of masking cannot be divorced from normative gender roles. Autistic difference can be hidden through passing as normatively and correctly gendered (Gould and Ashton-Smith, 2011). This is, as yet, an under researched area of autistic experience and embodiment. Whilst Yergeau (2017) argues that autism constitutes a form of neurological queerness, and autism psychologists such as Tony Atwood (2006), Simon Baron-Cohen (2016) and Gould and Ashton-Smith (2011) all suggest that gender is mobilised to obscure autistic difference, to my knowledge no study has taken this up as a central concern. I argue that it is important to consider how gender as an always-already normative category can be positioned as a form of passing, this will be discussed in the analysis chapters of this thesis.

There is a wealth of literature into passing from race studies (Lorde, 2017, hooks, 1992, Ginsburg, 1996, Smith, 1994, Dawkins, 2012). Passing in race theory refers to unintended or intentional acts of passing as white. Passing has also become a very popular experiential explanatory device within disability studies (Wilson and Brune, 2012, Selznick, 2014, Samuels, 2003, Titchkosky, 2001, Barnes and Mercer, 2016, Michalko, 2002). Passing has been negatively described as a method whereby an individual conceals their particular subjugated identity in favour of receiving some of the benefits of a more privileged identity (Titchkosky, 2001). This understanding of passing as depoliticised and as a passive

acceptance of oppression has been described as reproducing stigma. As Titchkosky (2001) writes: '[through passing] stigmatized conceptions of disability, at best, remain undisturbed, at worst, are re-deployed' (no pagination, online version). Passing has been used as a theory to describe assimilationist strategies commonly along the lines of race. Audre Lorde (2017) gives an example of the political resistance that underpins calls to be visible and to refuse to pass any longer:

But most of all, I think, we fear the visibility without which we cannot truly live. Within this country where racial difference creates a constant, if unspoken, distortion of vision, black women have on the one hand always been highly visible, and so, on the other hand have been rendered invisible through the depersonalisation of racism. Even within the women's movement, we have had to fight, and still do for that very visibility which also renders us most vulnerable, our blackness. [...] And that visibility which makes us most vulnerable is that which is the source of our greatest strength

(p.42)

There is, also, a particular anti-assimilationist political imperative when this rallying cry is aimed at disabled people. As Swain and Cameron (2003) write:

Coming out, then, for disabled people, is a process of redefinition of one's personal identity through rejecting the tyranny of the *normate*, positive recognition of one's impairment and embracing disability as a valid social identity. Having come out, the disabled person no longer regards disability for a reason for self-disgust, or as something to be denied or hidden, but rather as an imposed oppressive social category to be challenge and broken down ... coming out, in our analysis, involves a political commitment. Acceptance of a medical model of disability and being categorized by other others as disabled does not constitute coming out as disabled

(cited in Samuels, p.237, italics in original)

There are many things to unpack with this statement from Swain and Cameron (2003, cited in Samuels, p.237). In the first instance, they presume an unproblematised 'coming out' process where one proclaims an 'authentic' identity, and this consequently becomes a static state. This is not, of course, how coming out in the instance of coming out as non-normatively sexually orientated happens. Coming out is not a one-time event. Coming out presumes an endless reiteration to numerous others across an entire lifetime and in a variety of expected and unexpected contexts (Butler, 1990). Many LGBT people weigh up the consequences of coming out on the basis of any given encounter which implicitly or explicitly demands them to come out (Gutowitz, 2019). As Samuels (2003) writes '[...] even after a dozen gay pride marches, we must still make decisions about coming out on a daily basis, in personal, professional and political contexts' (p.237).

Furthermore, we must ask what changes when a disability is not visible. Both Lorde (2017) and Swain and Cameron (2002) position visibility – namely visible difference- as being the locus of political resistance. For Lorde (2017) the black woman is already hyper visible, so it is about acknowledging that visibility through strength and courage to make oneself vulnerable in difference and this vulnerability becomes the starting point for politics. Swain and Cameron's (2002) argument is similar; it is about reclamation of one's 'spoiled identity' as a form of political resistance through pride and being visibly different. Both Swain and Cameron (2003) and Lorde (2017) presume an already visible difference that one stakes a claim to as an identity by being critical to the subjugated position that has been marked out for those who fit its category. As Rosemary Garland Thompson, cited in Titchkosky, (2001) writes: "[T]he notion that someone with a very visible disability might "come out" perhaps seems oxymoronic to those for who the cultural assumptions that structure the normal remain unquestioned' (online version, no pagination). In this sense coming out means to come out 'from the seductive power of normalcy' (Titchkosky, 2011, online version, no pagination).

Samuels (2003) notes that there are two different kinds of coming out; 'coming out to' (which much include an object) and 'coming out (without an object)' (p.237). We could argue that 'coming out' is necessary to come out 'to'; individual acceptance or knowledge of identity is necessary to 'come out to'. Yet, implicit within both the individual and communal notion of coming out is the idea that passing is inherently wrong; that it is wrong for the individual to consider her identity as something to be evaded and furthermore, that it is detrimental to wider political movements. However, it is perhaps through passing that we have the clearest view of stigma and the production of othered identities. By examining the reasons, processes, pleasures and pains of passing we can see the political, social and cultural configurations which mark the boundary lines of the normal and the abnormal most clearly. Passing can give us a vantage point into how, where and why society must 'repress the embodiment of difference' (Siebers, 2004, p.3). Samuels (2003) also notes that passing may have its own subversive power in that it reveals both the production of identity boundaries and their instability; '[...] the passing subject may not be read as an assimilationist victim but as a defiant figure who, by crossing the boundaries of identities reveals their instabilities' (p.243).

Proving difference

Coming out as disabled when the disability is not visible brings with it a new set of challenges to those faced when one's disability, or difference, is visible. One could be charged with fraud, or not being 'disabled enough to count' (Lightman, et al, 2009). These admonishments can come from the disabled community or the wider community who do not assert or demonstrate a disabled identity. What one says one's identity is, is often not as convincing as what one's identity *appears* to be. As Titchkosky (2001) argues: '[I]n the face of trying to make visible to others what does not appear to them, the typical set of practices pursued is the seeking and offering of "proof"' (online version, no pagination). Or Gage, who writes: '[S]ome people offer such acceptance readily, others greet every statement of limitation with scepticism, and most need to be reminded from time to time' (cited in Samuels, p.239).

For non-visible differences or disabilities proof can be hard to come by, a medical diagnosis certificate can be offered in some situations, but in the majority of situations it will be through the visible movements, behaviours, speech patterns, and so on, where proof is sought and demonstratable. What passing and masking have in common is the shared insistence on the body as the key site where identity can be found. In the case of masking, a non-normative mode of being in the world is covered up by attempts of perceived normativity. Both passing and masking can be the result of choice (choosing to mask or pass in any given situation), they can also be a position that an individual is placed into (Carrington, 2020). Masking seems to suggest an individual actor who wilfully covers up a more natural, or 'authentic', way of being, however masking can be- or become- unwilful. As Livingston et al (2020) note, compensation techniques can become naturalised through repetition over many years (p.11).

The naturalisation of certain neurotypical behaviours and modes of being in the social world does not mean that the person is no longer autistic, but rather points to the mechanisms through which the body becomes normalised. This is not to say that there is a non-docile body that can be found underneath the normalised one, but that each normalising regime brings with its own regulations of embodiment (Wehrle, 2016, p.60). Thus, thinking with the idea of unmasking as a form of 'coming out' means autism must be demonstrated through the body in order to be visible to others, and even to oneself, as autistic. Though 'unmasking' could be said to be entering another normative regime, this is also the subversive power that unmasking is positioned as holding by those who promote it. As Wehrle (2016) writes: '[I]f the body has a subversive potential, then it consists in the fact that even through forced habituation the body gains forces and skills, which it can use otherwise than in the usual, normalized manner' (p.64). Consequently, coming out does not uncritically mean freedom from normalcy or from normative regimes. It does, however, mean being in a position to question normalcy and normative regimes and, to potentially, use the body otherwise. As Rod Michalko (2001) (cited in Titchkosky, online version, no pagination) states, "[T]he least normal thing we can do is to think about

normalcy." In the case of masking being related to using normative gender to cover difference, then it stands that gender might be the place where one can assert their autistic difference.

3.6 Conclusion and research questions

This chapter discussed the key areas where research is being conducted around gender and its connection, or entanglement, with autism. Beginning with the gender diagnostic ratio which has always presented higher figures of AMAB individuals, I asked the question, as others have, is this the correct picture? Several researchers from psychology and clinical psychology speculate that autism is missed in AFAB people or it is misdiagnosed (Gould and Ashton-Smith, 2011). Much research is being conducted into whether pre-existing gender bias prevents AFAB people from receiving a timely diagnosis. Despite this, certain pockets of autism research are interested in discussing whether autism can tell us something about gender; specifically, something about essential sex difference. This has led to autism becoming, in Gillis-Buck and Richardson's terms, 'a disorder of gender'. Davidson and Tamas (2016) and Jack (2011) argue that gender does not hold such an important place in how autistic people think about their identities. However, they have too argued that autism can be used as a mirror for understanding how normative ideals around heterosexual gender become reified and enacted. Thus, I argued that less than showing the processes of reification and materialisation of normative gender regimes they individualise gender trouble within the autistic person.

A crucial aspect missing from this literature is a focus on how the self is created through temporality with a defining point in narrative time being medical diagnosis. Consequently, this thesis situates the process and act of diagnosis as an interpolation which brings into being, at the same time as it pertains to give access to, a hidden truth about the individual. This idea of uncovering the truth of the subject can be found replicated in many autobiographical accounts, such as this quote on the back of a recent autobiography of a late diagnosed woman with autism: 'what do you do when you wake up in your

mid-forties and realise you've been living a lie your whole life?' (James, 2017). Furthermore, through the neurological aetiology of autism the brain is brought into sharp focus, as James writes: '[...] I obsess about the structure of my brain [...]' (p.11).

In this sense autism is positioned as an essence or ontology of the person diagnosed, and, as I speculatively argue, one that is *a priori* gendered. As autism is a neurological condition and firmly attached to the brain, does the diagnostic event come to bear upon how the individual thinks about their gendered identity? When Ashton-Smith and Gould (2011) and Belcher (2016) discuss the reasons that AFAB individuals are missed from diagnosis and suggest that they mimic or mask their autism they do not make any great leaps to challenge the normative gender regime which is at play within the discourses that make autism knowable. Likewise, they do not challenge the underlying claims to a gendered ontology of autism, rather they suggest that by diagnosis the 'truth' of the individual can be uncovered and that the act of diagnosing will be emancipatory, not merely in terms of accessing services and support but in coming to know and understand oneself under the label of autistic. I argue that this understanding relies upon an autistic subjectivity being revealed (through diagnosis) as a stable identity and this must be interrogated in terms of how one comes to understand and produce their subjectivity through the discourses that structure what autism is.

In the discussion around masking and its relationship to passing and 'coming out' we see that there is the potential for thinking about the diagnosis as not simply a moment where one's autism is revealed but as a potential imperative to enter into a new normative regime of autistic embodiment through discursive practices. What is missing in the literature cited is an examination of the ways that gender becomes implicated within masking techniques and unmasking techniques. If Hull, et al (2017), Gould and Ashton-Smith (2011), Lai, et al (2017), Atwood (2007, 2006) Baron-Cohen, et al (2015) and Cassidy, et al (2018) are correct in their assertions that AFAB individuals are more likely to mask to pass as non-autistic then gender needs to be presented as an analytical category and important

intersection of autistic embodiment. I do not mean simply using sex/gender difference as a stable category for understanding the causality of masking in relation to sex/gender difference, but to understand if masking and unmasking is always-already entangled with gender. For example, if one utilises their gender to pass as non-autistic by performing normative gendered behaviours and roles as has been suggested, then does that mean that an autistic embodiment necessarily queers gender?

Therefore, what is needed is an understanding of what the category of autistic means, how is it framed medically, socially and culturally. How do these understandings of autism become used by diagnosed individuals to construct their identities and how are they resisted? And, indeed, do they even come to matter in how autistic people think about their gendered identity? Does the pathological masculinity, or the gender trouble, that is attached to the neurology of the individual diagnosed need to be reconciled with their existing understanding of themselves? *What are the stories that people tell about themselves in relation to autism and their gender identity?*

Autism, on the so-called 'higher functioning' end of the spectrum is given most commonly to individuals assigned female at birth as adults. Thus, the diagnostic event holds an important place in the narrative of someone's life. Autism is positioned as a lifelong condition, present from childhood, and thus the act of naming autism in an individual takes on a retroactive role. This means it has the potential to explain certain behaviours, difficulties or traits which may be reconstructed into a legible autism narrative by the individual diagnosed. Given the temporal significance of many AFAB individuals being diagnosed as adults and the fact that many did not 'know' they have autism until the diagnosis, the process of diagnosis and the act of naming autism in an individual is significant. What parts of the popular and medical understandings of autism are taken on to form subjectivities and which are rejected or resisted? How is gendered identity bound within this? What is the relationship between the gendered rationalisation of autism and discursive power? These are the questions that this thesis

asks. For, as Margret Shildrick (1997) writes: '[...] the one who acts is not a pre-existent bounded being, but [...] she constructs her very self-hood in the process of normalisation' (p.54).

Chapter 4

Methodology

4.1 Introduction

This chapter will reflect on the research design which guided the data collection for this thesis. The theoretical underpinnings of this research were considered in terms of how to best answer the research questions. This chapter will begin by expanding upon the theoretical lens through which I read and interpreted my data. It will be explained why this theoretical guidance alongside the chosen methods were the most useful for this. Following this, information about recruitment will be discussed. Then, the demographics of the participants along with some background information about each one will be presented. Why this information was necessary for the analysis will be briefly discussed.

A critical discussion around the interview as the chosen method to answer the research questions will follow. A large portion of this chapter will be dedicated to reflecting upon the specificity of the research participants being autistic and how this comes to problematise the use of standard qualitative methodological frameworks, due to the difficulties in normative interactional communication autistic people might have. Consequently, different modes of communication were offered to my participants: the interview could take place in person, online via Skype through text based or image and speech or it could be written on an adapted interview questionnaire which was emailed to me or, it could take the form of an 'object focused' interview. A descriptive account of how the interview data was analysed and interpreted will follow this subsection. Certain accessibility measures were also implemented. These measures disrupted the idea of the reciprocal and interactional space of the qualitative interview as it works along normative lines, this will be discussed during the sections on the interview and the analysis of the data.

4.2 Analytical framework and research objectives

The focus of this thesis is to discover whether gendered discursive knowledges of autism are utilised in order to construct an understanding of the autistic subject by those diagnosed in adulthood. And, whether this has any bearing on how the autistic subject thinks about their gendered identity post diagnosis. Particular focus is placed upon the essentialised masculinity that is constructed through the medicalised, popular and cultural discourses of autism. Put in Foucauldian (1972) terms, the aims of this thesis are to understand ‘the processes in which dominant reality comes into being’ (p.22). The dominant reality is presented here as being the masculinised character of autism which consequently becomes essentialised through its neurological underpinning. The processes are the resources and interactions (medical engagement, technologies, internet technologies, blogs, Twitter, conversations, books, self-discipline, discursive practices etc.) which bring autism into being in a relational and ontological sense.

The ‘dominant reality’ of autism is not to be presumed to be all encompassing nor static. There is always room to create new formations through the dominant discourse. This works within the initial framework of power but can provide alternate modes of being and knowledge (Hall, 2001). With the case of autism and the production of autistic subjects I aim to uncover to what extent assigned female at birth individuals (AFAB) interact with the dominant discourse and to what extent they push the boundaries of what we understand autism to be. As I have stated previously in this thesis, I do not dispute that there is a ‘real’ to autism. However, one must be clear when they use the term ‘real’. What is the real to which one refers; which conceptual and philosophical framework is used to understand the ‘real’? This is important to reiterate when one is assuming a seemingly socially constructed view of things. A major dispute to the notion of performativity and discursive regimes is the notion that nothing exists beyond the ‘text’ (Xie, 2014, Nussbaum, 1999).

The two objects concerned in this thesis, autism and gender, are both so subjected to intense scrutiny and consequently it is not necessarily the best approach to argue that these categories are solely socially constructed without fully elucidating what is made by this claim. This approach in the wrong hands can be used to deny the reality of autistic experience and of gendered experience. Nor, can it strictly be said to be true. Social constructionists do not have to necessarily deny that certain things exist but that we understand, produce and negate them through our existence as social beings. In this I am thinking with scholars such as Elizabeth Grosz (1994), Anne Fausto-Sterling (2012), Annemarie Mol (2003), Elizabeth Wilson (2015) and Des Fitzgerald (2017) who argue for the understanding of the entanglement of categories rather than a binary of nature/culture or ontological/epistemological. Moreover, they unshrinkingly move our focus from questions of origin, depth or Truth, to an analysis of the complexity and nuance of the objects we study, even if that move forces the inevitable uncomfortableness and unsurety when one is no longer standing on solid ground.

As I noted in the introduction chapter, I do not feel beholden to sticking regimentally to one particular theoretical framework or to one particular thinker. Though I am working within the broad field of social constructionist thought, I have borrowed (and perhaps mutated) certain modes of thinking to find the evidence of the stitchery that holds together the dominant discourses of autism and gender (Haraway, 1991). As such, this thesis treats autism as a condition that is not simply socially constructed but one that can only be fully understand through examining the social conditions which enable certain conditions to emerge. I also understand autism as being deeply and inextricably connected to normative social regimes which produce autism as a category of social impairment. I understand the category of autism, once it is named and diagnosed in an individual, as being productive of ways of understanding the self and productive of new categories of people. Others have, of course, treated disability categories in similar ways (see Campbell, 2013, Nadesan, 2005, McGrath, 2016). In particular, Thomas Campbell's (2013) genealogical approach to dyslexia provided guidance to this project.

However, this thesis is not a genealogical one and it focuses primarily upon embodiment and how subjectivities are formed. I focus on the processes through which the individuals who took part in this project were able to come to the point where they could state: 'I am autistic'. This thesis is one which centres around the idea of becoming, taking as essential a Deleuzian field whereby ontologies are formed through their relationality to other things, bodies, knowledges and so on. I maintain that whilst the experiences shared by the participants in the project might be said to come from a specific difference in neurological biology, we cannot claim some singular essence to either what autism is, or how autistic embodiment is experienced (Hollin, 2017). Thinking in this way autism can be considered as multiple. As Deleuze (2004) writes:

'[M]ultiplicity,' when used as a substantive, designates a domain where the Idea, of itself, is much closer to the accident than to the abstract essence, and can be determined only with the question *who? how? where and when? in which case?* – forms that sketch the genuine spatio-temporal coordinates of the Idea'.

(p.95-96)

I argue that we cannot understand autism at all unless we ask the questions that Deleuze poses. Should we find a genetic origin of autism it would be useless for understanding autism because autism is a human condition, lived by humans, produced by humans and therefore only understood through examining the wider conditions of human life which are able to convince of 'this thing called autism' at this moment in time (Fitzgerald, 2016).

The concern of this thesis is not, however, an overview of the material, social, political conditions which enable this, but I am focusing primarily on gender, arguably, the foundational social category that orders societies, produces subjects and is the most susceptible to essentialist origin stories (Haraway, 1985). I have argued so far in this thesis that gender has been positioned as a potential cause for autism

and, vice versa, gender trouble can be attributed to autism. These two origin stories are making it difficult to see what else is at play with autistic people's understanding of their gendered identities and their autism diagnosis. Thus, this thesis looks at the objects being considered – autism and gender – from a slightly difference angle, not to find causes or 'reasons why', but to see the ways that autism and gender are always a work in progress; a becoming of.

The concept of gender I rely most heavily upon is Judith Butler's (2006, 2011, 2004) early Foucauldian influenced work; that gender is a continuous repetition and needs to be continuously reinforced and reproduced. As Butler wrote; 'gender ought not to be conceived of as a noun or a substantive thing or a static cultural marker, but rather as an incessant and repeated action of some sort' (2006, p.146). However, in much of Butler's work on gender it is hard to see *how* certain modes of gender become embodied as discursive practices and there is not a particular focus on temporality within performativity. In Foucault's conception of power, it is defined as 'everywhere' and 'comes from everyone' (Foucault, 1982). Thus, I argue in order to add to these understanding of power, the analysis of this thesis has paid attention to how autism becomes materialised as a reality for the participants of this study and aims to understand how the disparate and distinct traits of autism become understood by autistic subjects as autism. As such the interview questions were not heavily orientated to how it *felt* for the participants to have the experiences they had, but rather what those experiences were. Moreover, what was important to me was not just an analysis of how people discursively understood their gender before and after their autism diagnosis but how this affects their lives and, what material, institutional and political powers became impacted by this change.

I brought embodiment and the spatial and temporal elements of the life course to the fore in the interview to gain a sense of how and where power becomes a material phenomenon. In this way I was able to determine whether a diagnosis of autism brings into being new categories of people and new categories of the self. I am not arguing that the moment of diagnosis will necessary function as simply

as a singular event but that it may act as an interpolation which must be repeated and habit forming before one can say: 'I am autistic'. It might not necessarily mean that the participants will consider themselves as neurological subjects, and as masculinised ones through virtue of this, but, this research seeks to uncover what is *done* with these knowledges about autism: are they discarded, are they taken on as modes of being or as discursive practices, are they resisted and in what ways? Does autism as a diagnostic category, as it is embedded within power networks, engender any change in the subject? Did the diagnosis function as a diagnostic event? That is, did it bring a new reality into being in the form of a new set of discursive practices enacted through and on the body? In what ways is gender and gendered embodiment entangled with autism?

As such, the research questions which guide this thesis are as follows:

- 1) Does the diagnostic category of autism act as a discursive event and a gendered technology of power for late diagnosed autistic people?
- 2) How do autistic people assigned female at birth produce a sense of the autistic self through the existing discourses of autism?

4.3 Recruitment of participants

Recruitment for the study utilised a mixture of online and offline standard practices in recruitment (Eide, 2008, Macdougall, C., and Fudge, E., 2001). Two posters were designed for the study, including one which was 'dyslexia friendly' (see appendix 1). Autism and dyslexia are commonly found together and even if dyslexia is not present, using text and colour in line with dyslexic accessibility measures can aid reading ease for people who have sensory issues which are also common to autistic people (Autism Help, 2019, Bogdashina, 2016). This poster was free of information other than the necessary key

criteria for interested participants and an email address to express an interest for more information. The poster was printed on coloured paper and used a larger font type with spacings in accordance with dyslexia guidelines (British Dyslexia Association, 2019). This consideration of the accessibility of recruitment material is essential for gaining a wide range of participants with varying accessibility and/or support needs and it is seemingly neglected in wider psychological and sociological (primarily) non-autistic researcher led autism recruitment guidelines, of which there are few (see: Gowen, E., et al., 2017, Fletcher-Watson, et al., 2018). The second poster included more information including more details around the project and organisations which provide support for autistic and LGBTQ autistic people. The two posters were placed close to one another in public places.

The posters were placed by the researcher in a variety of places across Leeds. LGBTQ friendly spaces were chosen as research suggests that a higher proportion of autistic than non-autistic people identify as LGBTQ (Georges and Stokes, 2018). Addiction services and homeless organisations were also targeted as the scant preliminary research on the area suggests that autistic people are disproportionately affected by drug and alcohol addiction and homelessness (Churchard et al., 2018). Leaving posters at these organisations was also tactical in order to attempt to gather a mixture of class and racial backgrounds for the study. As recent government reports suggest racial and ethnic minorities are disproportionality effected by homelessness (Race Disparity Office, 2018). Those from working class backgrounds are more likely to utilise these services, in part due to poverty and essential service cuts disproportionately affecting that demographic (Shelter, 2019). Posters were also left in several Universities, colleges, arts organisations, social spaces and music venues across the city of Leeds, U.K.

