Building Employability: An Exploratory Study of the Experiences and Perceptions of Autistic Higher Education Students in Preparing for Graduate Work

Laura Dean

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Abstract

Autistic graduates have significantly poorer employment rates than both their disabled and non-disabled peers. Despite this there is little research about the lived experiences of autistic people, particularly those who do not have an associated learning disability, because autism research tends to be from a clinical tradition and therefore a positivist perspective. This exploratory study investigated a small group of autistic higher education students’ perceptions of employability, experiences of employability development and what they felt universities could do to assist them to achieve meaningful employment post-graduation. The study used a mixed methods approach and an initial questionnaire used both qualitative and quantitative questions to establish contextual information and to act as a recruitment tool for the interview phase of the research. In this phase autistic penultimate year students from a Russell Group university in the North of England took part in semi-structured interviews regarding their experiences. Similar interviews were then conducted with neurotypical students matched for gender, age and subject of study to establish which elements of the responses could be considered specific to autistic students. Thematic analysis was used to interpret the qualitative data and six main themes were identified. These looked at the intersection of autistic identity with gender; the adjustments made during study and work; personal identity; future plans; impairment effect related issues and the framework required for support.

The discussion drew the six themes into five analytic categories to establish theoretical frameworks for the concepts covered. These five looked at: impacts of historical treatment on current behaviours; impairment effect related issues; how identity was managed, and disclosure was undertaken; the effects of a ‘hidden’ curriculum and, what would be required to develop a more effective support system. Sociological and psychological theory were used to understand these themes including Bourdieusian concepts of capital and maintenance of the status quo, Social Identity theory, Feminist theory and Social Constructivism. Recommendations for service provision looks at the theoretical models used for framing careers and employability interventions. It is recommended chaos and strength-based approaches are used for career counselling. Recommendations for future research consider the need to foreground the intersectionality of identity.

Key words: *autism spectrum disorder, Asperger’s syndrome, higher education, employability, careers, recruitment, ASC*

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**List of Abbreviations Used**

AGCAS – Association of Graduate Careers Advisory Services

ASC – autistic spectrum condition

ASD - autistic spectrum disorder

CBI – Confederation of British Industry

DDSS – Disability and Dyslexia Support Service

DLO – Disability Liaison Officer

DSM-IV – Diagnostic and Statistical Manual for Mental Health (4th Edition)

DSM-5 – Diagnostic and Statistical Manual for Mental Health (5th Edition)

HE – higher education

HEI – higher education institutions

HESA – Higher Education Statistics Agency

NAS – National Autistic Society

NUS- National Union of Students

TUC – Trade Union Congress

# Chapter 1: Introduction and Theoretical Framework

## Introduction and Definitions

This study explores why autistic people’s employment outcomes are poorer than both their disabled and non-disabled peers. The purpose of this research is to analyse autistic students’ perceptions of employability and their university-led practical experiences and preparations to ensure they are able to find meaningful employment upon graduation. It is anticipated that the findings will provide new insights into the experiences and treatment of autistic higher education students as well as providing recommendations to higher education services. The fieldwork was conducted using mixed methods including surveys and semi-structured interviews with both autistic and non-autistic students. Interviews were conducted with support and academic staff at their institution in order to contextualise data.

Key terms used in this thesis include autism and employability. Definitions and a discussion about nomenclature employed is included to explain language used in this study. Next, background and context about autism research is provided, leading to the problem statement, statement of purpose and associated research questions. The researcher’s positionality is then explored with statements about researcher’s perspectives and assumptions. To conclude this introduction a brief descriptor of the remainder of the thesis is provided to aid reader navigation.

### **1.1.1 Defining Autism**

The focus now turns to definitions. Use of terminology from British and non-British nations is explored because most autism research takes place within the USA and Australia. Therefore research from these places will be considered in this study. The most widely used diagnostic manual worldwide is the Diagnostic and Statistical Manual of Mental Disorders (DSM) produced by the American Psychiatric Association. Systems of diagnosis and definitions have changed several times since its original creation. The changes relevant to this study are those which have occurred within the lifetime of potential participants of this study. These are reflected in the 2000 and 2013 versions of the DSM, which are DSM-IV and DSM-5 respectively[[1]](#footnote-1). It is the DSM-IV which led to the medical terminology of Autistic Spectrum Disorder (ASD) being used internationally. The condition falls within the wider bracket of Pervasive Developmental Disorder (PDD). ASD has been further defined as one of four subtypes dependent on presence of developmental language delay and intellectual disability. These four were: Asperger Syndrome, Childhood Autism/ Autistic Disorder, Atypical Autism, and PDD-unspecified. Diagnosis was made by looking at three domains: impaired social interaction, abnormal communication, and restricted and repetitive behaviours and interests often referred to as the ‘triad of impairments’ (Wing and Gould, 1979). In the UK diagnosis is made by a panel of experts from different professional areas, typically, a paediatrician, a clinical psychologist, and a speech therapist, as a minimum. Many countries allow diagnosis with input from only one medical professional. For example, in the US a general medical doctor can diagnose. There is some evidence that in the USA Autistic Spectrum Disorder (ASD) is used as a ‘holding label’ to access resources until further investigations are conducted. For example, Judy Rapoport, former Head of Child Psychiatry at the National Institute of Mental Health, is quoted as saying, in relation to autism, ‘I am incredibly disciplined in the diagnostic classifications in my research but in my private practice, I'll call a kid a zebra if it will get him the educational services I think he needs’ (Silberman, 2015, p423-4).

This diagnostic system was in place until 2013 when the fifth version of the Diagnostic and Statistical Manual (DSM-5) was released. Therefore, for the purposes of this study, participants with a diagnosis are likely to have received it under the older criteria, as most diagnoses are performed in childhood. From DSM-5 onwards the criteria changed. For diagnosis, individuals have to demonstrate both delayed or atypical social interaction, and delayed or atypical communication. There must also be the presence of repetitive or restricted interests and activities (American Psychiatric Association, 2013). The subtle difference is that DSM-IV required delayed or atypical social interaction ***or***delayed or atypical communication. However, it is likely that most pre-2013 diagnoses would still stand: Silberman (2015) describes the work of Volkman (n.d.) which shows clinicians always used ‘and’ rather than ‘or’ to diagnose and that under the old criteria about 75% of those who did not get a diagnosis should have done under the terminology of the DSM, at that time. An overview of the effects of the new categories argues it has not led to the feared loss of services for those with a diagnosis (Zeldovich et al., 2019). However those with high cognitive ability are now less likely to be diagnosed.

Autism diagnosis rates in the West are explored fully in chapter two. The US Centre for Disease Control and Prevention (2015) reports a diagnosis rate of 1/68 children in 2015. However, the figure of diagnosed autistics is lower in the UK and, in high functioning autistic people the condition is often diagnosed later, even into late adulthood. Therefore, this study includes participants who believe themselves to be autistic but do not yet have a diagnosis. In this study anyone receiving a diagnosis on the Autism Spectrum with any condition, or who believes themselves to be on the Autistic Spectrum is described using the same nomenclature: autistic person/student/participant. This is in line with both the current DSM-5 diagnostic criteria and with other studies in the field (e.g. Ranson and Byrne, 2014). Another change under DSM-5 is that the specific condition Asperger’s Syndrome was removed. People previously receiving this diagnosis would now receive the generic diagnosis of Autism. The specifics of this nomenclature are now considered.

### 1.1.2 Nomenclature Used

A range of terms are used, sometimes interchangeably, to describe people on the autism spectrum. Some are, or have been, derived from diagnostic categories such as High Functioning Autism or Asperger’s Syndrome. It should be noted that the diagnostic category descriptor was Autistic Spectrum Disorder until 2013. In 2000, autism researcher Simon Baron-Cohen, suggested removing the value element to the descriptor, replacing ‘disorder’ with ‘condition’. This change has gained traction and it is now unusual to see ASD as a descriptor with ASC (Autistic Spectrum Condition) in its place. Therefore, ASC or autism will be used in this thesis as context-appropriate.

The development of these terms into descriptors for individuals is a matter of contention in the autistic community and this point will be revisited in some depth in chapter five in the context of both Disability Theory and Social Identity Theory. The point of this discussion is to explain terminology in use throughout this thesis for readers unfamiliar with positive language arguments. Standard grammatical structure in UK English is to describe things which are negative following the noun. Examples include ‘student with cancer’, ‘boy with broken leg’ rather than ‘cancerous student’ or ‘broken-legged boy’. The rationale, when made explicit, is usually that saying cancerous student implies having cancer is a central part of their identity and/or the most important thing about them. Because it is negative this is seen as bad form. The same is not said about positive adjectives. They tend to be used before the noun. Examples include ‘clever student’; ‘beautiful boy’ rather than ‘student who is clever’ or ‘boy who has beauty’. To turn to autism, preferred language by those who see the condition as mostly or purely negative is to use ‘people first’ language, i.e. ‘person with autism’, ‘student with Asperger’s Syndrome’. In contrast Kenny et al.’s (2015) survey of the autistic community found that whilst professionals preferred ‘person with autism,’ individuals with the condition preferred ‘autistic person’ as a descriptor. The reason given was in relation to whether the term implied deficit or not: the professionals’ version did; the autistic people’s version did not. Many autistic people would go further and describe themselves as an autistic, much in the same way someone might describe themselves as a brunette or as a blonde rather than a blonde person. There was not consensus though and it is worth noting autistic adults were most likely to endorse the use of ‘autistic’ (61%); friends and family members slightly less so (52%); and professionals much less so (38%). In line with this Kapp et al. (2012) found that the more people aligned to the idea of neurodiversity, the more likely they are to prefer this descriptor-first language. Therefore, descriptor-first language will be used in this thesis.

### 1.1.3 Defining Employability

‘Employability’ has no universally recognised definition. The term will be problematized during this study as the concept is explored with participants. However, it is still beneficial to start with some discussion of how the term is currently used as this forms the basis for the employability interventions which participants have access to. Most definitions explicitly mention employability involving ‘an ability to secure and retain employment’ (Department of Education Employment and Training, 2000, p37). Being employed is, in common language, used as a measure of employability. This is demonstrated by the use of the term employability by universities when advertising the employment data gathered through the Destinations of Leavers of Higher Education Survey (DLHE), accessible through each university’s website and powered by the Unistats data management system[[2]](#footnote-2). This DLHE data is widely used as a comparator by prospective students as well as organisations creating judgements on HEI’s individual value and subsequent league table placement. Theorists and researchers do not conflate employment and employability, recognising them as related but dependent on different contextual factors. Yorke argues ‘employability implies something about the capacity of the graduate to function in a job and is not to be confused with the acquisition of a job, whether a ‘graduate job’ or otherwise’ (2006, p6). Fugate et al. put it into more practical terms as ‘one’s ability to identify and realise career opportunities’ (2004, p23). These definitions imply employability is an acquired skill and the synonyms used for employability emphasise this component. The Commission for Employment and Skills (UKCES, 2009) name some synonyms: core skills, key skills, essential skills, functional skills, skills for life, generic skills and enterprise skills. Mayer (1992) had previously listed some others: key competencies, transferable skills, underpinning skills.

