

**An exploration of the worklife experiences of autistic women in the
UK**

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Abstract

Existing studies suggest that few autistic women are employed in the workplace. However, because many autistic women have been diagnosed or self-identify later in life they may well have been employed in numerous workplaces, without appearing in statistics. This study explores the worklife experiences of autistic women in the workplace in the United Kingdom using oral history interviewing techniques with 35 autistic female participants. The qualitative research is analysed using reflexive thematic analysis (Braun and Clarke, 2019) and a theoretical and conceptual framework of autism and identity.

This study shows that autistic women carry out a wide range of jobs which go beyond stereotypical assumptions of what they might undertake as employment. However, the research demonstrates a chaotic employment pattern with multiple jobs undertaken. The study also shows that autistic women undertake identity work, impression management and masking in the workplace which may trigger anxiety and stigma. Prior to being diagnosed or self-identifying, women may be unable to resolve their identity in the workplace, leading many to feel stigmatised or broken, but after receiving a diagnosis or self-identifying the women were able to reappraise their careers and lives. Having an autism diagnosis can provide a gateway to workplace support and accommodations and allows a woman to access measures that might improve the interview or employment experience. The study has also shown a variety of challenges faced by autistic women in the workplace and suggests that these are driven by double empathy problems where a breakdown of communication or understanding has occurred between an autistic woman and their allistic co-worker, supervisor, or manager, and vice versa. The study also demonstrates that exhaustion or 'autistic burnout' was a feature for many participants resulting from the amount of masking needed to 'fit in' at work. Reasonable adjustments were patchy in the workplace, due either to participants not disclosing their diagnosis, or to a lack of understanding by employers about what adjustments could be made. The study also found that autistic women were often value driven in the workplace and considered that they were doing more work than the allistic worker or had a greater work ethic.

The study contributes to the literature on autism, identity, and stigma in the workplace by helping understand their historic patterns of employment and the implications of an early or late diagnosis. It also considers the longitudinal patterns of employment of autistic women and where employers and support organisations can enhance their provision, in offering support. The interviews conducted for this study do not represent the views of all autistic women or all autistic people and so it represents an exploratory study of the multitude of issues associated with employment. This study was also limited to the UK and does not cover the experiences of autistic women in other countries who may also be affected by other intersectional or structural issues in their countries. The study highlights the continuing need for easy access to autism diagnostic services to enable autistic women to access appropriate support for all areas of their lives. Career guidance for autistic people could include guidance from older autistic workers currently in the workplace ensuring that careers opportunities are understood beyond stereotypical IT or analytical jobs.

Keywords: Women, autism, disability, neurodiversity, employment, work, identity, stigma, masking, monotropism, double empathy, social model, critical autism studies, oral history

AUTiSM

I am not the word
or the letters
& the spaces in-between
Or the person in your imagination
U think I should have been
I am #human

Jon Adams
Artist
(with permission)

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Glossary

Allistic	Term increasingly used by autistic people to describe non-autistic people
Aspie	Term historically used by a member of the autistic community to describe themselves. Typically, this term was used by people with a diagnosis of Asperger Syndrome to differentiate from those with an autism diagnosis.
Asperger Syndrome	Diagnostic term used to describe some ‘higher functioning’ autistic people and named after Hans Asperger. Asperger Syndrome was removed from the diagnostic manual in 2013.
Atypical	Something or someone who is not typical.
Autism	The National Autistic Society describes autism as a condition that affects people in different ways, but autistic people are likely to have difficulties with some of the following: social communication and social interaction, repetitive and restrictive behaviour, over or under sensitivity to light, sound, taste and touch, highly focused interests or hobbies, extreme anxiety, meltdowns and shutdowns (NAS, 2023).
Autie	Term often used by a member of the autistic community to describe themselves.
Comorbidity	Usually used in an autism context to describe a condition or range of conditions that are generally found alongside the autism diagnosis. For example, autistic people may also have other diagnoses such as anxiety, post-traumatic stress disorder (PTSD), dyslexia, dyspraxia, dyscalculia etc.
Double empathy problem	This is a theory of autism proposed by Damian Milton, an autistic academic. It argues that for social interaction to be successful, it requires the participation of two people, but that autistic and allistic people have no conception of the understanding and experiences of the other, leading to misunderstandings.
DSM5 or DSMV	<i>The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition</i> is the diagnostic manual for mental health and brain related conditions. It is produced by the American Psychiatric Association.
Dyslexia	A learning difficulty that affects the skills of accurate and fluent word reading and spelling.
Dyspraxia	A developmental coordination disorder affecting movement and coordination which can also affect attention, memory and time management.
Emotional labour	Management of own feeling, demonstrating understanding of other people’s feelings and desires before your own.
ICD-11	The ICD-11 is the eleventh revision of the International Classification of Diseases and is developed and updated annually by the World Health Association. It is another diagnostic manual used to diagnose autism and other neurodivergent conditions.

Misophonia	Misophonia is a dislike or intolerance of certain sounds such as breathing or chewing food.
Monotropism	Monotropism is a theory of autism proposed by the late Dinah Murray and developed with Wenn Lawson, both autistic autism researchers. Murray et al (2005) argue that there is strong evidence that uncommon patterns of attention are a feature of autism and that the restricted range of interests that the current diagnostic criteria refer to is central to the autistic experience, and it is this that they term 'monotropism'.
Neurodivergent	Term used to describe people who diverge from the neurological norm. The term covers people with a diagnosis of autism, attention deficit hyperactivity disorder (ADHD), dyslexia, dyspraxia, dyscalculia, Tourette syndrome, or with acquired neurodiversity from brain injuries.
Neurotypical	Term used to describe non-autistic people.
Predominant neurotype	Another term used to describe non-autistic people.

Chapter 1: Introduction

1.1 Background to the study

Like many late diagnosed autistic women, I started questioning my identity following the diagnosis of my then teenage son with Asperger Syndrome, dyslexia, and dyspraxia. After having spent years telling people that he was ‘just like me’ I had some serious thinking to do. I had often felt the loner, and somehow disconnected from work colleagues, and although I had had, up to that point, a successful career making constant progression, I had always been searching and seeking for the nebulous thing that would make me ‘more successful’ or ‘more accepted’ or ‘better connected’ because everyone else seemed to be having a much easier time and work seemed to be effortless for them, and they did not seem to be affected by stress and anxiety. Getting promoted to senior positions of leadership felt more comfortable because other leaders seemed to be more remote, or had tighter networked groups, and it was easier to fit in, but it often felt that everyone else was in on the secret (whatever that was) except me. Finally, being privately diagnosed with Asperger Syndrome myself at the age of 49 was a revelation, but this was initially denied to me by my doctor who looked at me when I made the request and said, “what on earth makes you think you are autistic when you sit here with no communication problems?”. Of course, I obviously then changed the subject and never mentioned it again, so now I have a diagnosis and no official support, and like so many other autistic people I now negotiate life with a range of co-morbid conditions which are part of my autistic identity but which I disclose in preference to my autistic challenges. This means that I will request for a quieter space to work, without saying that I feel completely overwhelmed in noisy offices, or that I ‘struggle a bit with anxiety’ when too many competing demands are made on me. The process of relearning who I am, has been transformational. I can now be kind to myself and just not attend work socials. I do not have to constantly struggle to ‘be a better person’ that will get more noticed at work and that more people will like. I can just be me. In the process of being kinder to myself I can also spot other people struggling to swim upstream against the flow when it would be easier for them to turn around and float downstream. For me my identity is now highly intersectional, as a post-menopausal woman, an autistic woman, and a woman whose health has been impacted by cancer treatment.

Having paused and reframed my own life I wanted to know how other autistic women had managed to get into the workplace, negotiated their worklife and what challenges they had encountered. This therefore is the background to this research, a desire to hear the lived experiences of autistic women in the workplace, and to bring these experiences to a wider audience.

1.2 Definition and Terminology

The terminology adopted throughout this study is identity first, in accordance with the researcher's own preference for the use of critical disability theory within the social model of disability and neurodiversity. The social model of disability challenges medicalization and proposes that disability is a social construction (Oliver, 1990). Research shows that the autistic community prefer identity first language (Kenny et al, 2016 & Taboas et al, 2023). Therefore, this study refers to people as autistic rather than as 'a person with autism' (person first language) which could imply that the autism is separate from a person's original 'unspoiled' identity. Autistic is a blanket term now often used interchangeably to describe people 'diagnosed' or who identify with the term autism or were originally diagnosed with Asperger Syndrome.

This study was originally constructed as an examination of the worklife experiences of women with a diagnosis of Asperger Syndrome, or who identify with Asperger Syndrome. However, the label of Asperger Syndrome was removed from the 5th edition of the main diagnostic manual, the DSM-5 (APA 2013), and many people who previously described themselves as having an Aspergers Syndrome diagnosis or being 'aspie' now describe themselves as autistic. Alongside this, the term neurodiversity and neurodivergent to identify an autistic person has increased in popularity and is now increasingly the preferred term of autistic and allistic (non-autistic) communities.

1.3 Research Aims and Objectives

The primary aim of the study was to explore the worklife experiences of autistic women in the UK. A further aim of this research was to understand to what extent it was possible to conceptualise, understand and derive generalisations about these worklife experiences, and

to understand what implications the worklife experiences of autistic women had on disability and employment legislation.

This thesis has examined the worklife experiences of autistic women using a theoretical framework of autism and identity literature (Tajfel & Turner, 1979). It has investigated and addressed the following research questions:

- a) What jobs do autistic women do?
- b) How do autistic women resolve their identity in the workplace?
- c) What challenges do autistic women face in the workplace?

1.4 Original Contribution

Within the academic field there has been little focus on research that seeks to improve the lived experience of autistic people. There is critically a significant lack of academic literature on disability and the workplace, autism and the workplace, autistic women and the workplace and autistic women and identity. This study contributes to the literature on autism, identity, and stigma in the workplace. It makes a significant contribution to knowledge by promoting a discussion about patterns of employment for autistic women, and the implications of an early or late diagnosis. It also examines and comments on the longitudinal employment of autistic women and how more can be done by employers and support organisations, to support them.

1.5 Structure of the thesis

This thesis comprises 8 chapters. This chapter sets out the background of the researcher and context of the research, outlines the gaps in original literature and introduces the research questions. Chapter 2 introduces a critical account of autism literature starting with the medicalised conceptualisation of autism that focuses on a deficit approach (Wing & Gould, 1979, Baron-Cohen et al, 1985). It considers the prevalence of autism (Talantseva et al, 2023) and the diagnostic process (WHO, 2022 & APA, 2013), before turning to a discussion of women who are particularly likely to have a missed or late diagnosis (Jones et al, 2014 & Stagg & Belcher, 2019). The chapter then turns to a discussion of the social model of disability (Oliver & Barnes, 2010) and critical autism studies (Goodley, 2012),

before a discussion on neurodiversity (Doyle, 2020), and the conceptualisation by autistic scholars of monotropism (Murray et al, 2005) and the double empathy problem (Milton, 2012). The chapter then considers the existing literature on autism and employment, first taking note of the legislative and policy framework (United Nations Convention on the Rights of Persons with Disabilities 2008, Autism Act 2009, Equality Act 2010), before considering estimates of autistic people in employment (Butterworth & Kovas, 2013), and the disability employment gap (Adam et al, 2023). Finally the chapter concludes by examining specific employment challenges such as the job search, recruitment and selection phase, social communication, and bullying and masking in the workplace.

Chapter 3 focuses on the conceptual framework of identity utilised in this study, examining Mead's concept of the self (1934), social identity (Tajfel & Turner, 1979 & Abrams & Hogg, 1990) and self-categorisation theory (Oakes & Turner, 1990), before consideration of intersectionality and disabled identity (Shakespeare, 1996) and a specific discussion of disability in the workplace, stigma management (Jones & King, 2014) and identities and identity work within organisations which can have a significant impact on the worker's life in the workplace (Alvesson & Wilmott, 2002; Ibarra & Barbulescu, 2010; & Ibarra (1999). Finally, this chapter examines autistic identity and stigma (Pearson & Rose, 2023), and the tendency for autistic people to 'mask', which is the term adopted by the autistic community for the identity work they carry out to 'conceal' their autistic self (Pearson & Rose, 2021). Research suggests that autistic people experience stressors at a higher rate than the general population, that their trauma is much more multifaceted due to stigma, and that they experience a higher likelihood of Post Traumatic Stress Disorder (Pearson & Rose, 2023). As a result, autistic burnout may develop and autistic people may manage the impact of 'masking' by the use of self-medication (Higgins et al, 2021 & Weir et al, 2021b).

Chapter 4 is the methodology chapter and sets out the interpretivist philosophy used and the researcher's role as a participant researcher using a qualitative research strategy, within an interpretivist and constructionist orientation (Bryman, 2016). This chapter discusses the research strategy and the two literature reviews undertaken, the first review of autism and employment literature, and the second review of identity literature. There is a detailed discussion about data collection and the recruitment of participants for the research which was initially conducted via a Jisc Online Surveys recruitment questionnaire. The decision

was made to limit the research to the UK and the chapter considers the choice of semi-structured oral history interviews (Leavy, 2011) and the focus of the interview schedule, all interviews of which were completed in person face to face, on Skype, by phone, or by emailed questionnaire. The chapter then introduces the three research questions: what jobs do autistic women do, how do autistic women resolve their identity in the workplace, and what challenges do autistic women face in the workplace? before a discussion on sample size or information power (Malterud et al, 2016). The chapter then examines the interview analysis utilising the process of reflexive thematic analysis (Braun & Clarke, 2022) from which the conceptual framework was produced (Ravitch & Riggan, 2017). Three main themes have been constructed – chaos or control, wearing a mask, and lost in translation. Finally, the methodology chapter discusses the research ethics process.

Chapter 5 presents the findings on the theme ‘chaos or control’ which focuses on autistic women in the workplace and the jobs they are doing, their original ambition when leaving school or education, their ideal jobs, and their overall perception of their careers. This chapter addresses the first research question, what jobs do autistic women do? Chapter 6 then presents the findings on the theme ‘wearing a mask’ which focuses on identify, anxiety and stigma. This chapter addresses the research question how do autistic women resolve their identity in the workplace? The participants' views are aired on their diagnosis and the impact the diagnosis had on them, together with whether they had disclosed this to their employer. Discussion then turns to the stigma the women had encountered with their disclosure and their own self-stigmatisation, as well as the support they had been able to ask for or access at work. Many women were actively involved in masking but noted the effect this had on them, including the effect on their health, as well as the considerable self-stigma from having to perform a separate identity. Chapter 7 presents the findings on the theme ‘lost in translation’ which focuses on the impact of double empathy, the work environment and organisation. This chapter also seeks to address the final research question, what challenges do autistic women face in the workplace? This examines the identity work autistic women carry out in the workplace and the double empathy issues that arise through the interaction, or lack of interaction, between autistic and allistic people. First, there is a focus on the underutilised skills the women felt were being ignored in the workplace, and at their preferences for work organisation. The chapter then examines

teamwork, sensory issues, anxiety and lack of control over work, stress, socialising and boredom. It also examines exhaustion from masking in the workplace, people skills and unwritten rules, support needs in the workplace and available adjustments. The chapter finally concludes by looking at perfectionism, managing and being managed and executive functioning.

Chapter 8 draws conclusions in the form of a conceptual model of the worklife experiences of autistic women illustrating the generalisations derived from the primary data and interpretation. It also discusses the original contribution of the study, implications for theory and practice, and finally, areas for further research.

Chapter 2: Critical account of Autism, Disability and Employment Literature

2.1 Introduction

In the last chapter the research aims and objectives were introduced, together with the three research questions addressed by this study. This chapter is the first of two literature reviews in this study. In this chapter the focus is on how autism is conceptualised, where autism sits within a wider framework of disability, and what is the current evidence for autistic people in employment and the challenges they face.

First the chapter considers the conceptualisation of autism, starting by critiquing the medicalisation of autism, beginning with Kanner and Asperger's original theories of autism which were primarily focused on males and adopted a deficit laden approach. The review then considers Baron-Cohen's Theory of Mind and Empathising-Systemising Theory which also focus on autism as a deficit that needs fixing. The chapter then questions whether the deficit laden approach allows for the development of a strong positive identity for autistic people, especially when autism research funding is concentrated on biology areas rather than support services. Next the chapter turns to consider the prevalence of autism, the male: female gender ratio, and the ways in which autism is 'diagnosed', and how access to diagnosis remains a challenge. The chapter then considers the particular case of autistic women and girls and the way in which they tend to camouflage or mask their autism in order to 'pass' in society, and how detrimental this can be to their mental health, and identity. The chapter then turns to consider the social model of disability, critical disability theory and neurodiversity which all seek to place disability within a society which is not set up to meet the needs of disabled people, and neurodiversity as a natural part of human development. There is then particular discussion of monotropism (theory about autistic focus) and the double empathy problem (theory about the need for double empathy between autistic and allistic people) which can cause misunderstandings, and problems in the workplace. The chapter concludes with consideration of autism and employment, examining the legal framework and policy agenda for autism as a disability, before looking at the particular challenges that autistic people are known to have when they seek or are in employment.

2.2 The medicalization of autism

Autism was first used as a medical term in 1906 by the Swiss psychiatrist Eugene Bleuler (Ritvo, 1976), though it was not until the 1940s when Dr Leo Kanner, an Austrian born, American child psychiatrist, provided a definition through an investigation of the unusual behaviour patterns of 11 children (Kanner, 1943:247).

Independently of Kanner, Hans Asperger, a Viennese paediatrician, subsequently published a paper (1944, in Frith, 1991) which described 4 children with similar characteristics to the 11 children observed by Kanner. Asperger's description of the children demonstrated behaviour patterns that differed but overlapped Kanner's own group. Subsequent papers built on Asperger's description of children with circumscribed interest patterns as 'autistic psychopathy' (van Krevelen & Kuipers, 1962; van Krevelen, 1971; Wurst, 1974).

In 1956 Kanner modified his criteria, coining the term 'early infantile autism' (Eisenberg & Kanner, 1956). He described five common characteristics observed in children (Waterhouse, 2000:15):

1. The inability to relate to and interact with people from the beginning of life.
2. The inability to communicate with others through language.
3. An obsession with maintaining sameness and resisting change.
4. A preoccupation with objects rather than people.
5. The occasional evidence of good potential for intelligence.

Autism is now most often referred to as a 'triad of impairment' (Wing & Gould, 1979), featuring difficulties with social communication, social interaction, and social imagination (Eikeseth, 2009; Fabio et al, 2009; Matson & Boisjoli, 2007; Matson & Mahan, 2009; Matson & Neal, 2009; Matson et al, 2007; Matson & Wilkins, 2007 & 2009). As well as the difficulties within the 'triad of impairment' autistic people may also have a love of routines, sensory sensitivities, special interests and learning disabilities or difficulties such as dyslexia, dyspraxia and dyscalculia (Wing & Gould, 1979).

Autism is believed to be present at birth and diagnosable by 18 months of age (Kuban et al, 2009; Matson et al, 2009a; Matson et al 2009b; Watson et al, 2003) but is a lifelong condition (Matson et al, 2003) with a strong neurodevelopmental component (Lacroix et al, 2009; Matson & LoVullo, 2009; Niklasson et al, 2009). There are currently no known biological markers for autism, meaning that it is not possible to screen in any form, and it is defined using behavioural descriptions which may change in individuals over time (Hill & Frith, 2003). It is suggested that the heterogeneity of etiology may be one of the reasons why, despite the belief that autism has a strong genetic factor, there is no progress in identifying specific biological paths (Fletcher-Watson & Happe, 2019). Because of this a significant amount of funding is spent on finding the cause and a 'cure' for autism, and an insufficiency of funding into services and societal issues of interest and use to autistic people such as employment (Pellicano et al, 2013).

Therapeutic interventions are typically divided into two categories of biological treatments and behavioural therapies (Happe, 1994). Biological treatments such as drug and diet therapies have not been successful in helping all autistic people (Malone et al, 2005). There is some evidence that behavioural therapies may be helpful for some autistic people (Baker 2006, Frith 2003, Happe 1994, Shea 2005), but this relies on autistic people being able to distinguish between 'acceptable' and 'unacceptable' behaviour.

Within the medical model, one of the prevalent explanations often proposed to explain difficulties encountered by autistic people is "theory of mind" (often abbreviated as ToM). This explanation is highly controversial with autistic people as it utilises a test developed by Baron-Cohen, Leslie and Frith (1985) nicknamed the 'Sally-Anne experiment'. In this test a child was shown a scenario with dolls named Sally and Anne. Sally put a marble away in a box and then left the room. While she was out of the room, Anne transferred the marble from a box to a basket. When Sally returned the child was asked where Sally would look for the marble. Research with groups of children representing those without disabilities, those with Down syndrome, and those labelled 'autistic' showed that the first two groups would state that Sally would look in the box. However, the autistic children were more likely to state that Sally would look in the basket. From this it was inferred that autistic children lacked a 'theory of mind'.

Baron-Cohen has extended this theory to incorporate a concept called 'mindblindness' which, in his view, describes the inability of autistic children to predict other's behaviours based on understanding others' mental states (Baron-Cohen, 1995). Whilst Theory of Mind and mind-blindness seek to find an explanation for the social and communication difficulties in autism, they do not take account of other so-called 'traits' such as repetitive behaviours, narrow interests or the resistance to change. Baron-Cohen has proposed an empathising-systemising (E-S) theory which seeks to classify an individual's strength of interest across these two dimensions. According to this theory, autistic people would be expected to have low levels of empathy, but also average or above average levels of systemising (Baron-Cohen, 2009). Baron-Cohen describes systemising as the compulsion to analyse or construct systems and empathising as the drive to identify a person's thoughts and feelings and to respond to them with the appropriate emotion. Systems follow rules, and when a person systemises, they are trying to identify the rules of the system in order that predictions on how the system will behave can be made (Baron-Cohen, 2006). Baron-Cohen's studies showed that in one group of autistic children the evidence showed high levels of systemising, above the level normally expected on a physics test, and that children as young as eight to eleven years old scored higher than a comparison group of older teenagers (Baron-Cohen et al, 2001). Whilst a theory of empathising-systemising may appear to explain some difficulties that autistic people may face within society, overall, many autistic people are highly critical of Baron-Cohen's 'theory of mind' concept as it defines autism as a deficit which needs fixing.

Autistic people themselves often describe their own experience as individual and diverse (Smukler, 2005). Many autism theories and professionals however seek to try and categorise or homogenise 'autistic impairments', and because in a historical context these professionals have not been autistic, the autism construct is conceptualised as a negative or deficit from the norm. A deficit-oriented approach is dehumanizing, and the language often used to depict autistic people within the medical model is presented as tragic, i.e. "an individual *suffers* from autism; autism *strikes*; autism is *cruel*" (Smukler 2005:17). One specific criticism of the medical model is the view that once 'labelled' children tend to be defined by their diagnosis, lose their individuality, and are limited by people's perceptions and expectations of them (Molloy & Vasil 2002). It could be argued that this is particularly

the case in educational settings, and may be why older autistic people, once diagnosed debate whether to disclose their diagnosis to employers.

Kanner (1973) posited that the outcomes for autistic people might improve in future years as awareness and recognition of autistic conditions increased as well as knowledge about effective educational and therapeutic facilities. However, despite claims on the effectiveness of various therapies there has been no evidence to suggest that the long-term outcomes for any autistic person could be significantly improved following a particular intervention programme (Howlin 1998). Indeed, the most commonly applied programme used with children, Applied Behaviour Analysis (ABA), is now widely criticised because of the link with high levels of post-traumatic stress disorder (PTSD) experienced by autistic children (Kupferstein, 2018).

The construction of autism as a deficit impacts on the development of a strong positive identity for autistic people (Brownlow 2010), particularly when society places emphasis on the desirability of strong social skills in employment and other life choices where autistic people struggle. Society tends to place less emphasis on the traits and skills at which autistic people excel and thereby autistic people's positive contributions can be invisible. An alternative future could be posited where these neurological differences were highly valued by society, perhaps viewed as an evolutionary refinement in an increasingly information technology centred society.

A key report, *A Future Made Together*, commissioned by Research Autism (Pellicano et al, 2013) found that whilst the UK autism research output had grown in recent years it lagged significantly behind research in the US and other parts of the world and was heavily concentrated on understanding the underlying biology, brain and cognition of autistic people (53% of all UK research). The same report also summarised the outcome of a survey of the autism community (autistic people and family members, practitioners and researchers) and found that their future priorities for autism research focused heavily on public services supporting and promoting the life chances of autistic people. The autistic people surveyed also identified the major challenges to them as societal and attitudinal ones rather than finding a 'cure' for autism (Pellicano et al, op cit).

2.3 Prevalence

It is not known whether the prevalence of autism spectrum conditions is increasing, or whether it is the result of increased diagnosis, though there is regular speculation on this (Chakrabarti & Fombonne, 2001; Herbert et al, 2002; Nicholas et al 2008; Tidmarsh & Volkmar, 2003; Willemsen-Swinkels & Buitelaar, 2002; Williams et al 2006; Wing & Potter, 2002). Early estimates suggested the prevalence of autism spectrum conditions as less than 10 in 10,000 individuals (Chakrabarti & Fombonne, 2001; Sevin et al, 2007; Willemsen-Swinkels & Buitelaar, 2002; Wing & Potter, 2002). Data from recent studies of autism prevalence is variable (Talantseva et al, 2023) showing a median prevalence of 100 per 10,000 children (Zeidan, et al, 2022) or 60 per 10,000 (Salari et al, 2022). Prevalence data from 2020 released by the Centers for Disease Control and Prevention (CDC) in the US in March 2023 shows that 1 in 36 8-year-old children in the US are autistic (Maenner et al, 2023). The CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network also noted that Black, Hispanic and Asian or Pacific Islander children showed a higher prevalence than their white counterparts for the first time since the data was collected, suggesting that some racial disparities were being broken down. In England the standardized prevalence of autistic children was 1.76% in 2017 (Roman-Urrestarazu et al, 2021) and it was noted that children from minority ethnic groups had some of the highest rates of diagnoses with the standardized prevalence of black pupils standing at 2.11%. However, it was notable that there was a significant male to female diagnosis ratio disparity between Burnley (12.87:1) and Craven (2.44:1) suggesting the shortcomings of the current diagnostic process for females, certainly within some parts of England.

Although the number of people diagnosed with an autism spectrum condition appears to be rising, the cause of this is not clear, with some attributing this to changes in diagnostic criteria over time (Lenoir et al, 2009) and to greater awareness of structural racism within the health service (Roman-Urrestarazu et al, *ibid*). As autism is discussed more widely, particularly in the media, parents' awareness has been raised (Wing & Potter, 2002), and this awareness may in turn have led to an increase in assessments and perhaps for these to have been more widely accepted. However, a survey carried out for the NHS Information Centre for Health and Social Care (2012) on the prevalence of autism in the adult population demonstrated that autism is common among people with a learning disability, regardless of

where they live in the community. From this, the Centre has estimated that the overall prevalence of autism in England is 1.1 per cent, a significant increase on the previous estimate of 1.0 per cent in the 2007 Adult Psychiatric Morbidity Survey. Whilst the methodology involved sampling from private households, stratified by age, gender and type of residence, none of the presented results are broken down by gender meaning that this survey provides no insight into the division between men and women with an autism spectrum condition.

Initial estimates of the gender ratio of the male:female autistic population were around 12:1 male:female (Fombonne, 2003), with current estimated gender ratios standing at 3:1 male:female (Loomes et al, 2017). This ratio has decreased due to wider understanding and recognition that girls and women can also be autistic (Haney, 2016; Sedgewick et al, 2021) and that they may also be better at masking (or camouflaging) their autistic identity (Pearson & Rose, 2023). However, as was shown above (Roman-Urrestarazu et al, 2021) estimates of the gender ratio do not match the current male to female ratio in many parts of England.

2.4 Identity and Identification

Autism is traditionally 'diagnosed' through use of one of the two international classification systems, the International Classification of Diseases 11 (ICD-11) (WHO, 2022) and the Diagnostic and Statistical Manual of Mental Disorders which is now on its 5th edition (DSM-5) (APA, 2013). Both systems have similar criteria for the diagnosis of autistic spectrum conditions and are based on the so-called 'triad of impairments' with diagnostic categories expanded. ICD-11 is the diagnostic most used in the UK, and this groups autistic spectrum conditions under the broader heading of pervasive developmental disorders (PDD) (Marwick et al, 2005).

Definitions in autistic spectrum conditions are not straightforward. Several diagnostic criteria are available for use with Asperger Syndrome. In addition to the Diagnostic and Statistical Manual of Mental Disorders and the International Classification of Diseases systems mentioned above there are also criteria set by Gillberg and Gillberg in 1989 (Gillberg, 1991) and criteria set by Szatmari et al (1989). Distinctions within the autistic

spectrum also remain controversial and research findings tend to contradict each other (Worley & Matson, 2012). A study by Leekam et al (2001) found that of 200 individuals with autistic spectrum conditions, whilst all met ICD-10 criteria for autism (in use at that time), only 1% met the criteria for Asperger Syndrome. In contrast 45% fulfilled Gillberg's criteria for Asperger Syndrome.

The American Psychiatric Association (APA) has worked on a major revision to the Diagnostic and Statistical Manual of Mental Disorders and DSM-5 was controversially introduced in May 2013. Because autistic spectrum conditions have largely overlapping diagnostic criteria with no discrete boundaries or definitions (Duffy and Healy, 2011, Lanovas and Sladeczek, 2011 and Wouters and Spek, 2011) and longstanding controversy around the boundaries (Matson et al, 2007 and Tantam, 1988), DSM-5 abandons distinct diagnostic criteria in favour of an overarching definition of autism (Kaland, 2011) and therefore erased the diagnostic criteria of Asperger Syndrome. Some autistic people objected strongly to the loss of the Asperger Syndrome 'label' in DSM-5 which they used in preference to the term 'autism' or 'autism spectrum disorder' (Wing et al 2011) and there was concern within the autistic community on whether DSM-5 would appropriately identify those with 'less severe' symptoms.

One of the continuing problems with autistic diagnosis, however, remains access to the diagnostic process. Many of the older women in this study would have been children in the 1960s and 1970s when awareness of autism generally was low. More recently Howlin and Asgharian (1999) found, in a study of over 1000 families, that the average age of 'diagnosis' for children with Asperger Syndrome was over 11 years, compared to 5 years for those with autism, with many people not diagnosed until their late teens or adulthood. The gender bias which results in women and girls being under diagnosed has serious consequences for their health and wellbeing and is flagged by the autistic community as a key issue to be addressed (Pellicano et al, 2014).

2.5 Women and Autism

Hans Asperger's original subjects were predominantly male, and subsequently those diagnosed with similar characteristics were also, unsurprisingly, male (1944, in Frith,

1991). This appears to have led to the assumption that autism was therefore a male condition.

Tony Attwood, who wrote the original key text on Asperger syndrome that parents were often directed to following their child's diagnosis explains that 'the majority of children referred for a diagnostic assessment for Asperger syndrome are boys' (Attwood 2006:46). However, an analysis of his diagnostic assessments over the 12 years prior to 2006 revealed a ratio of 4:1 male to females, significantly different to the 11:1 ratio seen in a Swedish area (Gillberg et al, 2006).

Current international diagnostic criteria do not give examples of the specific types of difficulties women encounter (Gould & Ashton-Smith 2011), and there is general concern that the male bias in autism spectrum conditions has led to females being both under researched and under diagnosed. If women with autism present differently from men, then this may have profound implications for the processes used for diagnosis and the interventions offered (Gould & Ashton-Smith, 2011). Evidence suggests (Posserud et al, 2021) that the male to female ratio is much lower in adults than in children and that the previous recorded male bias is a result of under detection in women and a gender bias in diagnostic practice.

Cases of undiagnosed autism are thought to be as prevalent in the population as diagnosed autism (around 1%) (Baron-Cohen et al, 2009) and numerous studies demonstrate that women are particularly likely to have a missed or late diagnosis (Belcher et al, 2022). Common pathways for women being diagnosed include having a child or family member being diagnosed and then recognising signs in themselves (Zener, 2019).

Studies show evidence of a sex difference in the behavioural presentation of autistic traits (Lai et al, 2012). For example, autistic girls show better non-verbal communication skills, reciprocal social conversations, and the initiation of social interactions than autistic boys; whilst also demonstrating fewer repetitive and restricted behaviours and interests (RRBIs) than boys (Belcher et al, 2022). Women also have special interests, but unlike autistic men these are often less unusual and more in line, but with greater intensity to, those of other women (Gould & Ashton-Smith, 2011).

Women who were not diagnosed until adulthood tend to show much less severe repetitive and restrictive behaviours and socio-communication difficulties (Wilson et al, 2016) which would suggest that their autism was not noticed during childhood due to having good levels of social skills. This also suggests that girls were socialised in such a way that they concealed their autistic traits by 'camouflaging', were more able to 'pass' within society in general and to gain and keep employment due to the use of observation and imitation (Lai et al, 2012, Gould & Ashton-Smith 2011). However, a major drawback to the practise of 'camouflaging' or 'masking' for women is that whilst it can help women fit in to allistic socialisation or workplaces, it has been described as mentally exhausting (Lai et al, 2017), contributing to mental health problems in autistic women (Yau-Smith, 2008). High levels of self-reported camouflaging are associated with suicidal thoughts and behaviours, anxiety, and depression (Cassidy et al, 2018; Hull et al, 2019). Camouflaging can damage the woman's sense of self, and this is explored in the next chapter that examines identity and stigma. A major concern therefore with the under diagnosis or under recognition of autistic women is that they then receive little to no support for coping with the consequences from having lived with an unknown condition (Jones et al, 2014; Stagg & Belcher, 2019). Autistic women are however starting to find a voice with many autoethnographic accounts of their lives now being published (Attwood et al, 2006; Birch, 2005; Blackman, 2001; Clark, 2010; Grandin, 1996; Kearns Miller, 2003; Simone 2010; McGuinness, 2021; Brady, 2023).

2.6 A social model of disability

The social model of disability challenges medicalization and proposes that disability is a social construction (Oliver, 1990). It has done much to confront the way society views disability as well as how 'disabled' people view themselves (Finkelstein, 1980; Oliver, 1990; Thomas, 1999; UPIAS, 1976, cited in Tregaskis 2002; Oliver & Barnes, 2010). The social model provides an alternative opportunity to theorise autism and explains that people with impairments in Britain are disabled and/or excluded by a society which is not organised in ways that take account of their needs. Social model theory also draws a striking distinction between impairment and disability. Barnes (1991:2) explains that impairment is the functional limitation within the actual individual that is caused by physical, mental, or sensory impairment. Disability is the loss or the limitation of opportunities to take part in normal life on an equal basis to other people due to physical and social barriers.

The primary originator of the social model, Oliver, did not intend the model to provide a total explanation for disabled people's exclusion, but to be the starting point for debate (Tregakis 2002:458). Accordingly, the social model remains an area of great debate, but provides a relevant theoretical base from which to consider autism. In developing the social model, a range of 'protective belt' theories (Chalmers, 1978:76-77) have been proposed that support the social model in various ways, but also conflict with one another. The most influential of these is a modern materialist approach which explains that the disabled have faced a specific and explicit exclusion under modern capitalism and will only be socially included once capitalism is replaced (Finkelstein, 1980; Oliver, 1990, 1996). This approach may be useful to start to consider how autistic people are excluded from the workplace.

Other 'protective belt' theories (including a materialist and post-structuralist approach) highlight the role of culture and media in justifying the exclusion of disabled people (Abberley, 1987, 1997; Barnes, 1991, 1996; Hevey, 1992; Shakespeare, 1994). Harpur (2012:327) suggests an alternative non-Marxist approach to the social model that he describes as the 'non-radical social model' which focuses on the role that culture has in disabling people with impairments. Just as Smukler (2005) highlighted the negative language used to describe autism and autistic people, cultural images are used to socially construct disabled people as an unwelcome 'other', and negative imagery is used in the media and literature (Thomas, 1982, Barnes, 1991, Morris 1991, Hevey, 1992, Hafferty & Foster, 1994, Shakespeare, 1994, Peters, 1996). Language is very important, and it is notable that one of the longest debates in disability studies focuses on the difference in descriptors used by the USA/Australia and the UK. In the UK the term 'disabled person' is preferred to 'person with disabilities' which it is believed attributes the disabling effect to the individual rather than society (Clark and Marsh, 2002). In the USA and Australia, the disability is placed behind the individual to emphasise that the person should not be defined by their disability, hence 'person with disabilities' (Goggin and Newell, 2003:25). Harpur (2012) argues strongly for an ableism rather than disablism agenda.

Other developments of the social model include a feminist reading of disabled people's exclusion, the rejection of approaches which avoid disabled people's subjective experience, and the integration of learning from disabled people's experience (Morris, 1991, 1996;

Marks, 1999a, 1999b; Thomas, 1999). The capabilities framework developed by economists and political philosophers also provides an explanation of the social, economic, and environmental barriers to equality experienced by individuals (Sen 1980, Nussbaum 2000 & Burchardt 2004).

Many feminist accounts (Lloyd 2001) have been criticised by the materialist social model theorists for the importance they place on the experiences of individual disabled people and the oppressive attitudes they face (Finkelstein, 1996; Priestley, 1998). Morris (1991, 1996) raises the question of the domination of the disabled people's movement by men (including the academic field) and believes that this has led to the exclusion of disabled people's personal experience from social model theory. The absence of women from much autism literature could therefore be affected by the predominance of male academics in the field in much the same way that women's voices were previously unheard in many areas of daily life. Tregaskis (2002:467) has pondered why no one has attempted to theorise non-disabled people's experiences using social model principals as a means to encourage them to more inclusive practice. She also asks why there is still so much resistance to combining aspects of different social model accounts to provide a more holistic theory of disabled people's exclusion.

Whilst the social model of disability provides an approachable and inclusive model there are concerns that it is too overarching and all-encompassing and therefore not an attainable concept (Shakespeare & Watson 2001:19). Gabel and Peters (2004) have highlighted that the central theme in many theories inherent to the social model of disability is resistance, but that there is little practical application of the theory to the social, economic, and political struggles of disabled people. Whilst the adoption of the social model in preference to the medical model represents a clear resistance to and rejection of oppression, Gabel and Peters believe that the social model itself has undervalued resistance and poses a risk to adherents as the emphasis on collective solidarity could develop a form of oppression from within. In the context of autism for example there are tensions within the National Autistic Society between autistic people, parents or carers of autistic people and professionals working in the field. Each group has different interests and a resistance which is situationally malleable (Gabel & Peters, 2004:596).

Another emerging theorisation is that of critical disability theory (Campbell, 2009; Shildrick, 2009; Meekosha and Shuttleworth, 2009; Goodley, 2011; Shildrick, 2012). Goodley (2012) describes critical disability studies as starting with disability but then providing a space to consider the influences of other accounts such as feminism and engaging with complex identity politics. Davis (2002) believes that disabled people are the ultimate intersectional subject, through which exclusion and resistance can be understood. Impairments are important because each is different, but the social model can only explain so much before it is necessary to turn to the experiential realities (Goodley 2012:4). This is particularly the case with autism where each person's impairment and lived experiences are different. This is perhaps illustrated by phenomenological disability studies (Michalko 1999, 2002, Titchkosky 2003, 2006) where sense, connection and community are entwined. Braidotti (2003:44) conceptualises the body as an interface or threshold where intersecting material and symbolic forces converge with multiple codes of sex, class, age, and race. Intersectionality is an opportunity to consider both convergence and divergence. Garland-Thomson (2002, 2005) argues that a cross-referencing of feminist and critical disability studies may elicit new insights or reimaginings for feminists and disability activists.

2.7 Neurodiversity

Autistic people who were once isolated, have been enabled to connect and form autistic spaces and communities through the growth of the internet and digital services (Leadbitter et al, 2021) and in time these connections have grown into a thriving autistic culture, self-advocacy movement, and more politicised viewpoints about autism as an identity and way of being. Key to this shift is the development of the concept of neurodiversity whose central tenet is that variations in neurological development and functioning are a natural part of human development and not an abnormality (Kapp, 2020).

Neurodiversity is increasingly popular as a workplace concept but is often poorly understood, with conflicting definitions and little practical guidance (Doyle, 2020). Originally developed by people drawing on the social model of disability it is based on the term 'biodiversity' where a high level of biodiversity is believed to be important for the planet. Neurodiversity therefore suggests that drawing on the strengths of autism,

attention deficit conditions, dyslexia and dyspraxia is better than highlighting their weaknesses (Doyle, op cit). Importantly psychologists define neurodiversity 'within individuals' and not 'between individuals'. Hence a 'neurotypical' person is someone whose cognitive scores fall within one or two standard deviations of each other, demonstrating a flat profile. A 'neurodivergent' person is someone who has large disparities in their profile, showing peaks and troughs, often described as a 'spiky profile'.

2.8 Monotropism

Monotropism is a theory of autism which focuses on attention and was proposed by the late Dinah Murray and developed with Wenn Lawson, both autistic autism researchers. Murray et al (2005) argue that there is strong evidence that uncommon patterns of attention are a feature of autism and that the restricted range of interests that the current diagnostic criteria refer to is central to the autistic experience, and it is this that they term 'monotropism'. Murray et al (op cit) argue that there is a tension between attention and task demand and that monotropic people are likely to have problems with tasks where they need to:

- a) See the point of the task and understand the goal;
- b) Value the point of the task and are motivated by it;
- c) Understand how to perform the task – what it is and how to go about it;
- d) Know how to take the identified steps in a task.

If these criteria are fulfilled, Murray et al (op cit) argue that monotropic (autistic) people will tend to perform the task well but also to lose awareness of information relevant only to other tasks. This attention to a narrow field of focus or attention tunnel means that autistic individuals build up an expectation to an ordered experience, and anything outside of this happening spontaneously can cause discomfort and distress. Jordan (1990) postulates that autistic individuals tend to be phenomenologists, learning from what they see, hear, feel, and smell, whereas allistic people tend to distance themselves from experiences on a sensory level but rather learn from inferences, implications and language that underpins this. Furthermore, Jordan et al (1999) suggest that allistic people are part of a socialisation

system that teaches them similar behaviours, whereas autistic people are more different from each other, because they tend not to be socialised into a common culture.