When it was not possible to visit an organisation or venue to leave recruitment materials these were emailed to the appropriate stakeholder to circulate the information. Posters were also mailed to several organisations with a request to place the posters in an appropriate space. The main concern

with asking organisers or support service management to circulate information was that they, in effect, act as a gatekeeper to recruitment and there may be a level of coercion if a participant felt inclined to contact me because of personal relationships with the gatekeeper. To alleviate this risk, I requested that posters be put up but that I did not need the information to be verbally relayed or discussed in a group or individual setting. This encouraged full informed consent on the part of the interested participant and the project could not be seen to be specifically endorsed by key workers or support group workers.

However, despite the physical presence of these posters across the U.K, including the major cities of London, Edinburgh, Leeds, Bradford and Birmingham, the most successful method for recruitment was on social media and, in particular, the networking platform Twitter. All eight participants who have taken part in this project responded to the recruitment call through Twitter (see appendix 2). As has been noted by Benford (2008), increased use of the internet technologies has functioned as a great emancipatory tool for those with autism. For those who cannot often leave the house due to physical disabilities or sensory issues and those for whom social and communication disabilities make it difficult to meet and communicate with others, the internet functions as an incredibly powerful assistive technology. What became clear in the recruitment stage of the research is how incredibly important the internet to those with social or physical accessibility issues. I engaged in autistic online communities on Twitter, I was clear about my status as a researcher who isn't autistic, and it is through these autistic led discussions that I believe many challenges to the stereotypes of autism are emerging and that these are influencing research aims and areas, including this particular research, in a form of 'looping' as Ian Hacking (2006) names it. This presents the idea that participants in research such as this are not merely objects of study or resources to be mined, but are active participants in the shaping of research designs and theoretical enquiry of the study of so-called human kinds (Hacking, 2006).

What is most illuminating is the challenge that internet based autistic modes of communication bring to the stereotype that the autistic mind is lacking reciprocity, due to a lack or deficit in empathy (Baron-Cohen, 2001, 2012). What is shown time and again online is the ability that autistic people have for humour, empathy and reciprocal conversation. As Yergeau (2018) writes if you talk with or observe these online communities all residual caricatures and outmoded stereotypes fade away. Indeed, to refer back to Hacking (2006) we might suggest that the use of internet by autistic individuals, communities and autistic activists has aided in debunking this historical understanding of the autistic mind. In part, the belief in the deficit of empathy and lack of what Baron-Cohen cited as 'theory of mind' stems not from the autistic individual but from the behavioural modes of identifying autism in a hierarchised clinical setting. As I have discussed in the literature review, the shift to behavioural observational techniques in the clinic placed the focus away from the psyche or the inner thoughts of the patient onto the observable and visible ways in which she deviated from the norm (Evans, 2013).

The autistic voice (here voice points to interiority, to subjectivity) was not often heard in the form of signifying meaning outside of signifying simply autism (Dolar, 2006, Yergeau, 2017). Indeed, the trope of the speechless autistic individual and the experts who are necessary to speak for them is represented through the very naming of the *Autism Speaks* organisation which reifies autism as distinct from autistic people and, ironically, the organisation has no autistic people on its board (McGrath, 2016, p.4). It is of course not correct that all autistic people can speak in the sense of verbal communication, but we might rightfully argue that all autistic people (and non-verbal people who do not sign) can communicate in one way or another (see Melanie Yergeau's (2017) discussion on 'shit smearing'; or consider utterances, tics and echoalia, for example).

Moreover, when those with autism can speak such as with many people who would have been given an Asperger's diagnosis, then that speech is still pathologised and, though not included in the diagnostic criteria, used as one of the non-official indicators for potential autism (Autism Society,

2019). The speaking autistic person has an untimely voice: they are verbose before their years; they are 'little professors' lecturing on their chosen subjects from small children; they are not so distant future hybrids of machines/humans with their 'robotic voices'; or they are stuck in time with 'childlike' voices way into adulthood (Baron-Cohen, 2002, p.189, Bonneh, Y, et al., 2011, Marshall, 2013).

Whilst some autistic people can communicate verbally, others may not be able to communicate verbally either at all, others still can communicate through spoken language but only with great difficulty. The widespread usage of the internet technologies and the particular use of them by autistic people compels us to update and rethink *how* we engage with autistic communities as researchers in order to begin to hear autistic concerns and issues from autistic people themselves. We must pay attention to the ways that autistic people feel most comfortable and are able to relay information. The interactions I have had with autistic people online led me to adapt my data collection methods to include the possibility for engaging with the research questions via a text based medium, either through online platforms such as the Twitter chat function or Skype, or by filling out the interview questions and posting or emailing them back to me. I also offered the option of having an 'object based' interview; this will be elaborated upon further in the 'interview' section of this chapter. Certain adaptations to the interview space were also made; these techniques will likewise be returned to in the interview section of this chapter.

Consequently, Twitter became the main platform for recruitment. However, using this platform is of course not without its limitations. Despite seeking to find a participant group which was representative of a wider group of autistic adults diagnosed in adulthood I only received requests for information from those who had received higher educational training and who were in steady employment. Racialised and working-class voices are missing from autism research more generally. Recruiting via Twitter meant that I also received interest from those with the social and cultural capital to be able to engage with a researcher and also the means to use a computer and to have the time and freedom to

take part in an interview, which likewise delimits the range of participants I connected with. Another demographic that is missing is those who have more support needs. As Mark Osteen (2007) comments, autism research from the humanities and social sciences whilst often being routed in foundational disability politics often fails to engage with those who have higher cognitive or intellectual support needs. In autism research this is very often the case. There is more research that examines those who are termed 'higher functioning' than those who do not fit this criterion (Osteen, 2007). This latter point will likewise be returned to within this chapter.

As Potter and Hepburn (2012) have suggested the recruitment process and its materials must be made transparent. This is in order to understand how the data collection was possible, who was attracted to take part and who was not, and to understand the ways in which the interview constructed the knowledges which form a research project. A selection of tweets, the recruitment posters and message board posts which I wrote have been included in the appendices of this thesis. By examining these it is clear that a very specific and pre-demarcated group emerged. The language I have used around autism and the gender terminology utilised only pertains to a select group of the autistic community, specifically those autistic people who have the social and cultural capital to engage with the recruitment material, and perhaps those for whom gender and autism politics are already important aspects of their lives. The particular group of people who took part in this project suggest this to be the case. This is undoubtedly an oversight in this research, and to gain a wider representational group different phrasings of recruitment material should have been used. This will be amended in future research I conduct in the future and should be a consideration for others conducting similar research.

4.4 Participant demographics and identifications

The following table shows the demographics and additional relevant information of the eight participants. All participants were given a basic questionnaire which asked for background information

(see appendix 3). Previous mental health conditions and previous neurological conditions were asked for as well as demographic information pertaining to location, class, gender and sexuality. This question was asked in order to ascertain whether a transition from a mental health diagnosis to a neurological one (if relevant to the participant) had any bearing on the individual's understanding of self.

Research conducted to date has suggested that late diagnosed autistic individuals are likely to have received input from mental health services as a result of an untimely autism diagnosis, thus I also wished to add to these statistics if this were the case (Gould, 2017., Crane, et al., 2018). The categories of gender, sexuality and class identity were all self-identified by the participants. A further question asked what the participants caregivers or parents were employed as when they were growing up as one way to determine class positioning through -albeit unnuanced in relation to the data- reference to economic wealth and security nets (Manstead, 2018). All names are pseudonyms and were chosen by participant, with the exception of the asterisked names which the researcher chose.

Name	Age	Age Diagnosed	Gender	Sexuality	(Self-defined) Class	Other psychiatric/neurological diagnoses
Esther	28	19	Female	Asexual	Lower middle class	Epilepsy
Mary*	46	44	Female	Heterosexual	Working class	Panic disorder; Generalised Anxiety Disorder; Borderline Personality Disorder; Agoraphobia
Sarah	25	21	Female	Missing data	Middle class	Dyspraxia; Anxiety; Depression
Sally	42	41	Female	Bisexual	Working class	Alcoholism; Anxiety; Depression; suicidal and self-harm behaviours
Aime*	18	18	Non-Binary	Asexual	Middle class	N/A
Hannah	24	21	Female	Bisexual	Lower middle class	Eating disorder; OCD; Anxiety
Sara	24	20	Female	Bisexual	Working class	Anorexia Nervosa; Depression; Anxiety
jojo [sic]	44	41	Female	Asexual	Working class	Anxiety; Depression; Suicidal and self-harm behaviours

(table showing demographics and previous neurological or mental illness diagnoses)

4.5 Why interviews?

If I try to give an account of myself, if I try to make myself recognizable and understandable, then I might begin with a narrative account of my life, but this narrative will be disorientated by what is not mine, or is not mine alone [...] The narrative authority of the "I" must give way to the perspective and temporality of a set of norms that contest the singularity of my story.

(Butler, 2005, p.26)

Although, it may seem unnecessary to discuss a research methodology so commonly deployed and written about so much, I want to do so in order to destabilise the idea of the so-called normative communicator being the individual owner of language and of the narrative they tell about themselves. I start this section with this quotation from Judith Butler in order to highlight how necessary it is to take the 'I' to task and interrogate the discourses, spaces of interaction and relationality which enable a temporally specific 'I' to come into being. It also addresses the issue of narration as a process which is addressed to another. Narration is never a process one undertakes by oneself; another is always present. Narration is, likewise, never an act of giving the 'truth' of yourself to another. Not only is this because narrative needs an interlocutor or an addressee, 'real or imaginary', who will interpret and analysis what has been narrated in a multiplicity of divergent ways, but also because as Butler suggests, in the act of narrating the truth of the self the self becomes separated from us (Butler, 2001, p.26).

To create a coherent 'I' the self must always make use of norms which construct it as legible and as understandable. Thus, much of what constructs a narrative cannot be the property of the one who speaks but it is constructed and constituted in its relation to others, (human and non-human), institutions, laws and so on. Butler's position is not one of a fatalistic social constructionist one whereby the self can never be known and accountable for itself, thus rendering social scientific qualitative methods useless. Rather, Butler suggests that we examine the relationality between the self and the addressee, or examine the similarities that emerge between the self and the other. This, for Butler, is an ethical problem and, for this particular research project it is useful for thinking about the ethics of interaction within an interview setting; though of course Butler did not mean it this literally. By beginning with this quotation from Butler we are also reminded that we are not owners of our communication; that it is it is not a property of an individualised autonomous self. This enables a re-thinking of the normative nature of communication which privileges certain people; those who can speak, see, hear, walk, within the normative lines.

Thus, in many ways, how I theoretically position myself in regard to thinking about autism and gender came prior to the collection of data and, even prior to the framing of the initial research questions themselves. Butlerian and Foucauldian interpretations have guided the conception and construction of this thesis. As Kvale and Brinkman (2009) state: '[W]e understand conceptions of knowledge as prior to issues of method [...]' (p.xviii). These knowledges have in doubt shaped the findings of these thesis. However, though I entered the research with a specific set of beliefs, assumptions and philosophical knowledge which I oriented myself towards epistemologically, I have aimed to be as open as possible to what I might find throughout the data collection process and to change the ways in which I position myself epistemologically if required. This openness and willingness to have my assumptions altered guided the entirety of the project and, not least, the way in which I approached interviews and the questions which I asked. As will be discussed, this methodological and epistemological openness is essential for interviews with autistic people who have been historically situated as without power to shape the discourses which intimately affect their lives. A semi-structured interview was constructed as the tool for guiding the conversations I had with my participants and it was continuously updated and added to throughout the process (see appendix 4). Interviewees were likewise asked to contribute to the building of the questionnaire ('what would you like to have been asked?', 'Is there anything you think I have missed?', 'How were the questions to answer?'). Where relevant these interview sections are included in the analysis chapters.

The interview was loosely structured around the temporality of childhood to adulthood with the medical diagnosis of autism forming a loose central point. The aim of the interview was to understand how the individual considered their gender identity pre-and -post the diagnosis of autism. A key focus to the interview was understanding whether the autism diagnosis had any effect on the individual's gendered embodiment and, whether the diagnosis acted as a discursive event bringing into being new discursive gendered regimes. It is important to note that in the interviews I *did not* ask specific questions around the essentialised and masculinised discourses of autism. How gender was

experienced as a direct line of questioning also only featured lightly, as I wished to see if it emerged in the conversation without prompting. In this approach I follow Müller et al (2017). who advise caution against assuming that what happens in medical research will be directly integrated as identity and collective understandings of the self in what Müller et al, (2017) term 'biosociality'.

Interviews were chosen as the data collection method for this research for two key reasons: firstly, to gather information about autistic people's lived experiences and their engagement with the discourses that construct autism, interviews offered the clearest way possible to ascertain this information within the time frame of this project. This information would then go on to guide the analyses and conclusions that this thesis makes. For as Kvale and Brinkmann (2009) suggest:

[Q]ualitative methods in general have [...] become endemic today in many disciplines [...] At the backdrop to the increasing popularity of qualitative methods stands what may be called a qualitative stance. From this stance, the processes and phenomena of the world are described before theorized, understood before explained, and seen as concrete qualities before abstract qualities. The qualitative stance involves focusing on the cultural, every day, and situated aspects of human thinking, learning, knowing, acting, and ways of understanding ourselves as persons [...]

(p.12)

The second key reason for choosing to do a qualitative research project with autistic people is to come to some way to what Fletcher-Watson et al (2018) term 'participatory research methods'. As Fletcher-Watson et al (2018) discuss, autism research is proliferating rapidly in many disciplines however the research is not often guided by the core issues which matter to autistic people nor is it necessarily informed 'by the values of the community' (p.2). What is at the core of participatory research is a revisioning of traditional researcher/object relationships *and* a practical application thereof in order

to address how power is unequally distributed between the researcher and participant. As Fletcher-Watson et al (2018) define it:

By participatory research, we mean incorporating the views of autistic people and their allies about what research gets done, how it is done and how it is implemented (Cornwall and Jewkes, 1995). A key principle of participatory research is the recognition, and undermining, of the traditional power imbalance between researcher and participant (Nelson and Wright, 1995)

(p.1, italics in original)

However, including autistic people in research project is not enough for this to be considered participatory, for this can fall foul of what Fletcher-Watson et al define as ‘tokenism’ (Fletcher-Watson et al, 2018, p.2). That is, it is not enough to claim the ethical validity or participatory nature of a research project simply because it incorporates the interview data of autistic people. Including autistic people into an already demarcated and finalised research project which, for example, perhaps inadvertently utilises normative and consequently potentially inaccessible methodological techniques will ensure that the power imbalance of the autistic subject and the researcher remains intact. Fletcher- Watson, et al (2018) suggest the following as key to doing ethical research that works for aims of autistic people:

Specific manifestations of participatory research might include leadership by autistic researchers, partnership with autistic people or allies as co-creators of knowledge, engagement with the community in general (e.g. via social media) and consultation with relevant individuals or community organisations. Another key feature of participatory research is inclusiveness including adapting the research environment, methodology and dissemination routes to permit the widest and most accessible engagement, or engagement from specific groups

(p.2)

I argue that this particular research project and its design has not come far enough in challenging the power structures inherent within qualitative research. I have not co-worked with an autistic collaborator for example. However, this is not possible within the remit of such a thesis. However, efforts have been made to ensure that autistic people have played a part in shaping the project. I have engaged with autistic people and communities online and offline since the inception of this project. I have sought to understand what issues concern the autistic community to shape the relevance of this project and I have updated terminology to that which is preferred and in use by the people I have engaged with. I have consulted with autistic autism experts and sought their informal guidance. I have attended autistic-led conferences in order to pay attention to the key concerns of the community.

I can perhaps sense here that it might be argued that this thesis is too abstract to be of any value to autistic communities. However, I would argue that the fundamental concern of this thesis is to discover how the medical, popular, and cultural discourses of autism shape autistic people's experiences in both positive and negative ways. This does not remain on the level of abstraction but alerts us to how important the ways that diagnoses are framed and constructed are to autistic people gaining both access to timely support through diagnosis which is preceded by gatekeepers holding correct information about autism. Moreover, it aids in an understanding of the self. Pellicano et al's (2014) study asked key stakeholders of autism research which issues were important to them and 'accurate public awareness about autism' was cited as high on the scale of relevance (p.76).

As Atkinson and Silverman (1997) state '[i]nterviewing is *the* central resource through which contemporary social science engages with issues that concern it' (cited in Rapley et al, 2004, p.16). It can be presumed that the majority of people understand what is meant by an interview. Interviews are all around us and they form an important part of our lives. From celebrity interviews, through to job interviews; the interviews function is to gather information which is deemed to be an authentic

representation of the interviewee's interiority, their past and present experiences and the ways they envisage their future selves. However, as has been stated at the start of this section, as researchers we must problematise this notion of the interview as having privileged access to the 'real' of the thing which we research. The interview must be situated as an important part of the construction of the overall procedure of data collection. It is through the interview that the narratives and discourses can be known, and it is perhaps only in that space/time that they exist for the interviewee. As Dingwall (1997) cited in Rapley (2004) suggests: '[t]he interview is an artefact, a joint accomplishment of interviewer and respondent. As such, its relationship to any "real" experience is not merely unknown but in some senses unknowable' (p.16)

There is considerable debate that suggests that the interview can never produce 'naturalistic' data, for the interview produces the data (Nikander, 2012). If the interviewer composes the questions and sets the scene, literally and figuratively, then of course it cannot be known whether the discussions that follow actually have any bearing on an individual's experience outside of the interview space. Though as Nikander (2012) suggests we should be wary of there being such a thing as naturalistic or unbiased data since all data, whether produced through interaction with human or non-human participants, has always been produced by human actors. The question of bias will be returned to later in this chapter. As this project is positioning interviews as a mode of discovering how discourse and discursive formations become embodied or interact with autistic individuals, we cannot think that the interview is a value free space where information is simply relayed and an authenticity of subjectivity emerges. The interview is one of the spaces where these discourses which are being interrogated are in a sense magnified and even created in the dialogue between the interviewer and interviewee.

In recognising these considerations around the role and purpose of interviews as a data collection method, I follow Potter and Hepburn's (2012) guides for making clear that the interview is both an

interactional space and a discursive space. As Potter and Hepburn (2012) write, key concerns for producing rigorous research that can add to academic knowledge include:

1. improving the transparency of the interview setup,
2. more fully displaying the active role of the interviewer,
3. using representational forms that show the interactional production of interviews, and
4. tying analytic observations to specific inter- view elements

(p. 556).

Following these guidelines enable the research project in its entirety to be evaluated ‘more comprehensively by readers’ (Potter and Hepburn, 2012, p.556). This in turn enables research to be followed up by interested scholars, adding to the body of knowledge. Moreover, these guidelines place the interviewer in the frame, and thus encourages better analyses and understandings of the data both by the lead researcher and critical readers of the project by providing transparency from the recruitment process to the interview. As Tim Rapley (2004) writes:

When it comes to analysing interviews, I argue that *you should analyse what actually happened* – how your interaction produced that trajectory of talk, how specific versions of reality are co-constructed, how specific identities, discourses and narratives are produced.

(p.16. italics in original)

Following Tim Rapley’s (2004) and Potter and Hepburn’s (2012) advice, when I first introduce each interview participant through their quotation in the analysis chapters I have included brief information about the interview space if possible. And, how I, as the researcher, and the participant interacted in

that space and how that enabled or didn't allow discourse between us. I have included some of the interviewer's questions for this reason. This is not simply to situate the specificity of the interview as key component in the production of meaning but also to show how adaptive methods can aid autistic people in participating with social scientific research. The specific considerations and accessibility measures of using semi structured interviews with autistic participants will now be discussed.

4.6 Autism, communication and residual myths

The interview as a methodological technique has been discussed critically but now, we must specifically address the issue of using interviews with the particular demographic of this project: autistic people. Autism is a condition which is identified by its core differences or difficulties within the realm of sociality. The medical definition which cites 'impairments' in social imagination and social communication suggests that an autistic individual may not have the ability for reciprocity in language and an ability to engage social situations (Wittke, et al., 2017). An autistic person may have a difficulty in knowing when it is their turn to speak, how long to speak for or when they have said enough on a topic. An autistic person may also have difficulties with sensory input and may struggle to 'filter' all the environmental information in such a way that they can concentrate on the primary task at hand (Pellicano, 2013, Bogdashina, 2003).

For all these reasons, it could well be presumed that using interview techniques with autistic individuals would not be the best method for answering the research questions at hand. This is of course a key issue in terms of accessibility. The choice to utilise interview methods will be discussed from this position as it is clear that this has dramatically foreclosed the participants who were able to take part in this project. However, before considering these differences from an ethical and accessibility point of view, I would like to briefly think about how these traits of autism have been reified in the discourses around disability and autism and how these have worked to figure the autistic

as that whom cannot give a full account of themselves. In this rhetoric and discourse of deficit in sociality, the autistic individual remains outside of language and isolated from an understanding of others and from a sense of the self (Yergeau, 2018). A discussion around accessibility and ethical considerations will follow this section. This will argue that in-depth considerations of accessibility issues specific to research with autistic participants, a reconsideration of what is meant by autistic sociality, and endeavouring to come as close as possible to what Damien Milton (2014) cited as 'interactional expertise' need not preclude a certain section of this population from engaging in interview-based data collection methods. As has been mentioned above this research design was informed by the guiding principles of 'participatory methods' (Fletcher-Watson et al, 2018).

Autism has often been situated as a pattern of shared 'impairments' which are more or less common across the autistic population. Though the levels of difficulty the individual will face varies greatly (Happé and Frith, 2005). These impairments lie primary within the spheres of sociality and suggest that the autistic individual is lacking in certain areas which preclude them from engaging in normative social behaviour and communication. Some of these deficits have been outlined in the preceding paragraphs and others may include an inability to 'read' social situations including difficulties in understanding facial expressions, emotions and nuance in spoken and written communication (Luyster, et al., 2011). When existing together these traits have been theorised by Simon Baron-Cohen et al, (1995) as being symptomatic of a lack of theory of mind.

The theory of mind module (ToMM) hypothesis suggests that the autistic individual has an inability to infer meaning from the behaviours and communication techniques of others in order to engage actively and fully in reciprocal communication. Famously, this was highlighted by the Sally-Anne test (Baron-Cohen, et al., 1985). Participants (importantly, the participants for this test are children, but tests using the same logic are still in use for adults in diagnostic screenings) are asked to watch a video

of two figures.¹⁷ A doll is lying in view on the table. One figure, Sally-Anne, leaves the room and the other places the doll in a box so it is hidden from view. The participant is then asked where Sally-Anne will look for her doll when she returns to the room. An autistic participant is more likely to answer that Sally-Anne will look in the box. This is suggested to be because the participant cannot infer that Sally-Anne will not have the same knowledge of where the doll is as she or he does. Answering in this manner is presumed to be indicative of a lack of theory of mind, or as it otherwise called, mind blindness (Baron-Cohen, 1997).