This notion of employability as the acquisition or ownership of specific skills underpins many definitions, particularly those used in practice. For example, the Confederation of British Industry (CBI) definition created **after extensive collaboration with businesses states ‘[Employability is] a set of attributes, skills and knowledge’ (2009, p8).** Their previous definition (CBI, 2007) drew out specific skills notably: positive attitude; self-management; teamworking; business and customer awareness; problem solving; communication and literacy; application of numeracy; and application of information technology. T**he** UKCES’s (2009) definition built on these adding in personal skills which involves elements such as self-management. The UK Sector Skills Councils adopted the Conference Board of Canada’s (2000) definition, which includes attitudinal elements such as being responsible, adaptable and learning continuously.

The notion of adaptability and responsiveness features more often in academic definitions. For example, Butterwick and Benjamin highlight the need to ‘adapt to rapidly changing work environments and requirements including emerging technologies (2006, p302). That is not to say practice definitions never mention this. The CBI had earlier recognised the need for adaptability, commenting on [meeting] ‘the changing needs of employers and customers’ (1999, p1). The difference between practice and academic definitions is that academic definitions draw out the notion of employability as a personal capacity rather than a series of skills. Yorke describes it as ‘a set of achievements – skills, understandings and personal attributes – that makes graduates more likely to gain employment and be successful in their chosen occupations’ (2001, p8). Forrier and Sels (2003) acknowledge the multi-faceted nature of employability and use the metaphor of a complex mosaic. Other theorists refer to skills and job knowledge (Hillage and Pollard, 1998); ability to rapidly learn and develop (Lane et al., 2000); and personal attributes (Moreland, 2006).

UKCES (2009) argue that although definitions vary there are sufficient similarities to ensure agreement on the broad concept. At one level similar skills, attributes and abilities are described. However, it is in the detail of presentation that crucial differences are revealed. Individuals’ needs and desires are absent from practical definitions. Documents to inform practitioners talk about a specific type of success, workplace efficacy, and emphasise the individuals’ responsibility in relation to that success. For example, the joint CBI and National Union of Students (NUS) define employability as a ‘set of attributes, skills and knowledge that all labour market participants ***should*** possess to ensure that they have the capability to be effective in the workplace – to the benefit of themselves, their employer and the wider economy’ (italics added) (CBI/NUS, 2011, p8). Success is about workplace productivity in this definition. Moreland’s guide for HE practitioners presents a muted version of the same principle as he describes ‘A set of skills, knowledge and personal attributes that make an individual more likely to secure and be successful in their chosen occupation to the benefit of themselves, the workforce, the community and the economy’ (2006, p21). Personal responsibility is not explicit here but the conflation of success with economic benefit remains. In contrast, theorists more often speak of personal satisfaction as a feature of employability and more idiosyncratic definitions of success. These range from something that makes ‘a person more likely to choose and secure occupations in which they can be satisfied and successful’ (Dacre, Pool and Sewell, 2007) to ‘the ability to realise potential through sustainable employment’ (Hillage and Pollard, 1998, p24). A further feature of academic definitions is that they recognise the importance of working in ‘sustainable employment appropriate to one’s qualification level’ (Hillage and Pollard, 1998, p24), i.e. employability is not just about being employed in any job. Drawing on these definitions, this thesis defines employability as having the skills, attitudes, attributes and cultural capital which allow one to engage in work of a type and level that one finds personally meaningful and satisfying, given the appropriate external environment. However, the concept is later problematised.

## Current Foci of Autism Research

Research with autistic people predominantly focuses on specific sub-groups: males; children and those who also have learning difficulties of other types. Qualitative research is rarely conducted (Bölte, 2014) and there is an overwhelming focus on deficits and how these might be addressed. In part this occurs because most of the academic literature is cited within the healthcare field or, if within education, is considered in the context of developmental delay and additional needs. The deficit approach is so pervasive that it has led to a series of parody sites with titles such as Institute for the Study of the Neurologically Typical (e.g. Engdahl, 2010). Where adults’ educational needs are considered it usually remains within the context of basic skills or primary level education (e.g. Jones, 2002), despite there being a greater proportion of autistic people with IQ scores in the ‘superior’ to ‘very superior’ ranges than in the general population (Barnhill et al., 2000) suggesting they should be disproportionally represented in higher education. There is a relative dearth of research focusing on these individuals.

That research with autistic people focuses on deficit is indicated by the range of journals devoted to deficit, as something needing a cure, or which intrinsically tie autism to other problems. Influential titles include: Education and Training in Autism and Developmental Disabilities (previously titled Education and Training of the Mentally Retarded); Autism and Developmental Language Impairment; Autism Research and Treatment; Focus on Autism and Other Developmental Disabilities and the more benign sounding Research in Autism Spectrum Disorders which in fact describes itself as focusing on treatments. More recently journals have been established which describe themselves as having alternate foci. For example, the 2019 launched Autism in Adulthood and Autonomy, and the 2017 launched Critical Journal of Interdisciplinary Studies. The latter aims to ‘foster cross disciplinary discourse between the fields of medical research, education and sociology’ (Open Journal Systems, 2017). However, both are small scale journals with no star ranking and limited reach. The articles tend to be of smaller scale or more thought pieces. That is not to say there is no research which focuses on autistic people as independent and capable, or that considers how they might navigate higher education. It is however bounded and focuses on themes of disclosure of the condition and educational support with no consideration of transition from education to the workplace.

Diagnosis and disclosure are issues impacting quality of research on autistic adults in higher education. These themes are picked up in the literature review chapter. However, they are also briefly considered here because they can lead to unrepresentative research samples and can skew findings towards those who fit more stereotypical versions of autistic adults. Most notably there is a research skew towards male participants, in part because of the association between autism and maleness (Goldman, 2013; Kirkovski, et al. 2013; Krahn and Fenton 2012). Chapter two covers this in more depth. Suffice to say at this stage the participant groups used are often less diverse than the general autistic population. Higher education students often choose not to disclose their autism at all (Simmeborn Fleischer, 2012; Taylor, 2005) or to wait until after enrolment (Yin Cai and Richdale, 2016) and only when there had been a significant problem associated with the condition (Yin Cai and Richdale, 2016; Gobbo and Shmulsky, 2012). This may impact the representativeness of research.

Whilst transition from higher education into employment is poorly researched there is work which focuses on support needs as young adults transition into higher education. This spans a range of cultures including the United States (e.g. Zager and Alpern, 2010; Van Begeijk et al., 2008); Belgium (e.g. Van Hees, Moyson and Roeyers, 2015); and Australia (Yin Cai and Richdale, 2016). However, there is little focus on the British experience and there are significant differences between different higher education systems and the support they offer. There are insights from these studies which can inform this research, though it should be noted that there is little research overall. Gelbar et al. (2014) undertook a literature review, searching the Medline, Embase and Psychinfo databases for articles which looked at post compulsory age autistic students. The only inclusion criteria were that they were in a peer reviewed journal and in English. Despite such loose criteria, of the 3,553 originally found using their search terms, there were only twenty studies identified that examined the HE experiences of autistic people in any form. All involved very small samples; there were only sixty-nine participants in total across these studies.

Van Hees, Moyson and Roeyers study (2015) looked at the higher education experiences of twenty-three autistic students in Belgium using a grounded theory approach and semi-structured interviews. Whilst their focus was on the interaction between the condition and education some of the emerging themes concerned transition to the workplace. The themes they drew out included some related to transition into higher education such as, searching for structure, and practising living without structure. Others were related to interacting with others in this space, for example striving to fit in, managing social demands, and awareness of social problems. Another meta-theme concerned practical issues: processing information in fits and starts; sensory overload and mental health problems. Two themes directly related to graduating were: worries about transition to work and doubts about disclosure. Neither theme was picked up in the practical or further research recommendations in this work, which instead focused on successful academic study. This is in line with other studies of autistic higher education students: a preoccupation with educational, or sometimes social success but little or no consideration of career aspirations or employment success.

In higher education, educational and social success are the primary and secondary foci. However, both have insufficient support: in the US, Van Begeijk et al. (2008) reported that higher education autistic students are less likely to reach their academic potential than their peers. In Australia, Yin Cai and Richdale (2016) studied twenty-three autistic higher education students’ experiences finding only 63% felt educationally supported and only 27% felt socially supported. These feelings are likely to contribute to lower completion levels for autistic students. Various studies have considered different factors impacting completion and concluded this relates to high stress levels, social isolation and familial dependence (Glennon, 2001; Howlin, et al. 2004; Jobe and White 2007; Van Begeijk, et al., 2008). Barnhill (2016) argues that higher education disability services are ill equipped to deal with the non-academic support needed by autistic students, citing evidence from Dillon (2007); Graetz and Spampinato (2008) and Pillay and Bhat (2012). It should be noted UK HEIs do not receive specific funding for social or employability support for disabled students. The organisation considered in this research described creative ways of ensuring funding was available for non-academic activities and support *(Personal Communication, Jones, 13th June 2017).*  However, this is not routine and was a vulnerable resource. Some elements of social support may be available through the legislated educational support that students should receive, because as Gobbo and Shmulsky comment ‘the classroom is a social venue with social challenges’ (2012, p41). However, the previous research outlined has demonstrated that students are finding this support insufficient. In summary, the current literature focuses predominantly on educational and social support for autistic higher education students with little or no consideration of developing employability and how this is or is not achieved.

## Lack of Support for HEI Autistic students

Little is known about autistic students’ engagement with employability development. Cai and Richdale (2016) have also established that higher education institutions’ approaches and guidance into how to work with autistic individuals comes primarily from professionals’ expert knowledge and that there is little direct examination of the lived experiences of these individuals. Many autistic HE students do not access the available resources as they perceive the services to not understand them and fear labelling and stigma as an outcome (Denhart, 2008), indicating a knowledge gap which has practical implications for students.

There is national recognition that many jobs are poorly constructed and that there are many employees insecure and unfulfilled in their roles. The Taylor Review (Taylor et al, 2017) of work published by the Department for Business Innovation and Skills calls for a framework which emphasises the need for good work with explicit rights and which meets the reality of people’s wider lives. This report does not mention autism but acknowledges some groups are more vulnerable to being in poor work than others. However, the National Audit Office (2009) specifically considers support for autistic people. It describes autistic people, without additional learning difficulties, receiving poor support, recognising that those who are academically able are sidelined. The Comptroller and Auditor General personally commented in this document that ‘Greater awareness of the numbers of people with autism, as well as better understanding of autism amongst those providing health, social care, benefits, education and employment services, would lead to improved quality of life for those on the autistic spectrum. Specialist support and joint working across all areas – clinical, social and employment – could improve the transition from childhood to adult services, make services more effective and improve value for money.’