Murray et al (op cit) particularly challenge the deficit models which point to autistic people having an inability to do something. They argue that if understanding and motivation are present, autistic people can do some things particularly well and therefore it follows that it is more correct to describe autistic people as sometimes having difficulties with tasks rather than incapacities.

Monotropic interests are deep attention wells, and an autistic person's attention cannot easily get diverted. Because of this Murray (op cit) argues that unanticipated changes can cause a total dislocation from a safe state for the autistic individual. Monotropic tendencies may also explain why social interaction is impaired because autistic people may not recognise the existence of other people outside their attention tunnel, and because they need to be motivated to do this in the first place, and there needs to be a value attached to doing this, these skills ultimately develop piecemeal. Murray (op cit) also describes how if something does not work out for a monotropic thinker, they are unable to work out alternatives and therefore the outcome is a total disaster. Failure to meet their own or other people's expectations can also cause dread and anxiety, an overriding emotion for many autistic people (Lawson, 2001).

Turning finally to examine communication skills, it can be seen that the rules are complex and nuanced. The monotropic person may have difficulty knowing when it is 'their turn' to talk, or they might be overwhelmed by perceived differences between what they can hear people say and what their faces or body language might show. Murray (op cit) points out that the monotropic person who has some mastery in communication may notice that the person they are trying to communicate with is losing interest and points out that this can lead them to feel inadequate, cause distress and can lead to depression.

2.9 Double Empathy Problem

A further development in autism research is the attempt to examine empathy by Milton (2012). Milton's double empathy theorisation is rooted in the social model of disability and argues that for social interaction to be successful, it requires the participation of two

people. It follows neatly from discussion of monotropism, where Murray et al (2005) concluded their analysis in hoping that greater understanding of and between monotropic and polytropic individuals should be developed in practice. Milton's (op cit) Double Empathy theory argues that in the case of unsuccessful interactions between one autistic person and one allistic person, that both parties should take responsibility. Research shows that allistic people can form negative first impressions about autistic people very quickly (Sasson et al, 2017) based on how they appear and sound. If given the work of autistic people to read, allistic people however do not judge them any differently to other non-autistic people. This would suggest that double empathy may have a significant impact in the working environment where communication is often likely to be verbal, and less likely to be written.

More recent research (DeBrabander et al, 2019 and Morrison et al, 2020 in Crompton et al, 2021) has tested whether autistic people connect with other autistic people more easily than they do with allistic people. Results showed that contrary to expectations, autistic people were not poor at social interaction where both parties were autistic. This suggests therefore that autistic people find it easy to connect with, and form friendships with people like them. Further research (Heasman and Gillespie, 2019) also suggests that autistic people give each other more freedom of expression within interactions and are less likely to adhere to social expectations for interactions. Understanding more about this double empathy problem is important in order to improve understanding of autistic and allistic people in relation to the other person's viewpoint, and to avoid making assumptions and be judgemental about interactions.

2.10 Autism and Employment

The 2009 Autism Act brought about a legal requirement for the UK Government to introduce and keep under review an adult autism strategy. This was accompanied by statutory guidance for NHS organisations and local authorities in 2010 and was revised in 2015 (Parliament, House of Commons, 2023). Autism is classed as a disability under UK legislation, regardless of whether the autistic person considers themselves disabled or not. It is also the only lifelong condition with a condition specific Act of Parliament (LGA, 2022). Separate strategies have been published for England, Scotland and Northern Ireland

following legislation, and a Code of Practice is currently being developed for Wales (Table 2.1).

Table 2.1 UK Autism Legislation and Strategies		
Legislature	Strategy	Date
England	Fulfilling and rewarding lives: the strategy for adults in England Think Autism National strategy for autistic children, young people and adults: 2021 to 2026	2010 2014 2021
Scotland	The Scottish Strategy for Autism A Fairer Scotland for Disabled People: employment action plan Scottish Strategy for Autism 2018-2021	2011 Refreshed in 2015 2018 2018
Wales	Autism Spectrum Disorder (ASD) Strategic Action Plan for Wales Autism Spectrum Disorder Delivery Plan 2018 to 2021 Autism Delivery Plan 2021 to 2022 Code of Practice on the Delivery of Autism Services	2008 Refreshed in 2016 2018 2021 2021
Northern Ireland	Autism Act (Northern Ireland) Autism Strategy 2013 to 2020 and Action Plan (2013-2016) Autism Interim Strategy 2021-2022 Autism (Amendment) Act (Northern Ireland) Autism Strategy 2023-2028	2011 2013 2021 2022 2023
Adapted from Parliament, House of Commons (2023)		

The Government’s 2021-26 Autism Strategy said that by 2026 it would improve support to help autistic people find and stay in work. This is proposed through a combination of measures such as improving employer awareness of autism, improving the accessibility of employment programmes and making Jobcentres more autism-inclusive. The Department of Work and Pensions subsequently announced a review in April 2023 of how to improve the work prospects of autistic people (Parliament. House of Commons, 2023).

The Equality Act 2010 is the UK’s primary legal framework for protecting the rights of disabled people. The Act lists nine protected characteristics – age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. The Act defines any person as disabled who has a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities. Autistic people therefore have a right to protection from any direct or indirect disability discrimination in employment or recruitment. The Act also expects employers to make reasonable adjustments across all

stages of the employee lifecycle, including recruitment, and training and development (Equality Act, 2010). The employee does not need a formal diagnosis of autism to access support, and any support should be based on the autistic person's specific needs. Employers can particularly struggle to understand how to make reasonable adjustments because there is no official list, and therefore both employer and employee may not be clear on what works. The process usually starts with a workplace needs assessment normally conducted by an external agency (Heasman, 2020).

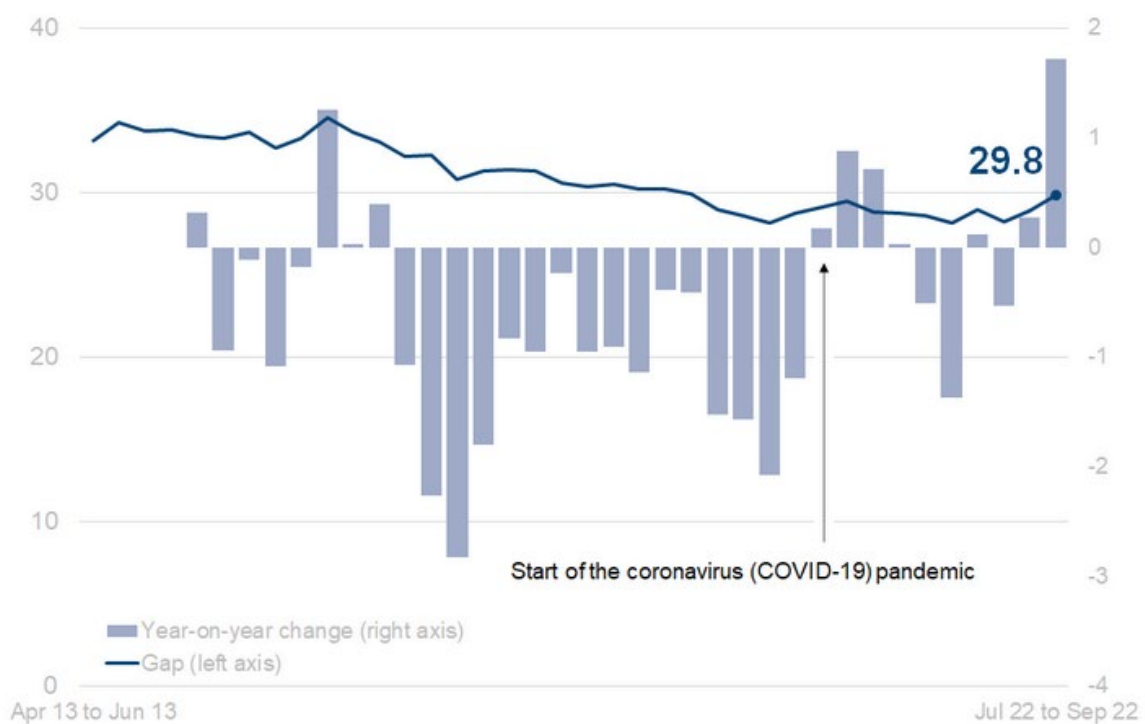
In addition to the Equality Act 2010 the other significant legislation related to disabled people is the United Nations Convention on the Rights of Persons with Disabilities. This was adopted by the United Nations (UN) General Assembly in 2006 and entered into force in 2008. The UK signed the Convention in 2007 and ratified it in 2009. Specifically related to disabled people in the workplace or training, Article 26 imposes a duty on states to offer services to help disabled people attain, regain and improve their skills, whilst Article 27 provides an equal right for disabled people to work and employment, prohibiting discrimination and imposing a duty on employers to make reasonable adjustments (Parliament. House of Lords, 2018). In 2015 an investigation was launched into the UK Government by the UN Committee on the Rights of Persons with Disabilities after a formal request by UK disability organisations stating that "serious and systematic violations of the provisions of the Convention were occurring against persons with disabilities" (United Nations, 2016:3). In the UK the Equality and Human Rights Commission, the Equality Commission for Northern Ireland, the Northern Ireland Human Rights Commission and the Scottish Human Rights Commission were designated as an independent United Kingdom Independent Mechanism tasked with promoting, protecting and monitoring implementation of the Convention on the Rights of Persons with Disabilities in the UK. An inquiry report was prepared in 2016 and a follow-up report by the United Kingdom Independent Mechanism in 2023 found that there had been very slow progress towards implementing the inquiry recommendations, and that the Covid-19 pandemic had had a disproportionate impact on the human rights of disabled people (UKIM, 2023).

Since 2016 the National Autistic Society has used a statistic derived from their own survey of autistic people suggesting that only 16% of autistic people are in employment (NAS 2016). More recently, the Office of National Statistics suggests that only 22% of autistic people are

currently employed in any type of employment (Adam et al, 2023). However, both statistics may underplay the number of autistic people in employment as both these surveys only capture people with a diagnosis and contributing to the survey in question. In fact, Butterworth and Kovas (2013) estimate that approximately 10 percent of the UK workforce, which represents over 3m employees has a diagnosed or undiagnosed neurodiversity condition.

Nevertheless, ONS statistics (Adam et al, 2023) show a bleak picture for disabled workers in the labour market in general (Fig 2.2), where fluctuations in the disability employment rate have resulted in the disability employment gap (the rate of disabled and non-disabled people in employment) now being at its widest since 2018.

Figure 2.2: Disability employment gap (percentage point), people aged 16 to 64, UK, April to June 2013 to July to September 2022



Source: Labour Force Survey data (2022) in Adam et al, 2023

Autistic adults can experience both frequent unemployment and underemployment with unfulfilling or repetitive work tasks, socially isolated at work and unfairly dismissed from employment (Baldwin et al, 2014). There is also evidence to suggest that autistic people change their jobs frequently and earn less money than their counterparts (Jennes-Coussens et al, 2006) whilst Eaves and Ho (2008) suggest that autistic people entering the labour

market rarely achieve high levels of responsibility, due to job hopping (Barnhill, 2007) resulting from a poor working environment and stigmatisation from co-workers (Beardon and Edmonds, 2007) or overqualification leaving them feeling unfulfilled in their job (Baldwin et al, 2014). Howlin et al (2004) also observe that the employment results for those with autism demonstrate outcomes much lower than would be expected given the individual's intellectual functioning. Indeed, many autistic people find it difficult to find the right vocation at the correct level for their ability, maintaining employment and negotiating the social relationships of the workplace (Hurlbutt & Chalmers, 2004).

Recent research claims to find evidence that autistic individuals would work well in technical fields and that those with ADHD should work in high paced environments, perhaps in industries where novel thinking and creativity is valued and suggesting that ADHD may be an advantage to those seeking entrepreneurial pursuits (LeFevre-Levy et al, 2023). However, other views (Praslova et al, 2023) point to the danger of typecasting as limiting and dangerous and point out that entrepreneurship rates among neurodivergent individuals possibly reflect the lack of employment opportunities open to them.

Szechy et al (2023) argue that studies of autistic adults in the workplace often focus on addressing assumed deficits in the autistic person but should instead be looking at the double empathy problem and ways of developing mutual understanding between autistic and allistic workers. Bury et al (2021) found in a study of autistic employees and employers, that both parties attributed social problems in the workplace to internal characteristics of the autistic employee. In such situations it was left to the autistic employee to apologise and adjust themselves to the workplace environment. As a result, this left the autistic employee with self-stigma and accumulated stress and anxiety, and in a rapidly spiralling situation continuing misunderstanding and avoidance of autistic and allistic coworkers increased the marginalisation of the autistic worker.

Particular challenges preventing autistic workers entering the workplace are often cited (Ezerins et al, 2023) as the job search, recruitment and selection phase, as well as leaving them with a dilemma over whether to disclose their diagnosis during recruitment. Other suggestions have been made that whilst autistic people may have the technical skills required for a job, they may have difficulties engaging in reciprocal conversation or be able to quickly respond to questions during a job interview (Barnhill, 2007 and Romoser, 2000).

In the workplace autistic adults themselves have cited poor social communication between employer and employees or coworkers, social skills deficits, and sensory issues as the main problems they faced (Hurlbutt & Chalmers, 2004). However, others have found workable strategies to provide a positive working environment. These centre on job modification, supervision, co-worker relationships and social interactions, and support services (Hagner & Cooney, 2005). However, evidence now suggests that post hire many of the challenges impacting autistic workers performance and retention are due to the double empathy problem of a lack of mutual understanding between the autistic worker and the allistic manager or workplace and Ezerins et al (op cit) and Richards et al (2019) strongly suggest that managers of autistic employees need their work reconfiguring to allow them extra time to support employees with diverse needs. A study of autistic workers (Cooper and Kennady, 2021) found a high consistency of negative experiences around bullying and masking in the workplace and observed that these experiences meant that the workplace failed to benefit from any strengths or creativity of their autistic employees. They also observed however that with an understanding manager the autistic workers could contribute effectively, leading to calls for better neurodiversity awareness training in the workplace, and for Department for Work and Pensions and JobCentre Plus employees.

Whilst autistic employment is often focused around matching autistic strengths to job features there is evidence to suggest that autistic strengths such as attention to detail, could also be an indicator of a difficulty with executive functioning such as inflexibility and difficulty adapting to new routines (Bury et al, 2020) and that it is therefore important that consideration of work-based tasks providing advantage also consider what support is needed to enhance that advantage, and also what might undermine the advantage.

Autistic people often have their own suggestions for ways to improve their employment situation. These include initiatives like the provision of a job mentor and a national foundation to educate employers about autistic people (Hurlbutt & Chalmers, 2004). Allistic people may also be unsure how to interact with autistic people and their reactions can lead to considerable distress for autistic people (Tantam 2000).

A theory mapping of the employment outcomes for autistic people (Mpfu, 2023) found that there was little concrete evidence on what worked best to help autistic adults gain and retain employment. However, it was found that the investment by family members in

helping autistic adults access work in terms of emotional, material and time costs was significant (Hillier & Galizzi, 2014). Participating in employment support programmes can improve employment outcomes for autistic people, however there is also evidence that employers need to ensure better training of their staff to ensure that focus is not on the perceived limitations of autistic people, but rather on building supportive work environments (Hedley et al, 2017). The National Autistic Society provides an employment service called Prospects to support both people with an autism spectrum condition and employers in the workplace. There is no cost to the employer for services such as orientation in the workplace, identification of training need, job analysis, disability awareness training, social training awareness and instruction on the 'unwritten rules' or culture of the workplace (Barnhill, 2007). Many employment options are now available including training centres, supported employment and competitive employment (NAS 2023). Innovative new forms of employment are springing up, including social enterprises such as Specialisterne, a Danish social enterprise which utilises the special qualities and interests of some people with autistic spectrum conditions by offering employment as software testers (Specialisterne 2023).

Although the Equality Act entitles autistic people with a right to seek support or workplace accommodations, if you are an undiagnosed autistic woman you may realise that you are struggling in the workplace but may not know why, nor that you can request support to help. If you do have a diagnosis or have self-diagnosed your autism you may therefore need to divulge this diagnosis when seeking workplace accommodations. A report for the Discover Autism Research & Employment project for the Autistica charity (Heasman, 2020) found that often neurodivergent job seekers or employees reported that their managers were unaware of what adjustments could be implemented in the organisation due usually to a lack of information about adjustments previously used in the organisation, or the different types of support needs and respective strengths of different adjustments. The burden of identifying adjustments was often put upon the neurodivergent employees who might not have the skills to speak up about any concerns they had. The report also found that where adjustments could be identified their successful implementation was not always guaranteed due to the self-stigma of the employee who might be concerned about being identified as difficult, or a lack of clarity over where the request should be made. Another

major issue was about the refusal of adjustments which often involved disagreements between managers and employees over whether adjustments were “reasonable”, reflecting differences of opinion in adherence to the Equality Act 2010.

Table 2.3 shows the wide range of workplace adjustments available, many of which may not be known about by the autistic community or by HR or workplace representatives.

Table 2.3: Work related strengths and difficulties attributed to neurodivergent conditions, together with workplace adjustments

	Strength (adapted from Doyle, 2020)	Difficulty (adapted from LeFevre, 2023)	Workplace Adjustments (adapted from Heasman, 2020)
Autism	<p>Memory and other skills such as calculation, music, reading and artistic skills</p> <p>Detail observation and innovative thinking</p> <p>High verbal comprehension</p>	<p>Social interaction such as reading social cues</p> <p>Sensory concerns</p>	<p>Job role and management processes</p> <p>Accurate job descriptions (not emphasising presentation skills when not necessary, or clarifying the actual likelihood of taking on additional responsibilities)</p> <p>Advance notice of changes</p> <p>Avoid role-play on training courses</p> <p>A culture of asking one question at a time</p> <p>Explicit communication (written instructions rather than verbal)</p> <p>Evolving job role based on strengths</p> <p>Extra breaks to prevent the employee being overwhelmed</p> <p>Extra time meeting with managers</p> <p>Flexible deadlines</p> <p>Flexible work hours to avoid commuting in rush hour</p>
Attention Deficit Hyperactive Disorder (ADHD)	<p>Creative thinking</p> <p>Hyper-focus</p> <p>Visual-spatial reasoning ability</p>	<p>Maintaining attention</p> <p>Time management</p> <p>Procrastination</p>	<p>Frequent feedback</p> <p>Longer time allowed to familiarise with new routines when changes take place</p> <p>Maintain consistent job roles, patterns and working partners where possible</p> <p>Minimise unnecessary away days</p> <p>Minimise unnecessary face to face meetings and face to face interaction</p> <p>More time for tasks</p> <p>Online access to information about sources of support for job role, wellbeing and mental health</p>
Dyslexia	<p>Entrepreneurialism</p> <p>Visual reasoning</p> <p>Creativity</p> <p>Story telling ability, practical skills, and visual-spatial skills</p>	<p>Memory</p> <p>Spelling</p> <p>Decoding language</p> <p>Slower processing speed</p>	<p>Option to work remotely where possible</p> <p>Process for having concerns recorded and taken seriously</p> <p>Manager expectations to be realistic</p> <p>Specify clear action points in emails so that the recipient understands what is being asked</p> <p>Trialling workspace before starting</p> <p>Using an external mentor to help manage challenges</p> <p>Using internal advocates to communicate on behalf of the employee</p>

Table 2.3: Work related strengths and difficulties attributed to neurodivergent conditions, together with workplace adjustments

	Strength (adapted from Doyle, 2020)	Difficulty (adapted from LeFevre, 2023)	Workplace Adjustments (adapted from Heasman, 2020)
Dyspraxia	High verbal comprehension ability	Interpretation of information	<p>Weekly plan with manager Neurodiversity training to be made available to all employees Written communication preference over verbal communication Written questions for job interviews to be circulated before the interview</p> <p>Physical environment and equipment Ability to adjust temperature where possible Allocated desk (especially in a hot-desking environment) Allocated parking space Avoid fluorescent strip lighting Avoid open plan office Blue screen filter for computer screen to see colours more easily Clear signage throughout building and designated quiet areas Devices to communicate key information (i.e. slider on desk when working from home) Designated quiet space Ear defenders and/or ear plugs Ergonomic chair, wrist rest and keyboard Fast response to equipment issues (e.g. flickering light) Laptop stand Maximise personal space Noise cancelling headphones Online resources to help get up to speed in a new role Option to work in a quieter space away from doorways and busy pathways Repositioning of desk to avoid people approaching from behind Secondary glazing Site blocker software to avoid internet distractions Desk lamp if overhead light needs augmenting Tinted glasses if overhead lights overpowering</p>

Table 2.3: Work related strengths and difficulties attributed to neurodivergent conditions, together with workplace adjustments

	Strength (adapted from Doyle, 2020)	Difficulty (adapted from LeFevre, 2023)	Workplace Adjustments (adapted from Heasman, 2020)
			<p>Visual partitions of workspace to avoid distraction and sounds</p> <p>Social and cultural practice Team culture that is aware of: sensory impacts including strong perfumes, encourages quieter lunchtime conversations, educates about negative language (e.g. not describing autism as a tragedy), avoids language that is difficult for autistic people to interpret, respects preferences about physical contact like handshakes. Ability to explore other job roles in the organisation Access to senior mentoring Being asked about preference for social events Ensuring all team members understand and respect adjustments (especially in the absence of the manager or supervisor) Flexibility on clothing choice if possible Handouts in advance of training or presentations A culture of respecting and keeping promises when made Increased patience and flexibility from colleagues and team members in the case of misunderstandings Offering the option to refuse to take on more work Reduced overnight stays where possible Relaxed obligations for social commitments Specified hours for responding to emails Training staff on neurodiversity and specific needs Ability to work near understanding and familiar colleagues</p>

2.11 Conclusion

This chapter has examined how autism is conceptualised, where autism sits within a wider framework of disability theory and practice, and critically, what are the issues autistic people face getting into the workplace and thriving there.

First the chapter considered the conceptualisation of autism by critically analysing the medical deficit model on which the highest proportion of research funding is currently focused (Wing & Gould, 1979; Baron-Cohen, 1995; Baron-Cohen, 2006), but which does not address the autistic community's demands for research on services (Pellicano et al, 2013). Evidence was presented to suggest that it is not known whether the prevalence of autism is rising or whether this is due to increased diagnosis (Talantseva et al, 2023), but current estimates of the gender ratio have fallen from 12:1 male to female to 3:1 (Loomes et al, 2017), although access to diagnostic services continues to be challenging and is one of the areas autistic people are demanding more funding for (Pellicano et al, op cit). Autistic girls and women show better non-verbal communication skills and initiate social interaction more than boys and men (Belcher et al, 2022), and may camouflage or mask their autism in a way that allows them to 'pass' through observation and imitation of role models (Lai et al 2012, Gould & Ashton-Smith 2011). However, the process of masking can contribute to mental health problems, anxiety and depression as well as impacting on their self-identity (Hull et al, 2019).

The social model of disability helps frame and explain autistic women's experiences as disabled and excluded by a society that is not organised in a way to acknowledge their needs (Oliver, 1990) and the concept of neurodiversity helps autistic women to view their neurological development and functioning as a natural variation in human development (Kapp, 2020). This theoretical framework underpins the study. In addition, autistic researchers have theorised autistic people's ability to focus as monotropism (Murray et al, 2005) and the inability of autistic and allistic people to understand the other person's viewpoint as the double empathy problem (Milton, 2012). Both of these theories provide unique autistic perspectives on their own experiences, and the double empathy problem is critical to improving understanding of autistic and allistic people in relation to the other person's viewpoint and is returned to in Chapter 3 on Identity, Stigma and Masking, and also

in the Findings Chapters 5, 6 and 7. Current UK legislation provides a legal requirement for the Government to introduce and review an adult autism strategy and this is supported by statutory guidance for the NHS and local authorities (Parliament, House of Commons 2023). Other legislation supporting disabled employment is the Equality Act 2010 and the United Nations Convention on the Rights of Persons with Disabilities. Autistic people therefore have a right to protection from any direct or indirect disability discrimination in employment or recruitment.

One challenge in understanding autistic employment is that the statistics are flawed as they only take account of those with a diagnosis who disclose. The question of diagnosis being central to an autistic identity is further discussed in Chapter 3 Identity, Stigma and Masking. The National Autistic Society estimate only 16% of autistic people are in employment (NAS 2016), the Office for National Statistics (ONS) claim 22% of autistic people are in employment (Adam et al, 2023), and Butterworth and Kovas (2013) estimate approximately 10 percent of the UK workforce has a diagnosed or undiagnosed neurodiversity condition. Whilst the 2023-26 Autism Strategy made provision for measures to help autistic people find and stay in work, ONS statistics (Adam et al, 2023) demonstrate that the disability employment gap (the rate of disabled and non-disabled people in employment) is now at its widest since 2018. Specific challenges preventing autistic workers enter the workplace are often cited as the job search, recruitment, and selection process (Ezerins et al, 2023), and leave autistic people in a dilemma over whether to disclose a diagnosis during recruitment. In the workplace difficulties include the working environment, sensory issues, and poor communication between themselves and the employer or coworkers. These challenges are also returned to later in the Findings chapters 5, 6 and 7. Autistic people also face problems with bullying in the workplace and need to mask their identity (Cooper and Kennady, 2021) (this is discussed further in Chapter 3). There is limited support through employment support programmes or employment services available through the National Autistic Society or other bodies (Barnhill 2007, NAS 2023). The Equality Act requires employers to make reasonable adjustments across all stages of the employee lifecycle, but employers often struggle to understand what adjustments can be made, and equally autistic workers may also not know what adjustments would be helpful for them (Heasman, 2020).

The next chapter on identity, stigma and masking is the second of the literature review chapters and will elaborate upon the identity related issues from this chapter about autism and disability.

Chapter 3: Identity, Stigma and Masking

3.1 Introduction

The last chapter examined how autism is conceptualised, as well as where autism sits within the wider framework of disability theory and practice. It also critically highlighted that autistic people can face problems with employment such as recruitment processes and keeping their employment. In the last chapter the double empathy problem, bullying and masking in the workplace were introduced and explained and these are discussed in more detail in this chapter which covers identity, stigma and masking.

This chapter is the second of the two literature reviews in this study. In this chapter the focus is on identity, stigma and masking and the link is made with autism and the impact of stigma and masking specifically on autistic women.

First the chapter introduces identity theory and then moves to explore social identity theory and the way in which people seek to attach themselves to groups and have a value attachment to them. The chapter then considers self-categorisation theory where people's attachment to groups depersonalises their own identity, but which is an automatic process related to the situation they are in. Following this the chapter considers intersectionality and the way in which people may have multiple identities reflecting the different positions they have in life. Disabled identity is also discussed, specifically the way in which disabled people may wish to disclose or conceal their identity as they often form a minority in the workplace. Ableism may become embedded in organisational practices, although accommodations in the workplace may remove or alleviate barriers. The chapter also considers how for some autistic people their autism is the identity they have, and diagnosis is the key to enabling them to have this understanding. The chapter then turns to stigma at work, and the identity work that takes place within organisations, observing that identity work has a significant impact on a worker's life in the workplace. The chapter concludes with a lengthy consideration of autism, identity and stigma and the specific issue of autistic masking – a term that the autistic community use for the identity work they carry out to 'conceal' their autism identity in the workplace. Masking can produce autistic burnout and other conditions such as depression, anxiety and Post Traumatic Stress Disorder (PTSD).

3.2 Self

Mead's (1934) concept of the self argues that every one of us creates a sense of our own 'self' through engaging with the 'selves' belonging to other people (Elliott, 2013). Mead (1934) believed that human communication primarily took place through the shared use of symbols which people use to represent objects in our minds and those of other people. We recall these symbols and undertake a process of reflection. The symbols also enable us to have a shared understanding with other people and it is through this that we begin to understand our self and interact with other people (Burke and Stets, 2009). Mead (1934) believed that there is a commonality to the concept of self, which means that by observing your own thoughts and feelings you can therefore interpret the thoughts and feelings of others. This therefore leads us to believe that we know exactly how another person is feeling or might react to something because we know how we might react or feel (Elliott, 2013). This also links to emotional synchrony where even carrying out meaningless activity in conjunction with other people causes prosocial behaviour and social identification – a sense of union with other people (Paez et al, 2015).

Mead (1934) believed that there is no division between our own sense of self and those of others as they are created by the interaction or agency between these. The process of interacting with someone, and the understanding of their position or views, means that the individual self is also made up of the attitudes of others. As individuals, we view ourselves as others see us, which Mead described as 'the conversation of gestures'.

Mead further distinguishes between what he terms the socialised and unsocialised self. The socialised 'me' is created through the experiences we internalise from our birth. The unsocialised 'I' is the personal desires that spring spontaneously into our experience (Burke and Stets, 2009). The unsocialised 'I' of the self is the agent actor that starts action to bring about the result. The socialised 'me' aspect of the self is an observer that looks at the action, the environment, and the relationship between both. We become self-aware, when because of our development, we can distinguish between both the 'me' and the 'I' and keep a differentiation between the two. The 'me' is a duality of both social meaning and individual, that develops a knowledge and understanding of our self needs. Our 'me'

identity is reflexive and can see our self both as distinct from others, as well as a self that has developed meaning in the community of other people (Burke and Stets, 2009).

Mead (1934) argued that we develop a shared understanding of meaning by seeing each other's responses and reactions. This concept of shared understanding of meaning was developed further by Blumer (1969) and is described as symbolic interactionism. Blumer argued that human interaction is subject to heavy mediation by participants interpreting and finding out the meaning of each other's actions. Symbolic interactionists believe that social interaction is highly complex and subject to substantial interpretation by the participants. In contrast, however, Elliott (2013) argues that symbolic interactionism is too rational and cognitive and excludes any notion of emotion or passion. Elliott also believes that symbolic interactionism ignores the tension and conflict between the individual and society. This sense of self, however, is far more complex for autistic or neurodivergent people because of the feedback, other's responses, and reactions, which are observed and internalised as a spoiled identity, where there is little shared meaning.

Stryker (1980) was one of the first people to try to conceptualise 'identity theory' and did this by focusing on role identity, arguing that everyone has a position or role in society, and for each of these they also have an identity. Most people have many roles and therefore many identities (Stryker and Burke, 2000). Stryker (1980) also developed a version of symbolic interaction called structural symbolic interaction that takes a scientific approach to the relationship between identities and the social structure of society. Both forms of symbolic interaction share the view that it is possible to understand why people act the way they do by getting 'inside their head' and find the meanings they give to their environment (Burke and Stets, 2009). Symbols are named objects or categories relevant for social interaction that also have shared meanings. In turn we therefore expect that these shared names and meanings mean that other people will respond in a comparable way to ourselves, and as this is learned we respond to them as 'positions' within the social structure. These positions are patterns of interaction and meanings, and expected behaviours are associated with them. The meanings of the behaviours are important, and these are constantly shifting and developing within society. When agents agree a consensual approach to meaning then the structure is stable, but when there is little

consensus the structure shifts and changes. Symbolic interaction refers to the meaning of the behaviours, while structural symbolic interaction is concerned with the way in which behaviours take place within the structures of society and are highly interdependent on them (Burke and Stets, 2009). Whilst Stryker's conceptualisation was critical in focusing on role identity it did not address the socialised self, or the social identities that people adopt during their working and social lives, key to this study.

3.3 Social Identity

Whereas identity theory focuses on the self, social identity theory is a social psychological theory which examines the socialised self, intergroup relations, and group processes (Hogg et al, 1995). Social identity is about a person's knowledge of the groups they are a member of, the attributes necessary for membership of that group, their emotional attachment to the group, and awareness of how that group stands socially in relation to other groups. The main theoreticians are Henri Tajfel who has written extensively on social perception and the social belief aspects of discrimination (Tajfel 1959, 1963, 1969, 1970) and later joined by John Turner (Tajfel and Turner 1979, Turner 1982). Social identity theory has been further developed, most recently by Abrams and Hogg (1990).

Social identity is defined by Tajfel (Hogg, 2011) as a person's knowledge that they belong to one or more social groups and have some form of value attachment to that group membership. Each membership, and therefore social identity, leads the person to an understanding of what a member of that group should think and behave. In this way, a social identity can lead a group member to behave in a certain way that may become the normative or accepted behaviour. Anyone behaving differently to the normative and stereotypical behaviour of the group would be viewed as outside that group. Because of this, group members would have a strong incentive to adopt behaviour to support group allegiance, and to regulate the self (Hogg et al, 1995).

Festinger (1954) argues that people constantly check attitudes and perceptions through comparing with the attitudes and perceptions of other similar people. This can ultimately bring about greater integration amongst people (Hogg, 2011). Intergroup comparisons can also take place to show distinctiveness between your own group and that of other

groups. Thus, a person's own self-conception or social identity is also centred on making comparisons which produce similarity within groups and differentiates between other groups (Tajfel, 1981).

Turner (1982) argues that the drive for group distinctiveness is caused by people's motivation for self enhancement, driven by the need for positive self-esteem that influences social identity processes. Abrams and Hogg (1988) suggest that low self-esteem motivates social identification and inter group behaviour, and that self-esteem can be increased by social identification. Later research has suggested that variables may affect this hypothesis such as the degree by which the person identifies with the group, or the amount by which the group and members may feel under threat (Hogg, 2011). However, overwhelmingly the human need to belong is driven by a need to increase self-esteem and reduce uncertainty (Baumeister and Leary 1995).

The subjective belief structures of people are important in showing how groups relate to one another. These beliefs may or may not be real and may be ideological in nature and influence the behaviours of group members in pursuing self-enhancement through positive social identity (Hogg, 2011). An example would be a group that felt it was possible to reach a higher social status by moving into another group, with the members not showing solidarity or allegiance within the group but would seek to disengage and seek membership of the other higher status group. Another example might be a group of disabled people who felt that their group was viewed as being of a lower status, and considered this was illegitimate. This group might collectively therefore try to improve the status of their group through competition with others.

Crosby et al (1993) and Jost and Banaji (1994) have found that people sometimes find it difficult to challenge the status quo within groups and that belief systems can develop that make it easier to give way to others. This might be explained by social dominance theory where people differ in their desire to accept or reject the legitimisation of equality. Over time social identity theory has been further revised and developed to understand in more depth the processes involved, resulting in self-categorisation theory which uses a fuzzy set of attributes in a concept called prototypes to categorize similarities and differences (Turner et al, 1987).

3.4 Self-Categorization Theory

Turner theorised an important development of social identity theory in the 1980s, with self-categorisation theory. Social categorisation of self and others into prototypes, with fuzzy attributes and features that describe and prescribe the attributes of the group, can lead to a process of depersonalisation. People then lose their individuality and become a prototype of the ingroup attributes. This can lead to depersonalisation of the person's own self-conception leading to stereotyping and ethnocentrism (Hogg, 2011). Prototypes are central to self-categorisation theory and might be representations of 'ideal' group members. They embody attributes such as behaviours, feelings, and beliefs that people believe may categorise groups and distinguish them from others. Prototypes are based on meta contrast, maximising similarities within the group and differences between groups. They are dependent on context and significantly are affected by whichever outgroup is dominant at the time. Social identity can therefore be considered dynamic and changes depending on whichever group is being compared with (Hogg, 2001). An example of this dynamic change might be how a group of autistic women might compare itself with a group of autistic men and a group of allistic people.

Self-categorisation (social identity) is largely an automatic rather than a deliberative practice that people undertake, drawing on social categorisations that are particularly valued in the situation they are in (Oakes and Turner, 1990). When in a group people also tend to conform to the group and influence new members to conform (Turner, 1991). Group norms can become deeply ingrained and may affect the behaviour to attitudes relationship where attitudes significantly define membership in some way (Terry et al, 2000).

Within groups some people can be more prototypical than others, and people are highly aware of the prototypicality of group members (Hogg, 2001). Not surprisingly people who are highly prototypical are liked more and those who are not prototypical can be marginalised by the group (Marques et al, 2001). The reaction of the group to unprototypical members may be because they could threaten the integrity of the ingroup (Jetten et al, 2000). To regain credibility with the ingroup the outlier members may criticise outgroups, particularly where this is observed by an influential ingroup member (Noel et al, 1995). Autistic women without a diagnosis may therefore particularly struggle to find a

group they feel comfortable in and even where the self-categorisation fits the group they may feel marginalised for aspects of their hidden disability, but will not understand why, leading them to interact with multiple identities.

3.5 Intersectionality and Disabled Identity

James (1890) conceptualised the idea that people have multiple selves reflecting the different positions they occupy in daily life. Each 'self' comprises the multiple identities that a person has (Burke and Stets, 2009). When we interact with other people, we are usually interacting with one of these multiple identities, and one of their multiple identities responds back to us. Each of our identities in these interactions has a counter identity (Burke, 1980), for example parent to child, and the exchange of information or discussion in these conversations will naturally exclude other things not relevant to that identity. These exchanges can be complex if we use two (or more) identities at the same time, such as work colleague and being a friend.

The multiple selves described by James (1890) may also be found in the concept of intersectionality that Corlett and Mavin (2014) find has been conceptualised by different researchers as a crossroad (Crenshaw, 1991), axes of difference (Yuval-Davis, 2006) or dynamic process (Staunaes, 2003). The complex way in which people construct multiple and co-existing self-identities and social identities both without and within organisations can be understood through both an intersectional lens and identity/identity work. Research shows that organisations with positive representations of gender and race, have a positive impact on identity salience (Purdie-Vaughns et al, 2008 and Murphy et al, 2007). Gender alone cannot be conceptualised as an individual identity, but is a social construction (McGowan, 2016) and a gender identity is a person's own self-identity regarding gender categories (Catalano and Shlasko, 2010). The intersections of social identities result in qualitatively different meanings and experiences (Warner, 2008) and suggests therefore that the experiences of autistic women in the workplace are distinctive and not just a combination of the experiences of autism and being a woman.

As well as their autistic identity, autistic adults are more likely to belong to other marginalised groups. For example, autistic people may be more likely to identify as a

gender other than their sex assigned at birth (gender minority). They may also be more likely to identify with a sexual orientation such as asexual, bisexual, or gay (sexual minority). This intersection of autism with gender and sexual orientation may increase the stress experienced by them and therefore result in poorer mental wellbeing (McQuaid et al, 2023).

In his writing on identity and disability, Shakespeare (1996) argues that disabled people are socialised to think of themselves as inferior and are therefore isolated and separated both from each other and from sources of collective strength as they spend most of their time with non-disabled people. Shakespeare (1996) also questions whether disability identity can endure in a world without disabling barriers.

The importance of disability identity has unfortunately been overlooked in the workplace (Santuzzi and Waltz, 2016). Disability identity may vary considerably over time or in different situations (Baldrige and Swift, 2013 and Colella and Stone, 2005) and Santuzzi and Waltz (2016) argue strongly that disability identity is a dynamic concept. They draw on elements which create variability such as intraindividual experiences of impairment, interpersonal interactions, organisational environment, and society level changes. It is argued that the interplay of these elements will influence the decision of employees about disclosing their disability and any accommodations which may be needed.

Interpersonal interactions show that identity construction may be influenced by the views and reactions of other people (Goffman, 1959, Mead, 1934). Therefore, socialisation may have a significant effect on social identity and disability identity (Roccas and Brewer, 2002, Shakespeare, 1996). Because disabled people form a minority in the workplace, they are less likely to adopt a disability identity at work because they are engaged with abled people (LoBianco and Sheppard-Jones, 2007). Another important factor is the observer's perception of different types of impairments and whether these are perceived as legitimate disabilities. Hidden disabilities with low social awareness or perceived legitimacy in the workplace such as dyscalculia (Wadlington and Wadlington, 2008) or attention deficit hyperactive disorder (ADHD) (Patton, 2009, 2019, 2022) may be granted less accommodations by employers. Research shows that concerns about social stigma at the interpersonal level are strong predictors for whether workers with visible or hidden disabilities might present themselves in the workplace (Baldrige and Veiga, 2006, Earnshaw

and Quinn, 2012, Quinn and Earnshaw, 2011). Workers with hidden disabilities such as autism, may have relative success in 'passing' as an employee without a disability, but this is likely to be at high personal cost due to the extra physical or cognitive effort involved, and may affect performance levels (Santuzzi et al 2014). Interpersonal context may also affect the way or extent in which a disability identity develops (Galer, 2012).

The organisational environment can also play a significant part in a person's disability identity. Organisations may contribute to an employee's disabilities due to the environment in the workplace or the way in which work is organised, either directly through poor health and safety, or through exacerbating existing disabilities that were appropriately addressed or mitigated for in other workplaces (Santuzzi and Waltz, 2016). Employers who positively grant accommodation requests by employees tend to demonstrate a positive culture for disabled employees, while those who view disability less favourably may result in employees trying to minimise or cover up their disability identity (Kosciulek, 2007).

Ableism, being the ideas and practices, which presume able-bodiedness, and against which everything is assessed, conveys a collective belief that disability or impairment is a broken version of normality or being fully human (Jaemmers et al, 2016). Foster and Wass (2013) suggest that the disability employment disadvantage is significant, and far more than disadvantage associated with gender, motherhood, lone parenthood, ethnicity, class, or education. Attempts to apply scientific principles to employment (Rose 1988) persist in the modern workplace in the form of job descriptions, person specifications, performance, and payment (Hales, 2001). Researchers have observed how tools such as job evaluation schemes can introduce gendered controls into the workplace (Acker, 1990). Disabling practices and ablest assumptions can also become embedded in organisational processes but have been challenged far less than the gendered processes (Foster and Wass, 2013). Studies have shown that lean production systems exclude disabled workers (Zanoni, 2011), and job descriptions needing multi-tasking and teamwork assume that candidates with an impairment would be unfit to fulfil the requirements (Foster and Wass, 2013). Stereotypes of disabled people as having lower productivity or incompetence can also disadvantage in job selection processes (Heslin et al, 2012). Von Schrader et al (2013) found that disabled workers feel a constant need to disclose their impairment and persuade

both their employers and co-workers that they can be productive members of the workforce.