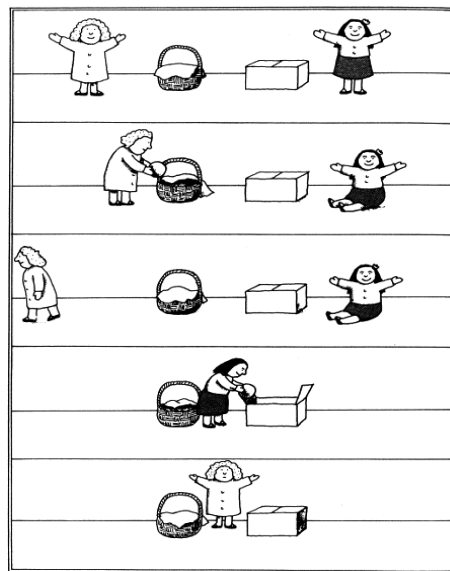


Figure 1, Scenario of Sally-Anne test. In: Uta Frith, 2001

Autism psychologist Uta Frith (2001) has argued that whilst ToMM, or mind blindness, does imply a 'failure' of communication to some degree it does not imply a 'global lack of social ability'. However, the idea of mind blindness has led to narratives of tragedy and irretrievable loss of bonds with other human beings. This can be seen in this quotation from John Tooby and Leda Cosmides in the foreword to Simon Baron-Cohen's (1997) book *Mindblindness: An Essay on Autism and Theory of Mind*:

¹⁷ Despite this test being conducted with children it still holds relevance, as many of the diagnostic screening tests have not yet been updated to work optimally for autistic adults (Murphy, et al. 2016).

[...] someone whose ToMM is impaired is blind to the existence other minds, while still living in the same psychical, spatial, visual and many-hued world as unimpaired people do. For beings evolved to live woven into the minds of mothers, fathers, friends and companions, *being blind to the existence of other's minds is a catastrophic loss.*

(p.xvii, own italics)

Uta Frith (2001) states that whilst mind blindness cannot account for certain behaviours common to autism, such as repetitive and restrictive behaviours and difficulties with motor skills, it can account for issues to do with language acquisition and language use such as 'muteness, language delay, echoing of speech and idiosyncratic use of language' (p.10). This, Frith (2001) hypothesises, may be due to the inability of an autistic child to follow the 'referential intention' of a caregiver who is the child's first guide in language acquisition. This can lead to objects being named incorrectly as the child does not pick up (or perhaps does pick up) on the arbitrary nature of signs and their referents. This may continue into adulthood. Whilst Frith (2001) does suggest that with 'appropriate allowances' for mind blindness social interaction can still be meaningful for the autistic person, Frith suggests that the individual lacks a full understanding of the other and consequently often remains 'egocentric' and thus deficient in the attributes which enable reciprocal communication and social engagement into adulthood (Frith, 2001, p.970)

Damien Milton (2012) has argued that ToMM needs to be critiqued for its prevailing ahistorical and acultural stance on sociality. As Milton (2012) suggests, the ToMM hypothesis and its connection to empathy; that is being able to infer, interpret and respond appropriately to another's emotions, relies upon an incorrect understanding of the social world. As Milton (2012) understands it, ToMM presumes that people who don't have autism and otherwise normative others have an instinctual understanding of the social norms and rules and are able to engage with them with ease. As Milton writes, this position relies upon a belief that society exists separately to individual actors, akin to how certain

functional sociologists interpret society (p.885). This ignores the interactional and relational nature of sociality which is culturally and historically produced and reproduced through the relations between human actors and thus, subject to change. Furthermore, it ignores the political organisation of communication norms. How we communicate, and why some forms of communication are hierarchised over others is politically and culturally significant. Indeed, the very term 'mind blindness' utilises the condition of blindness- a key sensory component of normative communication- as a metaphor. This presents us with the seeing, speaking and consequently thinking human as the normative and thus, fully human, human. As Melanie Yergeau argues: 'I believe all incarnations of ToM to be decidedly inhumane'. Yergeau suggests that ToMM 'stories' autistic people, and it's residual nature marks how autistic people understand themselves and how those who are not autistic understand them (p.19). Therefore, Milton suggests that what is necessary is a consideration of how the relationality between the medical discourses and autistic individuals, individualises and ontologises this pathology of sociality.

As Milton and Bracher (2013) have discussed, mind blindness and its correlative, empathy deficit are simply one part of a long history which has excluded the very people who have the condition. Milton and Bracher (2013) write: 'autism remains a condition which is defined and diagnosed by observation' and that historically autistic people 'were objects of inspection, rather than active participants in the creation of knowledge relating to their own experiences' (p.63) As Milton, et al, (2014) suggest, '[I]n this field, it is the voices and claims of autistic people regarding their own expertise in knowledge production concerning autism that is most recent in the debate; and traditionally the least attended to' (p.794).

Yet, as Melanie Yergeau (2018) points out, autistic people have been narrating their experiences through the written word since at least the 1950s. These have sometimes been written to inform non-autistic people about their experiences. Or, more often, they have been written for other autistic

people; for support, to build community and create meaningful dialogues. The very social things that the lack of theory of mind discourses of autism would suggest are lacking in autistic people. There are numerous books written by autistic people, and increasingly autistic AFAB individuals (see, Temple Grandin (1986), Leanne Holliday-Wiley (1999), Melanie Yergeau (2018), Laura James (2017), Katherine May (2018), Jennifer O' Toole (2019) - to name but a few). Since the internet became readily accessible autistic forums, vlogs and blogs have become multiple and they have come to play an integral role in autistic culture (Yergeau, 2018, p.39).

Autistic people have been telling their stories for decades, yet still these myths or discourses about the inability of the autistic to present their experiences persist. As Yergeau (2018) argues, it is not simply that that these autistic narratives written by autistic people are unknown and need discovering or bringing to light by a non-autistic who can give them the status they deserve, it is that they are systematically devalued as being 'true' accounts of autism. For as Yergeau (2018) suggests, if one is able to write a narrative account, or cannot recount their experience verbally through the vlog format, then the narrator cannot truly be autistic, or perhaps they had autism, but they have now recovered. This narrative, as Yergeau (2018) recounts, is one which has followed autistic writer, scientist and innovator Temple Grandin. For as the argument goes, autism is a condition which encompasses an impairment of sociality and reciprocity, and this does not lend itself to linguistic and oral feats such as vlogs, books and publishing books and articles. When autistic people tell their stories, they can be easily removed from the narrative of autism. As one autistic journalist states, when they tell their experiences of autism someone will always jump in and state something along the lines of: *'but you're not autistic enough to count'* (Kurchak, 2018, italics in original).

Alternatively, if they happen to be deemed as 'autistic enough' then their narratives are de-coded and analysed for evidence of the self-absorbed, ego driven psyche of autism (Yergeau, 2018). This reflects what Hans Asperger's wrote in the 1940s: '[T]he autist is only himself [...] and not an active member

of a greater organisation which he is influenced by and which he influences constantly' (Asperger in Milton, 2014, p.796). They do not tell their experience or their subjectivities: they simply demonstrate the asociality of autism through their linguistic style. In these analyses, the autistic person has no depth; autism forms their subjectivity and de-limits their ability to provide anything other than an account of their autism. When seen through the deficit model then a holistic autistic subjectivity cannot never be said to be demonstrable through language. As Yergeau (2018) elaborates:

Demi-rhetoricity is, I believe, the major topos from which clinicians draw when they wish to refute the desires or claims to identity of those whom they study. As a construct, demi-rhetoricity enables clinicians to claim the best of both worlds when they respond to autistic rhetors:

1. They can argue that autistic people are not autistic enough to make claims about autism.
2. They can likewise argue that autistic people are too autistic to make claims about autism

(p.50)

This understanding of autism does not allow for autism to be accountable for all the multiplicities in a person's character and engagements with the world, but rather it provides a flat sense of identity constructed and knowable solely through the deficit model of autism. Autism in this conception, as a neurological difference understood through lack, becomes the ever-deficient ontology of the autistic person. Lacking full entry into language they cannot give an account of human experience. This binary of biology and the social creates a paradoxical conception which suggests that non-autistics are somehow less driven by neurology and biology, which, of course, harks back to philosophical ideas of mind and reason. In this configuration the autistic is the ultimate figure of unreason and therefore outside of the realm of the storytelling social human.

As Yergeau elucidates:

[U]nlike allistic rhetors, our narrative practices cannot be read outside neurology, for without neurology we cannot map or filter autism onto our narratives [...] Autism's rhetorical function- in genetics, neurology, psychology, philosophy, and more – is to contrast those who are otherwise presumed to be cognitively and thereby humanly whole

(p.23).

'Autism', in this sense as a reified object, is often given more agency than autistic individuals. Whilst it becomes an ontology of deficit it removes intent and agency from the individual diagnosed. Autism has often been conceived of as a thief or a parasite which 'steals' a seemingly normatively developing child. As Ian Hacking argues: '[T]his is the ancient myth of the changeling, the troll child substituted in the dead of night for an infant sleeping in his cot at home' (p.44). This, suggests, Yergeau (2018) constructs autism as 'essential involuntarity' (p.8) Autism is an ontological category but what underpins it is an inability to account for oneself or to have a will, or the powers of reason. This involuntarity can be read in tics, seemingly irrational movements, echoalia, bursts of energy, irregular facial expressions, and so on. As Yergeau writes:

Because autism isn't a switch that can be turned off at will (trust me, I've tried), autism is frequently conceived as essentialised involuntarity. But beyond the illusion of choice, autism's essence, if you will, has been clinically identified as a disorder that prevents individuals from exercising free will and precludes them from accessing self-knowledge and knowledge of human others. *Its subjects are not subjects in the agentive sense of the word, but are rather passively subject to the motions of brains and dermis gone awry.*

(p.8, own italics).

What the above discourses of autistic rhetoricity, interaction and sociality suggest is that the autistic individual can never lay claim to themselves, much less narrate who they are to a researcher who is

not autistic. The history of how autism has been produced through medical and cultural knowledges are residual and still shape how we think about autistic people. We must be careful not to fight these discourses along normative lines. By this I mean, we cannot simply argue against this by stating that autistic people can take part in all research and they have the abilities to do whatever a person who is not autistic can. Nor can we simply ignore autistic specificity, tics, echoalia, stims, as to do so is to revert back to the norm and to work along ableist lines. Whilst an autistic person's abilities may vary day by day or hour by hour there are some clear differences in the level of support that someone might need. Autistic people have significant difficulties and challenges that should not be overlooked. Likewise, communication by means of speech may never be possible for some autistic people. Written communication might likewise elude some autistic people.

Furthermore, the researcher if she does not have autism must reflect upon the ways in which she not only runs the risk of not adequately addressing the communication needs of her participants, but that the interactional relationality of an autistic and non-autistic person may present communicative gaps that cannot be fully bridged. As Damien Milton (2012) outlines in his theorisation of the double empathy problem, full reciprocal interaction between an autistic individual and a non-autistic individual may be never be fully possible. Milton (2012) takes up the ToMM understanding of autistic cognition which I have outlined above and critiques this through a suggestion that interactional problems do not emerge from a deficit of empathy inherent to the autistic person but through a failure to consider communication as an interaction which is governed by social norms and rules which are fundamentally normative. Thus, as I have stated previously, this conceptualisation can only ever suggest that deficit of sociality lies within the autistic subject and cannot examine the conditions of interaction itself which are necessarily contingent upon cultural and social norms of communication. For, Milton (2012), this suggests that both parties (autistic and non-autistic) are 'mind blind' to the other. Though, as Milton (2012) suggests, the autistic individual is positioned in such a way that they have knowledge of non-autistic sociality and are often forced to learn the 'rules'. Non-autistic people

are not often confronted with, or forced to engage, with autistic sociality and this lends the autistic individual an insight which is lacking in the non-autistic population. As Milton (2012) writes on the 'double empathy problem':

The 'double empathy problem': a disjuncture in reciprocity between two differently disposed social actors which becomes more marked the wider the disjuncture in dispositional perception of the lifeworld- perceived as a breach in 'natural attitude' of what constitutes 'social reality' for 'non autism spectrum' people and yet an everyday and often traumatic experience for 'autistic people' (p.884)

For autistic people to take part in research projects then, a destabilising or deconstruction of normative modes of communication must occur, and thus, a destabilising of differences which are always hierarchical. In this instance, a destabilising of what constitutes normative communication and normative sociality must be approached as integral to the project at hand. Normative interaction is just as much ontologised in the neurotypical individual as is deficit in the neurodivergent. By this I mean it is situated as a property, or inherent skill or deficit, of the individual as they relate to the pre-existing social world. I will turn now to a discussion on what methodological alterations were made during this research project to attempt to come somewhat to a form of 'participatory research' (Fletcher-Watson et al, 2018).

4.7 Practical application through methodological adaptations

[...] autistic people have often become distrustful of researchers and their aims, and are frequently frozen out of the processes of knowledge production [...] The involvement of autistic scholars in research and improvements in participatory methods can thus be seen as a requirement, if social research in the field of autism is to claim ethical and epistemological integrity.

(Milton, 2014, p.794).

As I briefly stated earlier this chapter, from the inception of this research project I actively engaged with, or observed, online autistic communities on Reddit, Twitch, Wrong Planet, Twitter and Facebook. I posted on forums such as r/Aspergirls and r/Aspergers on Reddit and on Twitter using the popular hashtags #actuallyautistic, #autistic, #doilookautistic yet among others. I have met with autistic friends, colleagues, and acquaintances. I have been to autistic-led conferences and informally spoken with autistic research consultants. During these online and offline encounters conversations were had about what modes and styles of communication would be preferable for them if they were to take part in a research project such as this. I also sought to discover whether they saw relevance in my research questions and if the interview schedule was accessible. Several autistic taught postgraduate students in the School of Sociology and Social Policy, University of Leeds were kind enough to run through practice interviews with me. We discussed whether the way I planned to conduct the interviews was conducive to them being able to answer the questions. From all these conversations with autistic people several points key to doing research that was mindful of autistic people's needs came up:

- When recruiting via social media include the researcher's email address so that a prospective participant doesn't have to make public that they are autistic if they do not feel comfortable in doing so.
- The interview space must be chosen by the participant if they require this. This enables the participant to know the space beforehand, to be able to know how much noise or sensory input there will be in the environment. If the participant does not want to choose a space, then maps and detailed information about the room/building should be given before. This information should include any noises or lights and accessibility considerations (such as extraction fans or strip lighting, wheelchair ramps, availability of disabled toilets).
- A copy of the interview questions should be offered to the participants prior to the interview so that the interview isn't completely unknown.¹⁸ Interview questions should be available to look at during the interview itself.
- During the interview eye contact is not always necessary; for many autistic people eye contact becomes something to concentrate on and stops them from being able to think clearly. Seats do not need to be arranged facing towards one another. The interviewer and interviewee can sit side by side, for example. The interview can also take place during an activity, such as walking. This should be ascertained prior to meeting with a participant.
- The interview should be able to take any form, i.e., it can take place online through the Skype video chat function or through a text-based online platform. It can also be given in the form of an adapted questionnaire to be filled out alone and emailed or posted back to the researcher, or, it can take place as a standard face-to-face meeting.
- Tone of voice, facial expressions, body movements of the participant are not to be analysed or interpreted within a normative neurotypical framework in the sense of offering meaningful information for discussion chapters, or to be analysed in accordance with deficit models of

¹⁸ Interview questions were only offered to the participants of this study after all information about the project had been provided and consent forms had been signed.

autism. Movements can be discussed during the interview to ascertain whether the participant is anxious or struggling with the sensory environment.

- The participant should be allowed and encouraged to bring a family member or friend to the interview if they require this.
- Stimming, i.e., movements of the body such as rocking, flicking fingers, playing with fidget spinners should be acknowledged as accepted with the interview environment.
- Questions should be as clear as possible with follow up questions readily available to clarify points. Metaphors and other linguistic idioms should only be used if clearly articulated to avoid confusion. Some autistic people might not know to elaborate on questions so the researcher should be clear on when they would like examples or elaboration.
- Finally, to remember that each autistic person is different and will have different needs, thus each interview must be adapted based on the individual's requests and needs. These should always be ascertained by the researcher prior to, and ongoing during the interview. It should not be assumed that all people will tell the researcher what works best for them without prompting.

The above points were considered and implemented (if required) during every interview. The following table documents information about the interview as it took place for each individual:

Participant	Interview type	Further communication	Interview venue
Esther	Skype- phone no video	Email	N/A
Mary	Written questionnaire	N/A	N/A
Sarah	Skype- phone no video	Twitter chat function	N/A
Sally	Skype- phone no video	N/A	N/A
Aime	Skype- phone no video	N/A	N/A
Hannah	Face to face	Email	Participant's University library
Sara	Skype- phone no video	Twitter chat function	N/A
jojo	Face to face	N/A	Researcher's University

Each participant chose their preferred way to be interviewed, including whether video image was important, or indeed, if interpersonal communication worked for them. Mary was the only person who chose to not participate in any form of interpersonal communication. Due to the researcher being overseas during some points of the data collection Skype was offered as preferable to face to face meetings; this only affected two of the interviews, Aime and Esther, both of whom preferred a Skype meeting to a face to face interview. An 'object focussed' interview was offered as an option. This would be a discussion around an object or photograph that held meaning to the participant. It could also be discussion based around a particular activity or event. This option was to offer a more centred

conversation which could be given forethought by the individual. This option was not chosen by any participant. All participants were offered the interview schedule in advance. This aided in the individual knowing what to expect in the interview and to have a chance to think about what they would like to say. Giving the interview schedule in advance was agreed upon as being helpful by all participants.

4.8 Data collection and analysis

When an interview took place face to face or via a Skype call a Dictaphone was used to record the conversation. The Dictaphone was turned on from the moment that we had sat down in the room, or in our respective rooms. The recording included the introductions and the reiteration of the consent framework. Only Mary preferred to email her questionnaire sheet back to me, as such, no audio recordings are associated to Mary. I will discuss the in-person interviews before returning to Mary's interview at the end of this section.

After the interview had finished, I copied the audio files onto a University of Leeds computer and saved them on the 'M' drive to ensure privacy. These audio files were then transferred to a transcription program entitled 'Express Scribe'. I transcribed the interviews without any outside assistance. As Kvale and Brinkmann (2009) note '[...] transcription is an interpretive process, where the differences between oral speech and written texts give rise to a series of practical and principle issues' (p.177). Thus, certain decisions and considerations must be made with regards to how one deals with the audio recording in the transcription process. I made the decision to transcribe the interviews 'almost-verbatim', meaning I did not shorten, lengthen or otherwise alter the interviewees comments or answers. The only times I did so was when the audio cut out or speech could not be heard. In the later interviews I made the decision not to transcribe the introductions and concluding remarks where I discussed the consent form and practicalities, I did not transcribe conversational asides that were not relevant to the subsequent analysis. I included laughs, pauses, small sounds (e.g. mm, hmm) in the

transcription process. Sighs, laughter or sounds of crying were transcribed through using the verb or additional adverb to qualify, i.e; [laughs], [sobs], [sighs], [sobs briefly]. When I transcribed pauses, I used eclipses; [...]. These have been included in the interview quotations in the analysis chapters.

I also kept field notes in which I wrote down my own interpretation of the interview in detail directly after the interview had finished. In these notes I included my interpretation of emotions, rapport and content. These field notes were essential for aiding my memory when it came to the analysis of the data. The reason for choosing to transcribe all that was said or uttered in the interview was to ensure I was able to detail how the interview functioned as an interactional space and to understand how the interview produced some of the content. I did not use a specialised form of transcription as I was looking for content predominantly rather than for data to analysis linguistic style or interaction as might be more common in a psychological research project (Maynard and Turowitz, 2017). All recordings, transcripts of the interviews, the single typed questionnaire form and demographic information was anonymised and stored securely on the University of Leeds drive. Signed consent forms were kept separately to all other information in a locked drawer at the University of Leeds and have since been destroyed. All emails which included consent forms or identifying information have been deleted.

Analysis of the interview data followed Kvale and Brinkmann's (2009) question; '[H]ow do I carry on the dialogue with the text I have co-authored with the interviewee' (p.193 I understood the interview as a conversation which was co-constructed through 'two persons talking about common theme of interest' (Kvale and Brinkmann, 2009, p.192). As such, I aimed at analysing the interviews in line with what I – as closely as possible- believed the interviewee to be saying to me and the intention behind their comment or statement. Whilst, as stated earlier, I began this project with an epistemological positioning, the interviews were not being conducted to prove or disprove the value of any given theoretical position. Though I should state, that this was not always the case. The first interview that I

had with jojo forced me to reconsider my position significantly on this matter. I had entered this project thinking that I would find evidence of the masculinisation of autism impacting on people's lives in some way and, I had presupposed a negative way.

When I spoke to jojo I immediately realised that something else was at play with regards to the entanglement of autism and gender. I subsequently attempted to come at my interviews with a somewhat grounded theory approach (Glaser and Strauss, 2009). I realised after my first interview with jojo that I did not know what the participants were going to say to me before the interview and I attempted to allow the participants to produce the knowledge in the interview without my prior interpretations. This did not demand I change the research questions because I had written them without explicit reference to the gendered construction of autism, but it did demand that I 'let go' of that particular interpretation as I conducted the interviews. This most likely changed any follow-up questions I asked. Therefore, when I read and began coding the interviews, I utilised a mixture of inductive and deductive coding (Fereday and Muir-Cochrane, 2006). There is limited research into the understanding of the co-production of gender and autism, thus it was necessary to allow new ways of thinking and theorising to emerge through the interviews (inductive), this was supplemented through thinking how the interviews spoke to theoretical positions that are in existence (deductive).

Before coding, all the transcripts and Mary's questionnaire were first read several times, I also listened again to the audio recordings. After becoming acquainted with the interviews, I then hand coded them with pen. They were marked for similarities and divergences which were cross referenced with the other interviews. I also mapped them for similarities and differences in relation to the demographic information I had been given by each participant. Mary's questionnaire was the only interview which was difficult to code in this way. Mary had written very little under each question and I had very limited information to work with. There were similarities and divergences with the other interviews when they were cross-referenced so I was able to use some of Mary's interview. However, simply due to the

brevity of it, I was unfortunately not able to develop any new theoretical understandings from it. I did contact Mary via email to ask to follow up questions, but I did not get a response. The similarities and divergences became 'key themes' which were then used as subheadings to guide the analysis chapters.

4.9 What is missed

I hope here I have justified the case for utilising interview techniques, albeit adapted and made more accessible, with this particular group of research participants. I have acknowledged that certain sectors of the autistic population were excluded by this choice, thus, it must be stated that this project is not a generalisation of all autistic people. Rather, it is a snapshot of a particular group who fall within the broad diagnostic category and space of autism. The participants of this study were predominantly highly educated, all have taken, or were taking, higher education degrees, with several pursuing or undertaking graduate research programs. Two were professionals working in stable employment. This, as I have suggested, is partly a combination of the subject matters being discussed; gender and autism. Subjects, which whilst they affect the individuals in an everyday sense, are perhaps less likely to be considered on a conceptual and theoretical level unless one has already encountered these ways of thinking that were expanded upon in an educational setting, or more general habitus.

Thus, I would argue that one of the main limitations of this research is the decision, from the point of recruitment, is to narrow the focus to those who have the prerequisite abilities required for taking part. This has necessarily narrowed the scope of what can be known about the subject by demarcating who can take part. Furthermore, this thesis could perhaps be accused of presenting yet another study into 'high functioning' autism. As Osteen (2007) has stated on both the lack of research into people with 'serious' cognitive disabilities and the lack of these individuals doing the research:

‘[P]eople with serious cognitive or neurological difficulties often cannot communicate well enough to advocate for themselves. This circumstance presents another reason for disability studies’ relative neglect of cognitive disabilities and may also help to explain why autism and other cognitively disabled people are often deemed incompetent to manage their own therapy, or their own daily lives, let alone write about those lives’

(p.6)

Perhaps one way to think about the confusions and ethical considerations which go into devising a research project such as this, and the justification for both its line of questioning and its modes of operation, is to think with Donna Haraway about the question of bias. Haraway (1992), writing in *Primate Visions*, addresses the question of how we can think about the ways we orientate ourselves towards objects to be studied and why we do so. In *Primate Visions* the case in point is the study of primates as not simply beings in the world to be studied objectively but ones whose behaviours and study have been constructed within gendered and racial parameters. Due to the not-quite-but-almost human-ness of primates, Haraway suggests the study of them has been mobilised to understand and produce naturalised racial and gendered modes of understanding and organising the human in its varying social contexts. Haraway pays particular due to the ways in which heterosexual and heteronormative norms as mobilised by human beings are given weight and naturalised by the examination of these norms as seemingly exhibited by our nearly human cousins.

