

# Autistic Men in the Workplace: An Interpretative Phenomenological Study

by

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A thesis submitted in partial fulfilment for the requirements for the degree of MSc (by Research) at the University of Central Lancashire

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## Abstract

An Interpretative Phenomenological Analysis of working experiences of autistic adults was conducted. Four male participants with past or current experience of working were recruited through social media and organisations like the National Autistic Society. Three participants were interviewed electronically using a typing-only program, and one was given a written questionnaire comprising the same interview questions. IPA underpinned the design of the study and was the analytic method. Two main superordinate themes were found: Workplace Challenges (which comprises sensory sensitivity, anxiety and coping strategies) and Workplace Relationships (which encompasses issues relating to disclosure, quality of relationships). It was concluded that autistic workers face a number of difficulties which they learn to cope with through coping strategies like control or avoidance. Masking difficulties through strategies which hide but do not necessarily reduce difficulty was also observed. The nature of the difficulty experienced as a result of anxiety or sensory sensitivity was also discussed. However, sensory sensitivity was not always a difficulty or impairment – for some it was a source of pleasure or a valued occupational skill. Additionally, participants reported a certain amount of distance from others, which they enjoyed. Issues with communication and unintentionally causing offense were reported but could sometimes be resolved through disclosure. For the most part, disclosure was followed by negative experiences with others, and therefore represents a key issue that all participants have had to consider at some point in their careers. Limitations and implications for the future are discussed.

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## Key of Abbreviations

IPA – Interpretative Phenomenological Analysis

ASC – Autism Spectrum Condition

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## CHAPTER ONE: INTRODUCTION

# INTRODUCTION

## Aims of This Study

Working experiences of autistic adults is an under-researched area, and so this study aims to address this gap. Thus I will present a phenomenological study which investigates the experiences of four men with Autism Spectrum Conditions (ASCs) in workplace contexts. Specific aspects of the experience being focused on include anxiety, sensory experiences and how to cope with each of these, and working relationships.

In the following five sections I will establish the basis for my aims. I will explain and discuss my theoretical approach and how I view disability. Thereafter I will give a literature review of each key area, by discussing autism and employment, challenges faced in the workplace (such as anxiety, sensory experiences, coping) and working relationships. Once the basis for my study has been established, I will then introduce my study.

## 1. Theoretical Approach

### 1.1 Conceptualising and Defining Disability

Unlike certain other perspectives, the Social Model of Disability (Shakespeare, 2010; Thomas, 2014) places blame for a lack of involvement in society not on the individual with the ailment but on the society which does not adequately allow for or support the individual. The definitions and views of the Social Model describe my own view of disability.

The model began with The Union of Physically Impaired Against Segregation (1975, cited in Shakespeare, 2010), who stated that:

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*“In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society”.*

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Therefore, the individual’s impairment is their condition, disease, or injury, but it is the inability to participate in society due to a lack of adequate support which is their disability. This distinction separates the impairment from the ability to function within society, rather than attributing causality to the impairment itself, as the medical approach does (Shakespeare, 2010). Thus, the disability is not individual and private, but socially constructed and public (Shakespeare, 2010).

The medical approach to defining disability has been, for many years, the dominant perspective taken by society as a whole (Shakespeare, 2010). Informed by biomedical sciences, society has drawn on the beliefs of medical practitioners in defining disability. As a result, many have come to believe that any impaired ability to contribute to or participate in society (or activities which are deemed normal) result from an individual's injury, disease or condition, rather than the lack of support (Shakespeare, 2010; Thomas, 2014). As such, it is the responsibility of the individual with the ailment to obtain treatments or cures, and take steps to ensure that they can function 'normally' within society (Shakespeare, 2010).

In addition to inadequate supports, the language used by others can be considered disabling. The common terms used (which are informed by the medical approach to disability) are usually variants of 'person with a disability' (Shakespeare, 2010; Thomas, 2014). Here, this would translate to 'adult with autism'. This possessive form of speech implies individual ownership of the disability or the condition, and implies that one may separate the individual from the difficulty they experience under the right circumstances, which is rarely the case (Shakespeare, 2010; Thomas, 2014). Instead, supporters of the Social Model prefer to use the term 'disabled person', which describes the disability not as an attribute (a noun), but a state of being (a verb). The use of the verb as a pre-modifier demonstrates that the individual is the one being acted upon, rather than the owner and the one responsible for the disability. It is this phrasing which will be used in this thesis. Additionally, the medical terminology for the name of the disability in question is Autism Spectrum Disorder or simply Childhood Autism (WHO, 2016; APA, 2014). This wording is not ideal, as the term 'disorder' denotes permanent impairment or fault. Therefore, the term 'condition', which is associated with a manageable and steadily reducing impairment, is preferred and will be used throughout this thesis. Indeed, Howlin, Moss, Savage and Rutter (2013), showed that autistic traits do decline over time. Thus for the purposes of this thesis it will be referred to as Autism Spectrum Condition, autism, autistic or simply "ASC".

In the context of employment, the medical view of disability would place responsibility on the disabled employee for finding a way to function 'normally' in employment, while the Social Model would place responsibility on the employer for making the workplace and job role suitable and accessible to the disabled employee. The Social Model is becoming more prevalent, as evidenced by the increasing number of buildings and workplaces with wheelchair access and other features which enable more people to use the buildings. These changes are a direct result of various legislation, such as the Equality Act (2010), which places a responsibility on the employer to make "*reasonable adjustments*" to enable individuals with impairments to work. The Social Model, which encourages 'treatment' of disability through removing social

barriers which prevent them from participating, therefore has informed this legislation, by encouraging employers to remove barriers to work.

Furthermore, other more specific legislation has been created for this purpose. The first impairment-specific legislation of its' kind, the Autism Act (2009) places requirements on the government to make more of an effort to support autistic people, by creating a strategy for the regional governing bodies of the UK and the healthcare system to follow. Following this legislation, the strategies Fulfilling and Rewarding Lives (Department of Health, 2010) and Think Autism (HM Government, 2014) were created for the purpose of requiring local councils and health services to take a number of actions surrounding promoting autism awareness and acceptance (particularly in healthcare services and Disability-specific staff at Job Centres), supporting with daily living, developing independence, the judicial system, as well as employment.

Clearly, increasing focus from the government and healthcare services is being shifted towards supporting in employment. This is because employment is important for well-being. The National Autistic Society have described the ability to obtain and maintain a job, and to progress within that job as *"the best route out of poverty, and a central part of social inclusion"* (NAS, n.d.). Thus it is important for the financial and social well-being of autistic people that they receive support into work, and in keeping work. The Social Model places on members of society, including employers, the same responsibility that the recent legislation places on local councils and services: the responsibility to support and enable these people to live more independently through employment.

## 1.2 My Method and Theoretical Approach

As my theoretical approach, I have chosen Interpretative Phenomenology, for which the associated method is Interpretative Phenomenological Analysis, or "IPA". IPA is a method of conducting qualitative research. Qualitative research is useful for enabling researchers to understand the emotions, perceptions, actions and experiences of their participants (Avis, 2005), as is the aim here. The area of study here is experiences, and so a qualitative method and theory which may be used to explore experiences was chosen: phenomenology.

Phenomenological research *"starts with the experience or the perception of the subject"* (Hughes, 2014, p58). *Phenomena* is taken by researchers to refer to situations or experiences, which for phenomenologists means studying the experience and how it presents itself to those experiencing it (Langdrige, 2007). Consequently, phenomenology is concerned with the existential. Studies within phenomenology are broad in focus, because they explore what it is

like to *be* something. Namely, they explore states of being, such as studying the experience of disease, illness, condition, syndrome or other impairment.

Likewise, this was the same for previous phenomenological studies. For instance, some studies explore what it is like to be HIV positive or have AIDS (Flowers, 2011), some explore what it is like to be a mother of a disabled adult (Thackeray & Eatough, 2014), and some explore what it is like to be autistic and how autistic people perceive themselves (Huws & Jones, 2008). Some explore what it is like to be in a certain situation, like having a terminal illness (Maguire, Stoddart, Flowers, McPhelim & Kearney, 2014). Often these studies of experiences and states of being explore what the phenomenon is like from varying perspectives. For example, researchers might study it from the perspective of the sufferer or impaired individual, as in the study of perceptions of autism, from the perspective of autistic individuals by Huws and Jones (2015). Alternatively, researchers might study the phenomenon from the perspective of those around him or her (such as parents of adults with developmental disorders, by Thackeray & Eatough, 2014). Hence this method also lends itself to exploring experiences which relate to health conditions or illnesses, and so is suited for use in research about ASCs. As is common practice, though not necessarily always the case (as demonstrated), this study uses the perspectives of the individuals who have actually experienced working.

Additionally, as Smith (2009) and Gotham et al. (2015) argue, the one who has undergone the experience is considered the expert on the phenomenon, thus the participant has a unique perspective from which researchers try to gain new insights, explanations and theories. As a result, some consider phenomenology inductive in nature (Creswell and Clark, 2006), and certainly it can be used that way. Indeed, there is clear value to a theory which places the participant at the centre of the theory generation and researchers' attempts to make sense of the phenomenon in this way. Some phenomenologists try to approach the phenomenon being studied free from existing preconceptions, expectations or theories, though not all think this entirely possible (Smith, 2008). At the very least, phenomenologists attempt to use open-coding to search for emergent themes, and code the text without making reference to existing theories or models, in an attempt to allow the data (or the participant) to speak for itself (Smith, 2008; Smith, Flowers and Larkin, 2009). Given the absence of a need for pre-existing theories, phenomenology is therefore ideal for studies which aim to explore and bring insight, as this study does. This is particularly useful for new or under-researched areas such as experiences of employment in those with ASCs.

Furthermore, as phenomenology is interested in unique perspectives, it respects the validity of individuals' experiences as something which researchers can learn from. This is what enables

phenomenology to put the participant at the centre of researchers' efforts to understand the phenomenon. By viewing the participant as the expert, phenomenology is one of the few approaches that gives a voice to people whose experiences may have previously been ignored (Banister et al, 2011).

However, autistic people may struggle to get their voice heard. According to Strauss (2010) autistic people may not be accounted for by the Social Model of Disability, which requires marginalised individuals to speak out against discrimination and barriers which arise of society's medical view of disability. This is because autistic people may have non-standard ways of communicating, and may struggle to describe their experiences (Strauss, 2010). As this group of people typically have problems with communication and relating to others (APA, 2014), they might find it difficult to speak for themselves, or to come together as a group to form a community for this purpose, the way that other marginalised groups such as the LGBT community have, for example. However, by using non-standard ways to communicate with autistic people, such as written or typed communication where they may be more comfortable (Jones, Quigney & Huws, 2003; Davidson & Henderson, 2010), it may be possible to help them to have more of a voice. Indeed, this is partly the reason that typed interview methods have been used in this study. Moreover, the benefit of the semi-structured interview, is that interviewees need not narrate their experiences in full, but rather they answer a set of specific questions relating to specific aspects of their experience. Specific questions will therefore be easier for autistic participants to answer. Also, any gaps in their experiences, or unclear points, or interesting topics not previously considered, can be clarified and illuminated by the additional spontaneous questioning that semi-structured interviewing allows. Thus, using a typed semi-structured interview will likely serve autistic interviewees far better, and will facilitate their ability to speak out and consequently have their voice heard.

Moreover, it is important that researchers, policy makers, and 'allies' support autistic people to have their voice heard. It is the responsibility of all to ensure that impaired individuals are able to participate in and contribute to the community, (Strauss, 2010), which includes enabling them to speak out, no matter how difficult it might be to do so. This study aims to do precisely this, and may be one of the first to attempt to do this in the context of working experiences, (as opposed to observations of work, or explorations of outcomes and associated costs, as seen in the sections to follow). This is something for which a phenomenological approach is well-suited.

However, phenomenologists vary greatly in their perspectives, interests and approach to research. Two main branches exist: descriptive and interpretative (Banister et al., 2011). The

former focuses primarily on describing the phenomena or experiences, while the latter aims to explain (Husserl, 1970, cited in Lester, 1999; Giorgi, 1970). Both share the tendency to attempt to capture the nature of the experience. They each seek to learn what constitutes an experience, not through observation or testing performance, but through the use of the participants' unique perspectives and a specific approach. They both place importance on the subjective experience of the participant and how they experience and interpret their world, because "*it is through experiencing our world that we come to know it*" (Banister et al., 2011, p5). Thus, both place value on giving voice to the participant. However, this is where the similarity ends. For descriptive phenomenologists, hearing participants' voices, sharing their story and being able to describe their experience is sufficient (Sanders, 2008; Dalbye, Calais & Berg, 2011; Linton & Farrell, 2009).

For instance, phenomenological methods have been used to explore the nature of an experience, what it is 'to be' in that situation, what it is like. One of the main differences between descriptive and interpretative phenomenology, and indeed between the latter and other theories like Grounded Theory, is the focus. Grounded Theory aims to be heavily evidence based and can often be quite descriptive of phenomena, as in the study by Jones et al. (2003), who describe in detail their participants' sensory experiences. Other methods do this, such as in the case of Jones and Meldal (2001). Here, the authors quote their participants and point out some interesting patterns, tendencies and features of their experiences. Likewise, descriptive phenomenology focuses on the details of the experiences, specifically the constituent parts of it, the things that typically happen within the experience. Each of these methods aim to give voice to their participants, which descriptive phenomenology does by analysing what happens within cases and experiences, as can be seen in the study by Schwartz, Wiggins, Naudin and Spitzer (2005). Here, Schwartz et al. (2005) talk in detail about how their participant behaves, and the way he describes his view of the world, how he situates himself within his experience in relation to his schizophrenia, and what processes appear to be occurring within his narrative. For instance, they describe how their participant photographs objects to prove what they are doing, such as a car being parked, or driven away, and how this appears to serve the purpose of proving 'truths' to the participant. They go on to give descriptions of other participants, and the processes occurring in their accounts in a similar fashion, without drawing comparison. This is not the case for all descriptive phenomenological studies, as they often draw comparisons and collate experiences into summaries known as 'composites' (Giorgi, 1970; van Manen, 1984; 1990). However, these composites are used solely to summarise the nature of the experiences, and the features thereof.

In contrast, interpretative methods can be used with a wider and different focus. Researchers using these methods try to take a 'big picture' perspective, to look at the experience overall, and to see how certain topics of focus affect the 'big picture'. For instance, they might explore several aspects of an experience at once, exploring how the individual makes sense of them and attributes meaning to them. For example, Osborn and Smith (2006) used IPA to analyse interview transcripts, consequently they present one abstract theme in great detail, and which relate to how their participants view their body compared to the self, rather than solely focusing on what happens within the experience. Likewise, Jones and Huws (2015) used IPA to study their transcripts and present three detailed themes which demonstrate how the participants perceived themselves compared to others. Thus it becomes obvious how different descriptive and interpretative methods are: the former often favours the simpler, more concrete themes surrounding features and patterns within the experiences of participants, while the latter goes beyond this to more abstract concepts and themes across participants, and how they perceive and interpret their own experiences. While the former is useful in telling researchers what events and processes comprise an experience, the latter tells us more about how it feels and is conceptualised.

In contrast to descriptive methods, my aim is to try to understand the experience, for which an interpretative approach is therefore necessary. Investigating the self-perception of participants will enable this, by showing participants' perspectives on their experiences, as well as the nature of the experience itself. For a population who may sometimes struggle with communication (APA, 2014), and for interpretative phenomenological research in general, it will likely require a researcher to make sense of participants' meaning. Those 'highly functioning' enough to have held jobs are likely not to be as impaired in their ability to communicate, though through the role of the researcher (and the double-hermeneutic) it may be possible to bring to light relevant aspects or interpretations of the experience which they do not themselves observe. By analysing at a higher level, it may be possible to observe or focus on patterns within cases which participants may not have observed. In other words, interpreting the participant's interpretation of their experience, or double-hermeneutics, is required. Smith (2008) describes this as the researcher using their own knowledge and experiences of the topic to inform their decisions during the analytic process. Likewise, Smith et al. (2009) see this is a strength of the method, if the research has an interest, or even personal experiences to base their reflections on, because this helps to ground the analysis in reality somewhat, and enables the researcher to identify relevant topics and areas of particular value. Moustakas (1994) describes interpreting a text in such a way as to make clear the intended message, as an 'art' that is the part of the researcher's role to create. However, it



is important not to go beyond the data, and to interpret the data in keeping with the intended meanings, thus use of a semi-structured interview will allow the researcher to clarify and seek detail on many of the relevant areas during the interview itself, which will greatly aid in interpretation and understanding during analysis. By doing this, and taking an interpretative approach, it may be possible to gain greater insight than may be offered by other methods and research designs.

Thus, to understand the experience of men with ASCs in the workplace, the most suitable approach to take is an *interpretative* phenomenological approach.

### 1.3 A Brief Introduction to IPA

Smith (2008) developed the method IPA. Smith (2008) and Smith et al. (2009) describe the method as involving the following steps. First, the researcher wholly immerses themselves within the text, using open coding, sometimes coding line-by-line to label what is happening in that sentence. This is an iterative process involving referring back between codes and data repeatedly to ensure that all codes and subsequent themes are truly and faithfully reflective of the original text. Following this, they then categorise their codes according to the themes described in the data, forming abstract enough categories in order to explain and predict. They describe analysing their data one participant at a time as this method is designed to be idiographic. Once individual transcripts have undergone this process, the researcher then makes note of convergences and divergences between interviewee transcripts where there are more than one participant.