Accommodations in the workplace may remove or alleviate barriers to employment for disabled workers, but they do not challenge ableism (Kim and Williams, 2012) nor the disabling social organisation of work (Wilton and Schuer, 2006). Ableism builds on the social model of disability, which views disability as the effect of the social structures that oppress and marginalise disabled people (Foster, 2007). Furthermore, Robert and Harlan (2006) found that employers dislike giving accommodations because they are felt to grant 'special privileges' to disabled employees above other employees, and out of proportion to their worth in the organisation.

Ryan (2013) observes that for some autistic people their autism is ontologically linked to their self-identity, and rather than being a 'condition', it is the identity they have (Singer, 1999). A delay in diagnosis could therefore mean that there is a delay in accessing or understanding their identity. Diagnosis can offer autistic people access to support, thereby enabling them, for example, to return to university. Some theorists (Timini et al, 2011 and Runswick-Cole, 2014) question the use of medicalised labels or the use of concepts such as neurodiversity. However other researchers (Beardon and Edmonds, 2007, Milton, 2012, 2014 and Milton and Sims, 2016) argue that lack of understanding of the needs of autistic adults proves a significant challenge. Robertson (2010) states that professionals rarely discuss the social attitudes and norms that provide barriers for autistic people, citing the example of employment where the autistic person is made to adapt and fit the job rather than adapting the context to meet the needs of the autistic adult. Davidson and Orsini (2013) argue that the positive outcome of a 'diagnosis' for many autistic people, enabling an understanding of their own difference, raises questions about the way in which the term 'diagnosis' is most often viewed in a negative way.

Ryan (2013) observes that the struggle to 'fit in' for autistic people is consistent with Goffman's (1959) concept of dramaturgy which encompasses actions associated with front, backstage, setting, audience, performance, performer, and character. A front is the part of the individual's performance that 'defines the situation for those who observe the performance' (Goffman 1959:22). In contrast the backstage is where the individual can

'drop his front' and 'step out of character' (Goffman 1959:112). Fronts can become standardised as the type of performance expected in a given situation. This can result in stereotypical expectations and anyone not following the stereotype, for example an autistic person, or someone from a different culture, would stand out as not following the 'rules'. The links between the concept of dramaturgy and autistic people's experience is also highlighted in Davidson's (2008, 2010) analysis of autistic autobiographical material. The concept of dramaturgy can also be expressed as autistic masking, as an attempt to conceal an autistic identity and to fit into a social group or employment setting. Failure to mask or camouflage your identity, can result in stigma and a stigmatised identity and this is analysed later in the semi-structured interviews carried out with female autistic participants in this study.

3.6 Stigma at Work

Stigma derives from an attribute that is devalued in any context (Goffman, 1963). It can arise from a situation where a disease label is attached to a person, becoming a self-fulfilling prophecy. Having once acquired a disease label, Goffman (1968) described a person as having a spoiled identity. This could then lead to social stigma in the form of enacted stigma, through experiences of discrimination, and felt stigma, where a person's self-identity is affected.

Stigma management in the workplace can be a multifaceted process (Jones and King, 2014). Far from disclosure being a one-off event, workers may conceal, signal, and reveal their stigmas as part of a nuanced process. People with an observable stigma know that others are aware of that identity, while people with an invisible or concealable stigma such as autism may have the choice to decide how much and when other people become aware of that identity (Jones and King, 2014). It may be necessary to reveal a stigmatised identity to gain the benefits available to that social identity group (Roberts, 2005), however, on the other hand, workers with concealable stigmas must weigh up the disclosure dilemmas of each new situation (Ragins and Cornwell, 2001). Pachankis (2007) developed a process model that describes the psychological impact of identity concealment, highlighting aspects of concealable identities, such as the problem of finding other people with the same identity, or finding support, meaning that the stigmatisation might be increased, and have a

consequent impact on anxiety and impression management. Another disclosure process model demonstrates how people may choose whether to disclose a stigmatised identity to receive positive outcomes, or to conceal to avoid negative outcomes. The model's feedback loop suggests that a single disclosure event can affect later disclosure decisions (Chaudoir and Fisher, 2010). Both models relate only to social rather than workplace situations and focus on disclosure as a yes/no decision rather than as part of a longer process of moving from concealment to revealing the stigmatised identity (Jones and King, 2014). Jones and King (2014) further conceptualise identity management as a 'within' and 'between' person phenomenon. Stigma at work can therefore be complex and only a small part of the identity work that is carried out in the workplace.

3.7 Identities and Identity Work within Organisations

The way in which people navigate the relationship between their self-identity and social identity can be particularly fraught in the workplace. Indeed, Fiol et al (2009) predicts that identity-based conflict in the workplace is likely to increase as workplace and role complexity grow over time. Watson (2008) observes that in the workplace people are needed at different times to adopt 'corporate' personas which may be completely different from the one(s) that they adopt at other times, and in other parts of their life. The belief that these 'work orientations' (Goldthorpe et al, 1968) change over time again, challenges the more traditional view that identity is set and changes little over a lifetime. Identity is now seen as the meaning that people attach to themselves reflexively. These meanings might be obtained from interaction and take the form of narratives (Giddens, 1991), dialogues (Beech 2008) or dramaturgical performances (Goffman, 1967). Brown (2015) categorises identity theorising in organisations associated with social cognition (Ashforth and Mael, 1989; Haslam, 2004; Hogg and Terry, 2000), symbolic interaction (Blumer, 1969; Goffman 1959; Levi-Strauss, 1966), post-structuralism and power (Alvesson and Wilmott, 2002; Hall, 1996) and the psychoanalytic work of Lacan (Driver 2009; Harding, 2007) and Freud (Gabriel, 2000; Petriglieri and Stein, 2012).

The process of identity formation within organisations, and particularly the agency that people exercise in conducting agency work is described by Svenningsson and Alvesson (2003:1165) as referring to 'people being engaged in forming, repairing, maintaining,

strengthening, or revising the constructions that are productive of a sense of coherence and distinctiveness'. Watson (2008) has extended this to include an external aspect, arguing that identity work is about seeking to influence the social identities that apply to people in the places in which they operate or live their lives. Brown (2015) highlights that identity work does not just involve narrative or spoken word but also the work that people carry out on their physical appearance and their association with individuals and/or groups in the workplace (Snow and Anderson, 1987), and dramaturgical performances (Down and Reveley, 2009). Additional identity work in the workplace could include stigma management strategies such as trying to appear 'normal' or managing the disclosure of information (Goffman, 1963).

Identity work can have a significant impact on the worker's life in the workplace, affecting decision-making (Alvesson and Willmott, 2002), careers (Ibarra and Barbulescu, 2010), socialisation (Ibarra 1999), and engaging in entrepreneurship (Fauchart and Gruber, 2011). In fact, Brown (2015) argues that there is a body of evidence to suggest that identities and identity work is connected to nearly every topic in organisation and management studies. One particularly contested area is the identity work that takes place daily in organisations. Giddens (1991) believes that this is automatic and instinctive, and Alvesson and Willmott (2002) describe it as effortless. Beech (2011) and Gergen (1991; cited in Brown, 2015) attach more importance to this daily struggle where the individual treads a fine line between a context specific or desired self. Considerable research has also been undertaken on the identity work that takes place when a worker moves into a new organisation (Beyer and Hannah, 2002), new role (Ibarra, 1999), experiences identity threat (Collinson, 2003; Petriglieri, 2011) or experiences bullying at work (Kaufman and Johnson, 2004).

An important element of social identity is that of roles within groups, and these can be important in describing behaviours. Organisational psychology research suggests that in the workplace people identify more strongly with their work group within the organisation, than the organisation itself (Pratt, 1998). Roles within groups acquire status through the extent to which the person occupying that role has the necessary skills or behaviours necessary to

the group's purpose (specific status characteristics) and from the occupant's social status outside the group (diffuse status characteristics) (Ridgeway 2001).

Within a workplace, groups can sometimes be more polarised and more confrontational if there is no attempt to ensure demographic diversity. Subgroups will fight attempts by a higher-ranking group to subsume or merge it. Hogg (2003) notes that because subgroup members obtain their social identity from their group membership, they then view any externally imposed merger as a strong identity threat. However, at the same time in very large organisations people strive more for distinctiveness, perhaps by identifying with smaller units within the organisation.

Brown (2015) argues that in the ongoing debate about how identities might be theorized, there are five themes to which 'identity work' is key. These are the extent to which identities are chosen or given to individuals; can be considered stable, adaptive, or fluid; can be considered cohesive and coherent or fragmented and in conflict; motivated or not by a desire for positive meaning; and framed or not by the desire for authenticity. Brown (2015) further argues that identities are the effect of identity work that takes place in the space between domination and resistance (Mumby, 1997; Trethewey, 1999). Identities therefore arise in a constant struggle between structure and agency and much of the classic organisational sociology literature would appear to support this (Mills, 1956; Whyte, 1956).

Whereas some researchers believe that people in the workplace need a stable understanding of themselves to function (Ashforth and Kreiner, 1999), others support the need for flexibility allowing a dynamic response to changing situations (Markus and Nurius, 1986). Pratt et al (2006) identifies an evolutionary process of adaptation that takes place during career development and promotion. Brown (2015) states that research suggests that identity adaptation is measured, occurs incrementally, but involves considerable work. This gradualist view is backed by research on professional groups such as nurses (Currie et al 2010), police (Thomas and Davies, 2005) and hospital clinicians (Doolin, 2002).

Alongside the complex and often controversial views on whether selves can be described as unified and coherent, or fragmented and contradictory (Brown, 2015), there are multiple

views that describe identities as very rarely fully coherent (Nkomo and Cox, 1998), or including ambiguity (Beech, 2008). Role identity conflict, between organisations and professionals or work and non-work identities, and the ability of people to be reflexive have been discussed by Ashforth et al (2008), and a further body of literature highlights the way identity stories are challenged or denied by others (Roberts, 2005), as well as the way in which contradictory identities are created (Humphreys and Brown, 2002).

People's identity work is generated by a desire for a positive meaning or to promote a favourable self-view in the workplace (Gecas, 1982; Roberts et al, 2009). Unsurprisingly this is also a motivation for people who may have a stigmatised identity (Goffman, 1963), who will also work to change other people's perceptions of them, and seek self-evaluation criteria that favours them (Hogg, 2011; Tajfel and Turner, 1986). Some workers may also be consumed with self-doubt in the workplace and their need for validation becomes the central focus of their identity work (Collinson, 2003). Gabriel (2012) has coined the concept of 'miasma' to analyse how workers may regard themselves with a sense of loss and inadequacy to the point where they lose their confidence and self-esteem.

Many studies have shown how people believe that they have an inner 'authentic' core, or that they must be 'true' to themselves, and their 'preferred' identities (e.g. Brown, 2015). Where inconsistencies occur in people's search for authenticity, they may undertake identity work to suppress their personal values (Roberts, 2005). However, in contrast Kornberger and Brown (2007) argue that identities are constructed in situ and even though some identities are favoured more than others, the notion of authenticity or inauthenticity is obsolete.

Whilst seeing the potential for identity conflict where a worker tries to balance personal, relational, and collective interests in the workplace, Horton et al (2014) observed that internal and external changes were critical in creating conflict or bringing existing conflict to the fore. This was also the case with organisational level changes, although slow processes of organisational change could result in significant divergence and dissociation of identity over time (Drori et al, 2009). However, organisational change could also stimulate change management processes designed to better align the organisation with the individual (Horton et al, 2014). Ultimately identity conflict may also cause the worker to consider

current and future work goals and therefore be a stimulus to career change (Strauss et al, 2012). Identity work and stigma in the workplace are therefore important elements to whether a person has a successful and happy career, but this can be even more critical and multi layered to an autistic person, particularly before receiving a diagnosis and being able to resolve their identity.

3.8 Autism, identity and stigma

Returning to specific discussion on autistic identity, Pearson and Rose (2023) argue that there is minimal literature on autistic social identity due to conceptualisations of autistic people as mindblind, socially unmotivated or lacking the cognitive skills to be self-aware. Autism can contribute to both a personal identity, where the person views themselves as autistic having received a diagnosis, or having characteristics associated with autism, and a social identity, where the autistic person considers they are a part of an autistic community (Tajfel & Turner, 1986 & Pearson et al, 2023). Autistic personal identity, however, can also be shaped by an outsider's views and conceptualisations of autism and whether you fit with what is 'normal' for an autistic person. In this respect autistic people also face an 'epistemic struggle' to understand their own experiences in the face of other people's conceptualisations about what autistic people should be (Bertilsdotter Rosqvist & Jackson-Perry, 2021). It is argued that autistic people's first-hand accounts can be tainted by this outside constructed lens and framing (epistemic infection) (Pearson and Rose op cit).

Autistic masking (or camouflaging) is the conscious or unconscious suppression of natural responses, behaviours, and movement, and is the term adopted by the autistic community for the identity work they carry out to 'conceal' their autistic self (Pearson & Rose, 2021). Stigma impacts both on how individuals are viewed as well as their treatment by others. However, it also impacts on how that treatment is internalised and how that impacts and interacts with your identity (Pearson & Rose op cit). Earlier in this chapter it was explained how stigmatised people attempt to conceal 'spoiled' aspects of their personality in an attempt to 'pass' as normal (Goffmann, 1963) and autistic masking would appear to be an indicator that autistic people, because of their pathologized status, are attempting to carry out impression management and manage their stigma. This process of identity management and masking appears to be intrinsically interlinked for autistic people (Schneid

& Raz, 2020). It is known for example that autistic people are more likely to experience traumatic life experiences including victimisation and bullying (Griffiths et al, 2019; Lung et al, 2019). Cage and Troxell-Whitman (2019) have specifically looked at stigmatised identity and masking using Disconnect Theory. They found that autistic adults reported carrying out masking across a range of contexts such as the workplace, and in their relationships. Those who described using higher levels of masking or switching between masking/not masking, reported higher levels of stress. This is consistent with the concept that disconnection from your identity causes psychological distress.

Autistic people are also often presented in autism research in a way that is dehumanising, and media representations are often stereotypes (Jones et al, 2023). Recent TV programmes claiming to depict 'autistic women' also seem to employ lazy stereotypes. For example, the Saga Noren character in *The Bridge* is a high-ranking skilled detective but is portrayed as a robotic, sex crazed individual with little social skills. Similarly, the main character in *Astrid – Murder in Paris*, is also a woman highly valued for her ability to think differently and interpret evidence, but is portrayed as a robotic, rules driven individual. Given the largely negative depictions of autistic women in the media, it is perhaps not surprising that autistic women may feel stigmatised and may disconnect from their identity and seek to mask across a range of settings, including the workplace, which in turn can have a significant effect on their psychological wellbeing.

3.9 Impact of masking and stigma

Autistic women, and autistic gender diverse individuals, including transgender autistic people are at greater risk, relative to cisgender autistic males, for depression, anxiety and suicidality (McQuaid et al, 2022). However, having a positive autism identity predicted higher psychological well-being and lower social anxiety (Cooper et al, 2023) and being provided with post-diagnostic support can help autistic people to navigate their emerging identity. However, research suggests that autistic people experience stressors at a much higher rate than the general population (Pearson & Rose, 2023). Autistic trauma is much more multifaceted due to having been dehumanised and pathologised, ability/inability to access social participation, and the extent to which sensory differences are considered. It is therefore no surprise that autistic people experience a higher likelihood of Post Traumatic

Stress Disorder (PTSD) and complex PTSD (c-PTSD). Autistic trauma can exist because of generational trauma, sensory processing, interpersonal victimisation (IPV), invalidation/pathologisation, emotional experiences, behavioural interventions, and the result of educational and well-being practices (Pearson & Rose, 2023).

Autistic people regularly report an experience described by them as autistic burnout, and this is usually linked to the process of masking and the exhausting experience of keeping this up (Higgins et al, 2021). There is little academic research on this phenomenon from an autistic perspective, and existing general research on 'burnout' without an autistic context is focused on the workplace (Higgins et al op cit), whereas the key drivers of autistic burnout are seen to be the result of masking and the stress of living in an unaccommodating neurotypical world (Mandy, 2019). Only two studies have attempted to provide a definition of autistic burnout. The first of these (Raymaker et al, 2020:133) was produced using thematic analysis and a community-based participatory research approach and defined autistic burnout as "a syndrome conceptualised as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterised by pervasive, long-term (typically 3+ months) exhaustion, loss of function and reduced tolerance to stimulus". The second definition, (Higgins et al, 2021:01) used a Grounded Delphi methodology, coproduced with autistic and non-autistic researchers, and aimed to develop a consensus definition for clinical and research purposes that differentiated from non-autistic burnout and depression (which autistic burnout is often misdiagnosed as). This definition describes autistic burnout as "a condition involving exhaustion, withdrawal, problems with thinking, reduced daily living skills and increases in the manifestation of autistic traits" and warns that psychological treatments for depression may potentially make autistic burnout worse. Another way in which autistic people may 'manage' their behaviour or mask in social settings is the use of self-medication (Weir et al, 2021b), making them feel relaxed and able to socialise more easily.

3.10 Conclusion

This chapter was the second of the two chapters of literature review and has examined identity, stigma and masking, and critically, what are the specific issues around identity, stigma and masking that autistic people face getting into the workplace and thriving there.

First the chapter considered Mead's concept of the self (1934), and the way in which we build an understanding of our self by engaging and observing others. Second, social identity theory was outlined (Tajfel 1959, Abrams and Hogg, 1990), and the way in which we become aware of the social groups in which we are engaged, and the value attached to those group memberships. Self-categorisation theory (Hogg, 2011) built on that concept and it was argued that within groups some people are more prototypical or valued than others. The view that people have multiple selves, reflecting the different positions they occupy, was also mirrored in the concept of intersectionality (Corlett and Mavin, 2014). The chapter then considered disability identity and the way in which disabled people can be socialised to think of themselves as inferior, leaving them isolated in the workplace (Santuzzi et al, 2014). Despite this it was found that many autistic people viewed their autism as intrinsically part of their identity but that they masked this to fit in (Ryan, 2013), and to avoid stigma. The chapter also pointed to the minimal literature on autistic social identity (Pearson and Rose, 2023), mainly due to outside conceptualisations of autistic people as socially unmotivated, and as well as facing discrimination and stigma in the workplace, autistic people's identity could also be spoiled by having the 'wrong' kind of autism and not fitting allistic people's view of what was 'normal' for an autistic person (Bertilsson Rosqvist & Jackson-Perry, 2021). Stigmatised people will work to change other people's behaviour towards them in the workplace and in the case of autistic women there is considerable evidence of masking activity to conceal their autistic identity. This can cause autistic burnout and Post Traumatic Stress Disorder (Higgins et al, 2021).

This chapter linked the theorisation of critical autism and disability with identity, stigma, and the concept of autistic masking. This is because identity and stigma arose as issues highlighted by the female autistic participants in the semi structured interviews in the study. Without a self-diagnosis or autism diagnosis, autistic women are likely to experience stigma at the hands of workplace colleagues and/or managers, but without an understanding of what they are being stigmatised for. With a diagnosis they have some legal protections as a disabled person within the terms of the Autism Act 2009, the Equality Act 2010 and the United Nations Convention on the Rights of Persons with Disabilities.

The next chapter provides the rationale for the empirical research carried out in this study, and outlines the methodology used, where the focus on the workplace and the worklife histories of the autistic women has influenced a qualitative methodology, utilising semi-structured oral history interviews.

Chapter 4: Methodology

4.1 Introduction

In the last chapter, the second of two literature reviews, identity, stigma and masking were considered, concluding with specific consideration of the identity management, stigma and masking that autistic people face to get into the workplace and thrive there.

This chapter now provides the rationale for undertaking empirical research, outlining the methodology and methods utilised in data collection and data analysis and the qualitative approach taken by the researcher. The epistemological orientation is identified as interpretivist and the ontological position as a relativist one of social constructivism.

First the chapter discusses the research strategy adopted, utilising the research onion to explain the decisions taken, and aligns the study with the priorities for research requested by the autistic community. The study then outlines the approach taken to the literature review, discussing the search strategy, key words, and the need for a generalised literature review of disability and employment due to the gap in literature at the intersection of women, autism and employment. This chapter also discusses the research settings, the process for ethical approval, and the use of gatekeepers to advertise for participants. The chapter then looks at the recruitment survey design, launch, and at the decision to limit participants to the United Kingdom and the sampling frame and sample size. The chapter then details the data collection process using an oral history semi-structured interview approach either face to face, on Skype, the telephone or via email. The drafting of the interview schedule, influenced by the initial literature review, as well as the research questions which were also influenced by the pilot interview are then discussed. The chapter contains a lengthy discussion about the selection of reflexive thematic analysis as the approach for the data analysis, and works through all six stages of the process, including identifying the three themes created that form the next three chapters – chaos or control, wearing a mask, and lost in translation. Finally, the chapter discusses research ethics, outlining the University's ethics procedure, but also the researchers approach to align the research to the guidelines for conducting research studies with the autism community.

therefore been an interpretivist approach that could be considered highly appropriate to an understanding of the lived experience of autism given that autism may be considered as a construct that is interpreted differently by various researchers, and autistic or allistic people.

The ontological position adopted in the research is a relativist one of social constructivism. King et al (2019) assert that qualitative interviewing utilises the constructive nature of social interaction and the way in which participants play an active part in making sense of their experiences. This can lead to a rich negotiation of meaning between researcher and interviewee, and this is enabled in this research by the shared gender and neurotype of researcher and participants. The researcher occupies a special position within the methodology as a late diagnosed autistic woman and therefore a participant researcher. The researcher draws on a reflexive understanding of their own position as an autistic female, and a deep reflexive understanding of the research subjects due to a shared gender and neurotype. As a social constructionist the researcher has aimed to produce what Burr (2015) describes as a democratised research relationship, being a co-production of research between participants and the researcher. This is particularly evident in the selection of the research area, which is reflected as one of the priorities for research by the autistic community (Pellicano et al, 2014). As a social constructionist the research setting has provided the opportunity for the negotiation of meaning between researcher and participants. An example of how this extended to the choice of specific methods used is the decision to use individual semi-structured interviews rather than using focus groups to generate themes. This is because the researcher, as an autistic woman, has found group discussions difficult to follow and process quickly, and therefore a choice was made to identify an approach which allowed the researcher to actively listen to the participant and helped to made the participant comfortable (this also accords with the guidelines for conducting research with the autism community discussed in research ethics (Gowen et al, 2019)). An allistic interviewer may not have demonstrated this understanding and may have selected a methodology which gave the interviewer the greatest comfort, but which did not take account of the preferences of the autistic participants. Saunders et al (2019) suggest that the *approach* taken to theory development can be implied by the research philosophy, and in this study the approach taken is inductive, utilising an iterative process where

observations and findings generate further exploration of the theory generated. An example of this in this study is that the initial literature review of autism and employment, combined with initial interviews generated a further literature review of identity.

4.3 Literature Review

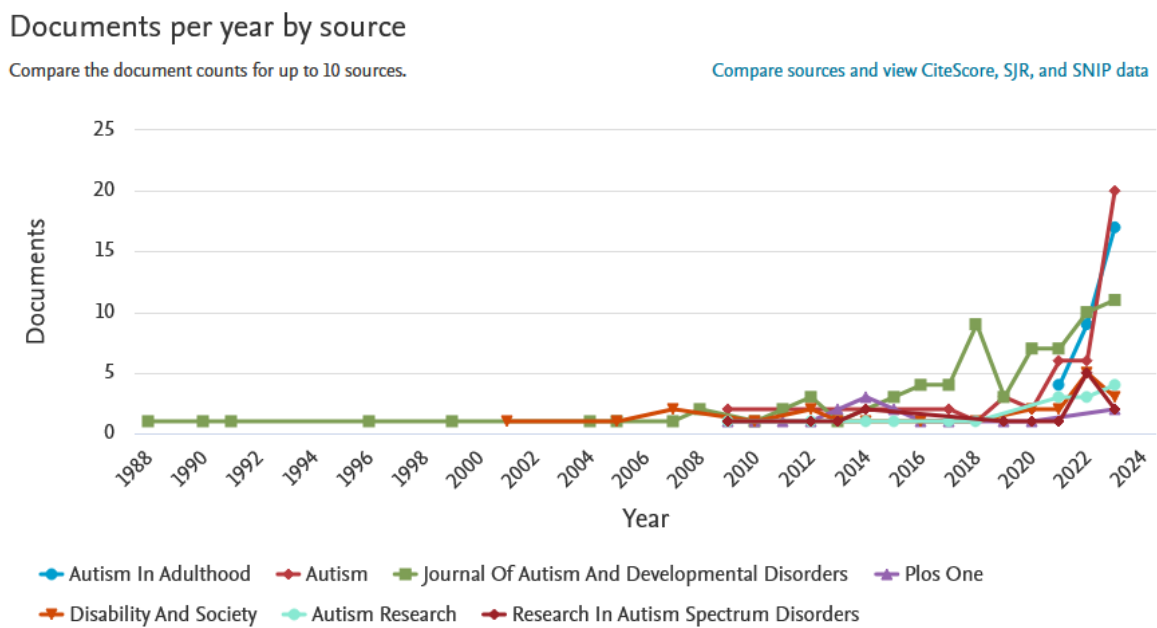
Kumar (2014) observes that the literature review is an integral part of the research process and informs every step taken. Taking an interpretivist approach the literature review was critical to gaining an overview of the research area whilst recognising that this was an uncertain process of discovery which could lead in different directions (Bryman, 2016). The literature review approach adopted followed a narrative approach rather than a systematic review which is normally considered as a replicable, transparent and in-depth process (Tranfield et al, 2003). From a starting point of the research question “what are the worklife experiences of autistic women?” a search was carried out across all EBSCOhost databases using the Boolean/Phrase search (autis* OR asperger*) AND (wom* OR female*) AND (work* OR employ*) NOT working memory which generated 1,644 scholarly texts. Excluding the subject term “male” produced only 314 results where women were the focus of the article. A literature search using ‘Google Scholar’ returned only 501 results using the search terms employment OR work AND autism OR autistic OR Asperger OR ASD. None of the results contained female or wom* in the title, however only one article contained the term male, meaning that the articles took a generalised, non-gender-based approach. Due to the apparent gap in the literature at the intersection of women, autism, and employment it was necessary to widen the search terms to look at more generalised literature about disability and employment.

An effective literature search should continue throughout the study period and the researcher initially signed up to the Zetoc alert service through the British Library to receive updates on new journal articles. Whilst highly effective, the service ceased in 2022. An alert was also created for Google Scholar articles with the search terms autism and employment and asperger and employment. Alongside this approach the social media platform X previously known as Twitter was used to track emerging literature and conferences.

At the point of data collection (Saunders stage of *techniques and procedures*) the researcher observed that identity was an empirical detail found throughout the experiences of late diagnosed women in the study.

A second narrative literature review was carried out from the starting point of the research question “how do autistic women resolve their identities in the workplace?”. A search was carried out on SCOPUS using the Boolean/Phrase search (autis* OR asperger*) AND identity in the title, abstract or key word which generated 999 scholarly articles only in the period 1968-2023. Figure 4.2 shows the very recent increase in articles on autism and identity shown here in the main autism and disability journals.

Figure 4.2: Main Autism Journal Articles containing Identity in the Title, Abstract or Key Word by Year



Source: Elsevier (2023)

4.4 Research Settings

The first phase of data collection followed the initial review of literature on autism and disability and an application made to the Social Sciences, Arts and Humanities Ethics Committee of the University of Hertfordshire for ethical approval for a study involving human participants. Before approval was granted the researcher was asked to provide assurances that it would be possible to recruit sufficient participants for the research. The researcher obtained permission and assurances from Research Autism and the National Autistic Society who agreed to publicise the research call on their websites. Access to both organisations was obtained through one 'gatekeeper' (King et al, 2019) acting for both organisations. The ethics approval is attached in Appendix A and the email correspondence about recruitment of participants is shown in Appendix B, which contains the text provided for the website about the research.

Once ethics approval was obtained the researcher's supervisors recommended setting up the recruitment questionnaire on the Bristol Online Survey platform (now known as Jisc Online Surveys) to act as recruitment for the research (see Appendix C). The Bristol Online Survey self-completed questionnaire was designed to capture the contact and demographic details of autistic women who wished to contribute to the research (see Appendix C). The researcher was experienced in a variety of consultation techniques having managed the consultation function within several large local authorities, which also involved working alongside external contractors such as Ipsos MORI, CACI and BMG Research to pilot and run large consultation exercises, as well as running small consultation exercises in-house. The researcher carefully designed the recruitment questionnaire to ensure that information was captured to provide consent, information about their autism diagnosis or self-diagnosis, age (in a range), highest education attainment, qualifications, employment status, type of organisation worked at (or previously worked at), and whether they had been a manager or supervisor. Participants were also asked for their name, address, email address, and telephone number to facilitate follow up contact. The full question descriptions and response options are shown in Table 4.3. The age bands, qualification options, employment options, and organisation option responses were selected to mirror those used in the Labour Force Survey (ONS, 2013) to ensure relevance and robustness. The recruitment survey was shared by the researcher with the supervisors and signed off for distribution.

Table 4.3: Information sought in the recruitment questionnaire

Question	Response Options
Do you agree to be interviewed for this research	Yes/No
What is your age?	18-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75 years or over
Have you received an Asperger Syndrome 'diagnosis' or have you self-diagnosed/self-identified with Asperger Syndrome?	Self-diagnosis/Self-identify with Asperger Syndrome Received a 'diagnosis' from a professional
How old were you when you received your diagnosis or first self-identified with Asperger Syndrome?	Under 12 years old, 12-17, 18-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75 years or over
What is the highest qualification you have received?	University Higher Degree (e.g. MSc, PhD) First degree level qualification including foundation degrees, graduate membership of a professional Institute, PGCE Diploma in higher education Teaching qualification (excluding PGCE) Nursing or other medical qualification not yet mentioned A Level Welsh Baccalaureate International Baccalaureate AS Level Higher Grade/Advanced Higher (Scotland) Certificate of Sixth Year Studies GCSE/O Level CSE Standard/Ordinary O Grade/Lower (Scotland) Other School (including school leaving certificate or matriculation None of the above Other

Table 4.3: Information sought in the recruitment questionnaire

Question	Response Options
Which of the following qualifications or vocational qualifications do you have?	Youth Training Certificate Key Skills Basic Skills Entry Level Qualifications (Wales) Modern Apprenticeship/Trade Apprenticeship RSA/OCR/Clerical and Commercial Qualifications City and Guilds Certificate GNVQ/GSVQ NVQ/SVQ Level 1-2 NVQ/SVQ Level 3-5 HNC/HND ONC/OND BTEC/BEC/TEC/EdExcel/LQL SCOTVEC, SCOTEC or SCOTBEC Other vocational, technical, or professional qualification None of the above Other
Are you currently?	Employed full time for wages Employed part time for wages Self-employed An unpaid volunteer Out of work and looking for work Out of work but 'not' currently looking for work A homemaker A student Retired Unable to work Other
If you do not currently work have you worked in the past?	Yes/No
What type of organisation do you work for, or if not currently working, your last employer?	Self-employed/your own company Private firm/company/plc Civil service or central government Local government (inc local education, fire & police) National Health Service or Higher Education Voluntary sector Other
Do you have, or have you had, any managerial or supervisory experience?	Manager Supervisor/team leader Not manager or supervisor
Your name	
Your address	
Your email address	
Your telephone number	

The questionnaire link was advertised on the research pages of the National Autistic Society, Research Autism, and sent to the Disability Research Jisc email distribution list, and list members encouraged to share to their own networks. The recruitment questionnaire link was also shared through social media outlets where autistic women might be found such as Facebook, Twitter, and online autistic communities such as 'Wrong Planet'. The National Autistic Society are the principal charity supporting autistic children and adults and their families and they maintain a page of links of research studies with appropriate ethics clearance. Autistic people and their families and carers are invited to respond to the study calls if they wish. Research Autism, another of the distributors, was an independent charity that provided information on autism interventions and evidence-based research but has since been incorporated into the remit of the National Autistic Society. The dissemination of the link to these groups ensured that it was reaching the target audience, and research suggests that autistic people in particular use social media as supportive communities (Zhao et al, 2019). One drawback to this approach is the observation by Rødgaard et al (2022) that autism studies sampled through online (social media) channels are at risk of sampling bias, including a reversed sex ratio (more women than men), higher education levels, less participants with an intellectual disability and a later age of diagnosis compared to samples from a population study. However, for this study the researcher's specific aim was to reach autistic women who had something to say about their worklife experiences. Another issue not initially considered, was the worldwide nature of recruitment by social media. The questionnaire link was opened on 11 March 2014 on the Bristol Online Survey platform (now known as Jisc Online Surveys) and closed in 2018. The link very quickly gathered 153 potential participants, but a significant number of responses were from international participants due to the social media outlets that had publicised the research. This potentially raised challenges in carrying out the interviews, but more specifically produced challenges to analysis where there may be different international or cultural experiences of employment or seeking employment. It was also considered by the researcher that this might affect the ability to generate policy findings from the data across different social, cultural, and economic settings. It was therefore decided at this point to limit the research to United Kingdom participants only.

To practise ethical research and to build trust between researcher and participants it was made clear to participants on being invited to an interview that the researcher was a late diagnosed autistic woman. This, together with the employment focus of the research, appeared to put participants at ease and build trust between prospective participants and the researcher. Recent research looking at autistic people's priorities for research (Pellicano et al, 2014) has found that autistic people want research to focus on issues having an impact on their lived experiences with a view to influencing significant change. Three sub-themes have emerged from this research - services and supports, knowledge about autism and research logistics. Under services and supports, autistic adults and parents of autistic children identified employment as a priority area for research. However, despite this 64% of UK grant funding is still focused on biomedical autism research, i.e. causes and genetic factors with only 1% on services (OARC, 2019).

4.5 Data Collection

Having generated a list of 86 potential UK women participants from the recruitment questionnaire data these were sampled using a systematic sampling technique by selecting every other participant and emailing them offering them a face to face, telephone or Skype interview, or emailed questionnaire, according to their preference. At this point some women declined interview, but the remaining were contacted resulting in 35 participants interviewed for the research, 15 of which were conducted either face to face in person, or by Skype or telephone. 20 participants opted to complete emailed questions. This flexibility took account of the needs and preferences of participants who could therefore contribute to the research without having to self-fund and travel long distances. Participants were sent the participant information sheet and consent form by email, with a request for a suitable date and time. Follow up emails were sent as a reminder if required.

The Skype, telephone, and face to face interviews were recorded on an Olympus digital voice recorder and these were fully transcribed by the researcher using a foot pedal into Microsoft Word. Care was taken to ensure familiarity with the recording equipment, and for each interview there was a check at the start that the recorder was recording sound correctly.

All the interview collection methods had different benefits or challenges. An initial face to face interview in person was conducted and enabled a multilevel rapport to be built. The venue for the interview was sourced through a call out on Twitter for a quiet room in London. This produced a private meeting room in Central London free of charge which was utilised. The initial face to face interview also enabled the interview questions to be trialled, and then tweaked and refined before rolling out across the remaining interviews. This refinement continued throughout the research.

The remaining participants were either interviewed on the telephone or via Skype, or via email. Some Skype interviewees asked for an audio feed only and did not want to be seen on the screen. There were some technical issues due to broadband reception, but the main problem encountered was a noisy fan on the laptop used that caused problems later when listening to the recording and transcribing the interview. Phone interviews were carried out in quiet rooms where the phone was put on loudspeaker in order that the conversation could be recorded. In these cases, the interviewee was informed that the researcher was in a private room and that the phone would be on loudspeaker to enable the conversation to be recorded.

In the case of the email interviews the researcher initially emailed the list of questions, but this meant that some responses were quite brief and did not go into the type of depth that was evident in the telephone or Skype interviews. This meant having to go back to these participants with supplementary questions to ask them to provide more detail. Subsequent emailed questions were therefore sent with half page text box areas in which the interviewee was encouraged to write or type responses. This encouraged participants to 'fill the box' and therefore subsequent emailed responses contained much more detail. A few women initially volunteered for an email interview but felt that the questions sent required more detail and time commitment than they were prepared for.

Each participant who volunteered to be interviewed was sent an ethics consent form and information sheet (Appendix B) and an email explaining the background to the research. In this email it was explained that the female researcher was a parent to an autistic man with an Asperger's diagnosis and that the researcher had also received an Asperger's diagnosis. Interview recordings were immediately transferred to the University's servers. Interview

recordings, completed interview questionnaires and interview transcriptions, together with ethics forms were kept securely on the University's servers which were regularly backed up, password protected and were not accessible to anyone except the researcher.

In reflection, in the case of any future research, the researcher would examine the option to interview people by Zoom or Teams, which post-Covid, many people have become more familiar with, and which now provides much higher quality sound and vision, plus the opportunity to use the chat function, providing another method in which to capture responses to interview questions in real time if the interviewee does not want to talk. This chat function would also allow for follow up questions to be asked in real time, rather than the more static form-based method of question and answers. It is also now possible to utilise the captions and note taking function on Zoom to enable some short cuts to help with transcription.

4.6 Semi-structured oral history interviews

The method chosen to collect primary source data for the study was semi-structured oral history interviews. Kumar (2014) describes oral history as a method of data collection synonymous with the study of people's perceptions and experiences of events or gathering of historical knowledge viewed by individuals. The focus on the individual participant and their interpretations of their experiences is key, or as Ritchie (2014:1) describes this "memory is the core of oral history, from which meaning can be extracted and preserved ... through recorded interviews". A decision was made at the start of the research to collect oral history testimony about autistic women's working lives, because it was anticipated that this would provide rich and detailed data providing first person lived experiences of the autistic women rather than third party (and probably neurotypical) interpretations of their working lives. The researcher had previously undertaken an oral history interviewing training course with the Oral History Society in the 1990s and refreshed this training through involvement with the University of Hertfordshire Oral History Group, and therefore was experienced in conducting oral history interviews and transcription.

The choice of the oral history interview technique was also informed by the knowledge that it was considered appropriate for providing a holistic understanding of lived experience,

connects biographical experiences with the social or historical context, can provide a comprehensive understanding, bearing witness and filling in the historical record, collaboration in the meaning-making process, and focuses on the participants' perspectives (Leavy, 2011:15-21) (see Table 4.4 which includes additional analysis relating to this study).

Table 4.4: Choice of the oral history interview technique (created from Leavy, 2011:15-21 with additional author analysis)

Tapping into processes	Oral history interviewing can be used to provide holistic understandings of life experiences. Here the focus is on worklife experiences.
Micro-macro linkages	Oral history interviewing can connect biographical experiences with the social/historical context. Here the focus is on the developing understanding of autism and the lived experiences of autistic people and equality legislation.
Comprehensive understanding	Oral history seeks comprehensive or holistic understanding. Here the focus is on developing an understanding across a range of 35 interviews with autistic women and includes their identity work in the workplace and in other realms.
Bearing witness and filling in the historical record	There are relatively few qualitative research studies focused on autistic women and the workplace.
Collaboration in the meaning-making process	The interviewer and participant collaborate to produce the interview transcript through their involvement in the interview.
Focusing on the participants' perspectives	The data collection process highlights the participants perspectives. Here the participants are experts in their knowledge and experience and have a hand in shaping the form and content of interviews.

Interviewers can run the risk of adopting either a very rigid interview structure where the participant responds very briefly to topics or questions, or a very free structure more like a conversation around a topic of mutual interest (Thompson, 2017). Mindful not to fall into either of these, an interview schedule was designed, and open, simple, and straightforward questions were drafted following the advice of Lofland (2006) to consider what was puzzling about the question and whether each interview question would help answer the research questions (Clark et al, 2021). In drawing up the interview guide care was also taken to consider the nine different categories of question suggested by Kvale (1996), being introductory questions, follow-up questions, probing questions, specifying questions, direct questions, indirect questions, structuring questions, silence, interpreting questions. Whilst some of these did not feature in the interview guide, they did feature in interviews. An

example of this is silence and interpreting questions where clarity was sought. The questions were therefore revised after each interview in the light of how easily they were understood, and what responses they elicited. The interview schedule is set out in Appendix D.

The focus of the interview schedule was to ensure that participants were enabled to share their worklife experiences in their own words, and an oral history interview format was initially followed. The interview schedule underwent changes and amendments following the initial pilot interview, and throughout the interviewing schedule. Particular attention was paid to ensuring questions were open and not closed format, however the free form nature of oral history interviewing where the interviewer would typically start with an open-ended question such as 'Tell me how you got to where you are today' was too vague and open to misinterpretation by the autistic participants. This was changed to a much more direct 'can you tell me about your first job' as an introductory question, with further questions asked to develop an overview of their work history and an understanding of their worklife experiences.

Funding was not available for transcribing the interview data and these were all transcribed verbatim in full. The researcher's early career as an audio typist was essential to facilitating the transcription which was completed using a foot pedal and typed into Microsoft Word. All the participants were anonymised and assigned a new name before storage of the transcriptions. The key to the participants original and assigned identity was also password protected and stored on the University servers.

4.7 Research Questions

Braun and Clarke (2013) advise that whilst the research topic and research questions are closely related, the topic is often much broader. In the case of this study the broad topic is an exploration of the worklife experiences of autistic women, which a review of the literature has revealed there is little existing knowledge about.

The topic therefore closely fits guidelines (Gough et al, 2003) that qualitative research questions should have social relevance and originality. The broad research topic was broken

down following the initial literature review and the pilot interview and expressed (Table 4.5) as:

- 1) What jobs do autistic women do?
- 2) How do autistic women resolve their identity in the workplace?
- 3) What challenges do autistic women face in the workplace?