In order to think critically about this, Haraway suggests that we must ask how these scientific ideas emerged, and which actors were promoting them to what ends? Moreover, how can scientists challenge these ways of doing research and what results should be gathered if perspectives or orientations were changed? Altering the modes of gathering information, who is conducting the research, who is participating, and what research questions are being addressed enables a new reality to emerge. This is what Haraway (1988) calls ‘partial perspectives’. Moreover, we do not need to take

those who we deem to be exerting excessive power in determining the course of research and research relevance to task in the form of academic attacks or polemics but rather, simply put, bias cancels bias (Haraway, 1992, p.290). Thus, this project engages with a group of people who have been largely neglected by research: adult autistic people who were assigned female at birth. It is never in the scope of one research project to cover all demographics of a specific group of participants, though I hope I have done justice to the ones who are included in this one.

4.10 Ethical clearance

This project was reviewed and given ethical clearance by the ESSL, Environment and LUBS (AREA) Faculty Research Ethics Committee at the University of Leeds (AREA 17-075). Clearance was given 12.03.2018.

4.11 Conclusion

This chapter has provided information about the research design of this project and its implementation. This chapter began with a discussion around the analytical framework which I have used to construct a narrative from the interview data. I then discussed how I recruited the participants of this study. Despite placing recruitment posters in a wide variety of places the key place where participants came forward to express interest in taking part in the project was through social media platforms. Subsequently, I discussed how the internet acts as a key emancipatory tool for those who are autistic. A considerable part of this chapter was given over to critiquing the residual myths which stick to autism and autistic people to suggest they cannot be the authors of their own experience. Though unconventional for a methodology chapter, which usually deal solely with the practical elements of a research design, I stand by this decision as necessary to show *how* I came to certain methodological decisions. In doing so I followed Potter and Hepburn's (2012) guide to research transparency. Following these guidelines enables the reader to see how certain narratives were able

to be constructed from recruitment to analysis. This proved especially important with the demographic included in this project. Making the modes of research transparent enables further research with autistic people and about autistic experience to be improved upon. A descriptive account of the data collection and analysis utilised in this project was provided and a brief discussion into who has been excluded from this project by the nature of its design closed this chapter.

The next chapter is the first of two analysis chapters and it examines the experiences of the participants prior to their autism diagnosis.

Chapter 5

Analysis I

'Like a Square Peg in a Round Hole': Experiences of Growing Up with Un/known Autism

5.1 Introduction

This analysis chapter is the first of two. It looks at the key moments in the lives of the participants before diagnosis, or prior to the self-realisation that they were autistic¹⁹. These key moments or periods of time were identified broadly as 'childhood', 'adolescence', 'relationships', and 'gender identity' (see appendix 4 for interview schedule). Throughout the discussion of these areas a theme shared by many of the participants was that a feeling of difference emerged in relation to others at different points in their lives. This difference was not yet named as autism and I argue that prior interpolations of the subject as girls led to a sense of 'performing' their sex/gender identities. This subsequently became subject to intense disciplinary regimes in order to somehow curb or manage this sense of un/known difference²⁰. Many participants engaged in 'masking' their un/known autistic difference and performing certain neurotypical roles through a management of their sex/gender. In the second half of the chapter I discuss this in relation to the politics of passing and discuss the ways this is similar to theories of passing but it also diverges at certain important points.

¹⁹ I have distinguished between the 'official' diagnosis and self-realisation because for many participants they were certain that they were autistic for a period of time before the diagnosis. As they had asked to be referred for a diagnosis through their GPs, they had already amassed knowledge around the condition which they had been utilising to make sense of their experience. In many cases the diagnosis was sought as a legitimisation of what they already believed to be true.

²⁰ I use the term un/known here following Joanne Latimer (2009). Breaking the word enables knowing/known and unknowing/unknown to be considered outside of a dichotomous framework. I particularly wanted to reframe the idea of being undiagnosed through this terminology. 'Undiagnosed', at least in my considerations, removes the agency of the individual in having some understanding of their physical, mental and cognitive states, it gives power to the diagnostic team to uncover the truth of the individual. Using the phrase un/known allows a sense that autism as a neurological condition was always there prior to the individual being diagnosed. It enables the feeling of difference and otherness that the participants felt prior to diagnosis to be considered within a framework of enabling and acknowledging agency. It also highlights the sense that the body, mind and cognition are always partially out of reach to us as a scientific fact. Using un/known rather than undiagnosed enables the fluidity and instability of embodiment and scientific knowledges to come to the fore.

5.2 'My body didn't feel like it belonged to me': The un/knowning body and the un/known world

The body is the palmary instance of the ambiguous

(James in Latour, 1996, p. 206)

For the majority of participants feeling somehow, and unexplainably, different to others became centred at the site of the sexed/gendered body. This generally started around adolescence, though several participants were aware of their perceived difference in early childhood, and the body became a contested site. The development of breasts, hips and increasing body fat constituted a spilling out into space and these bodies demanded considerable self-disciplinary techniques to be imposed. The body became the site of control and containment, it was circumvented or hidden. The sense that the development of bodies caused the participants to become more visible to others and this highlighted their sense of difference was a prevalent theme in the interviews. Moreover, a sense of lack of control of the body led to a feeling of alienation or of not 'belonging'.

This was the case for Aime. I spoke with Aime, an eighteen-year-old secondary school student over Skype. Aime identifies as non-binary because they do not identify with either the category of man or woman. At the time of our interview, they stated non-binary seems to work as the best description of their gender. Aime had mentioned feeling discomfort with their gender as a teenager and I asked them when this began:

My main thing was my periods, because my body didn't feel like it belonged to me, so it felt physically painful because it was physically painful but it also made, I felt like I didn't belong, I felt like I was faking everything [...]

[Aime, 2018]

Later in our conversation we discussed whether, retrospectively, Aime felt that their gender dysphoria and their autism were connected in any ways. Aime stated that the two were interlinked but that distinguishing one from the other was impossible as well as not necessary. Aime stated: 'I am autistic in the same way as I am queer' (I will return to this comment in the following chapter). I mention this because I don't want to override Aime's non-binary identity by suggesting it was caused by, or a symptom of, their autism. Non-binary, trans and other queer subjectivities frequently have their gender and sexual orientations questioned for causal origins and this is particularly the case for autistic queer people (The Atlantic, 2016, van der Miesen, 2018, Strang, et al, 2018). Aime's self-conflation of their autism and queerness allowed me to consider their gender identity as entangled with their autism in a way that meant I didn't have to engage with origin questions (for example, is Aime non-binary because they are autistic?). Thus, I want to take Aime's consideration that their body and the world simultaneously became hostile places as allowing a way in to thinking about how the processes of world building and the building of subjectivities take place through the body.

Aime's articulation of not belonging in social settings is centred around when their body began to change. Feminist scholars such as Marion-Young (2005) and Shildrick (1994) have argued that for all assigned female at birth people (they refer specifically to 'women') the body becomes contested ground once one becomes aware of their social status as the result of living within a heterosexist society which positions assigned female at birth people as both privative *and* fetishised. This simultaneous making privative and fetishised is centred on the sexed/gendered body as that which is reproductive, desired and repudiated. Aime's sense of not belonging began with the advent of their menstruation. Aime did not simply feel alienated from their body but they felt this change to be deeply indicative of their place in the social world. As Aime notes they felt as though they were 'faking everything'. The sense that Aime felt as though they were 'faking' was noted by other participants who directly related this to a sense of 'faking' or 'pretending' to be a woman.

Sally said something similar when she stated that she felt, in her words, she was 'pretending' to be a woman and that she was a 'crap one' at that. Sally is in her forties and had only recently been diagnosed at the time of our interview, thus she has spent a lot longer than Aime, who was diagnosed at eighteen, without an understanding of what makes her different. Sally spoke to me about her attempts to find identities that she felt she could fit into:

Sally: I did sort of hang myself on other identities in the past, but I worked out that recently that they were just means of me trying to find my place in the world.

Emily: What were some of those other identities?

Sally: So when I was in my twenties I threw myself into my work and I identified myself as very career orientated and very dedicated, um and I then, I went through a detox program for alcoholism six years ago and after that I tried to identify myself in a new age 'found myself' hippy way, but that still wasn't quite right.

Sally, being one of the oldest participants, had a long history of trying to find her place in society and an identity that worked for her. Sally had also struggled with alcoholism. She told me that this began at University and became exacerbated when she began working due to the pressure of being social in order to be seen as a good member of the team. Alcohol enabled Sally to enact her various identities without feeling so exhausted from the efforts that this took. Sally's various identities were often bound with her gender identity, she felt that she had to enact a certain persona in order to be understood as a normative woman. I will return to this point in the second half of this chapter. Sally talked to me about her experiences of University. Sally had adopted, in her words, a 'rock persona', she said this helped her feel at peace with her gender identity being one that is not overtly feminine. However, during her time at University and learning about the politics of sexuality and gender sparked off considerations about what her own gender identity was. As Sally states:

I spent quite a lot time ... there was quite a big chunk of my University time where I definitely thought I must be in the wrong body, that I was boy, that I was better at being a boy and I kind of understood that in relation to the women that I wasn't like and it was those stereotypical things around the make-up and the dressing up and the presentation and the looking for boyfriends and the obsessions with the relationships, and also because I didn't get them, and retrospectively I didn't really get anyone, I got on a lot better with a bunch of the male physics students who lived in the same halls as me [...] I felt I wasn't a girl and I felt I wasn't very good at being a girl. I had a couple of relationships with women which I felt reinforced this, so...

[Sally, 2018]

Here Sally makes reference to the sense that one's gender identity is contingent upon the ways one orients their sexual desire. Sally alerts us to what Butler (2006) cites as the 'heterosexual matrix'. To be intelligible then sexuality and gender must be mapped across a coherent framework. For Sally her desire for women led to a consideration that she was not 'good at being a girl'. To be a 'good girl' is necessarily to be heterosexual. To feel physical and psychological desire towards the same gender exposes the sense that the body doesn't fit. Much as Aime had considered, when the body seems to betray one's sense of identity then it becomes the primary object which is positioned as needing adaptation in order to make oneself intelligible. The quote from James cited in Latour (1996) which opened this chapter alerts us to the ways that our bodies 'become aware' through being affected and it points us the ambiguities of the worlds we construct and inhabit. The changes in Aime's body alerted them to the sense that the world in which they were supposed to fit did not belong to them, thus they could not belong.

Aime's sense of not belonging is articulated by actual physical pain, not only the pain of menstruation but this is an embodied affective pain. Becoming alienated from their body through physical pain made

Amie aware of the world they inhabited. It made them feel a sense of not belonging and of only pretending to fit in. This affectual embodiment that Aime experienced sparked a consideration about the dominant gendered regime into which they could not fit. This was not solely focused on their own body but on the sense that there was no place for them in the social order. This was also noted by Sally whose body became subject to intense focus as she tried to find her place in the social world. Kansfischer, et al (2017) have suggested that many autistic adolescents demonstrate an 'awareness of a 'mainstream' world they are unable to access' (p.662). There are numerous instances where we see the notion of *worlds* evoked when referring to autism, if there exists a world that autistic people cannot access then where do they inhabit? What worlds are constructed in this process of alienation from the 'mainstream' or normative world?²¹

Hannah articulated something similar to Aime and Sally, however in a more circumvented way. Hannah had developed eating difficulties as a teenager and she became fixated on keeping her weight a particular number:

I know why my goal weight was a certain number, um and I think it may have been because of, um, when I was a kid, I had some, I had a pogo stick and some stilts from the same manufacturer and their max weight was 50kg. So, I was like, that number, 50kgs. Um, but I don't know why, because there was a period of time where I was absolutely sure I was a trans man. But I've then subsequently realised that that could have been OCD, it could have been um, 'cos that's a thing that happens, people get.

[Hannah, 2018]

Hannah was a participant who repeatedly stated that she didn't consider her gender identity to be core concern during our conversation. However, in the background information in the gender

²¹ See, for examples, the popular autism blog *Wrong Planet*, the short documentary film by autistic filmmaker Geradine Wurzburg *Autism is a World* and *Worlds of Autism: Across the Spectrum of Neurological Difference*, a co-authored book edited by Joyce Davison and Michael Orsini.

identification section she had answered 'female, but I don't identify with it'. Despite stating a lack of consideration around her gender identity ('I never felt any pressure regarding gender when I was a kid, um, thankfully! [laughs]'), it did come up numerous times, especially in relation to her physical body and its changes in adolescence. I met Hannah at her previous University. She had graduated and was now working and planning to move in with her boyfriend. The conversation with Hannah was interesting for me because it was the first time I had interviewed someone somewhere I hadn't been before. I felt a shift in our dynamic of researcher/research participant which in turn made me feel slightly unsure of my role. Hannah initially took charge of our meeting; she chose a table and it was one in a busy area of the library where others around us could hear our conversation. However, our conversation was engaged, and we sat facing one another with the Dictaphone in between us. Perhaps more than halfway through the interview I decided to ask a direct question about Hannah's gender. It hadn't come up and I couldn't be certain whether Hannah simply didn't consider her gender to be integral to her narrative or if she hadn't mentioned it because I hadn't asked her.

Emily: [...] um, some people [...] have said [...] they just didn't understand as autism then, but they had a problem with being a girl. And, especially, that transition to becoming a teenager. Did you have any of those difficulties?

Hannah: Yes, yeah. I used to wear jumpers in hot weather because of the changes to my body, like, I used to stay in jumpers and keep those on, and um, I think it might have been one of the factors in my eating problems as well. Wanting to maintain a boyish figure, I guess.

When going through my interview with Hannah I realised, however, that of course she had discussed her sex/gender identity numerous times without having to ask any direct questions. That Hannah would articulate her focus on the weight on the pogo stick in relation to her gender identity acts as a metaphorical form of dislocation of her physical body onto an object. The particular object, the pogo stick, is one which she was able to use as a child thus, the pogo stick stands in for her childhood body

and thus her childhood body as it extends into space. As Hannah discusses in the second quotation, she would hide her body through large jumpers and discussing that allows her to consider her eating difficulties in the same framework. Moreover, Hannah discussed her beliefs that she may be as a transman in relation to wanting to maintain the body of her childhood. Hannah's comments highlight what Joanne Latimer cites as the un/knowning body. Hannah didn't will or necessarily understand the changes in her body; they were seemingly happening outside of her control, as Latimer writes:

'And bodies, to put it simply, despite our best efforts seem to get out of line: they do not just hurt, scream, giggle, leak, cramp, faint, get numb, they are times seem to conceal, rebel, falsify and distort. That is, bodies can seem to be or become *unknowing*' (p.4)

The changing body became understood as an enemy to Hannah as it did to Aime, seeming as it did to have a mind of its own. Hannah's refuge from this was to extend her body into space, to an inanimate object which was, however, not completely other to her, it was a representation of childhood self and of her body before it began to change in her adolescence. As Lorna Martens (2011) writes; '[O]ne's places and one's things extend the self into the world, the living and changing being into more lasting forms. Our ... things are not the other, not the not-me ... they grant the comfort of self-extension' (p.44). Thus, Hannah attempted to create a different world for herself where her discomfit at her changing body had the potential to be stopped in time, at least metaphorically.

jojo was a participant whose sex/gender identity was considered in a particularly negative light. jojo saw the relationality of sexuality and her position as an AFAB person in a heterosexual environment to be the main cause of her distress. I met with jojo and her mother at the University of Leeds. I had booked a seminar room in a quiet wing of the University. We sat facing away from one another with jojo's mum looking on at us from a seat a little distance away. The interview was, at least from my perspective, emotional. There were moments of tears from frustration and anger but also a current of

hopefulness that broke through at points. During the interview I felt that jojo, her mother and I developed a rapport, I felt we had the same aims to disrupt and challenge what is considered a legitimate way to be. jojo's motivation for speaking with me was to, in her words, 'make more space in the world' for her children, both of whom are also autistic. The interview was long, lasting nearly two and a half hours. I left the interview with a range of emotions; relief that jojo and I had so much to say to each other, drained from the intensity of the conversation and, a sense of anxiety about doing justice to the subject matters which jojo had framed which such urgency to make it so her autistic children didn't have to struggle the same way she did.

jojo's struggles with sex/gender emerged when she was a young adolescent. First, I asked that she talk a little about being a younger person, her hobbies, her school life and so on. jojo jumped straight to discussing her mental health issues which led to her not attending high school education for two years:

I liked primary school but as soon as I went to secondary school that's where my life went downhill. I, I had mental health issues, I eventually, I didn't finish secondary school, I think, was I thirteen? I took an overdose when I was 13.

[jojo, 2018]

I asked whether jojo has any idea why she didn't like secondary school:

I don't, it felt as... the more you're becoming sexually mature, I mean I didn't develop breasts, I've never developed anything like that, but your periods, I was quite fearful. I didn't start my period until I was 14 and I hid it from my mum, I didn't tell anyone. So, the more I became sexually mature, the more the male attention, I don't like that. It's that that I don't like. And because I'm female, my friend at the time she was obsessed with male attention and sexual things and because I'm female I thought I have to be like her, but I don't, but inside I don't feel like that. But I'm a girl, I've got to be like that, I've got to be like that. I'm supposed to do that, I'm supposed to get a boyfriend, I'm

supposed to dress, you know I'm supposed to flirt. [...] it's like but I don't feel like that inside, I don't understand, I felt like very lost and confused in the world like I was having to pretend to be a female kind of thing [sobs briefly].

[jojo, 2018]

jojo began to cry a little at this point and I asked if we should stop the interview. jojo asked that we continue stating that she was emotional because she was finally being 'honest' ('it's not like I'm upset, it's that I'm being true to myself. I'm being honest and I've spent my life not being honest [...]'). jojo also has a similar relationship to her body to Hannah and Aime in that it began to cause a sense of confusion as to her place in the world. For jojo being a 'female' is necessarily to be heterosexual, desiring and desirable. jojo's response to these pressures was to ultimately take her body away from what she saw at the intense regulatory pressures of secondary school peer relationships. After an intense period of self-harming behaviours, jojo took herself out of school and wouldn't leave her family home for two years. jojo felt that her changing body became the site of unwanted attention from the boys in her peer group. The implicit sexual and romantic demands placed on her caused confusion and distress.

jojo, Sally, Aime and Hannah all demonstrate the entanglement of their sex/gender identity and their feeling of difference. This sense of alienation became centred on the sexed and gendered body. This led to attempts to manage their un/known bodies through various strategies. Hannah restricted her eating in order to maintain 'a boyish figure' through a certain nostalgia of an androgynous childhood. jojo removed herself from the world entirely and did not attend school or the activities of public life for several years due to the perceived social demands placed on her by virtue of her sexed body. Aime articulated that their bodily changes in adolescence produced a feeling of not belonging and they described feeling alienated from both themselves and the world. Sally discussed the variety of identities she took on in the attempt to find her place in the world.

We could read these understandings of the sexed body as indicative that AFAB people seek to transcend the body, furthering the binarising opposition between mind and body. However, the intense focus on the body as the site of this discipline demonstrates the body's inherent entanglement with the world and the ability for it to be shaped and changed and for certain objects to become world making tools. It also suggests a deep philosophical engagement with the body as a site of perceived oppression. As Lester (1997) has argued discussing anorectic women the intense focus on the body demonstrates the embeddedness of the self within the body: that '*I am my body*'. However, I want to expand this slightly. What the participants show is not simply 'I am my body' but rather, 'I am my body as it is understandable and produced through the social order and its regimes'. Each participant quoted here made reference to finding something to position their perceived difference onto and something that could be managed. All the participants quoted here disrupt the idea of an 'undivided, integrated, self-contained solid' individual (Latimer, 2009, p.51). They demonstrate the becoming of bodies in the processes of subjectification.

This analysis must also problematise the idea of the world which exists as a social fact or, as there for bodies to inhabit. As disability scholars have taught us, the world is not simply there for us all to inhabit equally even if we should remove the restrictive societal constraints which order our sexed/gendered physicality, but it is shaped and constructed along ableist normative lines (Davies, 1995, Milton, 2014). This means that some bodies cannot comfortably inhabit the world. Thus, we must problematise the notion of a universal 'world'. I titled this chapter with a quotation from Mary ('like a square peg in a round hole') because it alerts us precisely to this idea; some bodies cannot neatly fit in the world if we think of it as a stable pre-existing fact. Neither can bodies fit in the world if they are considered as a pre-existing fact, or, as a perennial 'round peg'. This sentiment was offered by all of the participants of this project in one way or another. As Joanne Latimer (2009) writes:

... at the same time as noting how bodies are inscribed into their worlds by virtue of a variety of processes of discipline and accountability, it is necessary also to enquire more carefully into what *worlds* are elicited in the process. That is to say that, rather than take the social universe for granted, the interest is with the kind of limits and assumptions that would fix, albeit partially and temporarily, the nature of the 'world'. Thus, there is a need to recognize that differently performed bodies perform different worlds and vice-versa

(p.2, italics in original)

The four interviews I have quoted above all demonstrate a sense that a feeling of difference emerged around adolescence. As I have noted in the literature review this has been documented by numerous studies into autism and how it impacts those who are assigned female at birth. I argue that none of these research projects and articles have fully understood autistic embodiment as produced by the social world, and therefore inextricable from understandings of sex/gender/sexuality regimes which affect us all. There is an underlying sense that the over representation of autistic people outside of the normative regimes of sex/gender can be explained by arguing they lack the social skills to understand what is expected of them. Or, that the obsessive cognitive patterns common to autism may lend themselves naturally to a fixation on gender (De vries, et al., 2010). This position is what Gillis-Buck and Richardson (2014) described as autism as a 'pathology of gender'. If there is anything that is clear in my interview data, it is that the participants have an intimate understanding of what it means to be coherently sexed/gendered. There is no question, at least to me, that the participants I spoke to understood what genders role is in society and how they ought to do gender and how they should be presenting themselves in order to fit within a normative regime of how bodies are ordered and understood.

I would like to take a moment to think about whether this is a specificity of autistic AFAB people or AFAB people generally. Having not conducted this research with a control group of non-autistic AFAB

people it is not possible to provide any empirical findings which speak directly to the line of interrogation in this thesis. However, I hypothesise that whilst these feelings of alienation and confusion centred around the sexed/gendered body are most likely prevalent in the non-autistic adolescent community I think that perhaps a difference lies in how sex/gender becomes mobilised to circumvent difference or to find an origin for one's perceived difference. There was an unidentified and un/known difference that was causing the participants distress in adolescent, and it seems like the first point of interrogation was the individual's sex/gender and its intelligibility or lack thereof. I would also like to consider the idea that this is not specific to autism but may be found within others who have experienced a period of un/known difference. For example, we might find this among those with undiagnosed ADHD, undiagnosed mental illness, those who are LGB, and those who are racial minorities, for example. It is after all, as Judith Roof (2016) states, gender's job to make the subject 'fit' (p.2). Without any other self-understanding then, perhaps, it corresponds that sex/gender would be the first place to come under fire by individuals who already feel as though they are a 'square peg in a round hole' (Mary, 2018).