Despite many employers actively seeking individuals on the autistic spectrum, recognising the benefits they bring[[3]](#footnote-3), the unemployment rates remain alarmingly high. Redman et al. (2009) report only 15% of diagnosed autistic adults in work, compared to 31% of all disabled adults and 57% of all non-disabled adults. Similarly, Bancroft et al. (2012) report that 43% of autistic adults have left or lost a job because of their condition and 37% of autistic adults have never been in paid employment after age sixteen. It is important, however, not to confuse general employment figures with the subgroup of autistic people who have degrees. Unfortunately access to HESA data about this subgroup of graduates is patchy and mediated through the annual AGCAS reports. These give differing degrees of detail each year making comparison difficult across time, though clear within years. The HESA data is collected by individual universities annually, six months post-graduation and has a response rate of between 80 and 86% nationally, so can be regarded as relatively reliable. The most recent data shows disabled graduates are moderately less likely to be in full time employment than their non-disabled peers (51% versus 58%) but autistic graduates are significantly less likely to be employed at only 36% (AGCAS, 2017). This figure is improved from previous reports. The 2015 data (AGCAS, 2015) showed unemployment rates for autistic graduates was over four times that of non-disabled graduates, and significantly more than twice the rate for disabled graduates. However, it is clear that this is a fluctuating figure as in 2011 (AGCAS, 2011) 26% of autistic graduates were unemployed compared to 11.4% of all disabled graduates and 8.8% of non-disabled graduates. It should be noted that AGCAS do not code unemployment as the reverse of employment. Employment rates quoted are for those in full time work. The category unemployment is only given when an individual is neither engaged in any paid work, volunteering, caring activity or education. Whilst the data itself may be convoluted to compare it is clear there is a systematic lower employment rate, and higher unemployment rate for autistic graduates. In addition, when autistic graduates are in full time work, they are also significantly less likely to be in work categorised as graduate level (AGCAS, 2011, 2015, 2017).

These poorer graduate outcomes are associated with a range of additional problems which will be explored in chapter three. These issues are discussed here purely to provide a rationale for research in this area. Firstly, that these differential outcomes have a financial impact on the individual. Knapp, Romeo and Beecham (2009) estimate the lifetime cost for having autism without learning difficulties equates to approximately £800,000 per person in 2009 terms. A small part of this is the greater care costs when young but a large proportion is the lost wages in adulthood. Being unemployed and in poor employment is also associated with mental illness. SPICe (2010) estimate in their briefing to the Scottish Parliament that a third of autistic adults develop severe mental health problems because of lack of support.

## Identification of the Problem

### 1.4.1 Problem Statement

Research indicates that autistic people who do not have associated learning difficulties tend to lack the support necessary to fully reach their potential. There is little about the lived experiences of autistic people generally as most research in this field comes from a clinical and therefore positivist perspective. For those autistic adults who do enter higher education, destination data demonstrate they are significantly less likely to be employed than their peers. Therefore, despite their investment, both financially and in time, towards improving their life chances, few achieve the expected benefits. To date, there has been little exploration of this phenomenon.

### 1.4.2 Statement of Purpose and research questions

The purpose of this study was to explore the experiences of autistic higher education students in developing their employability. It is hoped that through better understanding of their needs, experiences and conceptualisations in relation to employability, information can be provided to services which support students. Ultimately it is anticipated this will assist with service planning and provision. In order to examine and understand these experiences data was also collected on other neurotypical students for comparison.

The main aim was to examine autistic students’ experiences of employability interventions. Within that there are several objectives: to examine the range of interventions which take place in and outside the curriculum and how autistic students’ needs are met within them; to investigate autistic students’ experiences of employability interventions; and to investigate neurotypical students' experiences of employability interventions to compare and contrast. These specific actions helped address the following research questions:

1. How do autistic students conceptualise employability and their future employment prospects?
2. What difficulties do autistic students experience in building employability?
3. How do autistic students experience employability interventions?
4. What are autistic students’ views on how universities should assist them in relation to employability?

### 1.4.3 The Researcher

I, the researcher, have been employed continuously at the university at which this research was undertaken throughout the research period, as a Programme Director for two masters level courses. However there have been no professional contact or links to any study participants: none came from programmes on which I work. Prior to this role I was Head of Employability at a Millennium Plus university and focused on embedding employability development within the curriculum. Consequently, I brought to this research practical experience and understanding of the type of employability interventions students may experience. My concurrent employment within the organisation gave me a better understanding of the environmental context.

My professional background impacts how I approach data collection and the lenses I use to assess and evaluate that data and draw out findings. I am a Chartered Occupational Psychologist. At the time in which I took both my undergraduate and master’s degrees in psychology the discipline was highly focused on positivist research. Qualitative studies were not included in reading lists and I was not introduced to the idea of qualitative research until my final undergraduate year. Even then this was within a positivist paradigm. Later study and education increased my awareness of both qualitative methods and different epistemological positions. I undertook a PG Diploma in Careers Guidance which drew out ideas of perceptions as truth and my, by-this-time, ingrained idea, that the scientific method **was** research gradually began to shift. The later chartership process involved doctoral level research, some using qualitative methods and so by the time I started this qualification I was no longer the hard-line positivist who left my undergraduate degree. However, this remains something with which I wrestle. The embedded ideas of validity and reliability as measures of credibility still impact how I view research on a subconscious level and so I am always mindful of my own initial research training and how that impacts my work.

I acknowledge that there are implications of insider researcher of this type which could impact credibility. Issues of trustworthiness are explored within chapter three. For preliminary context it is worth making clear that I attempted to mitigate such issues using various techniques. These included making explicit theoretical orientation and assumptions and engaging in continual critical self-reflection through the use of a reflective log. Procedural processes were also employed such as cross referencing of data and the use of mixed methods.

### 1.4.4 Assumptions

Based on the researcher’s background and experience as Programme Director at this institution and as a Head of Employability Services at a Millennium Plus HEI five primary assumptions were made. First it is assumed there is no academic difference between autistic and non-autistic students’ performance. This assumption is based on the overall degree classification achievements of students, of which there are no discernible group differences. Secondly because there are both financial and opportunity costs associated with university participation, it is assumed that all students intend to recoup those costs in improved work quality and value at the end of the study period. Therefore, it is assumed that they will have academic success. Thirdly because HE students are adults who have made an active choice to attend university, it is assumed they are motivated to succeed in their studies. Fourthly, because this participant group comprises students at an institution with high entry standards, and therefore have already achieved academic success, it is assumed they are capable of understanding instructions and guidance given to them and are motivated to listen to that advice and guidance if they see it as credible. Finally, that autistic students are no less likely than their peers to want to work generally or in graduate roles specifically.

# Chapter 2: Literature Review

The purpose of this study was to explore the experiences of autistic higher education students as they develop their employability. To undertake this study a critical review of current literature was undertaken. The initial phase of this work was conducted during the development of the research question; however, the process was continued throughout the data collection, analysis and synthesis elements of the study. Consequently, this critical review explores three separate areas of literature: 1) autism: its prevalence and effects and 2) employability: employment and its links to poorer life outcomes, particularly in relation to mental illness. A review of the literature on autism gives an understanding of the context and breadth of the issue for society and an insight into the limitations already experienced by autistic individuals. The employability and employment literature is reviewed to provide a context for understanding the knowledge and skills that the participants perceive as being necessary outcomes and to facilitate contrast and comparison between the individuals’ understandings and what research has demonstrated. Finally, in this chapter section 3) provides an exploration of the different meta-themes which can be employed to explain the research outcomes to date. This overview provides an understanding of how the literature fed into research design and influenced the interview schedules.

A range of sources were used to conduct this literature review. These included books; doctoral theses; professional journals; internet resources; academic journals and an exploration of my existing research database. The latter was the product of the synthesis of research data accumulated over fifteen years of working and studying in the field of employability. In searching for new material no specific limiting time frame was employed as in all three fields explored historical development was relevant. For this reason, an arbitrary time restriction might have led to the exclusion of relevant material. It should be noted that because of the nature of the areas covered, literature searches were broader than educational databases. Most notably broader sociological and psychological literatures were explored. The specific research tools used searched the entire resource collection of the universities concerned[[4]](#footnote-4). For this reason, there were no subject area barriers. The review began with a systematic analysis of peer reviewed journals generated through specific searches conducted before research design. Searches were conducted in several educational and psychological databases including Academic Search Complete; Education Research Complete; PsychARTICLES; and PsychINFO. Boolean searching was used with terms such as ‘Autism + Education NOT Primary’. However, the lack of research with autistic people in higher education specifically led to a broader search strategy being employed. A snowballing approach was used, in which articles cited in found research were followed and suggestions were taken up from peers and colleagues at educational conferences attended and in general conversations. On advice from a colleague some literature around gender nonconformity and queer theory was also explored because of the potential crossover in relation to what Goffman (1963) refers to as ‘marred identity.’ Some grey literature was also explored for context. For example, narrative accounts written by autistic people about their experiences of higher education (e.g. Prince-Hughes, 2002) helped to provide depth of understanding which allowed the researcher to more rapidly build rapport and better understand the data being generated.



## Autism: Prevalence and Effects

This section explores autism, starting with a consideration of how it is diagnosed to explain its official and probable prevalence. The strengths and weaknesses associated with the condition and comorbid conditions are also explored to give context for how this may impact: the student experience; engagement with employability interventions and eventual progression into and success in employment.

### 2.1.1 Diagnostic Processes

In the UK the DSM-IV-TR framework (APA, 2000) has been used for diagnosis. This was replaced in 2013 by the less sensitive DSM-5 which Wilson et al., (2013) used to calculate only 78% of those meeting DSM-IV-TR would now meet the new DSM-5 criteria. Diagnosis is undertaken through the health system using the outcomes of diagnostic tools such as the Autism Diagnosis Interview-Revised (ADI-R) (Lord et al., 1994) and the Autism Diagnosis Observation Schedule (ADOS) (Lord et al., 2000). The process requires input from a range of different professionals along with extensive evaluations. Consequently, diagnosis is resource intensive and may have contributed to underdiagnosis. Autism has a range of comorbid conditions such as: epilepsy (e.g., Hofvander et al., 2009); gastrointestinal disorders (Lugnegård et al., 2011); prosopagnosia (Barton et al., 2004); anxiety and depression (e.g., Berthoz et al., 2013).

Underdiagnosis in the UK is a significant problem with an average wait of three and a half years from first concern to diagnosis for all autism and eleven years for Asperger’s Syndrome (Crane et al., 2016). The Autism Act (2009) explicitly addressed the diagnostic process as an area for improvement. In the USA, White et al. (2011) surveyed 667 HE students and found 1.9% of students had significant impairment effects of ASC. They went on to formally assess eight students and found five of them met clinical criteria for ASC despite none of them previously having a diagnosis. Underdiagnosis means that it is difficult to gauge prevalence in the UK. Brugha et al., (2011) found 1% of older adolescents and adults had undiagnosed autism. Prevalence rates are important for this research to ensure the appropriate participant pool is considered. This point is revisited in the methodology chapter. Underdiagnosis and late diagnosis is also relevant because it potentially impacts the extent to which individuals feel that autism forms part of their personal identity: something that is revisited later in this chapter when identity theory is explored.