This method shares many of its' steps with other methods based on other approaches. For instance, this is the exact method described for analysis in a Grounded Theory study by Jones et al. (2003), and many of these steps bear similarity to the methods described by van Manen who advocates mixed descriptive and interpretative phenomenological methods (van Manen, 1984, 1990). In the cases of van Manen (1984; 1990), purely descriptive phenomenologists like Giorgi and others, the similarities in the method stop at the initial coding into themes and clusters (Giorgi, 1970; Sanders, 2008; Linton & Farrell, 2009). Beyond this, these researchers go on to do different things with the data. For example, unlike in IPA, van Manen's own method involves creating a composite description of the phenomenon, which is often used in strictly descriptive phenomenological research (1984, 1990). Creating a composite description involves writing an overall summary which identifies the key universal components of the experience, as found throughout the data. Such a description would encompass both the structural composition of the experience, in addition to the more subjective, emotional, personal elements of it, and would use only the more basic observations and themes to do so,

rather than the higher order or more abstract ones, or the comparison of these between participants.

For an experience which is being investigated in the context of four of its features or dimensions as is the case in this study, this may not be suitable. The four dimensions are sensory sensitivity, anxiety, coping, and relationships with others. These topics are vast and different, so creating a composite description of the overall experience of working would be cumbersome, and would not be practical or useful in sharing with the reader the insights gained for each dimension. A composite description could not encompass all four topics smoothly and still attend to each of the four areas in sufficient detail to give real insight. Nor would description be sufficient to facilitate understanding of the phenomenon. This would likely only tell researchers what events, perspectives and situations comprise this experience, not necessarily what it is like or how the participant views or makes sense of the experience. Thus, an interpretative method which allows for parallel analysis of related features is more apposite here, and would enrich our understanding of the individual's unique perspective and interpretation of their own experience.

However, not all methods are as different from IPA as that of van Manen (1984, 1990). Indeed, many use similar methods to IPA, yet produce different kinds of results. For example, thematic analysis uses many similar steps in the analysis as IPA, yet produces very different, arguably simpler or less rich data. This is because the method chosen is not the only important factor to consider, but the underlying theory. For instance, it is the theoretical approach used by Jones et al. (2003) that makes them different. Because of their Grounded Theory approach, the focus of their study is different. Unlike with an IPA study such as Osborn and Smith, (2006), for Jones et al. (2003) the focus of that study was not to explore the nature of a broader phenomenon, and what it is like. Their aim was to explore a narrow range of experiences (of sensory perceptions) in terms of what participants were sensitive to, and what their reactions to these sensations were. Thus a method which is similar can be used for a variety of purposes, and with different perspectives, approaches and focus.

Therefore, while there may be similarities in the methods of van Manen, Smith, and other descriptive and interpretative phenomenologists, what truly distinguishes them is their underpinning theory or approach. The underlying theory informs the focus of the study, and thereby will likely impact the nature of the results. In my case, I could take a Grounded Theory perspective and focus deeply on one aspect of an experience in order to understand it, or I could broaden my focus to look at the overall experience and attempt to describe it, but neither would enable me to understand the overall experience in as great detail, or how the

participants themselves make sense of it. Learning about the nature of the overall experience, or multiple parts of an experience, and how participants view it, is why I have chosen an interpretative phenomenological method.

## 2. Literature Review – a Background to the Current Study

In this section, an outline of some of the features of the daily experiences of autistic adults is provided. Topics discussed are those which may have a bearing on experiences in employment.

### 2.1 Autism

ASCs are neurodevelopmental disorders categorised by significant impairments to social communication and interaction, and restricted, stereotyped and repetitive behaviours which may include fixated interests (ICD-10, World Health Organisation or 'WHO', 2016) and hyper-/hypo-sensitivity to sensory stimuli (APA, 2014). ASCs may be masked somewhat by learned strategies in adulthood (APA, 2014). Autistic people are described to be on the 'Autism Spectrum', due to the way that traits vary in presence and intensity from one diagnosed individual to another, thereby making each individual different in the way that he or she experiences the condition. An individual at the 'lower functioning' end of the Spectrum typically experiences greater impairments as a result of the extent to which their autistic traits are evidence. Somebody with fewer traits and less severe impairment is termed 'high-functioning'.

Approximately 1.1% of both the population of the UK have autism (Brugha, McManus, Meltzer, Smith, Scott, Purdon, Harris & Bankart, 2009; Idring, et al., 2012) though it tends to be more common in men than women (1.8% and 0.2% respectively, Brugha et al., 2009; Idring et al., 2012). If there are 64.6 million people in the UK (Office for National Statistics, 2014), this would equate to a maximum of 710,600 autistic people across the UK.

ASC is known to be a condition which becomes visible typically during childhood (WHO, 2016) when impairments become obvious (APA, 2014). Hence ASC is considered a developmental disorder (WHO, 2016; APA, 2014). Ample research on autism has been made, the majority of which focuses on children, leaving adults highly under-researched (Howlin & Taylor, 2015; Howlin et al., 2015). Much of the research focuses on causes, for instance: autism has been associated with neuro-anatomical differences (Baron-Cohen et al., 2000; Piven, Saliba, Bailey & Arndt, 1997; Kurth et al., 2011); exposure to androgens during early pregnancy (Knickmeyer et al., 2006; Auyeung et al., 2009; Baron-Cohen, 2002); and genes (Hallmeyer et al., 2011;

Hoekstra, Bartels, Verweij & Boomsma, 2007; Frazier et al., 2014). Regardless of the cause, it has become clear that the experiences of autistic people are likely to differ greatly from that of non-autistic people, in the ways outlined in the following sections. Though research into causes is important, particularly if adequate treatments are to be developed, it is also important not to neglect the study of experiences. Doing so will enable development and improvement of support and interventions, all of which is lacking (Howlin & Taylor, 2015) but desperately needed for adolescents and adults as they transition into the working world. This will greatly enhance the quality of life, and will help to promote and create healthy, well-functioning workplaces.

## 2.2 Employment Outcomes

Most studies on employment in adults with ASCs give a bleak outlook on employment rates. National employment rates in the UK since 2009 have hovered somewhere between 91.5% and 94.7%, which is far higher than estimates for autistic adults (Labour Market Statistics – 2016).

For instance, various studies over recent years have been conducted which explore adult outcomes. Most find that only 15-36% of autistic adults were employed in some form, including supported and sheltered employment (Redman, Downie, Rennison & Batten, 2009; Roux, Shattuck, Cooper, Anderson, Wagner & Narendorf, 2013; Gotham et al., 2015) though one did find that as high as 61% were employed in some form (Farley et al., 2009). Furthermore, Roux et al. (2013) also found that only half had ever been in paid employment outside the home.

These findings were confirmed as far back as 2004, when Howlin, Goode, Hutton and Rutter's study showed that 33% were employed, though most left school without formal qualifications (78%), and few went on to Further or Higher Education. This contrasts with findings of other studies which showed that 14-42% of higher-functioning autistic adults had or were working towards degrees (Taylor & Seltzer, 2010; Farley et al., 2009; Gotham et al., 2015). In all cases, Higher Education is uncommon, though this appears to have improved over time, perhaps with the rise in importance of degrees as a pre-requisite to many skilled or higher-level jobs. Even so, many of those who are employed find themselves in low-level, unskilled jobs, often with poor pay (Howlin et al., 2004; Taylor & Seltzer, 2012).

It is unfortunate to find such poor outcomes for autistic people, especially with comparison to the general population. Furthermore, even the highest estimate of 61% being in any form of paid employment, it is still much lower than national employment rates. Thus by comparison, autistic people are far less likely to be employed. To be more precise, if recent employment

rates for autistic adults are somewhere between 15-61%, that is still more 37-80% lower than the national average for the same timeframe. This is even more unfortunate, given the association of employment status with well-being. Diener, Oishi and Lucas (2015) found that unemployment reduces subjective-wellbeing, but employment programs improve it. Thus, those 15-59% who are unemployed are likely to have a significantly lower level of subjective well-being.

Even without taking well-being into account, it is clear that more needs to be done to support autistic adults into employment. The benefits of reducing unemployment among the autistic people extend beyond that part of population. From a governmental perspective, increasing employment rates among those with ASCs has the potential to save a tremendous amount of money, which can positively affect the economy. For example, Howlin, Alcock and Burkin (2005) found that over eight years, putting 114 autistic people in jobs saved the Exchequer £179, 095. Jacob, Scott, Falkmer and Falkmer (2015) suggest that these savings can be seen in the context of spending on unemployment-related benefits and national insurance, and added income from receiving higher tax contributions. Moreover, sheltered employment was predicted to save country £67,800 per person over a lifetime (Järbrink and Knapp, 2001).

Furthermore, the government has the opportunity to save lots of money by moving away from providing care and towards providing support into working. For example, the costs associated with day centres and vocational rehabilitation programs are far more expensive than supported employment (Cimera, Wehman, West and Burgess, 2012; Järbrink and Knapp, 2001), and supported employment was more expensive than competitive employment (Schaller and Yang, 2005). Furthermore, a study by Ganz (2007) found that employment produces significant savings in terms of the lost productivity associated with able adults not working, and the cost of running adult care and day centres. Indeed, However, many of these current services which cater for those with ASCs are generic, as they are aimed at anyone with an intellectual disability. ASC-specific support is severely lacking, as is ASC-specific research on employment. Yet this is an area which can have vast benefits to the national economy, in terms of tapping the 'undiscovered workforce' (National Autistic Society, 2012), increasing the number of workers, and reducing the number on benefits.

Consequently, the costs associated with caring and providing for these people would reduce drastically, were these people in employment (Howlin et al., 2005; Jacob et al. 2015; Järbrink and Knapp, 2001). Indeed, these studies have shown that providing support into work is cheaper than providing constant care (Cimera et al., 2012; Järbrink and Knapp, 2001; Schaller and Yang, 2005' Ganz, 2007). Furthermore, on an individual level, the benefits could be

tremendous – from helping individuals to make their own way out of poverty, to boosting social inclusion (National Autistic Society, n. d.). Thus it is unacceptable that so little is known about employment in autistic adults.

What little there is centres around costing studies like those above or outcomes like those to follow. For instance, Henninger and Taylor (2013), in a review of the various outcomes studies over the last 50 or so years, found that the studies they reviewed generally indicated that autistic people rarely grew up to lead fully or semi-independent lives. Overall, poor adult outcomes were projected for those with ASCs. The authors, on the back of this, made a very relevant point. They stated that many of these outcome studies come from a time when employment was held as the benchmark for success in adulthood. Little value was attributed to meeting personal needs, values and aims for achievement. Thus, what few participants achieved seemingly positive outcomes by obtaining jobs and living independently, may not actually have found their lives satisfying, because they may have been in jobs which were a poor fit. As such, unenjoyable jobs were rated as indicators of success, regardless of what having this job meant from the individual's perspective, or what it meant for their quality of life. Henninger and Taylor (2013) and Furtstenberg, Rumbaut and Settersten (2005) also stated that the definition of adult achievements is changing, and that the definition is no longer limited to living independently, having a degree, a job and a family. Instead, young adults are living with parents longer (Gotham et al., 2015), and priorities are changing. Likewise, so should definitions of adulthood success, especially when applied to an under-employed group such as this. The emphasis should instead be on well-being and meaningful employment.

Indeed, Neary, Gilmore and Ashburner's study (2015), which found that only 30% were employed full time (and mostly in unskilled labour such as sales or customer services roles), also found that 57% of their sample were dissatisfied with their employment status. They also report that "*satisfying and appropriate paid employment*" was seen as the key to improving many other areas of the lives of adults with autism. Certainly, many who are employed are not satisfied with what little they have been able to get. Gotham et al. (2015) found that the majority employed autistic adults (53% overall) wanted more hours that they had been able to get. Likewise, two studies showed that many autistic people work between 24-27 hours per week, which is often not enough to independently sustain oneself (Schaller and Yang, 2005; Cimera and Burgess, 2011). Thus there is a clear difference between suitable, sufficient employment and employment as a whole. It is important for autistic people and employers alike to find work which is a good fit, and so a certain amount of selectivity is needed if individuals are to find appropriate work which meets their personal as well as financial needs.

Furthermore, finding meaningful employment is important to many autistic people and their families. Pellicano, Dinsmore and Charman (2014) surveyed autistic people and their families to explore what services and areas they thought were the most important for researchers to study. Employment and vocational training were deemed the most important areas for researchers to focus on. This might relate to the poor prospects that exist for autistic adults. In spite of poor prospects, adults with ASCs have demonstrated an increasing interest in enter the workforce over recent years, as evidence by the tenfold increase in use of vocational services in the U.S. (Burgess and Cimera, 2011), and the fact that Gotham et al. (2015) found that 41% wanted to work but simply could not find any. Moreover, vocational programs have been associated with reduced anxiety and depression (Hillier, Fish, Siegel and Beversdorf, 2011), which researchers related to the way it gives individuals an insight into what the world of work looks like.

Furthermore, while work can clearly benefit autistic people, autistic people working can benefit employers. The National Autistic Society (n.d.) have described autistic people as 'untapped talent', with a variety of skills and abilities to offer. For instance, in their guide for employers (which they wrote collaboratively with the Department of Work and Pensions and Lord Freud, the Minister for Welfare Reform), they point out that some strengths can include attention to detail, problem solving, excellent focus and concentration, reliability, loyalty, technical and specialist skills, excellent memory, resourcefulness, and a preference for routine which can translate to excellent job retention as they may stay in a job longer once settled.

Moreover, studies have confirmed that autistic people have plenty to offer employers. One recent study showed that most believe that autistic people's strengths include creativity, honesty focus, having a good memory, a good sense of justice and a special interest (Gotham et al., 2015). Furthermore, while autistic adults may not always have full-time jobs, having consistent jobs can be of benefit to both them and to employers. Two studies showed that many autistic people work between 24-27 hours per week, and are often committed and consistent workers, which can benefit the employers with consistent working hours (Schaller and Yang, 2005; Cimera and Burgess, 2011). Certainly, many are capable of working and contributing to society but struggle to find and maintain it, due to a lack of support, which Howlin et al. (2015) describes as a missed opportunity.

Yet, despite the importance of finding and maintaining employment, and the many skills, talents and abilities that autistic people can offer, employment appears restricted to a certain few of those on the Spectrum. Interestingly, Roux et al. (2013) linked employment to socio-economic background (higher-income households in particular), along with higher age, and

better conversational and functional skills. Having these skills and features tended to be seen in those who had ever had a job in their lifetime. Meanwhile, Taylor and Seltzer (2010) found links between employment and having fewer ASC traits in general, fewer maladaptive behaviours and more functional independence. In Gotham et al.'s study (2015) it was shown that 47% of higher-functioning and later-diagnosed autistic adults were employed, compared to 22% of the less able participants. Thus higher functioning is associated with better employment prospects. Moreover, the study by Mavranouzouli et al. (2013) showed that outcomes were better for those in supported employment. These findings demonstrate that higher functioning and access of supports is associated with better employment outcomes. Furthermore, a study by Howlin, Goode, Hutton and Rutter (2009) explored the outcomes of autistic savants and autistic adults with unusual, exceptional talents. They found that only 12.5% had found employed, and that overall, their special abilities did not contribute to better employment prospects. Clearly, high levels of unemployment among autistic adults is not related to a lack of talent, intelligence or skill, but functional skills and support.

There are also a small number of studies which explore the kinds of experiences had by autistic people who have been successful in obtaining and maintaining employment. A study by Scott, Falkmer, Girdler and Falkmer (2015) evaluated the perceptions and values of autistic employees and employers on various subjects related to obtaining and maintaining employment. Employees generally felt that feeling included, involved in workplace decisions and their talents/skills valued reinforces their dedication to work; that meeting business productivity requirements is important; that the structure of the environment influences job retention. While this study provides a useful starting point into what autistic employees perceive as important, there were also some topics which were not explored which the participants stated were important and should be studied. These include workplace bullying, anxiety in the workplace, and disclosure to colleagues and superiors.

These particular areas, and working experiences of autistic people in general, are highly under-researched, and this study by Scott et al. (2015) is one of very few to actually explore anything related this. Most studies of employment, like those cited, have been quantitative and focus on outcomes, and associated skills and traits, rather than experiences. While such studies can tell us a lot about what skills and abilities may be associated with better prospects, or how many are employed, or how much they work, or in Scott et al.'s case (2015), what they thought surrounding work are like, none of these studies tell us much about what it's like. They do not tell us what issues are faced on a regular basis, or what aspects of workplaces are particular causes of stress, or what might be done to improve workplaces, and consequently, individuals' ability to stay in employment. Therefore, a study which explores experiences of these areas is



necessary if we are to learn how to improve employment, working environments and quality of life for adults on the Autistic Spectrum. Indeed, Howlin and Taylor (2015) found that autistic adults felt that working in a highly important area for future research, as it is an area that can be a source of difficulty in adulthood, and one which is deserving of more support from employers and the government. However, the form that these supports should take, Howlin and Taylor (2015) felt, warrants further research. The importance of learning more about the perspectives of autistic adults is precisely the reason that the present study has been conducted. Learning more about the struggles that these individuals face, whether it be related to bullying, anxiety, disclosure, or other issues, will be invaluable in terms of the insight it can provide into these experiences, and will provide a solid foundation for the designing of appropriate supports.

### 3. Literature Review of Workplace Challenges

#### 3.1 Anxiety

Anxiety is likely to be an ever-present attribute of the working experiences of autistic people, because it is something which affects many throughout their lives. In fact, it is not uncommon in individuals with autism. Indeed, it is more common among autistic people than non-autistic people (Kim, Szatmari, Bryson, Streiner and Wilson, 2000; Bejerot, Eriksson & Mörtberg, 2014) and also more intense in autistic people throughout the Spectrum (Gillot & Standen, 2007). Furthermore, mood in general appears to commonly differ in autistic people. Studies have found anxiety and mood disorders like depression to be present in the majority (75-90%) of their samples (Mazefsky, Folstein & Lainhart, 2008; Gotham et al., 2015; Munosue et al., 2008).