Table 4.5: Research Question and Research Objective	
Research Question	Research Objective
What jobs do autistic women do?	To determine the types of jobs that autistic women carry out
How do autistic women resolve their identity in the workplace?	To understand to what extent autistic women mask their identity in the workplace
What challenges do autistic women face in the workplace?	To identify the challenges that autistic women face in the work environment

4.8 Information Power

Determining the sample size required in qualitative research appears to be a contentious area (Vasileious et al, 2018) with Bekele and Ago (2022) offering advice to novice researchers to consider the composition of the sample, scope of the study, nature of the study, quality of data and research design. Creswell & Creswell (2018) recommend ranges between 5 and 25 interviews for a phenomenological study and 20-30 for grounded theory. This study explores the heterogeneity of the autistic women’s experiences and the researcher therefore decided to interview 35 autistic women in depth which has generated rich content with which to work. In contrast a recent study looking at late diagnosed autistic adults, using oral history methodology sought to interview 24 adults in a range of genders (Pellicano et al, 2020).

An alternative approach to sample size and ‘saturation’ is to look at information power, a model developed by Malterud et al (2016) for determining the size of a sample for a qualitative project. This mode uses five interconnecting aspects to help decide whether a smaller or larger database is required. These aspects are research aims, specificity of the ‘sample’, the theoretical approach taken, the quality of the data, and the analytic approach. The larger information power the sample holds, the lower N is needed, and vice versa.

Table 4.6 shows a description of each information power item and the researcher's evaluation.

Table 4.6: Sample Size in Qualitative Interview Studies: Guided by Information Power – an analysis of this research		
Information Power Dimension	Explanation	Researcher analysis
Study aim	A broad study aim requires a larger sample than a narrow aim.	This study has a narrow aim to explore the worklife experiences of autistic women
Sample specificity	A less extensive sample is required with participants holding characteristics they are highly specific for the study aim compared with a sample of participants of sparse specificity	Sample specificity has been supported by wide recruitment of participants, accepting participants with a diagnosis or self-identifying, and with experience of seeking work as well as in work experience.
Use of established theory	A study supported by limited theoretical perspectives would require a larger sample than one where there was a wealth of theoretical frameworks to work with	With multiple theoretical frameworks relating to autism and identity there is an opportunity for new insight and there is an expectation that the information power of the research will be enhanced.
Quality of dialogue	Studies with clear and strong communication between researcher and participants will require fewer participants for sufficient information power.	The female autistic researcher is a participant researcher, able to communicate with other female autistic participants, and is a confident oral history interviewer and therefore the information power is increased.
Analysis strategy	Exploratory cross-case analysis would require more participants for information power than a project with in-depth analysis from a few participants.	The researcher is guided by reflexive thematic analysis which can be applied to a variety of qualitative data strategies.
Adapted from Malterud et al (2016) with author analysis		

Social constructivist research tends not to support the view that qualitative studies comprise an 'total' amount of facts (Alvesson & Skoldberg, 2009) and anyway 'saturation' is often subjective when one researcher may feel there is little new to learn, but another is still seeking new information (Malterud, 2012). Table 4.6 therefore demonstrates the researcher's analysis of sample size using information power, from which it could be

concluded that the sample could probably have been reduced, maybe to as little as 25-30 in depth interviews.

4.9 Reflexive Thematic Analysis

The researcher used reflexive thematic analysis (RTA) (Braun and Clarke, 2022) to analyse the qualitative semi-structured oral history interviews about worklife experiences. Reflexive thematic analysis is one of several varied approaches to conducting thematic analysis and its point of difference is the way in which the researcher's active role in knowledge production is key (Braun and Clarke, 2019). One aspect of reflexive thematic analysis is the understanding that no two researchers will code in the same way, and therefore there cannot be a perfect or 'accurate' set of codes waiting to be produced from the dataset. Braun and Clarke (2022) expand on this by stating that themes do not emerge from the data themselves and must be created in an active process by the researcher.

The reflexive thematic analysis process also allows for the researcher to begin analysis using an inductive approach free from any pre-conceived ideas (Byrne, 2021), although the researcher needs to have some criteria to start, and in this study this knowledge was obtained from the literature review and from the data collection process and familiarisation with the data. In this study an inductive approach was adopted which meant that data was open-coded and respondent/data-based meanings were highlighted.

Braun and Clarke (2013, 2019, 2022) propose a six-phase process (see Table 4.7) for carrying out reflexive thematic analysis, however they emphasise that the process is a set of guidelines rather than rules that should be applied flexibly to take account of the research questions and data involved.

Table 4.7: The Six Phases of Reflexive Thematic Analysis (Braun & Clarke, 2022)

Phase	Examples of procedure for each step
1. Familiarising oneself with the data	Transcribing data; reading and re-reading data; noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire dataset, collating data relevant to each code
3. Searching for the themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Developing and reviewing themes	Checking if the themes work in relation to the coded extracts and the entire dataset; generate a thematic 'map'
5. Refining, defining, and naming themes	Ongoing analysis to refine the specifics of each theme; generation of clear names for each theme
6. Producing the report	Final opportunity for analysis selecting appropriate extracts; discussion of the analysis; relate back to research question or literature; produce report

4.9.1 Phase One – Familiarisation with the data

The researcher transcribed each recording after listening back to the interview. The process of listening to the interview again builds familiarisation with the data and prompts 'active listening'. The interview was then transcribed in full into Microsoft Word using a foot pedal to keep stopping and going back over the recording. Once a full transcript was produced this was checked by listening to the interview again. Having carried out several interviews and having transcribed the data from each the process of coding began.

4.9.2 Phase Two – Generating initial codes

Braun and Clarke (2022) recommend that codes should be kept brief, but contain enough detail for them to be understandable. The preliminary coding was produced by using the comments function in Microsoft Word, thereby allowing the text to be identified by highlighting and the code to be noted in the margin area. No codes overlapped in this process. The researcher found that repeated iterations of coding helped identify which codes were able to be used to create a theme. The development of codes from initial semantic codes (descriptive analysis obtained from surface meanings of the data) towards latent codes (finding hidden meanings or underlying assumptions) were tracked in an Excel spreadsheet.

4.9.3 Phase Three – Searching for the themes

Phase Three began once all the interviews had been coded. At this point the researcher shifted focus towards the aggregation of meaning across the whole dataset. Multiple codes were collapsed into a single code and some codes were promoted in the hierarchy to occupy a more important position in the theme development. A miscellaneous theme was constructed to deal with all the themes which seemed to not fit elsewhere.

4.9.4 Phase Four – Developing and reviewing themes

In this phase Braun and Clarke (2022) recommend a review of the candidate themes and coded data in relation to the entire dataset and propose key questions for the researcher to address about the viability of the theme, the boundaries of the theme, the amount of evidence for the theme, the diversity of the data in themes, and whether the theme conveys something important. This phase, due to the reflexive nature of thematic analysis was more blended with Phase Three than a separate step. Figure 4.9 is an overview of research themes and coding diagram.

4.9.5 Phase Five – Defining and naming themes

Phase Five is concerned with further development around the themes and at this stage the researcher further refined theme names and created theme definitions which are summarised in Table 4.8.

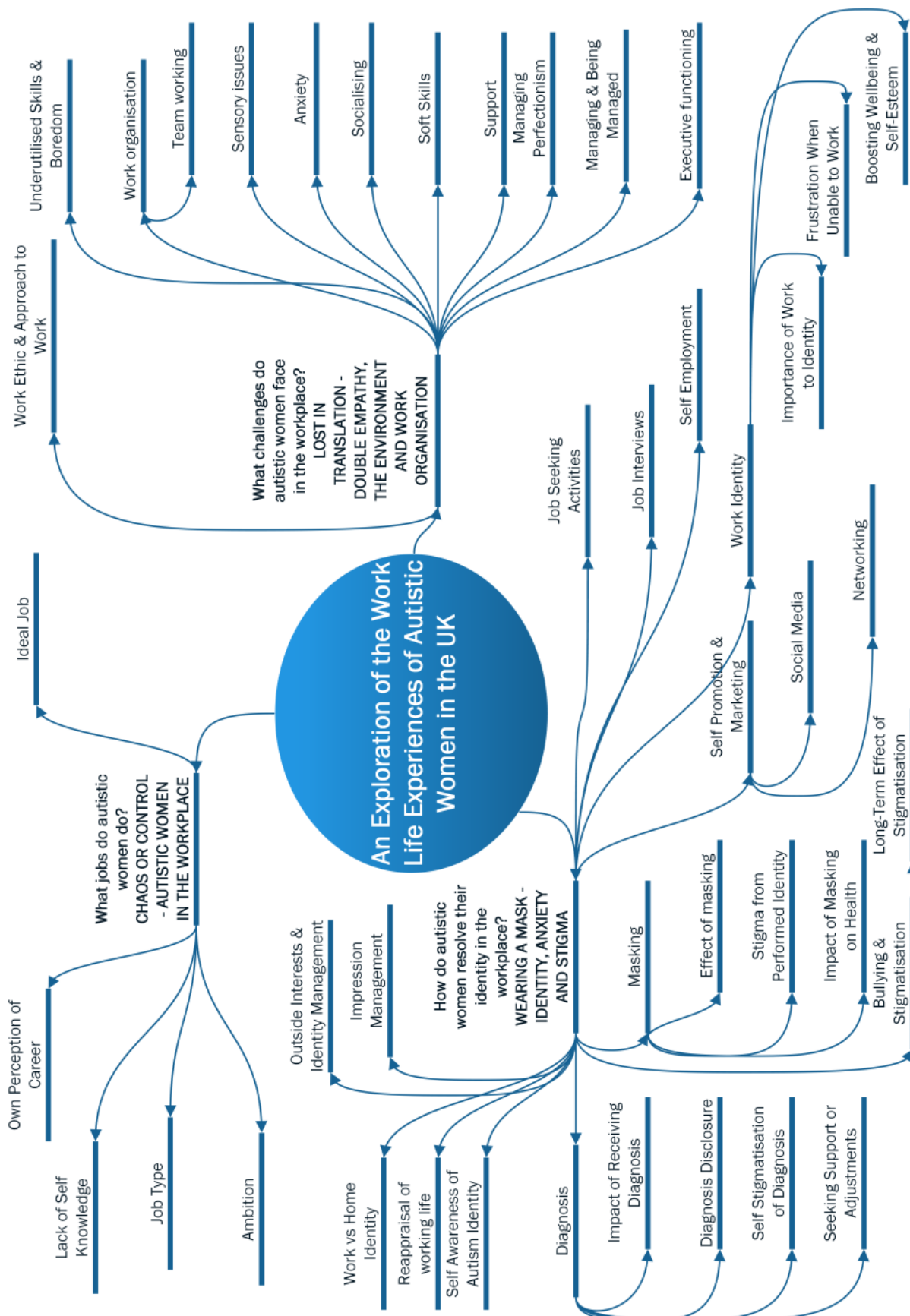
Table 4.8: Theme Summary Table

Theme	Characteristics
Chaos or control	Historical evidence of multiple jobs, sudden changes after critical incidents, wrestling back control through work organisation
Wearing a mask	Seeking a diagnosis/self-identification, utilising masking behaviours in the workplace to manage stigma
Lost in translation	Misunderstandings about work organisation between neurodivergent and allistic people; assumptions, prejudices and stigma about the other group (double empathy problem)
Adapted by the author from Hall et al (2012:143) and Braun & Clarke (2022:130)	

4.9.6 Phase Six – Producing the report

Braun and Clarke (2022) and Byrne (2021) both concur that the separation between phases five and six can be blurred. In writing up the analysis the researcher has aimed to ensure themes connect in a logical way, however reflexively the themes and analysis can always be reanalysed and rewritten in a different manner, producing different meaning. Finally Braun and Clarke (2022) recommend synthesising and contextualising data where reported, and not having a separate discussion section, and this approach has been followed by the researcher in this study. In writing up the reflexive thematic analysis the researcher has aimed to follow the advice of King et al (2019) to highlight the nature of the theme, give a sense of the character of the speaker, and to include longer extracts to ensure these goals are achieved. A summary description of the speaker and their current occupation is also supplied with each quotation. The analytic narrative also aims to go beyond description of the data, and make an argument in relation to the research question (Braun and Clarke 2006).

Figure 4.9: Research themes and coding diagram



4.10 Research Ethics

This study adheres to the University of Hertfordshire regulations UPR RE01 'Studies Involving the Use of Human Participants' requiring ethical clearance from the relevant ECDA (Ethics Committee with Delegated Authority which functions as a sub-committee of the Ethics Committee). In accordance with this Appendix A shows the ethics clearance provided by the Social Sciences, Arts and Humanities Committee Protocol No c/BUS/PG/UH/00412 for the period 11/12/2014 – 31/03/2016, which was further extended from 1/4/2016 – 31/3/2018.

Since commencing this study there has been ever increasing concern by autistic people and their communities that most autism research, being focused on medical interventions, does not reflect their own priorities for research that focuses on day-to-day living (Chown, 2017) and a series of guidelines for conducting research studies with the autism community (Gowen et al, 2019) have emerged. These make recommendations in four areas: pre-study considerations, recruitment of participants, study visit considerations, post-study considerations. The recommendations are ordered and build towards comprehensive models of inclusive working. Although these postdate the research design of this study the researcher has indicated in Table 4.10 how these recommendations have been responded to within this study. The researcher would further seek to follow these guidelines as closely as possible in any future studies involving autistic people.

Table 4.10: Alignment of this research to the guidelines for conducting research studies with the autism community (adapted from Gowen et al, 2019)

Pre-study considerations	Researcher response
Reciprocity should be a key consideration within research. All studies should have clear lines of outcomes and outputs that enhance or advance the scientific, social, and physical representation of autism	This study focus aligns with an identified key area of interest to the autistic community (Pellicano et al, 2013)
For transparency provide introductory information about why the researchers are interested in autism research	The position of the researcher as an autistic woman and parent of an autistic child was made explicit to participants
Closely involve members of the autism community as partners in specific research projects from the beginning to end, with co-produced outputs	The researcher has been highly engaged with the autistic community through Twitter, and events such as the Autistica Discover conference and the International Society for Autism Research (INSAR).
Factor payment for time and expertise into research grants for consultants from the autism community that give autistic experts by experience contributors equality with formal autism researchers	As PhD research it was not possible to provide payment for autistic participants or autistic consultants but would be explored for subsequent research where funding allowed.
Create an expert by experience panel with members of the autism community in order to have a collaborative approach to research questions and studies	The researcher would intend to follow this for subsequent research to ensure that research questions would be useful and relevant to the community. By adopting an iterative, reflexive approach to this research with participants, the researcher has aimed to ensure as collaborative an approach as possible within the remit of this doctoral research.
Lobby university ethics panels to make consultation with the autism community a pre-requisite for ethics approval of autism studies	The researcher will aim to lobby the relevant ethics panels within the institution.
Recruitment of participants	Researcher response
Include clear information on exactly what the participant will be doing in the participant information sheet	The researcher ensured that the participant information sheet was clear and easy to read and this was checked by the supervisors. For future research the researcher would recruit an expert by experience panel and ask them to read and comment on the participant information sheet.

Table 4.10: Alignment of this research to the guidelines for conducting research studies with the autism community (adapted from Gowen et al, 2019)

Use multimedia sources such as videos and photos which the participant can be sent alongside the participant information sheet to display exactly what the participant is going to be asked to do, and introduce the participant to the research team	The researcher did not consider using a storyboard approach alongside the participant information sheet, but this approach could be adopted in future research.
A participation impact assessment should be a key consideration for all research, and should cover financial compensation, whether the participant requires time to visit the local area, and what information participants needs about the research, findings, and their own personal results	The nature of the oral history interview methodology used in this thesis meant that a participation impact assessment was not needed but would be adopted if required in future research.
Have an expert by experience group read through information that will be received by participants to ensure the material is as clear as possible	The researcher did not follow this approach in this study, but as an autistic woman they drew on their own experience, however, the researcher would consider recruiting such a group in future research.
Actively seek more connections with the autism community via the internet, stakeholder agencies, and other associated organisations.	The researcher engaged widely with the autism community throughout the doctoral research, especially through Twitter and the internet generally, and specifically with the National Autistic Society, Discover Autism, Autistica and the Participatory Autism Research Collective (PARC).
Study visit considerations	Researcher response
Provide clear instructions, including photos or videos to reduce anxiety and stress about getting to the research venue	As the majority of the worklife oral history interviews were through online methods, the researcher did not need to do this, but would seek to provide these in the future when using a research venue.
Check with the participant whether someone needs to meet them at an arrival point	As the majority of the worklife oral history interviews were through online methods, the researcher did not need to do this, but would seek to provide these in the future when using a research venue.
Ensure planned breaks are flexible enough and provide enough time for people who need it	As the majority of the worklife oral history interviews were through online methods, the researcher did not need to do this, but would seek to provide these in the future when using a research venue.

Table 4.10: Alignment of this research to the guidelines for conducting research studies with the autism community (adapted from Gowen et al, 2019)

Provide a comfortable, quiet relaxation area with subdued lighting	The researcher always asked the participants at the start of the interview whether they were in a quiet and comfortable place and had water or other soft drink to hand.
Consider childcare or other caring responsibilities when planning the research	The researcher made sure to arrange interviews with participants at an appropriate time when they could give their full attention without interruption.
Incorporate provision of data sharing into ethics applications to allow sharing of screening tests so that participants are not repeatedly completing the same standard tests	This was not applicable in the context of this study.
Post-study considerations	Researcher response
Information should be provided to participants on what happens next or when a summary of findings will be produced	The researcher provided information on the study at the conclusion of each interview and provided updates on progress via the Twitter account @amazonians
Dissemination of research findings should have the autism community at the heart by using methods available to and accessible to autistic people	Research findings have been disseminated at the Discover Autism conference organised by Autistica. The researcher was also invited by the International Society for Autism Research (INSAR - the principal autism research organisation and conference) to provide a poster presentation but was unable to do this due to lack of funding.
Arrange open seminars and workshops related to the research project to enable discussion of the research findings	The researcher intends to try and secure funding for an autism employment seminar to share research findings and to provide a network event with similar researchers with a view to stimulating future research.

4.11 Conclusion

This chapter has detailed the methodology and methods utilised in the study. First the research strategy used in the study was explained with the research onion (Saunders et al, 2019). The philosophical assumptions of the study were discussed – the epistemology (what counts as knowledge) was identified as an interpretivist one, and the ontology (social reality) was identified as a relativist one of social constructivism. The philosophical approach was discussed as in line with the methodological approach adopted, an example of which was the way in which the initial literature review of autism and employment, and initial interviews generated a further literature review of identity.

Both literature reviews utilised a narrative approach, ensuring an overview of existing research in the field (Clark et al, 2021). Semi structured oral history interviews were chosen as the primary data collection method as the oral history interview technique is a central method for studying people's perceptions or experiences of events (Kumar, 2014) fostering collaboration in the meaning-making process (Leavy, 2011). The research questions generated by the broad topic and the oral history interviews followed guidelines for qualitative research questions, having social relevance and originality (Gough et al, 2003). Reflexive thematic analysis was used (RTA) (Braun and Clarke, 2022) to analyse the semi-structured oral history interviews. Three themes were created for use in the study – chaos or control, wearing a mask and lost in translation, and the researcher's approach in writing up has been to highlight the nature of the theme, give a sense of the character of the speaker, and include longer extracts to ensure the goals of King et al (2019) were achieved. Finally, the research ethics approach highlighted the alignment of the research to guidelines for conducting research studies with the autism community (Gowen et al, 2019).

The next chapter entitled 'Chaos or control' is the first of three findings chapters, created by following the methodology outlined here. The next chapter focuses on the research question: What jobs do autistic women do?

Chapter 5: Findings – Chaos or control - Autistic women in the workplace

5.1 Introduction

In the last chapter the methodology used in this study was outlined and the three research questions - what jobs do autistic women do, how do autistic women resolve their identity in the workplace, and what challenges do autistic women face in the workplace, were introduced, and explained.

This chapter focuses on the first of these research questions – what jobs do autistic women do? as well as the theme of ‘chaos or control’.

First, the chapter looks at the current job, previous jobs, and ideal jobs of each of the 35 autistic women interviewed, filling a research gap that was identified in the literature review. The chapter then considers the participants ideal job, and the ambition they had on leaving school or education. The chapter then concludes by examining the participants own perception of their career, and their apparent lack of self-knowledge and self-awareness.

5.2 Autistic Employment

Table 5.1 shows the current job, previous jobs, and ideal job of each of the autistic women interviewed for this study.

The theme of chaos or control conceptualised here relates to the rather chaotic pattern of numerous jobs previously undertaken by the women in the research. Compared to this their ideal jobs all reveal an element of control which suggests that having greater control over their working environment or working pattern would provide the women with less anxiety and greater satisfaction and wellbeing (Chapter 6 provides more detail and development). An example of multiple jobs having been undertaken is Nadia who when asked about her working background observed that to one of her partner’s jobs, Nadia had had 20. Nadia, when asked about the volume of jobs she had undertaken elaborated on what happened:

I've walked out of a number, I've never been sacked, but I've walked out of a number of jobs erm with nothing so I have had nowhere to go, I've had no money, I have walked out of waitressing jobs, I've walked out of a tutor's job, I've walked out of care worker jobs, erm because something would have happened, somebody would have said something, somebody will have done something that I've considered to be incorrect or sort of morally wrong you know. Once I worked somewhere for four days, it was, it was for a sort of education provider for the NEET kids, not in education or training erm and I'd written a lesson plan for the day and I was meant to be kind of shadowing a tutor and the tutor came in and he hadn't bothered to write a lesson plan so he just nicked mine and just used it erm and I walked out and I never went back again. It's always things that either I can't cope with emotionally or that upset my sense of justice and I will just go, I can't I can't think about it in a way that I can put perspective in there at the time, it's just, that's it, finished, erm and I'm gone. And often that's been obviously financially extremely detrimental to my family erm as often I've been a single parent for a number of those years.

Nadia, 47, self-employed autism trainer and consultant

The notion of a critical incident taking place and causing the woman to quit was evident in a number of interviews. Alternatively women might quit due to being overwhelmed by the job or the work environment. Wendy aged 40 and currently a stay-at-home Mum described having had 14 different jobs in Human Resources or recruitment which she had usually left because she "got to a point where I was about to be out onto capability review or sickness review. I couldn't cope but couldn't understand why at the time. I left and would change company or location in the country".

An alternative perspective can be found in the interviews with some of the older women who had reached a point of maturity in their career where they could work as freelance consultants or were self-employed and many were now working in the autism field or would like to do this. This maturity, combined with aspects such as self-employment gave them greater control over their worklife, allowing them greater ability to shape their working time, commute, or workplace environment. Working as interim or agency workers also

meant that they got recruited because they had a record of satisfactory work elsewhere, so came 'pre-recommended' and then did not need to undergo rigorous interviews.

Whilst ONS statistics (Adam et al, 2023) show that disabled workers are more likely to be self-employed than non-disabled workers, this could be problematic for some of the autistic women interviewed, and Chapter 6 shows some of the challenges that self-employed autistic women faced, particularly in relation to networking, marketing themselves, and the anxiety that went along with being solely responsible for how that job was practised.

Some women were employed in positions that they were told they 'should not be able to do' because they were autistic. However, their monotropic focus, passion for the job, and appropriate working environment with workplace accommodations meant that they were successful. One woman, Steph, aged 25, stated that she had been working in a contact centre for two and a half years:

My support worker from [REDACTED] was astounded. She said, 'I don't know how you do it'. She said someone with Aspergers you should totally not be able to do it. But I managed to do it and they were quite shocked.

[Steph had an interview and had to role play] I had to pretend I was selling a holiday but the holiday had earthquakes or something nearby and I had to change their location, but I managed to convince the person to have it, the interviewer, and I also managed to get extra things in it and she said she couldn't believe it, that was one of the best role plays she had ever seen. So, I'm obviously good at role plays, but then I like drama.

Steph, 25, Contact Centre administration worker.

Examining the work history and ideal jobs of the women interviewed suggested that they were particularly value driven and wanted to contribute to improving people's personal circumstances or society in general. Examples included wanting to combat global warming, and helping people with facial disfigurements for free, suggesting significant awareness and empathy for the circumstances of other people. This social awareness and empathy was

particularly at odds with historic research suggesting that autistic people lacked empathy (Baron-Cohen, 2009).

This research did not collect statistics on pay and pay rates given that the focus was on the worklife experiences of autistic women, however, it is noticeable that many of the jobs undertaken by the women would tend to suggest low pay, precarious employment, perhaps within the gig economy. This type of work could appear appealing due to its flexibility to help with the physical or mental health challenges of the autistic women but can often be within workplaces hostile to trade unions and therefore with lower working conditions, where there may be little understanding of autism and of possible accommodations and adaptations.

Table 5.1: Participant Demographic and Employment Information

Participant	Age	Age at Diagnosis	Highest Qualification	Current Job	Previous Jobs	Ideal Job
Amanda	38	34	Masters	Freelance Financial Analyst, Banking Sector	Waitressing (as a student) Programmer Trainer (working across Europe) SAF Analysis Credit Risk Senior Analyst Consultant – SAF Modelling [Additional income through property development]	“Autism advocate and trainer”
Belinda	36	35	Higher Diploma Biomedical Science	Unemployed	Proofreader Part time Chip Shop assistant Temporary Envelope Stuffer Analyst, Scientific company	“I’m trying to figure that out right now. I think it’s self-employment. Something that isn’t too physically demanding so I can still work when pain bad. Ideally producing something as studies show that helps minimise stress”
Claudia	20	12	A Level	Unemployed but volunteering with youth projects	Charity shop assistant Sunday School helper	“Something which has a set routine” “Working with kids”
Denise	34	33 (29 self-diagnosis)	Postgraduate Degree	Police Sergeant in charge of a team of 6 in a community policing team	Temporary office based administrative roles YMCA Intern in the US	“Engineering or emergency planning”
Eve	37	26 self-diagnosis	PGCE	Part time daily supply teacher plus self-employed work for educational consultants and non-profit organisations	Trainee web design Various part time jobs whilst a student Teacher	“Would involve writing, some type of factfinding/research, some teaching about equality and diversity ... ideally working with different inspirational people”

Table 5.1: Participant Demographic and Employment Information

Participant	Age	Age at Diagnosis	Highest Qualification	Current Job	Previous Jobs	Ideal Job
Fran	32	27	Half an A Level	Home educating special needs son and volunteer administrator for a home education group	Kitchen Hand Checkout Assistant Office Assistant Hotel assistant/barmaid Customer services representative Hospital outpatients booking clerk Retail Customer Assistant Purchase Ledger Assistant Avon representative Freelance review writer	“Published author or running my own company from home”
Gemma	29	29	MA Developmental Psychology	Residential care worker with young people with ‘challenging behaviour’	Residential care worker with young people School teaching assistant	“Where I’m ... able to get an understanding ... of why a young person is misbehaving and then being able to apply that to how you work with them rather than it just being behaviour management tools”
Helen	45	45	Some Open University modules & City and Guilds certificates	Currently unemployed and carrying out autism awareness activities	Office Junior Temporary office work Office Manager	“Something to do with the environment ... I feel very strongly about global warming
Isabel	57	50	BSc (Hons)	Freelance consultant and speaker on autism	Actor/Stage Manager TV Researcher TV Producer Oral history interviewer Project management for national charity	“A creative job ... successful writer ... drawing and writing”

Table 5.1: Participant Demographic and Employment Information

Participant	Age	Age at Diagnosis	Highest Qualification	Current Job	Previous Jobs	Ideal Job
Jan	33	33	A Levels	Full time office manager in the City	Assistant Hairdresser Fast food assistant Bra fitter Receptionist/Administrator Administration Assistant Office Manager	"Make-up artist specialising in films and special effects, but I wouldn't have to travel away from home, I could take my dog with me and I'd earn enough so that I could help people with facial disfigurements for free"
Kelis	44	44	PGCE	Self-employed piano and keyboard tutor	Saturday job in fast food outlet Summer job at Camp America Summer job at Barbican Concert Hall Church organist Various voluntary posts with local charities	"Half teaching and half performing music. Teaching only students who are interested/talented/work hard. A mix of work alone and with others"
Lena	26	26	BSc Psychology	Recent graduate looking for autism support worker job	Baby sitting Customer Service Admin Au pair Restaurant work	"To work from home ... either my own business or work with a really good team or distance working"
Marta	30	28	GCSE	Running self-development website	Started, but did not complete accountancy course Started training in hospitality industry Waitressing Qualified as a Plumber	"I'm going to put stories that I write on my website ... stories that may help people with their own self-esteem, and also at some point I will maybe do articles about astrology and things like that"

Table 5.1: Participant Demographic and Employment Information

Participant	Age	Age at Diagnosis	Highest Qualification	Current Job	Previous Jobs	Ideal Job
Nadia	47	42	O Level	Self-employed autism trainer and consultant	Quality Controller Kitchen Designer Lorry Driver Pool Lifeguard Fruit Picking Campsite Representative Potato Picker Pottery Assistant Play Scheme Assistant Cookery Book Writer Care Worker Waitress Adult literacy teaching Autism Project Manager	"I want to be Jasmin Harman on A Place in the Sun: Home & Away ... one of my special interests is property ... I love travelling ... me making decisions about how I run my days ... definitely outdoors ... somewhere foreign, somewhere sunny"
Olivia	23	23	PGCert Pharmaceutical Science	Insurance Salesperson and setting up a fashion label	Retail work in a café Retail work for two high street fashion stores Retail work for football stadium Various call centre positions Graduate position in data management for a pharmaceutical company	"I want to be a jewellery designer. I want to make things in my studio, employ 2 people to help me ... I would wear my cool clothes every day and set my own trends with my own items. I think the world doesn't want to let me in so I'm going to have to blaze my own trail"

Table 5.1: Participant Demographic and Employment Information

Participant	Age	Age at Diagnosis	Highest Qualification	Current Job	Previous Jobs	Ideal Job
Pauline	41	38	Highers/NVQ Level 3/OU Certificate	Full time carer for teenage autistic son	Temporary bar work and waitressing Hospital Catering Assistant Hospital Ward Secretary Part Time Creche Worker Volunteer School Librarian Part time Hairdresser and Salon Assistant	“Counsellor – not in any particular field, but just to sit and chat and listen to people who were finding life difficult for whatever reason”
Rosa	38	38	Undergraduate degree	Unemployed but looking for part time work	Office junior Customer service advisor in bank Receptionist Audio typist Medical secretary	“Sitting in an office with friendly people ... no phone or email, just audio typing”
Steph	25	Under 12	Diploma in Higher Education	Contact centre worker - administration	Health and beauty trainee Contact centre worker – telephone operative	“I would like to support people with the condition I have. I would like to work for the National Autistic Society”
Sara	26	22	BSc Psychology	PhD Student and part time special needs teaching assistant	Web site and book cover designer Office assistant	“Working in an environment with other people, but by myself doing research”
Teresa	39	32	RSA Typing Qualifications & Business Studies	Control centre administration for the Police service	Secretarial work Call centre Administrative work for children services	“I’d just like a job where people give me a bit of consideration, where people value me for the differences I have, and build on those differences in a positive way”
Ursula	29	21	BA Social Policy	Data Officer for a Pupil Referral Unit and undertaking part time MA	Short term administrative jobs	“Research into autism ... speaking and training people about autism”

Table 5.1: Participant Demographic and Employment Information

Participant	Age	Age at Diagnosis	Highest Qualification	Current Job	Previous Jobs	Ideal Job
Val	27	15	BA	Student	Youth Worker Chef	“Teaching cooking with a different curriculum so that everyone can learn”
Wendy	40	39	Higher National Diploma	Stay at home mum	Variety of administrative work for human resources or recruitment	“I have no idea”
Xanthe	46	46	None	Freelance journalist and author running a communications agency	Administrative work	“One where I had to do one task at a time and felt very secure”
Yvette	40	39	Postgraduate diploma in music	Self-employed piano teacher, plus study skills tutor for a dyslexia and disability service	Various retail work as a teenager Bar work Tapestry kit production line Wildlife Rescue volunteer Various freelance musician work	“Self-employed piano teaching with time to write a book, and a little bit of study skills, and I want to do a PhD in something”
Zara	53	53	Masters in Education	Currently unemployed and completing a part time PhD	Paper delivery Au Pair Geography Teacher Outreach Teacher Head of Teaching Charity English Teacher Supply Teaching	“Head teacher of a school where everyone had one to one tuition, or could do their own private study with a little guidance from others, both adults and young people”
Agatha	25	16	Masters degree	Associate Technical Business Analyst in the Technology Division of a financial institution	Temporary supermarket work Technology intern	“I like the job I have and I know it will change over time but only as and when I am ready for it to grow”

Table 5.1: Participant Demographic and Employment Information

Participant	Age	Age at Diagnosis	Highest Qualification	Current Job	Previous Jobs	Ideal Job
Brenda	52	47	1 st Class BA Honours Degree	Artist, part time gallery assistant, and small business making knitted toys and dolls	Chambermaid in B&B Illustrator Manager of Design department Waldorf Teacher Book store McDonalds	"To be paid, to work alone pursuing research in something I'm interested in"
Carla	40	40	BSc Mathematics	Software Developer	Thurstons Bar work Temporary work at HSBC Allders Fox's Music IT Project Officer Data Entry Temp DEFRA	"One which didn't have such an extrovert appraisal system and paid well yet let me alone, that I could do work in bursts, and still be ok doing that. And was interesting. Maybe a special type of Library? Or owning a bunch of houses that people rented via a company? Or making craft items? Somewhere where I wasn't beholden to a boss ..."
Debbie	51	48 self-diagnosis	MA Literature	Running private practice for consultant surgeon husband	Café work Toy shop Hotel chambermaid Nurse Beauty counter Assistant Manager for Record Store Nurse	"Counselling and running my own restaurant business"
Ellie	37	37	BA plus Chartered Accountancy qualification	Unemployed – writing a book	Chartered Accountant Publishing Company	"A small informal company offering an exciting and stimulating job"

Table 5.1: Participant Demographic and Employment Information

Participant	Age	Age at Diagnosis	Highest Qualification	Current Job	Previous Jobs	Ideal Job
Fabia	36	35	BA Hons	Stay at home parent	Library Assistant Assistant Area Supervisor (Local Govt) Teaching Assistant HR Officer Payroll Officer	“Something being creative. Working with my hands. Working for myself ... somewhere I can laugh and enjoy it. Somewhere I’d be me. No management speak ... just clear simple objectives and a freedom in how I get to them”
Gabi	50s	47	Degree	Cultural Engagement Officer for local council	Pattern repeat work for textile factory Designer for furniture and textiles business Freelance textile design Book cover design Assistant at Art Library Freelance graphic designer	“To be able to do my own work as an artist and to choose the people I would be working with”
Herta	40	38	Partial Degree and Masters in Electrical Engineering	Independent supporter and volunteer for Statement system	Computer lab technician for multiple employers Playgroup volunteer	“I sort of have done ... advocating on behalf of children/families”
Ingrid	30	30	Diploma in Contemporary Music	Cyber Crime Intelligence Officer for the police service	Driving airport assistance buggy Airport Cabin Crew Travel Consultant Customer Advisor in bank Analytical Research for police service	“I would be a full-time blogger. My ideal posts would be on travel - I’d love to write more travel guides and about my experiences”

5.2.1 Ideal Job

When asked what their **ideal job** would be many of the women described an occupation that would be classified as creative, with high flexibility that they had control over, such as being able to work from home.

Something being creative. Working with my hands. Working for myself, not directly with the public, but maybe with other people with a similar passion for the job.

Somewhere I can laugh and enjoy it. Somewhere I'd be me. Somewhere I would be told what was expected of me, clearly, and given genuine, quantifiable feedback. No management speak or analysing targets in stupid terms. Just clear simple objectives and a freedom in how I get to them.

Fabia, 36, currently a stay-at-home parent

However, although some relished the opportunity to be a sole worker, perhaps in research, many others wanted to work in small workplaces with a supportive team.

A small, informal company offering an exciting and stimulating job. It's a very difficult balancing act. On the one hand, I like routine, calm, and a certain amount of predictability, on the other hand I'd like to progress and to be challenged – but not too much!

Ellie, 37, Unemployed – writing a book and living off savings.

Ideal jobs often featured social justice elements such as helping other people or counselling, reflecting that autistic women can have highly developed empathetic skills.

Counsellor – not in any particular field, but just to sit and chat and listen to people who were finding life difficult for whatever reason.

Pauline, 41, former hairdresser, currently home educating autistic son.

A theme that reoccurred often was a role involving research, which would seem to reflect the way in which autistic women constantly engage their agency to make sense of the

world, and therefore explains how this skill could be highly developed and therefore useful in the creation of a satisfying career.

My ideal job would definitely involve writing, probably involve some type of factfinding/research, some kind of teaching about equality and diversity and/or alternative ways of living, working and being in the world. This job would ideally involve working on a one-to-one basis with different inspirational people (such as leaders of charities/nonprofits/social enterprises, and educational bodies/consultants), planning strategies and campaigns, making resources and sharing positive messages.

Eve, 37, Teacher

5.2.2 Ambition

Women's **ambition** on leaving school or education often appeared to be unfocused and given their later autistic diagnosis might also be considered unrealistic. Most appeared to have a lack of self-awareness at the time, and their subsequent reflection found incompatibility between their autistic identity and job-related aspects such as shift work (see Chapter 6)

When I left school, I wanted to be a GP. When I left college, I wanted to be a Biomedical Scientist (I reasoned I'd rather deal with bits of people than the actual person). I left uni early as I had a complete breakdown, so I never finished the degree. Apart from one role the majority of my jobs were not related to what I studied. I ended up doing the job that the company needed, and I turned out to be fairly good at some aspects.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

I wanted to be an Archaeologist or Solicitor when I was younger. As I hit my teens however, and encountered a number of significant traumas, I just wanted to be dead to be honest. Sad but true. At 17 I was offered free training to become a Legal

Executive, which is the equivalent of a Solicitor, but my self-esteem was so low that I did not think I was capable. I opted for Legal Secretarial training instead, but had a meltdown at work one day and stormed out :-/

Fran, 32, currently a full-time home educator and volunteer administrator for a home education group

At a later stage of their careers the women were aware of the impact that being autistic had on their daily lives and a greater awareness of the skills they had to offer, and the problems they might personally experience in the workplace. In the light of diagnosis some were therefore looking to adopt less stressful occupations, whilst others were specifically interested in pursuing a particular autism related role.

Well right now I'm just looking for a support worker role, an autism assistant and erm I'm looking for something part time because I really think a full-time job right now based on my autism would be too much, too overwhelming for me. I used to work, you know, eight hours, in a very noisy environment and during that year I became almost physically ill, I had panic attacks, I had a lot of pain, I had a lot of physical complaints across the whole year and I could really see the connection of being simply all overwhelmed during the day so that's why I don't think I can do a whole time job right now.

Lena, 20s, seeking work as a classroom assistant.

I wanna go and do research and work at university level. I was sort of also thinking I'd still like to somehow go into clinical work, so I think that once I have enough money behind me, and I had the opportunity I might convert my PhD into a clinical doctorate as well to maybe do that, but I want to keep researching women with autism, and looking into that more, but also making, doing more practical things, so not just in the research but actually setting up practical ways for women to get support and things.

Sandra, 26, special needs support assistant and part time PhD student

The way in which the women were able to push through adversity and take positive action when faced with difficulties reflects the findings of an earlier study of critical life moments in autistic women (Webster and Garvis, 2017). Here it was found that women saw themselves as 'agents of change', able to extricate themselves from problematic situations and effectively using their positive self-efficacy.

However, this was not always the case and some women felt that a lack of self-confidence had held them back, though it was not always clear if this was as a result of self-stigma or as a result of stigmatisation from allistic workers.

I feel my lack of confidence in myself has been a big contributor as to why I've not made more of my working life.

Pauline, 41, former hairdresser, currently home educating autistic son.

When I look back at what I have achieved despite my difficulties I often feel as if it was someone else not me. So much of my life has been dominated by a sense of failure, and constantly trying hide my difficulties, so that I would not be seen as inadequate, or exposed as a fraud.

Gabi, 50s, Cultural Engagement Officer for a District Council

5.2.3 Own Perception of Career

There were some very mixed and highly personal views from all the women on their own **perception of their career and working life**, ranging from negative to positive.

One f*** up after another.

Fran, 32, currently a full-time home educator and volunteer administrator for a home education group

A sodding mess, starting from a failure and proceeding onwards from there, landing me nowhere with no pay, really, but great satisfaction when a child gets the school or provision they need.

Herta, 40, currently taking a career break whilst volunteering as an Independent Supporter for families in the education system.

However, some women had found careers which particularly worked to their strengths, such as Agatha working in a rules-based environment and Denise working in an investigative, research environment.

I enjoy what I do and the life I am able to lead as a result of it. Being in a professional environment with so many rules is very comfortable for me.

Agatha, 25, Associate Technical Business Analyst in a leading financial firm.

It has been good for me, and I have enjoyed it, aside from the past 12-18 months.

Denise, 34, Police Sergeant and Community Policing team leader

The younger women in the study, just starting their careers, were in the main having a more difficult time. Claudia was doing volunteering work and had been told by the JobCentre to sign off looking for work because no apprenticeship opportunities were getting back to her. This suggests that the JobCentre did not know how best to support her:

I mostly have volunteering, in terms of paid work I did badly because I get panic attacks and something I call meltdowns, which is where my brain goes wrong, it's if something, too much is happening around me and all I really ask for of an employer is for a couple of minutes on my own whenever that starts to happen, and you can immediately tell from the looks on their faces that no one really wants to know after I've said that. I've even had that from a couple of volunteering places, apparently, I had an attitude because I was blunt which is pretty disheartening to be honest.

Claudia, 20, unemployed but volunteering with youth projects.

5.2.4 Lack of self-knowledge

Some women expressed regret at the fragmentary nature of their working lives. Some of this seemed to be centred on a **lack of self-knowledge** and self-awareness at the time, not just about their autistic status, but also due to the limited amount of careers advice

available to them, and this may overall be the reason why the women's careers seemed to be slow-burn or fragmented. The following example from Debbie emphasises the benefit of unmasking which is discussed in the next chapter.