### 2.1.2 Effects of Managing Impairment Effects

Suppressing identity and conforming to organisational requirements are features of many jobs, for example, using particular language; wearing particular types of clothing, and engaging in emotional labour. This is not unique to autistic people, but they are disproportionally impacted. A uniform may be more difficult for someone with hypersensitivity, a common impairment effect of autism. Being required to work with customers may be particularly draining for an autistic person who finds communication requires more cognitive effort. Being in a noisy office may be more difficult for an autistic person who finds it hard to reduce incoming stimuli. In considering potential issues for autistic people in the workplace it is important to first draw the distinction between impairment and disability as defined by social constructivist approaches to disability: something covered in more depth later in this chapter. Essentially social constructivist approaches distinguish between impairments and disabilities. Impairments are a feature of the individual, for example sight loss, or in the case of an autistic person difficulty in tuning out unnecessary stimuli. The disability results from societies’ responses or adaptations to the impairment. In the case of sight loss this may be having the office layout remain predictable with no movement of desks. In the case of autism, it might be having a quiet working environment. In the case of autism though impairments may also become advantageous in different circumstances or contexts. For example, inability to tune out stimuli is useful for pattern recognition in spotting new stars, observing unexpected aircraft in a specific space or finding errors in computer code, useful in the computing, geography or engineering fields. Difficulties with time management can be problematic if one works fixed shifts, but with more fluid work times it allows an easier move to periods of ‘flow’, in which creativity and efficiency is enhanced, for example in creative industries. Failure to fit in or conform, because one does not understand social cues or rules is problematic if it impacts customer relations, but it can be beneficial if one’s job requires one to remain objective or not experience social pressure, for example as a judge. Unfortunately, these are usually presented by researchers and society alike only as problems. In the education environment studies have found autistic students may experience organisational problems, especially time management, inability to self-advocate, sensory overload and social skills problems (Fleischer, 2012; Gelbar, Smith, and Reichow, 2014; Madriaga 2010; Madriaga and Goodley 2010; Taylor 2005). In the workplace concerns have been raised that Individuals may display inappropriate affective expressions or lack social skills (Baron-Cohen, 1997; Mak and Kwok, 2010). Communication is regarded as a major obstacle for autistic people. Ability to manage reciprocal elements of conversation has been documented as problematic for autistic people at all ages (turn taking, topic selection/maintenance etc). (Adams et al., 2002; Bellon-Harn and Harn, 2006; Brinton, Robinson, and Fujiki, 2004; Capps, Kehres and Sigman, 1998; Church, Alisanski, and Amanullah., 2000). In addition, autistic people can have problems with bearing in mind the listener’s interest and motivation when speaking (Colle et al., 2008; Seung, 2007; Shriberg et al., 2001); regulating voice and prosody (Church, Alisanski, and Amanullah., 2000; Shriberg et al., 2001); and knowing how to rectify misunderstandings (e.g. Hurlbutt and Chalmers, 2004, Colle et al., 2008; Seung, 2007). The focus of calls, to date, to support autistic people with these identified impairments has been in relation to making up a deficit by teaching tools and techniques. Barnhil, (2014), Friedman et al., (2013) and Van Bergeijk et al., (2008) all argue these specific skills should be actively taught in HE. Teaching is an option, and for HE students many will already have a repertoire of skills to draw on to make up for the impairments. However, the problem is that these never become natural skills and so always carry a cognitive load. Therefore they are more difficult for autistic individuals to do and create an additional burden for them in the workplace. An alternative strategy would be to alter the environment. This is the position taken by the Equality Act (2010) which requires workplaces to make reasonable adjustments for individuals. This fundamental right is beneficial if autistic people are aware of and know how to ensure it is upheld. In this case they can ask for a reasonable adjustment to be made to the role. It should be noted that reasonable adjustment is not just about environment though. It can also encompass job crafting, which is more than simply removing difficult elements. For example, whilst social jobs may initially seem unsuitable for autistic people Johnson and Joshi, (2016) found that they were not problematic if the individual concerned had an element of personal control in the social elements. Gal et al. (2015) found that autistic people had different working profiles to those matched control neurotypical peers and argue that work needs to match their specialist skill sets and temperaments. Specific benefits autistic people may bring to the workplace include the ability to focus intensely and be successful in visual perception tasks (Kellems and Morningstar, 2012). Autistic people also show relatively greater persistence and attention to detail (Sonne, 2009). In addition, Hill (2014) describes how autism can enhance language translation.

This section has drawn out the issues associated with autism in relation to support needs, potential advantages and disadvantages in relation to workplaces. This research project extends what is already known about autistic people entering the workplace and research in this section feeds into construction of the interview schedule for this research. The concept of employability and its relationship to employment are now explored.

## Employability, Employment and their Effects

This section considers the construct of employability, what purpose it serves and how the narrative of employability is used. It also looks at employment, and unemployment and what impacts this can have. It is important to contemplate employment post-graduation as this contextualises the students’ experiences and understandings of employability as they are explored in this study. This overview of research and theory in the area also highlights how the notion of employability links with longer term employment.

Over the last twenty years a narrative has resurged in the UK that education is critical for economic success. This is a message common to other Western nations and HE take-up has expanded dramatically. In the UK total numbers of HE students increased by more than twelve times between the 1960s and 2009 (HESA, 2009) reflecting population growth as well as increased engagement. Relative figures increased by nearly nine times from 5% of young people in the 1950s (BIS, 2009). In the UK the particular manifestation of this message initially was that widening participation into HE was required to meet perceived growing need. Over the last five to ten years that message has shifted into one of simply increased numbers with a rationale that HE represents steps to success in a meritocratic society. The most popular theoretical explanation for this belief is Human Capital Theory (usually credited to Schultz, 1961) useful because it can be applied at varying levels from the individual to societal. It describes investment in people as being no different to investment in other tangible assets such as machinery. In relation to HE this theory means that if economic benefit can be gained long-term then the government should invest in it until the net social rate of return is equal to the return on investment from another long-term investment project (Blaug, 1967). The then Department for Education and Employment argued: ‘*Learning is the key to prosperity. Investment in human capital will be the foundation of success in the knowledge-based global economy of the twenty-first century*’ (1998, p1) . Wolf et al. (2010) argue that there has been a dominant assumption in education policy that national prosperity is linked to individual take up of education and training and cite the work of Green et al. (2000) in reviewing the education and training policy across the EU between 1985 and 1999. Wolf et al. (2010) continue that in the UK context this discourse included blaming poor productivity on low skill level and so a focus on acquiring qualifications as a proxy for developing skills. In this context it is understandable that employability as a concept should be reduced to the acquisition of skills, as discussed in chapter one. At the individual level Wolf et al.’s work showed little benefit from such education. They analysed data from nearly 6,000 adults and found no significant relationship between upskilling and wage increases for most groups and at academic level 1 for males and occupational level 2 for males they found negative effects. There are positive effects for men at academic level 5, women at academic level 4 and 5, and at occupational level 3 and 4 but negative at occupational level 2. However, even these effects need to be considered cautiously. Given the number of statistical analyses conducted it would be expected to see one false positive and one false negative.

### 2.2.1 Widening Access to Higher Education to Increase National Productivity

The intention to continue with the previous Government’s expansion policies for HE long-term was reiterated by Jo Johnson in his role as Minister for Universities and Sciencein 2015when he explained

*The Prime Minister is committed to doubling the entry rate from disadvantaged backgrounds by 2020, compared to 2009 levels. We also want to see a 20% increase in the number of black and minority ethnic students going to university by 2020, with matched improvements in their completion rates and progression into work*.

A critical difference from previous similar pronouncements was a consideration of transition out of HE, as well as into it. Lane (2015) conducted a critical policy analysis looking at higher education policy from four white papers from 1987 to 2012. She found language had shifted from widening participation to social mobility and that the emphasis had shifted towards retention and outcomes with a dilution of lifelong learning and continuing education. However, there was a permanence of ideas about the underpinning role of human capital theory and meritocracy during this time. Whether the central driver is widening participation or meritocracy this expansion of HE should represent an upsurge in autistic students, and consequently autistic graduates too. As up to three quarters of autism diagnoses were in the PDD-NOS and Asperger’s categories using the old DSM-IV (Grinker, 2007) and because autistic people have greater numbers in the superior to very superior range than neurotypical people (Barnhill, Hagiwara, Myles and Simpson, 2000) they should be disproportionally represented in HE.

### 2.2.2 Employability as a Tool of Oppression

An additional effect of the governmental focus on education as a means to raise national productivity is that the concept of employability gained traction. The definition of employability was explored in chapter one and will not be revisited. The concept itself is now problematised by considering the issues associated with this focus on skills and from using the individual as a unit of analysis or comparison. To be of use as a developmental concept for individual students, such as those participants of this study, it is important that the term can be practically operationalised, i.e. it would need to map onto the actual factors which affected entry to, and success in, work. Pascale described it as ‘*An ill thought out concept infused with more hope than substance*’ (1995, p21). Similarly Rajan et al. argue ‘*It is one of the few words that has gone from cliché to jargon without the intermediate stage of meaning*’ (2000, p23). Boden and Nevada (2010) argue that there has been a discursive shift in definitions of employability. The result is that it has become only what can be quantified and compare across institutions and courses. Employability is, they argue, an amalgam of all the work universities do about creating well rounded citizens. When the concept is vague it is unhelpful to use in practice. However, when it is brought into focus it is only as a conflation of employment rates: something that is too future focused to be useful in practice and misses out many contextual factors and variables. As a straight application of skills required, it is incomplete. For example, Booth (2016) talks about fetishizing team work, something required for parts of jobs but often presented as a threshold skill for graduate work. In contrast other key job elements can be absent. Eurofound (2016) discovered 31% of employees supress emotion at work most of the time and 37% work to tight deadlines at least half of the time. Despite this neither ability appears in popular articulations of the concept.

A separate metric for employability for autistic people (The Autism Work Skills Questionnaire) has been developed by Gal et al. (2013). As with most tools it focuses only on skills but is at least an attempt to operationalise the employability concept for this subgroup. The scale assesses: work habits (persistence at task; attendance); working style*,* (ability to adjust to changes); independence at work, (incorporating understanding requests and confidence); routines and daily activities, (understanding and abiding by dress code) and interpersonal skills. Separating out some of these elements may be helpful: Gal et al. (2015) demonstrate differing capabilities between neurotypical and autistic students in four of these domains, but not in work habits. Neurotypical students score higher on these domains, which are subjective. So, this needs to be interpreted with cautiously. However autistic people have been shown to be reliable reporters of their own skills (Gal et al, 2013). Not all neurotypical people are.