I want to turn now to think about how the participants sense of un/known difference led them to a consideration that they were not performing their genders correctly. This was noted by all of the participants who I have quoted above. A sense that some of the participants were 'faking' their social identity was prevalent and bears certain similarities to theories of 'passing', albeit with some important divergences.

5.3 'I learnt quite quickly what was acceptable and what wasn't': masking as a form of passing?

I asked Aime why they felt that their autism was not picked up by themselves or others:

I learnt quite quickly what was acceptable and what wasn't, I learnt that you must make eye contact, you must do this, you must not flap, I learnt all of those things reasonably well on my own so I learnt to mask without anybody telling me to, I sort of just learnt just do this or it's another thing people will find you weird about [...]

[Aime, 2018]

Tobin Siebers (2004) has noted that 'passing is possible not only because people have sufficient genius to disguise their identity but also because society has a general tendency to repress the embodiment of difference' (p.13). Aime's suppression of their un/known autistic traits and of their strict adherence to the social norms which regulate behaviour enabled them to 'pass' as someone who doesn't have any differences to the norm. Everything that Aime 'learnt' they shouldn't do and should do are embodied; do make eye contact, do not flap arms. These allow Aime's behaviour to fit within a normative and acceptable framework of embodiment. Aime notes that they repressed their embodied difference due to a desire to escape the stigma of being found 'weird'. Importantly Aime, like many of the participants, did not consider that they were autistic until quite soon before they were formally diagnosed, thus this masking of difference was not yet known to be autistic difference. Thus, Sieber's idea of 'disguising an identity' does not quite fit for thinking about Aime's experience. However, it is important to remember that, as mentioned in the literature review, masking is relatively new concept to think about autism and its presentation in assigned female at birth people (Milner, et al., 2019). As such, the participants are engaging with- and reproducing- this as a discourse of autism. All the participants knew what was meant by this term and were able to understand their gendered experiences retrospectively through this lens.

For some participants, as I have discussed above, this difference became situated as a negative difference that was centred around their gender identity. This was the case for jojo who I quoted above. I want to revisit a section of her comment:

I'm supposed to do that, I'm supposed to get a boyfriend, I'm supposed to dress, you know I'm supposed to flirt. [...] it's like but I don't feel like that inside, I don't understand, I felt like very lost and confused in the world like *I was having to pretend to be a female* kind of thing.

[jojo, 2018, researcher's emphasis]

This was also mirrored by Sally who stated: 'I felt I wasn't a girl and I felt I wasn't very good at being a girl' and Kate: 'I remember having [gender] dysphoria type feelings in my teens and pre-teens' Of the participants who brought their gender identity up as a key concern in their adolescence the sense that they were only pretending to be women was prevalent. The participants mentioned so far all felt that their difference was initially centred as an incoherence in their sex/gender identity. As, I have noted above, Judith Roof (2016) has written it is 'genders job to make the subject fit'. Thus, it makes sense that gender would be questioned as the site where the subject becomes intelligible to oneself and others. However, what makes this specific to autism is not only the seeming prevalence of this gender trouble in autistic individuals but the ways in which the individual's un/known difference led a conscious performance of their gender identity. I argue that this particular form of gender trouble is not symptomatic of autism but rather symptomatic of a social world that punishes transgressions of the social order, much as Siebers (2004) noted in the quotation above. The sense that transgressions would be subject to the individual feeling as though they were singled out as 'weird', in Amie and Kate's phrasing, led to a period of intense focus on their embodiment and gender identity in order to make the 'subject fit' (Roof, 2016, p.2). The sense that gender trouble is individualised and centred within autistic individuals, as I have noted in the literature review, needs to be challenged by thinking about the places where, and how, gender becomes troubling to the subject and others.

Kate provided an explanation:

I think with people with autism there seems to be more obvious thoughts put into the performance of gender identity sometimes. Um, like, I'm not really sure if this example proves my point or not or if that's just showing that other people are enforcing their gender roles on these people ... but for example there's an autistic guy who I know who was telling me that he has a friend, who I'm pretty sure isn't autistic, who was saying to him that he needs to get a haircut, start going to the gym and get a girlfriend, um, and this autistic guy, he used to have long hair, very skinny and non-muscular and been single for a long time and didn't conform to hegemonic sense of masculinity at all. Um, and like, more recently he seems to have been making more of an effort to be masculine in a conventional way but it's sort of like he had to be given these explicit instructions on how to be a normal guy and it seems he's trying to follow these instructions.

[Kate, 2018]

Here Kate tells me an anecdote about an autistic friend who is taking tips from another man in order to do his gender correctly. In Kate's telling of this anecdote by not conforming to 'hegemonic masculinity' another man has decided to teach him how to be conventionally and subsequently, acceptably masculine, or in Kate's words 'a normal guy'. Kate's autistic friend's gender presentation was troubling to his friend, a masculine heterosexual man. Kate does not mention that her friend found his own to gender to be lacking. In this anecdote Kate's friend is disrupting a coherent sex/gender embodiment and he must work on himself in order to become 'normal' or, rather, normative. While there is some level of benevolence here through the friendship of the two men, one of whom wishes to enable the other to have success with women and become a 'normal guy' and subsequently 'to fit'. The true altruistic nature of this is challenged through thinking about how heterosexuality and its correspondent gender identity is always unstable and in need of constant reproduction. We could, therefore, read this story as attempts from an always-in-crisis heterosexuality to bolster and reaffirm a coherent correlation between gender presentation and sexual orientation.

This places a focus onto the social and political world rather than the pathologising overtones which often accompany discussions of autistic gender trouble.

Kate also notes in our conversation that she was aware of not fully understanding what gender is and how to perform and embody femininity in an acceptable way. Kate turned to women's magazines and followed their advice on how to be feminine. Kate discussed wanting to be seen as desirable and to be treated as such by people she encountered. However, this pressure was felt to be at odds with the sensory issues she has as part of being autistic. She discussed how her femininity was integral to achieving the aims of being interacted with 'positively':

Kate: [there are] instances when clothes are sort of tight and um, constraining I think it can be because they are perceived as more attractive. I've noticed that when I wear clothes that are sort of like form fitting, um, people seem to respond to me more positively than if I wear loose clothing that doesn't kind of highlight my curves.

Emily: and does that make you want to wear those kinds of clothes more? [...] do you find yourself wearing clothes that you find a bit more uncomfortable just to get those positive responses?

Kate: yes.

Here we see two examples of how gender is reinforced and (re)produced. The ultimate goal for Kate and the friend in the anecdote is to be heterosexual, desirable and (in)visible through their normativity. Kate discusses here the sense that to be autistic is at odds with normative femininity. jojo also expressed something similar which I return to in the next chapter. In this particular anecdote and her own experience embodying and performing a coherent heterosexual gender presentation enables one's difference to be negated by diverting attention to that which is positioned as positive within the heterosexual matrix. For Kate this comes at a cost to her autistic embodiment, she feels she must make

herself uncomfortable in order to gain this positive attention. I don't want to state that this is only the case for autistic women but that this expectant coherence of the subject (sex/gender/sexuality) and the modes in which the subject (re)produces these norms effects all people, especially women (Butler, 2006). Yet, perhaps what is distinct is the sense that a certain inability to reconcile un/known autistic difference with gendered expectations was common to most of the participants. As such, gender was performed as a mode of passing despite the efforts this demanded and often came at a cost to feeling comfortable. This is specific to autistic participants who often cite having sensory issues such as an extreme discomfit to wearing tight clothes, to having long hair or to wearing make-up (Wilkinson, 2017). That sensory issues mark the autistic experience has only recently come in medical and cultural understandings of autism (Grapel, et al., 2015).

As noted in the literature review, research into passing often focuses on passing as a heterosexual when one is queer, passing as a white person when one is a person of colour or passing as non-disabled when one is disabled (hooks, 1997, Buddel, 2011). In these accounts a *known* privative difference is made less visible through attempts to gain the privilege of fitting seamlessly into the social order. As Siebers (2004) notes, passing usually makes use of a dichotomy between the knowing subject and unknowing others: '[...] the [usual] structural binary represents passing as an action taking place between knowing and unknowing subjects' (p.15). Thus, perhaps what is particular to theories of passing is that they generally rely upon the idea of a self-reflexive subject who knows that they will gain certain benefits by being a member of a hegemonic social group by hiding their minority status, such as how Siebers made reference to the individual who passes having 'sufficient genius' to do so. For example, a light skinned person of colour will gain the privileges of being white if they are able to pass as white, a queer person will gain the privileges of being heterosexual if they do not embody or show their queerness. We know that this is not always possible though. Judith Butler has discussed a man who was murdered for his 'queer walk' (Butler, 2013). Sometimes our bodies betray us despite our best efforts. There are also times when you pass when you don't want to. For example, a person

passing as heterosexual might not be intentional and forms part of the erasure of non-normative sexualities (Hayfield, et al., 2013, Johnston, 2002, p.318). There are numerous arguments around passing; a prominent one is that it is a betrayal to your social or racial class, or to the queer community, should you attempt to pass because the one who passes doesn't take a visible political position (Samuels, 2002). Importantly, as noted in the literature review, theories of passing often rely upon the visual field. A visible difference is made invisible, or less visible.

I argue that where these theories of passing diverge when thinking about the participants of this study is the sense that the autistic participants didn't know precisely what difference they were masking. Attempts to alleviate a yet unnamed sense of difference, or, attempts to evade being labelled as 'weird' or 'odd', led to a focus on sex/gender as the site where this difference could be managed. Nor were techniques of managing the self utilised solely in order to make invisible a visible difference. Whilst tools such as magazines helped Kate pass as a normative feminine woman and Sally made use of many different identities in order to find one that fits, Aime and Hannah noted that they actively hid embodied difference. All the participants mentioned attempted to compensate for an un/known lack or difference through certain performed markers of normalcy within the neurotypical regime. The participants who experienced some form of gender trouble and who utilised gendered techniques, demonstrate the central role that gender plays in our subject formation. As Davison and Tamas (2015) have noted, autism seems to show us the socially constructed nature of gender. As Davison and Tamas (2015) state: '[f]irst-hand autistic accounts highlight the draining and relentless emotional labour that doing gender 'typically' requires [...]' (p.59).

5.4 'I was an odd one': negating difference through difference

Many of the participants discuss a key part in being able to hide one's difference and to alleviate some of the 'emotional labour' doing gender demands was to befriend their assigned male at birth (AMAB)

peers at school and in social events (Davidson and Tamas, 2015). This enabled a freedom from the focus on their gendered embodiment. That they as AFAB people were already different by virtue of the gendered assumptions and mythology that exists around the creation of difference allowed their un/known autistic difference to remain hidden, or, at least circumvented. Thus, the participants did not tend to hide their difference through assimilation into AFAB groups but into groups of AMAB peers where they could hide their difference in plain sight. This came up in my conversation with Kate:

Emily: do you know why you preferred spending time with boys? What was it that you liked about spending time with them?

Kate: in secondary school?

Emily: yeah

Kate: um, I think I can't really remember when I was younger so much but in secondary school, boys didn't really care about appearance and they would just talk about nerdy hobbies, whereas the girls in school were all to some degree preoccupied with appearance and boys. Whereas I liked talking about hobbies quite a lot. I think the fact that all of my friends were boys already made me feel quite different at school.

Here Kate notes both her preference for being friends with boys in her school because of shared interests and a lack of, what she saw as, a preoccupation with appearance, but, moreover, Kate notes that because of this she was already viewed as different. Leading psychologists Simon Baron-Cohen and Tony Atwood have both stated that autistic AFAB people are more likely to have AMAB friends. For Baron-Cohen and colleagues, this has been presented as being symptomatic of the inherent maleness of autism (Baron-Cohen and Wheelwright, 2003). For Atwood, '[b]eing a 'Tom Boy' in childhood, not being interested in fashion and femininity, make up and perfumes, as well as appreciating the logic of the male brain can lead to concerns regarding sexuality and gender identity' (2019, no pagination). These two examples, which are quite prevalent in the literature on autism and

AFAB people, do not appreciate that being friends with AMAB people as a child and adolescent might not be an attribute of the 'autistic mind', but rather, a way to pass as neurotypical through hiding in plain sight.

I wish I had explicitly asked Kate, and the others who stated similar things, whether they felt that being friends with boys or being somehow otherwise 'different' (such as Sally's 'rock persona') enabled their un/known autistic difference to be negated through this. It only really came to me that this was seemingly what was at play when I began reading and thinking about all the interviews and noticing that this was a theme shared by many. When I discussed this with other participants of the study similar experiences were brought up. For example, Sally also spent most of her time with boys, whereas Amie had friends who were much younger than them. Aime described to me how they were bullied in primary school and they were always positioned as the 'odd one':

I was just sort of ... I was an odd one. It was clear I was not one of the favourites, which always annoyed me because I wanted to be [...] it was weird because in year 6 I did have some really good friends in the infants, so about the year ones, because I ended up being one of the peer mediators and play leaders, so I was going down to the infant school a lot instead because they were a lot nicer (laughs).

[Amie, 2018]

Amie had talked to me about their struggles with primary school and being bullied and how the teacher was not often sympathetic to Amie's position when issues were brought up. Aime felt because they worked hard, and they were intelligent this should be enough to be one of 'the favourites'. This didn't turn out to be the case, so to avoid being positioned as 'the odd one', Aime became friends with the children in their school who were much younger, where their difference could be attributed to the age disparity, and therefore negated. Some of the participants struggled to make any friendships and

hadn't managed to utilise strategies such as Aime or Sally. This was the case Mary who stated: 'I was always different. I spent most of my childhood trying to please people in the hope that they would like me and be my friend, then being sad and confused when it didn't work. I was bullied a lot'.

Another participant whose un/known autistic difference was negated, albeit through completely different means was Sarah. Sarah stated she had never understood what gender was and she found gender confusing. However, Sarah did identify ways where she could 'hide things' though necessarily not through her sex/gender expression. Sarah identified herself as middle class and she had attended a private all-girls school. Sarah said to me that she felt in this environment it was 'easy to hide things':

Well of course this was ten years ago so, I think it was just, female autism wasn't particularly know about, um, I went to a private school and it was a girls only school and I suppose it was quite small and I suppose it was easier to *hide things in* [...] I mean they considered dyslexia at one point. But yeah, I think it was because it wasn't known about, nobody really talked about it as a thing. Lots of people in school got diagnosed with dyslexia growing up, but [...] I don't think I even knew what autism was at that age, um, apart from severely disabled sort of people.

[Sarah, 2018, researcher's own emphasis]

To return once more to Sieber's phrasing of the ability to mask one's difference as having 'sufficient genius' we can see that this is not what was at play for Sarah. Though Sarah states it was easier to 'hide things' (difficulties?) I do not have the sense that Sarah intended to hide or mask her un/known autism. Rather that, due to the historical impossibility of even thinking autism through an AFAB embodiment meant that her difference was considered to be dyslexia, a frequently administered educational diagnosis at the time when Sarah was in high school in the early 2000s (Campbell, 2013, p.1). As discussed in the literature review, Sarah's comment demonstrates the necessity of the prerequisite knowledge of both the self and those around them to even begin to think in terms of

certain diagnosis. She demonstrates the contingency which frames both which diagnosis one receives and whether one receives one at all (Goffman in Eyal et al, 2010, p.21). Yet, at the same time Sarah does make use of the phrase 'to hide things' without prompting.

Sarah was one of the first people I interviewed, and I hadn't begun to ask direct questions around masking at this point. I wished I had followed this up in the interview. I did contact Sarah again via email in order to ask for some clarification about this comment. Unfortunately, too much time had passed from the interview and Sarah couldn't remember the context which she had meant this. However, towards the end of our conversation Sarah had talked to me about whether she considered autism to be a disability. Sarah said that she didn't feel *her* autism should be considered a disability because she has economic stability. Sarah's stated that her parents act as an economic safety net for her so she does not worry that she would have to rely on state assistance at any point in her life. Being reliant on others outside of the immediate family was how Sarah defined being disabled:

Sarah: well mostly I think about society, it is still very class orientated, um, and I suppose I feel privileged that although I've got my autism diagnosis, I don't always feel I fit the statistics

Emily: in what way?

Sarah: so, for example, you see lots of statistics about disabled people not having any um any money or not having a job or things like that and I, not through myself, but through my parents because I have got some money behind me, that hopefully I won't fall into the situation of being in poverty as a disabled person, um, so I think that helps me to be a bit more, to not see the diagnosis as being detrimental whereas I think if I didn't classify myself as middle class and didn't feel I had to live hand to mouth and constantly have a job um, seeing those statistics of 75% of people not in employment it would worry me a lot more.

Considering Sarah's two comments about 'being able to hide' and her understanding of disability we can also think about this within a framework of passing. Sarah's privilege of not being forced into

situations in order to survive allow her to negotiate her difference in a way that is less beholden to narratives of poverty and tragedy or of visible disability. As will be discussed in the next analysis chapter disability is not only made visible through embodied difference but through making disability visible, often by force, when one needs assistance (Shildrick, 1994). This is particularly the case for those who must claim state benefits or assistance. Having little economic means often enforces a making visible of difference. Sarah also alludes to disability being framed through impairments being detrimental to other aspects of a life. Sarah's relative privilege and the social milieu which she lives within have both enabled her to 'hide' her differences and to not consider her autism diagnosis as 'detrimental'. We can consider this as an ambiguous form of passing. Ambiguous in that Sarah both felt that she should be hiding certain difficulties and differences but also that her particular environment facilitated this. Like all of the participants in this study, Sarah's eventual diagnosis of autism was much wanted and needed. Thus, as for all the participants, we can see how passing is not simply what one does as willed by a self-reflexive, or knowing, subject. Through this analysis of passing we can see the entanglement of social regimes, gender regimes, politics and individual embodiment and the demonstration of the power that the singular neurotypical and heterosexist world holds.

5.5 In Conclusion

This chapter looked at the experiences of the participants before they received their autism diagnoses. This chapter highlighted how the participants expressed a sense that they were different from others but that this difference was intangible, slippery and un/known. This un/known difference for some participants became centred on their sex/gender embodiment and attempts were made to normalise the self through management of their sex/gender identity and embodiment and that this demanded constant maintenance of its coherence to fit within the legibility of the heterosexual matrix (Butler, 2006). This chapter has been a demonstration of how bodies and worlds are made and in doing so challenges the ontological positioning of the autistic mind and neurotypical others. The next analysis

chapter will focus on how the participants came to receive their autism diagnosis and whether the diagnosis acted as a gendered technology of power for the participants. Did it bring into being any new ways of understanding and constructing the self? Did it make 'known' the difference the participants had voiced feeling?

Chapter 6

Analysis II

Coming Out: The Diagnosis as a Discursive Event?

... the exercise of power creates and causes new objects of knowledge and accumulates new bodies of information.

(Foucault, 1980, p.51)

6.1 Introduction

This second analysis chapter centres how the participants received their autism diagnoses and whether the diagnosis brought into being any new ways of thinking about the gendered self. The key areas addressed were the process of coming to diagnosis, relations with others post diagnosis, and how the participants experienced being autistic. The purpose of these questions was to understand if the diagnosis had any impact on how the individual understood themselves, and if any discursive practices were enacted post diagnosis. This chapter is framed by what was discussed in the preceding chapter: that being undiagnosed led to gendered regulatory regimes to be enacted on the sexed body. The first section of this chapter will examine awareness of autism pre diagnosis and motivations for seeking a diagnosis. Many participants suggested that gaining a diagnosis came along with the anticipation that they could begin to undo some of the normative and neurotypical modes of behaviours they had embodied, such as masking. The second part of the chapter will determine how the participants negotiate their new autistic identity in relation to their other existing identities. A common narrative cited was whilst the diagnosis of autism opened up new ways of being and doing their genders, this was also restricted by other existing aspects of their identities. Therefore, the idea that the diagnosis

interpolates the participants into a new sense of freedom is problematised through an analysis of the temporal and relational nature of discursive practices.

6.2 'Something Weird Men Had': Awareness of Autism

As I have noted, AFAB people are more likely to receive a diagnosis in adulthood due to being 'missed or misdiagnosed' in childhood (Gould, and Ashton-Smith, 2011). This is in contrast to many assigned male at birth individuals who are diagnosed in early childhood due to signposting from early educators or care givers (Giarelli et al, 2010). For many AFAB individuals it is speculated that they themselves are the driving force to gaining a diagnosis rather than being referred through other services (Research Autism, 2019). It is of significance that all the participants of this study, except Esther, referred themselves to their General Practitioners with autism as a provisional answer for their difficulties or perceived differences. From this visit the majority of participants were referred to a multi-disciplinary team of clinicians or a psychologist for an autism assessment. Prior to the initial visit to the doctor, a considerable amount of research, self-monitoring and comparison with others had been undertaken by each individual, giving the participant an intimate knowledge of autism. However, the knowledge they amassed was distinct from the dominant masculine discourse of autism. The first section of this chapter will highlight awareness of autism prior to diagnosis.

I asked each participant what they knew about autism before they sought a diagnosis. Sally first became aware of autism when she was studying at University:

[...] probably at University is the first time I came across this... [...] with people referring particularly to male students who were doing computer science or physics or maths as being 'a bit Asperger's or 'a bit autistic' and that would be where my overall impression came from. Then you have the big ones with Rain Man and the boy from the Curious Incident of the Dog in

the Night-Time. They were my impressions of autism. I was aware of it as something small children who were very disabled had, and weird men had.

[Sally, 2018]

Kate articulated something similar:

I do remember when I was younger and reading about Asperger Syndrome on the internet and thinking I might have this but then questioning myself because of the stereotype that um someone with autism is a maths genius so I thought I'm bad at maths so I can't have autism (laughs) [...] These characteristics that would throw me off, like you know this thing about being really good at maths or science. I know that isn't part of the diagnostic criteria, but I sort of relied upon more, I guess, people's descriptions of autistic people more than reading the criteria.

[Kate, 2018]

Here both Kate and Sally give a sense of the gendered cultural discourses that construct what we know about autism. In fact, all the participants noted that the 1988 film *Rain Man* was fundamental in how they came to have a vague idea about what autism was and looks like. As Jordynn Jack writes: 'perhaps more than any other rhetorical event [*Rain Man*] made Asperger's present to audiences' (p.108). A similar but more recent character to Dustin Hoffman's Raymond in *Rain Man* can be found in Sheldon Cooper from the *Big Bang theory* (2007-2019). Amie, the youngest participant at eighteen, makes use of this reference: 'I thought it [autism] was that [...] sort of Sheldon stereotype'. Raymond, Sheldon and Christopher, the boy in *The Curious Incident of the Dog in the Night Time*, form the holy trinity of cultural representations of autism. What all these characters share are, of course, their gender but also a savant like ability in mathematics, sciences and memory recall. They represent what many in disability studies have critically described as 'super crips' (Schalk, 2016). 'Super crips' are those who

overcome their disabilities in order to be exceptional at a particular thing, such as sports for example. When it comes to autism, particularly Asperger's Syndrome, it isn't so much a case of overcoming deficit as it is that autism is already bound with mythologised (male) genius.