Fragmented in that I don't feel that I particularly followed one line, some people just leave school don't they, get into one job, and they then stick with it for ever, which is like my husband has done whereas I've just moved around and according to a time in my life that sort of thing. I've not really sort of, until now, for the first time in my life I've actively pursued something that I feel like I really want to do and are driven to do. Before it was 'what shall I do, I know I'll be a nurse' you know, that sort of thing, and I think I put that down as not really having much knowledge at the time when I was young, and I would say that my children have much better self-knowledge now than I had at that time. So, it very much followed my nose, my work, has been to date and I think it's time for me to sort of drive it in the way I want it to go and I think I'm ready to do that now. Now that I can find work and I don't have to mask anymore, mirror anymore. I can be the real me, that's what I want to do.

Debbie, 51, manager of surgical private practice and part time MA student

Many women expressed pride at what they had achieved despite the difficulties that being autistic had presented them. Ultimately for some women having more control over their employment seemed to be an issue and many felt happier and more fulfilled with self-employment.

I feel like I've had many different roles, each in completely different areas to another – for example I've been cabin crew, I've worked in a bank, I've worked for the police. Each I've enjoyed and excelled at, but I've always felt like something is missing and not fitting with what I ultimately want to do. I find when I work on my blog and my own small business, I feel this sense of fulfilment I've been missing. This is largely down to the fact I'm able to work on my own and manage myself without having to deal with the day-to-day stresses of politics with other people/supervisors and such like. I think within the next 1-2 years I will become full-time with my own business and this way of life will suit me so much more.

Ingrid, 30, Cyber Crime Intelligence Officer

Nadia, who had had the most disjointed career path of all the interviewees said:

I'm mostly amazed that I've actually managed to achieve anything. But also, I suppose I feel kind of proud of myself really. The sort of knowledge of, of why I had so many scrapes in earlier life it's been quite a new one, cos the diagnosis is only sort of three or four years ago I suppose, but I guess when I look back the perception from other people, from my family, was always that I had wasted my intelligence, that I was a bright kid, I could have achieved, my mum was very much focused on money and all of that kind of thing. I wasn't really interested, I knew I couldn't play the game, I just sort of bumbled through for quite a long time. So actually I'm quite chuffed with myself that I've managed to find a niche, to do the things that I am good at, I'm, I'm, I'm very articulate, I'm good for, good language is my thing, so I've found myself a job where I can communicate with people on a subject that I know extremely well, I have huge amounts of time off, at certain times of the year I don't get any work, school holidays and stuff, I earn as much money as my peers do even though I certainly didn't for a many, many, years, I was very much the kind of skint one when everybody else was kind of zooming ahead. I've had two kids into the bargain and yeah in a way I just kind of, I'm quite relieved, chuffed, and I think it's all about niches. I think it's about being a big fish in a small pond, I think it's, I found a way that works for me. I look at other people in my industry and think enough, I look at sort of promotion, the next steps up, they're jobs I can't do, they're either clinical jobs, they're academic jobs working in universities, they require long term people relationships and I can't do those, so I'm better off on my own, go to an organization, do what I'm good at, get out. So actually, I have a perfect Asperger job for me and I don't think people look at it in that way I think they think my life is varied, they think I do a lot of people stuff, but it's not, if you really examine it, it's perfectly aspergerish, it's all on my terms.

Nadia, 46, self-employed autism consultant and trainer

It was clear however that some of the very recently diagnosed younger women were very frustrated with their careers, or lack of a career, and were rethinking and reconsidering their options in the light of their diagnosis.

I progressed throughout my twenties, but now my career has stalled, and I'm deeply dissatisfied with it. Knowing that I could never work as a manager, I'm now considering a complete career change, but I have no idea what it is I want to do.

Ellie, 37, Unemployed – writing a book and living off savings.

Partly because of personal circumstances and partly, I keep having complete breakdowns which tend to f**k things over somewhat. Stress gets to me a lot and I have to be careful about how much I take on. If I get this job with the new school, I'm also applying for a PGCert with [REDACTED], it's an online thing, and if everything comes through, I'm going to be forced to drop something cos I don't think I'm going to be able to cope with everything at once. So, I'm really conscious of the fact that I get burnout really quickly and really easily and when I burn out, yeah I'm not in a good place. But at least I'm aware of that now.

Yvette, 40, working in a university disability and dyslexia service

In contrast to the women who regretted not receiving an earlier diagnosis one older and late diagnosed participant reflected that she felt that had she been diagnosed earlier she may not have had such an interesting career because she may have self-limited her career choices, or not been allowed to do certain jobs due to the stigma of the diagnosis.

Because of the type of work I've done I've had access to people most people would never have spoken to and done jobs that have got me just as much as most people. It's been really, really, varied and I've loved that about it. Had I had a diagnosis of autism when I was young, and had I disclosed it I can promise you I wouldn't have got most of the jobs I got into or university to the course I did, the University I went to at the time. So, I could have been a lot more impoverished interest wise, excitement wise, with a diagnosis or whatever, although I don't necessarily know, it might have been a lot easier emotionally, though I don't know

that it would have. I talked to my sister who was also diagnosed at 50, and she is very angry because for her, because she hasn't been able to maintain working as much as me, because she had a misdiagnosis when she was 25 of schizophrenia and stuff like that, she hasn't had a career and she is very angry that she didn't get a diagnosis when she was young. I've always liked the fantasy aspect of theatre and books and things like that, so it's been, not fantasy, imaginative things have always interested me, but I've only ever been able to do the practical jobs. I would have really loved to be able to get more of the creative work, but people saw my ability to do, to put my head down and do the hard practical stuff, and always gave me that type of job and never asked if I could do the other. It is a shame.

Isabel, 57, freelance project manager

Finally, one woman highlighted the need, for her, of feeling valued and respected by colleagues as part of a team. This to her typified a transition from a job you did, to a job she would and could enjoy and where she could contribute her talent and skills.

I'd love to find a job where I could actually enjoy being there, where I'd feel valued, where I could feel respected, where I could feel part of a team because of what I contribute, and I might be able to contribute rather than just being there because I happen to be there.

Teresa, 39, civilian resource planning assistant with the Police service

This seems to reflect the need to feel an integral part of a high performing or successful team, which is often considered to be a vital asset in modern workplaces.

5.3 Summary

The widely quoted National Autistic Society survey statistic suggesting only 16.6% of autistic people are in employment (NAS, 2016) is unhelpful given that the late diagnosed women in the study suggests that many autistic women are in fact working. The data from the 35 participants shows a very mixed picture on where they have got to in their careers, depending on the career stage they are at and other external factors such as caring

responsibilities. Indeed, many of the older women appear to have reached senior positions in their careers, in occupations that are not stereotypically deemed to be 'suitable' for autistic people and in contrast to published literature. Howlin et al (2004) suggests that employment results for autistic people are much lower than expected with their intellectual functioning and Eaves and Ho (2008) found autistic people rarely achieved high levels of responsibility, which seems counterintuitive to many women in the study for example: TV producer, Police Officer, Cyber Crime Intelligence Officer, Software Developer etc.

One scenario from this study may be that some of the women achieving high levels were in very structured environments with career progression routes which had very clear and defined job descriptions and person specifications attached, perhaps with more structured support that the women in turn benefitted from despite their lack of diagnosis.

The educational accomplishments of the participants also suggest that career choices may have been restricted in some cases due to a lack of achievement in 'gateway' qualifications, which may be due to not receiving an early diagnosis and support in the educational system. Another observation about the 'chaotic' pattern of jobs and occupations followed by some of the women is that this is markedly different to the stereotypical view of autistic people as rigid rule followers needing consistency. These women seem to embrace change, willing to try new jobs or careers to find a good fit for themselves.

It is therefore very important to the women's ability to shape their careers that they can receive an early diagnosis and essential that the Government ensures resources are in place to enable this. However, early diagnosis needs also to be supported by informed and well-resourced career guidance and potentially supported by a mentoring programme with older autistic women as mentors. Employers, support organisations and trades unions also need a greater understanding of the impact that poor employment practices will have on the emotional and financial wellbeing of the autistic women. This impact also needs adding into equality, diversity, and inclusion training for employees. Autistic women working in self-employment or setting up a business may also need additional support to help them consider the impact of the double empathy problem on their business or service. An example might be where an autistic person sets up an employment agency or employment support organisation for other autistic people but may lack the necessary networks and

contacts to be able to market the services to employers and therefore needs to work closely with allistic people to help them grow their business or operate successfully.

5.4 Conclusion

This chapter has demonstrated the wide variety of jobs that autistic women do carry out and answered the research question 'what jobs do autistic women do?'. It has, however, also revealed the somewhat chaotic pattern and number of jobs that many of the women have undertaken, suggesting that critical incidents, not feeling a good fit in their job, or being stigmatised for the undiagnosed hidden disability that they did not realise they had, may be to blame. Furthermore, it is suggested that where a job has interested the women, providing some job satisfaction despite any negative elements, a monotropic focus and positive workplace double empathy, has enabled the woman to carry out the job successfully. It is not known whether the women with an early diagnosis have been dissuaded from certain careers 'because autistic people cannot do them successfully' but they seem slow to establish their careers, though this may be because of stigma on disclosing their diagnosis. More publicity about autistic women and their careers would enable younger autistic women to make better and more informed choices, with a greater understanding of some of the challenges they may face, together with some of the solutions to deal with them. A practical solution may be to establish a workplace autistic mentoring scheme to increase the confidence of young autistic women entering the workplace and enable them to make more informed choices. Autistic women in self-employment or starting a business may also need specialist mentoring or support services to help them thrive and grow their business.

The next chapter entitled 'Wearing a mask' is the second of three findings chapters and focuses on the research question: How do autistic women resolve their identity in the workplace?

Chapter 6: Findings – Wearing a Mask – identity, anxiety and stigma

6.1 Introduction

In the last chapter the first research question – ‘what jobs do autistic women do?’ was considered alongside the theme of ‘chaos or control’. It was evident that the participants held a wide variety of jobs, challenging the notion that only a small number of autistic people were employed in the workplace. Many of the women had however had chaotic careers suggesting that critical incidents in the workplace and/or their undiagnosed status had contributed to identity challenges.

This chapter focuses on the second of the research questions – ‘how do autistic women resolve their identity in the workplace?’ with the theme of ‘wearing a mask’.

First, the chapter discusses the challenges of autism diagnosis, the benefits and disbenefits to an early diagnosis and whether this may result in a ‘spoiled’ identity, and the transformative nature of receiving an autism diagnosis. The chapter then moves on to discuss diagnosis disclosure and the stigma that might result, whilst also discussing how this could be concealed by disclosing other co-morbid conditions, and considering the self-stigmatisation that might result from disclosure. The chapter then considers the support and adjustments available to the women in the workplace, and the reappraisal of their working lives that the diagnosed women undertook. The chapter then focuses on masking and the specific identity management the participants undertake, the stigma they encounter and the impact of masking on their health. The chapter then discusses the participants self-awareness of their autism identity, as well as identity and masking around job seeking activities, interviews, self-employment, self-promotion and marketing. The chapter concludes with an examination of bullying and stigmatisation, impression management and the performativity around a work identity and home identity.

6.2 Diagnosis

There is now an increasing amount of literature on women’s lived experience of the diagnostic assessment process, revealing issues with misdiagnosis or mislabelling and a lack of professional knowledge about autism in women (Leedham et al, 2020 and Bargiela et al,

2016). These issues included having difficulty accessing an autism diagnosis (the average diagnostic delay is over 5 years) (Jones et al, 2014), having possible autism traits dismissed by General Practitioners (GP's), autism being missed or concealed by other mental health conditions, or being told their communication skills were too good to be autistic (Murphy et al, 2023).

The barriers that exist to obtaining an autistic diagnosis mean that many adults are increasingly self-identifying as autistic (Overton et al, 2023). One of the downsides to this is the inability to access formal support and some autistic people then turn to online autistic forums and groups. Unfortunately, some of the users of these are highly sceptical about the validity of self-identification (Sarrett, 2016). Within this study 3 of the women had self-identified as autistic, but 1 of these had gone on to obtain a formal diagnosis.

Because autism only emerged as a diagnostic criterion from the 1960s in the United Kingdom, many of the older women in this research missed being diagnosed as children. Indeed, many of the older women only received a diagnosis as an adult, and some felt they had not been diagnosed as children because they did not appear to have significant challenges.

There are very few people over 50 who were diagnosed when they were children who are able to talk about it, because most of the people who were diagnosed when they were children had such complex needs that they can't articulate their problems. So, there are few of us diagnosed, the diagnostic criteria have changed and broadened out so that more of us do fall within it, but we are only just the first generation to age that know we are autistic, and we are articulate. So, I think we are at the front of the wave washing over people which is why they are so worried about the cost of autism as they call it.

Isabel, 57, freelance project manager

Seeking a diagnosis as an adult was perceived to be difficult by participants, underlining the results of previous research cited above. This could be because other gatekeepers did not perceive them as autistic and therefore made seeking or receiving a diagnosis

difficult. Autism diagnosis could also be a difficult and frustrating process where participants had previously received other incorrect diagnoses or had sought diagnoses for co-morbid conditions such as dyslexia or dyspraxia. Seeking a private diagnosis was also prohibitively expensive for most people.

At the minute I don't even have an official diagnosis of dyspraxia which I should have, it all went so badly wrong at work. So the chances of me getting an official diagnosis of ASD I just can't be arsed to go through with that at the minute because I'm still struggling, because I know I am and need a diagnostic report for the dyspraxia from a psychologist to be able to go to my GP because otherwise I'm just going to be waffling and not be able to get the words out, so I want something official to go to my GP with.

Yvette, 40, working in a university disability and dyslexia service.

I got my diagnosis by an expert. Well basically it was paid for by my company. I work for [REDACTED] Police, and I was having a few issues and erm they had a lady in the control room where I worked that had the condition and who thought that I had the condition as well. Obviously she has a lot of the traits and I initially went to the doctor to try and get a diagnosis but they wouldn't put me through or pay for an expert because it was about £3000 for a private diagnosis and erm the doctors weren't prepared to pay for that and I ended up with a psychiatrist like person who said as far as he was concerned I had the condition but wouldn't confirm for definite. And then that wasn't good enough for my company. So, they actually then found an expert locally to us and actually paid privately for me to go to him and have a diagnosis, yes or no, and he came back and confirmed that I had the condition.

Teresa, 39, civilian resource planning assistant with the Police service

There were mixed views about the benefits and disadvantages of an early over a late diagnosis. Many participants felt very clearly that if they had been diagnosed as a child their

lives could have been different and they could have avoided being bullied or having to mask their identity.

My diagnosis, if I had been diagnosed as a child, may have been different because they do say that diagnosis as an adult is quite difficult because of the learned behaviours that you have. So, you know, a mild to moderate as an adult, a 32-year-old adult, had I been diagnosed as a 10-year-old child, would I have been different? Probably I would have been. I am what I am, I live with what, you know, as a child I would have probably got more support than I would have done as an adult, but you can't turn back the clock unfortunately. So, you just get on with it.

Teresa, 39, civilian resource planning assistant with the Police service

However, some participants felt that receiving an early diagnosis may result in more limitations through being labelled with a 'spoiled' autistic identity. The autistic person themselves may have also had different ambitions or aspirations.

Most children are being diagnosed now by 9, and so they are spending their life being autistic and society is telling them, telling people that are autistic, that there are all these jobs, programmes on TV isn't there, that you see just lately about people that are trying to get jobs. The media is putting that out that autistic people don't get jobs. It's in the research isn't it. Autistic people don't get jobs. The statistics, all parents are given the statistics, your children will not get a job, whereas those of us that have gone through life and we knew were different and we knew that we found things difficult, we didn't have the expectation that oh we're not going to have a job so we muddled through and I think that very much how I've gone through my life and very much found my way, muddled through, never really given up, just kept driving really and sometimes it's worked and sometimes it hasn't worked and I think that kind of needs addressing somehow for other people coming through in order for them to be able to function better and have their work future and potential.

Debbie, 51, manager of surgical private practice and part time MA student

6.2.1 Impact of receiving diagnosis

For many women in the study the **impact of receiving an autism diagnosis** seems to have been transformative in their personal and working lives. This concurs with recent research suggesting that when autism had previously been unrecognised, an adult diagnosis can lead women to increased self-compassion and much less self-criticism (Murphy et al, 2023).

It made me realise, with hindsight, how much more effort I had to put into my career, how much more stressful it had been for me (compared to the average employee), because I had to pretend to be someone I'm not. Just doing a normal 9-5 office job was stressful for me, because of all the people around me, the noise in an open-plan office, lack of control, meeting new people, ad-hoc demands that interfered with my routine etc.

Ellie, 37, Unemployed – writing a book and living off savings.

Diagnosis was an affirmation of me as a whole person - I could include all the bits of myself that I had hidden away or tried to escape from and didn't understand - it was life changing - on an internal level. This has happened gradually though since my diagnosis. Real differences with 'coming out' as I have always masked my autistic traits and have 'passed' to be able to work/earn a living to the detriment of my sense of self. So much damage, so much dissociation over a lifetime. A lot of the time things were ok because my *raison d'être* was to fit in and to do this well enough. I can look back now and see that the mistreatment I experienced in various jobs was a result of my autism - this has made me feel a huge sense of relief, because I realise that I wasn't stupid, or bad. And I realise that I have spent a lot of time at work in some of the jobs I have had just not understanding things but pretending to....

Gabi, 50s, Cultural Engagement Officer for a District Council

Gemma found that the diagnosis helped her in the workplace to unravel her frustrations with autistic workers, and what they in turn were thinking, suggesting the value of diagnosis to starting to work on the double empathy problem.

I think it's made me understand my frustrations when I get frustrated at work sometimes I'm able to kind of reflect on that and think it's that I'm thinking differently in this situation to what they are, and the different perspective and understanding why I'm so frustrated with people and I think before I had that attitude of erm why are they doing that, why are they thinking that way, they're like not just being able to understand and erm the way that somebody else receive something or the perspective they might take and actually now I can think that yeah I am I'm thinking differently I'm perceiving this differently to them and that helps to manage my frustrations at other people.

Gemma, 20s, Residential carer for young people

6.2.2 Diagnosis disclosure

Some women had **disclosed their diagnosis** to their employer, either on applying, or subsequently once in post. Some women argued that the benefit of pre-disclosure was that they got the opportunity of adjustments being made to the recruitment process, whilst later disclosure meant that they perhaps avoided initial stigmatisation by their employers or other employees.

I disclosed about 4 weeks into my current job as I wanted people to get to know me beforehand. I was struggling a bit with the lighting in my office being too bright, so I told my team leader I've got Asperger's (I call myself autistic in private but Asperger's to people who I think don't get it fully) and that it just means I get a bit stressed and fatigued sometimes cause of sensory input and it was fine! In my past job, I disclosed autism, but management suddenly started treating me as though I had an awful disease that they didn't want to ask about. It made me feel like sh*t, to be quite honest. Very isolated.

Olivia, 23, part time insurance salesperson/developing own creative business.

Yeah possibly I think I think in terms of getting through that interview process and actually if it's you know if it's possible for adaptations to be made then to help me, then I would because at the moment obviously you know you know I do struggle

with that interviews I do struggle with that process and it's not about my knowledge or what I know it's about how it's erm how it's put across and erm certain exercises that you're asked to do that you know I struggle with.

Gemma, 20s, Residential carer for young people

In some instances, however, disclosure appeared to result in stigmatisation due to the lack of knowledge and understanding about autism by the employer.

When I started at the [REDACTED] Technology School, I declared my disability. I got a taxi from home to school paid for by Access to Work – the government. They would have paid for a teaching assistant to help me, but the school were so slow in organising this that the opportunity was missed. With this help I may have survived until the school closed in the July.

In the end it was detrimental as they said I could only work for 3 days per week, on 60% of the pay. I actually needed to work five days per week so that I had continuity of classes.

Zara, 53, former maths teacher currently studying for a part time PhD.

I'm losing confidence in organizations ability to treat people well on disclosure. Cos, I thought, the fact that this is a DDA in the university, I work for them, and they are treating me as badly as they are is kind of making me lose trust in going to other organizations who are not supposedly knowledgeable on this. So, I kind of think well they're supposed to be the ones who are good at this stuff, but if they're not good at this stuff what hope have I got going somewhere else.

Yvette, 40, working in a university disability and dyslexia service.

Many women who self-identified or received a diagnosis later in life had not disclosed at any point and were debating whether they would do so in the future.

It's only been a relatively recent discovery, so I've not had to deal with this yet. I think it will depend on the job and employer if I decide to disclose this. It also

depends on getting an official diagnosis because I don't think I'd feel confident to say I have something without it.

Pauline, 41, former hairdresser, currently home educating autistic son.

6.2.3 Disclosure of other co-morbid conditions

Some women had not disclosed their diagnosis but had **disclosed other co-morbid conditions** which they felt were also not always dealt with sympathetically by employers. In the post-Covid world it would be particularly useful to gain an understanding of whether employers are now more open to the type of hybrid working that would enable autistic women with co-morbid conditions greater flexibility to deal with their symptoms.

I haven't disclosed Autism as I haven't worked since I received my diagnosis. I think this is detrimental and had I been diagnosed sooner I would have disclosed to my most recent employer who seemed well able and willing to make reasonable adjustments.

I have disclosed bowel conditions, PMS/bad periods and more recently stress/anxiety. I don't think disclosing these things was particularly detrimental but the culture around working at home in the UK is more suspicious than abroad and I feel that my working from home when unwell definitely had a damaging effect on my career and my stress levels.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

6.2.4 Self-stigmatisation of diagnosis

Women's responses to this question often revealed their own self-stigmatisation about having a disability or being autistic, or their perception of the societal stigma of autism due to the public's lack of knowledge and understanding.

I was not diagnosed when working. I had realised I might be autistic whilst working in Payroll but didn't think of it as real until diagnosed.

I would worry that people would assume that I was stupid or cold and unempathetic. I am none of those things. I just don't always project my emotions well and loathe small talk.

Fabia, 36, currently a stay-at-home parent

I don't know because one half of me the very naive part thinks, you know, yeah I should be able to tell them, and you know they should do all this but in reality just what I've experienced in people you know even if they say 'oh yeah ok fine', you know, with anything, not just cos of that, you know, something else, ulterior motives would be going on in the background and I think they could then use it against you because I think no matter what laws or systems are in place it is always subject to human failure ... people in really high positions can do really bad things, so I just think it would be really hard to trust and I also think that if you put it on a CV when you apply for a job you probably wouldn't even get an interview in a lot of cases because I think a lot of people just wouldn't know what it is and even if they had a vague idea they would be no, no, no its a disability, that's a headache, you know. I would probably think twice before disclosing because as much as I'd want them to do the right thing, they rarely do which I find hard to accept but they rarely do.

Helen, 40s, former university administrator currently working for husband's business.

It was very clear that all the women found the issue of disclosure challenging and there was no support available to help them with this decision.

I told one person in my team who is very caring and motherly to the rest of the team. Having her know was helpful at first as she was able to give me some extra guidance. Since then, most of my team has changed and I haven't told anyone new mainly because it hasn't come up. I find the idea of having a 'disclosing conversation' really awkward without a big reason to have it. Many people have a strange idea of autism, and I might not fit into it so they are likely to ask lots of questions that I am not comfortable answering. One of the reasons I wanted a mentor in this space was to help me approach that conversation.

Agatha, 25, Associate Technical Business Analyst in a leading financial firm.

6.2.5 Seeking support or adjustments

After self-identifying or receiving a diagnosis, many women were able to **seek support or adjustments at work** (see also 7.9 in Chapter 7).

After I received my diagnosis it put my mind at rest as to why work sometimes leaves me feeling so overwhelmed. I was finding being in a busy office around people, loud noises, music, and general office buzz quite stressful, often meaning I was exhausted and unable to finish my work on time ... I was able to approach my work and ask for support. Initially they were reluctant to help, I believe this is down to the preconception of an adult with Aspergers being less 'normal' than I am or having more learning difficulties. They found it hard to believe an articulate, educated female could have Aspergers too. However, after multiple visits to occupational health, a Dr was able to provide a letter ... and my work were then duty bound to make the adjustments for me. Since my diagnosis, I've been given a laptop and am able to work from home for 1-2 days a week or whenever I'm feeling overloaded by the working environment. I am also allowed to adjust the lighting and music is kept to a minimum or relaxing tones. My manager and colleagues are also able to give much clearer instructions to me, without using so many metaphors. They also now understand why I may ask questions or want to know the finer details of a situation as before if I asked detailed questions, they would begin to feel annoyed.

Ingrid, 30, Cyber Crime Intelligence Officer

It has made me much kinder to myself – I accept why I'm different and try and come up with strategies to help me cope. I don't force myself so much to try and present neurotypically when I'm in my free time (although I do mask when I'm at work). In terms of work, it's helped me to understand why I don't want to socialise with co-workers outside of work, even though they seem to enjoy it. I just excuse myself and say I don't want to. Before I would have worried about being looked on down for not joining in and so may have gone with them and drunk too much and been hyperactive (hyperactivity is a symptom of stress response/meltdown). I've realised

that receptionist work is probably not best suited to me as I often have a blank face and don't respond with the "correct" facial expressions. When I have to participate in situations where I feel extremely uncomfortable and socially inadequate (meetings etc), I coach myself internally and say it'll be ok and it'll be over soon, whilst trying to keep a gist of what's going, control my face etc etc. I no longer beat myself up over my feelings of inadequacy and spiral into a silent panic attack. I've realised that I'm good at and enjoy data input and analysis and so I veer my work towards those.

Jan, 33, office manager

Steph, reported having a very supportive team leader who had worked with her to gather statistics to prove the efficacy of an adjustment, and had made a presentation to win it:

Because of the background noise of people typing on their keyboards, those awful lights, you know the normal ones that, skylights, skylights which of course are, I've been told by my support worker are a big no, no for people with disabilities, but you can't really tell them the truth. We've got skylights, we've got all tapping on computers, people going up and down, so it's very, very noisy, and my team leader went to the AD of the company and did a whole presentation on how an iPod or an audio cassette could help me to concentrate and she showed them I could improve with that and yeah she got it. It took her weeks and weeks to do this presentation because she had to sit there with me, and I had without and with so that she could show the figures to them. Because they like to know figures.

Steph, 25, Contact Centre administration worker.

6.3 Reappraisal of working life

The process of diagnosis had had a significant impact for some women, causing a **reappraisal of their working lives** and reshaping their ambition.

I trained as an accountant straight after leaving university. I worked until June 2015, when I quit my job to write a book. This is partly something I've always wanted to do,

but I also felt that I needed a break from the office, that I couldn't continue working 9-5, that I was burnt out.

Ellie, 37, Unemployed – writing a book and living off savings.

I think I need to be more creative about my working life now ... looking back now ... it was difficult for me to function well in a team environment because I was so conscious of myself and how I was mixing with others and I would ruminate for a long time afterwards and get very stressed about communications and whether I was doing it right or wrong or not, and I've since discovered that I had a lot of sensory triggers and I have a lot of need for down time and things. So, I think from now I will look towards becoming self-employed rather than being an employee so that I can be more in control of my work. So that's the way I see forward for me from now.

Debbie, 51, manager of surgical private practice and part time MA student

6.4 Masking

Many women directly observed the **masking** that they did at work to 'fit in' at the workplace. This might involve having a whole performance of dressing differently or appearing to have a more 'bubbly' personality to appear 'normal'.

I do between two and four days a week at the gallery, for a few hours a day. That is a complete performance from the minute I walk in there, that's a performance. So, I'm very nice and very smiley. I remind myself to constantly ask other people about themselves. So, although I want to really pick their brains because, as a struggling artist I want to know how to be more successful, I do tell myself all the time don't talk about you, talk about them, how they're doing and stuff. Yeah, I have certain clothes that I only wear at work and, this has been the most successful job I've ever had because, I'm not doing it full time. So that performance is copeable with. But to have to perform like that full time is really hard. And I always have done, I've always put on a performance at work, but there have been times in the past where it's slipped and that's been really difficult. You have to be normal and I'm not

normal. But I'm trying to be normal, trying to be friendly, trying to, yeah just kind of fit in and not stand out too much and yeah just try and be normal really.

Brenda, 52, artist

I dress smartly, I make small talk, I'm more polite than I used to be, I try to be upbeat and pretend everything's fine, even when I'm feeling depressed. I pretend to be someone I'm not, but no matter how hard I try, I still don't fully fit in, and other people notice. Some people are more tolerant of my little quirks than others.

Ellie, 37, Unemployed – writing a book and living off savings.

After dropping out of Uni I ended up starting work as a receptionist in a very busy Architect's office on Oxford Street. I felt I could apply for this job as I present as quite "normal"/neurotypical, and I have seen representations of receptionists on TV and in films so often that I could mimic what to do and draw from that.

Jan, 33, full time office manager in the City of London

Some women described how they would have to appear to be a blank canvas, stifling their own personality to fit in with colleagues and show the 'correct' response.

I've had to temper my initial reactions to things in such a way that I must impose a 'blank mask' on my face when listening to instructions/comments until such point I feel I can 'fake' the appropriate reaction. It's incredibly exhausting.

Ursula, 29, Data Officer for local authority Pupil Referral Unit

I also felt as if I had to stifle my whole personality in order to 'be' a teacher. I always felt like a square peg. My colleagues always seemed to be thinking totally differently about everything. This led to me feeling isolated, and as if everyone thought I was odd. It made me a bit paranoid about what people thought of me.

Eve, 37, Teacher

6.4.1 Effect of masking

Many women commented on **the effect of masking** and the strange effect that the workplace performance had on them, and how tiring this was, both physically and mentally.

For me, being at work, involves pretending to be someone I'm not and its hard work. Now, at the age of 37, I am taking a year out. I am probably suffering from burn-out. Even though my last few jobs haven't been stressful in terms of the workload, I just need some time to myself, away from the office environment.

Ellie, 37, Unemployed – writing a book and living off savings.

I am a mimic and I quite often mirror the people I am with to fit it as I'm not sure about the rules or conventions. So, I think I am a different person at work than I am in real life. I have to present a particular face and persona in the workplace. This 'passing' has a very very draining effect on me. For example, I am going to work tonight and am absolutely dreading any interaction with the public as I find it so taxing. This is a cumulative effect of doing it for so long and I am sure that after a break I would be able to do it again a bit more successfully.

Denise, 34, Police Sergeant and Community Policing team leader

I definitely feel that until the last three years ago, when I was diagnosed, that I haven't been able to be the real me and that I've gone from pillar to post, from job to job from relationships to settings where I've not really understood me and I've not really found it easy to fit in anywhere so that in order to fit in I've spent most of my life mirroring people and that's one of the masks I've work. Every time I've moved into a new place, I've picked somebody or something, a role model or an image or something to mirror so that I can fit in. That's really quite exhausting and you end up after many years of doing that completely confused about your identity. So I'm just spending, I actually started this therapy in February this year, that is all about me unpacking all the mirrors and masks that I've sort of adopted over most of my lifetime and through all my jobs when I did, you know, trying to fit in with people, and relationships, and now taking them all away, peeling them away,

like you are an onion, and the person that is underneath, and I'm very keen on finding that person from underneath to make sure that the next part of my life, the second part now is the real me doing what's good for the real me, and following the path that I want to be following.

Debbie, 51, manager of surgical private practice and part time MA student

6.4.2 Stigma from performed identity.

Many women also felt significantly **stigmatised** from having to perform a separate identity.

Well, you're never your real self. You have to cover up your real self all the time because your real self is unacceptable. The way that I think, the way that I view the world, is unacceptable. The stuff that I'm interested in, is weird and unacceptable. The way I would dress if I was allowed to be myself, is weird and therefore unacceptable. Holding yourself back when you couldn't, you can work fast, you can see the problems, but other people can't because they're not gifted with the same way of seeing the world as you. That's quite difficult. Performing what do you think an acceptable, white, female is. But it's always been a performance.

Brenda, 52, artist

It's created distance between me and people. How could I ever connect when they're not meeting the real me. The entire work-me is a façade designed to get people to leave me alone to get on with it. It's been isolating. But I fear that letting it all hang out could result in a different kind of judgement.

Fabia, 36, currently a stay-at-home parent

I feel that who I really am would not be accepted, and I have loads of experience of this i.e. mistreatment, but as I have become more and more aware of how I disguise my autistic traits and how damaging this is and has been - I feel I am being more me (hence the colleague's comment "you've become worse since you told us") but difficult to gauge this, and still trying things out tentatively e.g. I used to try

desperately to join in, it did work but it got me to a place I didn't want to be... e.g., constantly drunk.

Gabi, 50s, Cultural Engagement Officer for a District Council

6.4.3 Impact of masking on health

Masking and performing a different identity also had an effect on the **health** of some women.

My work persona could only be sustained for short times. Once I got home, I had to do the rest of my work so I had no downtime or relaxation. I was constantly fighting to keep up and frequently sick with a virus or infection of some kind as my battered immune system couldn't protect me from what lurked on the copier buttons or kettle handle. I worked hugely on myself to be a trainer; part of the programme I trained involved detailed feedback sessions with other coaches. It was very useful. I was taped and even videoed and critiqued. Someone told me I have a 'nodding dog' tick. Which is true. I had to pretend that I could stay in that environment for minimum 8 hours a day. I had to pretend that I could endure the noise and the smell and the challenges. I now realize that a career based on this false persona is harmful and that it's not something I can sustain without damaging my health. I am considering what to do next but the idea of returning to the corporate world makes me sick so I don't think it will be that.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

When I'm at schools I think that's also why I'm so tired I have to put on this act of energetic kind of teaching mode because a lot of the teachers there are naturals with the children. ... I find I'm having to put a front on the whole day to also be this like happy young teacher person that knows what they are doing and that's really exhausting, and I ... think that's why I end up cancelling work when I work two days in a row because I can't keep it up and I do it for one day and the next day I'm just like I've gone into school where I'm just a zombie and people are asking me 'are you

ok, you look out of your depth'. I'm like this is just my resting face I do look out of my depth most of the time because that's just how I look, and yesterday I was putting an act on to just look more happy and energetic.

Sandra, 26, special needs support assistant and part time PhD student

6.5 Self-awareness of autism identity

Ultimately the rejection of masking resulted in some women being more **self-aware of their autism identity**, and more aware of the changes required in society.

One of the things that I didn't like about deciding I'd got Aspergers that I'd always thought that everyone else was really weird, but actually then you think oh maybe it's me actually who is different to everyone else rather than the other way round.

Amanda, 40s, freelance financial analyst in the banking sector

After a lifetime of trying to fit in I now believe that it is time for others to make changes... I feel passionate about this - I believe that the social model of disability benefits all, and 'accommodations' only need to be set down as such because society/employment, is based on specialised ways of being which have become the 'norm'. We have already made too many accommodations in order to fit in, most to our detriment, which remain unacknowledged sometimes even by ourselves.

Gabi, 50s, Cultural Engagement Officer for a District Council

One woman reflected on the impact of being autistic and how this had affected her career changes and ultimately led her on a journey of self-awareness.

With hindsight I can see a pattern that wasn't visible to me before – I have a tendency to change employment abruptly for reasons that are to do with my perception of myself in a certain role, the pressures of the role, and my professional relationships with other people. Depression also has a lot to do with it, but I believe this to be directly linked to my Asperger's, so it is all related. I was finally able to make a huge change in my working life – giving up full time teaching – when I was

able to confront the knowledge that I have AS, and the challenges that had made my working life unbearable. Through CBT counselling I was able to see that I don't have to keep on doing something detrimental to my mental health, just to make myself feel that I am keeping up with my peers – I am allowed to look for an alternative! I now see myself as a strong person who has faced daily challenges without any support all my life, rather than someone weak and incapable, who isn't able to hold down a job long term.

Eve, 37, Teacher

6.6 Job seeking activities

Whilst some women found it easy to carry out **job seeking activities**, others found this extremely challenging, especially where it involved activities such as telephone interviews. Some women appeared to use particular skills to adopt successful strategies.

I find I'm pretty good at seeking work and marketing myself to the point I often give my friends/family career and CV advice. I think I have an eye for working out exactly what they are looking for in a new employee and ensuring my CV/Application form answers exact keywords or phrases they are looking for.

Ingrid, 30, Cyber Crime Intelligence Officer

I learnt a few techniques as a teenager from a TV show that have always proven successful for me! I mirror the interviewer's body language, and smile and open my eyes wide when I talk, as well as ensuring that my body language is 'open'.

Fran, 32, currently a full-time home educator and volunteer administrator for a home education group

On the other hand, many women found some aspects of seeking work particularly difficult or overwhelming.

[I'm] not very good at it, don't really know how to sell myself beyond just talking about what I've done. Don't really ever know what the employer/recruiter is looking

for as job descriptions are either very generic and vague or ridiculously specific ruling most people out.

Ursula, 29, Data Officer for local authority Pupil Referral Unit

Seeking work, I struggle with anything that involves phones. Email and online is so much better. I wouldn't even apply for a job that started with a telephone interview.

Fabia, 36, currently a stay-at-home parent

Some of the women were at a stage in their career that they were able to rely on recruitment agents or consultants to find work for them or place them with a client.

Fortunately, as a qualified accountant, I can rely on recruitment agents to do that work for me. I can't imagine being self-employed and having to market myself. I wouldn't be any good at it.

Ellie, 37, Unemployed – writing a book and living off savings.

6.7 Job interviews

Research suggests that inclusive recruitment practices can enable more autistic people to access employment (Erickson et al 2014), however there are some areas which can be more problematic such as the interview process. Active research with autistic and allistic job seekers has now identified specific support and adaptations (Maras et al 2021) that employers can make to assist autistic job seekers with interview questions. In this study some of the women recognised that they interviewed particularly well and that they had been successful in this by drawing on their strengths to research the role and the company in detail and some were then able to use this research to 'perform' as an ideal candidate. This underlines the point that there is no 'generic' autistic person or autistic woman, and therefore it follows that generic accommodations will not be appropriate for everyone and that an individual approach needs to be taken and time invested in providing individual responses and accommodations.

Although I get very nervous, I think I've always been quite good at interview stage. This is down to meticulous preparation and large amounts of research into what the employer is looking for and fitting this into my pre-prepared answers beforehand.

I think as I'm so well-practiced at 'putting on a brave face' interviews feel just like a heightened version of this. I've been told I don't come across as nervous at all, but inside is a different story!

Ingrid, 30, Cyber Crime Intelligence Officer

I can act my way through interviews pretty well if I can get there but I find the process very difficult particularly if I end up put in a position to socialise with other candidates – it's expected to say 'good luck' to them but that's not what I want to say at all – I want to get the job not them!

Ursula, 29, Data Officer for local authority Pupil Referral Unit

Some women identified that interview questions were a problem for them as they were often too abstract.

The worst interview I ever had was one question, "Tell me about yourself and why you'd be good here." That was it. It was awful. I had no idea where to start or finish. I was lost.

Fabia, 36, currently a stay-at-home parent

Abstract or open-ended questions also posed many of the women with a dilemma in trying to identify what the 'correct' answer might be.

I'm not actually that good at interviews because of the structure of the questions ... I don't really know what they mean. Again, interviews feel like a little bit of a dance that I'm going to ask you something and you're going to answer it in a very specific way whether it's true or not. I've failed at interviews because I just don't know what they want in the question it's too abstract. I remember going for a contract interview once and they asked me something about 'Will you be able to manage to

complete the work within the time frame' or something like that and I said 'What do you mean by that' and they said will you be able to do the work in time, by the deadline day, and I went 'well of course I will otherwise I wouldn't have applied for the contract in the first place' because the deadline was in the contract. So, I kind of understood the question but I didn't know why they were asking the question, because surely anybody who couldn't have done it, wouldn't have bothered to reply because it was very clearly ... So, I end up looking awkward and looking difficult, looking like I'm being pedantic. But it was 'why are you asking me a question, the answer of which is, what am I going to do, say no? I've come all this way I'm at an interview.' I did do one where my application, the feedback I got on my application was that I hadn't answered the questions in quite the way that they wanted, and I did actually write back and say your questions are extraordinarily abstract ... you've told me that you want people on the autistic spectrum to apply, but actually I think that your procedure discriminates against people on the autistic spectrum because your questions are too abstract.

Nadia, 46, self-employed autism consultant and trainer

I look great on paper but fail at the interview stage because of either saying something in opposition, or just missing the point completely of a question. I applied for a librarian position at the public library and in the interview was asked if I was a member – I replied 'No – if I want a book, I buy one'. Cue shocked librarian who made some comment about how I obviously had lots of money if I did that. I meant that when I buy a book, it's generally one I'll read over and over, or pass on to friends, or I'll take ages to read depending on how I'm sleeping, so getting a book on a time limit doesn't really suit me. But it's things like that why I don't come across well in interviews.

Pauline, 41, former hairdresser, currently home educating autistic son.

One woman illustrated how the abstract nature of interview questions caused her to give different answers to an allistic interviewee and this has been demonstrated in a study (Maras et al, 2021) with unadapted interview questions and a field of autistic and allistic

participants. Here employment professionals recorded lower ratings of autistic interviewees answers and their perception of them, in comparison to allistic interviewees. This research further looked at adapted interview questions where autistic participants were still rated less favourably than allistic participants, but their answer quality improved significantly whilst the allistic participant's responses did not.

I used an analogy ... gave them an example that they can relate to. I said if you turn round and ask me in an interview what would I do if there was a fire in the building. I said what would your answer be, and they said well they would escape by the nearest fire exit, and go to the muster station and you know, answer their name. I said fine, but for me it's not that simple, because the first question I would ask is where's the fire, in my head, is the fire in front of that fire exit, because if it is then I can't get out the fire exit. Is the fire exit blocked in some way, because again, I'm not given all the criteria I need in order to make an answer? So that's the first thing I would look at, is the exit blocked, how do I get out the building, what's the other options. How do I even know if I'm going to get out, if I'm in the middle of the room and its toxic smoke, I might not even make it to the fire exit, you know. My problem is with the scenario that there are too many other things in there that could prevent me from giving an answer. So, in order for me to answer the same as everyone else you've got to give me all the parameters ... I can then be on a level playing field.

Teresa, 39, civilian resource planning assistant with the Police service

Some women identified that telephone interviews proved much easier for them than a face-to-face interview as they did not have to concentrate on the other person's face and interpret what they were thinking or doing.