Perhaps the prevalence of mood and anxiety disorders relates to difficulty with specific, autism-related concerns. The study by Gillot and Standen (2007) seems to confirm this, as they found that high stress and anxiety was highly correlated with difficulty coping with change, sensory stimuli, anticipation and unpleasant events. This makes sense, given the known difficulties with resistance to change and sensory stimuli that are part of the diagnosis (APA, 2014). Gillot and Standen (2007) summarise these findings by stating that anxiety was positively correlated with difficulty coping with these demands. They cite a study by Howlin (1997) who suggested that fear of change, anticipation and sensory stimuli contribute to stress, which their results confirm. Furthermore, the study by Freeth, Bullock and Milne (2013) found social anxiety in particular to correlate positively with autistic traits, implying that social anxiety may be more common among autistic people, and especially among those with a higher number of autistic traits.

Thus there is certainly a precedent for anxiety affecting autistic people dramatically in many areas of their life, so it is logical to assume that these are difficulties which may impact autistic people at work. Social situations, change, and sensory difficulties are certainly likely in working environments. Other causes for anxiety have been identified, and may include social interaction (including small talk), performance anxiety (such as public speaking), noise in the environment, health worries, unexpected change and disappointment (Trembath, Germano, Johanson & Dissanayake; 2012). Trembath and colleagues also found that anxiety can inspire an array of physical and emotional reactions including frustration, depression, withdrawal, feeling robotic, racing heartbeat, sweating, nausea. Therefore, it is unsurprising that these participants felt that anxiety was a barrier to normal functioning, plaguing much of their lives, especially when leaving the comfort zone of their home, or interacting with others.

From these studies, it is clear that anxiety, and mood more generally, can be a real problem for autistic people. However, the research which exists is sparse in relation to individual experiences of it, especially in the context of working. Likewise, the area of coping with anxiety is similarly sparse in these areas. For instance, it is known that individuals can struggle with anxiety, that anxiety can interact with sensory sensitivity or get worse in the presence of it (Gillot & Standen, 2007; Trembath et al. 2012), and some cope with it by reactive rather than preventative measures (Trembath et al., 2012). Coping strategies can involve withdrawing, exercise, relaxing, and escaping (by listening to music, watching movies or exercise). However, what one does in the workplace to cope is a mystery, and how one experiences anxiety in the context, or what causes and worsens anxiety in the workplace is also an under-researched area. This study aims to address these gaps in knowledge, in an effort to glean some knowledge about anxiety in working environments and what can be done about it.

### [3.2 Sensory Perception](#)

Sensory processing is a major difficulty faced by individuals on the Autistic Spectrum, which can affect working experiences.

Studies have shown that experiences of sensory perception can be quite different for those on the Spectrum, and that these differences have been associated with anxiety (Trembath et al., 2012; Gillot & Standen, 2007). For instance, some report experiencing physical pain and discomfort when exposed to certain stimuli, such as loud or roaring noises, certain images or colours, smells, the feel of fabrics or textures. Others report sound to be distracting, and certain sensations make it difficult for them to focus, and that sensory stimulation can be overwhelming at times. As a result, they have developed their own coping strategies, such as distraction via another sense or simply.

Some studies show that sensory stimuli, specifically loud noises (though this can extend to certain colours, bright or artificial lighting, strong smells, the feel of certain fabrics or textures of food), have the power to cause pain, nausea, anxiety and discomfort (Jones et al., 2003; Young, 2012; Robertson & Simmons, 2015). The difficulty experience with sensitivity to sensory stimuli has also been found to worsen in the presence of anxiety or other negative emotions (Robertson & Simmons, 2015). Naturally, these reactions to sensory stimuli can affect one's ability to work and concentrate effectively, leading to autistic employees' struggles would be misinterpreted for difficulty processing information or even low intelligence (Young, 2012). On the basis of what is known about the profoundly different sensory experience of autistic people, it is expected that this is something which will be found to affect working experiences in this study.

Furthermore, as with anxiety, autistic people develop ways to cope with sensory over-stimulation. Robertson and Simmons (2015) found that coping strategies typically involved controlling or avoiding experiences, such as by blocking sound out with ear buds, or ordering the eating of multi-textured foods according to texture. However, the responsibility for enabling autistic people to function comfortably, particularly in workplace environments, should be placed on the community, the employers and those responsible for workspaces also (Strauss, 2010; Equality Act, 2010). Thus, adjustments should be made for autistic. People making modifications to the sensory environment would make it easier for autistic employees to work, by reducing the potential for distress and discomfort employees (Young, 2012; Robertson & Simmons, 2015).

Therefore, experiences of sensory sensitivity and strategies for coping are likely to influence experiences of the workplace. As a result, these are key areas which this study explores, in an effort to shed light on what sort of adjustments could be made to improve working experiences. However, most employers will not make any adjustment without a reason, such as an employee disclosing that they have different sensory needs, thus disclosure is also a topic worth consideration.

#### [4. Literature Review of Workplace Relationships](#)

##### [4.1 Disclosure](#)

A study by Scott et al. (2015) evaluated the perceptions of autistic employees and employers on various subjects related to obtaining and maintaining employment. The study found that disclosure was identified by participants (autistic workers) as important and worth study. Perhaps this is due to the fairly mixed experiences autistic workers may have following

disclosure. According to a study by Davidson and Henderson (2010), disclosing in the workplace often helped to clarify and explain any unusual tendencies and enabled participants to obtain support, though in other cases it resulted in feeling like people saw them as less capable. Indeed, discrimination is unfortunately common for autistic people (Gotham et al., 2015). As a result, participants preferred not to disclose and were actively encouraged not to (Davidson & Henderson, 2010). Autistic people are often discouraged from disclosing by family, friends, doctors, other professionals, and private job agencies (Berkshire Autistic Society, n.d.; Trunk, 2009; Davidson & Henderson, 2010).

Davison and Henderson (2010) found that those who did not disclose often actively worked to conceal their difficulties through masking strategies. Many described trying to pass off their struggles using commonly accepted, “normal” sounding explanations, such as feigning a headache or bad hearing rather than explaining that they are feeling overwhelmed by or cannot pick up sensory stimuli. Using these masking techniques, participants enable themselves to tolerate difficult situations without arousing suspicion (about the true nature of their difficulty) or receiving unwanted attention, and without having to disclose.

Thus disclosure is an important area to study. It can affect behaviour and functioning in the workplace, it can influence whether someone is discriminated against, and is a serious concern for autistic people. Deciding whether to disclose can have serious long-term impacts on the way one works with others. Therefore, this is something which is worth consideration, particularly in the context of workplace relationships, and which is investigated in this study.

#### [4.2 Social Interaction](#)

Social interaction impairments are a core feature of autism, and therefore are present to some extent in all autistic individuals (WHO, 2016; APA, 2014). Difficulties with social interaction can affect many areas of life leaving many individuals on the Spectrum socially isolated, more so than those who are young, female, not autistic, or have other impairments (Howlin et al., 2004; Roux et al., 2013; Liptak, Kennedy and Dosa, 2011; Osmond, Shattuck, Cooper, Sterzing and Anderson, 2013; Taylor & Seltzer, 2012; Baron-Cohen & Wheelwright, 2003).

Furthermore, social isolation and loss can influence whether a person with autism acquires mental health issues, particularly anxiety- and depression-related issues (Hutton, Goode, Murphy, Le Couteur and Rutter, 2008). Factors that typically led to social isolation included (but was not limited to) lack of work, specifically difficulties in finding and maintaining work (Hutton et al., 2008). Thus the impacts of social interaction and social isolation are not to be taken lightly.

Moreover, it is not only the finding and maintaining of work which can cause difficulty in work. There are a number of issues in the recruitment process, within job roles and in workplaces which can cause difficulty. Indeed, Neary et al.'s study (2015) of autistic adults following high school found that for participants, the main barriers to employment included social skills as well as interview skills. Likewise, Young's study (2012) found that social aspects of working such as small talk and 'office politics' could cause difficulty, and that autistic workers preferred to avoid these areas. Participants reported having their performance questioned on the basis of their disinterest in these things, but Young (2012) feels that individuals should not be compelled to be involved in social relationships with others. With all of the difficulty with others, it may be more in their interests not to compel them to engage in these superficial workplace relationships, though this may add to their social isolation. However, those who obtain employment are often bullied (Liptak, Kennedy & Dosa, 2011), so perhaps the risk of isolation would be worth it if this mistreatment were avoided.

Furthermore, as with employment outcomes, favourable social outcomes have been associated with functioning. Various studies have found that social isolation is associated with difficulties with communicating conversing, literacy and reduced cognitive abilities (Osmond, Shattuck, Cooper, Sterzing and Anderson, 2013; Orsmond et al., 2004; Howlin et al., 2004), and less severe autism (Liptak et al., 2011; Orsmond et al., 2004).

Thus overall, cognitive and communicative behaviour was positively associated with social support. Social support has also been strongly associated with better well-being (Humphrey, Nahrgang & Morgeson, 2007, cited in Diener et al., 2015). Similarly, social and vocation skills interventions have been shown to reduce anxiety and depression, likely due to the ability to make friends and socialise with others undergoing the intervention, giving them an opportunity to practice these newly improved social skills (Hillier et al., 2011).

It comes as no surprise then, that less social (i.e. written forms) of communication seem to be more popular across the Spectrum. Gillespie-Lynch, Kapp, Shane-Simpson, Smith and Hutman (2014) explored the benefits of computer-mediated communication and found that their autistic participants favoured it more than their non-autistic participants. Autistic individuals liked electronic communication methods more, as it was felt that it helped with controlling who one interacts with, and by nature was useful in terms of giving them more time between responses to think about their own response. Communicating using this written (or rather typed) method was associated with being better able to express one's true self. Furthermore, it was associated with a greater ability for comprehension of others, which is a known difficulty in the workplace, particularly in the context of understanding and following directions (Neary

et al., 2015). Similarly, Diener et al. (2015) found an association between the open and clear communication of supervisors with workers with overall happier workplaces (Colquitt, Conlon, Wesson, Porter & Ng, 2001, cited in Diener et al., 2015), and that higher worker satisfaction in this manner leads to greater productivity and profitability (Fried, 1991, cited in Diener et al., 2015).

## 5. [My Study](#)

From the literature it is clear that autism is prevalent, multi-faceted, and can impact upon many areas of life, not least employment. Ample research has been conducted on areas like causes, traits, outcomes and costs. Some has also been conducted on sensory sensitivity, anxiety, coping and relationships. What has not been explored is how these features relate to one another, how they are experienced together, and especially not from the perspective of the autistic person. With the rise of the Social Model of Disability, and the various recently created legislation, it is becoming increasingly important to hear the perspective of individuals actually experiencing the impairments, difficulties and mistreatment, so that barriers may be removed.

Therefore, this study has been conducted with the aim of gaining an ‘insider perspective’ on these things, in the context of working. This has been done with the intent of giving a voice to a group of relatively under-researched participants (as most research focuses on autistic children and adolescents). I hope to learn what it is like for my participants to be employed, which will shed some light on their experiences, elements of which may well reflect wider-spread experiences. My research questions relate to the key areas discussed and are listed above. These are:

1. *What is their sensory experience like and how does it affect their experience of working environments?*
2. *What coping strategies do they develop to manage sensitivity and stress?*
3. *What are their relationships with others in this environment like and does disclosure affect these relationships?*

## CHAPTER TWO: METHOD

## METHOD

In the following sections I will discuss the method of data collection that I have chosen, how I have chosen and recruited my participants, the materials used, and how my data will be analysed.

### 6. Design

The qualitative method IPA was used to study this phenomenon, and so a small sample of four participants was recruited. Semi-structured interviews were conducted electronically.

#### 6.1 Methodological Rationale

Various phenomenologists use a small number of participants for this kind of study. Generally, 3-15 is deemed sufficient any research project because it enables deeper, more detailed exploration than larger samples (Smith & Osborn, 2009; Creswell & Clarke, 2012). Indeed, in IPA studies sample sizes are usually within this range (Osborn & Smith, 2006; Smith & Osborn, 2007; Hawtin & Sullivan, 2011; Maguire, Stoddart, Flowers, McPhelim & Kearney, 2014; Cooper, Fleisher & Cotton, 2012; Huws & Jones, 2015; Thackeray & Eatough, 2014). Given the level of detail required and the number of topics to be used, it was felt that three to four participants was sufficient, and allowed for more depth in the analysis than a larger sample would. Therefore, with a sample this small, it is easy to recruit a fairly homogenous set of participants. Homogeneity in interpretative phenomenological research is deemed advantageous for studies of a shared condition or experience because it allows the exploration of the experience rather than individual differences. This is why homogeneity is important here. Thus participants are selected purposively (Osborn and Smith, 2006; Smith & Osborn, 2007; Smith, 2009; Huws & Jones, 2008). Admittedly, no sample will be truly homogenous. From the participant biographies in section 7.3, it is clear that there are some noteworthy differences between members of the sample, which in some ways make the sample heterogeneous. However, what is important is that the sample is similar enough, and that they have all experienced the phenomenon at hand in similar enough contexts. All sample members meet the inclusion criteria in terms of gender and capacity, and have all been employed in the Western world. Thus the sample selected was sufficiently homogeneous for the purposes of an interpretative phenomenological study.

The high level of detail acquired through studying a small sample of participants is also the reason for using semi-structured interviews in this study. Other reasons exist for not using other measures like self-report, such as the tendency of those with ASCs to struggle with introspecting and identifying emotion and therefore struggling with self-report (Hillier et al., 2011). However, the most important reason for choosing to use semi-structured interviews is



that of detail. Semi-structured interviews allow the researcher to inform the interview by setting a few standardised questions, while still leaving room for the participant to guide the interview content by providing new insights into topics which the interviewer can delve deeper into by asking additional questions. This could not be achieved using a fully structured method (Osborn & Smith, 2006; Smith & Osborn, 2007; Smith & Osborn, 2009; Banister et al. 2011). Thus, the participant, who is seen as the expert in the phenomenon being explored, has the ability to share their expertise and raise topics of interest which researchers might not have been aware of themselves, which the spontaneous probing questions of the interviewer can explore further.

Instead of conducting these interviews face-to-face or via a program with voice and camera recording capabilities, a typing-only form of interview was used. (The program used, "Adobe Connect", facilitated synchronous communication, like many "instant messenger" programs.) This was done to minimise any social anxiety participants may experience, given the social communication difficulties implicit in ASCs (APA, 2014). There is a precedent for this, as various studies have used synchronously and asynchronously typed data (Walker and Tobbell, 2015; Jones et al., 2003; Davidson and Henderson, 2010). They state that typed communication can be a preferred method for autistic individuals, who may feel better able to express their meaning this way than verbally or in other social situations. Walker and Tobbell's (2015) study showed that using a means of synchronously typed communication for interviewing is highly suited to an autistic population, particularly for those who may struggle with verbal communication.

Moreover, it is expected, given the requirement of previous employment experience, that the participants in this study will have sufficient communication skills required to communicate their meaning effectively during these interviews, as communication is a skill required in most forms of employment. Thus, this method of interview was chosen solely for the comfort of participants (rather than to enable them to communicate), on the assumption that they would have the capacity for communication and a preference for this method. The program used facilitated synchronous communication to enable a similar level of spontaneity in participants' responses to face-to-face, spoken interviews. Using Adobe Connect in the present study therefore preserved the benefits associated with a typed medium (such as avoiding any anxiety), and also these benefits of a semi-structured interview. It also stored the conversation histories on servers owned by the University, making the data secure.

One potential disadvantage of this method is the potential for brevity of participants' answers, leading to a lack of richness of data. Participants may find typing more taxing than speaking would be, and so give shorter answers. This is why a semi-structured method was chosen. The

ability to follow up the standardised questions with additional ones, probing questions and requests for detail enables the researcher to seek further detail and avoid such brevity in responses.

However, Duncan, one of the four participants, requested to participate asynchronously, via questionnaire. This was of course facilitated, because regardless of the method, it was still felt that Duncan had unique experiences and expertise to offer (Smith & Osborn, 2009). A questionnaire was therefore created by removing the interviewer prompts from the interviewer schedule, and including some of the re-worded versions of questions seen in the schedule. This was sent in a Word document to the participant. Thus Duncan was given the same questions as other participants in a questionnaire-style format. Yet, the main strength of the method chosen (semi-structured interviewing) is also the main drawback when including this participant, who participated asynchronously. As a result, the data obtained from Duncan is treated as an addition, rather than a main constituent of the data. The information gained from Duncan is therefore treated carefully, and is used to support themes drawn from the other participants, not as a primary source of data.

In summary, semi-structured interviews with a small number of people were conducted via Adobe Connect. Greater detail can be gained through semi-structured interview. Using a type program, due to the communication preferences of some with ASC, may be especially suited to autistic people. It was also expected to make participants more comfortable.

## 7. Participants

As recommended by Smith and Osborn (2009), three participants were recruited for interviewing, and one completed a questionnaire version of the interview schedule. Participants were recruited subject to meeting the inclusion criteria, which are below. Two other individuals expressed interest in participating, though ultimately did not participate. One was not contactable to arrange an interview and the other began an interview, which he left early and was not contactable thereafter. After two weeks of being uncontactable, these two were considered withdrawn from the study, and their details and any data deleted. As a result, four participants were included in this study, with the extra information from Duncan used as an addition to rather than a main component of the data.