If one temporarily accepts the argument that autistic students are deficient in these specific skills relative to peers, it makes sense to institute remedial training to counteract this. However, this may not be such a simple process. It depends on the individuals recognising the benefits of such training and trusting the providers. Morningstar (1997) found that adolescents with disabilities looked to their family for career guidance rather than professional services which they mistrusted. For autistic students the problem may be more acute as Camarena and Sarigiani (2009) describe the way in which parents of autistic children had a ‘history of having to ‘fight the system’’ p120. They describe how, in many families, the mother had stopped working to engage with the education system and advocate. These experiences may deter autistic students from accessing such services.

It could be argued that the employability concept is not consciously oppressive, but simply poorly mapped against what is required to achieve and succeed in work. If this position is adopted, then one should strive to better map the concept to make it useful in practice. However, there are alternative explanations: the concept could represent a specific tool of oppression by placing blame onto individuals for failures of the economic and societal failures which leave them workless or underemployed. An example cited earlier was the definition created by the Confederation of British Industry (CBI) in conjunction with the National Union of Students (NUS), in which employability was defined as ‘a set of attributes, skills and knowledge that all labour market participants should possess to ensure that they have the capability of being effective in the workplace-to the benefit of themselves, their employer and the wider economy’ (CBI/NUS, 2011, p8). That the CBI should prioritise business interests is not surprising. That the NUS, a body specifically representing students’ interests takes this position indicates how pernicious that narrative has become. ‘Employability’ is a tool used to shift responsibility. Whilst there is no specific research in relation to autism there is much which looks at social class. For example, Tilley (1998) describes the practical process by which individuals can be locked out of opportunities which are apparently open to all, referring to opportunity hoarding whereby invisible barriers are imposed, such as relying on extracurricular activity and softer skills in recruitment and cultural and attitudinal barriers when recruiting. These are often features of education through private, though not state, schooling and act to replicate class relationships. The Learning and Skills Council (2004) concur that explicit differentiators for recruitment, i.e. education or qualifications are less important than other factors. The status of the specific HEI attended is another invisible barrier important in labour market success (e.g. Brown, 1997; Pitcher and Purcell, 1998; Purcell et al., 2002; Brown et al. 2002; Brown 2003; Brown and Hesketh, 2004). This differential recruitment of employers from different universities is acknowledged by the Government. In the White Paper, The Future of Higher Education (DfES, 2003) they comment ‘Students decide which HEIs to apply to, and employers decide which to recruit from...’ (para 4.2). This is problematic because no matter how ‘employable’ an individual makes themselves, if they went to the ‘wrong’ university their chances of getting graduate work are greatly decreased. This is a systemic issue because working-class students are predominantly located in new universities (Boliver 2011). They are often unaware of institutions’ status (Greenbank, and Hepworth 2008) and attend more local HEIs, to reduce costs (Forsyth and Furlong, 2000; Reay et al., 2001). In addition, more prestigious universities are perceived by those from non-traditional backgrounds to be the preserve of the privately educated, white upper-middle-class (Ball et al. 2002; Hutchings and Archer 2001; Reay et al. 2001). More recently the growth in unconditional entry offers from less prestigious universities, sometimes coupled with financial incentives is regarded as a disproportionate draw to those from poorer families and particular socioeconomic backgrounds (UCAS, 2019)

Whilst there is no specific research to show that this impacts autistic students, their relatively high dependence on family for support means it is probable they also attend the most convenient HEI. More critical writers argue this is not simply an unfortunate series of events but that employability as an individual responsibility acts as a smokescreen for systematic discrimination in society. Wiggan (2015) adopts a Marxist perspective in relation to programmes to support entry to the labour market arguing they do not work because their aim is to increase people’s willingness to accept low paid and insecure work. Much research on employment support programmes for those with impairments focuses on the physical. These have been criticised because of the power relations and the underlying aim to socialise those with impairments to conform to societal expectations (e.g. Watermeyer, 2013; Scott, 1969). However, Vaughan and Omvig (2005) argue programmes can support empowerment and self-efficacy when run well and are about education and personal and disability consciousness. There is also evidence that such programmes can lead to increased employment and increased higher level employment (e.g. Bell and Mino, 2015; Cmar, 2015 look at the case for individuals with sight impairment). However, even this ‘success’ does not disprove the existence of structural inequalities and neither does it mitigate them, except as a token gesture. or that certain societal groups are advantaged when individuals taking personal blame for their perceived lack of employability. For the concept to work it needs to be believable and acceptable so that people buy in. To do this some people have to be successful through this route. The system needs token successes to act as role models or examples in order to argue that the system is fair. Therefore, a working-class judge may appear on many pieces of advertising literature and give talks at educational establishments to showcase the benefits of employability, they remain a novelty. Whilst only 7% of the population attend independent schools three quarters of judges are privately educated, as are 70% of finance directors, 45% of top civil servants and 32% of MPs (Panel on Fair Access to the Professions, 2009). There does not need to be a large-scale conspiracy for employability to play this role. The concept can be used in good faith. It is possible to see the cognitive dissonance can persist when, for example, subjects who address issues of systemic bias and inequality within their courses also allow university marketing departments to advertise those same courses using organisation wide ‘employability’ statistics whilst knowing the outcomes for students are worse in these non-STEM fields. Peter Horrocks the incoming Vice Chancellor of the ‘second chance’ HEI the Open University (OU) spoke about the need to develop cultural capital amongst students in his talk to the Associate Lecturer Assembly in 2015 showing he recognised their disadvantage in the workplace. He argued the OU’s uniqueness came from ‘social justice and cultural capital which we create,’ seemingly unaware of the definition of cultural capital. This shows buzz words can proliferate whilst meaning and critical consideration is lost. Negative outcomes can result not just from active behaviours but from inactivity and non-responsiveness. Employability, as a concept has become an excuse for government, society and even families to use in criticising individual graduates for lack of career success. It shifts discussion and blame from societal level causes. Ultimately it is in most people’s interests to use the term, and to not engage with any associated concerns. Research activity rather than pedagogy is traditionally rewarded in universities (e.g. UKCES 2008; Lowden et al. 2011) and there is little systematic evaluation of employability programmes’ long-term impact with most HEIs using anecdotal evidence instead (Lowden et al., 2011). Therefore there is no real driver for anyone to question the concept at all.

### 2.2.3 The Effects of Individual Responsibility for Employment

The effects of individuals bearing the blame for poor employment outcomes may be catastrophic. Employment, or lack of it, is a critical correlate of mental wellness for adults (Zulke et al., 2018) and a predictor for suicide (Lundin and Hemmingsson, 2009; Eliason and Storrie, 2009). For adults with disabilities unemployment is one of the most important indicators for mental illness (Turner and Turner, 2009). This section considers how unemployment may impact autistic adults and discusses the mechanisms of action which cause unemployment to have those effects. Employment rates are particularly low for autistic people. Figures for the general autistic population are extremely low, though exact figures are hard to establish as there are no national records. Different employment rates are quoted in different studies ranging from 4 to 17% being involved in non-sheltered employment (Ballaban-Gil et al. 1996; Eaves and Ho 2008; Howlin et al. 2004; Taylor and Seltzer 2011). Focusing specifically on autistic people classified as ‘higher functioning’ employment is much improved but remains significantly lower than both their non-disabled peers and those who have disabilities (Sanford et al., 2011; Burke et al., 2010; Shattuck et al., 2012; Taylor and Seltzer, 2011 Hendricks and Wehman, 2009). Holwerda et al.’s, (2012) systematic review describes an overall employment rate of 25% and Barneveld et al.’s, (2014) longitudinal study of higher functioning autistic people give a 50% employment rate. Different studies use different definitions of employment itself though: some having criteria of minimum hours or wage levels, others including anything which the individual regards as work. Capo (2001) emphasises that when autistic people are in employment, they are significantly less likely than their neurotypical peers to be in roles which match their potential. Consequently, both unemployment and underemployment are issues for this group.

Being autistic is only one aspect of a person’s identity and it is important to consider that intersectionality of identities occurs for many people. They may be members of multiple groups who are societally disadvantaged: because of their racial identity, or gender. Shattuck et al., (2012) highlight that autistic young people from lower income families are even less likely to have good educational and employment outcomes than the wider autistic subset. They argue that the employment itself is usually poorer and less stable, drawing on the studies of Hendricks (2010) and Hurlbutt and Chalmers (2004) for evidence. This intersectional dimension is under researched. Samples in autism research generally tend to racial and socioeconomic homogeneity. There is also a significant gender imbalance.

As discussed earlier in this chapter anxiety and depression are comorbid with autism and SPICe (2010) estimate a third of autistic adults have severe mental health problems and autistic people have a greater risk of developing psychopathologies (Friedman, Warfield, and Parish, 2013; Pinder-Amaker, 2014; Shattuck et al., 2012). Lack of adjustment in society for autistic peoples’ needs may be one explanation. Underemployment may be another. As previously explored employment is linked with mental wellness. Several potential mechanisms may account for this correlation: that unemployment impacts availability of resources; that social contact is affected; that personal identity is impacted; and that sense of personal efficacy is damaged.

Unemployment leads to lower income and so less independence and fewer resources. For autistic people poverty is a real issue with 36% of autistic adults dependent on social security benefits (Barneveld et al., 2014). Work has other benefits for mental health through providing an opportunity to socialise. Social isolation is usually studied in aging populations where it has been linked to mental illness (see Andersson, 1998 for a review). The National Autistic Society (2018) report 79% of autistic people feel socially isolated and are four times as likely to feel lonely as the general population. Another explanation is that unemployment damages one’s sense of identity. Carr, (1997) found in a female population that career success and failure had a major effect on sense of self-worth, well-being and mental health. One reason is unemployment has an associated sense of shame (Pultz, 2018). For autistic people the shame can manifest itself in relation to two separate pressures: firstly, a sense of general personal responsibility for failure to be employable as previously discussed; and secondly a sense of failure because of one’s autism. There are a range of negative autistic stereotypes, for example that autistic people are rude or dangerous (Gray, 2001; Hinshaw and Stier, 2008; Mawson, Grounds and Tantam, 1985). Ultimately the negative effects of unemployment can impact one’s sense of self-determination or personal efficacy. Self-determination has five component traits: self-actualisation, assertiveness, creativity, pride and self-advocacy (Ward, 1988) and is correlated with a number of beneficial outcomes for students with disabilities such as: self-esteem; physical health, psychological health and general well-being (Deci and Ryan, 1985; Field and Hoffman, 1994; Wehmeyer and Schwartz, 1997). There have been programmes to develop self-determination as a result at secondary and higher education level (Field, Sarver and Shaw, 2003; Stodden, 2001). However, these programmes may be at odds with concurrent messages about skill development; personal responsibility for employability and an overall deficit approach when talking about autism.

This section has described the negative effects of lack of work which result because individuals are poorer and more dependent but also because they take on board a sense of blame for this situation for which the concept of employability exacerbates and encourages. This research explores how that concept is understood by autistic people and considers how they engage with it.