I found the telephone interview easier because the face to face is just so much work, the distraction involved, then my anxiety gets a bit too strong and then I can't really think ... Their tone of voice, their facial expressions, I'm not sure what they think, and I'm just trying to think what they think, and if I'm doing the right thing for them, am I saying the right thing, and um I'm constantly checking if I'm doing ok, it's very

distracting. My mind can go blank suddenly, so I prefer to look elsewhere, I know what it is I want to say but the sentence in my brain, cos I know that in those situations your frontal lobe is just like 'shut up' and you've got really an excess of information. I really feel that's what happens to me.

Lena, 20s, seeking work as a classroom assistant.

Some women also expressed opinions about assessment tests and their ability to complete these.

I'm not good at doing my OPA (self-assessment online for appraisals) I don't like to blow my own trumpet as I see it as bragging about stuff people should already know I can do.

I didn't used to have trouble in interviews as, being oblivious, I got through with high test scores and “quirky life story” anecdotes. Nowadays I can't pass an interview as they are all about these Extrovert Competencies which I am no good at relating the Competencies to what I have done...

Carla, 40, Software Developer

At my first call centre job they used psychometric and IQ tests to evaluate candidates. I was told I scored the highest they'd ever seen in those tests.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

6.8 Self employment

Whilst many women had identified **self-employment** as an ideal job, the reality of the business and marketing side of this proved to be challenging for many.

I advertised and things, but I just wasn't any good at ringing up or putting myself out there too much ... I was kinda self-taught. I had a lot of difficulty going to meetings

and talking to people and I found I just didn't come across very well when I was trying to sell my work and things.

I think I was too laid back about it. I'm not a very good seller and so I think the people I was pitching at would have wanted something a bit more, a bit cheaper and a bit more I guess someone who really knew what they were doing and understood better, and I couldn't portray that I understood what I was doing very well.

Sandra, 26, special needs support assistant and part time PhD student

Self-employment and entrepreneurial activity therefore appear to have both positive and negative constraints allowing the autistic woman to control the amount and type of work, but also introduced uncertainty such as finding the work and running the business side, therefore introducing anxiety.

6.9 Self-promotion and marketing

Some women found **marketing** themselves and their business fell into the area of a performance and found it a considerable strain to come across as 'normal', having to work out what a neurotypical person would do, and then how they could imitate that.

It's quite difficult. Marketing I'm doing now obviously in terms of, erm selling my products and selling myself as an artist. I find that quite hard because I don't know what people want to know and anyway why would anybody want to know, do you know what I mean. Particularly now I have to go on Twitter a lot and social media, talk about the business and I sort of think well really, is anybody really interested, if I just whine on about something that I just made. I don't know that they are, I know that I'm supposed to do it but, so yeah, I do find that quite difficult. But it depends what you mean by marketing yourself, that's quite hard.

Yeah, and I mean and I think once you've got the message out there once it's a quite difficult thing to keep repeating it. I have spoken to people who have said 'look don't worry about it just keep saying the same thing over and over again'. So, I have little bursts where I'm quite good at it and I can do that and then I have longer bursts

where I just think 'oh would the like that', I don't know 'would that be boring?' Because I'm constantly having to negotiate myself in terms of other people, people erroneously say that's a lack of self-confidence but I don't think it is a lack of self-confidence, it's just trying to be normal. It's trying to appear normal when you're not. It just becomes habit that you constantly assess how you're performing, I think.

Brenda, 52, artist

6.9.1 Social media

Other women found the introduction of new technology and advent of **social media** rather liberating and felt they were able to successfully make use of these in their business.

It's quite easy now online, because I've got a website and I'm quite good with technology which is nice because a lot of other teachers aren't, so I've got a bit of a head start there. So I've got a YouTube channel and my Twitter profile and I've got a music teachers profile which does generate quite a little bit of influx and I've got a blog and a website. So, once you've got all those things running, I don't really have to do much else. I've just got to make sure that I keep them updated properly and that's it really, that's all I really have to do. Most of the rest is just word of mouth.

Yvette, 40, working in a university disability and dyslexia service.

6.9.2 Networking

One woman particularly highlighted the issue of **networking** and the extent to which this is required in employment.

My work involves going to organizations, maybe delivering a day of training or something, so I might be there for a day. I'm appallingly bad at networking. I'm aware that I need to do it as a self-employed person ... I went to a conference and usually when it's lunch time at the conference I'm looking for the empty space, I'm looking for the corner, I'm looking for the place to just hide, and I saw a particularly influential individual sitting at a table by themselves and I thought, you need to go

and talk to that person, it's what other people would do, it's an OK thing to do, you know who that person is, so it wasn't awkward, I knew that she knew me, she'd been in my presentation and I thought this is what everybody else does just get on with it, just don't miss these opportunities and actually I think it was very valuable, ... she was fine about it and quite happy to see me, and we had a really good talk, and potentially there'll be some opportunities that I get out of it. Some things I told her about my experience that she didn't know, so it was good but it was like having a kind of coach on the sidelines going 'go on, go on, you'll be all right, you'll be alright' and me going <crying baby talk voice - want to go in the corner> 'What if she doesn't want to talk to me, what if she wants to be by herself, what if all those seats are being saved for somebody else in the queue. I'm going to look an idiot; I'm going to be brushed off'. That's always the kind of fear, so networking awful, if people talk to me, I'm fine, but if I'm the one that has to initiate, it can't happen. Zero.

Nadia, 46, self-employed autism consultant and trainer

6.10 Bullying and stigmatisation

Several women spoke openly about **bullying** in the workplace because they did not 'fit in' and were being 'othered' or **stigmatised** because of their diagnosis.

I was often bullied and didn't understand what I was doing wrong. Being bullied for not "fitting in" regardless of productivity.

Fabia, 36, currently a stay-at-home parent

Well, I'm a fairly forthright person, I say what I think, and I don't gossip and I don't get involved in workplace politics. So that singled you out. So, the person who is singled out becomes the target for anybody who wants to raise their own profile by being the joker, if you see what I mean. So somebody would tell a joke at my expense and I would laugh along and not realising that it was at my expense, and that was hugely entertaining to people so they would do it more and of course by the time the penny drops you've made a complete idiot of yourself really, I found,

and at that point my response, which I think is typical, in quite a lot a people. Yes these were all before the diagnosis, except for the last one which was for a project management job, during which time I had the diagnosis and at which point I went to the person who was bullying me who was a Director of the charity, because I was a senior person in a small charity, and it was her who was bullying me, and I said if you continue to bully me that constitutes disability discrimination and I went to the National Autistic Society and I said can you offer this person autism training and they did. They rang up, offered her some autism training and the only thing that she wanted to know was whether she had the right to tell my colleagues that [I] was autistic. And they told her no she didn't, but she wasn't interested in actually hearing about women and autism, what she did was take a brief look at some of the material on the NAS website where she learnt about little boys and autism and learning difficulties. At which point her tactics changed to standing in the middle of the open plan office shouting at me what I had to do in words of one syllable and then bellowing 'did you understand that?' to which I had to answer yes or no, which resulted in me having complete meltdowns but I had the ability to go out into the car park to have them, so she never saw them. So, the bullying changed, and the NAS helped to make it really good. So, my next job of course was for the NAS. I think how they arrange what they do for 'consenting adults' if you see what I mean. They talk about 'them' to 'their carers' the parents of children. Having done three years putting adults and ageing material onto their website, the link is now where you can't find it and they don't provide any, not any, of their core funding for adults over the transition to adult period. So, whereas I would say two thirds of autistic people are over the age of 20, they ignore them so I'm not a great fan, I'm glad to be away from it. I was also told to call myself a person with autism while I was working there, though they have changed that at last. The view that I held made them change that.

Isabel, 57, freelance project manager

It was a factory, a charity, the employees were all blind or blind deaf people and I and they made toiletries and packaged toiletries and things like that. My job was to

measure the levels in the bottles of the toiletries and carry out statistical analysis and stuff on them. I left because somebody said something to me which quite possibly was probably just a joke, but I took it so seriously that I never went back. I just walked and just never went back. And it may well have just been a bit of banter really. He gave me a lift home, he was sort of one of the maintenance kind of guys and they used to sit in the corner smoking pot all day and they were jolly and they were friendly and that was fine and they knew that I lived with my boyfriend and you know I was a happily partnered young girl of sixteen and one of them gave me a lift home and as he dropped me off on a Friday he said 'What are you doing this weekend, going out whoring?' and it was probably not a particularly nice joke but probably just a bit of East End banter and I was so upset by that comment that he might presume that I was that kind of person that I never went back.

Nadia, 46, self-employed autism consultant and trainer

6.10.1 Long term effect of stigmatisation

Being stigmatised in the workplace also had a **long-term effect** on many of the women and appears to have impacted their self-esteem and mental health.

I never believed anyone liked me, even when I was repeatedly told that this was untrue. It always felt like a revelation to discover that someone had said something nice about me or my work. I also never got a card when I left my last job even though that was the normal procedure. I cried all the way home that day.

Olivia, 23, part time insurance salesperson/developing own creative business.

At one point I was suspended “for insubordination, poor time keeping and unprofessionalism” by my line manager who had little time for me and the feeling was very mutual. The head of the hospital heard the case and threw it out, saying he had no idea why I was brought up in front of him. My line manager was reprimanded but it ruined the job for me after that because not one person came forward and said, ‘hey this is wrong’. My mother was diagnosed with leukaemia not long after this, and I was signed off so I could help look after her. When she died, I was still

signed off with depression and chronic illness. I decided I wasn't going to return and handed in my notice.

Pauline, 41, former hairdresser, currently home educating autistic son.

6.11 Impression management

The autistic women seemed to be very **aware of other people's perceptions** of them and their skills and abilities. Some women shared views that seemed to reflect this balance of strengths and weaknesses.

They probably think I am cold, aloof, and unfriendly. But also conscientious, good at my job and keen to do the best that I can.

Kelis, 44, self-employed piano and keyboard teacher

I think overall people think of me as being friendly and chatty, maybe a little on the nerdy side. They know I am very thorough with my work and often comment about how other people will miss points, but I never do.

I think sometimes I can be seen as stubborn as I will have fixed ideas on how I want to do something, and I will often agitate people as I speak up if I feel something isn't right or if I/someone else is being treated unfairly in the workplace. This has led to quite a few disagreements with colleagues as I've found most people will just keep quiet, even though they are unhappy.

Ingrid, 30, Cyber Crime Intelligence Officer

However, some autistic women described very negative, and often complex, perceptions of them in the workplace.

Works hard. Aloof. Arrogant. Intelligent. Honest. Nice. Thinks she's better than us.

Fabia, 36, currently a stay-at-home parent

I think people are fraudulent in their “autism acceptance” at work. They can handle a cute 7-year-old boy who loves Sonic the Hedgehog, but they react badly to a grown woman who gets overwhelmed and stressed by the day and doesn’t act “sweet”. They can’t deal with the actualities of autism in adults, and they try to make us feel lesser because we aren’t immediately comfortable in their environment.

People think that I make them uncomfortable often or that I am stupid or weird. They don’t seem to realise that I think that they are prone to acts of stupidity themselves, or that their words can really upset me too. I am much better at tolerating others’ flaws than they are at tolerating mine. I don’t get other people’s jokes but make lots myself which I think is hard for people to parse. My intelligence is often undervalued because of my breezy naïve disposition, the fact that I’m hyper verbal and make lots of jokes, and the fact that my gaze wanders around the room. But I think that’s common to lots of young women at work, autistic or not. I struggle to get along with other women at work unless they’re really no nonsense in their approach and don’t go in for bitchiness or extremely complex social politics, and I am very cautious of men because I’ve been sexually harassed and assaulted so frequently in my lifetime by men who I thought I could trust.

Olivia, 23, part time insurance salesperson/developing own creative business.

I’ve been told I am too stressed, too anxious. My face in meetings is not well controlled. I look grumpy and unapproachable when I’m concentrating. I don’t know how to say no. I’m viewed as odd, peculiar but useful for odd things, approached with caution by new people who say, ‘so and so told me if I came to see you you could help me set up my voicemail?’. One of my managers called my thinking catastrophic and black and white, which made me laugh when I started to read about Autism. I was described by one person as ‘keen on recycling and cares about the environment’ and I know I’ve been described as a crazy cat lady too.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

Depending on the situation and job being done, women could be **highly valued** for demonstrating or using some skills or **stigmatised and othered** on the other hand.

I have been called the details freak because if I set up a shoot, which I know exactly where everybody's going to park their car, and it's hugely useful when time is money to have every detail worked out, to have everything planned, back up for it.

Isabel, 57, freelance project manager

Being regarded as very direct and sometimes abrasive has had a negative impact on my career. Some managers have been more open-minded, while others have severely criticised me. I've worked with men who were equally blunt, but who were simply described as "characters". As a woman, you are expected to be much more polite and considerate.

Ellie, 37, Unemployed – writing a book and living off savings.

6.12 Work identity

Many women felt that they had developed a defined **work identity** that they used or adopted. This often seemed to focus on the need to appear 'professional' and may have come about due to stigma about behaviour, either in themselves or others, which people defined as 'unprofessional'.

I want people to think I am professional (which they invariably do, but also think I'm aloof and arrogant, which I'm not), but actually it's a way to distance myself from people. I can get through the day and all its changes and interactions so long as it's office me performing. She's a set rule. I won't stim. I won't twitch. I'll be her.

Fabia, 36, currently a stay-at-home parent

I try to be the most professional, successful version of myself I can be.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

Some women felt that their **work identity was evolving** as their worklife changed.

I used to place importance on being a 'professional' – I used to enjoy the fact that being a teacher made me appear normal, competent, and responsible; whereas now I still see my identity as bound up with work, but the work is starting to move more in line with my true personality, aptitudes and interests. (I don't mean the supply teaching, of course, but the charity work, volunteering, and writing.)

Eve, 37, Teacher

This acted out 'professional' role extended in some instances, to the way the women dressed or physically presented themselves.

I call her Office-me. She dresses smartly (I don't), wears makeup (I don't), straightens her hair (I don't), never swears (I do). She is professional and efficient, and not me.

Kelis, 44, self-employed piano and keyboard teacher

I find dressing for work really hard. For my last job every morning I had to text a photo of what I was wearing to my partner and sister for them to OK before I left the house. Even with a 'uniform' of shirt and trousers they didn't trust that I wouldn't look daft for some reason. They are most likely right; I just don't really care so much.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

I have 'cheats' if I have to work in a place with a dress code because I hate wearing smart clothes, so I have some very stable heeled ankle boots and a range of really comfortable jersey dresses to wear in those occasions. Luckily my current job is casual dress!

Olivia, 23, part time insurance salesperson/developing own creative business.

Interestingly some women explained that it became confusing when their **differing identities came together in one place.**

I change personality depending on who I'm with. Especially, that actually causes me problems with friendship groups as well because if I'm with two people and I have slightly different personas I get really confused even within emails that I do, group emails, cos I use different language with different people because I know I'm using different people's language. So then when I write an email to person A and person B, because for some reason I've got to copy in them in, I don't know what kind of language to use and I get really, really stressed out because I mimic person A and then I mimic person B and then when I'm copy them both in I have a bit of a panic attack. But in terms of work I tend to, I find myself mimicking the behaviour a little bit of the person that I'm with so I am almost a different person for each student that walks in through the door. I change, I feel myself kind of changing as the students change. But I don't know how much of that is just being a teacher and how much of that is me.

Yvette, 40, working in a University disability and dyslexia service

6.12.1 Importance of work to identity

There were divided opinions on the **importance of work to the women's identity.** For some women work was unimportant and simply a means to exist, and there were sometimes very practical reasons for not wanting to be defined by their work, due to the emotional or physical labour involved from masking.

It is just a way for me to get money. So, I always approach jobs saying I'm just doing this for the money so if it doesn't work out that's ok, if I'm not the best, then it's ok because I just need the money.

Sandra, 26, special needs support assistant and part time PhD student

However, many considered that **work was central to their identity,** and that this often meant they physically spent long hours engaged in that work.

It is me, it's like there is nothing outside of it. - I mean employment and my own art practice - being an artist is my identity - it allows me to be who I really am.

Gabi, 50s, Cultural Engagement Officer for a District Council

My job is very important to me. I spend 45-50 hours per week in the office so it's a huge part of my life.

Agatha, 25, Associate Technical Business Analyst in a leading financial firm.

6.12.2 Frustration when unable to work.

Because of the importance of work to some women, they demonstrated **frustration when they were unable to have a career or were unable to work**, perhaps due to receiving incorrect careers advice.

I hate that I'm not currently contributing. I hate that I've never had a fulfilling career. All I ever wanted to do as a child was design robots. Why did no teacher or parent ever suggest engineering as a career path? Why was I pushed towards the arts when I loved maths?

Fabia, 36, currently a stay-at-home parent

Without it [work] I feel completely redundant, and like I have no societal value. I don't like being on benefits.

Fran, 32, currently a full-time home educator and volunteer administrator for a home education group

6.12.3 Boosting wellbeing and self-esteem

Many of the women expressed **pride in their working lives**, and the way in which work boosted their **wellbeing and self-esteem**.

It was always front and centre with me. I was never ambitious to climb to the top of the greasy pole. But not being very good socially, I identify, you know, I got my only self-esteem from how well I worked in television. It was very much about teamwork

and I'm very good at team work at work in places where everybody comes to work with their own, I mean I started what was, as I say a researcher, ended up as a producer at the BBC, and was involved with a lot of programmes, and I could lead teams and that wasn't a problem.

Isabel, 57, freelance project manager

6.13 Work vs home identity

Many women observed that they had very **separate and different identities at work and at home**. This might cover how they dressed, how they spoke, or executive functioning.

Office-me is tidy, organised, immaculately presented, self-aware, desperate to lose herself in a task.

Home-me is scruffy, disorganised, untidy, smiles more, likes to enjoy the moment, notice things, takes time to stim and relax.

Fabia, 36, currently a stay-at-home parent

A friend of mine once laughed at me on the phone because I completely changed the way I spoke, and she found this hilarious. I can't say I noticed I did that until she pointed it out. I don't speak about personal things at work, and I don't really speak about work at home so they're very much separate parts of my life. At least they were when I was working. I've always held positions involving confidentiality though so keeping personal and worklife separate was mandatory.

Pauline, 41, former hairdresser, currently home educating autistic son.

My work identity is more adult, competent, and efficient than my home identity, which suffers as a result. It is different because historically I have desperately put all my energies into surviving and keeping a job/money coming in, as I don't have a family to fall back on if things go wrong.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

Many women observed that having these dual identities meant that they had to spend some time at home adjusting or recovering from their performances at work.

I have to use my time at home to recover from work. I spend a lot of time by myself and doing my own thing at home, generally allowing myself to be autistic, which I can't do at work. It has to do with 'passing' as normal and getting by at work.

Denise, 34, Police Sergeant and Community Policing team leader

I change personality depending on who I'm with. Especially, that actually causes me problems with friendship groups as well because if I'm with two people and I have slightly different personas I get really confused even within emails that I do, group emails, cos I use different language with different people because I know I'm using different people's language. So then when I write an email to person A and person B, because for some reason I've got to copy in them in, I don't know what kind of language to use and I get really, really stressed out because I mimic person A and then I mimic person B and then when I'm copy them both in I have a bit of a panic attack. But in terms of work, I tend to, I find myself mimicking the behaviour a little bit of the person that I'm with so I am almost a different person for each student that walks in through the door. I change, I feel myself kind of changing as the students change. But I don't know how much of that is just being a teacher and how much of that is me.

Yvette, 40, working in a university disability and dyslexia service

6.14 Outside interests and identity management

Some participants identified other **outside interests as more relevant to their identity creation.**

I don't rate my current role as important to my self-identity. I see it as a method of paying my bills and earning an income, however my work creating my blog is a huge

part of my self-identity as it is where I express myself creatively. I find this outlet hugely important as part of my self-identity.

Ingrid, 30, Cyber Crime Intelligence Officer

6.15 Summary

The women in the study identified receiving a diagnosis as an important step in resolving their identity, but there were mixed views about whether an early diagnosis might open up different opportunities or whether this might actually become a barrier due to stigmatisation attached to having an autism diagnosis and the perceived doors this might close. Many women spoke about the value of the diagnosis in seeking adjustments at work or seeking a new direction to their career. During the reappraisal of their working lives post diagnosis some women were able to understand that difficulties in the workplace were caused by allistic workers misunderstanding and mistreating them suggesting that this is an example of the double empathy problem.

As seen in the previous chapter, the problems of disclosure often seem to centre on the reception of management and co-workers to the diagnosis when disclosing, and there was evidence of the women managing the disclosure by talking about environmental sensitivities or other co-morbid conditions rather than 'autism'. Although public awareness of autism is growing, this seems mainly to be about children in educational settings which is very different to autistic women in the workplace, and it was clear from the women that had tried to disclose that people's reactions were not always what they had expected.

The study amplifies the extent to which the women claimed that their working lives were a performance to mask their true personality or identity in order to fit in at work or directly mirroring other people. This practice is leaving the women stigmatised from performing a separate identity and extremely exhausted, both physically and mentally. This might also impact on the working time they could endure, which then has an impact on their income and potentially their pension income. There is evidence in some accounts that after 'performing' in a role at work some women were then going home to complete the rest of the work in a 'performance free' space. This was adding to their fatigue as they then had little downtime or leisure time. Some women also said that they had a separate

professional wardrobe of clothes to help them adopt a work identity and a very separate home identity.

Although inclusive recruitment practices meant that finding a job was supposed to be easier for autistic candidates the study shows very mixed experiences of this, largely due to the women's own confidence in the recruitment process. Some women treated it as another performance to be rehearsed and practised, whereas some women found it difficult to sell themselves, and were even more daunted by processes like a telephone interview which is often seen to be less intimidating for allistic candidates. It is therefore important that recruitment practices are scrutinised to ensure a level playing field for all candidates by offering a variety of interview modes.

The autistic women who had reached a higher level in their careers and were now working as independent consultants or interims were able to use their expertise and known value in the workplace. Recruitment agents would put them forward for vacancies which would prevent them having to go through gruelling and long-winded recruitment exercises. It would be helpful if this approach could be made available for every autistic woman seeking work, allowing the recruitment consultant to 'place' the autistic woman in a suitable work environment where they would be valued for their skills and where the woman would be well supported. Investment in this approach by Government and recruitment agencies could ensure many more autistic workers could participate in employment, and as a result enjoy better mental and physical health.

Whilst self-employment was identified by many of the women as an ideal job, there was evidence that many had not initially considered that they would also need to run the business side of the enterprise and carry out activities such as finding the work or marketing the service. The women appear to have struggled to carry out these additional activities, and this side of running a business or being self-employed, the interface with other people, appears to be a barrier to success and missing from the literature. There may be an opportunity for autistic business to business leads, but also a clear need for informed allistic business support services, equipped with appropriate equality, diversity, and inclusion training, to help autistic entrepreneurs.

The autistic women seemed to be very aware of other people's perceptions of them, sometimes very balanced strengths and weaknesses were discussed, but often very stigmatising, negative comments had been shared such as 'the crazy cat lady'. There was real evidence of cruelty from co-workers such as the woman who did not receive a card on her last day at work and cried all the way home.

6.16 Conclusion

This chapter focused on identity, anxiety and stigma and the theme 'wearing a mask'. To answer the second research question, how do autistic women resolve their identity in the workplace, they do this through identity work, impression management and masking, and that this can cause anxiety and stigma.

The findings suggest that prior to being diagnosed or self-identifying women were unable to resolve their identity in the workplace. There is evidence of significant identity work being carried on by the autistic women to function in the workplace. They describe this as exhausting as they would repress their own identity or traits to 'fit in' with other workers. Before understanding they were autistic this identity work led many to feel stigmatised or broken. After receiving a diagnosis or self-identifying the women were able to reappraise their careers and lives.

The findings also suggest that whilst having an autism diagnosis would allow a woman to access workplace accommodations which might improve the interview or employment experience, without a diagnosis an autistic woman would likely feel stigmatised in the workplace but would not be able to identify what they were being stigmatised for. Repeatedly facing this situation and experiencing the consequential stigma could result in a lasting impact on the woman's mental health and ability to put herself forward for the workplace. Further research could be useful for example to consider whether women are seeking opportunities where they are underemployed to minimise their contact with complex recruitment exercises.

It is also seen that some participants felt they had developed a defined work identity, often focused on the need to appear professional, and that as their worklife changed their work identity also changed. The professional role that some women adopted also extended to

the way they dressed or presented themselves (impression management). However, this ability to perform a different identity could become 'unstuck' in situations where two different group identities converged. Whilst some participants felt that work was simply a means to exist or that other outside interests were more relevant to their identity creation, others felt that work was central to their identity, and they spent many hours engaged in it. The participants who were not working felt that they had no value, and those whose careers did not fulfil their original intention felt frustrated. However, clearly some participants were particularly proud about their working lives, and this had increased their sense of wellbeing and self-esteem.

The diversity of the findings provides further evidence that autistic women or autistic people should not be seen as a 'group' identity. They are all very individual and unique and therefore allistic co-workers should not seek to understand what 'autistic people' all need in the workplace. There is no 'generic' autistic person or autistic woman, and therefore it follows that generic adjustments will not be appropriate for everyone and that an individual approach needs to be taken and time invested in providing individual responses and individualised adjustments and accommodations.

The findings demonstrate that identity work, stigma and masking all have a significant impact on the health and wellbeing of autistic women in the workplace. The next chapter entitled 'Lost in Translation' is the final of three findings chapters and examines the impact of the double empathy problem, the work environment and organisation. Many of the issues raised in this chapter on how autistic women resolve their identity are analysed in more detail in the final findings chapter which focuses on the final research question 'what challenges do autistic women face in the workplace?'

Chapter 7: Lost in Translation – the impact of double empathy, the work environment and organisation

7.1 Introduction

In the last chapter the second research question – how do autistic women resolve their identity in the workplace? was considered alongside the theme of ‘wearing a mask’. It was shown that predominantly autistic women seek to resolve their identity in the workplace through identity work, impression management and masking, and that this can cause anxiety and stigma.

This chapter focuses on the third and final research question – what challenges do autistic women face in the workplace? with the theme of ‘lost in translation’.

First, the chapter discusses work organisation, teamwork and sensory issues, before moving to consider anxiety and some specific triggers such as lack of control over aspects of work and job security. The chapter then considers socialising in the workplace before moving to a discussion on underutilised skills and the boredom which resulted. The chapter then looks at the physical and mental exhaustion or ‘autistic burnout’ mentioned by the women, before a discussion about soft skills or people skills in the workplace and unwritten rules. The chapter then discusses the available support that the women reported, before a discussion of managing perfectionism. There is then a discussion of the women’s experiences of managing other people, and of being managed. The chapter then concludes with consideration of executive functioning and autistic work ethic and approach to work.

7.2 Work organisation

In terms of **work organisation** there was a strong preference from all the autistic women for working on their own. Often cited reasons were that it enabled them to be more productive and more focused.

I work from home once a week just to give myself a break from all the noise and sheer amount of people at the office. This is another thing that has changed over the last several years, what with the move, and the horrible décor and even more open plan, the lighting.

Carla, 40, Software Developer

I love it. Leave me alone and I'll not only do my work, I'll come up with new and more efficient ways of doing it. I love to problem solve. Not having to worry about communication and interaction means I'm far more efficient.

Fabia, 36, currently a stay-at-home parent

However, some women noted that in some situations such as new work areas, they would need support and, in those situations, lone working could be detrimental.

I am ok working on my own if that is what the job needs – but not if I am in a situation where I need support and don't have it.

Gabi, 50s, Cultural Engagement Officer for a District Council

I prefer working alone in a sense as I don't like to feel management breathe down my neck and I don't get harassed by others; however I am a social being and like to bounce off others' energies. In addition, I can get distracted if I am working alone and get less distracted working with others who are also working.

Olivia, 23, part time insurance salesperson/developing own creative business.

Some women also noted that whilst they preferred sole working it could also lead them to feel lonely, particularly where they were self-employed and had limited support networks.

I work almost entirely on my own (with my students). I like the autonomy but at times it can get lonely. I'd like more contact with other music teachers. I think I am well suited to working on my own, and working with others all the time would probably drive me crazy.

Kelis, 44, self-employed piano and keyboard teacher

7.2.1 Team working

Many women felt that they were good at **team working**, although Xanthe, a 46-year-old freelance journalist and author, running a communications agency said “I am not good at teamwork. My working style is slightly haphazard, meaning others feel confused.”

Often this meant taking on a variety of roles within the teams, but several women indicated that they liked taking a lead in teamwork.

I’m actually pretty good at teamwork, especially if it’s brainstorming/planning/strategy. I do have a tendency to want to take over and do things my own way - and I hate delegating. I enjoy making a plan with others though and sharing ideas. I can get a bit over excited and forget myself sometimes – embarrassing in front of a boss.

Eve, 37, Teacher

If I’m in a team, I lead it. I’m not good at sitting back and having no opinion. I enjoy it in some ways, but I’m aware I can take over. I prefer to work alone. Just to be left with my workload and do as I please.

Fabia, 36, currently a stay-at-home parent

Why do I avoid teamwork? I either take over, or I don’t understand what is going on. I can’t read body language, so miss things.

Zara, 53, former maths teacher currently studying for a part time PhD.

In contrast some women felt they could not effectively make a contribution to teamwork, and that their voice would not be heard, or that their point of view would be considered odd.

I mostly choose not to. I’m usually silent, completely silent. I think I quite often doubt my conviction, so if I have an idea, I perhaps presume that it’s a stupid idea and that surely if it was a good idea then somebody else would have thought of it already, and there’s a whole bunch of people here that haven’t so maybe I need to

shut up. I think sometimes my ideas are a bit off the wall and so they're they're often knocked down quite quickly, even though sometimes it turns out that I was correct. So, I think it's a lack of courage of my convictions really.

Nadia, 46, self-employed autism consultant and trainer

I can come off as rude or defensive sometimes if I don't agree with others but over time I've learned to try and "keep a lid on things". I often am a bit controlling and lead the group if we're all at the same skill level, or if there are more qualified people in the group, I will be quiet and listen to them. I enjoy sharing best working practice in groups, as it's helpful for me to get better at my own job rather than just struggling alone. I welcome helpful feedback and take it well but if I feel like the feedback is personal or overly nasty, I get upset.

Olivia, 23, part time insurance salesperson/developing own creative business.

I don't mind a small amount of team work as long as I get on with the others in the team and they accept me as I am. However, I have not had much opportunity in my life to do teamwork. In a group I often close down and am very quiet, letting others take the lead. I usually will go along with what the group decides, I don't like arguments and find them very difficult.

Kelis, 44, self-employed piano and keyboard teacher

Some women's careers had been spent working extensively in team working environments. In these situations, they particularly highlighted situations where some people pulled their weight and others did not. The need for well-balanced teams was also highlighted in the way in which competitiveness developed.

Nursing is all working in a team ... it doesn't always work because some people pull their weight more than others and you can get bickering and you can get people sort of competing and that sort of thing and these kind of social politics of, you know, working on a team, being in a group in a work environment I find really quite difficult and I'm quite sensitive to it and I will often, you know, in passing if I felt things were

getting too competitive or over nasty or over back stabbing or whatever that sort of thing was, I would just get on with my work quietly and just try to stay out of things and once again it was all about trying to be positive, ... gaining from your work experience and not bringing competitiveness into it. I understand that other people are very competitive, I'm not. The only person I compete with really is myself. So once people start trampling on other people, I'm like, whoa, that's not very nice. I'm kind of wary of being trampled on myself a little bit so, you know, I always keep myself a little bit distant so that I don't get dragged into these things.

Debbie, 51, manager of surgical private practice and part time MA student

I'm rubbish at teamwork. I think this is my biggest problem with employment. I can't, I find it really difficult to work in a team and it really stresses me out because I don't, I can't, control what other people are doing, and I don't understand what they're wanting me to do all the time and I'm having to constantly feed back to them and there's expectations of what I have to do and I just don't understand it enough. I would rather know what I was doing and know that I'm in control of completing it than have to think all these people I've got to interact with to get this done.

Sandra, 26, special needs support assistant and part time PhD student

Some women expressed a preference for a balance between lone working and team working.

In most of my jobs, I have worked mainly on my own, but there were weekly team meetings, and I didn't feel completely isolated. That was the perfect arrangement for me.

Ellie, 37, Unemployed – writing a book and living off savings.

We always work as a team. Even if we are on individual projects, others in the team will get involved in code reviews and anyone will gladly step into a room to discuss

software design for your project. Working in a team makes me feel comfortable as I know there are a lot of people who really want me to succeed.

Agatha, 25, Associate Technical Business Analyst in a leading financial firm.

I have worked mainly in teams since the beginning of my working life. I am ok to work in a team and understand how to get on with people, however I feel I'd be so much happier working alone. As my role is unique, I am able to work on my own and within a team at the moment and I prefer my days away from the team so much more. I often find other people in a team frustrating, especially in my current role, usually for things such as lack of organisation and lack of motivation. I often do other people's work in my team as I feel they will not do the same job as I can do, generally down to lack of motivation, not that they are not able to do it!

Ingrid, 30, Cyber Crime Intelligence Officer

7.3 Sensory issues

Whilst many women discussed having some **sensory issues** in the workplace, these were all highly individual and context specific. Having sensory issues could present the woman with an issue they had to deal with themselves, or that the employer had to manage for them. For example, having to stay and complete work because a busy office environment meant they were unable to focus earlier in the day.

Most of my sensory issues relate to touching things with my hands and I find typing quite pleasant. The only time it affected me was when I had to do filing and the sensation of putting my hands into the drawers to remove files was very uncomfortable. My main job was to do filing and I found it excruciating and would find any excuse not to do it. They eventually brought someone else in to do the filing for me but not because I had explained this to them just because I was so behind.

Rosa, 38, currently unemployed and seeking part time work.

I had no idea of the impact my sensory issues had on me until recently. My partner was more aware of them than I was. I am sensitive to noise (talking, mobile phone sounds, tape dispensers, doorbells, air con units, water coolers), smells (food, body odours, nasty machine coffee, chemicals in carpet/cleaning products, body sprays/perfumes), temperature (I was always too cold at work, wore thermals most of the year round, had a cardigan and wool scarf on my chair and a pair of fingerless mittens to type in. The office manager thought I was cantankerous and overdramatic, but she still had an air con vent moved from above my desk). I hate people walking up behind me and being in my space so when someone sat at my desk to ask for something I was always very uncomfortable. I used to clean the greasy food fingerprints off door handles, copier buttons and light switches. I couldn't bear to use the microwave or any of the shared kitchen things. I found all these things very distracting and difficult to deal with, especially at certain times of the month when my sensitivities are much worse, and I have pain to contend with as well.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

Sensory issues could also be dealt with by masking and adopting a work specific role.

I've found I now have misophonia and ... can't be in a room with people eating, even breathing sometimes can make me feel very panicky and quite ill. So, you would think that I wouldn't be able to be in a career such as nursing with those difficulties, but I would say my sensory problems have got worse as I've got older and the only thing that happens when you go into a hospital as an employee is that you put on a different persona. So if you were to come across a person in the street, who their finger had got chopped off and you'd be like 'Oh my God the blood is horrible, what do I do?' but if somebody walked into a hospital and you're wearing a uniform, you've got staff around you, you would find yourself saying 'that's ok, we can deal with that'. So, I think that when I went into nursing in particular, I could leave my sensory issues at the door and then, you know, pick them up again when I went back home. Now once again I think there are enough reasons for me to want to work

alone or for myself, independently, because I like to direct things myself, so that I can limit any triggers that I might come across and deal with them in a way that I feel comfortable.

Debbie, 51, manager of surgical private practice and part time MA student

Noise is a big issue for me, as well as sitting near the aisle, with people constantly walking past. Not being able to open a window and having to rely on the air-conditioning can also be difficult. I always have to go outside at lunchtime, but ideally, I would like to “escape” mid-morning and mid-afternoon as well.

Ellie, 37, Unemployed – writing a book and living off savings.

Experiencing sensory issues in the workplace could also present an opportunity for bullying activity by other colleagues or managers.

I’m visually attuned, I find offices very difficult because most people are really messy in an office. And I remember my boss laughing at me because I always needed everything to be straight and if I put, if we put any posters or notes up on the wall, I always needed them to be straight and she thought that was hilarious and would sort of deliberately mess things up. But visual clutter is very, very difficult. Because I have to look at everything and measure it all out and you know with my eyes I'm constantly, almost drawing lines between things and yeah, looking at things, and it's a very cluttered office it's pretty grim.

Brenda, 52, artist

The impact of dealing with sensory issues could also result in masking behaviours such as drinking.

Well before I had no sensory issues ‘cos before I was drinking a lot, but now after two, three, years I haven’t had any, so I stopped drinking completely, now I think the alcohol was actually stopping the sensory things cos now I’m very sensitive to smell and noises. I think before I was drinking to cover that, even drinking at work

sometimes so I don't remember if there was any sensory issues cos I think I wasn't properly there if you see what I mean, but now that I am all myself I'm very sensitive to, I get, irritated by noises like plastic bags or feint smells, I can smell anything from any distance.

Marta, 30s, self-employed self-development website associate

7.4 Anxiety

Anxiety is a major co-morbidity for autistic people, with a lifetime prevalence of up to 42% (Hollocks et al, 2019). Studies have shown that autistic people have a risk of an anxiety diagnosis two and a half times higher than the general population (Nimmo-Smith et al, 2020). Some of the most significant contributors to anxiety in autism are alexithymia (ALX), emotion regulation difficulties, intolerance of uncertainty (IU) and sensory processing differences (Riedelbauch et al, 2023). All of these contributors to anxiety could be causal to employment anxiety for autistic women, specifically finding a job, commuting, the type of employment undertaken, and relationships in the workplace.

Some women clearly felt that their anxiety was having an impact on their ability to 'do the job' in the way they or others expected.

I am unable to 'present' to other professionals in my field, or network, or attend an interview without suffering severe and disabling anxiety. In the field that I work, you have to network.....

Gabi, 50s, Cultural Engagement Officer for a District Council

Whilst working as a contractor or being self-employed had benefits for some of the women, there were downsides such as their lack of ability to control the flow of work, or interactions with other people in the pipeline, which could raise their levels of anxiety.

I do contract work as a self-employed person and one of the people I've worked with had a habit of emailing me at sort of six or seven o'clock at night with documents that were a little bit late and that she wanted me to look over, within the next twelve hours or something and I crafted this very careful e-mail which just sort of

said 'As you know I do have Asperger Syndrome, my life's quite scheduled, which it is, I plan my days, they're always full, I don't have any gaps, I can schedule your piece of work in for another time but I just don't do stuff ad hoc, I can't do it, I can't cope with it'. It was one of the first times I'd ever really asked for a concession for me, to just say, you're making me so stressed, you know, I would just cry, I'd get these emails and just cry because I was so overwhelmed by this <sharp intake of breath> and I would get this tightness and sense of panic and then all of a sudden, and the next morning I got an email back from her going, 'yes, yes, OK, yes I completely understand, but if you just could have a quick look at it, by ten o'clock this morning'. It just makes me lose hope when you do your best to politely, politely reiterate what this person already knows about you, and they kind of, they kind of know it on one hand, but just sort of override it on the other and I I don't know what to do with that. How do I then go back and say 'look, I can't do it. I've got bloody autism'. How do you do that politely when you've got to maintain a working relationship with people and yes, I'm just not prepared to be a difficult person. So, I end up just doing the work before ten o'clock in the morning, get a migraine and hate myself, hate her, hate the world. But I take it on myself rather than put that on other people and I think that's a woman thing.

Nadia, 46, self-employed autism consultant and trainer

I was imagining that I would go to someone's house on my own and do my own thing. But I know this is stupid, but I was fixated that's what I wanted to do, I was imagining myself driving my car along and going to people's houses. Until I had to go to people's houses and then I started to be anxious because I was like 'Oh my God, I have to go into someone's house, and I don't know them', they could do anything to me, or, you know. So yes, sometimes I would make things up in my head and get anxious about it.

Marta, 30s, self-employed self-development website associate (on stopping being a plumber)

Having a **lack of control** over aspects of work seemed to be a major factor in raising levels of anxiety.

Fortunately, I haven't had to do much overtime over the last few years. I can get very worked up about it because I like a fixed routine. If a manager warns me in advance that e.g., April is going to be a busy month, then I can at least try and mentally prepare myself. But if I suddenly discover during the course of an afternoon that I will have to stay longer, then I get very annoyed and stressed.

Ellie, 37, Unemployed – writing a book and living off savings.

Before I had a diagnosis, I felt constantly, how else shall I put it? Terrorised at the thought of upsetting management or not performing well enough.

Herta, 40, currently taking a career break whilst volunteering as an Independent Supporter for families in the education system

I find it very hard to switch off from work at the end of the day; I completely change my outfit as soon as I get home to try to 'shed' work for the night, but things still play on my mind long into the night, often disturbing my sleep.

Ursula, 29, Data Officer for local authority Pupil Referral Unit

The issue of job security was also raised by an older woman who had previously had more insecure jobs and felt that this had resulted in a more anxious, stressful working life.

For all jobs as well, job security equals security, and security equals a much more confident life. An anxious, stressful life for many of us, will never have job security in our lives, and I've wanted it. Mind you I have chosen jobs that are terribly insecure and competitive, but that idea of wanting job security matters a lot, and the fact that it's gone I think is going to make life, is making life an awful lot harder for many people. It's not just about what it's like when you are working, it's the anxiety of being of working age and having a job. Always knowing that [the loss of a job] is a possibility is very, very, stressful.

Isabel, 57, freelance project manager

Finally, one woman posited the view that she might be more able to deal with stress than other people, but perhaps then experienced stress much faster.

I wonder if people are less stressed and easily distracted than I am, and that affects my quality of work. I am better at dealing with stress than some people who aren't autistic, but the fact is I experience stress faster than them.

Olivia, 23, part time insurance salesperson/developing own creative business.

7.5 Socialising

Many women reported significant discomfort at **socialising** in the workplace or the need to participate in work social events. Most described attempts to avoid work social events with a variety of excuses but were aware that this lack of engagement with colleagues was seen as a mark against them. The women also often viewed workplace socialising by allistic workers as a negative activity that meant that they were not focused on the work needing to be completed.