### 7.1 Recruitment

Participants were recruited electronically between March and May 2015. Organisations such as the National Autistic Society, Research Autism and IDEAS Lancashire agreed to share the study's advertisement (Appendix 1) electronically with some of their members, who had consented to be contacted about such things. This advertisement was also displayed publically

on social media, and some popular groups on Facebook (“Asperger’s Syndrome Awareness – Bryan’s Advocacy” and “Asperger’s Reality”) agreed to share the advertisement publically where their page followers could see it. No individuals were directly approached to request participation, and all who expressed an interest in participating were reminded of the voluntary nature of participation. This was also made clear on the advertisement. Regardless, two individuals known to the researcher through social circles chose to participate (Colin and Eric). Special care was taken to emphasise the voluntary nature of the study, especially since these individuals might feel compelled, as friends, to participate. They were reassured that all interview content would be kept confidential, and that participating or choosing not to participate would in no way impact on existing relationships. This was done for all participants, but especially for these participants to emphasise that they were not compelled to participate just because they know the researcher. They were very interested in participating, and agreed to do so, and were aware that participation was not compulsory. All were made aware that they could withdraw at any point until two weeks after the interview was completed.

The advertisement provided information about the eligibility criteria, and an overview of the topics that they would be asked questions about. The information sheet provided greater detail on both of these things, and was required to be read prior to signing a consent form (see Appendices 2 and 3 respectively). Consent was also confirmed at the start of the interview.

### 7.2 Inclusion Criteria

A written advertisement was used to publicise this study. It featured inclusion criteria, as follows. Individuals needed to:

- Be age 18 or older
- Be male
- Have experience of working in paid employment
- Speak English as their first language
- Have access to a computer with an internet connection.

The age restriction was imposed to ensure that appropriate employment (i.e. formal employment post-legal working age) was discussed in the interviews. This was achieved, as all participants were between the ages of 24 and 61.

An all-male sample was chosen because men are more likely to be diagnosed with autism than women (Fombonne, 2005; Gillsberg, Cederlund, Lamberg & Zeijlon, 2006; Chakrabarti & Fombonne, 2001). As a relatively homogenous sample was sought after, choosing a single gender was appropriate, especially given the increased prevalence amongst men, and consequent convenience of an all-male sample.

English being spoken as their first language was made a criterion to eliminate any additional communication issues (beyond those associated with the condition). Naturally, access to a computer with an internet connection was required because all communications were done electronically. Those being able to view the advertisements were therefore those with access to the internet, and therefore only those with the means to participate were made aware of this study.

Lastly, it was also required that participants have a formal diagnosis of an “Autism Spectrum Condition” or Asperger’s Syndrome. Participants were expected to confirm this, without being compelled to provide evidence of it. It is assumed that all participants had sufficient capacity to consent to participate. To have been employed, participants must have demonstrated sufficient communication skills and capacity to perform a job, so an interview of this nature is something which they are likely to be capable of. Those who lack the capacity for this are unlikely to have responded to the advertisement. Thus, there was no need to require participants to have a diagnosis high-functioning autism specifically in order to participate, as simply participating in this study implies this.

### [7.3 Participant Biographies](#)

Below is some basic information about each participant.

#### [7.3.1 Colin](#)

Colin is 34, currently single, living in the UK with no dependents and currently no employment. He has held a number of different positions in entry-level jobs such as administrative work, retail work like in shops, and a temporary job building computers. Most recently, he worked as an IT Technician, responsible for diagnosing and resolving technical issues. He received a Higher National Diploma (an exit award for completing part of a Bachelor’s degree), has a Microsoft Certified Professional award and is currently working towards qualifications in computing (as a Microsoft Certified Systems Engineer). He also reports having dyslexia, cerebral palsy, asthma and possible (though not diagnosed) dyspraxia.

#### [7.3.2 Michael](#)

Michael is 32, in a long-term relationship, with no dependents and works as a part-time tutor and a “college professor”, implying that he lives in the USA. He has held various jobs, working in a variety of entry-level customer service and retail environments, and at a summer camp program for a number of years before going into academia. Now he teaches psychology to college students. He has a Master’s Degree. He reports no other disabilities or conditions.

Note: the fact that Michael may be from the U.S.A. might detract from the purposive, homogenous nature of the sample, as his experiences of workplaces might differ in

terms of legislation around access to work (Americans with Disabilities Act, 1990). However, it is felt that as the U.S.A. has equivalent legislation on providing 'reasonable adjustments' (Americans with Disabilities Act, 1990), that this issue will be of little concern. Individuals with ASCs share enough similar traits, that country of origin is not likely to make the participants' experiences so fundamentally different that the nature of the experience of working and being autistic is different between countries. Both the U.K. and the U.S.A are Western, wealthy countries in similar economic states and hold relatively similar values. Participants, by virtue of their condition, share enough similar qualities that any cross-cultural differences are unimportant. Thus in spite of this moderately heterogeneous trait, the sample is deemed sufficiently homogenous for this research.

### 7.3.3 Eric

Eric is 24, in a long-term relationship, with no dependents and has worked as a Senior Quality Control Laboratory Technologist since he was 18. He started work in this chemical manufacturing company as a Laboratory Assistant, and has been moved to the quality control department and consequently promoted. This is the only company he reports having worked for and reports no other employment outside these three positions. He is currently working towards a Bachelor of Science in Chemistry. He also has post-thrombotic syndrome, due to having repeated blood clots.

### 7.3.4 Duncan

Duncan is 61, widowed, (having been with his partner for 20 years prior to her passing), he has no dependents and is currently self-employed. In the past, Duncan has worked extensively in entry-level and administrative roles, such as a clerk, University Admissions Assistant and personal assistant. He has also been involved in publishing and in counselling and therapy. Currently, he works in more academic fields as an author and owns a distance-learning tutoring business, tutoring students and developing psychology courses. Duncan possesses a Bachelor's in Psychology, a PhD in Hypnotherapy, and other training and postgraduate qualifications in therapies like CBT and hypnotherapy. He has prosopagnosia and reports experiencing mild Reynaud's Syndrome.

Note: as with Michael's potential difference in country of origin, Duncan's age may be considered a heterogeneous factor. However, as Duncan shares the same condition found in the rest of the sample, this is deemed sufficient to render this difference in age unimportant. Thus the sample remains sufficiently homogenous regardless of this difference.

## 8. Materials

### 8.1 Participant Information Sheet

The information sheet (Appendix 2) gave prospective participants information regarding participation. Participants were required to read this before signing the consent form. The information sheet informed participants about the inclusion criteria, the requirement of having internet access, how they would participate (by being given a link over email to Adobe Connect), and that the duration of the interview should be approximately an hour. They were also given information about the researcher and the supervisory team and how to contact each of us, how to contact the university, and what support services they can use if they become distressed. Prospective participants were informed of the purpose and topics of research, and were given a little more detail here than was shown in the advertisements.

In the information sheet, prospective participants were given information about withdrawal and anonymity. They were informed that all participation was voluntary and that at any time before, during or shortly after the interview they had the right to withdraw. They were also made aware that the interview transcripts would be saved, stored on University servers, and used in any publications or publically available reports written by the researcher, but that all identifying information would be removed, and their identity concealed (and that only I and my supervisors would have access to non-anonymised transcripts). This anonymisation of the transcripts, prospective participants were informed, would take place two weeks following the interview, and so they had until this time to withdraw from the study, after which it would not be possible. Participants were also informed that their participation was in no way linked to their employer or employment. It was also made clear to participants that they should think carefully about participating, as some of the topics might be distressing for some to discuss.

### 8.2 Designing the Interview Schedule

My research questions informed the creation of the interview schedule. Thus a section comprised of one to four questions was allocated to each topic. Other sections were included, containing questions relating to other aspects of working experiences, which covered topics like perceived performance, satisfaction and pay; social, familial and romantic relationships. These were added in order to explore the impact of these features on the working experience, and to investigate the relevance of them to the research topics. However, these were considered secondary to the research topics, and so were not focused on in any detail in analysis, as (based on how little participants discussed these topics) they did not appear to be relevant here.

The interview schedule can be found in Appendix 4.

## 9. [Procedure](#)

### [9.1 Ethical Approval](#)

Ethical approval (Appendix 5) was granted by the Psychology and Social Work Ethics Committee on February 26<sup>th</sup>. No changes have been made since approval was granted.

### [9.2 Data Collection](#)

Individuals who had seen the advertisements contacted me by email to express a desire to participate. They were asked to read the information sheet, sign the consent form and send it back to me.

Once consent had been received, the participant and I would arrange a convenient time to complete the interview. Participants were then sent the link to the Adobe Connect private chat room shortly before the agreed interview time. Upon arrival in the chat room, participants were asked for confirmation that they had read the information sheet and consent, and were reminded of their rights to withdraw and how to do so. As can be seen from the interview schedule, participants were first asked for a brief employment history, followed by the main interview questions relating to the research questions. These questions and the answers given were discussed, creating a dialogue and allowing me to work towards an understanding of the way participants see their experiences. The final question asked participants about their positive working experiences, in an effort to avoid participants feeling negative when leaving the interview. Some brief demographic questions were then asked, followed by asking participants' permission to contact them again if it became necessary for whatever unforeseeable reason. Lastly, they were given thanks for their participation, reminded of their right to withdraw, and reminded that withdrawal was only possible in the two weeks following the interview, as this is when anonymization of transcripts would take place.

Four participants completed the interview process without withdrawing. After the agreed period, their interview transcripts were anonymised and pseudonyms replaced their actual names in the transcript. Analysis of the transcripts was then performed. Note that the transcripts feature a number of spelling and typographical errors. With spoken methods of interviewing, this is not an issue, but given the typed nature of these interviews, this issue was quite common. These errors were not corrected. To bring attention to and ask for correction of each spelling or typographical error during the interview would not have been conducive to maintaining an open, honest, comfortable relationship with the participant. Likewise, to make corrections and contact participants afterwards would not have been achievable for those who did not give permission to be contacted after the interview and might have made participants feel uncomfortable. This is especially true for Colin, who was dyslexic, and may therefore have

been self-conscious had this been mentioned. As long as the intended sentiment of participants' communications were clear, I chose not to point out and clarify these mistakes, as is common practice with spoken interviews where colloquialisms and syntactical errors are made. Such mistakes have been corrected when quoting in this thesis, and words which have had their spelling corrected are indicated through the use of square brackets. Likewise, alterations to pronouns or tense when embedding quotes within the text of this thesis are indicated using square brackets also.

The two that withdrew without completing the interview process were considered withdrawn, and their contact information and data were deleted.

### 9.3 The Double-Hermeneutic

The process of performing IPA is very similar to that of other methods such as Thematic Analysis or Grounded Theory methods. In addition to the underlying theory, a key difference between such methods and IPA is the double-hermeneutic. Ultimately, gaining an understanding of the way participants interpret their experiences was an aim, and is something which must be considered throughout the research process, from design, to data collection, to analysis. In this study, a qualitative, interpretative phenomenological method was chosen to reflect my interest in the experiences of the individual and how they perceive and understand them. Next, a data collection method which is not restrictive (i.e. semi-structured as opposed to structured interviews or questionnaires) was chosen. This was done so that where an understanding is not gained from previously selected questions alone, additional ones can be asked to follow up and gain a better understanding of participants' perspectives. Thirdly, the use of IPA as an approach and analytical method fulfilled this desire for the double-hermeneutic, as during analysis it was possible to focus on, explore and compare participants' interpretations of their experiences and reality.

### 10. Analytic strategy – IPA

The method used in this study was drawn directly from Smith and Osborn (2009). They describe four steps for performing analysis of one transcript, which I followed. The steps that I took, described by Smith and Osborn (2009), are:

1. Immersing oneself in the data and becoming familiar with it by reading and re-reading the transcript a few times.
2. Beginning to analyse the themes which emerge. First, I made a note of recurring ideas, concepts, and language use. I then made a note of the meaning of each line or so, breaking the text up into meaning units (as Smith and Osborn describe is optional) before more detailed analysis. Next, drawing on the initial notes and the descriptions



of the meaning units, I went back to the beginning of the transcript and began writing down emerging theme titles at what Smith and Osborn (2009) refer to as a “higher level of abstraction”. This process involves transforming all initial notes into themes. Throughout this and the following steps, it is important to continually refer back to the transcript to ensure that all themes are faithful to what participants have said, and to ensure that there is adequate evidence for each theme, in an effort to avoid going beyond the data.

3. Clustering themes. On a separate piece of paper, themes are listed chronologically (as they appear in the transcript), and I used this list to look for connections between themes and for superordinate themes. Once completed, a second list is made which organises themes and clusters according to the connections identified. At this point, Smith and Osborn (2009) state that it is optional to “compile directories of the participant’s phrases that support related themes”, which I did as I felt it would be useful in the next step and when reporting the findings.
4. Using the lists and the directories produced in Step Three, a table of themes is created which lists themes and gives exemplary quotations to demonstrate the meaning of the theme or cluster. It also gives a reference to where in the transcript this quotation may be found.

For each transcript, this process was performed. Once complete, I then made a note of convergences and divergences across the transcripts. A single table of themes was then created to show all of the findings across participants.

## CHAPTER THREE: ANALYSIS

## ANALYSIS

In this section, the results of the Interpretative Phenomenological Analysis of my interview data are presented. Quite a number of sub-themes emerged from the data, including qualities as a worker, maintaining focus and variation in non-work relationships, to name but three. For a full list of the sub-themes found, please see Appendix 6. Only two super-ordinate themes (each consisting of two sub-themes) are focused on here, which are ‘Workplace Relationships’ and ‘Workplace Challenges’. These were selected primarily due to relevance to the research questions, but also due to the richness of detail on these topics. They are introduced in the table of themes below.

Themes	Participant/page/line	Example Quotation
1. Workplace Challenges Sources of difficulty  Coping	Eric 3.6-7  Duncan 4.19  Colin 5.46-48	“I get stressed when management aren't very clear on what they need”  “cannot bear incandescent bulbs in my direct line of sight – it physically hurts my eyes”  “I find the contrast between very light and very dark hard to cope with... as such I change the colours on most computers I work on the allow me to deal with it.”
2. Workplace Relationships Disclosure  Quality of social relationships	Eric 5.17-18  Duncan 5.1  Eric 6.1-2	“She said "I wouldn't have hired you if I had realised you were Autistic"  “I have few colleagues”  “I have a couple of people I am closer [to]”

*Table 1. The themes of Workplace Challenges and Workplace Relationships.*

These superordinate themes have been selected because they directly relate to the research questions. These sub-topics were discussed by all four participants. Those which have not been selected for inclusion typically were not as relevant to the research questions as other topics, and were less rich in how they were discussed by participants.

Firstly, Workplace Challenges will be discussed, beginning with the sub-theme of sources of difficulty, followed by coping. Workplace Relationships are discussed thereafter, beginning with disclosure, then following and concluded with social interaction.

## 11. Superordinate Theme One - Workplace Difficulty

In this section, common difficulties faced in the workplace are presented. This focuses on sensory sensitivity and anxiety, how these are experienced and how they are coped with. The findings presented here relate to two of the research questions:

1. *What is their sensory experience like and how does it affect their experience of working environments?*
2. *What coping strategies do they develop to manage sensitivity and stress?*

### 11.1 Sources of Difficulty

Various sources of difficulty were outlined, relating to topics like lighting, sound and dealing with management.

One cause for concern at work was dealing with supervisors. Three of the four participants described having different problems with those in managerial positions. Duncan talks about experiencing stress when multiple different supervisors would place conflicting demands on his time, while Eric talked about struggling with confrontational supervisors. Interestingly, two participants talk about similar issues: unclear instructions cause anxiety. Michael states that in a previous job, a more experienced staff member thought that the best way to deal with him, as an autistic person, was to take charge and *“give direct orders without attention to comprehension which made me nervous and worse at what I [was] doing”*. Likewise, Eric states that he gets stressed when management do not give clear instructions. Clarity of instructions seems to be an important topic, as three mentioned this, though only Michael and Eric talk about the stress that arise when they are not clear. Colin also talks about the importance of clear, methodical, step-by-step instructions:

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*“Instructions need to be as precise as possible. Don't leave anything to chance. Don't assume someone with AS will be aware of something and simply do it.” - Colin*

---

Without this, detrimental effects can occur. Michael talks about a job in which he was not given any training whatsoever because his employers thought he would learn everything by himself. He felt that this was not going to happen, and after months of feeling as though he was underperforming and likely to be fired, he quit. Thus adequate support is important, whether it be training or instructions on what tasks to perform and how to do them (Berkshire Autistic Society, n.d.), with attention being paid to whether they actually understand the instructions.

Sensitivity to sensory stimuli was also a cause for stress and discomfort. Most notably: light and sound. These were the only senses mentioned in any level of detail, and were generally talked about as affecting participants quite negatively. Noise and sound were described as ever-present, something which *“always impact [them] everywhere [they are]”* (Michael). All four talked about finding sound difficult to experience and deal with. For some, *“sound is the biggest”* (Michael) cause of difficulty, out of all of the senses. Meanwhile, three of four talked about light being a source of difficulty that could cause pain, feel unbearable, or *“drive [them] nutty”* (Colin).

Indeed, sensory sensitivities often caused feelings of discomfort, pain or stress. When describing their experiences, participants typically use words and phrases like *“intolerable”*, *“difficult”*, *“I struggled”*, *“make me feel sick”*, *“hard to deal with”*. Specific kinds of sensory stimuli were associated with certain uncomfortable feelings. For example, participants indicated that lighting was associated with pain and intolerance:

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*“Flickering neon lights are [horrible]” – Colin*

*“VERY bright light I cannot cope with” – Colin*

*“cannot bear incandescent bulbs in my direct line of sight – it physically hurts my eyes” – Duncan*

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Overall, artificial and bright light was painful and hard to endure for Colin, Duncan and Michael. This is consistent with the findings of Robertson and Simmons (2015) who found that

flickering light made one of their participants irritable, and artificial, fluorescent and bright light made all of their participants uncomfortable. A clear pattern in Robertson and Simmons' data (2015), as well as that of the present study, was that natural lighting, especially softer lighting, is much preferred. This is explicitly stated by Colin and Duncan (above). Interestingly, only Colin stated that lighting could be pleasurable to him:

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*“VERY bright light I cannot cope with, so very bright sunlight is hard to deal with, even though I love being in it” - Colin*

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Here, Colin discusses discord between how he feels when being in the light and the effect it has on him visually. Note the distinction he makes: bright light is generally difficult to cope with, but bright *sunlight* specifically is simultaneously difficult to handle and enjoyable to be in. His recognition of the discomfort implies that the pleasure of the sensation outweighs the discomfort. Thus, he enjoys bright sunlight *in spite* of the difficulty it presents. Only this participant describes both enjoying a sensation and finding it uncomfortable at the same time, though this is something that has been found elsewhere. In a study by Jones et al. (2003), one participant reports a desire to be touched, and yet reports finding the physical sensation of being touched completely unbearable. Thus there can be a disconnect between the sensory experience and how an individual feels about the stimulus. In other words, the nature of the sensation does not necessarily dictate how an individual feels (emotionally) about it.