These representations are of course not overly favourable though they suggest skill and even genius, due to the lack or deficit that is also inherent to autism when we conceptualise it this way. However, these discourses do not, when attached to cisgender men and boys, challenge a fundamental sense of gender identity. Autism when it functions in the 'super cripp' framework stays within masculine boundaries albeit pathological. Consequently, it functions as a form of pathological masculinity. This discourse enabled Sally's fellow male students at University to be labelled as autistic whether or not they are. The prevailing trope of the socially inept but technologically or mathematically gifted autistic was cited by these participants as preventing them from considering they were autistic. Whilst Kate only relied on reading other people's experiences and therefore couldn't see a correlation between herself and these representations, Sally explicitly states that a certain amount of stigma around autism foreclosed her exploration of the diagnosis, as she describes autism as being synonymous with 'weird men'. Thus, the gendered discursive formation of autism prevented a stumbling block for Kate and Sally to even think that autism could be the diagnosis that explained their experience. Jack (2014) has written about the tendency for dominant representations of autism to actually add to the numbers of those diagnosed autistic, but only if they match the representations that are already available. For example, scientifically or technologically inclined men or adolescents who also struggle with interpersonal relationships may be more inclined to seek a diagnosis due to the existing gendered discourses of autism (p.146).

For AFAB people these dominant discourses can not only foreclose their own ability to recognise themselves as autistic but also those of medical professionals. Gatekeepers such as General Practitioners were cited as being less willing to refer them to specialist services by some of the

participants. This leads some AFAB individuals to pay for a private diagnosis through independent services (Research Autism, 2019). This was the case for Sally who paid for a private diagnosis. Sally then took this private diagnostic report which stated she was autistic to her GP to ask to be referred for an NHS diagnosis. It is of note that private diagnoses are not permissible evidence for state support or services related to being autistic, which can further disadvantage autistic AFAB people (Bargeila et al, 2016, Citizens Advice Bureau, 2019).

6.3 'Full Research Mode': Producing Knowledges

From the lack of self-recognition in the cultural discourses which produce autism to receiving the diagnosis the participants had conducted a considerable amount of research around the condition. Aime describes this as going into 'full-on research mode':

If I hadn't done the full-on research mode, I would have very much viewed it as a guy's thing. When you look at, the very, very minimal representation of it [...] or what it could be possibly be considered autistic characters, it's always guys in media and stuff so...

[Aime, 2018]

Sally said something similar. I asked Sally how she came to receive her autism diagnosis despite, as she had stated, not seeing herself in discursive representations and medical definitions:

I read the Sara Hendrickx and I went 100% special interest in autism for two years, I have probably read more books about autism than most people who train other people on autism now [laughs].²² I just read ceaselessly. Neurotribes, everything Sara Hendrickx wrote, 9 Degrees of Autism, lots of autism biographies by women and men, books on how to get diagnosed.

²² As described on her website, Sara Hendrickx is an 'independent specialist consultant and trainer in Autism Spectrum Conditions'. Hendrickx is also a late diagnosed autistic woman, among other books, she has written the

Within these accounts we see an entanglement of medical knowledges and experiential accounts. All the participants of this study have experiences of mental health difficulties or difficulties with executive functioning which led to a myriad of alternative diagnoses being given to them.²³ Yet, for all the participants their prior diagnoses did not seem to fully describe their experience. An autism diagnosis was actively sought by each, but in order to gain this diagnosis each participant gathered information from what is already known about autism. As Sally states, she even read 'books on how to get diagnosed'. This active engagement in the discursive knowledge available about autism bears similarities to what Sandy Stone (1993) writes about in *The Transsexual Manifesto*. Stone (1993) discusses how transsexual people (who we would now call transgender) have to adhere to the dominant and intelligible narratives and discourses which construct transgender identities within a medical framework. This is necessary to gain a diagnosis which would enable healthcare and transitional services. As Stone (1993) states, the transgender body is never granted agency, it is inscribed by, and reproduces, the cultural ideals of sex/gender and their origin stories. As Stone (1993) writes:

[the transsexual body is] a hotly contested site of cultural inscription, a meaning machine for the production of ideal type. Representation at its most magical, the transsexual body is perfected memory, inscribed with the "true" story of Adam and Eve as the ontological account of irreducible difference, an essential biography which is part of nature. A story which culture tells itself, the transsexual body is a tactile politics of reproduction constituted through textual violence. The clinic is a technology of inscription.

general guidebook 'Women and Girls with *Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age* (2015). Hendrickx conducts many educational talks and also offers private diagnoses with a specialisation on women and girls at her independent clinic in the U.K.

²³ Executive function or executive functioning refers to aspects of cognitive processing. When someone has difficulties with executive functioning they may struggle to stay organised, have difficulties controlling impulses and find it hard to pay attention, among other things (Diamond, 2013).

There are certain similarities between the above quotation and the ways that autism has been positioned as proof of the ontological and irreducible difference between the sexes (Baron-Cohen, 2002). Where Stone's account of transgender engagement with medical services diverges with the participants of this study is that medicine isn't configured as an outright enemy to be fought with tactical manipulation. For Stone's transgender individuals, institutionalised medicine functions as a gateway to be passed in order to gain gender transition surgeries and hormonal treatments. For the autistic participants the medical understanding of autism is something to be continuously engaged with. It is through this medical understanding that they could come to identify as autistic. Such as how Kate stated that she relied upon experiential accounts rather than the medical criteria, implying that this would have been where she found herself. Yet, rather than simply positioning themselves through the existing dominant discourse of autism they sort out counter narratives and built on these by constructing new knowledges that interweaved with the dominant discourse.

Moreover, the diagnosis of autism was for many participants a necessary step to a feeling that they understood themselves, or that they could access the truth of themselves. This functions as what Foucault (1980) termed as knowledge/power. As Sally stated about her coming to autism:

[...] when I was doing all my reading and self-diagnosing, I veered between being absolutely sure and then feeling completely convinced I'd just found another thing to hang the peg of my difficulties on. There was something about wanting an external person to tell me I was right.

[Sally, 2018]

Aime received their autism diagnosis in an unconventional way. Rather than being referred to a specialist autism clinic, their GP diagnosed them in his office. Aime stated that this somewhat

'unofficial' diagnosis has led to worry over whether her diagnosis is valid. As Aime states: 'I have a never-ending fear that I haven't got an official diagnosis and it's all going to come back and ah! but I'm going to ignore that for now'. Here we see that autism is not something that one simply *is* but rather, something that must be *co-constructed* through the individual and the institutional powers of medical professionals. Aime's worries about an 'official' diagnosis are not related to receiving medical support or state services but are deeply attached to hopes that Aime has an intimate knowledge of their selfhood:

[...] if I was autistic all my suspicions are correct, I do kind of know what's going on with who I am, it makes sense, and I'd seen stuff online and it was like, this feels like it's describing me and if I wasn't, it was going to be like, 'oh, I don't know me that well'.

[Aime, 2018]

6.4 'Who am I?': The confessional space of the clinic?

As noted above the diagnosis was important for several of the participants due to a belief that it would enable a deeper understanding of the self. As noted in the 'sociology of diagnosis' literature review, autism holds a strange place in terms of diagnoses; whereas other cognitive or psychological conditions generally have treatment plans included post diagnosis, at least for those with fewer daily support needs, autism does not. This is mirrored by Aime's description of what their doctor said after their diagnosis: 'he said it was because I was an adult and that's it, there's no support in [Aime's hometown], deal with it'. Though Aime's description of their doctor's advice post diagnosis seems overly inconsiderate it is true that services for adults are lacking (Murphy, 2016, Lorenc et al, 2017). This can be especially the case for those who do not fall into the catchment criteria for social services support or state benefits (Lorenc et al, 2017). None of the participants of this study received any additional

support services and the diagnosis was positioned as holding the key to self-understanding and acceptance more than anything else. However, for a couple of the participants there was the hope that gaining a diagnosis would enable them to complete college or attend University. Such as for Sarah:

I remember going to see my GP when I was probably 20, um, just sort of being quite depressed and talking about, I think, I wanted to go back to college because I'd been to college before but it hadn't worked out, um and I wanted more support when I was at college and I thought having some kind of, um, diagnosis of a learning difficulty or autism, I wasn't totally sure what it was, um, or what would be helpful.

[Sarah, 2018]

A diagnosis is positioned as having the possibility to open up access to support services which are believed to be useful to help Sarah successfully complete college. Other participants, such as Hannah, who does not think of her autistic spectrum condition as a disability, or indeed as causing her much difficulty, stated when I asked about why she wanted a diagnosis:

Um, I would sit on the floor and do the thing with the toes, you know, curling your toes under your feet ... um, my insistence of things being a certain way and um, going a bit, um, getting a little bit irate when things didn't work out, um, other things about, um, just general obsessions [...] but, um, yeah, just little things.

[Hannah, 2018]

I followed this up:

Emily: But ... did you find those things a problem? or was it just that you noticed a difference between you and other people?

Hannah: I think it was more of a difference, because um, I've, um, I pass fairly well for not being autistic.

The sense that Hannah did not necessarily struggle with anything related to autism was present throughout our entire conversation. Indeed, several of the participants didn't particularly discuss wanting to have an answer to specific difficulties but more an answer for perceived differences. I found myself wondering several times what it is that defines this group of participants as autistic. Indeed, during the interviews the participants were producing knowledge about what autism is and looks like which challenged my sense of what autism is. The things that make up autism were constructed as multiple and fragmented and taken on their own did not signify very much, or they signified something totally different. As Esther noted, autism was a useful catchall category for her because she worried that would need around 'fifteen different diagnoses' in order to make sense of all her various difficulties and traits. A process of self-analysis and mentally collecting disparate behaviours, ways of perceiving, motivations and desires and connecting them to one another through engaging with the discursive knowledges of autism was necessary to enable autism to come into being as a probable diagnosis for the participants. For Hannah, it is on 'the little things' of perceived difference that the possibility of autism rested. Margrit Shildrick (1994) has written about disabled welfare claimants who must self-document every physical difficulty in order to gain financial aid: 'no area of bodily functioning escapes the requirement of total visibility, and further, the ever more detailed subdivision of bodily behaviour into a set of discontinuous functions speaks to a fetishistic fragmentation of the embodied person' (p.48).

It would seem that because the welfare claimant is not being physically examined by another that this is a more benevolent form of power. However, Foucault (1995) argues the idea that either the patient

or the prisoner (the two are interchangeable regulatory regimes in his theorisation of power) should freely offer up their inner self to an another is not a move away from an authoritarian power. It is rather a 'dovetail' of this prior form of power into a new all-encompassing form of power whereby the individual becomes responsible and accountable for monitoring their every desire and behaviours (Foucault, 2003, p.242). This consequently delves deeper into the subject and her body through what Foucault defines as 'capillary power'. The individual and society are implicated within capillary power, for it is through this self-interrogation and construction of knowledge about the self that this power/knowledge can then circulate in society. In some ways, this bears similarities to Ian Hacking's (2006) theory of 'looping effects'.²⁴ New categories and ways of being are co-created by institutional power, individuals and the processes of knowledge transmission.

In Shildrick's (1994) usage of this Foucauldian understanding of power the disabled person is still beholden to an authoritarian power regime. The difference is that the individual yields to this power and consequently they are made accountable and responsible for the outcome of the bureaucratized system they must engage with. The claimant does the work for the regime in their observation and documentation of the self. As Shildrick (1994) writes:

The gaze now cast over the subject body is that of the subject herself. What is demanded of her is that she should police her own body, and report in intricate detail its failure to meet standards of normalcy; that she should render herself, in effect, transparent.

(p.48).

²⁴ It is important to note here that despite Hacking's distinction of natural kinds and human kinds he does note that there exists a third category; one which acknowledges the limits of this social construction approach. This third category is called 'interactive kinds'. I am of the mind that nearly everything we deal with in the Social Sciences would fit into this last category but for Hacking it has specificity. For example, Hacking argues that autism could be considered an interactive kind. This is because when the condition becomes known through the naming of it as a distinct diagnosis, it changes the experience of the individual, both in how they experience themselves and how others conceive of them. This is the sense that I am making use of Ian Hacking here (Hacking, 2000).

Hannah was not seeking welfare payments nor was she asked to submit to a bureaucratised documentation of herself for any other type of aid. Yet, she did so through her own volition and monitored her behaviours to the minute degree. This was much like Esther who had considered many other mental health and cognitive conditions which could each explain seemingly disparate fragments of her experience. We could quite easily suggest that Shildrick's (1994) analysis of welfare claimants is what is at play within Hannah's and Esther's monitoring and subsequent reporting of the self to medical experts who can determine what their particular deviances from the norm suggests. Regardless of Hannah's lack of desire for support, it is true that having an autism diagnosis would open up access to certain financial aid and support. Thus, there is an anticipatory material benefit in gaining a diagnosis of this kind. However, Shildrick's case studies are *forced* to make themselves transparent and are consequently removed of their agency. I argue that the participants of this study are, in many cases, willingly seeking a diagnosis and this confounds the traditional understanding of the pathological and the normative. In particular, Hannah discussed how prior to her diagnosis she felt forced into a normative mode of being: 'I think I've done a lot of learning, about how to be in ... um, I've got a lot in my repertoire of, um, social situations, so I can go, um well this (audio cut out) for this situation, I pass as non-autistic [...]'.

Consequently, Hannah's own management of her autistic traits have meant that they do not present a problem for her, yet they do constitute a difference and that perceived difference was what pushed Hannah into seeking a diagnosis. As Hull et al. (2017) write:

Essentially, social imitation may be a form of acting, whereby girls with undiagnosed ASC may be coping without receiving a diagnosis *or even needing a diagnosis* because their acting is relatively successful. Success here may be defined as simply not having overt functional impairments or raising concerns of teachers or other professionals [...]

(p.2534, own italics).

The above statement challenges what we understand autism to be. As autism is considered to be an ontological fact of the person, it is not 'outgrown', nor can it be 'overcome'. As Frith (1991) has noted the autistic person will have strategies of 'adaptation and compensation' but autism will always be present (p.58). For a medical diagnosis such as autism the ways autism is experienced must also present 'impairment'. In the above quotation a diagnosis is presented as something given under requirement of need. Yet for many participants a diagnosis was sought as legitimisation of certain difference that they felt and knew to be their experience. As Samuels (2003) has suggested, we often think of people who are able to 'pass' - as not disabled, as straight, as women when trans, for example - as being privileged yet this ignores the harm that social exclusion does to an individual when they are continuously forcing themselves into a round hole, to borrow Mary's phrase again. This medical understanding of autism explicated through Hull et al, (2017) assumes the behavioural approach of autism diagnosis, rather than an exploration into the underlying worries, anxieties and fears that many undiagnosed autistic people have. Whilst they may seem to be successful, it is an 'act' as Hull et al (2017) note. For many of the participants the diagnosis was not sought for access to support, treatment or curative strategies but rather as a liberation from intensive normalisation of the self, as seen in the previous chapter.

For Hannah, difficulty or impairment had been significantly worked through by intense attempts of normalising the self. Thus, although Hannah's concerns about her difference from the norm seem to suggest a reproduction of the binary between the pathological and the normal, I argue that through this particular mode of articulation Hannah is opening autism up to be less pathological and more grounded in possibilities of what the body does and can do. As it relates to the discussion of 'masking and passing' in the preceding chapter, Hannah's use of the term passing suggest a realisation that her perceived difference was always already being monitored from outside and she sought legitimisation

of the self through seeking the diagnosis. Being diagnosed was positioned by Hannah as allowing her more freedom to enact different ways of being.

The diagnosis for Hannah was key to her understanding both her limitations and simultaneously her possibilities. As Hannah states:

All the people who I interact with now, they all know how I interact, they all know the way I interact, so I never actually have to do the thing of feeling anxious before I say something, or worrying that I'm going to say the wrong thing and all of my encounters now are much smoother.

[Hannah, 2018]

For Hannah the diagnosis acted, in her words, as a 'stamp of legitimacy'. However, rather than interpolating her into a framework of pathology Hannah suggested that it enabled her to enact her difference rather than to continue hiding it through concerted efforts of normalisation. From Hannah's self-monitoring of her the smallest detail of her bodily movements (the curling of toes) to Sally's extensive engagement with the autism literature, all of the participants who took part in this study demonstrate that they are utilising technologies of the self. In Foucauldian terms this means the belief that one has access to the truth of the self through both the self-monitoring and intimate exploration of the self, combined with the expertise, in this case, of medical professionals, psychologists and

psychiatrists.²⁵ The participants took all their prior bodily and discursive knowledge to their autism diagnostic appointment.

All of the participants of this study recounted their diagnostic experience as being partly composed of observation and of narrating their childhood and their current thought patterns, behaviours and motivations to a team of clinicians. As we have seen in the first analysis chapter some AFAB people are supposedly adept at 'hiding' or 'masking' their autism so what takes place in the diagnostic room is configured, in part, as a revealing of the truth of the self. The clinician's office is a confessional space where disparate moments of a life become signs of autism. Notably, it is necessary to have this narrative of childhood because autism has to be present from early childhood, thus diagnosis takes place, in part, retrospectively for late diagnosed people. Some of this knowledge can come from school reports or early caregivers which are interpreted for signs of autism but for many these documents have been long lost, caregivers have died or simply cannot remember (McGrath, 2017). Thus, for many people the narrative must be given by the person seeking diagnosis.

This was the case for Aime who talked to me about what happened at their initial assessment:

We talked through them [Aime's suspicions they were autistic], he [the doctor] asked me questions about my school, my school life and stuff that had happened there, I explained the whole IKEA meltdown situation and that [...] was what most of it was talking about.

[Aime, 2018]

²⁵ Here we can include engagement with autistic literature (medical, autobiographical, journalistic), self-diagnostic tests which are popular and widely disseminated across the internet and the monitoring of the self for perceived differences against the norm.

What is interesting about these techniques of the self being not only used by, but expected of, autistic individuals is that it presents a profound disruption to what is expected of autistic people. Historically, autistic people, as discussed in the methodology chapter, were not presupposed to have an in depth understanding of the self, much less the ability to recount that to another. Moreover, what is demanded in the uncovering of truth of the self is to talk to someone else, an expert, who holds more power than you do to determine your selfhood. This co-construction is productive in that it brings something new into being. For the participants of this study it brings an autistic subject into being.

This is not only the case in psychiatry but in all areas, from the institutional to the most intimate areas of desire and love. Precisely why this confessional system has become so common place is because it is presumed to hold the key to liberation (Foucault, 1990). Power is presumed to deny access to truth and consequently uncovering these power structures through confessional acts paves the way for the liberated subject to emerge. This is indeed the narrative that is played out for the participants of this study; liberation, or freedom, from normative and neurotypical modes of being were sought. As Mary wrote: 'I think I wanted to become more understanding of myself, kinder to myself because there was a reason for my difficulties, I wasn't just "weird"'. However, it is not accurate to think of what emerges in the clinician's office as *the truth*, but rather as 'truth effects' for the potential that these encounters have for creating truths.

The ability to engage in this mode of subject production in the clinician's room is of course dependent on existing power relations and the subject positioning one already holds. To be able to have prior access to the knowledge that produces autism is a distinct privilege. Like the majority of the participants in this study, Sally is well educated and also had the time available to research and understand what autism is. As Sally stated: 'I think there's a massive discrepancy particularly for women of lower class who [...] haven't grown up with the socialisation that gives them the tools to talk about their mental health and to access mental health services'. Despite the literature that Sally

engaged with not always representing how she experienced being autistic she was able to build on this through her own experience, creating new discourses about autism (liking art, being creative). Through this accumulation of knowledge, to refer back to Foucault's words which opened this chapter, new bodies of information are being created, not only bodies of information in the sense of medical knowledge and discourse but new modes of doing and being bodies.

6.5 The Diagnosis as a Discursive Event?

After receiving a diagnosis many participants noted that they felt they could begin to enact certain behaviours which they defined as autistic. In some cases, the diagnosis with the statement 'you are autistic' given at the end of a long period of assessment acted as an event. It simultaneously named and made sense of the subject, at least for a period of time. Prior to diagnosis, as I have discussed in the first analysis chapter, for many the body was un/known and un/knowning. Receiving a diagnosis, for most participants (with the exception of jojo, who will be discussed later) the diagnosis 'legitimised' a new set of discursive practices to be mobilised through the body. I asked Sally if after she received her autism diagnosis, she felt that she could behave in different ways:

Yes. I'm trying it out. I'm trying out being autistic and not masking and I'm enjoying it, it's quite fun. Um, one of the things that people talk about that I didn't quite take seriously for a while was, [...] post diagnosis, [...] people talking about rediscovering stimming after they've, they've sort of had hidden stims all their lives and I really enjoy it. I really enjoy waving my arms about and having a bit of a dance in the living room and generally being a bit autistic. And, flapping in the cinema because I thoroughly enjoying flapping my arms about in the cinema [...] I will wave my arms about at the cinema and it's just fantastic, having that freedom to do it [laughs].

[Sally, 2018]

Aime also articulated something similar:

I don't do the stereotypical autistic flap, but I need to do a slightly more controlled version of it [...] I feel free enough to be able to do that now and do those small things in public. Like, I don't do any of the stuff that would really draw attention to me because I hate being the centre of attention [...] but it does feel very freeing to think '*I could do this*'.

[Aime, 2018, emphasis in speech]

However, enacting autistic behaviours was not free of concerns such as appearing that they were 'faking' being autistic. Such as for Aime when they discussed how they related to people after receiving their diagnosis:

I felt I wouldn't seem autistic enough, which, I hate that phrase but it's what I felt like, but, so I sort of felt like I had to prove I'm autistic to them and then like to people who I shared the diagnosis with I sort of felt that there was pressure to not mask too much in front of them ... but there was also the pressure to [mask]... that it wasn't like I'd suddenly changed and I'm putting it on.

[Aime, 2018]

Aime highlights both the behavioural performativity common to both 'masking' and being autistic. Whereas Hull et al (2019) suggest that masking leads to a sense of faking or pretence, Aime alerts us to the temporal nature of embodied discursive practices. A diagnosis of autism does not give access to an authentic self which can simply be uncovered and lived in its truth. The becoming from one status (undiagnosed) to another (autistic) is (re)negotiated and situated in relation to different encounters and environments. For Aime, the pressure to appear 'autistic enough' was felt the most around other autistic people. This bears similarity to how Aime situates themselves as a queer person, Aime is asexual and non-binary. Aime feels that their non-binary gender identity and non-object orientated sexuality

leaves them outside of queer communities. Thus, we could understand Aime's attempts to seem autistic enough as a way of seeking acceptance within others who share the diagnosis. Yet, this is not a seamless transition and Aime must demonstrate themselves as being autistic through considered behaviours which are the shared identifiers or markers of belonging. Aime must also not transgress the expectations of what their new autistic community expects of an autistic person. Despite entering into a new behavioural regime and still having one foot in the old one, Aime states that they now have the possibility to behave in different ways and they feel a certain 'freedom' to explore that. Thus, the diagnosis opened a new range of possibilities for what the body can do for Aime. Of course, the ways that this 'new' was framed was already constructed by what is known to be 'typical' autism and the correspondent autistic behaviours (flapping the hands or arms, for example).

Autism is largely what we would call an invisible condition. Therefore, whilst it may come to form a person's identity (much as most of the participants stated that autism was a key part of their identity) it is not always be visible to others. There is a disconnect between the identity and the embodied visibility of their condition which Aime highlights here. To refer back to the first analysis chapter and the section on passing, here we see the tension between wanting to be viewed as autistic and the behaviours one must enact in order to be accepted by others (and the self) as being autistic. Rather than thinking about passing as non-autistic as assimilationist attempts I prefer to consider it as Samuels (2003) does: 'passing can be a subversive practice and [...] the passing subject may be read not as an assimilationist victim but as a defiant figure who, by crossing the borders of identities, reveals their instability' (p.243). In my conversations with all of the participants, not only Aime, the sense I got was that whether they passed or whether they were seen as autistic they continuously demonstrated the thin and always fragile hierarchy which delimits where we belong and who we are. These identities demand constant attention, reproduction and negotiation.