I don't do politics; I just want to do my work and go home and spend my money on my family and things I like doing...

Carla, 40, Software Developer

Work drinks are quite difficult because they are usually unstructured. I normally find one or two people I know and stay with them for an hour or two before people begin leaving and I can feel I 'achieved' at that event and can leave. Because I am younger and more junior than most people, no one tries to make me drink alcohol if I do not want to. I don't like drinking alcohol if there is no food at the event. We sometimes have team breakfasts instead, which is good as there is an organised activity (eating) that we are expected to do, and it is shorter. I can usually get away with not talking much and just listening at those.

Agatha, 25, Associate Technical Business Analyst in a leading financial firm.

Many women also struggled with the in-work social chit chat around family activities.

[My] current job is majority 40-60-year-olds who want to talk about their children most of the time. I find it difficult to not express my desire to tell them that I really don't care and that if they want to leave early to go to their kids' sports day or whatever then it should be unpaid leave and they should finish their work before they go and not leave it for me/others to do. In virtually every job I have held fellow female colleagues seem to think I want to hear all about their children's latest exploits and general family chit-chat when most of the time I couldn't care less and am certainly not going to respond in kind when asked about my 'love life' by people I associate with only due to employment.

Ursula, 29, Data Officer for local authority Pupil Referral Unit

One woman articulated that she felt less of an 'ordinary woman' because of the way she felt about the social relationships in the workplace.

I think this is specifically a female thing is the sort of social relationship in the workplace particularly in the office or factory environment that if you're not if you're not an ordinary woman, who doesn't do the chit chat, doesn't bring in the cakes, I think that's had quite an impact on me, ... you know people coming in and crying in the toilets because their relationship was in trouble. I just sit there on my computer carrying on because I just don't give a shit and I got a schedule and a list to get through but I think that, as a woman, there is an expectation in larger organizations that women do ... tend to have to be more nurturing, more social, perhaps just sort of a bit looking after people a little bit, you know that they're in charge of the tea bags and the biscuits and the social experience, I mean, you know, just saying that they are in charge of the tea bags and the biscuits is kind of diminishing their role but you know it's that sort of cohesion perhaps, they're the ones that organize the Christmas party, they're the ones that organized the meal out, they're the ones that comment on what each other's wearing or who's on a diet.

Nadia, 46, self-employed autism consultant and trainer

Finally, one woman identified that promotion was the ideal solution for workplace socialising.

I was glad when I got promoted and it gave me an excuse not to socialise with people out of work!

Denise, 34, Police Sergeant and Community Policing team leader

7.6 Underutilised skills and boredom

Many women identified that they had **underutilised skills** which they felt they were unable to use in the workplace. These might be soft skills, or those in which they had experience but no formal qualifications. However, many identified problem solving as one of their main skills and seemed to derive a lot of satisfaction from the occasions on which they were able to use this effectively.

I can think outside the box on a lot of things, that other people can't. For example, the blinds in the office. Two of the slats fell down, they were laying across mine and my colleagues' desks and they were annoying the hell out of me and I kept saying to somebody, can somebody, you know, do something about them. 'Oh well Buildings and Estates won't fix them because the blinds are too old'. So, I got in early one morning, I got a chair that wasn't swivel, stood on it and looked at the blind. I could see the problem was that there was a hook on the blind, on the actual pull part of the blind that the blind connected to and there was a hook that should clip onto the loop. Unfortunately, over time, it was plastic and it had broken off, so I thought what else can I use instead, and what I did in the end was I undid and broke in half a paperclip, made it into a hook, pushed it through the blind at a point where I knew it would hold and hooked it through. Once I got it to the right level, I squeezed the two ends together to make sure it was working. I did that with both of them and I got down off the chair and I actually pulled the blind across, and it worked fine, and it would even go, you know, turn to either side so you could have it so the light would like come in or like wouldn't, and I fixed it with a bit of a paperclip. Those people couldn't even fix it, you know, otherwise this is what I say, I have skills I don't even know I have until I need to use them.

Teresa, 39, civilian resource planning assistant with the Police service

There was a fellow that used to do it on the telly a number of years ago which was a trouble shooter, somebody that went into a company and just kind of looked at what everything everybody was doing and just homed in on the problem. And I always think that that's a skill that I have is just being able to just cut through all the rubbish and just hone in and go that's where you're going wrong and nobody else sees it they're too wrapped up in the emotions, in the objectivity, in the relationships, in the history, but to just brutally cut to the chase, and no I've never had the corporate experience for anyone to let me near doing anything like that. But that's something I would absolutely love to do.

Nadia, 46, self-employed autism consultant and trainer

Experiencing **boredom** at work, or with work, appeared to be a common feature in many women's experiences, particularly early in their careers. Sometimes this was the nature of a temporary job, but a common comment was that the job was not sufficiently challenging to maintain the woman's interest.

Well, the jewellers I got the sack because they never said, I think it was because I couldn't feign interest in a really, really boring job. It was one of these high class jewellers, really really big little independent ones and it was just really tedious because there was never any customers but when there was a customer we were all supposed to simper all over them because they would spend, you know, six, seven thousand pounds on a ring, and it was seriously so boring most of the time, we would stand around chatting, and I think I got the sack from that. I find it difficult to pretend I'm interested in something that I'm not interested in which you kind of have to do in boring jobs. I find it quite difficult to understand because if it's a really boring job then I don't see why you should be expected to pretend that you're interested in it.

Yvette, 40, working in a university disability and dyslexia service.

Another aspect of boredom was where the woman was trained in a particular work area, but then became bored with this and wanted to do something else.

Sometimes I will get obsessed with things. I had this thing, this plumbing, and wanted to be a plumber, everyone was telling me there were no plumbers, you know you're a woman, I just thought I wanted to and then when I did it, after a year, I was bored I didn't want to do it anymore.

Marta, 30s, self-employed self-development website associate

Sometimes this obsessive interest in a job or function, followed by boredom could be seen to follow a distinctive pattern.

I don't have one thing that lasts my whole life, I've always got something on the go, and they usually last a few years, so erm, I know I do them in an over-the-top fashion. When I was a landlord, I was 'Property Woman of the Year' and I bought loads of properties in a really short space of time and, I still am a landlord, but I'm not as obsessive about it as I used to be. So, it was a good obsession to have because I was really successful, sort of spent so much time and worked really hard and researched it really well, but then I have the ones that aren't as good, like there was a game on my phone that I did for over a year. The reason I deleted it off my phone was because it got to the stage where I was thinking of setting my alarm so that I could wake up in the night and I could set some more dragons off going in the night and then go back to sleep, and then I thought what are you doing, you're setting your alarm to wake yourself up, and then I thought, that's ridiculous so I deleted it off my phone. Then at the moment, so in the last few years it's been Forex Trading, and I've been doing that, I've had loads of spreadsheets and, but I haven't been successful. I lost a bit this last year, then this year I lost a bit less, so I'm definitely getting better at it, but erm I've chosen to stop doing it because loads of little things but I don't think it's possible to ever get successful so you are winning consistently so luckily I'm not a risk taker cos I just sense it could be quite a dangerous obsession if you had loads of money and were risk taking you could probably lose a lot so I only lost a few hundred. And then around the time of

getting, starting to lose interest in that erm the autism thing started, that's why I think that's my new thing then, I'm getting a bit obsessed about, so I spend loads of time reading on it, and I'm doing a Masters which seems a bit excessive really when you've not even been diagnosed erm but it's interested me, I am enjoying doing it.

Amanda, 40s, freelance financial analyst in the banking sector

7.7 Exhaustion

Many women mentioned the **physical and mental exhaustion or 'autistic burnout'** they felt as a result of carrying out their jobs. This appeared to be due to a variety of reasons, mainly because of trying to 'fit in' at work. The effort involved in masking at work might also impact on alcohol intake, and ultimately potentially at problem levels of drinking.

Chapter 3 discussed descriptions of autistic burnout (Raymaker et al, 2020 and Higgins et al, 2021) and the participants description of exhaustion being driven by masking behaviours concurs with these descriptions.

I'm constantly having to be alert like I have no time to space out a little bit and just, I guess I spend a lot of my time going into my own little world, and just chilling out and kind of closing myself off from people and I have to constantly be alert and then even on my lunch breaks in the staff room is like horrendous, I hate going in there. It's like there's no break, I go to my car and eat my lunch in my car because I'm just, it's the only time I get some space but then you only get half an hour and it's, I guess it's constant interaction with people, that's the problem.

Sandra, 26, special needs support assistant and part time PhD student

I think it's just the er the amount of effort that goes in you know to a normal working day to day and coming away from that and actually realizing how exhausted you are erm because of the amount of thinking that's, that you've had to put in, that other people I work with, it's just, that's nothing to them it's normal interaction, who you're working with and young people and making phone calls or erm those kind of

things that other people will just do, those are the things that are tiring to me because I'm having to think so much about them when I'm doing them.

Gemma, 20s, Residential carer for young people

If you're working all the hours and some of the jobs I've done have been like 80 hour weeks ... so much of your energy getting along, getting through the day, being nice to people, it costs more energy than it can cost non autistic, you know, the amount of concentration or sometimes the extra hours you've got to do to cover up that you're not finding some things easy to do, means that at the end of the day you are exhausted, and when you're exhausted at the end of the day, year after year after year your social life dies, your diet goes to pot, in my instance I got very reliant on wine for a very long time, sort of teetering on the edge of it being a permanent problem, reliant, you know, but you function. I'm one of those autistic people who never found it easy to sleep from infancy to today, and that wasn't work related. So, you tire, so the effect on your physical health is tough, the effect of liking people, however crap they treat you all the time has a cost to your emotional realm too.

Isabel, 57, freelance project manager

7.8 Soft skills

People skills are often cited as important in the workplace. It was clear that the autistic women interviewed were significantly self-aware of their skills in this area and worked hard to continuously improve but struggled with the social aspect of people skills.

Good when it involves practical things like answering questions or solving problems.

Poor when it involves people's feelings or thoughts.

Denise, 34, Police Sergeant and Community Policing team leader

I get on fine with people within the department, but meeting new people is always a challenge. I am very quiet but have learnt to make small talk. I don't stay in touch with former colleagues and have never become close friends with anyone. I

wouldn't be a good manager; I'm no good at being encouraging, giving feedback, or praising someone.

Ellie, 37, Unemployed – writing a book and living off savings.

One woman had adopted a very analytical approach to working out what everyone wanted to their interactions, and as a result found this very successful.

I work with our internal clients a lot and enjoy interacting with them. Work-based interactions feel comfortable as there is an expected format and specific topics that need to be discussed. I spend time ahead of interactions ensuring I know what is important to that person so I can ideally go in with a solution ready for them. I think that because I have always had to analyse my interactions with others, I find it very natural to do this for work-related interactions whereas NTs may not have considered it that way before and therefore are less effective. I am less comfortable and feel I act awkwardly with interactions that are more social-like such as team lunches or impromptu chats. I usually resolve this in larger groups by staying out of the conversation most of the time and people do not seem to mind.

Agatha, 25, Associate Technical Business Analyst in a leading financial firm.

Some women demonstrated frustration at the level of **unwritten rules** in the workplace.

There are always unwritten rules in any workplace and getting people to tell you them can be very difficult. Explaining that I need it stated can make me very frustrated which often presents in me crying. I then become more frustrated as the other person assumes I am upset which is definitely not the case. There is a large stigma about crying in the workplace and it could be avoided if they just told me what the unwritten rules were.

Agatha, 25, Associate Technical Business Analyst in a leading financial firm.

I am hopefully more aware of how I relate to people. I do think differently about myself since the diagnosis and having a 'negative' label applied to me. It has made

me less confident. But I am also aware I have ‘superpowers’ my main superpower is music, and that is the area in which I work.

Kelis, 44, self-employed piano and keyboard teacher

7.9 Support

Most women volunteered very patchy and mixed levels of **support** available to them in relation to work. For many women ‘support’ would be available from parents, siblings, partners, or other friends and could range from someone to listen to their problems, to a more active approach in helping to find the right help and solutions through Government programmes and benefits. Very few women appeared to have received support from a trades union. Some had accessed workplace support from the National Autistic Society. Support from Human Resources departments in terms of work adjustments was very mixed.

I had a union rep when I was suspended. Other than that, it’s been friends I’ve turned to because I know them. I find it difficult to open up to people I don’t know when I have an emotionally charged situation.

Pauline, 41, former hairdresser, currently home educating autistic son.

People outside the department, friends and family and couple of people within the department who are actually management and my union. The union are quite good, but they are a little bit clueless, because they don’t really understand all of this.

Yvette, 40, working in a university disability and dyslexia service

A fundamental problem with seeking support or workplace accommodations is that to request these means having to divulge a diagnosis. Furthermore, a report for the Discover Autism Research & Employment project for the Autistica charity (Heasman, 2020) found that often neurodivergent job seekers or employees reported that their managers were unaware of what adjustments could be implemented in the organisation due usually to a lack of information about adjustments previously used in the organisation, or the different types of support needs and respective strengths of different adjustments.

The report also found that the burden of identifying adjustments was often put upon the neurodivergent employees who might not have the skills to speak up about any concerns they had. The report also found that where adjustments could be identified their successful implementation was not always guaranteed due to the self-stigma of the employee who might be concerned about being identified as difficult, or a lack of clarity over where the request should be made. Another major issue was where adjustments were refused for a variety of reasons. There were often disagreements between managers and employees over whether adjustments were “reasonable”, reflecting differences of opinion in adherence to the Equality Act 2010.

Figure 2.3 shows the wide range of workplace adjustments available, however these are not always widely known either by the autistic community or by HR or workplace representatives. Some women in the study expressed frustration that their workplaces expected them to always know what they needed.

HR is being slow. I don't feel like I am supported at work, and I keep getting “the ball is in your court” from my manager as to organising stuff (which of course I find hard).

Carla, 40, Software Developer

Hand on heart I don't really think, despite the fact I've been asked numerous times what reasonable adjustments I require, I don't really think I've ever had reasonable adjustments that suit me or have been put in place for me by any, by this employer especially. ... I've got a pretty good awareness of me in some aspects because of that, but in other aspects I mean what I need as a reasonable adjustment is difficult because, and this is what I said to people because Aspergers has been with me for so long, and it is who I am, how do I know what I need in order not to be me. If that makes sense. You know because I don't know what normal is in their eyes. So, I can't say what I need in order to be normal because I've never been normal to know what I've not got.

Teresa, 39, civilian resource planning assistant with the Police service

Women also expressed frustration at the process to achieve even minimal adjustments within their workplace, and anger at the process when things went wrong, and their autism was not taken into account.

I have encountered many problems over time within the workplace. The only example that relates to Aspergers was the amount of time/effort it took to convince Sussex Police of my diagnosis and get some support. I had to involve the Sussex Police Disability Association, HR, Occupational Health, and Sussex Police Charitable Trust. The process took some months before I was even accepted for a risk assessment and to have reasonable adjustments considered. During this time, I found it most upsetting as I was coming to terms with the diagnosis myself, let alone not being 'believed' at work. It was also stressful as I'd asked for such minimal adjustments, such as a laptop to work from home (when everyone else in my team has one already) and for the lights to be dimmed. I feel there needs to be more support around the 'disbelief' when an organisation is trying to prove if the person has a disability or not as it's really degrading and upsetting.

Ingrid, 30, Cyber Crime Intelligence Officer

I received no support at all when I was off with stress for nearly 4 months. Union - help was next to useless - they advised me to just talk to my manager!! HR seemed to be actively supporting my manager not me, and communications I got from them made me feel that they thought I was taking advantage in some way and/or disbelieved me. This was because I could not communicate with them, so all communication they got was from my manager's point of view. With the OH report a major change to my job was implemented without my input. When discussing this I was sent home because I got so distressed and was further distressed because I was being sent home. The National Autistic Society came in to do a workplace assessment, but none of their recommendations were implemented, because when we sat down to discuss this, the management employee relationship had already broken down. e.g., one of the main things I felt was important was a mentor who I could go to - my manager felt that this would be too much responsibility for the person and told me at a 1:1 that she was concerned I would expect them to do my

job for me. When I complained about this comment, I was called to a meeting with 2 managers and threatened with a disciplinary if 'it' happened again. The awful thing was the slow dawning that I was not going to get any help or understanding from anyone at work. I was cut off from colleagues - I felt that I could not draw them into this. All other managers who got involved backed the manager I was having difficulties with and could not understand why I felt so stressed. I felt frightened the whole time because I could not believe all this was happening. It felt like I was caught in some terrible web that was winding itself around me tighter and tighter. I did manage to get a year's support from ASF (via NAS and Access to Work) and this did help get me back into work and to stay there, and I am so grateful for this. The manager went off on maternity leave and has not returned. I had support for a year in my current job (I had been in the job for 13 years without a problem - apart from the underlying 'normal' stress/anxiety of doing a job and hiding my autism - 'coping' and sometimes not coping), via Access To Work, because a new manager set off a level of stress at work that I was unable to cope with and I was off for 4 months - during this time I was suicidal, and terrified that I would lose my job. My GP advised me to leave - but he obviously had no idea of what that meant to me being autistic - the thought of looking for a new job was even worse even than what I was experiencing - it took me a lifetime to find this particular job.

Gabi, 50s, Cultural Engagement Officer for a District Council

Faced with a problem in the workplace, some women were very isolated and had no one to turn to, particularly those who did not have a diagnosis at that point.

I didn't seek any help because I couldn't see any availability. I didn't have many friends, I was autistic, work it out. I was friends with colleagues. Bullying always came from above, it very rarely came from colleagues until later on, when there were ambitious younger people. But basically, you know, the bullying came from managers who were sort of insecure at dealing with me, and that was, it was about them and their perceptions of them, because those same managers were getting (more of a glow?) and were inviting me to do the next job and the next and the next. You know, so I couldn't have worked it out, I never worked out why they

targeted me until I was able to look at it from the perspective of a post diagnosis when I read that other people, I was able to talk to other autistic people who found the same. Before that, of course, you beat yourself up, you think 'what's wrong with me'.

Isabel, 57, freelance project manager

Women who were self-employed had to find their own solutions, and this seems to have been achieved by actively seeking out support, or where possible, employing support directly.

I have been applying for funding for an arts project - it took me a year to fill out the form, and it was unsuccessful. For me the form was incredibly complex as the questions could be interpreted in a number of different ways. I found it difficult to ask for help because I couldn't put into words what I needed help for... My difficulty is structuring/organising what I have written and putting my thoughts about ideas into words. I am now getting support from the organisation to resubmit this... (I didn't realise I could get this because the information wasn't explicit enough for me, so I didn't think it applied to me i.e... it didn't refer to autism). They have put me onto another artist who has been really helpful, support is communicating via Skype but text only and this has been really good... I can't believe that after all this time I am getting support for this.

Gabi, 50s, Cultural Engagement Officer for a District Council

I think I'm, have got much better at understanding my own limitations when I started my own business I used to do everything myself because that's what you do when you start your own business and I was getting a lot of phone calls, a lot of e-mails, so I'd be out doing a day's training and then during the breaks there would be messages and sometimes it would be people with quite lengthy problems that they wanted to talk to me about. I was working easily until ten, eleven o'clock at night most nights catching up with admin, preparing courses, doing all the printing, all of that kind of stuff to the point that I probably had some sort of physical kind of collapse where I

just became utterly exhausted and just for about three or four months just kind of lost the will to do anything. So now I have employed an administrator who is kind of the buffer really who is the first point of call, the first person anyone speaks to so people who have big problems tend not to offload to her because she's not the one they want and this has helped enormously because as soon as she says 'I'm just the administrator' they cut it short ... and that's just changed my life phenomenally. I mean obviously she has, she has to be paid and that's cut down my income but it's absolutely changed my life completely having, not just the physical work that she does, but actually taking, making a gap between me and the rest of the world, because I just couldn't take on their needs, their problems and everything, so I just do the work.

Nadia, 46, self-employed autism consultant and trainer

7.10 Managing perfectionism.

Many women described having a **perfectionist** approach to their work. Whilst it could give them some satisfaction in their work it also appeared to give them significant stress and often highlighted that they had a different approach to that of other people in their workplaces.

I always feel like a perfectionist, a very, very high achiever, so even the way we put mayonnaise on the table has to be perfect and I can feel like I get bad stress when I see other people not doing their job properly and I feel like I want to explain, and I want to manage them, and I want to tell them how they could be more efficient, but of course in my role, it creates this sort of tension in me that I am there and they should do their job well and they could do better and then I'm not in the position of actually saying anything about it. I have to really be careful with that because sometimes I could just say it very bluntly to the manager, this person didn't do this right, and I realise other people don't say that people don't like that. I had to kind of like, just suppress it really, or just walk out.

Lena, 20s, seeking work as a classroom assistant.

There was one really important figure that was going to be in the financial report of Lloyds Bank, so it was at a high level, with a lot of eyes on it, and I was the only analyst working on it ... I was really, really stressed and I had to work really long hours to get it by the deadline, but one of the things that went wrong with it, there was a variable in it and it was ... four decimal places when I'd finished. I spent a good three weeks rerunning all of these things, the data sets, all of the different models, and from the outside everyone saw how hard I was working. I was even coming in on weekends and people who were close to it thought I was so dedicated. And then afterwards one of the other more senior people ... realised that I had got the daybook at four decimal places and then everyone else had thought it was because I didn't have it and was trying to get it and recreate it, and then he said it wouldn't have made a difference to the final figure, you didn't need to do all that. But he knew that I had done a bad job then, but other people thought I was dedicated, working all those hours to get it done on time.

Amanda, 40s, freelance financial analyst in the banking sector

7.11 Managing and being managed

Some of the autistic women had advanced sufficiently in their careers to be **managing other people**. Others were absolutely adamant that they did not want to manage or supervise anyone.

I feel like quite a hands-off supervisor. I sometimes feel like I miss things that other people see (problems within the team, personalities etc) because I do not understand them. I am keen to help my team and will try my best to answer any questions they have or deal with any problems as quickly as I can. I don't really 'get' the way others think and so at times it doesn't occur to me that people would do or think things that I don't. For example, someone I manage at the moment has a terrible attendance record. On the other hand, I have never been off sick. I do not understand why a person would not go to work if they were not genuinely sick, so I always think people are genuine.

Denise, 34, Police Sergeant and Community Policing team leader

I've thought about it long and hard on several occasions. And there are pros to doing that, and there are cons to doing that. I'm not totally sure that the pros outweigh the cons. It's a very difficult call because until people can actually understand some of the decisions that I would make, which to them would seem strange and weird and everything else, then I don't really know that I could manage staff successfully, you know, because I think there'd always be people there thinking more does she know what she's doing, blah blah blah. I think if I got the right team, and I got the right people then yes, I could probably do it. But I think it would have to be something that I'd feel very very comfortable in and that, you know, in order to be able to manage people, because I think I don't feel confident enough in my own ability, although everybody tells me how good I am at what I do, I don't feel confident enough in my own ability to actually, you know what I mean, manage others.

Teresa, 39, civilian resource planning assistant with the Police service

Some women felt that character traits such as the tendency to be blunt did not make them suitable candidates for management.

In my last job I managed one employee. He was very sensitive and self-conscious and needed plenty of encouragement. He had a habit of trying to read between the lines and trying to find hidden criticism everywhere. I felt so nervous every time I spoke to him, I didn't feel up to the job at all. I'm rather blunt and direct and here I was speaking to someone who not only cared about what you said, but about the way you said it as well. I didn't feel I could give him the encouragement he needed (my social skills aren't great) and I was acutely aware that what I said could potentially affect his career. I couldn't cope with the responsibility. It was the only time I had to manage someone, and I told myself never again!

Ellie, 37, Unemployed – writing a book and living off savings.

Many women revealed high levels of empathy in their responses, and aimed to be approachable managers, reflecting on how they would like to be managed themselves.

I would like to think I was a very fair manager, people approachable, I'd like to think that people felt they could approach me and that they would, which usually would happen within Our Price because we'd be similar age we would have grown through the business together, so a lot of us were very familiar with each other though I was never really in a position where I had to discipline anybody or there was never any times where things were challenging for me in that role there and we worked very smoothly and just being a fair and effective manager meant that staff were fair and effective in return. In nursing we, once we'd qualified, we would supervise the next nurses that were training that would become us in the future and once again I always tried to be really, really helpful and you know, put myself, I think I always put myself back into the position that I was in at their point. So I tried to remember where were my anxieties, what did I find confusing, and just keep checking in with them to say is everything ok, that sort of thing, so I wasn't really a sort of an autocratic leader, I was more of a democratic and I think that kind of is how I raised my children as well, we implemented democracy in the house, much to my husband's disgust. I think sometimes he would like to be the boss.

Debbie, 51, manager of surgical private practice and part time MA student

When you've got someone who's struggling a bit and you try and figure out how to, where their area of difficulty is and what can we do to kind of make that better. And I did have that experience at Waterstones with a young lad who was really struggling, he was not very good at his job. In fact, he was dreadful at his job and my boss said to me look you need to give him a good talking to because if he doesn't pull his socks up we're going to kick him out. But I decided not to do that, I decided to almost kinda lie, I just focussed on the things that he was good at, or made them, if they weren't so terrible, I made them better than they might likely be. And we had a, we had a sit-down talk about it and I was like, you know, you can do business. And later on, he came to me and said do you know you are the first person who's ever told me I'm good at something. And I now found out that he's actually managing his own store and still is working for Waterstones, I found that out a while ago. So I feel really happy about that because, you know, I know what it's like to be on the end of

feeling crap about yourself and I don't want to do that to anyone else, so, yeah I've really enjoyed those times where I have either managed people or I've been in a teaching situation and able to bring people on, that's lovely.

Brenda, 52, artist

Overwhelmingly the autistic women interviewed expressed a preference for **being managed** in an open and empowering way.

I find the more my manager trusts me to get on with my work and has faith in what I do, the better I become. When I am told what to do and am not trusted to do my work without constant supervision, I feel I can't do my best as I'm being so highly monitored. The more I like and respect a manager, the harder I will usually work for them. When I'm in an office environment where I feel miserable, I feel I'm only able to give my work the minimal effort required. I have a pride in my work, so I would always get everything done but I would never go above and beyond for a manager I didn't get on with. I often want to do things differently to other people, so I like a manager that will listen to my point of view.

Ingrid, 30, Cyber Crime Intelligence Officer

There were mixed views about the management style that the women responded to well. Most said that they found managers who 'micro-managed' them particularly difficult. They also found it difficult to receive critical feedback, and some commented on the lack of positive feedback they received when completing a task well. However, there were mixed views about managers that let them get on with work with no guidance and many said that they preferred structured guidance and feedback.

Feedback has varied greatly. Some managers have been open-minded about my slightly unusual character and have praised my attention to detail, my conscientiousness, my efficiency. Others have called me blunt, abrasive, stubborn and impolite. I try my best to fit in, but sometimes I don't have the energy and my differences shine through. There is not a lot I can do about it, other than hope that I end up with an understanding, tolerant manager.

Ellie, 37, Unemployed – writing a book and living off savings.

I can't cope with managers who are unclear about my job duties and expectations. At my last job, managing clinical data for a pharma company, the environment was really passive aggressive, and I knew several managers had a problem with me because I was "weird" and not gender conforming, but my manager didn't deal with it that well and made me feel very paranoid. My current team leader is great because he is very direct and does not mince his words – if I have done something wrong, he explains it and then tells me what I've done well. I also cannot hack being "micromanaged" as I start to get tearful and make mistakes until I snap and start sobbing. I benefit best from just being trained properly, then supervised from a distance and trusted to do my job well.

Olivia, 23, part time insurance salesperson/developing own creative business.

I find encouragement and praise when used genuinely, incredibly important. I cannot stand mendacity. I won't see it; I won't know it. In HR my manager would call us girls. It was patronising and awful. She didn't listen when I told her I had been given too much work and was now over capacity. When I left, they had to hire two people to replace me and cover the work load. I need to be listened to. I need honesty. I maybe need bluntness at times. But mostly I need encouragement.

Fabia, 36, currently a stay-at-home parent

I think in terms of, I've had quite a few different managers and the management style I respond better to is very direct. So I think managers who, don't get me wrong, have been supportive, and are good managers, but it's not suited my style because they've kind of, they allow people to kind of get on with things whereas I prefer a manager who's a bit more directive and will assign things for you to do rather than allow you to just kind of get on with something, you know I like to be told what to do. I like that direction because I think that then helps me focus at work.

Gemma, 20s, Residential carer for young people

Many women articulated the view that any problems with colleagues or managers were usually as a result of the relationship they had with them. A woman might have no problems at work until a manager or supervisor moved on and another person with a different style and approach took over.

My problem was the manager that I had, and she didn't really, although she came from a HR/people services background, she didn't have a clue how to deal with an autistic person and when my stress levels started to rise and the autistic traits started to get worse because obviously when I start getting stressed my autism comes to the fore far more than that. She started to get nasty with me. She started to get in some ways obnoxious with me, she started to be awkward with me, and that doesn't help when you're autistic and it doesn't help you as a person because you've still got feelings, although they may not be perhaps the same as other people, they're still there, and that I think is what started basically the relationship that we had on a downward spiral. She started to find me awkward, and she started to find me argumentative and everything else. It's not that I was argumentative because I wanted to be, I was argumentative because I wanted to get things done once right, and not the same way that we've been doing it for the last four years where it's all gone wrong. Because I knew if it went wrong, I was the one who would have to spend the next two days putting it right.

Teresa, 39, civilian resource planning assistant with the Police service

Some women particularly valued the managers they had who were able to put themselves in the shoes of the autistic woman, and not just expect them to be like everyone else.

My most recent manager ... who's just left. I think she was very good at recognizing where I wanted to go and how I thought and using that to the benefit of me and the team. I think understanding how I thought things through as well, so my perspective on situations, and I think maybe with other managers not quite understanding the way I think whereas I think this manager who has just left I think she understood that you know the way I talked about things.

Gemma, 20s, Residential carer for young people

For some women, dealing with managers or situations at work would prove so difficult and clear cut that they would just leave the job, which could explain the complex career journeys that the participants could be seen to have in Chapter 5.

I don't really like authority, so if someone said something, you know, it just annoys me, so instead of dealing with situations, or talking to my manager, if I got any issues with anything at work, I wouldn't go on and talk about it I would just leave the job, or if I feel like someone doesn't like me, which often happened, because in my mind I put them as people who didn't like me or so, so, that happens all the time, as soon as there is a problem I would just leave the job instantly instead of talking about it or looking for a solution.

Marta, 30s, self-employed self-development website associate

Some women demonstrated the fine line between what to them would be supportive management or unsupportive management. Whilst they did not like to be micro-managed, they needed some management which set out both a strategic overview and an understanding of their role within that. Whilst wanting to be left alone to get on with work, there was clearly a need for the manager to be sure that the woman was progressing appropriately as otherwise they might not ask questions.

Consistency is key. I don't like or need to be micromanaged, but I do need to be managed. I appreciate support with planning, achieving goals and deadlines from someone robust enough to protect me from the wilder demands the business will have. I prefer to know the whole picture, as much information as possible. I get frustrated if I feel I'm being kept in the dark and it hampers my ability to be effective. Sometimes people don't know what's the best solution until they tell you fully what they're trying to do. I prefer honesty, directness, and welcome feedback, it's always a gift regardless of how it's delivered.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

I feel like I do not require much supervision. I do not ask questions or raise issues like I see others doing. I just get on with it. From the other side, I have gone through a lot of supervisors (6 in 2 years!) so there is not much stability, and I would have been reluctant to discuss my AS with some of them. I do not like intrusive supervision and much prefer to work on my own.

Denise, 34, Police Sergeant and Community Policing team leader

Managers often forget I am Autistic and need frequent reminding that I work in a different way to others and may need adjustments made. Managers can be too vague in their instructions, too often changing their mind or retrospectively altering their own memories of conversations to fit the thoughts they now have. Most managers have been pretty bad at being autistic friendly and a few of them have been downright shocking; some having a tendency to blame my problems on hormones (a female manager as well!) and another blaming my autism for me arguing with their proposed change 'you just don't like change' – no the idea was a stupid one and was proved so further down the line!

Ursula, 29, Data Officer for local authority Pupil Referral Unit

An interesting perspective from the line managers of autistic workers is provided in research by Richards et al (2019) which found that line managers of autistic workers had to perform extensive and high levels of emotional labour to line manage them and further emotional labour with numerous parties to agree reasonable adjustments. A key finding was that reasonable adjustments were more likely to be successful where the line manager overseeing them was trained in emotional labour. The findings also stressed a need for line managers to have autonomy and a workload allowance for managing neurodiversity in order to build trust and long-term relationships. This seems to support the concept of double empathy where the autistic employee and allistic line manager needs to understand the challenges of the other person in more depth to build a good working relationship and to ameliorate the emotional labour involved for each party.

7.12 Executive functioning

Many autistic people have problems with **executive functioning** that might impact on how organised they are, or in starting specific job tasks. Without an autism diagnosis and awareness of this it is therefore possible that an individual, or a work colleague or manager might think the worker was lazy and not completing work.

I've only just found out about executive functioning and when I did it was a huge revelation to realise how it had affected me at work. Sometimes I would just sit at my desk – my head whirring – unable to do anything. It had an almost physical sensation this block in my brain. I thought I was just lazy and disorganised – everyone else was managing.

Rosa, 38, currently unemployed and seeking part time work.

Many women were able to manage any executive functioning issues by becoming very organised.

I use my outlook calendar for meetings which take up 20-25% of my time. In busy weeks, I also use my calendar to block out set times when I will work on specific pieces of work or projects. For project tasks, I usually make a project task list at the start of the project which I go through. This has been in a variety of formats depending on who I need to share it with and what is most appropriate. For ad-hoc tasks, I go through phases of using post-its, an on-screen post-it application, and formal ToDo list paper. I am now used to reprioritising work as new tasks come in but if I am ever unsure, I reach out to my manager for help.

Agatha, 25, Associate Technical Business Analyst in a leading financial firm.

I used a strict notebook system, I took it everywhere, every task was written in, then ticked off once complete. It gave a sense of control; meant I knew what I'd done and what I had still to do. Also, if I got ambushed in the corridor by someone, I could write down what they asked for so didn't have to try and remember. Then learned to

say 'can you email me that request please' so I wasn't responsible for wording it & could understand it better.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

However, many women also mentioned that they often found it hard to get started on work. This could be for a variety of reasons including their surroundings and the actions of others at work.

Varies from day to day depending on many factors. How well I cope at work is massively affected by the mood of my manager, the boss, the rest of the staff etc. I try very hard to keep on an even keel during the day, but other people's actions and behaviours affect me so much it can be really difficult. I have an incredibly hard time coping when my colleagues are overly excitable and very noisy – particularly because they have no care for how it affects me.

Ursula, 29, Data Officer for local authority Pupil Referral Unit

Because they found it difficult to get started on work at the relevant times, some women needed to work more creatively out of hours.

I need frequent stretches of uninterrupted time to 'get into' the work and accomplish the clever things that can be done with a little thought. I've never managed to find those stretches in the office, that's something I do at home alone usually at 4am.

Belinda, 36, formerly an analyst at a scientific company but currently unemployed following autism diagnosis

As a teacher I always ended up working very long hours, as I was too socially tired at the end of the day to mark and prep lessons, so I'd have to do it once I'd mentally 'wound down' and decompressed. That meant working late every night, often until midnight or later.

Eve, 37, Teacher

7.13 Work ethic and approach to work

Many women expressed a very strong personal **work ethic**, but also expressed a highly critical view of allistic work ethic.

I will do a job not just as well as other people, but in most cases better than other people. Because my work ethic is such that I don't sit around chatting, and I don't sit around messing around on my phone, or on my phone texting. Me, the black and white this is, at work I work, at home I do other stuff. So, from the moment I walk through the door to the moment I leave I'm working. I have to, obviously I had to learn slightly that's not always the case, sometimes there is banter that you have to join in with to sort of be part of the team. But other than that, then yeah, I'm working.

Teresa, 39, civilian resource planning assistant with the Police service

It was kind of a joke that I wasn't very good at what I did which kind of upset me a bit because actually I did do a lot of work there, I just did it really quickly, so I'd do it all really quickly because I'm quite a fast worker. I'd get all my stuff done and I'd be doing a lot more than other people in the office because at the time there was a lot of people in the office that didn't want to be there and were just sat all day on Facebook. One of them next to me just slept, you could see she was sleeping, or she'd have a magazine under her desk, so I was actually doing more work than most people in that office all be it kind of what I wanted to do it. So, it annoyed me, but it was just because I was more vocal about it. It annoyed me that everyone had this impression of me as being bored all the time, not wanting to work, on my phone all the time, when actually I was getting more done, because I was more efficient at what I was doing, and I understood the computer better than they all did. So, I just got it done quicker, so it was a bit of a joke, that you know, I was there because my mom and I wasn't really doing much, and I was bored all the time.

Sandra, 26, special needs support assistant and part time PhD student

There were many areas in which the autistic women believed that they had a **different approach to work** to that of their allistic or neurotypical colleagues. Significant areas which were raised continuously were work focus, and passion and enthusiasm for the work itself.

It feels like I care more than other people – other people have said that to me – don't take it so seriously – it's only a job. 'JUST' – it is my life and my identity.

Gabi, 50s, Cultural Engagement Officer for a District Council

Whilst many of the women identified this as a strength in themselves, they also reflected that this could create problems in the workplace when their approach diverged from other people.

Sometimes my focus and commitment is better than other people around me. But other times people get stuff that I don't get and that's quite important. So, no, it depends on the situation. I mean I'm a brilliant problem solver. Often in, we've been in a situation where we've had meetings. Meetings I'm really terrible at but we've been in a situation where we've had meetings and I've been able to see the problem ahead really quickly, almost instantly, because it's a visual thing and I will say to my colleagues, this is how we need to fix it. And of course, that doesn't really go down terribly well. And sometimes that frustration has been that it's taken months for everyone else to get to the point that I got to in that meeting. And I have been very difficult in the past, my ability to problem solve is exceptional. But I've had to learn that there's other things around problem solving in a business situation in a working environment, even though they are pointless and stupid, you have to do them. So even though you solve the problem, you kind of can't tell anybody and you kind of have to chivvy people along gently and, and just mention little things so that eventually everybody thinks they solved the problem together, and that might take weeks to do and that's quite frustrating.

Brenda, 52, artist

I find that people don't go into such detail that I do. Especially with research, they will just do the basics however I will analyse things in more detail.

I get frustrated with the lack of detail in other people's work and their lack of organisation. Often important points will be missed due to this.

Ingrid, 30, Cyber Crime Intelligence Officer

Many women identified that being passionate about their work meant that they spent more time developing their roles and skills and as a result appeared to gain greater satisfaction from this.

I like to read around outside my job or my studies and can get quite obsessive about it. In my current role I'm benefitting hugely from having such a good memory as I'm able to talk to customers on the phone about an enormous breadth of topics and having good quality conversation on the phone makes me more likely to make a sale.

Olivia, 23, part time insurance salesperson/developing own creative business.

Recurring comments were raised about the lack of work ethic in other workers, and how the autistic women found this hard to understand.

I am single minded. I go to work to do the work, not to have the yap that you know that some people do. But I've tended to do jobs where other people go to work predominantly to do the work, that work hard also party hard, and I've not been able to keep up there. I don't understand people who are lazy at work. I don't understand how they can get away with it, and why they'd want to, because it must be very boring sitting there all day.

Isabel, 57, freelance project manager

I have a very strong work ethic. I am at work to work. Other people seem to be there to socialise, eat, avoid work. I find that confusing. I would find it awkward talking when being paid to work. I want to do my job.

Fabia, 36, currently a stay-at-home parent

One woman gave a focused example of the difference in her productivity to that of a new team, and how this difference resulted in the other team members having to significantly increase their work output, resulting in the team moving from underperforming to top team.

I was part of a west child care team, and I got asked if I would mind being seconded for a few months over to the east child care team in a different building because technically the teams were supposed to work in the same way, and because they were short staffed and I was an experienced member of staff and we had plenty of staff on our team. I agreed, I didn't mind. I walked in on the first day and there were four members of staff that had been there a long time. They all knew what they were doing, they were all highly competent. I'd seen them a few times, obviously they knew me, and the building was new, the environment was new and there was a temp who didn't have any access to the council system, and all she could do was use word to type letters. Nothing more. And I introduced myself and I got settled down, I found a desk, and about half past nine, I'd come in at 9 o'clock, they all turned round and said to me, apart from the temp, the rest turned round and said 'oh we're off now' and I said 'no where are you off to?' and they said 'oh we've got a team building day'. They went off. Now I obviously had asked where the work was, and I found the in-tray. And this in-tray was a wire basket, and it was filled, not only full but it was over full with probably piled double itself with stuff to do, and I started ploughing my way through it because obviously to me it was the logical thing to do. On top of that I was dealing with anything that came in at that time that needed urgently dealing with. I got through most of that, I found at the bottom stuff that was like four, five months old that nobody had bothered dealing with, so I then managed to track people down and literally I'm like a blood hound. I will go and I will find that person, I will hound them until I can, and I literally finished them and at the end there was three pieces of paper left in that inbox that I couldn't do because I didn't have the knowledge of that particular thing to do, but I cleared the entire inbox myself on that day, and they all came back up at quarter to four, we were due to leave at 5 o'clock and I'd just finished the last little bit and they looked over and they said 'where's all the work gone?'. I said, well I've done it and they said what

happened to the stuff that was in there from, and I said I've done it all, I found the person and I've sorted it all out. I said I've done the filing, all the filing that was there, I've done the inbox, but I can't do those three pieces of work because I don't know enough about them, and you could tell that their whole demeanour changed, they were like 'oh my God'. Because I did in one day what four people couldn't do in three months. From that day on they were playing case catch up and they knew, they all bucked their ideas up and all of them were trying to keep up with me because they knew if they didn't then I'd just, you know, it was just they'd look really bad and everything else, and from that moment on, from a team that was slacking and not really doing anything to a team that were actually working, yes I was still doing more work than they were but they were actually working, they stopped complaining about this and about that and they were actually doing their job. And for me that was the biggest eye opener on my work capacity at that time.