In contrast, while bright, artificial lighting was associated with pain, sound was associated with distraction and stress. Various participants indicated that sounds of a certain nature were always distracting to them. This is consistent with other research findings that distraction is a common effect of noise (Young, 2012; Jones et al., 2003). In this study, specific types of sounds such as irregular, unpredictable, uncontrollable noise proved more distracting than other kinds of sound. Michael describes any unpredictable noise negatively, including phones ringing, while other participants were more specific. Such uncontrollable, distracting noise can include overheard conversations (Colin), construction noise (Duncan), *“whistling (especially), tinny radios, drilling noise”* (Duncan). Concentration is particularly difficult when an individual must talk in the presence of such noise, or work in the presence of noise from other peoples' conversations (Michael and Colin). Colin described this as impairing his ability to *“listen and hear and understand what was happening on the telephone”* which was *“very stressful”* for him.

For Colin, trying to concentrate when surrounded by noise or other sources of discomfort can in some cases be exhausting. Colin found that noise had a profound effect on his concentration. He stated that this *“could actually also explain why when I got home I fell asleep most nights for at [least] half an hour before tea. So much stress and concentration”*. However, unlike the other participants who talk about these noises *always* being distracting, the stress-inducing distraction effect was context-dependent for Colin. Colin reports:

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*“Sound can be distracting under certain conditions. Sometimes I like classic FM on and it relaxes me and helps me to concentrate actually, other times having [music] on just gets on my [nerves] especially when it music I don't like” – Colin*

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Here, Colin contradicts himself by stating that sometimes music helps and sometimes it is a hindrance. Thus it is clear that whether one experiences sound as a distraction from a work task depends, at least somewhat, on how the individual feels about the nature of the sound. This reflects what he said regarding bright sunlight being both a positive and negative sensation to experience, while bright artificial light (for Colin, Duncan and Michael) was always a negative sensation to experience. Indeed, the notion that the effect of the sound (or any stimulus) depends on how the individual feels about it is echoed in the account of another participant.

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*“in retail jobs i'd have to listen to looped recordings of ads and video clips, 4 times a shift, which drove me very very insane, beyond the typical amount of irritation though. i'd often turn it off because it would bother me too much, or play a stereo instead, which i would be allowed to at times but eventual[ly] was asked to stop and that was probably one reason i [had] to leave” – Michael*

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As this quote shows, Michael would either avoid or replace the source of over-stimulation with something he preferred. His ability to replace it with a similar, sound-based alternative implies that it is not necessarily the presence intensity of sound, but the nature of it and the feelings it causes which determine whether it is over-stimulating. This again confirms the notion that sound only has a negative impact if it is not liked by the individual.

Disliking the stimulus may not be the only reason it had a negative impact on Michael. Perhaps, ultimately, Michael had no real control over it. Indeed, when asked not to play his stereo, and thus lost his ability to exercise control over what was bothering him, he eventually left the job. While this was not the only reason for his quitting for Michael he states that it was a contributing reason. This loss of control subjected him to a discomfort-inducing sensory sensation, which had been bearable while he had been in control. Thus it is possible that this quote (and the previous one about finding music he likes helpful and music he does not distracting) is evidence that control over the stimulus may at least partly dictate whether the individual finds it stress-inducing.

Certainly, many of the sources of difficulty mentioned in this section seem to imply a relationship between control and stress. For instance, various noises are described as distracting or stress-inducing, but they cannot be prevented or controlled (*“construction noise”, “whistling”, “drilling”* – Duncan; *“[unpredictable] noise”* – Michael; noise from conversations around Colin). Additionally, Colin and Duncan talked about struggling with bright or artificial lighting, which is present in nearly all workplaces, and which cannot be dimmed by employees in most workplaces. Likewise, the non-sensory difficulties mentioned often related to things outside of participants control, like treatment by managers. A lack of control seems to be a common denominator in many of these cases.

An association between lack of control and negative experiences such as stress, discomfort and distraction, is not a finding unique to this study. Control of a sensory stimulus was reported by Robertson and Simmons (2015) to be a deciding factor in whether that stimulus was experienced as pleasurable or a cause for discomfort, which is also visible here. Thus it is unsurprising that control features heavily in the next section about coping with difficulty. Certainly, control might explain the divergence in Eric’s experiences. While Eric reports that he while sound used to be a problem for him, he no longer experiences sensory difficulties. In fact, he reports that sensory sensitivity has *benefitted* his career:

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*“My sense of smell and taste is exceptional. If anything that is one of the reasons why I have been promoted so highly so quickly. A job that involves testing the chemicals organoleptic qualities is very easy for someone with such a good sense of smell and taste... My first ever pay rise at the company was basically because of a bet I had with the owner of the company which I won due to that trait..”*

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*We deal with around 6000 chemicals. I told my boss that he could pick any 20 chemicals. Put them in a mixture and mix them and I would be able to name all 20 [chemicals] and at what levels they were put in. He didn't believe it was possible and so we carried it out. At which point I got a pay rise and promotion to quality control.” – Eric*

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From this quotation it is clear that Eric finds his sensitivity to olfactory and gustatory stimuli useful in his line of work. Indeed, he is the only participant to describe sensory sensitivity as beneficial to employment, though other studies have shown similar findings. In the study by Huws and Jones (2015) it was found that a number of autistic adults felt that their heightened abilities gave them an advantage over others. Thus we see a tendency towards positivity about the self, not in spite of one's differences, but rather *because* of them.

The reason for Eric's positivity here might lie in the control Eric has over these senses. Odours, unless powerful, are typically only detected in close proximity to the source of the odour. Proximity is something that the individual can control by coming close or moving away. Similarly, flavours are only detected on contact with the tongue, and so to prevent gustatory sensation one must simply not put the substance in one's mouth – giving the individual absolute control over this type of sensory sensation. Unlike light and sound which are ambient in the environment and are continuously experienced when in the presence of them, smell and taste involve a greater degree of control on the part of the individual, and so sensitivity in these areas is likely to produce less discomfort (Robertson & Simmons, 2015). That is not to say that discomfort is absent. Participants in other studies have reported the textures and flavours of certain foods, especially when mixed together, to cause great discomfort (Jones et al., 2003). Likewise, Duncan (the only other participant to discuss olfactory sensitivity) reports that strong smells had the power to induce feelings of nausea. However, in Eric's case, his sensitivity does not seem to be as strong as Duncan's, but strong enough for it to be considered an asset in his employment.

Moreover, regardless of the level of control, there is already a precedent for viewing autistic traits as positive. Davidson and Henderson (2010) recommend viewing the traits associated with disabilities (such as autism) as *attributes* which may hold value, not simply symptoms of a disorder, or physical/mental representations of a disease. Certainly, this would be very much in line with the views of Social Model supporters such as Shakespeare (2010) and Thomas (2014).

In summary, participants demonstrate that a number of things relating to working can cause them difficulty. Dealing with management can be difficult, as can sensitivity to light or sound. In most cases sensory sensitivities were negative attributes and experiences, but for Colin, some were pleasurable, and for Eric, some were beneficial to his employment and even helped him to get a pay rise. Thus while many sources of stress and discomfort were universal, some of these same experiences senses had positive influences on the experiences of individuals. Therefore, an ideal working environment would likely involve moderate levels of noise and lighting, preferably natural lighting, and perhaps offices where workers like Colin and Michael can work quietly, without loud noise to distract them. This is an area which might benefit from further research, as finding out more about the ideal, autism-friendly working environment might help to inform employers about what adjustments they might be able to make to support their workers. This would aid the functioning of autistic workers in these environments, and help them to know exactly what help is available.

## 11.2 Coping Strategies

Participants talked at length about the ways that they cope with stress and sensory overstimulation. Most of the participants talk about using one of two methods to cope: avoidance or control. Both of these were the main methods described in the study by Robertson and Simmons (2015), so these results seem somewhat consistent with existing literature.

### 11.2.1 Control

Firstly, control. Controlling the situation, the environment or the source of difficulty was the most commonly favoured method of coping, when it was possible. Participants report doing things to prevent difficulty, for example Michael in his role as a college professor prevents his students from allowing their mobile phones to ring by deducting points from their final average. This deters the students from allowing their phone to ring, thus preventing an unpredictable noise from being encountered. Likewise, when he was a camp leader, there was a game which *"irritated [him] sensorily"*, which he was expected to play with his group. He *"just wouldn't do it and wouldn't have [his] group do it either though [his] boss would often tell [him] to do it"*. Thus in both cases he utilised the authority of his position to exercise control over what was present in his sensory environment so that he would not have to experience any discomfort.

Regarding their difficulties with supervisors, two participants demonstrate an overall tendency toward attempting to address the issue directly. Duncan, when set conflicting demands by different managers coped by modifying the way he worked, by prioritising tasks to manage his workload. Meanwhile Eric resolved his issues with being given unclear instructions by requesting more detail.

In terms of sensory difficulties, when it was not possible to prevent or directly control the stimulus, some participants talk about modifying how the stimulus is received. For instance, Colin talks about doing this with the computers that, as a computer technician, he is responsible for:

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*“I find the contrast between very light and very dark hard to cope with... as such I change the colours on most computers I work on the allow me to deal with it.” - Colin*

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Interestingly, instead of simply reducing the brightness of the monitors, he changes the colours on the computers in order to make them easier to deal with. This might relate to his dyslexia, though he attributes the difficulty with contrast to autism. The solution he describes is a simple one which takes advantage of his awareness of colour and the effect that light and colour can have on his vision. This is interesting because he talks about experiencing difficulty when entering new environments, due to of all of the visual and auditory stimulation he experiences. Visual processing and sensitivity is clearly a difficulty for him. This finding was also observed in a study by of Jones et al. (2003), who found that unfamiliar settings had the ability make one participant feel over-stimulated by the amount of information to process. This caused feelings of anxiety and confusion for one participant in their study. Colin’s solution is to try to ignore the environment and force himself to display certain social behaviours:

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*However being polite and putting on a smile tends to work well. Forcing a small amount of eye contact. Having to ignore the surroundings and force yourself to partly ignore what is going on around you etc. THIS IS NOT EASY! Especially when the office is a loud or a quiet one. – Colin*

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Colin’s attempt to focus on what people are saying instead of all of the new information in the environment echoes findings by Jones et al. (2003). Thus exercising control over what is noticed by modifying what an individual pays attention to is a coping strategy which is not unique to Colin. This strategy of modifying how one responds to a stimulus is different from Colin’s way of dealing with the light on computer monitors. With the computer monitors, instead of adopting a strategy which modifies his behaviour, as he does in the above quotation, he adopts a strategy which involves modifying the source of the difficulty and how he receives this input. Therefore, Colin demonstrates some awareness that his coping

strategies involve modifying one or the other: either how he receives or mentally responds to the input/environment around him. Modifying one over the other is a choice that he has made differently in different contexts, implying that the nature of the coping strategy used is dependent on context. This likely relates to control: when entering a new environment, one cannot control the presence of new stimuli, as one can with the settings on computer monitors. Thus perhaps the defining difference between the two experiences is that he has control over the computers, but not over what is present in a new environment.

Furthermore, by modifying a feature of the environment (changing the colours on the computer monitors), Colin is potentially changing something so insignificant that others are not likely to notice, or at least not to attribute it to sensory sensitivity. This effectively masks his difficulty, as would forcing social behaviour like eye contact. Similarly, when Michael worked in a shop, he found it difficult to listen to the looped recordings of advertisements and video clips in the background, and so would turn them off or replace the noise with a stereo instead. In replacing the noise with music, he did something which reduced his discomfort without drawing much (if any) attention to himself. In Michael's case, this was not likely to appear abnormal to those around him, thus he is both addressing and masking his difficulty. Indeed, Colin reports using masking strategies to "*appear 'normal'*". This is supported by the study by Davidson and Henderson (2010), who found that their participants frequently used masking strategies to appear more 'normal' and hide their autism-related difficulties, like sensory sensitivity issues. Thus methods which both address and mask the difficulties are often favoured, both here and in the literature.

Furthermore, masking difficulty is not the same as addressing it, and coping strategies do not always do both. Some may only mask, like Colin forcing himself to display social behaviour, and some only address the source of difficulty, like Michael preventing his students and camp groups from doing things to over-stimulate his senses. In the latter case, while Michael may not have been masking his difficulty, his position of authority over the others present negated any necessity for giving 'normal' sounding excuses for his behaviour. For decisions like banning mobile phones from ringing, it is unlikely that students would question their professor, so no excuses would be needed for something so ordinary. Likewise, any negative treatment is less likely when one is in a position of authority. So he may not have masked his difficulty in the same way here because he likely did not need to. Therefore, masking may only occur in the presence of equals, superiors, and who the participant wants to see them as 'normal'.

However, masking in the absence of coping can simply add to participants' difficulty without making the experience much easier to tolerate. Colin gives an example of this when he states that he would often come home from work feeling exhausted, and would often go straight to

sleep until dinner. Thus, masking strategies may enable participants to appear as though they do not have an ASC, but ultimately, they can add to their existing discomfort.

However, this need to hide their discomfort from others implies that participants do not feel accepted as they are, and that they therefore feel uncomfortable with others knowing of their struggles. This notion is supported by the way participants only talk about masking in the context of sensory difficulties, but not anxiety. Anxiety and stress are considered 'normal' for anyone to experience, so the fact that participants talk exclusively about addressing the causes of their anxiety, with no mention of masking, might relate to the way that anxiety is considered 'normal'. In contrast, sensory sensitivities are difficulties specific to the ASC population not the general population, and so difficulty in the presence of aversive sensory stimuli may not be considered 'normal'. Thus, for ASC-specific difficulties participants use masking strategies, but for 'normal' difficulties like anxiety, they do not because they do not feel that their experience is abnormal. This is the same as was found by Davidson and Henderson (2010), whose participants 'normalised' their sensory difficulties by feigning headaches and sickness, to pretend that these were the reasons for their discomfort and self-soothing behaviours. Ideally, participants should feel comfortable dealing with their difficulties without the added burden of masking them, but this may require a greater level of acceptance from those around them in the workplace for this to occur.

However, participants may not always feel accepted, as will be discussed in the next section. Sometimes, rather than tell others about their difficulties, participants choose not to disclose, making true acceptance impossible. As a result, participants try to cope with challenging situations unsupported. As evidence by the various strategies discussed for coping and masking, they demonstrate some degree of success at this, though this depends on them having the ability control the stimulus, their behaviour or their response to it. Thus the absence of control may stop them from being able to cope. Indeed, participants gave examples of times when lacking control proved disadvantageous for them. They described absence of control over the stimulus as difficult to deal with. For instance, before his promotion, Eric had little control over the way he was allowed to work, and describes what it was like:

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*“Interviewer: [it] sounds like you have a lot of control over the way you work*

*Eric: I do. It wasn't always like that. It took a long time to get to that stage and I must admit it was hard before I got there” - Eric*

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Once promoted, Eric had the ability to work alone, and prevent other staff from entering the laboratory uninvited. While he states that the latter was more for their protection against the harmful chemicals he worked with, he stated that this level of control over his environment was advantageous, and not having this level of control had previously been difficult for him. Similarly, Michael talks about how, due to the leniency of his line managers, he has full control over how he works, describing it as “wonderful”. Additionally, referring back to what Colin said about his difficulty processing new information, he clearly found it difficult to endure exposure to an environment where he had no control over what he perceived. Thus a lack of control and autonomy may be associated with greater difficulty than the presence of control.

### 11.2.2 Avoidance

Generally, the coping strategies described by the participants often tend not to involve drawing attention to what the individual is experiencing. While this might be achieved by exercising control over one’s environment, it may often involve avoidance of aversive stimuli. For instance, this is the main coping strategy talked about by Michael and Eric. While they do sometimes attempt to address issues directly, usually, they often talk about avoiding these stimuli (or situations) entirely. Michael describes being concerned that he does not dress appropriately for work, which makes him “perpetually fear for losing [his] job”, and so he copes by avoidance:

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*“I don’t want to ask anyone above me about it for fear they’d notice for the first time... I try to avoid other staff while at work” – Michael*

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Contrastingly, this is not something he feared in the past. In a previous job where he felt he was struggling to learn the role, and did not feel comfortable asking for help, he chose to quit “in order to avoid being fired, which [he] expected would happen soon”. Similarly, Eric states that he becomes stressed whenever he must interact with one of his managers, and so avoids interaction with him wherever possible:

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*“As for how I deal with it. Well I don’t really. I [avoid] talking to him whenever I can help it” – Eric*

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Interestingly, while he and most other participants talk about avoidance being one of the ways that they manage their stress, Eric demonstrates that he does not deal with the issue, avoiding

it *instead*. Clearly he does not think that avoidance constitutes a way of dealing with problems. Yet he still reports it as a way that he responds to the stress. Likely he chooses to avoid this manager because he has no choice but to work with him. Eric has no control over this person being his hierarchical superior, and someone he is required to interact with. So it is probably due to the lack of control Eric has over the situation that made him choose to avoid the individual instead. Naturally, avoiding the source of the stress reduces the likelihood of it being experienced, so avoidance is one way to *manage* one's experiences, but for Eric this is not the same as actively dealing with the problem (which his lack of control leaves him unable to do).