## Explanatory Frameworks

In education research the work of a small number of eminent theorists are used regularly (Tooley and Darby, 1998). The negative impacts of focusing on such a narrow group has been drawn out by several authors. Dale, 1992 refers to it as ‘theory by numbers.’ Andreski, (1972) describes social science as sorcery and Ball (1995) pronounces it the mantric use of theory. In this research it is important to look into different academic traditions because this research crosses disciplinary boundaries. In establishing an appropriate theoretical research framework, the aims must be considered. Whilst this is not an action research project the intention is to produce not just theoretical but practical outcomes. Therefore, several theoretical perspectives will be considered and applied. This research is not to test theory, nor to see if predictions can be made from that theory. Rather theory will be used in this chapter, to explain metanarratives for the existing literature. It will be used in later chapters to consider the research findings and establish if they also fit into broader narratives or conceptual frameworks.

Firstly, the sociological work of Bourdieu will be explored. This perspective is chosen because Bourdieu looks at the societal level as the unit of analysis. Consequently, these ideas consider structural inequities as well as identity and representation of individuals. This can be regarded as a high theory of social justice. It has great explanatory power but is less beneficial for operationalising into practicable, immediate solutions. Because of these shortcomings, social constructionism will be the second theoretical framework outlined. This approach similarly considers societal effects, but the focus is different. Social constructionism focuses on individuals as victims. Because of this more practical focus it is more often used in action research projects: it allows more immediate changes to be made to deal with the issues raised. Thirdly identity theory will be considered. There are many crossovers between aspects of identity theory and social constructionism but identity theory stems from a psychological rather than sociological tradition. As a result, it looks more at groups and individuals as the unit of analysis. Identity theory does not have the same political overtones as Bourdieu or social constructivist approaches. It draws on evolutionary as well as social psychology for understanding and consequently is often used in an explanatory rather than emancipatory approach contrasting with the social constructivist approach. Finally, the positive psychology approach is considered. This represents an alternative way of approaching research as a whole and is (somewhat) detached from political or social justice issues (Seligman and Csikszentmihalyi, 2000). It is included as a potential approach to future research in this field.

### 2.3.1 Bourdieu Habitus and Capital

This section focuses on Bourdieu’s theories. After laying out the key aspects of the theory, general supporting evidence will be considered. Then follows a discussion about how well these concepts fit with the literature covered so far. Whilst Bourdieusian theory is most commonly used to explore social class, it is also a useful tool to explore how the concept of employability impacts autistic students. Finally, the theoretical and practical issues with using this framework are explored.

Bourdieu believed that societal systems allowed the replication of power across generations through the use of ‘capital’, with the social world subdivided into many ‘fields’ Some examples are education, family, leisure activities and disability. (Bourdieu, 1977). Bourdieu argued that each field has rules which govern behaviours. Each field also contains different forms of capital which give players a range of resources, for example physical resources and status within that field. This capital and rules mean that the existing social order, categories, classes and groups are maintained (e.g. Bourdieu and Passeron,1970). Moving into new fields is difficult. An example of how social reproduction works is seen in pedagogical processes which teach privately educated pupils to lead; and state educated pupils to follow rules and look to authority figures. Other authors offer similar critiques: Bowles and Gintis’s (1976) Correspondence Theory views educational structures and ethos as reflections /mirror images of the structures and ethos of capitalism generally. Coleman’s (1966) and Jencks et al’s (1972) reports demonstrated that education was only slightly correlated with overall income distribution or general life chance in the United States. Similarly, in Bourdieu’s home of France, Althusser argued (1968, translated into English in 1971) that the education system had replaced the church as the dominant ideology to perpetuate class positions. It could be argued that similarly the field of ‘employability’ reproduces attitudes to/beliefs about autism.

Bourdieu uses the term ‘habitus’ to describe an individual’s positioning in society. His co-researcher’s definition is ‘the way society becomes deposited in persons in the form of lasting dispositions, or trained capacities and structured propensities to think, feel and act in determinant ways, which then guide them’ (Wacquant 2005, p316, cited in Navarro, 2006, p16).

As this conceptual approach, and the original evidence for it, are now a half century old more recent evidence is now considered. One example is how graduate roles, which ostensibly are open to all, can prioritise certain groups. In Bourdieusian terms those individuals have a form of capital allowing them entry to the field. Smart et al. (2009) examined the Teach First scheme. They found bias towards middle-class graduates because they possessed social and cultural capital which facilitated their acceptance on the scheme. Bourdieusian theory would regard general disability, autism specifically and higher education as fields; social structures with their own specific rules and mechanisms, for example differences in the credibility and status of different types of HEIs which maintain the status quo (Bathmaker, 2015). Crozier et al. outline differentiated recruitment based on ‘students’ own sociocultural locations; namely class, gender, age and ethnicity’ (2008, p167). Therefore, even working-class students attending the ‘right’ university do not have the ‘right’ capital to be successful in accessing graduate careers. The Social Mobility and Child Poverty Commission (McKnight, 2015) described how elite recruiters focus on soft skills such as personal style, accent and mannerisms which can be regarded as forms of cultural capital which exclude working-class entrants. Focusing on soft skills may also be detrimental to autistic students. The report also demonstrated 70% of job offers from elite firms went to graduates who had attended selective state or private schools despite only 13% of people attending these schools.

A counter-argument is that government programmes actively promote social mobility: providing funding to encourage non-traditional entrants into higher education. However, that might be regarded as window-dressing, simply distracting people from the real systems and processes which impact life chances. Evidence for this is seen in the All-party Parliamentary Group (2012) presentation about truths around social mobility. They suggested returning to a tripartite system of HE, similar to the post-war secondary system (Committee of the Secondary School Examinations Council, 1943; Ministry of Education, 1959). However Gleeson (2000) argued this did not remove inequalities but perpetuated them. Brown and Hesketh, (2004) and Panel on Fair Access to the Professions (2009) confirm that employers discriminate by institution / by social class. In parallel with government HE widening-access programmes, employers participate in positive action recruitment schemes for disadvantaged graduates but in reality these are often one off schemes for public relations purposes or tokenism. The employment figures show no real change.

If Bourdieu has correctly described systemic inequities, then it is not surprising that beneficiaries of that system would consciously or unconsciously encourage its perpetuation. If, as I argue, the concept of employability is a mechanism for perpetuating the status quo then it is not surprising that organisations such as the CBI would use the concept as they did as early as 1989. One might not expect the TUC, a workers’ organisation to do the same however, as they also did from 1989. There are several explanations for this. Firstly, this can be understood in the context of intersectionality and matrices of power relations. Bourdieu focuses on class, but other writers would draw out power differentials between other groups based on disability, gender, age or other factors. The TUC’s position could be understood in the context of white male employees using unions and professional organisations as a mechanism to shelter jobs for themselves, as has previously been documented (e.g. Cockburn, 1983; Reskin, and Roos, 1990; Rubery, 1978; Walby, 1986). They are also viewing skills as basic craft/technical qualifications not sophisticated interpersonal skills. A Bourdieusian interpretation, however would focus on the way in which individuals are socialised into particular roles or beliefs. Bourdieu argued that ‘habitus’ (culturally ingrained likes, preferences, beliefs and ideas) exerts such a strong hold, that individuals act against their own best interests: because of their socialisation (Bourdieu 1984, 1998). Whilst this is a fairly fixed process it can ‘be changed under unexpected situations or over a long historical period’ (Navarro 2006, p16). Autistic people are less susceptible to social influence, consequently they are more resistant to habitus. May be less constrained by their habitus. Bourdieu describes habitus as something occurring ‘without any deliberate pursuit of coherence… without any conscious concentration’ (Bourdieu 1984, p170). One strength of autism is relative immunity from such pressures though, but autistic people have to actively seek out the socialisation. Bourdieu has been criticised for overemphasising the role of socialisation generally. A process which Lovell refers to as individuals becoming ‘mere bearer of social positions, one who comes to love and want his/her fate’ (2000, p15). This idea of acceptance has been challenged by empowerment and consciousness raising movements. For example, some feminist researchers criticise Bourdieu, arguing women ‘do not slip easily into the feminine position marked out for them by their sex’ (Lovell, 2000, p17). Similarly, when autistic people are given a voice, they refuse to accept imposed negative stereotypes. Bourdieu’s work has other critics who focus on aspects such as the lack of definition of core concepts such as field (e.g. Warde, 2004) or cultural capital (see Bloor and Bloor’s, 2007 illustration of the case of stamp collecting clubs who have unique discourse but no power). Despite this, various researchers argue that Bourdieu is useful for some elements of analysis of HE, in particular looking at competitive strategy, but that it must be used in combination with other theorising (e.g. Warde, 2004, Naidoo, 2004).

There are many aspects of the literature already discussed which can be interpreted using a Bourdieusian perspective. Indeed several of the researchers explicitly use this framework. Reay, David and Ball (2001) use Bourdieu’s theories to explain that habitus impacts higher education choices and Reay et al. (2001) found that social class imposes both emotional and material constraints on decision making. A counterargument would be that there are examples of people from one habitus or from one particular social class being successful in another which in this perspective is not marked out for them. However, such anomalies do fit as Bourdieu argued because positioning within a field is a series of negotiations based on ‘the impossible, the possible and the probable’ (Bourdieu, 1977, p78). It is not that people cannot gain power, just that it is improbable. Further to this, I would argue that the allowance of a small minority to succeed in this way helps to perpetuate the system. They can then be held up as case studies and examples to support the claim that the education and employment are both egalitarian and meritocratic. Similarly, government-led affirmative or transformative practices such as widening participation programmes act as a smokescreen. Fraser (1995, 2005) looked at practices which people may think of as transformative because they support individual students by acting to ‘correct inequitable outcomes of social arrangements without disturbing the underlying framework that generates them’. She argues that truly transformative practices aim to restructure ‘the underlying generative framework’, by changing the underlying political and economic structure and in so doing changing conditions for all (Fraser, 1995, p82). She would regard the concept of widening participation as a sop or distraction. Bourdieu’s principles look primarily at social class, but they can explain explain structural inequities around disability too. Sharp and Earle (2000) are critical of adjustments made for disabled students arguing the structure of assessments needs to be critically examined instead to make it appropriate to real life problems. It is a theme of disability rights activists that systemic issues which need to be addressed, not personal issues.