Teresa, 39, civilian resource planning assistant with the Police service

7.14 Summary

The study shows how work organisation is a significant factor for the autistic women interviewed. The women mainly wanted to work on their own, but there was recognition that they might need other people to bounce ideas off, or to provide support, or that a mix of lone working and team working was preferable. There is often a view that autistic people are loners, yet many women felt they were good team players, though there were concerns that they might either be ignored or that they might be tempted to take over the lead. For the women that had spent a lot of time working in teams there were some concerns about whether their allistic colleagues were doing a fair share of the work, highlighting potential double empathy problems. Many women had problems with executive functioning and could become 'blocked' on how to proceed with work tasks.

Anxiety seems to be a significant co-morbid condition for the women in the workplace. This can impact on and worsen sensory issues, and can be a major cause of work organisation issues. Many women also mentioned their own perfectionism in the workplace as an issue and managing this gave them further stress and anxiety as a result. Whilst the autistic

women saw self-employment as a freedom from the control of the workplace and other co-workers they do not seem to have considered the burden of responsibility of being the sole person in charge when self-employed and the need for constant decision making and the impact this would have on their anxiety (see also the previous chapter for discussion about support for autistic businesses and the self-employed with support services such as finding work opportunities or marketing services). Work socialising was also a cause of significant discomfort although one woman noted that being promoted meant that you needed to socialise less with some people in the workplace.

Many of the women identified that they had many skills that were underutilised or unused in the workplace, particularly problem solving. Many however were bored in their job usually due to the work not being challenging enough, or they wanted to change to another career, in line with the chaotic pattern described in Chapter five. The women were putting in effort to understand workplace culture and the unwritten rules in the workplace and this is an area where human resources teams should devote time to ensuring autistic women have effective, sympathetic and well-informed workplace mentors to help them navigate these. Support from external organisations or from workplace human resources teams were patchy and the challenge was that to access these meant having to disclose a diagnosis. Workplace adjustments do not appear to be widely known about, probably because they will differ according to the needs of the individual worker, and many of the women seem to have had trouble when these needed to access an adjustment. Overall this suggests that greater flexibility needs to be available to autistic workers in the workplace that should also be extended to all employees. Workplace adjustments for work organisation, sensory issues, and working time for example should be available for all employees on request which would remove the stigma from autistic women needing to disclose their diagnosis to access the adjustments.

Some of the autistic women interviewed did not want to be managers, whilst others were doing this already. However many women showed high levels of empathy and thought about how they would like to be managed when managing others. Typically the women wanted to be managed in an open way and highly disliked being 'micro-managed'. The women's thoughts about this particularly evidenced the double empathy problem as they

observed that they worked successfully with managers who put themselves in the shoes of the autistic women. However, literature suggests that this is causing the manager to carry out high levels of emotional labour, suggesting both parties are impacted by this support relationship. This suggests that there needs to be much more formal support to managers of autistic workers in the workplace to support and build their levels of empathy and understanding, and ensure this is supported by human resources processes within the business. The autistic women interviewed mostly expressed a very strong personal work ethic, combined with a highly critical view of the allistic work ethic, thus further emphasising the relevance of the double empathy problem.

7.15 Conclusion

This chapter focused on the impact of double empathy, the work environment and organisation and the theme 'lost in translation'. To answer the third research question – what challenges do autistic women face in the workplace? it has been seen that these are many and largely driven by double empathy problems where there exists a breakdown of communication or understanding between autistic women and allistic colleagues, supervisors, or managers.

Working environments for the participants were largely influenced and determined by allistic culture and practice. Double empathy impacts where autistic women may feel bored or underchallenged by their work due to misunderstandings about their capabilities or capacity or how to utilise their strengths. They may be struggling with perfectionism, trying to over deliver to feel accepted and less stigmatised in the workplace. Double empathy issues seem to particularly explain differences of understanding where autistic and allistic workers clash over how and when work is completed.

The findings suggest that many participants had a preference for working on their own and this may be because they could develop more certainty in the workplace from relying on their own skills, knowledge and behaviours. There were however very individual views on team working, but with a pragmatic understanding that it was sometimes necessary. Where issues arose around team working these tended to be flashpoints with specific people.

The sensory issues identified in the workplace were highly individual and context specific, but also likely to prompt bullying. There was evidence of the impact of sensory issues on the participants health, and the use of alcohol to manage masking. There was evidence through the participants contributions of significant anxiety associated with the workplace and an intolerance of uncertainty seemed to be a particular driver of anxiety. Similarly, socialising activities were also anxiety forming because they were largely unstructured and uncertain.

The findings show that many participants had developed useful problem-solving skills but were frustrated that these weren't more widely used within the workplace or celebrated. However, early in their careers some participants were bored in jobs where they weren't stretched enough, or if they felt the jobs were no longer relevant to their values or aspirations. Many participants mentioned the exhaustion or 'autistic burnout' which they received from their jobs. This appears to be due to the amount of masking needed to 'fit in' at work, meaning that the autistic woman was not only doing the job, but having to also adopt a different persona to do it. This effort might also impact health and wellbeing due to using masking activities such as drinking alcohol to cope.

Another flash point identified in the findings was the amount of soft skills or people skills required in the workplace, which most participants identified that they were poor at. However, one woman had determined to work out in an analytical way what was required to work effectively with internal teams/customers. Again, this suggests the additional amount of work, effort and emotional labour required by participants to attempt to 'perform' on a level playing field with allistic colleagues. Unwritten rules or understanding workplace culture was another area of frustration for participants.

The findings suggest that support in the form of reasonable adjustments were patchy in the workplace. In some cases, this was due to the participants not wanting to disclose their diagnosis for fear of stigma and bullying. However, in other cases a practical issue was often that employers had little understanding of what adjustments could be made, or the onus for finding adjustments was put on the autistic worker, who similarly was unaware of what was possible, or what would help. The findings suggest therefore a gap in awareness and knowledge that adjustments can be made, or where to get this information. The findings also highlight the isolation that the autistic woman often feels in this situation and the way

in which they are treated with disbelief by the employer and/or co-workers. Another concern is the self-employed who might require practical support for funding bids, or with organising their business for which they needed practical administrative support. These add additional costs that an allistic self-employed person may not require.

The findings also suggest that the participants had a difficult relationship with perfectionism. They obtained satisfaction from doing work in a manner, and to a level that pleased them, but also obtained significant stress if they felt they had somehow failed.

The findings also reveal some interesting perspectives on being a manager or being managed. Some of the participants had reached a point in their career that meant they had become managers or taken on a supervisory role. They mainly appeared to do this in a 'hands off' way as there seemed to be a particular dislike amongst the participants for being 'micro-managed' themselves. Double empathy was significantly present in the way participants felt they were not praised enough or received enough thanks for doing a good job. This suggests that the autistic participants were perhaps suffering from burnout from being perfectionist and trying their utmost to perform well. However, the effort involved in this was likely unnoticed and unacknowledged by their managers. For this reason, it is not surprising that some women praised their managers who were able to put themselves in the shoes of the autistic worker and understood what they had done, how they had done it, and the overall effort involved, together with any performative masking required. The research (Richards et al, 2019) about the emotional labour involved in line managing autistic workers is particularly illuminating and highlights that there needs to be investment from both the autistic worker and the allistic manager for the workplace to be seen to be supportive and successful from both sides.

It is also revealed in these findings how executive functioning affected the autistic women, with some finding it particularly difficult at times to get started on individual allocated tasks or work. Sometimes this meant that the autistic women needed to 'catch-up' out of hours, suggesting that there could be a lot of unpaid overtime that autistic workers are doing to 'keep afloat' in the workplace.

Finally, reflecting that autistic workers are often value driven, it is no surprise to find that some of the participants felt passionate about their jobs and the way they carry it out.

Given that allistic workers are not carrying out all the additional emotional labour and additional work to produce a high value service or output it is perhaps not surprising that the autistic women felt that they were doing more work than the allistic worker, or had a greater work ethic, and that the allistic worker seemed not to care to the same extent. However, because each of these workers has no real understanding or conceptualisation of what the other is performing or going through to reach the result, the result is another example of the double empathy problem.

Chapter 8: Conclusion

8.1 Introduction

This study originated from the researcher's own diagnosis as an autistic woman and journey to claim an autistic identity, as well as a curiosity about the worklife experiences of other autistic women. The purpose of this concluding chapter is to clarify the original content of this research on the worklife experiences of autistic women in the UK. This chapter draws together and highlights the important features of the preceding chapters. The study has drawn together literature on autism and identity and has developed a conceptual model highlighting the role of autism, identity, stigma, and double empathy, on the worklife experiences of autistic women. Drawing on the model this chapter then demonstrates the theoretical and methodological contributions of autism and identity. Finally, this chapter examines implications for research and practice, as well as research limitations before identifying further areas for future research.

8.2 General Conclusions

Chapter 1 set out to share the motivation to carry out this research. It also set out the rationale in focusing on an under researched area of autistic women in the workplace. Drawing on the literature on autism Chapter 2 critically examined the autism and employment literature and builds the case for using a critical lens on conceptualisations of autism, rejecting medicalised and deficit models, and adopting the social model of disability and utilise compelling autistic conceptualisations of autism such as monotropism and the double empathy model, and seeking autistic understandings of the struggles that autistic people face in and out of the workplace.

Chapter 3 conceptualised identity, drawing out the concepts of a disabled autistic identity and stigma, drawing attention to the intersectional nature of being female and autistic. Concepts of self-identity and social identity are of paramount importance to understand the worklife experiences of autistic women. For autistic people, their autism is intrinsic to their identity, and as such is inseparable. It is the identity they have. They can mask it in some way, but it cannot be 'taken away'. The intersectional elements of being an autistic woman,

also combine with other social identities in their lives, so that being an autistic woman in the workplace, or seeking work, is distinctive and not just a combination of being female and autistic. Autistic women may be transformed from feeling like a failed member of the neurotypical community, to a functioning member of the autistic community, by self-identifying or having received an official autism diagnosis. Becoming part of the autism community may also help the autistic woman's social identity, as she may have felt disconnected to, or rejected from allistic groups. Having an invisible disability in the workplace the autistic woman, without a diagnosis, will only encounter multiple examples of being stigmatised, but with no understanding of the cause. With a diagnosis she may decide either to conceal her diagnosis and mask her identity, or to embrace her autistic identity and seek workplace adjustments. Being 'masked' enabling her to 'pass' may come, however, at a high cost to her physical and mental health.

The methodology chapter, Chapter 4, highlighted the researcher's participant researcher methodological stance and underlying research philosophy as interpretivist with a social constructionist ontological viewpoint. This chapter highlighted the qualitative research strategy adopted in the study, and the completion of two separate narrative literature reviews, the first on autism and employment and the second on identity, stigma and masking. The data collection of semi-structured oral history interviews with the 35 autistic women participants was discussed and the process of transcription and analysis using reflexive thematic analysis (Braun and Clarke, 2022) was explained. The chapter concluded with consideration of the research questions posed, the sample size or information power, and the research ethics.

8.3 Main Conclusions

8.3.1 Research Question 1: What Jobs Do Autistic Women Do?

This study has shown that autistic women carry out a wide range of jobs which go beyond stereotypical assumptions of what they might do for employment. However, it was found that autistic women may have a chaotic pattern to employment with multiple jobs undertaken sequentially. The argument was made that this suggested that critical incidents, not feeling a good fit in their job, or being stigmatised for the undiagnosed hidden disability that they did not realise they had, may be to blame for this chaotic pattern. Where a job

particularly engaged the interest of the autistic woman, providing some job satisfaction despite any negative elements, a monotropic focus and good workplace double empathy, enabled the woman to carry out the job successfully. A concern was recorded however, that women with an early diagnosis may have been dissuaded from certain careers due to stereotypical views about what they ought to be able to do, and therefore more publicity and information about autistic women and their careers would enable younger autistic women to make better and more informed choices, with a greater understanding of some of the challenges they might face in the workplace, together with some of the solutions to deal with them.

8.3.2 Research Question 2: How Do Autistic Women Resolve Their Identity in the Workplace?

This study has shown that autistic women undertake a great amount of identity work, impression management and masking in the workplace which can trigger anxiety and stigma. Prior to being diagnosed or self-identifying, women were unable to resolve their identity in the workplace, leading many to feel stigmatised or broken, but after receiving a diagnosis or self-identifying the women were able to reappraise their careers and lives.

Having an autism diagnosis was a gateway to workplace support and accommodations and would allow a woman to access measures that might improve the interview or employment experience. Without a diagnosis an autistic woman would likely feel stigmatised in the workplace but would not be able to identify what they were being stigmatised for, leading to significant identity confusion. Repeatedly facing this situation and experiencing the consequential stigma could result in a lasting impact on the woman's mental health and ability to put herself forward for the workplace.

Some participants in this study had developed a defined work identity, often focused on the need to appear professional, and as their worklife changed their work identity also changed. The professional role that some women adopted also extended to the way they dressed or presented themselves (impression management). However, this ability to perform a different identity could become 'unstuck' in situations where two different group identities converged. There were diverging views where some participants felt that work was simply a means to exist or that other outside interests were more relevant to their identity creation, whilst others felt that work was central to their identity, and they spent many hours

engaged in it. The participants who were not working felt that they had no value, and those whose careers did not fulfil their original intention felt frustrated.

The diversity of the findings suggested that autistic women or autistic people should not be seen as a 'group' identity, and that allistic co-workers should not seek to understand what 'autistic people' need as a generalised group in the workplace. No evidence appears in this study for a 'generic' autistic person or autistic woman, and therefore it follows that generic adjustments would not be appropriate for everyone and that an individual approach needs to be taken and time invested in providing individual responses and individualised workplace adjustments and accommodations.

8.3.3 Research Question 3: What Challenges Do Autistic Women Face in the Workplace?

This study has shown a variety of challenges faced by autistic women in the workplace and suggests that these are largely driven by double empathy problems where a breakdown of communication or understanding has occurred between an autistic woman and their allistic co-worker, supervisor, or manager, and vice versa. Working environments for the participants were largely influenced and determined by allistic culture and practice. Some autistic women felt bored or underchallenged by their work due to misunderstandings about their capabilities or capacity or how to utilise their strengths. Some were struggling with perfectionism, trying to over deliver to feel accepted and less stigmatised in the workplace. Many participants preferred working on their own suggesting that this was a way they could develop more certainty in the workplace, relying on their own skills, knowledge, and behaviours. There were however some very individual views on team working, and where issues arose these tended to be flashpoints with specific people. The sensory issues identified in the workplace were also highly individual and context specific, but also likely to prompt bullying. The use of alcohol by at least one woman suggested masking behaviours and evidence of the impact of sensory issues on the health of the participants. A major driver of anxiety in the workplace appeared to be linked with the autistic woman's intolerance of uncertainty.

This study has also shown that many participants had developed useful problem-solving skills but were frustrated that these weren't more widely used within the workplace or celebrated. Early in their careers some participants were bored in jobs where they weren't

stretched enough, or if they felt the jobs were no longer relevant to their values or aspirations. Exhaustion or 'autistic burnout' was a feature for many participants. This resulted from the amount of masking needed to 'fit in' at work, meaning that the autistic women were not only doing the job, but having to also adopt different personas to do it. Again, some women reported using alcohol to help relax and cope with the effort of masking.

Underlining the link with double empathy, participants identified that they were poor at soft skills or people skills, but some could perform these if they used an analytical approach, demonstrating the additional work, effort and emotional labour required by participants to attempt to 'perform' on a level playing field with allistic colleagues. Understanding unwritten rules or workplace culture were also areas of frustration for participants. Reasonable adjustments were patchy in the workplace, due either to participants not disclosing their diagnosis, or to a lack of understanding about what adjustments could be made, by their employers. This could leave the autistic worker feeling isolated. Similarly self-employed autistic people requiring support had little guidance or help with additional costs.

This study also found that the participants had a difficult relationship with perfectionism, and obtained satisfaction from doing work in a manner, and to a level that pleased them, but also gave them significant stress if they felt they had somehow failed. This study has also revealed some interesting perspectives on being a manager or being managed. Some of the autistic participants had reached a point in their career that meant they had become managers or taken on a supervisory role. Participants disliked being 'micro-managed' themselves, and this dislike meant that when in a supervisory or managerial role they preferred to be more 'hands off'. Double empathy was significantly present in the way participants felt they were not praised enough or received enough thanks for doing a good job. This suggested that the autistic participants were suffering from burnout from being perfectionist and trying their utmost to perform well, but ended up being disappointed when their effort was largely unnoticed and unacknowledged by their managers. Some women praised their managers who were able to put themselves in the shoes of the autistic worker and understood what they had done, how they had done it, and the overall effort involved, together with any performative masking required, but these examples were very

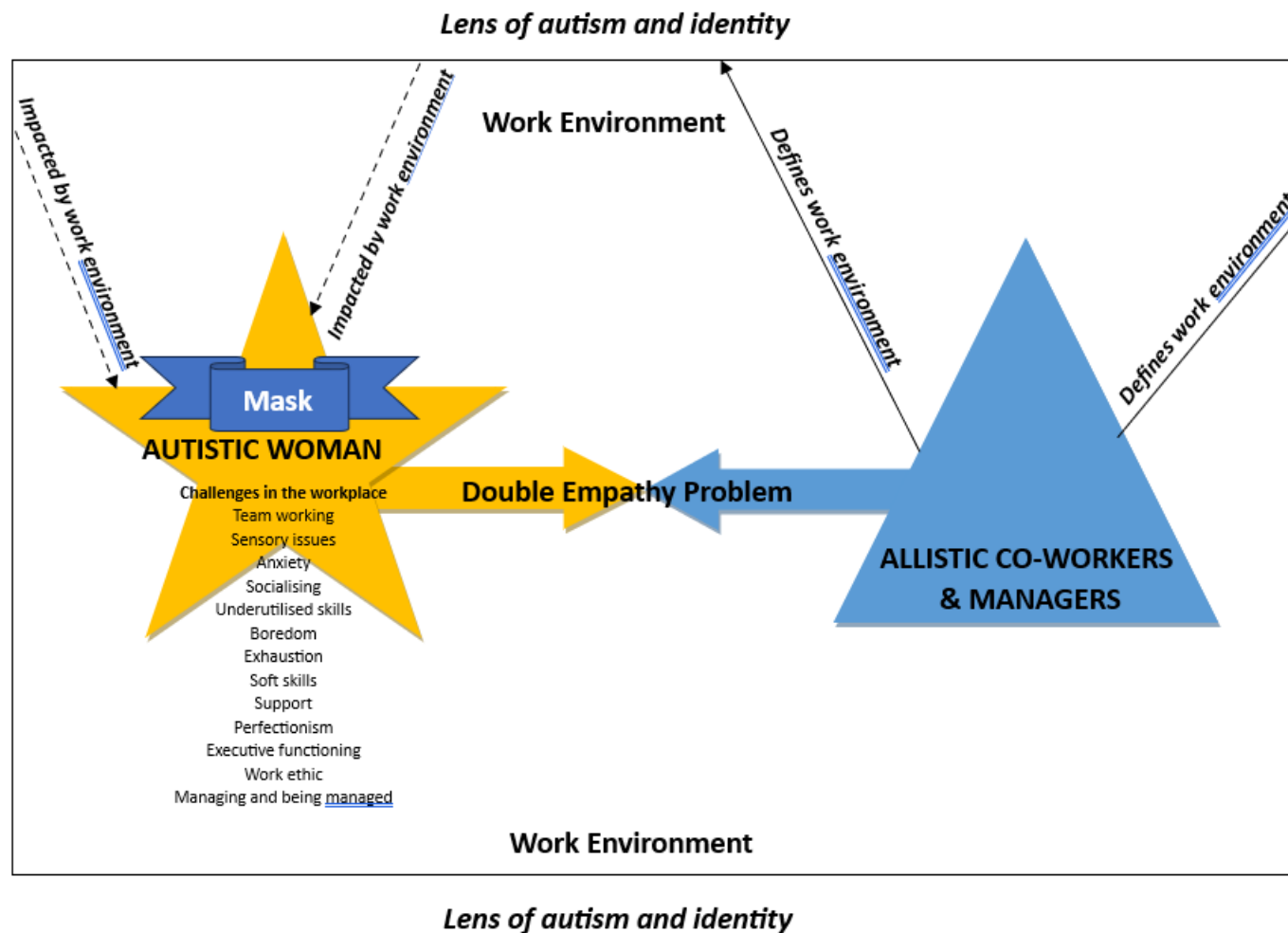
few. Executive functioning was also seen to affect the autistic women, with some finding it particularly difficult at times to get started on individual allocated tasks or work. For some autistic women this meant they needed to 'catch-up' out of hours, suggesting that there could be a lot of additional work and unpaid overtime being carried out in order that the autistic women could 'keep afloat' in the workplace.

Finally, this study found that autistic women were often value driven in the workplace, with some of the participants particularly passionate about their jobs and the way they carried it out. However, the autistic women considered that they were doing more work than the allistic worker, or had a greater work ethic, and that the allistic worker seemed not to care to the same extent. This underlined the impact of double empathy where each of the autistic and allistic workers had little understanding or conceptualisation of what work or emotional labour the other is performing or going through to reach the result.

8.4 Final Conceptual Model

The final conceptual model for an exploration of the worklife experiences of autistic women in the UK is presented in Figure 8.1. This conceptual model is a major contribution of this study and shows how using a lens of autism and identity to interpret what is going on we can see how the allistic co-worker or manager defines, determines, organises or affects the work environment that the autistic person works in. This work environment impacts upon the autistic woman who is likely masking in the workplace to conceal her autistic identity and becoming exhausted by the effort. This alien work environment then creates and causes challenges in the workplace for the autistic woman such as sensory issues, team working with people she does not understand, and who do not understand her (double empathy problem), causes her executive functioning or perfectionism issues, and work which is not organised to suit her strengths, but perhaps is boring and under skilling.

Figure 8.1: Conceptual Framework for the Worklife Experiences of Autistic Women in the UK



Conceptual Framework for the Worklife Experiences of Autistic Women in the UK

8.5 Theoretical and Methodological Contributions

This unique doctoral study has made important theoretical and empirical contributions throughout, and these are now discussed in detail in this chapter.

The major contribution of this study is the conceptual framework exploring the worklife experiences of autistic women in the UK. This was realised through the use of reflexive thematic analysis (RTA) (Braun and Clarke, 2022) on 35 semi-structured oral history interviews with autistic women. The analysis created three main themes for this study (see Figure 4.7) of chaos or control, wearing a mask, and lost in translation.

There is little business and management literature on this topic and this research fills the gap at the intersection of autistic women and the workplace. This study makes the case that a significant amount of conflict in the workplace is likely to arise from double empathy issues where the autistic woman and the allistic manager, supervisor or colleague have a different understanding or perspective, bringing the two into conflict.

This study contributes to the literature on autism, identity, and stigma in the workplace. It makes a significant contribution to discussion about patterns of employment for autistic women, and the implications of an early or late diagnosis. It also comments on the longitudinal employment of autistic women and how more can be done by employers and support organisations, including trades unions, to support them.

8.6 Implications for Research and Practice

Although some women mentioned receiving support in the workplace (see 7.9), and some support from organisations such as the National Police Autism Association, there was little evidence of mainstream trades union support from the women interviewed. Some trades unions have been actively working in this area (notably some of the rail unions) carrying out and sponsoring research, identifying best practice, and making this available to union representatives and members. Trades unions perhaps need to do more to ensure that they are relevant to, and able to support, autistic workers, and that their allistic members understand and are willing to support autistic members in the workplace.

The study raises concerns about the career advice being given to autistic people diagnosed at an early stage. Careers opportunities need to be extended beyond stereotypical IT or analytical jobs. Many women in the research had or craved more creative occupations. Younger autistic people need access to the worklife experiences of older autistic workers to understand better the benefits or disbenefits of specific jobs or industries so that they can make informed choices themselves. Older autistic people in the workplace could act as career mentors, helping smooth the way for young people entering the world of work for the first time.

There is still need for easier access to diagnostic services for autistic people, and following that, for help, support and guidance with mental health, wellbeing, and careers support. Finally, there is of course a need for more research in this area, and for an acknowledged tripartism between autistic people, employers, and trades unions to support more autistic people to thrive in the workplace, to normalise autistic contributions in workplaces, and eliminate stigma, bullying and PTSD at work for autistic workers.

8.7 Research Limitations

The research interviews in this study do not claim to represent the views of all autistic women or all autistic people. However, they do provide an important insight into the world of some autistic women seeking to get into work or get on at work. This study was also limited to the UK and does not claim to speak about the experiences of autistic women in other countries who may also be affected by other intersectional or structural issues in their countries.

8.8 Future Research Use of the Conceptual Framework

Further work is required to better understand the worklife experiences of autistic people, and to understand what differences, if any, exist between male and female workers, and what structural issues or workplace adaptations can help them to make their contribution to the workplace, whilst avoiding a stigmatised identity, and increasing their well-being.

A funded longitudinal study would be useful to look at and track the worklife experiences of those autistic women, or autistic people in general, who receive an early diagnosis to

understand whether this allows them to make considered choices about their future careers, or whether this limits them in their choices due to stigma.

It is also suggested that co-produced research with autistic workers and HR professionals would be useful to improve understanding/eliminate double empathy problems and increase the inclusion and acceptance of autistic people in the workplace.

Whilst there remains a debate about the underdiagnosis of women and the under recognition of masking in women (female compensation hypothesis), further research would be useful to look at sex differences and intersectional issues in the workplace as the older women in this study will also have been impacted by gendered issues such as the impact of the menopause, caring responsibilities for older and younger generations, in ways that male workers may not. These intersectional issues will undoubtedly have impacted on the women's identity work, stigma, anxiety, and health.

Finally, there is currently very little research on autism and employment within business and management literature, with most research appearing in disability or psychology literature (Ezerins et al, 2023) and it is therefore important that future researchers use the framework outlined here and work with the autistic and/or neurodiversity community to co-produce research that will have a significant impact and effect on their well-being in the workplace.

The conceptual framework developed for this study is unique in bringing together autistic women and employment, examining identity and the double empathy problem. It is envisaged that other researchers will want to use the framework to advance autism research in the workplace, and increase the very limited business and management literature in this area. Some examples of future research could be to test:

- a) across a much broader female or male/female population worldwide
- b) men only on a similar basis to the current study in the UK
- c) across a wider neurodiversity population
- d) any of the populations in a,b,c in a longitudinal study.

APPENDICES

APPENDIX A: ETHICS APPROVAL

UNIVERSITY OF HERTFORDSHIRE
SOCIAL SCIENCES, ARTS AND HUMANITIES

MEMORANDUM

TO Tracy Turner
CC Dr Moira Calveley
FROM Dr Tim Parke, Social Sciences, Arts and Humanities ECDA Chairman

DATE 11/2/14

Protocol number: cBUS/PG/UH/00412

Title of study: The worklife experiences of women with Asperger Syndrome

Your application for ethical approval has been accepted and approved with the following conditions by the ECDA for your school.

Approval Conditions:

Supervisor to approve the recruitment request for participants, which must include the UH protocol number and the name of the approving Committee;

Supervisor to approve the interview schedule and the questionnaire prior to recruitment and data collection.

This approval is valid:

From: 11/2/14

To: 31/3/16

Please note:

Your application has been conditionally approved. You must ensure that you comply with the conditions noted above as you undertake your research. Failure to comply with the conditions will be considered a breach of protocol and may result in disciplinary action which could include academic penalties. Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

UNIVERSITY OF HERTFORDSHIRE
SOCIAL SCIENCES, ARTS AND HUMANITIES

ETHICS APPROVAL NOTIFICATION

TO Tracey Turner
CC Dr Moira Calveley
FROM Dr Tim Parke, Social Sciences, Arts and Humanities ECDA Chairman
DATE 12/01/2016

Protocol number: acBUS/PG/UH/00412(1)

Title of study: The worklife experiences of women with Asperger Syndrome.

Your application to extend the existing protocol cBUS/PG/UH/00412 as detailed below has been accepted and approved by the ECDA for your School.

This approval is valid:

From: 01/04/2016

To: 31/03/2018

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

APPENDIX B: LETTER SEEKING PERMISSION TO CONDUCT RESEARCH

From: Turner, Tracy
Sent: 27 November 2013 15:38
To: Bernard Fleming
Subject: PhD Research: Request for Research Participants

Dear Sir/Madam

I am a member of the National Autistic Society and a PhD research student at the University of Hertfordshire. My research title is 'The worklife experiences of women with Asperger Syndrome' and having conducted an initial literature review I am about to apply for ethics approval from the University's Ethics Committee.

My research will involve women with a diagnosis or self-diagnosis of Asperger Syndrome. I will be adopting a qualitative research strategy which employs:

- A large scale survey
- Semi-structured interviews
- Critical incident/self-reflection diaries

My supervisors have suggested that I write to the NAS and yourselves to ask whether you can confirm that subject to my ethics approval you will be able to publicise my call for research participants. This is to answer any questions the Ethics Committee may have about my ability to publicise the call for participants.

I realise that without the ethics approval you cannot yet publicise my research, but would be grateful if you can confirm that you would be able to do this following approval in order that I can submit your response with my ethics application.

Many thanks

Tracy Turner

Tracy Turner BA, MA, PgCert LTHE, PgCert AS, FHEA, FRSA
Visiting Lecturer
Department of Management, Leadership & Organisation
M218
Hertfordshire Business School
University of Hertfordshire
de Havilland Campus
Hatfield
Herts
AL10 9AB
UK

Email sent to Richard Mills at the National Autistic Society and Bernard Fleming at Research Autism on 19 March 2014

Dear Richard and Bernard

Many thanks for agreeing to include my request for research participants on the relevant website pages of Research Autism.

I am attaching my ethics approval memo together with some text for the relevant webpage to introduce my research and give a link to my call for participants.

Regards
Tracy

Tracy Turner BA, MA, PgCert LTHE, PgCert AS, FHEA, FRSA
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UK
e-mail: t.turner2@herts.ac.uk

The Worklife Experiences of Women with Asperger Syndrome Protocol Number: cBUS/PG/UH/00412, University of Hertfordshire Arts & Humanities ECDA

Are you a woman with Asperger Syndrome who would be willing to contribute to doctoral research on your experiences of work or seeking to gain employment?

I am a PhD student at Hertfordshire Business School (part of the University of Hertfordshire) conducting research into this important area. The aim of my research is to give a voice to, and explore the experiences of, women with Asperger Syndrome in the workplace. The research will include women who are currently employed, previously employed, or who are seeking, or have sought, employment. If you are over the age of 18, have received a formal 'diagnosis' of Asperger Syndrome, or if you have self-diagnosed or you self-identify with Asperger Syndrome, I would like to hear about your worklife experiences.

If you would like to take part please complete the short questionnaire at <https://sdu-surveys.herts.ac.uk/womenasperger> which collects some basic demographic and contact details. I will then use these to arrange a mutually convenient time and method to interview you.

The interviews, which should take no longer than an hour, would be face to face, by telephone or by Skype, all at a time convenient to you. All information collected will be kept strictly confidential and you will not be able to be identified in the final research or any conference presentations or publications that may arise from it.

If you would like further information about this research please contact Tracy Turner at t.turner2@herts.ac.uk

PARTICIPANT INFORMATION SHEET: PhD

Title of Research

The ~~worklife~~ experiences of women with Asperger Syndrome
Protocol number: ~~CRUS~~PG/UH/00412

Introduction

You are being invited to take part in a research study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide ~~whether or not~~ you wish to take part. Thank you for reading this.

What is the purpose of this study?

The purpose of the study is to investigate and explore the ~~worklife~~ experiences of women with Asperger Syndrome. As a result of the ~~study~~ it may be possible to draw policy conclusions in relation to workplace human resource practices, disability and employment legislation and for policy in the wider society.

The study seeks to involve women over the age of 18 who have been diagnosed with Asperger Syndrome or who have self-diagnosed. If you would like to take part in the study you will need to have some experience of work outside the home, or of seeking to obtain such work. This could be full time, part time, or voluntary employment. It does not matter how much employment experience you have had, or the number of employers or workplaces you have worked at.

Do I have to take part?

It is completely up to you ~~whether or not~~ you decide to take part in this study. If you do decide to take ~~part~~ you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you ~~have to~~ complete it. You are free to withdraw at any stage without giving a reason.

What will happen to me if I take part?

If you decide to take part in this study, you will be contacted to arrange an interview which will take place by email, face to face, by Skype or by telephone, at a time to suit the participant. The interview will be based around themes related to your experience of working.

~~In order to~~ accurately write up your answers to face to face, Skype or telephone interview questions it will be necessary to make a recording of the interview. The audio recordings of your responses made during this research will be used only for analysis. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. At the end of the research these recordings will be deleted.

Care will be taken to ensure confidentiality when the research is written up, with no participant being able to be identified.

It is anticipated that face to face, Skype or telephone interviews will take at least 30 minutes but no longer than 1 hour. If you feel that you have a lot to talk about and it is likely that the interview will take longer than 1 hour you will be asked whether you want to carry on with the interview or would prefer to finish off on another date and time more convenient to you.

What are the possible disadvantages, risks or side effects of taking part?

There are no anticipated disadvantages, risks or side effects of taking part.

What are the possible benefits of taking part?

The personal benefits of taking part are that you will be contributing to research which may ultimately improve your working life and that of other women with Asperger Syndrome.

How will my taking part in this study be kept confidential?

It will be necessary to collect some personal details such as your name and contact information so that you can be contacted if you want to participate in the interviews. However, all the information collected about you during the course of the research will be kept strictly confidential. **You will not be able to be identified in any reports or publications.**

What will happen to the results of the research study?

The research will be used in the final thesis for a PhD on the worklife experiences of women with Asperger Syndrome. The research may also be used in academic articles and in material written for organisations concerned with employment or autistic advocacy. **You will not be able to be identified in any reports, publications, conference presentations or articles written as a result of this research.**

A summary of the research will be compiled and made available to participants by email, post, or via a weblink.

Who has reviewed this study?

This research has been reviewed by the University of Hertfordshire Ethics Committee.

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing or by email: Tracy Turner, Department of Management, Leadership & Organisation, Hertfordshire Business School, University of Hertfordshire, De Havilland Campus, Hatfield, Hertfordshire, AL10 9EU. Email: t.turner2@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University Secretary and Registrar.

Thank you very much for reading this information and giving consideration to taking part in this study.

APPENDIX C: THE RECRUITMENT QUESTIONNAIRE

Bristol Online Survey Recruitment Questionnaire		
Purpose	Question	Options
Participating in this research	Do you agree to be interviewed for this research?	Yes/No
Age	What is your age?	18-24 years old 25-34 years old 35-44 years old 45-54 years old 55-64 years old 65-74 years old 75 years or older
Diagnosis/Autistic Identity	Have you received an Asperger Syndrome 'diagnosis' or have you self-diagnosed/self-identified with Asperger Syndrome?	Received a 'diagnosis' from a professional Self diagnosis/self-identify with Asperger Syndrome
Age at Diagnosis/Autistic Identity	How old were you when you received your diagnosis or first self-identified with Asperger Syndrome?	Under 12 years old 12-17 years old 18-24 years old 25-34 years old 35-44 years old 45-54 years old 55-64 years old 65-74 years old 75 years or older
Qualifications	What is the "highest" qualification you have completed?	University Higher Degree (e.g. MSc, PhD) First degree level qualification including foundation degrees, graduate membership of a professional Institute, PGCE Diploma in higher education Teaching qualification (excluding PGCE) Nursing or other medical qualification not yet mentioned

Bristol Online Survey Recruitment Questionnaire

Purpose	Question	Options
		A Level Welsh Baccalaureate International Baccalaureate AS Level Higher Grade/Advanced Higher (Scotland) Certificate of sixth year studies GCSE/O Level CSE Standard/Ordinary (O) Grade / Lower (Scotland) Other school (inc. school leaving exam certificate or matriculation) None of the above Other If you selected other, please specify
	Which of the following vocational or other qualifications do you have?	Youth training certificate Key Skills Basic skills Entry level qualifications (Wales) Modern apprenticeship/trade apprenticeship RSA/OCR/Clerical and commercial qualifications (e.g. typing/shorthand/book-keeping/commerce) City and Guilds Certificate GNVQ/GSVQ NVQ/SVQ - Level 1 - 2 NVQ/SVQ - Level 3 - 5 HNC/HND ONC/OND

Bristol Online Survey Recruitment Questionnaire		
Purpose	Question	Options
		BTEC/BEC/TEC/EdExcel/LQL SCOTVEC, SCOTEC or SCOTBEC Other vocational, technical or professional qualification None of the above Other If you selected Other, please specify
Employment status	Are you currently ... ?	Employed full time for wages Employed part time for wages Self-employed An unpaid volunteer Out of work and looking for work Out of work but "not" currently looking for work A homemaker A student Retired Unable to work Other If you selected Other, please specify
	If you do not currently work have you worked in the past?	Yes No
	What type of organisation do you work for, or if not currently working, your last employer?	Self employed/your own company Private firm/company/plc Civil service or central government Local government (including local education, fire and police) National Health Service or Higher Education

Bristol Online Survey Recruitment Questionnaire		
Purpose	Question	Options
		Voluntary Sector Other If you selected Other, please specify
	Do you have, or have you had, any managerial or supervisory experience?	Manager Supervisor/team leader Not manager or supervisor
Contact Details	Name	
	Address	
	Email Address	
	Telephone Number	

APPENDIX D: THE SEMI-STRUCTURED INTERVIEW SCHEDULE

Question	Prompt	Reason for question
Why did you want to contribute to this research?	Greater understanding of AS by other people Opportunity for personal reflection	To understand motivation/interest/importance
When did you receive your diagnosis or when did you self-diagnose/self-identify?	Child Teenager Older adult What prompted self-diagnosis?	To understand what impact the diagnosis might have had on working life (links to later question)
How many jobs (paid and unpaid) do you estimate you have had in your working life so far?	Paid Unpaid Full time Part time Contract	To understand whether employment patterns have been varied or follow a more stable, traditional pattern
Can you briefly run through, in chronological order, a synopsis of your working career please (paid and unpaid work).	Mode of employment Job title Employer Why did you leave job How did you find new job What were challenges What did like least about the job	To understand the complete working history of the interviewee
What did you want to do when you left school/college/university?	Career goal Childhood ambition Keep occupied Pay bills	To understand original ambition compared to career achieved

Question	Prompt	Reason for question
Have you disclosed your disability at any point of your working career?	Purpose Benefits Disbenefits Consequence	To investigate whether disclosure has had any effect on individual jobs or overall career
Do you think there are any differences in your working life pre and post diagnosis?	Modification of own practice or behaviour Acceptance of self Less willing to accommodate other people/people's attitudes	To investigate whether a diagnosis affects decisions made in relation to career or overall identity or acceptance of self
What role does working have to you and your identity?	Work central to identity Work is the means to get money Work is means to try and socialise	To investigate whether working has an impact on identity and self-worth
Can you tell me about your experiences of your managers and being managed by them at work	Relationship with manager Accepting/rejecting feedback Accepting/rejecting criticism Own acceptance/rejection of other workers Dealing with authority/management Dealing with conflict/disagreement	To investigate attitudes to and responses to managers and management
Can you tell me about your experiences of managing other people at work	Relationship with subordinates Giving feedback Accepting/rejecting feedback Accepting/rejecting criticism Dealing with others view of your authority/management Dealing with conflict/disagreement	To investigate approaches to managing other people at work

Question	Prompt	Reason for question
Can you tell me about your experiences of working in a team?	Agreeing team roles Leading/following Accepting/giving feedback/criticism/praise	To investigate working preferences and approaches/attitudes to working in a team
Can you tell me about your experiences of working on your own?	Preference/rejection for working on own Benefits/disbenefits Dependent on circumstances Communicating progress to others	To investigate working preferences and approaches/attitudes to working on own
Can you tell me about your experiences of work socialising and work politics and whether this has had a positive or negative effect on your working life?	Regular work socialising Special work events, ie Christmas Party Work gossip	To understanding acceptance/rejection of work socialising and impact on working life/career
Can you tell me about your experiences of executive functioning at work, ie how you manage your time and get things done?	Organising self Organising work Starting and planning work Timely completion Procrastination	To understand difficulties encountered in typical working context
Can you tell me about your experiences of seeking work or marketing yourself?	Interactions with agencies Researching companies Speculative applications Advertising services Social media	To understand how employment is obtained and the successes, difficulties or barriers encountered
Can you tell me about your experiences of interviews and assessment tests	Applications Preparation Interviews Assessment Centres Adjustments/accommodations	To understand any difficulties encountered in recruitment interviews, tests and assessment centres and adjustments required and/or provided

Question	Prompt	Reason for question
Who do you talk to or confide in about work problems or issues?	Work colleague Friend Coach/mentor Family	To understand the importance of any supportive relationships in the working context
How would you describe your interactions with people at work?	Team members Manager Customers External contractors/stakeholders	To understand how the participant interacts with people at work and any difficulties encountered
What would be your ideal job?	Flexible Intellectually stimulating Accommodations Financial benefits	To understand what the participant would view as their ideal job at which they would feel most comfortable or be most successful
What have you done to try to get on in your career or to fit into the workplace?	Adapting own style Mirroring successful people	To understand the adaptations or changes the participant has made to their own style or behaviours to fit into their workplace
What is your overall perception of your working life or career?	Success Failure Mixed – some positive, some negative Regret – missed opportunities	To understand the participants own view of their career
What is your perception of how people have viewed you in the workplace?	Challenging Problematic Successful	To understand the participants own perception of other people's view of them

Question	Prompt	Reason for question
How would you like to be perceived in the workplace?	Understanding Valuable contribution Acknowledgement of significant effort	To understand the workplace contribution which the participant would like to be acknowledged for
Do you feel that you have skills and knowledge that you have not been able to use in your working life? Why is this?	Challenge Insight	To understand the workplace contribution which the participant feels they have not been able to make (the gap)
Is there anything I have not asked you about that you think it is important for me to know about your worklife experiences?		To understand any other issues which the participant feels are significant

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