No other participants make the distinction between dealing with an issue and avoiding it, though it is difficult to ascertain the reason. They may simply not see it the way Eric does, or there may be some other reason. It is possible that this relates to what was demonstrated by Colin (and to a lesser extent, Michael) in the previous section regarding masking strategies. Colin and Michael often talked about methods of coping which involve masking, like Colin feigning social behaviour when overwhelmed in new environments or Michael replacing irritating recordings in a workplace with his own music on a stereo. Thus perhaps to Colin and Michael reducing and hiding their difficulty was more important than tackling it directly, like Eric felt. In this sense, Colin and Michael's coping strategies seem to be reactive rather than proactive like Eric's. They seem to try to reduce difficulty and the appearance of it, while Eric seems to try to reduce sensitivity to aversive stimuli instead, which is preventative.

This might relate to how participants make sense of their difficulty. Certainly, it is clear is that participants conceptualise difficulty differently. For example, Eric repeatedly makes mention of sensory sensitivity and poor memory being "*weaknesses*" of his, and describes how he purged himself of these "*weaknesses*" by training himself:

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*"Ever since I was quite little I always had the vision of being the Blade version of Autistic, so I have spent years trying to improve the [strengths] and iron out the weaknesses... I watched [the movie adaptation of the comic book Blade] when I was quite young and I was [fascinated] by the whole "All of their strengths, none of their weaknesses" [concept] and so I figured if that could apply to made up vampire hunters surely it could be applied to aspergers syndrome too... I identified the strengths and weaknesses that I have and then worked on either improving the strengths or eliminating the weaknesses... I spent quite a while training my memory to improve it. I threw myself into social situations that I knew that I was no good at in order to practice being in them..." – Eric*

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*“I used to find it difficult to be around loud noises, but I practiced dealing with that and got used to it. When I was a teenager I would [purposely] go to places that were really loud to get used to it” – Eric*

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The way that Eric refers to his impairments as “*weaknesses*”, and talks about “*eliminating*” them from himself seems to draw influence from medical definitions of disability. Unlike the Social Model, which views impairment as individual and disability as socially constructed (Strauss, 2010), the medical approach attributes all impairment and disability to the individual as Eric does. Eric’s description of his impairments as “*weaknesses*” distinguishes him from others, making him different, and his talk of “*eliminating*” his weakness implies that he draws on the medical model of disability when making sense of his disability and how he chooses to ‘treat’ it.

No other participants refer to their difficulties this way, describing them instead as things that they experience, using descriptive words like “*horrible*”, “*irritating*”, “*distracting*”, “*struggle*”, “*sensitive to*”, etcetera. Thus, other participants seem more influenced by the Social Model of Disability than Eric, in terms of how they make sense of their impairment. In essence, Eric talks as though stress and sensory sensitivities are within his control (and his responsibility), while Colin and Michael do not.

Interestingly, Eric appears to have been successful in his endeavours to remove his impairments, as he reports no difficulty with sensory sensitivity and implies that his memory is better too. He attributes the success he has had in training himself to become accustomed to stimuli he previously found stressful to his belief that these difficulties are “*weaknesses*” to be eliminated, and that “*practice sorts everything in the end. There is nothing that can’t be achieved if you just try*”. Thus perhaps Eric feels that dealing with difficulties must involve learning how to handle these situations better in future, or purging one’s “*weakness*” (as described above), which avoidance does not involve. This might be due to the way that his preferred method of training himself to improve involves utilising some degree of control over the self and the situation. Avoidance does not involve control like this. Eric seems to prefer methods which involve taking control over his difficulties, but when this is not possible, avoidance is his second choice.

Other participants do not seem to hold Eric’s preference for training himself over avoidance, though a participant in the study by Robertson and Simmons (2015) did exactly this. While Eric is alone in this sample, he is not the only autistic person to use this method. In direct contrast, most participants attempt to avoid difficult situations. For instance, Michael avoids exposure



to aversive stimuli almost completely by wearing earphones between the classes he teaches to “[keep] out [unpredictable] noise”. Michael also avoids excessive exposure to stimuli by doing things to reduce the intensity in which they are received, such as wearing sunglasses when the sun is bright. Likewise, Duncan, who reports sensitivity to temperature changes and especially cold, reports wearing extra layers and turning the heat up where ever he works to avoid sudden cold. Similarly, Colin avoids excessive exposure by limiting interaction with others to contexts in which he is not at risk of over-stimulation. For instance:

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*“I have to talk to people when in a quiet and [pleasant] area otherwise it's  
VERY [difficult]” – Colin*

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In both participants’ cases here, they describe methods of coping which enable them to prevent excessive exposure to aversive stimuli without drawing the attention of others. By wearing sunglasses and earphones, Michael does something seemingly ordinary, as was found in the previous section. Again, this is similar to the findings of Davidson and Henderson (2010), whose participants used ‘normal’ sounding explanations for ASC-specific difficulties. Thus these strategies may all be seen as useful for masking and coping.

Generally, participants seem to choose between control and avoidance according to what is possible in the given situation. Participants tend to talk more about methods which involve taking control, which implies that they prefer these methods. Indeed, the situations in which participants talk about avoidance of stress and aversive stimuli typically are situations where they are not in a position of control, and thus are not able to use a method which involves control. For example, Michael using earphones between classes or sunglasses reflects how he is not able to prevent the noise or bright light present in these environments. Like Michael, Duncan is not able to prevent temperature changes in his surroundings easily and take action to avoid the cold. Similarly, Colin limiting his interactions with others to quiet areas demonstrates that he did not have control over the noise in some of the environments where he had to work.

In contrast, participants used methods involving control when they had the power to, such as Michael using his position of authority to prevent those around him from engaging in activities which caused him discomfort, like allowing phones to ring or playing certain camp games. Certainly, methods which involve taking some sort of control seem to be popular. For instance, when absolute control in the way that Michael describes is not possible, and participants cannot avoid a stimulus, they sometimes take control in other ways. Namely, Colin: by

modifying the colours on computer monitors, or how he manages his attention in new environments, Colin is taking a small degree of control over an unavoidable situation he cannot control entirely. Even Eric, who does not always deal with his difficulties, prefers to utilise control by forcing himself into difficult situations in order to get used to them. Therefore, there appears ample evidence that participants choose to exert control when they are able to, and use avoidance when they cannot. This tells us that the best solution for supporting autistic workers may be to offer them control over how or where they work, and give them the option to avoid things which might cause them difficulty. The answer to this is perhaps to enable autonomous working.

In summary, Michael and Colin demonstrated a tendency towards avoidance as a coping strategy, and also as a masking strategy. Eric also managed his experiences of potentially aversive stimuli through avoidance, though demonstrated that he did not see this as a way of actually dealing with difficulties. Thus, a key difference in how participants conceptualise their difficulties might be the reason that Eric did not see this as a coping method, but Michael and Colin did. Moreover, the data seems to support the notion that participants prefer to use methods which enable them to exert control over sources of difficulty, or avoid them where control is impossible. Enabling autistic workers to take control over the causes for anxiety and discomfort in their role appears to be the most helpful way that managers can support them.

## 12. Superordinate Theme Two - Workplace Relationships

In this thesis, “workplace relationships” are taken to refer to relationships with any staff member within the organisational hierarchy, irrespective of seniority. The sub-themes discussed in this section related to the third research question:

3. *What are their relationships with others in this environment like and does disclosure affect these relationships?*

Thus the sub-themes discussed are presented here: disclosure and quality of relationships and interactions.

### 12.1 The Impact of Diagnosis Disclosure on Relationships

Participants talked frequently about diagnosis and disclosure and how they were treated by following disclosure. Sadly, most of these experiences were negative, as found with Eric, Colin and Michael. Experiences range from being victim to explicit discrimination, to being prevented from working due to a lack of ‘reasonable adjustments’ which employers failed to ask participants about, to treating participants differently because of their diagnosis.

For instance, Michael and Eric both had issues with superiors following disclosure. In Eric's case, a discriminatory statement was made against him by the owner of the company:

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*"She said "I wouldn't have hired you if I had realised you were Autistic". Since then, we have never [gotten] along and I think thats a large part of why I don't get paid so well... I have had quite a lot of problems with her since the day. Although a large part of that was because I responded to her with "I wouldn't have accepted the job here if I had realised you were such a [c\*\*\*]". Since then it has very much been a, I would get called out on things others would get away with etc... I think [discrimination] has all to do with it. She is exactly the same to one other person and even said the exact same thing to her but this was because of dyslexia. I think she is very set in her ways." – Eric*

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Given the reported attitude of the employer and the response of the participant it is unsurprising that further problems with this employer were common. This is the most severe example of workplace discrimination in the sample, but not the only example. It is consistent with the findings of Davidson and Henderson (2010), wherein some participants report others seeing them as less capable following disclosure. Michael gives an account of a somewhat similar experience:

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*"This co-worker at my maid job was mildly familiar with autism and said I really shouldn't be working there because I'd do a terrible job..." – Michael*

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Like Eric, it was questioned whether Michael was deserving of the job simply due to his diagnosis. Like Eric, Michael was consequently treated differently by the person that he had disclosed to. In Michael's case, this was attributed to a low level of awareness, as he stated that the co-worker was "*mildly familiar with autism*".

Similarly, Colin also experienced a form of discrimination which influenced how he was treated by others. Colin reports that once his boss realised that his file said that he was autistic, they became concerned about the lack of 'reasonable adjustments' made for Colin and so stopped him from working:

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*“they suddenly [realised] they [hadn't] done anything [about the] autism thing so they instantly stopped me from doing [literally] anything at all” -  
Colin*

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This, Colin reports, resulted in him being given no work to do for two consecutive weeks and being encouraged to take his annual leave instead of coming into work because *“they wouldn't give [him] work to do”*. Colin found this frustrating, particularly when his colleagues began asking his supervisor questions like *“why [can't he] do this, he can easily do this”*. This demonstrates that his colleagues were confident in his capacity to perform his responsibilities, but the line managers appeared not to be. Colin felt he was *“in [bubble] wrapping with no arms”*, repeatedly describes them as *“scared”* or *“afraid”* of getting in trouble for not providing him with support. Yet, he also said that they would not let him explain his needs to them:

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*Well - it would have been nice to simply allow me to explain it to them which they [didn't] allow... They wanted to get 'official' help through etc to try and stop me [from] saying 'oh they haven't given me this or that' - Colin*

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This finding was mirrored by participants in the study by Scott et al. (2015), who found that employers often lacked confidence putting supportive measures in places for autistic employees without guidance from an ‘official’ disability-related organisation. Despite this, Colin was still by far the most positive. Indeed, he is the only participant with positive things to say about his bosses. Before his difficulties with his supervisors relating to his diagnosis, Colin had a boss that he describes as *“amazing”* and *“kind”*. He states that:

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*“her son has more severe Autism than I do so she spotted it in me almost [immediately] and kinda helped me through things the way she does her son and it worked” – Colin*

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Unlike Michael’s co-worker who was somewhat aware of autism, Colin’s first boss was aware and did not treat him negatively because of it. She, like Michael’s co-worker and Eric’s boss, modified how she treated and supported Colin, except what she did actually helped him. Likewise, when this boss left her job, she was followed by another who *“didn't have a clue about AS but quickly looked into it, ... and only wanted the best for [him]”*. Colin describes her

as “fair” and “understanding”, and though “she did the best she could under extreme stress [in the] job herself. However the boss above them was a [total] prune and no one really liked him”. Similarly, Eric describes positive relationships with his colleagues, to whom disclosure made no difference and was simply a source of light-hearted banter:

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*“People used to make comments when they found it but that was more made in a banter sort of way and they never treated me differently because of it...no offence was ever [meant]. They had even admitted that if they weren't told I was [autistic] then they never would have known” – Eric*

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While quite positive compared to the experiences of others, Eric reports that his disclosure made little difference to his relationships beyond providing a new source of banter. He describes this as effectively harmless. Indeed, he is the only participant to report that disclosure made no difference to his relationships.

In direct contrast, Duncan (who was unable to disclose due to his very recent diagnosis) reports being mistreated, though he believes that disclosure might have helped. Sadly, he reports various instances of mistreatment throughout his career, including one incident where “once someone lowered a mock noose made of string around [his] neck from a mezzanine balcony”. Interestingly, Duncan believes that had he received a diagnosis earlier and been able to make them aware, he might have been “treated with more understanding” across many of his adult relationships, including working relationships. Similarly, in his romantic relationship he feels he and his partner “would have been able to have a much better level of communication”. Overall, it is clear that he feels that having the ability to disclose to others would positively impact his relationships and treatment by others. Indeed, Colin reports that being able to explain his behaviour as resulting from his diagnosis of autism has helped his colleagues to show be more forgiving of any abnormal social behaviour. He says that his has allowed them to learn to ignore any abnormalities and get to know him better. Consequently, he feels that this has helped him to make friends, as they were able to learn that he was not “simply annoying”. In both of these cases, participants demonstrate an optimistic outlook regarding disclosing to colleagues. They do not talk about any such positivity in disclosing to line managers, only to colleagues that they must work interact with.

More generally, participants do not tend to discuss how they feel about disclosing to line managers, with one exception. Michael reports not feeling comfortable doing so. Michael describes starting a new job in a shop and struggling to learn the tasks at the pace expected,

stating that he was not given much training because they expected him to pick it up by himself. “[He] didn't feel comfortable telling them that this was not going to happen”. Certainly, choosing not to disclose is not uncommon among autistic employees (Davidson & Henderson, 2010). As a result, he was offered no additional support, and continued to struggle – a main shortcoming of not disclosing, identified by Davidson and Henderson (2010). He became so concerned by what he deemed as inadequate performance on his part that “[he] quit after 6 months in order to avoid being fired, which [he] expected would happen soon”. Indeed, firing employees is an option that line managers have to consider when any worker’s productivity is low (Scott et al., 2015), and so was a justified concern. Had he disclosed he might have been given some support, however, he did not feel comfortable disclosing, which is unsurprising given the difficulties he had experienced with criticism and mistreatment throughout his career. Mistreatment is something that all participants have at some point experienced. This can make it hard for an individual to feel comfortable disclosing. For Michael at least, it appears that feeling comfortable is an important pre-requisite to disclosing.

Thus, on this basis of this experience, and the other negative experiences he, Eric and Colin have experienced, it is not unusual for participants to consider not disclosing. Indeed, whether to disclose is a decision that autistic individuals must make carefully. Davidson and Henderson’s (2010) study identified a number of concerns one ought to take into consideration when deciding whether to disclose, which largely relate to trusting the other person to have the individual’s best interests at heart. Judging by Michael’s lack of comfort, one can speculate that perhaps he did not have a trusting relationship with his supervisors, and so opted to leave the workplace rather than risk it.

It is interesting to note that Davidson and Henderson (2010) place importance on others having the individual’s best interests at heart. Colin explicitly states that the supervisor he had “only wanted the best for [him]”. Yet this is the same supervisor who was managing him when his diagnosis came to light and he was prevented from working. Colin also reports that eventually, after a while of being prevented from working, and asking every single day to be given a task, his manager “kinda bent the rules very slightly and got me back [on the] phones as she knew very well I could do everything. OK it was [boring] but at least it was better than nothing”. Clearly, while he felt that she had his best interests at heart, she was still bound by rules and unable to stop Colin from being discriminated against, though she did make an effort. This shows that, from Colin’s perspective, good intentions are not always enough to prevent discrimination within organisations.

In conclusion, participants have discussed a mixture of positive and negative experiences with disclosure, tending towards the negative. Following disclosure, some participants report experiencing discrimination or being prevented from working. However, reporting negative experiences was not uncommon in the absence of disclosure or even a diagnosis. For instance, one reports being bullied, while one reports struggling with the job but not feeling comfortable disclosing and ultimately quitting the job. In spite of the negative experiences, some participants remain optimistic about the effect of disclosure, which may be a result of the positive impact disclosure had on their relationships with colleagues and equals. Moreover, negative experiences tended to occur more when disclosing supervisors than peers. Ideally, this should not be the case, as autistic workers should feel comfortable disclosing, and disclosing should be worth it. Appropriate workplace adjustments were not really discussed here, nor were the circumstances required for disclosure to occur, which are both things that would be worth further investigation if employers are to make disclosure worth it for employees with ASCs.

### 12.2 Quality of Working Relationships and Interactions

In this section a number of smaller themes are presented which relate to this topic. These include social isolation and unintentionally offending others.

Unfortunately, participants do not report many close, positive relationships with colleagues in their workplace. Duncan simply states: *"I have few colleagues"*. They typically report a small number of positive relationships with others. For instance, both Colin and Duncan talk about finding people that they got on with quite well, such as when Duncan describes finding a *"kindred spirit"* that he would talk frequently with. For the most part though, participants tend to have few, distant relationships with most colleagues, and demonstrate a degree of social isolation with which they are surprisingly satisfied.

Several participants report distance between them and their colleagues. Generally, they appear to prefer this, because they seem to value being able to work alone. For instance, Duncan, Michael and Colin talk about preferring to work alone. While Duncan attributes this to disliking *"office politics"*, Colin attributes this to enabling him to concentrate better when it is quieter. In contrast, Michael simply describes disinterest in his colleagues. Michael talks repeatedly about working separately from other staff, not talking to other staff and sharing an office but not interacting with them. Indeed, he expresses disinterest in them because he deems their views to be *"gross and anti-learning"*. He appears to judge them by their views, and chooses not to befriend them causing himself to be isolated. Furthermore, like Eric he reports that he does not really interact with his line managers either. For Eric this is limited to

short meetings at the beginning of the day to receive his tasks and instructions for the day, while for Michael, this is limited to polite exchanges in the hallways on the way to class. When he does interact with them, he reports that these interactions are “*brief, logistical, professional*”. He is quite positive about distance from others, describing it as “*essentially like being self-employed, it's wonderful*”. Furthermore, working alone and particularly in a separate office away from others seems to be popular throughout the sample. Eric echoes this opinion, describing how “*it was hard*” before he was promoted into a role which involved working alone in a laboratory.