It has been shown Bourdieu’s sociology can help to explain the existing literature and although it may not ultimately explain all of the data covered his concepts are as Jenkins commented ‘good to think with’ (2002, p11). Concepts of particular relevance include the idea that both higher education and the workplace can be viewed as fields of social action, laden with power dynamics and graduates must ‘play the game’ (Bourdieu, 1993, p72). In addition, Bourdieu’s concept of habitus is powerful in understanding differing impacts of dominant employability discourses and practices on autistic students relative to neurotypical students

### 2.3.2 Social Constructivism

The second theoretical approach which may explain the existing literature comes from social constructivist theory and is more focused on disability as a specific research field. Like Bourdieu, this approach is sociological in origin and has roots in both Bourdieu’s field theory as well as Gee’s (1990) notion of discourses. The central principle in this approach is that ‘*the experience of self exists in the ongoing interchange with others… The self continually creates itself through narratives that include other people who are reciprocally woven into these narratives … This conception of self is at odds with the skin-bound container with fixed contents (resources)’* (Freedman and Combs, 1996, p17). For this reason, Gergen (1990) argues we should conceptualise learning disabilities only as a product of cultural practices and social relations rather than a real issue with individual people. This postmodernist approach differs from Bourdieu though in that whilst it similarly argues individual identities are developed within the context of social relations, it recognises individuals may have different identities for different contexts. Denhart describes the core principles of this approach in relation to how disability should be viewed, i.e. as ‘*a) socially constructed, b) part of normal human variation, and c) requiring voice to deconstruct it*’ (2008, p484). She concluded from her study with higher education students with a learning disability label that ‘their barriers stemmed largely from external social causes, rather than individual pathology’ (Denhart, 2008, p483). In this perspective the problem is not with teacher nor student but rather the problem *itself* is the problem and it is up to each individual to explore their relationship with that problem.

Evidence for the Social Constructivist position comes from thought experiments as well as research. In part this requires the deconstruction of assumptions inherent in other models. For example, Nussbaum (2002) critiques the assumption that people do not normally require bodily help and care for survival. She points out that everyone has periods of dependency throughout their life and so to conceptualise people as different if they have a diagnosis of a disability is ridiculous. Dudley-Marling argues that the very concept of learning disabilities exists because it has been viewed through a medical lens. He suggests it would be framed totally differently through a sociological or anthropological lens. He argues this medical approach leads to the individual becoming the unit of analysis so that the question is ‘*What’s wrong with Johnny?*’ (2004, p483). He argues forming the question this way forces acceptance of the idea that the individual is at fault. This is akin to the notion of asking ‘Why cannot autistic people get work?’ with the current response that ‘They are not employable.’ In relation to educational success, Dudley-Marling argues the discussion needs to be reframed so that we ask ‘*what’s wrong with an institution that produces so much failure?*’ and ‘*what’s wrong with a culture that created an institution that creates so much failure?*’ (2004, p483). This medical approach has additional impacts on autistic people because its core is about deficit: focusing on what people cannot do rather than looking holistically to also see the things they can do and the things they can do exceptionally well. Furthermore, it is not simply that people do less well against a well-defined standard and that ‘remedial’ has clear and specific meanings in the real world; but rather that failure is a prerequisite both within education systems and society more widely because both insist ‘everyone do better than everyone else’ (McDermott, 1993, p274). This requirement means that failure can be attributed to individuals rather than systems and the notion of learning disability ‘*can be viewed as the means by which the failures of the system and the exclusionary pressures within it are transformed into the failings of students’* (Booth, 1998, p83). I argue that similarly the concept of employability fulfils the same function: as an arbitrary standard used to shift blame onto individuals.

The practical conclusions of this theory are advocated by disability rights proponents such as Oliver, (1990); Shapiro, (1993); and Williams, (1996) who argue that using a medical model perpetuates a myth that individuals with disability (and by definition then autism) have a deficit and should be dependent on others. They argue instead for changed society to recognise relative strengths and differences. The notion of deficit is pervasive in relation to autism though: the medical approach dominates. For example, O’Neill (2008) describes the differences between the deficit models used in professional circles regarding autism, contrasting them with the language and concepts used in autism communities. O’Dell and Brownlow explored how autism was framed in relation to media discussions about the MMR vaccine. They demonstrated the primary image was of something one must fear and seek to avoid. Language used was uniformly negative. Autistic people were conceptualised as being ‘*damaged’* and ‘*faulty’* or simply as a ‘*problem’* (2005, p198). They also considered ‘parents’ voices’ which were similarly negative descriptors using the contrast imagery between the pre vaccine ‘*normal child’*, or ‘*normal happy boy*’ and ‘*normal development’* with post vaccine descriptors of ‘*damaged’* child who had ‘*lost language’*, ‘*went downhill very rapidly’* and ‘*was about to lose the ability to even identify himself in the mirror’* (p197). Moreover, even positive traits are negatively framed. Silberman describes how by the late 1980s ‘*Clinical accounts of Asperger's syndrome tended to reframe neutral or even positive aspects of behaviour as manifestations of deficit or impairment, intense curiosity became perseveration. Precociously articulate speech became hyperlexia. An average score on a test became a relative deficit-*evidence of an uneven cognitive profile.’ (Silberman, 2015, p432). A more recent example comes in a briefing for careers advisers from the Association of Graduate Careers Advisory Services. In it, Leggett (2018) writes in her role as Employment Consultant for the National Autistic Society. The whole article is a deficit discussion of autism and focuses entirely on how careers advisers might assist individuals in filling gaps.

The Social Constructivism approach explains the existing literature around disability explored thus far. I also argue that it explains the use of the employability concept as a mechanism for shifting blame onto individuals. This raises a question of what happened prior to the rise of this concept though. If the concept is linked to beliefs about causes of unemployment or underemployment this specific concept itself is not necessary. It is simply *some* similar idea is necessary to perform this function to maintain existing power relations. Prior to the employability concept this has been performed by various notions: blaming the working-class if they are uneducated or prior to that, the belief individuals were born into their life roles with their societal position preordained. There have also been parallel ideas to the employability concept which serve the same function but have been less influential. For example, career success has been shown to be correlated with levels of self-efficacy and career maturity (e.g. Bandura, 1997; Super, 1980). The ideas are linked: self-efficacy refers to the extent to which one believes one can successfully achieve tasks (Bandura, 1977) and career maturity is an amalgam of the factors which would lead one to believe that one could be successful, i.e. self-awareness, awareness of opportunities, ability to select goals, plan and appraise (Crites,1981). Using these concepts, one has to be able to conceptualise oneself as capable of success in order to be successful. Individuals are deemed to be deficient if they do not have these attributes (e.g. Taylor and Betz, 1983). Self-efficacy and career maturity are portrayed as something which need to be developed. However, the absence or even conscious repression of these attributes is quite reasonable if one is not able to successfully achieve tasks (e.g. gain appropriate work) for example, because of the economic, social or political system. Encouraging individuals to feel capable when their multiple barriers mean they are not, as with the employability concept, puts the onus of failure on them as individuals. So, whilst Super (1980) argues the ability or willingness to make long-term career plans is a sign of career maturity, it is also a sign that there is a purpose in making those plans: there is a reasonable likelihood of success, and so it is no surprise that this is related to socioeconomic status. Bandura (1977) describes the mechanisms of developing self-efficacy, which include encouragement and vicarious learning. So, encouragement about one’s likelihood of success can be used to increase self-efficacy even if it conflicts with vicarious learning resulting from observations of unemployed/underemployed graduates. This is, arguably, the process used by successive UK governments in attracting young people into higher education: telling them they will be successful in career as a result, even whilst they see their older siblings, parents, friends and family fail to secure the most prestigious graduate roles. Successive cohorts continue to enrol and work hard. Graduate roles continue to go to the same types of graduates.

This theoretical approach has advantage over field theory in that it leads to clear practical implications. Whilst both frameworks advocate wholescale change this approach suggests that even smaller change is effective. Labelling is a clear example of this. There are discrepancies between whether individuals and professionals agree about diagnosis, as well as whether people feel that having a diagnosis negatively impacts them. For example, Newman et al.’s (2011) US longitudinal study found that 63% of students who had been labelled as disabled by their school said themselves that they did not have a disability when they left secondary education. A further 9% of the study participants said they had a disability but chose not to disclose it. Of those people tracked who had an autism diagnosis 37% said they chose not to disclose the disability to their educational institution (Newman et al. 2011). This theoretical framework has helped to inform the discussion within the introduction about naming one’s own situation and condition.

### 2.3.3 Social Identity theory

Social Identity theory bears some resemblance to Social Constructionist theory but stems from a psychological, rather than sociological tradition. It also looks at how self-identity and sense of self is constructed by reference to other people and by one’s interactions with those others. It considers this at the group, rather than societal level though, and frames conflict between groups as a natural part of human behaviour resulting from preference for one’s in-group. This theory explains how some of an individual’s behaviours are influenced by how they perceive themselves in relation to the groups of which they are a member (Tajfel, 1978). Essentially, a person behaves in such a way as is dictated and expected by wider society of members of that group (Turner, 1999). So, if an individual is part of a group regarded as poorer at maths, they will become poorer at maths as a result. If they are regarded as being good at sports, they will strive harder and therefore perform better at sports. These effects can be both positive and negative. They can stop people aspiring to achieve (e.g. Schwarz and Bless, 1992) by dampening self-belief, lowering mood and decreasing feelings of self-worth (e.g. Lockwood and Kunda, 1997; Pelham and Wachsmuth, 1995). There can also be positive outcomes for people perceiving themselves as being a member of a particular group. If others perform well in that group there can be a process of ‘basking in the reflected glory’ of the other (Cialdini et al., 1976; Tesser, 1988) which leads to improvements in mood. A further effect is that people have been found to have preference for their own in-groups, i.e. a group of which they identify as being a member: viewing other members as having more positive characteristics; as each member as more unique than members of outgroups and as superior to outgroup members (Tajfel, 1970*;* Tajfel, 1974*)*. For this effect to take place the individual has to identify with that in-group however, i.e. accept they are a member. Whether they identify as a member of the in-group though another person can identify them as a member of their own outgroup. So, one might not believe oneself to be autistic but if others label one so, then the negative effects of being in an outgroup to neurotypical people can occur. Older studies such as Humphrey and Lewis (2008) and Ochs et al. (2001) find that both victimisation and rejection by peers are common experiences for autistic people. Blake et al. (2012) found these experiences are more common amongst this group than neurotypical young people in their US based study, something which can be explained through this mechanism.

Recognising the extent to which autistic people take on their autism as part of their identity is key to understanding whether the notion of in-group makes sense in this context. MacLeod, Lewis and Robertson found in their study of six HE autistic students’ diagnoses that they felt the Asperger’s identity was usually perceived as ‘fragile and inconsistent’ (2013, p41). The authors described some participants as deliberately ‘othering’ people with Asperger’s Syndrome, refusing to be labelled themselves. However, the label Asperger’s rather than autism generally has been shown to be preferred by many autistic people. When the specific label of Asperger’s Syndrome was removed from the DSM-5 it drew concern from many members of the autism community including researchers, clinicians, autistic people and parents (Kite et al., 2013; Linton et al., 2014; Volkmar and Reichow, 2013). Negative stereotypes of autism deter autistic people from identifying with that subgroup. Goffman’s (1963) work on spoiled identity investigated the effects of dissonance between personal and social identity. Disability is one category of ‘spoiled identity’ as Goffman describes it.