Esther provided a similar critique which speaks to the temporally situated nature of discursive practices and presents a challenge to the notion of the self being uncovered through the diagnosis:

After my diagnosis I guess I did explore more kind of can I just be this way and I think they [Esther's parents] suddenly struggled with me behaving in more autistic ways, or what looked to them as more autistic ways [...] because of course, not many of my colleagues know I'm autistic, a few of them do, but I'll often end up in conversations where people talk about autism and how none of us are autistic [laughs] and it's like, oh I can't say anything now! So sometimes I guess that there's a tension of uh, how should I put this, looking autistic, but not too autistic.

[Esther, 2018]

Here Esther highlights a tension within her family and also in her workplace. Esther is a doctoral student studying neuroscience with a focus on autism. She was encouraged to see a psychologist at the age of eighteen before her parents would allow her to attend University and begin living independently. The psychologist referred her for an autism diagnosis which she then received. However, here Esther talks about her parents 'struggling' with her more overt autism despite her family already having noted her struggles and difficulties. My conversation with Esther revealed certain tensions between what autism is and looks like and who can be autistic. Esther is well educated and comes from a medical family; she now works with other young scientists. There was an underlying sense that autism is stigmatised and does not 'fit' with her background and her profession. This was highlighted through Esther's desire to seem autistic but not 'too autistic'.

The diagnosis also came to bear upon how some of the participants considered their gender identities. For Sally the diagnosis enabled her to stop feeling as though she were 'rubbish at being a woman'. As noted, Sally has struggled with alcoholism and has taken on many identities prior to receiving her

autism diagnosis. Sally had a period of wondering if she was transgender, much like Hannah (see analysis I), and on receiving the diagnosis Sally could (re)imagine her younger self as an autistic person.

As Sally states:

[...] after University I didn't wander around inferring that I was a man anymore, I just kind of settled into having a job and a life, and an ordinary life sort of thing and ... but what the autism diagnosis did was put to bed any of these ideas that I was crap at being a girl [...] because the autism is what made me not fit in, not the fact that I was rubbish at being a woman, I wasn't rubbish at being a woman. I was rubbish at interacting with people in a neurotypical world. I have found my tribe on Twitter and on Facebook. I have found other autistic women [...] whose experiences resonate with me.

[Sally, 2018]

Despite this being Sally's experience, it is important to note again here that autistic transgender people have historically been situated as not being transgender and solely being autistic (de Vries, et al., 2010, Van der Miesen, 2018). That is, their gender trouble is situated as being caused by their autism. Whilst in some cases, (such as Sally and Hannah) being an undiagnosed autistic person and feeling a profound sense of difference can lead to considerations around gender identity, as discussed in the previous analysis chapter, this should by no means be assumed as being the same for autistic transgender people. This was something that Sally was aware of and she was cautious to advise that she only spoke from her experience.

Though I have highlighted some positive aspects of what it means to become autistic, or to 'come out' as autistic, through beginning to feel as though one can begin to live differently and enact different modes of using the body, the participants were still largely bound within the confines of what a neurotypical world expects of them. Moreover, we can see the push and pull of identity negotiation

and the individualised nature of constructing the self through the ways in which it is monitored and adapted. We have gained a picture thus far that destabilises notions of a preconceived ontology of the self and the other. The participants have articulated some of their processes of subjectification; in this case to becoming an autistic subject.

The participants I have discussed make it clear that whilst an autism diagnosis is, in many respects, a positive legitimisation of difference and it means one can effectively 'come out' and say 'I am autistic', it does not ever completely act as a 'totalization of this 'I'' (Butler, 1990, p.309). There are still regulatory norms which define what ways a body is gendered and in what ways a body is to be in a neurotypical world. This always temporally and spatially contingent upon where and who the individual encounters and engages with. This was felt most clearly by jojo. I will spend some time with my conversation with jojo because she most clearly identified the struggles between wanting to become autistic and feeling beholden to her prior interpolations. In particular, jojo discussed a deep ambivalence between being autistic and being a woman. This was something that was not articulated as strongly with the other participants, although many noted that prior to the diagnosis they felt at odds with their gender identity.

6.6 'I still think I'm trapped in my gender': Inability to become Autistic

jojo articulated a sense of not fully being able to 'become autistic' despite wishing that she could embody some modes of being autistic. jojo evoked an idea of an ideal autism that was genderless and, yet, at the same time she cannot escape the expectations of her gender:

jojo: I still think I'm trapped in my gender, I still think I'm trapped in the role. You know I'm a mother, I'm a partner, I'm still trapped in that, which I don't like.

Emily: In what ways does it make you feel trapped? I think I know what you're getting at ...

jojo: That I've still got to be a certain way for the outside world. Say with my children, I couldn't be overtly autistic in the outside world with my children, I've still got to, you know, I don't know. I've still got to look presentable, I've got to, I'd love to just shave all my hair off, but I'm not allowed to do that am I...

Emily: Why would you like to shave your hair off? The feeling...?

jojo: I don't like hair on the back of my neck, I still put make-up, I don't know why... I've still got to present myself as an attractive female, I don't know why, even though I detest the attention of men, but ... I don't know why, I'm still conflicted, I don't know...

jojo's sensory issues which cause her distress and are a part of her embodied autistic experience become a way for her to articulate a sense of how autism and femininity cannot coincide in a way that makes her feel comfortable. However, being autistic and having the knowledge of her condition does not free her from feeling as though she doesn't have to perform certain markers of femininity. I have quoted the following section of our conversation at length because it demonstrates the intersections of autism, gender and class and age that are so often missing from research into autistic experience. jojo was the oldest participant, with the exception of Mary. However, my interview with Mary was written so I did not have the opportunity to follow up on some of Mary's points. jojo's age was integral to her not feeling as though she could explore other modes of being gendered:

jojo: you know, if I was diagnosed as a teenager maybe I could have been what I was meant to be, you know, maybe...

Emily: How would you have like to exist...

jojo: I don't like being a woman

Emily: So, would you prefer ... in an ideal world if you could have been born a boy?

jojo: Yes, I'd prefer to be male

Emily: ... because of the freedom men have? men can shave their hair off, they don't have to wear such tight clothing or make-up...?

jojo: They can be more themselves [sic], can't they. We are so confined by stereotypes as being female.

As jojo considers, perhaps if she had been diagnosed as a teenager, she would have had a legitimisation to explore a less rigid way of enacting gender. The freedoms jojo sees in being assigned male at birth are correlated to feeling more comfortable in her autistic embodiment. Despite wishing she could transgress her gender, jojo feels she cannot. This is tied to her role of a mother to two young children. Being a mother and being 'overtly autistic' for jojo are incompatible. Ultimately, for jojo the diagnosis of autism did not offer a sense of freedom to explore different modes of being, predominately because her diagnosis was not received in time or, indeed, at the right time. When jojo and I discuss the accessibility of younger people to different ways of doing gender, jojo takes an ambivalent position:

Emily: what do you think about this [...], um, well I guess about how people are thinking about their genders right at this moment in time?

jojo: I don't, I think it's a little bit, it's that group mentality and I think we just want to label ourselves as this as we'll get through the door into this group, kind of thing. But life's not like that, just because I don't know, you like one thing and another person likes another thing doesn't make them a good person, but again that could be younger people, so maybe it's for younger people [...]

Emily: uhmm, but I guess on the other hand, as you said earlier if you could have been born a boy you would have been happy with that [...] and I think maybe, having that freedom to identify as the gender that you want could be quite helpful for people, can you see that side of it?

jojo: yes, yes, totally, I can see that side of it

Emily: but you just don't, you would rather maintain your, um, kind of identity as a female and present yourself as a woman and that seems easier for you than going down a different [...] different path?

jojo: Yeah, I'd rather not kind of challenge, you know, social stereotypes, I'd rather, where I come from in [jojo's hometown] saying I am this [not binary gendered] everyone would be like '*what!*', my children would get bullied. I can't do that, I'd love to be able to shave my hair and whatever, but I can't, I can't do that.

[emphasis in speech]

Here, jojo discusses how her class and her location are also a fundamental part of her not being able to shake free from some of the social stereotypes of being a woman. Through this, jojo alerts us to the notion of queer privilege. Though queer privilege is paradoxical sounding, it is an important point to consider. For many the term queer is synonymous with an ethical non-normativity as a political position against heterosexuality and its enshrinement in law and governance. Or, as Warner cited in Epstein (1991) describes it; queer is in 'opposition to the normalising regime'. As jojo stated a certain identity does not make you morally unaccountable or a 'good person'. To be able to enact queerness is at one and the same time a subjugated, and yet privileged, positionality. Donna Haraway's (1988) discussion on the privilege partial perspectives critiques this notion when she writes:

The positionings of the subjugated are not exempt from critical reexamination, decoding, deconstruction, and interpretation; that is, from both semiological and hermeneutic modes of critical inquiry. The standpoints of the subjugated are not "innocent" positions. On the contrary, they are preferred because in principle they are least likely to allow denial of the critical and interpretive core of all knowledge. They are knowledgeable of modes of denial through repression, forgetting, and disappearing acts-ways of being nowhere while claiming to see comprehensively.

(p.11)

Innocence, for Haraway, is not only impossible but an attempt to de-politise oneself and to state an inculpable position whereby one does not replicate and reproduce certain modes of oppression. In jojo's account she acknowledges the conflict between a desire to be, and to live, as an autistic person which for her means someone who isn't beholden by gender stereotypes and the modes in which she must uphold her prior interpolations as a feminine heterosexual mother who doesn't disrupt the coherence of her position in the social class. As jojo articulates it, her position as a woman comes directly from being seen as heterosexual: 'I feel trapped in my circumstance now because I'm in a heterosexual relationship, I'm trapped to being a woman.' Here jojo highlights the relational construction of gender through heterosexuality which in turn produces the category of woman. As Monique Wittig (1992) wrote: For what makes a woman is a specific social relation to a man [...] (p.10). Moreover, what is clear in jojo's case is a responsibility to her children to be a woman and a mother and her articulation she cannot be 'overtly autistic'. This is not because being autistic would mean she could not be a good mother, but because of the stigma that would come from suddenly enacting a form of gender queerness which she believes would directly affect her children negatively.

Elsewhere in our conversation jojo and I discussed the politics of location. jojo is from a small working class town in Northern England. As many other small towns in Northern England, it was once a thriving community and had industrial and clerical jobs for many. Now the area acts more as a commuter town for those who want cheaper rents and mortgages and who have employment in the surrounding bigger cities. Jobs in jojo's town are few and poverty is high. jojo discussed this as a key restriction on how she could be a gendered subject. Despite a disidentification with her working-class positioning (jojo identified herself as working class, yet she constantly stated how she wasn't working class like the 'others' around her) she had to maintain certain modes of identification particularly through heterosexuality *and* hiding her autistic traits which she sees as not compatible with one another within her class positioning. Beverly Skeggs (1997) has written there is an 'emotional politics of class' and for working class women this is a politics of 'disidentification, insecurity and unease' (p.75). For jojo, this

unease makes her feel like an alien: 'I feel like an alien in [jojo's hometown]'. This bears similarities to the alien metaphor that is found commonly in discussions of autism: see, Ian Hacking's (2009) article 'Humans, Aliens and Autism', the autism online forum 'Wrong Planet' or Temple Grandin's (1995) proclamation 'I'm an anthropologist on Mars', to name but a few. Here jojo suggest that her feelings of being alien-like do not come from *being autistic* but, rather, from an *inability to be autistic*.

If jojo felt she could be 'more herself', as she states, then she would feel, in her words, more 'comfortable' and yet she discusses that the possibility isn't there because of her geographical location. In particular, its reproduction of certain forms of compulsory heterosexuality and correspondent femininity and motherhood which are only intelligible and valid through performed heteronormativity. Through her comments, jojo alerts us to a sense that as she understands it to be autistic is to be gender queer. For jojo the normative modes of being a woman cannot co-exist within autistic embodiment. As jojo sees more pressures on women to be normatively gendered then her solution would be to have been assigned male at birth. To be queer with less threat of violence or social ostracization can be class privilege. Or, to be more precise, it is a privilege for those whose social milieu prizes visible queerness as both a product of, and proof of, the tolerance of liberalism.

Moreover, to be able to be queer is, for jojo, inherently linked to a social and political temporality where the ability to be queer as an autistic person is a privilege of younger people and especially those who are technologically engaged. This emerged when we discussed younger people's understanding of different gender and sexuality categories, especially in how people talk about their identities on social media platforms such as Twitter. The quotation cited below followed the discussion I noted earlier about young people's gender expressions. Earlier jojo was dismissive toward young gender queer people, yet here she admits to jealousy:

[...] I totally respect young people, I think that's great that they can find a like-minded group and I think that's brilliant and so freeing and they're so open and I really respect that and I am a little bit, probably, jealous of that, 'cos I missed out ... because I missed out on that.

[jojo, 2018]

Through jojo's comments we can see that an autism diagnosis does not automatically enable certain discursive practices to be enacted, nor does it enable gender to be queered despite a desire to be less tied to certain gendered behaviours. However, a certain space is opened up for consideration, if not necessarily enactments of different modes of doing gender. As Sally stated: '[...] I also think there's something that nobody's quite managed to articulate about, um, autism giving you the freedom to be that [queer]. Or, of autistic people being more predisposed or more open to ideas about that [...].'

Jordynn Jack (2012) writes: '[a]utobiographies, blogs and internet posts show how autistic individuals view gender as a *copia*, or a tool for inventing multiple possibilities through available sex/gender discourses' (p.1). It is perhaps true that gender can be *viewed* or *considered* in its current potentialities. However, as jojo shows us, there are important intersections to consider if we want to translate this to everyday lived gendered experience. Moreover, jojo's experience alerts us to the untimeliness of her experience. The worlds one can create and embody has expanded considerably for queer and gender queer people in the U.K, yet perhaps only if they are still young, with age comes added responsibility (motherhood, work expectations, for example) and as such, increased social stigma should one transgress boundaries as jojo discusses. Furthermore, it is important to remember the medium of the internet is incredibly important for autistic people and autistic queer people, but it does not mean that these radical positionalities can necessarily be lived offline.

What became clear to me during the process of interviewing, transcribing and analysing the data which has gone into this thesis is the sense that a bigger thing is at stake than simply finding and diagnosing AFAB autistic people. If we stop here, we are simply saying: 'you are autistic, now you know your truth'.

This is especially unhelpful when secondary support services are not available for many. The diagnosis did actually enable some participants to enact and realise autism – of course within the discourses of autism and what is known and knowable, but it was not a straightforward path which ended in liberation because autism is always entangled with other aspects of their identities. The participants continue to *become* autistic by enacting various behaviours and eclipsing others. We need to think about the ways that not only the diagnosis of autism has its own regulatory regimes but that being told one is autistic does not enable one to escape the regulatory regimes inscribed upon them from their prior interpolations.

6.7 In conclusion

This chapter began by ascertaining what the participants understood autism to be prior to their diagnosis. It was apparent that many of the participants could not recognise themselves as autistic through the dominant discourse, as they described understanding autism as being attached to cultural and social ideas of masculinity and maleness. However, through extensive self-motivated research into the discursive knowledge of autism, combined within monitoring and mapping their own traits and difficulties allowed several of the participants to see autism as potential diagnosis. Some of the participants sought a diagnosis to explain their un/known difference that was discussed in the first analysis chapter.

A sense that a diagnosis would enable certain possibilities and freedoms to be enacted emerged. Aime and Sarah suggested that the diagnosis would allow them the possibility to complete education. Hannah and Sally suggested that a diagnosis enabled them to begin to behave in more overtly autistic ways. Sally also suggested that the diagnosis allowed her to ‘put to bed any of the ideas that I was crap at being a girl’. For all the participants, the diagnosis did act as a ‘stamp of legitimacy’ of their perceived difference, to borrow Hannah’s phrase. Or, as Sally stated the diagnosis affirmed her difference as

positive: 'yay! I'm official'. The diagnosis, for many participants, acted as a legitimization of difference but certain disidentifications with the deficit driven, or pathologically defined, understandings of autism were also apparent. The participants presented alternative ways of understanding what autism is, which were distinct from how autism is typically understood. Such as Sally who argued that her creativity and artistic interests were never included in autism definitions. Despite the participants pushing the boundaries of what autism is, and how one is able to be autistic, the path to liberation from neurotypical norms was not straightforward and was perhaps not even fully possible. The prior interpolations which constructed the participants subjectivities continued to restrict their path to becoming autistic.

Despite their never being an explicit mention of sex differences and the brain, or an engagement with the more polemic discussions around the extreme male brain, there was always a persistent undercurrent that the autism that is already in existence does not fully name the condition that the participants of this study experience. And, whilst they might enact certain forms of being autistic (flapping, modified ways of being social, for example) they challenged the sense that being autistic is an ontological entity which is individualised and medicalised and that one simply owns, or that which makes up the knowable body, or that which makes the body knowable. As Bruno Latour (2001) has stated 'one is not obliged to define an essence, a substance (what the body is in nature), but rather *an interface that becomes more and more describable when it learns to be affected by many more elements*' (p.2, italics in original). For the participants of this study the diagnosis enabled the body to be more readily described. Yet, autism cannot describe the entirety of the participants experience (p.2). In short, an autism diagnosis does not give access to an essence or a truth of the subject.

The contexts in which one could be autistic are restricted by other normative modes of being, such as gender and class. I would like to have added race to this but that will be saved for another project. Consequently, it is clear from the participants here that autism does not simply emerge in the

clinician's room nor was it always 'known' by the participants but that it is an emergent way of being that is temporally and spatially contingent on all the intersections mentioned in this chapter. Perhaps, the key problem articulated by the participants cited above is a disconnection between what is presumed to be the medical understanding of autism (pathological, always, already defined and a negative difference) and the modes in which some of the autistic people in this study seemingly understand their autism (processual, non-pathological and positive difference).

To return back to the Foucauldian analysis, we can see how the participants of this project disrupt the notion of a universal autistic subject and consequently in doing so, refute the idea a unified essence of subjectivity. Rather, we see how autistic subjectivities are constructed within a framework of what is knowable and what can be done with the body and its desires, whether that is through the regulatory regimes of autism or of gender. Despite the restrictions which are placed upon the participants of the study (femininity, heterosexuality, neurotypicality, for example), they have opened a space for us to consider that autism is not solely something one *is*, but it is something one *does* and consequently it emerges differently in relation to other things and people.

Chapter 7

Discussion and Conclusions

7.1 Introduction

This chapter concludes the thesis. This chapter begins by revisiting the context which facilitated and motivated the project from its inception to its completion. The research objectives and questions will also be revisited. I will summarise the various narratives that were co-constructed through the interviews I held with the participants and the narratives I developed through the data analysis. I will then discuss how this research aids to the sociology of gender and autism. This chapter will close with a brief discussion of how this particular intervention into autism research can be mobilised in further projects and empirical work.

7.2 Revisiting the research context and the research objectives

This thesis was an explorative empirical study into how people assigned female at birth understand, talk about and produce their gender identities through the discourse of autism. The thesis took as its starting point the ways that gender has been a focus point in much research into autism. From the disparity in gender diagnosis rates, to the ‘extreme male brain’ theory, to the idea that autism people do not have a strong sense of gender identity, I have argued that autism, as a diagnostic category, a neurobiological condition and a socio-cultural phenomenon has come to constitute a form of gender trouble (Gould and Ashton-Smith, 2011, Baron-Cohen, 1997, Baron-Cohen, 2014, Baron-Cohen, 2018, Jack, 2012, Davison and Tamas, 2016). In particular, this thesis has explored if autism’s connection to, what I have called, ‘pathological masculinity’ impacts how people assigned female at birth understand their gender identity when diagnosed in adulthood. The diagnosis was tentatively positioned as a discursive event and I examined whether the diagnosis of autism functioned as a regulatory gendered regime. I posed two foundational questions to guide this thesis:

- 1) Does the diagnostic category of autism act as a discursive event and a gendered technology of power for late diagnosed autistic people?
- 2) How do autistic people assigned female at birth produce a sense of the autistic self through the existing discourses of autism?

To answer these questions eight participants took part in this study. All the participants were assigned female at birth and had received their diagnosis from the NHS at age eighteen or over. I have argued that recent research into autism and gender is rarely conducted using qualitative methods and it is rarely conducted with autistic adults. Furthermore, the research in existence does not often think of the diagnosis as an event that brings into being discursive practices and one that is potentially productive of new ontologies, or understandings, of the self. In particular, to my knowledge no research has asked what the *a priori* gendered discursive formation of autism does to individual's sense of, and production of, gender when one is diagnosed in adulthood. Thus, this thesis stepped into this gap and asked the question; *what does autism do to gender?*

7.3 Summarising the narratives

When I began thinking about this research all the way back in my Master's degree, I had considered that autism's entanglement with gender, specifically essentialised maleness, would impact on late diagnosed autistic people who were assigned female at birth. Considering the ontological status that autism has, through it being considered as a neurological condition and one which is not acquired which forms the entirety of experience and is life-long, I posed the following question: does the neurological aetiology of autism entangled as it is with ideas of masculinity and normative gender ideals come to bear on how autistic people think and produce their gender identities? I wondered if AFAB individuals had to reconcile the notion that autism is neurologically and discursively connected

to masculinity and even essential maleness and, whether this promoted a new consideration of the gendered self through the new gendered regime of autism. I hypothesised that the diagnosis would act as a discursive event and would interpolate the participants into a new gendered regime which would in turn be enacted through discursive practices which make autism legible. To put this in a simpler way, I had considered that the essential masculinity which frames autism may be enacted by those who receive a diagnosis in order to legitimise their autism to themselves and to others. I initially hypothesised that the gender norms which produce autism as a 'pathology of gender', to borrow Gillis-Buck and Richardson's (2014) phrasing, would impact somewhat negatively on the participants of the study. I considered that the diagnosis would interpolate the participants into a new restrictive gendered regime and that a diagnosis would potentially lead to a crisis of gender.

I wanted to understand how people *become autistic* within a network of relationality which encompasses scientific discourses, lay understandings, and popular cultural discourse about autism. Whilst I began this research feeling a certain level of feminist anger towards the essentialist claims of sex/gender that were being foregrounded in certain areas of autism research, throughout this project I came to think with ideas of entanglement and ambiguity rather than through polemics or the search for an alternative origin story (Fitzgerald, 2017, Wilson, 2015, Haraway, 2016). I realised that the interviews in relation to the bodies of knowledge I had amassed were too complex to offer a "new" autism narrative which could counter the essential sex/gender claims of certain sectors engagement in autism research. That is, countering the idea that AFAB people were being subjected to neural centric gendered ideals through the construction of a male brain being 'transplanted' into them at the point of diagnosis (Moreover, I found that, quite simply, people didn't care about the idea of 'the extreme male brain'. The participants didn't see these discourses as interacting with their lives in any meaningful way and they barely played a part in any of the interviews). Consequently, during the thesis production process I widened the scope of my research hypothesis. Whilst the extreme male brain theory may be brushed off as inconsequential or as 'bad science', as my participant Aime had briefly

stated, there were still many ways that being diagnosed autistic allowed the participants of the study to (re)consider their gender identities.

When I began speaking to the participants of this project, I realised that it was not necessarily the discourses of autism which provoked and produced a sense of gender trouble, but that gender trouble was, for several participants, a presence in their lives long before the diagnosis. Indeed, the diagnosis was in many ways framed as an anticipatory freedom from the restrictive gender norms which structure neurotypical sociality. Perhaps there is something about autism which means that autistic individuals are more critical and sensitive to the arbitrary connections of the signs and signifiers which order and make legible our gendered experience. This I can't say with any evidence or full conviction, but what emerged through this research project is a sure sense that for some participants the gender trouble that is recognised within autism was often seen to be a positive legitimation to begin to (re)think and enact different modes of doing gender, and of being a gendered subject, once they received their diagnoses. During the interviews all the participants whom I spoke with in person or on Skype calls I felt a sense of relief when we came to discuss how they felt when they eventually received an autism diagnosis.