Surprisingly, Eric, who by virtue of the entirely solitary workspace, is the only participant to report having friendships with working colleagues. Colin and Michael talk about friendships outside of work, while Duncan describes social isolation in all areas of his life since the recent passing of his wife, but none of these describe any current working colleagues as more than acquaintances. Only Eric does this. He states that he has “*a couple of people [he is] closer to*”, and goes on to describe his interactions with these people:

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*“Eric: To be honest, with the [exception] of the previous mentioned girl the people who I get on with best are all foreign. I find them much easier to speak with and be around... [in relation to] The way they speak English. They always say exactly what they mean. They don't use sarcasm etc...”*

*Interviewer: is conversation something you struggle with then?*

*Eric: Not really anymore, I just prefer it when it is with people who won't use sarcasm and won't use expressions and says what they mean” – Eric*

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It is interesting that Eric reports a preference for people who are “*foreign*”, due to the way that they speak English. Duncan shares a similar experience, in which he talks of a “*kindred spirit*” who, he reflects, may have also had Asperger’s Syndrome. Given that conversational impairments are part of autism and have been associated with difficulty in forming friendships (Osmond et al., 2013; Orsmond et al., 2004; Howlin et al., 2004), it is logical that these participants have formed friendships with people they may be better able to converse with. Perhaps it is the ease with which Eric is able to converse with those whose second language is English that make Eric different from the rest of the sample in terms of current workplace friendships. Eric describes them as “*easier to speak with and be around*”, which may be something that the other participants have not found with their current colleagues. For many



jobs, having workers be on such good terms as Eric and his “foreign” colleagues may not be necessary for good performance or high productivity, but in the interests of social inclusion, employers may find it beneficial to provide language awareness training. Such training should teach staff that using literal, more straight-forward language can benefit autistic employees and enable them to better interact with and understand others. The government is required, by the Fulfilling and Rewarding Lives strategy (Department of Health, 2010), to provide such training to front-line healthcare workers and Disability Employment Advisors in Job Centres, so perhaps extending this training to employers and workplaces would be the next step. Certainly, it would benefit autistic workers to at least base such training on that which the government provides, so perhaps employers should seek to provide training which mimics this.

Providing any autism-related training would raise awareness of autism, and may help to reduce isolation and improve communication more generally in the workplace. This is particularly important, as miscommunications do happen, and are more likely where communication impairments are present. Indeed, participants talk about a number of experiences where verbal or non-verbal miscommunications have occurred and upset other staff. For instance, Colin states that this is quite common, and describes how when he becomes uninterested in a conversation he physically turns away from the speaker without realising:

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*“I’ll kinda still half listen but haven’t actually realised that my body language is [saying] a big fat GO AWAY I’M BORED and I DONT CARE... Even though I am listening. I have upset many people in my life with this” – Colin*

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Colin demonstrates that he does not intend to be impolite, and that this non-verbal behaviour can cause problems. Likewise, other participants report problems with saying things that offend others. For instance, they report being “unintentionally rude or unsympathetic” (Duncan), or “occasionally blurt[ing] out something others considered inappropriate without understanding what it was” (Michael). This was not uncommon, and Michael mentioned multiple instances of having issues with this. Sadly, the recipients of this unintentionally upsetting social behaviour do not always address the issue directly with participants. Indeed, “most people don’t tell [him] they are upset and just walk [off] and don’t tell [him] directly” (Colin, referring to work colleagues). Colin reports a preference for people telling him when this has occurred so that he can rectify the issue or apologise. Duncan and Colin feel that disclosure may help in this case. Colin finds that explaining behaviour this way makes it easier for others to understand why this has happened and that they are not simply being “annoying”

(Colin). Indeed, both participants in addition to Michael report that at times they have felt merely tolerated by other staff. Perhaps through disclosure and raised awareness of staff about some of the common issues in autism, such as this, might enable other staff to be more considerate and forgiving of these unintended offenses.

In summary, participants report that they often do not have particularly close relationships with others at work. Generally, they prefer to work on their own. Perhaps this relates to their difficulties with communication, which is indeed implied from the way that Eric has formed closer friendships with people who speak more simply, which may make them easier for him to understand. Communication difficulties were common, and so was the tendency to report unintentionally offending others with the words or body language that participants used. Thus, it is possible that autism awareness training which incorporates training surrounding language and the benefits of using literal, straightforward language to communicate with autistic people may help staff to interact better with and be more forgiving of autistic people and any social or communicative mistakes.

## CHAPTER FOUR: DISCUSSION

## DISCUSSION

### 13. Summary of Findings

This study explores the unique experiences of four high-functioning autistic adults in the workplace. The research questions focused on the nature of the sensory experience, how it affects experiences of working environments, what coping strategies were developed for managing difficulty (sensory sensitivity and stress), what relationships are like, and the role of disclosure. Key findings in relation to these questions are as follows. Firstly, these participants showed unusual tendencies regarding sensory perception, which often can become painful, distracting or uncomfortable, causing the environment to be difficult to tolerate. In some cases, participants also found aversive stimuli simultaneously pleasurable, and in other cases, sensitivity to these stimuli was deemed a highly useful skill that could be utilised in their line of work, leading to career progression. This is surprising, as the majority of the findings here, and in other literature also (APA, 2014; Howlin, 1997; Trembath et al. 2012; Gillot & Standen, 2007; Jones et al., 2003; Young, 2012; Roberson & Simmons, 2015), imply that sensory sensitivity is a burden, often an impairment. These findings show that this is not always the case, demonstrating that there is scope to experience or utilise one's sensory sensitivities in positive ways.

It was also found that, with a greater tendency towards anxiety, autistic individuals face hardship in many areas of life, including social interaction. Added impairments to social interaction, anxiety, and atypical reactions to sensory stimuli, can make navigating the world of work difficult. Participants demonstrated an awareness of some of their impairments, and developed coping and masking strategies, though the strategy used appears to be context-dependent.

Participants tended towards two main coping strategies, which they used in dealing with sensory difficulties as well as anxiety. They typically used proactive methods of controlling the stimulus or their own response. For instance, modifying how the stimulus was received (using their own music instead of the music that was provided, or modifying colours of the computer screen), or slightly more passive methods of coping like avoidance. Specifically, participants would try to avoid exposure to aversive stimuli by either avoiding the stimulus or the situation in which the stimulus was present (e.g. quitting a job where the stimulus was always present). In some situations, participants would choose a coping strategy which also masked their difficulty (such as wearing earphones between classes to prevent people from people speaking to them, which is a common behaviour that would not appear unusual to others), making their

discomfort imperceptible to others. In other situations, they would simply choose a masking strategy which offered no anxiety- or difficulty-reducing benefits.

As a result of the difficulties faced, deciding whether to disclose is something to be considered carefully, as negative experiences with others may often follow. Some report being treated differently by others, even feeling bullied or spoken negatively about, following disclosure. In contrast, some reported experiencing difficulties which could be associated with non-disclosure. Overall, participants showed no consensus in terms of their thoughts on disclosure, as some are for and some are against it, but all have thought about it, and discussed it. Some feel it would influence their experiences at work, for better or for worse.

#### 14. Methodology and Analysis

This study used an innovative method of data collection. The literature suggests that autistic individuals may be more comfortable communicating via written or typed methods (Gillespie-Lynch et al., 2014; Neary et al., 2015), and so interviews were conducted via an online, synchronous messenger program. While there are limitations with any form of semi-structured interview, many of which relate to the interviewers skills in interviewing (such as leaving appropriate time for the participant to consider their answer before responding), this method was deemed appropriate. Indeed, other studies have used synchronous and asynchronous typed methods like this before (Walker and Tobbell, 2015; Jones et al., 2003; Davidson and Henderson, 2010). Walker and Tobbell (2015) even stated that synchronously typed interviews are highly suited to an autistic population. Additionally, the fact that participants talked about personal experiences, implies that they were comfortable talking to me (which was the purpose of this method). Also, lots of rich, detailed data was obtained. This suggests that choosing to interview electronically is both suitable, effective, and makes participants feel comfortable enough to undergo interview. This, therefore, supports Walker and Tobbell's (2015) argument that this method is suited to autistic participants.

Furthermore, the semi-structured interview enabled me to interact well with my participants, creating a dialogue and learning about their interpretations of their experience. Having a set of pre-determined questions was useful in informing the topics discussed, but having the freedom to ask additional questions enabled me to seek clarification from participants, or probe on topics related to what they were talking about. This made the most of participants' time, because a good understanding of participants' feelings and intended meanings was achieved, enabling me to more easily interpret their view of their experiences.

My ability to interpret the views of my participants was considered carefully throughout the design of the study. As such, double-hermeneutics featured heavily in the choice of data

collection method, as semi-structured interviews enable the researcher to reach a deeper understanding of their participants (I was able to seek clarifications, examples, and delve deeper into the issues as perceived by participants through probing). Double-hermeneutics also featured heavily in the design of the interview schedule. Care was taken to ensure that the questions were specific enough to the topic to guide the interview in the right direction, without being too prescriptive, so that participants were free to discuss what they thought was relevant. A series of optional probing questions were also devised to enable me to hone in on the desired topic or underlying concept being communicated by the participant. For instance, one of the structured questions was “please describe what changes could be made to make your working environment more suited to your sensory needs”. This question was designed to make the participant consider what are the key difficulties and ideal solutions for workplaces, which would shed light on what they usually struggle with at work. However, it was left specific enough (i.e. possible changes to their work environment) that the question was targeted at the right topic, yet clearly open enough that the participant could craft a detailed response longer than 10 words. As a result, participants typically gave relevant, adequately detailed responses, which were easy for me to interpret, or could be explored further where needed.

### 15. Reflexive Account

My family has a history of autism. My mother is autistic, and she found out when I was a teenager. I grew up watching my mother struggle because of it, both socially and occupationally. She would get a job, and within a year or so would find herself unemployed, either because of workplace bullying, or a lack of adequate support. For instance, in one job, the noise was too much for her, leaving her struggling to cope. Her performance was always objectively good as she would always meet and even surpass targets and obtain bonuses as a result, but it was the social or sensory elements which caused her difficulty. As a result, I became interested in learning more about autism, and what can be done to improve quality of life for autistic adults, because clearly the difficulties can extend beyond childhood. Thus, based on my mother’s experiences, I was aware of sensory and social difficulties in the workplace, and issues around stress and performance. My mother’s experiences influenced me from the outset, as they led me to believe that these topics were important to explore, which was confirmed in the literature review. As a result, these issues influenced the construction of my interview schedule, and the attention paid to these issues during analysis. It is therefore possible that these issues were consequently highlighted more than they might have been had I not been actively looking for them. However, if this were the case, and these issues were not important aspects of working experiences, one would expect for participants to have little to say on the matter or even explicitly state that they were unaffected by these

issues. Indeed, Eric does report that he no longer experiences difficulty as a result of sensory sensitivity, and Michael reports experiencing little difficulty at present given how he manages his difficulty. However, all report this to have been an issue in the past (Duncan with the noises outside his workplace, Colin with regards to light from computer monitors, Michael regarding the loud music in the store, Eric's discussion about training himself to be better around loud noise), and most recount specific instances where it made working difficult for them, demonstrating the relevance of this issue. Thus, while it is possible that this topic was over-attended to due to my own personal biases, there is substantial enough evidence that this theme would have been found anyway.

Ultimately, this research project has been a learning process, and has taught me plenty as a researcher. Prior to this project, quantitative methods were my main area of experience, and I had little awareness of qualitative methods or their value. By completing a literature review and conducting a research project using these methods, I have gained an appreciation of the value of such methods. I have found that there is much that can be learned from qualitative methods that simply cannot be achieved through quantitative methods. Quantitative findings rely on tests which explore the patterns across the data, the data trends, the average scores or values, often with little consideration for the vast array of individual differences. Thus quantitative methods are more likely to tell us about the statistically average person, their traits, behaviours, tendencies. However, they do not tell us much about the individuals within the sample, and what the variations between people mean, or what these differences result from.

Qualitative methods enable researchers to better explore in detail certain facets of the person or their experience which often cannot be learned any other way, but which tell us much more about that individual phenomenon. In this case, qualitative methods did more than simply tell us which stimuli were aversive, they told us that sometimes the same stimuli that can be both aversive and enjoyable, and that sensitivity can be useful in employment. This level of detail regarding the complexity of sensory experiences could not have been captured through other methods. Thus I have learned first-hand the value of qualitative methods.

More specifically, I have also learned the value of interpretative phenomenological methods. In my experience, they allow the researcher to obtain great detail and work towards gaining an understanding of a topic, without denying the usefulness and validity of the role of the researcher, which is part of the value of the double-hermeneutic. By nature, the researcher will bring experience and biases to the project, to the interview, and to the data. Such bias, in both qualitative and quantitative research, cannot be avoided, because it is this bias which motivates the research to be conducted. It heavily influences how the data is interpreted,

which in the case of exploring experiences, (particularly in new areas of research), is useful in double-hermeneutic studies as it gives the researcher something to look for. The personal experience of the researcher gives them a frame of reference, or a starting point.

In this case, my awareness of some of the issues faced by my mother gave me an idea of the topics that might be relevant and interesting to explore. This helped immeasurably, because it helped me to make decisions during the study design process. For instance, being aware of some of the areas which might be relevant enabled me to look for confirmation or contradiction in the literature. Upon confirming which issues were relevant and important, I was then able to use these to devise my interview schedule, and influence my understanding of participants' perceptions regarding their experiences. My personal biases, confirmed by the literature, have therefore been invaluable throughout my research, and have contributed heavily to the approach taken. These biases will also have influenced the way that the data was interpreted, thus affecting the double-hermeneutic, impacting on the interpretation of how participants interpret their experiences. Indeed, this is the same for any research project. More realist approaches attempt to minimise the impact of the researcher through objective statistical testing. However, interpretative phenomenology involves acknowledging, accepting, even valuing the role of the researcher and their biases. Ultimately, no research can be done without a researcher, so I believe that researchers will always have a role and therefore will influence the research process and findings, as has been the case for me.

## 16. Limitations

As with any method, a number of disadvantages and limitations exist. Any interview or other method of data collection is prone to technical errors which might lead to the loss of data, or interference with the collection of the data itself. This study was no exception to this. One disadvantage that was specific to this type of study is that one hour of typed conversation may give far less data than an hour of face-to-face interviewing. So while clarity of intended meanings may be gained by the synchronous communication method and the semi-structured interview design, the level of depth and detail gained may be lower. However, this issue, which is inherent with this method, may also be a strength of it. If typing takes longer than speaking, then having to type responses will force people to consider their responses before and during typing. This may have aided participants in crafting their responses coherently, in a way that verbal speech prohibits. When communicating verbally, colloquialisms, poor grammar, fragmented sentences or unclear phrasing is common, especially for those who respond quickly. This can result in the need for additional clarification by the listener. Typed responses enable the speaker to review and edit their response as they go, allowing them to choose more precise and accurate wording. Indeed, this is something that Gillespie-Lynch et al. (2014)



found to be a benefit of electronic, asynchronous communication. For those who may experience difficulty with communication, having the ability to do this is quite useful in increasing the precision and clarity of their communications. Thus, while there might be less talk in one hour of typed communication compared to verbal, it is possible that what is said is of higher quality, thereby compensating for this issue.

## 17. Future Research

This study set out to explore the experiences of males with autism in the workplace, and this was achieved. This study establishes solid foundations for future research on workplace experiences. For instance, one avenue for future research is reasonable adjustments. This study identified some key areas of difficulty for these participants, including sensory sensitivities, clarity of instructions and social interaction, and adjustments that can be made. Future studies could build on this. For instance, by exploring, on a larger scale, what autistic workers might benefit from, and what they have already benefitted from, in terms of reasonable adjustments would be helpful in identifying exactly how individuals on the Spectrum can be supported, and what adjustments have been effective in the past. Attention should be paid to known difficulties, such as those identified in this and other studies (Jones et al., 2003; Robertson & Simmons, 2015; Trembath et al., 2012). Such studies should also allow for exploration of as-yet unknown difficulties, so a semi-structured approach would be of most use. Furthermore, participants' manner of speech in terms of the way that they made sense of their experiences implied alignment to either the Social or Medical Model of Disability. In any study of workplace adjustments, it might be of interest to explore participants' views on how they attribute responsibility for effective workplace participation, as this might influence how workers see workplace adjustments and how they cope, as it did in this study. This in turn might impact upon accessing available supports and disclosure. For instance, if they feel that it is their own responsibility to manage their difficulties, they might choose not to disclose or seek support.

Similarly, a study of the nature, experience and circumstances preceding disclosure would also be of worth. If autistic people are to be encouraged to work, particularly those who may not be deemed 'highly functioning', disclosure is likely to be a necessary step, to enable them to seek the support they need to maintain their employment. Thus, exploring what makes autistic people feel comfortable disclosing would be useful in determining how exactly employers can create a safe working environment which encourages employees to disclose. Certainly, such a study could be beneficial to workers of various disabilities, so this could include individuals with various impairments and diagnosed conditions. Again, exploring views around

responsibility for disability, and the Social and Medical Models for Disability might shed some light on how participants make decisions regarding disclosure.

## 18. Conclusion

Thus, this research adds to the pool of knowledge on the subject of autism and employment. While studies exist which investigate topics related to employment in isolation, this study is among the few to cover multiple of these topics together. This has allowed the relationships between these issues to be investigated, and insights have been gained as a result. In addition, an innovative and relatively new, uncommon method was used to learn of these participants' experiences, and found to be a useful tool for research using autistic adult participants.

Furthermore, this study is among the first to explore workplace experiences from the perspective of autistic people, and therefore offers unique insights into how they make sense of this phenomenon. Through this study, it has been learned what sorts of reasonable adjustments can be made in terms of lighting, noise levels, working arrangements and the importance of autonomy, control and clarity of instructions given to staff. It was also found that sensory sensitivity is not always experienced as an impairment, but rather in some cases as a source of pleasure or a skill. Additionally, it was learned that coping behaviours can extend beyond coping to masking, which may effectively hide any difficulties from others, but which can cause further problems. Encouraging acceptance and awareness in the workplace may reduce the need for masking, depending on whether the individual chooses to disclose. Disclosure should be considered carefully, as from these participants' perspectives, disclosure does not always result in positive consequences. Views on both disclosure and coping may also be associated with the way these individuals make sense of their impairment, as this study showed that the Medical and Social Models may influence decisions on methods used to cope (i.e. control, avoidance or masking). Future efforts should work towards improving workplace functioning and relationships. This may be done by promoting awareness and acceptance of autistic people in working environments, and by improving the supports that are available to autistic workers, particularly in relation to sensory aspects of the workplace environment.

## Appendices

## Appendix 1 – Study Advert

### Advert for my study - “The Experience of Adults with Autism in the Workplace”

Do you have an Autism Spectrum Condition?

Have you ever been employed?

If yes, then we want you to share your experiences!

My name is Leah Derham-Boyce and I am working on a Master’s Degree at the University of Central Lancashire. My thesis is entitled “The Experience of Men with Autism in the Workplace”. For this I am investigating the perspectives of men with autism in relation to their emotional states (such as anxiety), environmental stressors (like noise or lighting levels), job performance (how well you think you perform), and professional and personal relationships (e.g. the quality of your friendships with work colleagues and your line manager or boss).

I would like male volunteers of age 18+ to participate in an e-interview. The interview will be conducted via Adobe Connect, and will be typed (no speaking, no microphone or camera). You just need access to a computer and the internet. The whole e-interview should take approximately an hour though it can be done in smaller sessions over different days if preferred.

To participate:

- You must have a formal diagnosis of an Autism Spectrum Condition (including Asperger’s Syndrome),
- Your first language must be English,
- You must be currently or previously have been employed (either in full-time paid employment or part-time paid employment).

Note that participation is entirely voluntary.

If you are interested in participating, please email me to find out more about what is involved in this. I will send you a full information sheet and consent form to review so that you can decide whether you would like to participate. If you decide that you would like to participate, I will arrange an e-interview with you at a time and date which is most convenient for you.

To find out about participating email me at:

[LDerham@uclan.ac.uk](mailto:LDerham@uclan.ac.uk)

Alternatively you can contact my supervisor for more information at:

Email: [CSullivan@uclan.ac.uk](mailto:CSullivan@uclan.ac.uk)

Telephone: +44(0)1772 893420

Address: School of Psychology, Darwin Building (DB216), University of Central Lancashire, Preston, UK, PR1 2HE.

Appendix 2 – Participant Information Sheet  
“The Experience of Men with Autism in the Workplace” - Information Sheet

My name is Leah Derham-Boyce, and I am conducting a study on adult autism in the workplace for my Master’s thesis with the University of Central Lancashire. I am working on this with the support of my supervisors Cath Sullivan, Lynda Holyoak who are lecturers at UCLan, and Fiona Wilks-Riley who is an external advisor. Dr Wilks-Riley works as a Lecturer in the School of Psychology at UCLan and also as a Consultant and Forensic Psychologist. She is employed in this capacity at Alpha Hospitals, Bury; Care Quality Commission, NHS; and in private practice.

I am looking for people to volunteer to be interviewed about their experiences of autism and the workplace. You are reminded that to participate you must:

- Be 18 years of age or older
- Be male
- Have a formal diagnosis of an Autism Spectrum Condition (including Asperger's Syndrome)
- Have previously been employed or be currently employed
- Speak English as your first language
- Have access to a computer and the internet

The questions participants will be asked centre around four topics: work environment; stressors and emotions; job performance; and, relationships with others. If you decide to participate, I hope to learn more about:

- What the environment is like and how you respond to this environment, (e.g. light levels, crowding and their impacts)
- What stressors or difficulties may exist (e.g. noise levels) and how you managed or coped with such stressors
- What your job performance and satisfaction is like (e.g. job type, how much you enjoy your job and how well you think you do your job)
- What relationships with others in this environment are like and how this affects your other relationships.

Participating in my study involves being interviewed electronically. Participants will be asked to communicate solely by typing into the chat program called Adobe Connect. It is a program similar to Skype or MSN messenger. You will not need to download anything, as this is a program which uses your internet browser only (such as Internet Explorer, Google

Chrome or Mozilla Firefox). If you participate you will be sent a link via email which will take you into a private chatroom with the researcher (myself). The chatroom is only accessible by this link, so no-one else will be able to access or view the interview. There will be no use of camera or voice recording. Participants will not be interviewed face-to-face or required to meet the interviewer. The e-interview should take approximately an hour to complete.

Please note that study is in no way linked to your employer.

If you think that these issues may be distressing for you to discuss, please think carefully about participating. If you choose to participate, you do not have to discuss any topics that you do not want to. If at any time during the interview(s) you decide that you do not want to participate, for whatever reason, you may stop the interview by telling the researcher. You may also withdraw your data after the interviews at any time up to two weeks following the interview(s).

If you wish to participate, please be aware that this will involve allowing me to record your responses, and quote you in the reports that I write based on the interview data. These reports will be publicly available. However, your data will be anonymised i.e. your name will not be used and all information you give which could be used to uncover your identity (or that of your employer or company) will be removed from any quotes that I use in publicly available documents. For example if you mention your employer by name, the employer's name will be removed. All details that could be used to identify you or your company will be removed. (Alternatively, as a way for you to remain anonymous throughout the interview, you may choose to use a pseudonym or false name for yourself, your employer and/or your company, though this is not required).

Anonymising the data in this way will take place two weeks after the interview, so you have up to two weeks to withdraw your data. After this, it will not be possible to withdraw your data.

If you do decide to withdraw, your data will be removed and will not be used. All data is stored exclusively on UCLan's servers. The actual text recordings and transcripts (original and anonymised) will only be seen by me and by people at the University who have a legitimate need to see them (for example those people supervising or marking my work).

Finally, your contact details will be kept until the end of the project (estimated December 2015), just in case of exceptional circumstances and we need to contact you. It is highly unlikely that you will be contacted at

all though. If you would not like to be contacted in any circumstances, please indicate this during the interview.

If you have been affected by any of the issues raised in this study you can contact the following for support:

- Get Connected is a helpline especially for people under 25 who need someone to talk to about their problems. Call them on 0808 808 4994 or <http://www.getconnected.org.uk/>
- MIND is a mental health charity that aims to support people and help them learn about their rights and treatments. Call them on 0300 123 3393 or see <http://www.mind.org.uk/>
- The National Autistic Society are a charity for those with autism or Asperger's Syndrome and their family. They offer support, information and conduct cutting edge research. Call them on 0808 800 4104 or see <http://www.autism.org.uk/>.
- The National Careers Service offer a helpline for you to get support and information about careers and courses. They give advice, or tutoring for C.V.s, cover letters, job applications etcetera. Call them on 0800 100 900 or see <https://nationalcareersservice.direct.gov.uk/Pages/Home.aspx>
- The Samaritans are a registered charity which aims to support people by giving them someone to talk to. Call them on 08457 90 90 90 or see <http://www.samaritans.org/>

If you would like to contact me or my supervisors for more information, their contact details are:

Me, Leah Derham-Boyce – [Lderham@uclan.ac.uk](mailto:Lderham@uclan.ac.uk)

Director of Studies, Cath Sullivan – [Csullivan@uclan.ac.uk](mailto:Csullivan@uclan.ac.uk); 01772 893420

Supervisor, Lynda Holyoak – [Lholyoak@uclan.ac.uk](mailto:Lholyoak@uclan.ac.uk); 01772 893429

External Advisor, Fiona Wilks-Riley - [fiona@wilks-riley.freemove.co.uk](mailto:fiona@wilks-riley.freemove.co.uk)

Or you may write to any of us via the University:

The School of Psychology, Darwin Building' University of Central  
Lancashire

Fylde Rd

Preston, Lancashire

PR1 2HE

If you wish to complain about any aspect of this research, or discuss it with somebody who is not directly involved, you can contact the University Officer for Ethics at:

[OfficerForEthics@uclan.ac.uk](mailto:OfficerForEthics@uclan.ac.uk)

Note: the information sheet featured a running header which said:  
“Please keep this information sheet to hand during the interview if you choose to participate.”



### Appendix 3 - Consent Form

Thank you for agreeing to participate in this study titled "The Experience of Men with Autism in the Workplace". This study aims to investigate what it is like for you to be an employed adult with autism, in terms of your emotions, job performance and relationships.

You are reminded that to participate you must:

- Be 18 years of age or older
- Be male
- Have a formal diagnosis of an Autism Spectrum Condition
- Have previously been employed or be currently employed
- Speak English as your first language

If for any reason you would not like to participate, or you do not meet these criteria, you may withdraw now by telling the researcher. You also have the right to withdraw your data (the content of the interview) up to 2 weeks after the interview. After that time you will no longer be able to withdraw.

If you would still like to participate, please sign below. To do this, just type your name in the field provided. (This is instead of writing your signature by hand.)

By signing this form you are agreeing to be interviewed, and for the things you tell the researcher during the interview to be recorded and quoted (anonymously) in this study's report.

Participant Name:

Participant Signed:

Date:

Researcher Name: Leah Derham-Boyce

Researcher Signed: Lderham-Boyce

Date: 17.3.2015

## Appendix 4 - Interview Schedule

Good morning/afternoon/evening, thank you for arranging to talk with me.

Before we start can I confirm that you have read the information sheet and signed the consent form?

(Await reply and respond accordingly).

I would like to reiterate that by consenting to participate in this interview, you are giving me permission to record your responses, use them as part of my research for my Masters' and any reports or papers I write as a result, and quote you (anonymously). I would also like to reiterate that your participation is completely voluntary, you do not have to participate. You do not have to discuss anything you do not want to and you have the right to withdraw your responses and data for up to 2 weeks from now. Are you happy to continue on this basis?

(Await reply and respond accordingly).

Thank you. Do you have any questions before we start?

(Await reply and respond accordingly).

OK. Let's begin.

Please give a brief description of your previous employment history. Please explain what each role was like, and what it involved. Potential prompts if participant is uncertain of what to talk about:

- *We will talk about your current job later. Please tell me about a previous job.*
- *What did you do?*
- *What was that like?*
- *How did it/that make you feel?*
- *What happened next?*
- *What did you like about your job?*
- *What did you not like about your job?*
- *What makes being at work harder?*
- *What makes being at work easier?*

The following four sections relate to stressors and coping, environment, job performance and satisfaction and relationships with others. Please answer these questions in relation to your current or most recent job role.

1. Things that make you feel stressed or anxious, and how you cope:

- Describe 3 difficulties you face at work and how you deal with them.
  - *Rephrase: for example, break times, travel, the nature of the work.*
  - *Prompts: OK and how did you deal with that? What did you do to manage or solve the problem? Can you tell me about another difficult which made you anxious or stressed?*

2. Environment and the senses:

- Sensory sensitivity is often experienced by those on the Autism Spectrum, and involves a person being either hypo- or hyper-sensitive to stimuli from one (or more) of the senses. For instance certain noises or frequencies feeling painfully jarring, or making

you feel uncomfortable/anxious/stressed. Please describe whether sensory sensitivity has impacted on your work-life and if so, how.

- *[Rephrases/prompts:*
- *How does sensory sensitivity affect you while you're at work?*
- *Sensory sensitivity in relation to those with autism spectrum disorders is generally defined as experiencing information received from the environment more intensely than those without autism spectrum disorders. For example, some people with autism spectrum disorders experience sound more intensely, and as a result can become overwhelmed, anxious, frustrated or emotional. This may cause them to find loud environments difficult to be in. Therefore, this question aims to find out what sense-related difficulties you may or may not experience while you are at work. Please can you tell me about how this might apply to you and your workplace?*
- *In other words, do you ever struggle with excessive or insufficient noise or light levels, odours, the way objects feel, etc. at work? If so, in what way? If not, why not?*
- *What makes it better or worse?*
- *Please describe what features of your working environment may have caused difficulties relating to any sensory sensitivity you may have experienced. For example, overly bright lighting, reduced noised levels, textures of materials or furniture.]*
- Please describe what changes could be made to make your working environment more suited to your sensory needs.

### 3. Job performance and contributors

- What do you currently do for a living? What does this involve? – excluded as repetition
- Do you enjoy your job?
  - *Prompt: If not, why?*
  - *Prompt: Is there a way around this problem? (Vary according to job type and reason given for not enjoying)*
  - *Prompt: What do you like/not like about it?*
  - *Prompt: What made you think/feel that?*
- Do you feel you are paid fairly for your work?
  - *Prompt: If not, why?*
  - *Further prompts as needed*
- How well do you think you perform at your job?
  - *Rephrase: do you think that you are good at your job?*
  - *Rephrase: are you good at your job? How good?*
  - *Prompt: why? Or why not?*

### 4. Relationships with others

- Describe your relationship with:
  - Your colleagues
  - Your boss
  - Your friends and acquaintances
  - Your partner (if you have one)
  - Your family

*[Prompts for these questions might include:*

- *What makes you think/feel this way?*
- *How do they make you feel?*
- *How do you get on?*
- *What do you have in common?*
- *What differences do you have?*
- *What do you bond over?*
- *What makes you clash/argue?]*

Do you have any other comments?

Lastly, please describe 3 positive experiences you've had in your most recent workplace.

(Follow up questions to be determined during the interview).

Thank you. Now I would like to know some more general demographic information about you:

- What is your age?
- Please describe your level of education
- Do you have any other conditions or disabilities which may have impacted on your working experiences?
- Do you have any dependents? If so, how many and what age?
- Are you willing to allow me to contact you before the project ends, if necessary? This will only be in unusual or exceptional circumstances.

OK. That is the end of all of my questions. Thank you for participating in this study by talking with me today. I appreciate it.

I would just like to remind you that everything we have discussed today has been discussed in confidence. I will use the information you have given in my Master's thesis, but I will not share your identity. Anything you have said which could be used to identify you, your employer or your company will be anonymised. If you decide that you would like to withdraw some/all of the information that you have provided today, you may do so up to 2 weeks following this interview by contacting me by email.

Do you still have your information sheet? I can send you another if you like.

Do you have any further questions?

(Await reply and respond accordingly).

Thank you for your time.

NOTE: Past tense used where relevant, and repetitive questions removed.

Appendix 5 - Ethical Approval Letter



26<sup>th</sup> February 2015

Cath Sullivan/Leah Derham  
School of Psychology  
University of Central Lancashire

Dear Cath/Leah,

Re: PSYSOC Ethics Committee Application Unique Reference Number: PSYSOC 178

The PSYSOCS ethics committee has granted approval of your proposal application '**The experience of adults with autism in the workplace**'. Approval is granted up to the end of project date\* or for 5 years from the date of this letter, whichever is the longer. It is your responsibility to ensure that

- the project is carried out in line with the information provided in the forms you have submitted
- you regularly re-consider the ethical issues that may be raised in generating and analysing your data
- any proposed amendments/changes to the project are raised with, and approved, by Committee
- you notify [roffice@uclan.ac.uk](mailto:roffice@uclan.ac.uk) if the end date changes or the project does not start
- serious adverse events that occur from the project are reported to Committee
- a closure report is submitted to complete the ethics governance procedures (Existing paperwork can be used for this purposes e.g. funder's end of grant report; abstract for student award or NRES final report. If none of these are available use [e-Ethics Closure Report Proforma](#)).

Additionally, PSYSOCS ethics committee has listed the following recommendation(s) which it would prefer to be addressed. Please note, however, that the above decision will not be affected should you decide not to address any of these recommendation(s).

Should you decide to make any of these recommended amendments, please forward the amended documentation to [roffice@uclan.ac.uk](mailto:roffice@uclan.ac.uk) for its records and indicate, by completing the attached grid, which recommendations you have adopted. Please do not resubmit any documentation which you have **not** amended.

Yours sincerely,



Cath Larkins

Deputy Vice-Chair

PSYSOC Ethics Committee

\* for research degree students this will be the final lapse date

*NB - Ethical approval is contingent on any health and safety checklists having been completed, and necessary approvals as a result of gained.*

### Appendix 6 - Full List of Sub-Themes

- Awareness (of abilities and tendencies which relate to autism. Self-awareness of these things and others' awareness of these things)
- Receiving instructions
- Receiving criticism
- Low level jobs and pay
- Trust and secrecy in the supervisor/employee relationship
- Being underestimated or undervalued by supervisors and colleagues
- Unreasonable demands and mistreatment
- Unusual dress
- The value of control and autonomy
- Resistance to others' ways of doing things
- Unintentionally upsetting others
- Maintaining focus
- Sensitivity to sound and light (most common), and to smell, taste and temperature (least common)
- Causes of anxiety
- Coping with anxiety and sensory sensitivity
- Diagnosis and disclosure
- Varying quality of relationships with parents
- Distance in colleague relationships
- Difficulty in colleague relationships
- Social isolation in and out of work
- Varying quality of romantic relationships
- Differing emotional needs in romantic relationships

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