For some participants, such as Esther, the diagnosis was able to make sense of a number of seemingly unconnected difficulties and differences. I didn't write about this in the analysis chapters, but Esther told me that she had recognised herself as different from others from her first day of nursery school. Esther came home after her first day and asked her mother: 'mum, am I disabled?'. From this very early sense of difference to the age of nineteen when she received her diagnosis Esther had never had a framework within which to understand her experiences which she had, from such an early age, understood to position her as different. For other participants, such as Sally, the diagnosis was connected to understanding why she had never felt like she was being true to herself, this was echoed by jojo who stated she was finally 'being true to herself'. For Sally, jojo and Aime the diagnosis was

connected to their gender identity in numerous different ways. Sally felt it enabled her to understand herself as not being a 'crap woman', in her words, but as instead missing the social cues and lines along which sociality functions. For Aime, it enabled them to suggest a link between their queerness and their gender identity such as when they stated; 'I am autistic in the same way as I am queer; it's who I am'.

It was not so evident that the diagnosis opened up the path to gendered liberation in such simple terms though. Although it was clear that the participants experienced a sense of relief upon receiving the diagnosis this was framed by ambiguity and conflict between enacting their autistic self and still feeling beholden to a neurotypical regime. For Hannah the diagnosis came to stand in as a freedom from the social norms; through stating her autistic difference she could legitimise not taking part in conversations and she felt as though she could ask for clarification when she didn't understand something. Sally felt an embodied freedom whereby she could flap and stim. This embodiment still needed to be read as autistic and as such must be within the framework of what makes autistic difference legible. This was mirrored by Esther who felt a confliction between wanting to be seen as autistic but to not look too autistic. Aime noted that they felt a pressure to be demonstrably autistic in order to fit into autistic culture. Thus, the diagnosis clearly has its own set of rules through which one is legible as autistic and it is not as simple as the diagnosis acting as a moment which opens up the ability for one to be 'true to themselves'.

Participants such as Aime and Sally utilised queer discourses to articulate this ambiguity, and the diagnosis functioned and was framed, in many ways, as a 'coming out.' Much as in Butler's (1990) understanding of what it means to come out, the participants who used this framework noted the constant efforts that coming out as autistic demands. One cannot simply come out and be autistic even though they have received the 'stamp of legitimacy' from a medical team, to borrow Hannah's phrasing. For the younger participants who attempted to build an autistic queer subjectivity this was

reliant upon community building and finding other queer people with whom to collectively build a sense of identity as a queer autistic person. I argue this acts as a (dis)identification with the autism diagnosis (Munoz, 1999). That is, being interpolated into a form of gender trouble enabled a legitimisation to further subvert and disrupt gender norms.

As noted in the first analysis chapter, the majority of participants struggled with an un/known difference and attempts to manage this difference often became focussed on the sexed/gendered body. These particular difficulties have been little researched and, when it is the subject of research, it is often cited as being attributed to autistic sensory difficulties or to autistic specific restrictive and repetitive actions (Goldschmidt, 2019). These are often the arguments when autistic AFAB individuals with eating disorders are discussed (Baron-Cohen et al, 2013). I argued that this need for bodily control in autistic adolescents has not been considered as a feminist issue and nor has it been considered as produced by a gendered and neurotypical world which enforces normative gender presentation as a prerequisite for social inclusion, thus I argued that when considered in this framework, gender trouble for undiagnosed autistic individuals might be found to be less symptomatic of autism but indicative of the foundational importance that gender has to subject formation. I find this to be somewhat a trite point but considering the almost absolute absence of this way of thinking about autism and gender I believe it necessary to highlight this.

The participants who made use of the coming out metaphors furthered added to this idea, to come out as autistic is to break with the social order, the visual field and the ordering of bodies. To come out of autistic is a radical act for some, such as for Aime who clearly stated their autism and their queerness to be intimately entangled. It is not the case that all the participants felt this way about autism. Two participants, Esther and Sarah, never noted any considerations around gender, but they did note that this was not because they felt it to be an unquestioned identity, but because they had simply never considered it as an important identity category that shaped their experience. Esther noted that she

understood her gender in the same way as she considered her eye colour. As younger people, prior to diagnosis there was a sharp divide between the participants; those who considered their gender to be unstable and something they had to actively perform thus causing distress or, deep reflection, and those who also felt their gender was something superfluous to their sense of self but they did not feel that it caused them any distress. What was common to the majority of participants was the notion that gender isn't fixed. Whilst in many cases this notion preceded the autism diagnosis, I argue that the diagnosis was integral for many participants in (re)constructing their gendered identities. For some participants, such as Sally, the diagnosis enabled them to retrospectively consider their gender and to alleviate guilt that they were, in Sally's words, simply a 'crap woman'. For Esther, who maintained she had never considered gender, the diagnosis and its connection to gender prompted her to actually realise that gender is something that other people think about, something she said she had never considered prior. Thus, the autism diagnosis acted in many ways as a legitimisation to begin to think about and sometimes create different ways of being gendered subjects.

Whilst, as I have noted, for many of the participants the diagnosis of autism was positioned as potentially liberatory from the intensive gendered regimes that they felt they had to embody prior to diagnosis, this was not the case for all participants. jojo was the participant who felt most strongly that she was still restricted by what her gender is supposed to look like and do. jojo was one of the oldest participants and she is also a mother. A sense of responsibility towards her children meant that she felt she could only embody a conventional cis gendered presentation. Importantly, jojo suggested that this gendered regime is as at odds with being autistic. jojo felt her children would be bullied if she gave up a traditional femininity in favour of something that would make her more comfortable in her autistic embodiment. jojo wanted to take on a far more androgynous gender presentation than she felt she could do. Ultimately jojo stated that in an 'ideal world' she would have liked to have been 'born male' because she felt they have more freedom. jojo also felt a pressure to be desirable to men despite having no sexual or romantic attraction to them. jojo showed most clearly that a diagnosis of

autism does not enable an autistic subjectivity to emerge. In fact, the diagnosis changed nothing for jojo in terms of her behaviours, and gendered presentation. jojo still felt trapped by her prior and ongoing interpolations as a heterosexual presenting mother.

I want to end this research project by suggesting that it is an impossibility to fully realise a finished autistic subjectivity in an ontological sense. I want to argue from a radical position and suggest that the autistic individuals I interviewed are engaging with a project of alternative autistic world building. This is centred at the intersection between the body, identity, medicine and the social world. To return back to the Foucauldian analysis mentioned earlier, we can see how the participants of this project disrupt the notion of a universal autistic subject and consequently in doing so, refute the idea a unified essence of subjectivity. Rather, we see how autistic subjectivities are constructed within a framework of what is knowable and what can be done with the body and its desires through the regulatory and intersecting regimes of autism and gender. Despite the restrictions which are placed upon the participants of the study (femininity, heterosexuality, neurotypicality, for example), they have opened a space for us to consider that autism is not simply something one is, but it is something one does, it emerges differently in relation to other things and people.

In order to enable people to become autistic we need to address autism as materialising in various interrelated openings and, simultaneously foreclosed in others. To put that in another way would be to state that we need more than an identity politics around autism. We need to understand that in order for autistic people to live comfortable, dignified lives then autism cannot simply be reduced into a pathological ontological (in the traditional understanding of the word) fact of the individual whereby they remain a 'square peg in a round hole' to quote Mary again. This is, of course, not to deny the challenges and distinct difficulties that people with autism face, but to also address the challenge of the difficulties of being different in a singular 'world'. To return back to jojo's comment from the previous chapter; 'we need to make more space in the world' which doesn't have room for those who

don't fit the mould. Rather than suggesting that those AFAB autistic people take on the mantle of autism as it is currently conceived as a form of affirmative identity building, as in the categorical; 'I am autistic', I would like to push this even further and suggest that we need to begin to attune ourselves to the existence of multiple worlds, where studying relationality and how certain ways of being can be enacted is key to understanding how we conceptualise and live ethically with difference.

7.5 Contributions to the field of autism research and looking forward

In this thesis I have approached the issue of gender trouble in autism. Whilst there are a number of papers from psychology which focus on gender trouble in autism, there are very few from the social sciences and the humanities (Davidson and Tamas, 2016, Jack, 2012, Gillis-Buck and Richardson, 2014). It is difficult to see past a correlation sometimes to the wider world that has produced this correlation. The correlation being the over representation of autistic people who are gender queer, non-binary or trans and all the research prior that suggested that autism and gender were inextricably linked (Aspergers in Frith, 1991, Baron-Cohen, 2010). It seems to be the simple answer that autism is the *cause* of this. However, this individualises and depoliticises non normative gender as a product of a different neurology. Thus, non-normative gender can be policed and contained by attributing it as the product of an already non-normative neurology. This conclusion also occurs within certain social science and humanities approaches, such as Jack (2012) and Davidson and Tamas (2016). I did not want to take this as the answer and I wanted to understand how autistic people think about, create and produce their gender identities through the discourses which already attribute a certain gender trouble to autism. If we don't situate gender as a societal and political issue and we focus solely on autistic people's experiences then we can't understand, or even improve, the gender conditions that produce all of our subjectivities, not simply autistic ones.

In this way I have thought with scholars of critical disability studies such as Dan Goodley, Margrit Shildrick, Katherine Runswick-Cole and Lennard Davies with the belief that centralising disability in research allows us to interrogate the complexities of human life. At the same time, it doesn't erase the experience of being disabled in a world that is governed by and for those who fit seamlessly within it. Critical disability studies is necessarily interdisciplinary as it traces and uncovers the political, social and cultural regimes which produce disability and ability, or as Goodley cites it; 'dis/ability'. I have attempted to keep autistic experiences at the forefront of this project, but I have also aimed to given equal weight to critiquing the normative and neurotypical world within which autistic people are encouraged to be a part of. This thesis has aimed to understand how people become autistic through these gendered discourses of autism. I hope this thesis has shown that autism and autistic subjects do not live outside of, and distinct from, the governing rules that structure our gendered experience and our expectations of gendered subjects.

Furthermore, I hope I have shown that the circular and causal understandings of gender and autism are not particularly useful for understanding how autistic people experience their gender. Moreover, I have argued that autism and gender have an emergent – or a co-constituent- relationship to one another. By examining the temporal and spatial moments where autism and gender emerge in their relationality to each other and to other things, people, discourses and institutions we have a unique vantage point on the ways that autism and gender are enacted and where they are restricted from fully becoming. This particular focus should be taken up to understand other intersections of autism, autistic embodiment and identity, including class and race.

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Appendix I. Recruitment posters

This study has been approved by University of Leeds Research Ethics Committee ref: AREA 17-075



UNIVERSITY OF LEEDS

Have you been diagnosed as autistic by the NHS after the age of 18?

Would you be willing to speak to a non-autistic researcher about your of experiences of being diagnosed autistic and how this interacts with your gendered identity?*

Researcher: Emily Maddox

Email Address: E.V.Maddox@leeds.ac.uk

*You must have been diagnosed with what was previously called Asperger Syndrome or 'High Functioning Autism'

*All gender identities welcome

Please email for more information or to take part

Do you need support?

MindOut

01273 234839

NAS Autism Helpline

0808 800 4104

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Appendix II. Twitter recruitment

These screenshots from my Twitter account document the tweets I put out at various stages of the recruitment period. Also included is a tweet asking for advice on participatory methods.



↻ You Retweeted



Emily Maddox @emily_289 · Apr 17, 2018

I'm a PhD student looking at male brain theories of autism & gendered ideals which surround the diagnosis. I want to find out if these impact your understanding of yourself after diagnosis. Get in touch here or at e.v.maddox@leeds.ac.uk for more information. RT please

7 63 26

↻ You Retweeted



Emily Maddox @emily_289 · Apr 24, 2018

Still looking for a few more participants on my study into women/trans/non-binary experiences of being diagnosed with autism.. get in touch here or e.v.maddox@leeds.ac.uk if you or someone you know might be interested. Thanks!

1 19 5

↻ You Retweeted



Emily Maddox @emily_289 · Jun 6, 2018

Any #ActuallyAutistic people interested in having a conversation about how you understand autism and gender and the relations between them for PhD research? DM me for more information, thanks!

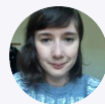
4 23 9



Emily Maddox @emily_289 · Apr 24, 2018

Still looking for a few more participants on my study into women/trans/non-binary experiences of being diagnosed with autism.. get in touch here or e.v.maddox@leeds.ac.uk if you or someone you know might be interested. Thanks!

1 19 5



Emily Maddox @emily_289 · Jan 22, 2018

I'm interviewing autistic people for my PhD research and I am interested in what specific participatory methods should be implemented to make the process as inclusive as possible.. any thoughts? #ActuallyAutistic #Neurodiversity #Autism

1 5 1

Appendix III. Information sheet for participants

This information sheet was given to all interested participants on the first email correspondence.

How do People Assigned Female at Birth think about their Gendered Identities after a Diagnosis of Autism in Adulthood?

Introduction

I would like to speak to women and trans/non-binary identifying people who were assigned female at birth*²⁶ and who have received a diagnosis of autism over the age of eighteen. You must have been diagnosed with what would have been called Asperger Syndrome or 'High Functioning Autism' prior to the change to Autistic Spectrum Condition. You must have been diagnosed in the United Kingdom and by services which are a part of the National Health Service.

This research aims to understand how you think about your gender after receiving a diagnosis of autism in adulthood. I would like to know how you think about autism and what you understand about the diagnosis. Topics covered in the interview will relate to areas such as; what you understand about autism and how you feel about your diagnosis, how you came to receive a diagnosis, your memories of childhood before you received a diagnosis and whether you think about autism in relation to your gender identity. I am not interested in looking for causal links between autism and gender identity. I am interested in whether the construction of autism as a diagnostic category has shaped how you think about yourself as an autistic person and whether you think about gender in relation to this. This pays particular attention to how autism has historically been conceived of as a male condition and is tied to ideas of masculinity in popular culture and medicine alike.

Why am I doing this project?

²⁶ This means the medical professionals said you were a girl when you were born but now you may identify as a man, a trans-man, non-binary, Agender, or you may identify as a woman.

I am a PhD student at the University of Leeds in the School of Sociology and Social Policy. I am interested in how people assigned female at birth think about their gender after receiving a diagnosis of autism. My research project is examining how the diagnosis of autism is attached to gendered ideas about men and women. There is emerging research which suggests that people assigned female at birth are missed from diagnosis because of their gender, but not many researchers are thinking about how the diagnosis impacts on your understanding of yourself and how you think about your gender.

I am a non-autistic researcher and I came to this research through working with autistic adults and realising that there was more work to be done with regards to gaining a full picture of how individuals experience the diagnosis of autism. Ultimately, I hope my research is part of a move towards autistic people assigned female at birth gaining timely and ongoing support with their varying support needs.

What will you have to do if you agree to take part?

You will fill out a short questionnaire with some initial information. This will be sent to you by email.

We will have a discussion, either by email or phone, so we can work to make the interview as comfortable as possible for you.

At present I am based outside of the U.K so our conversation will take place on Skype. This will be a voice call and I will not record images only audio. The conversation will be recorded with audio recording software and stored on a hard drive which will be kept separate from my laptop.

How much of your time will participation involve?

The questionnaire will take around ten minutes to complete.

The interview will take one to two hours to complete, but it may be longer or shorter.

You can end the interview at any time and for any reason.

There will be no repercussions should you chose to end the interview, and any information or recordings I have will be destroyed.

What are the advantages of taking part?

Whilst there are no immediate benefits to taking part in this research there may be some long-term benefits. This might include having the chance to tell your story of how you think about and understand

yourself after receiving an autism diagnosis. In turn, this information could help change understandings of autism which could be beneficial to many people.

What will happen to the information gathered in the interview?

The research you take part in will form my thesis, but it will also be used for conference presentations and journal articles, this will enable alternative and emerging stories about autism to be heard by a wider audience. On completion of the thesis it will be uploaded to an online repository so other researchers in the area can benefit from the findings.

The interview may be made available online in full for other researchers if you consent to this.

Two years after the completion of my PhD thesis all of the information you have given me in interviews will be destroyed with the exception of what has been used in the thesis. You may request your interview and corresponding information to be removed from this project at any point until June 2020.

All your information will be anonymised, and I will ask you choose a pseudonym which will be used at all times in reference to your interview. This includes discussions of our interview in my thesis, in conference papers and publications and in discussions with my supervisory team.

What are the disadvantages?

We may touch upon sensitive issues in the interview, this could be upsetting for you. To alleviate this please be aware that you do not have to answer all the questions and you are free to leave the study at any time.

We will talk about ways to make the interview as comfortable as possible based on your individual preferences. We will talk about your individual preferences prior to meeting. This can through email or a phone call to ensure that you are as happy as possible with the entire process of taking part in the project.

Do you have to take part in the study?

No. Even if you agree to take part in the research you are free to leave the study at any point, including during the interview itself.

What happens now?

If you are still interested in taking part in this research, then please contact me on the email below to express an interest and we can begin to make arrangements for your participation in this project.

Thank you for your interest!

Researcher: Emily Maddox

Email: e.v.maddox@leeds.ac.uk

Appendix III. Interview Schedule

The interview schedule was used as a guide for the conversations with participants. I generally asked each question but the order which I asked differed in each interview. Some follow up questions were asked at points. The schedule was given to the participant before the interview so they could feel prepared. I verbally pointed out where we were on the schedule whenever I began a new section. I aimed to make the interview process as transparent and structured as possible.

1. Opening questions and self-identification

Opening warm up questions

- 1) Preferred pronouns, gender identification, disability first/person first language?
- 2) Can you tell me a bit about yourself? (What do you like to spend your time doing? do you work?)
- 3) What identities would you ascribe to yourself?/ what words would you use to describe yourself? (for example, mother, friend, teacher, autistic, child, artist)
- 4) If you could be an idealised version of yourself what would that look like? (eg. successful in relationships/work, being a mother/parent, pursuing a creative talent)

2. Reflections on life before diagnosis

Home life, Education and Background

- 1) Can you tell me a bit about your home life when you were a child? (eg. who did you live with? family dynamics, education, friendships?)
- 2) How were your experiences of primary school and high school? Please elaborate.
- 3) Did you feel like you ever struggled with particular things as a younger person? (eg. mental health difficulties, friendships, romantic relationships) Please give examples here.

- 4) Did anyone pick up on things you were struggling with in school or in your home life and were you offered any support? Please give examples here.

Life as an adult before diagnosis

- 1) What did you do after high school? (eg. college, University, start a family)
- 2) How did you find this transition?
- 3) Did feel like you learnt to behave in certain ways in order to 'get by'? Some people talk about masking autistic behaviours, did you do this and if so, can you give some examples of when you felt like you were 'masking' or performing learnt behaviours? Please elaborate here.

Gender Identity

- 1) Did you feel comfortable with your identity as girl, or being read as a girl?
- 2) How do you understand gender and how do you think about your own gender?
- 3) Can you think of a specific instance where your gender influenced events? (for example, gaining preferential treatment, being denied access to something, bullying on the basis of your gender?)

Awareness of Autism

- 1) Were you aware of autism before you received the diagnosis? (Did you know anyone who had it? TV/film representations?)
- 2) What did you think about autism before you received your diagnosis?

3. Reflections on the diagnostic process

The diagnosis

- 1) How did you come to receive an autism diagnosis? (eg. self-diagnosed, referred through another service, recommendation from friend or family member)
- 2) Why did you want to seek out a diagnosis? What would have gaining one meant for you?

- 3) Can you tell me about the autism diagnostic process? (where did it take place, how long, when, how old were you?)
- 4) How did you feel throughout this process?

4. Post diagnosis

Self-identification post diagnosis

- 1) How did you feel about the diagnosis after you received it?
- 2) Did the diagnosis of autism change any ways that you thought about yourself?
- 3) What did it change? (Some autistic people have talked about a wanting to understand which parts were 'them' and which were autism, did you feel like this?)
- 4) Did you consider the neurological underpinning of autism in any way?
- 5) Do you ever think about how autism is positioned as an extreme form of masculinity and do you have any opinions on this? Please elaborate here.
- 6) Do you understand autism as a disability? Would you consider yourself a disabled person because you are autistic?
- 7) When did you start referring to, or thinking about, yourself as an autistic person?

Relations with others post diagnosis

- 1) Did you share your diagnosis with anyone? (friends, family, employees, educators?)
- 2) Did you feel interactions between you and the people around you changed in any way as a result of the diagnosis?
- 3) Did you ask friends or family whether they believed you to be autistic prior to the diagnosis?
Did you ask for specific examples which could be signs of you being autistic?
- 4) Do you feel like you have to look/act a certain way for others to see you as autistic or believe you are autistic?

How do you experience being an autistic person?

- 1) Could you talk me through some of the ways that you experience yourself as autistic? For example, do you have difficulties communicating? do you stim? Have any tics or echolalia? What form does this take?
- 2) Do you have sensory issues and what forms do these take? (eg. aversion to certain clothing or bodily sensations, tastes, sounds)
- 3) Have you ever struggled, or do you currently struggle with any aspects of the social roles expected of being read as female? (for example, connecting with other women, making and maintaining romantic relationships, being a mother?) please elaborate here.
- 4) Have you ever, or do you currently struggle with, some of the ways women's bodies are 'supposed' to act or look? (for example, maintaining a slim and feminine body, being confident in how you move, walk and position yourself in different spaces?) Can you give an example?
- 5) Have you ever felt, or been made to feel, like an inferior or failing woman because of some difficulties you have that are related to being autistic? Please give an example.

Gendered identity

- 1) Did you find your autism diagnosis allowed you to rethink your gendered identity or to better understand it?
- 2) In which ways? (i.e., did it give you the freedom to not perform a certain identity because you have autism? Did it legitimate your gendered identity in some way?)
- 3) What ways do you see other people around you with autism thinking about their genders?
- 4) Do you think the diagnosis of autism impacts on how others think about your gender and/or sexual orientation?
- 5) Are there any other factors that you think impacts on your experience as an autistic person? (eg. Class, ethnicity, age, nationality)

- 6) Do you see any connections between autism and your gender identity and/or your sexuality?

Are you aware of any ways that others discuss connections between autism and gender identity and/or sexuality?

Understandings of autism post diagnosis

- 1) How do you understand autism now?
- 2) What did you use to understand autism? Did you read autobiographies, use forums online, watch T.V shows or read medical literature?
- 3) Which representations did you agree with (see yourself in) and which did you not agree with?

Engagement with autistic communities

- 1) Do you talk to others who are autistic? What platforms do you use to do this? (ie, do you use Twitter, Facebook, Tumblr, specialist internet forums?)
- 2) Do you think that your relationships with others with autism has allowed you to think about your identity in different ways?
- 3) Do you see people discussing their genders in relation to autism (online or offline)?

Reflections on childhood post diagnosis

- 1) How do you feel about receiving a diagnosis of autism as an adult?
- 2) Did you reconsider your childhood through your autism diagnosis, and did it bring up any confusing thoughts or, any enlightening thoughts about the person you are now?
(i.e., has it allowed you to think back on past events and explain them through the autism diagnosis? Or does it allow you to alleviate self-blame around issues like childhood bullying or abuse if these were an issue for you?)

Conclusion

- 1) Is there anything you would like to add here? Anything you think is important that I have missed?
- 2) How did you find these questions to answer?