Not all autistic people view autism as spoiled identity. MacLeod and Johnston, (2007) described some autistic people viewing it as a life sentence indicating they would always need support. However, Murray (2006) found that for some people an autism diagnosis represented a positive experience and Humphrey and Lewis (2008) found a subset of teenagers with an Asperger’s syndrome diagnosis who found it a source of celebration. Equally many personal descriptions of autism describe diagnosis as a turning point at which the individuals began to develop self-awareness and understanding from others (e.g. Lawson, 1996, Williams, 1992). Researchers (e.g. Grandin, 2009) and autistic individuals (e.g. Lawson, 2010) alike argue that autism’s strengths should be emphasised and celebrated, implying that it is a positive in-group to be part of. Bagatell, (2010) describes how some members of the autistic community regard their autism as a positive aspect of identity and particularly beneficial specifically because it brings them into the wider autism community. Self-esteem is a factor when choosing to identify with this group. Myles and Adreon (2001) found that American autistic students in advanced programmes felt positive impacts on their self-esteem and feelings about autism. Cash (1999) refers to autistic young people in gifted and talented programmes as ‘twice exceptional learners.’ This represents an interesting counterpoint to those UK based autistic graduates who find themselves in double deficit: because their autism is regarded as negative and because their level of employability shows deficit. This theory adds to this research beyond the frameworks already discussed. It gives themes to explore in the data collection phase. It suggests that identification with this aspect of identity is relevant: something to explore in discussion.

### 2.3.4 Positive Psychology

The common feature of the previous three theoretical frameworks is that they focus on negatives: problems in society and issues that need to be fixed. The final theoretical approach explored acts as a counterpoint to these. Positive psychology, as an approach is included because it can inform the framing of the research and rather than explaining the existing literature it illustrates the negative focus of previous research. Positive psychology is not a theoretical framework as such, rather it is a practical way of thinking which governs attempts to understand. A core principle is to avoid pathologising. Peterson describes it as [the] *‘scientific study of what goes right in life, from birth to death and at all stops in-between’* (2006, p1). The positive psychology movement had a long history through approaches such as humanistic psychology and existentialism, but this incarnation of the ideas was founded in 1998 by Martin Seligman in his role as American Psychological Association President (Petersen, 2006). It focuses on research questions around positive subjective experiences, traits or institutions. It looks at questions such as the power of positive emotions, resilience, self-actualisation and appreciative enquiry.

In relation to this work the approach is in line with regarding autism as a ‘*different way of seeing the world*’ as Kenny et al. (2015, p448) found most autistic adults did. This approach acknowledges that things can represent actual facts but that it is only through the omission of other facts that they come to have specific meanings. It recognises that facts about deficit can be true but that they only have significance because facts about strengths are omitted from the popular narrative. It is hoped that this research can use principles from positive psychology to bring depth and richness in the facts presented so that a more evenly weighted position is taken.

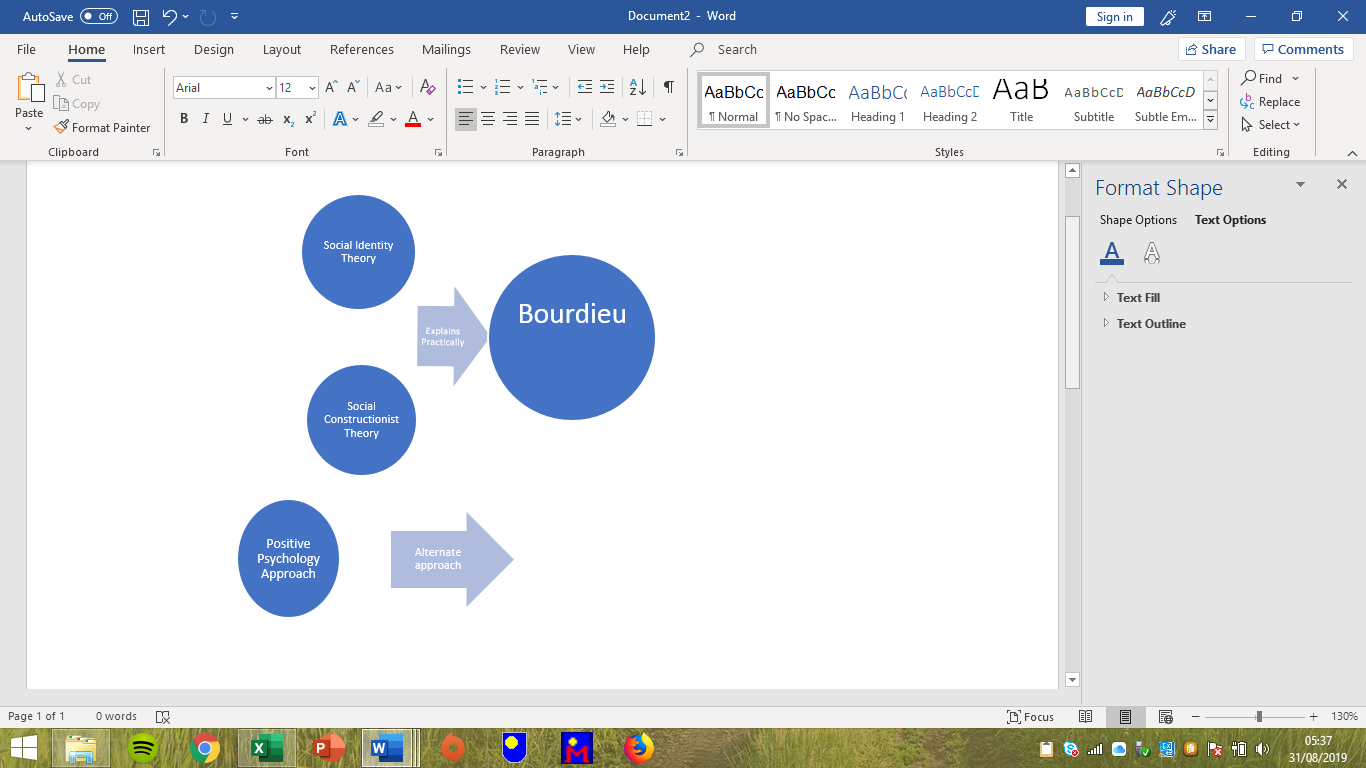


Figure 1: Model showing interrelationship between theories used

# Chapter 3: Methodology



The core purpose of this study was to explore the perceptions and experiences of autistic higher education students in relation to the socially constructed concept of employability and related practices they encounter in higher education. In order to examine and understand these experiences data was also collected on neurotypical students for comparison. The overall aim generated several objectives: to examine the range of curricular and extra-curricular interventions and how they meet autistic students’ needs; to investigate autistic students' experiences of employability interventions; and to investigate neurotypical students' experiences of employability interventions to compare and contrast. These specific actions will help to address the following research questions:

1. How do autistic students conceptualise employability and their future employment prospects?
2. What difficulties do autistic students experience in building employability?
3. How do autistic students experience employability interventions?
4. What are autistic students’ views on how universities should assist them in relation to employability?

This chapter considers the theoretical and practical aspects of the research design. Following a brief overview of the study to contextualise the succeeding elements, seven separate areas are explored. Firstly the epistemological and ontological positions taken are described. Then sampling procedures are considered. Following this the research design section gives a broad-brush overview of the theoretical aspects of the study. The next sections look at the data collection methods and then the data analysis and synthesis processes. Ethical considerations and how trustworthiness was established in this research are then explored. Finally, the limitations of this research are examined alongside discussion of how these limitations have been mitigated in conducting this work.

## Ontology

Whilst it has been argued paradigms are ‘ideal types which involve an inevitable simplification of complex concepts and practices’ (Craib 1997 p2) it is important to make clear statements about the approach taken in this research. Lincoln argues ‘paradigms and metaphysics do matter. They matter because they tell us something important about *researcher* *standpoint.* They tell us something about the researcher’s proposed *relationship to the other(s).* They tell us something about what the researcher thinks *counts as knowledge,* and *who can deliver the most valuable slice of this knowledge.* They tell us how the researcher intends to *take account* *of multiple conflicting and contradictory values* she will encounter’ (2010, p7). Therefore, this research adopts an interpretivist approach: developing and constructing theory in relation to autistic students and how they approach employability development and how this may be supported. This approach is deemed most appropriate because the researcher’s own position is that objectivity is not possible given that the notion of objectivity is a value in itself (May, 1997). Of all ways of knowing the positivist, scientific method might be that with most support, but this researcher’s view is in line with Wittgenstein in saying that ‘even when all possible scientific questions have been answered, the problems of life remain completely untouched.’ (1919 as quoted in Kenny, 2006). This research concerns individuals’ perceptions of their world and Griffiths (1998) argues it is a researcher’s duty to work with subordinated groups to empower and allow them to liberate themselves and to so do it is essential that their own worldviews are represented through such interpretivist research. Similarly, it is important to lay out the ontological position taken. A constructivist stance has been taken here. This assumes that knowledge is something which is produced through social relationships, rather than something that is ‘found’ or ‘uncovered’ as a realist position would assume. Taking these epistemological and ontological positions together it is rational that a qualitative approach is the main mechanism for generating knowledge in this research. Qualitative methods allow for individuals’ unique voices to be heard; facilitate the mining of rich and deep knowledge with participants; and allow scope for exploration of alternative explanations to be considered and for novel ways of thinking to germinate.

This research has four phases with both deductive and inductive elements. Phase one was an online questionnaire which, using logic, splits to examine the provision of employability interventions and the take up of those interventions by different students. This phase also served to attract participants to phase two. The outputs of this phase were used to deduct whether there are differences between different groups in relation to their use of and perceptions about different employability services. The questionnaire contained open text responses which were inductively examined and provided the basis for questions to be used in phase two. Phase two consisted of semi-structured interviews with autistic students. Students were asked about their experiences of higher education, the support they had received and any employability interventions they had been involved with. Students self-identified to be involved in phase one when they completed the phase one questionnaire. This phase was inductive: drawing out meaning from participants’ responses and building theory about participants’ experiences and support needs. Phase three consisted of semi-structured interviews with neurotypical students who acted as matched controls to those phase two participants. An interview schedule built on that used in phase two was used with autism specific questions removed (e.g. how old were you when you were diagnosed.) This element of the research was used as deductive check to assess whether the themes drawn from phase two are specific to that group. Phase four consisted of semi-structured interviews with members of staff who offer employability interventions as mentioned by participants in phases two and three. The purpose of this phase was to clarify the intent of these interventions and to clarify and contextualise findings.

How the researcher understands autism impacts the approach taken in terms of design, interpretation and analysis and so is worth explicating here. The researcher does not believe that autism is a disability. Disability Studies traditionally distinguishes between impairment and disability (e.g. Disabled People International, 1982, as cited in Mallett and Runswick-Cole (2014) arguing that disability results from a societal response to an impairment. The researcher does not believe that autism is either a disability, nor an impairment. For every impairment associated with autism there is a parallel strength. For example, inflexibility in thinking is problematic to neurotypical people but flexibility in thinking allows cognitive dissonance: an alternate problem. Autism is simply an alternate way of approaching the world, acquiring and using knowledge. There is nothing intrinsically problematic about this. The condition is labelled a disability because difficulties emerge due to this alternate way of thinking not fitting with capitalist culture which focuses on conformity in thinking, efficiency and productivity. When difference occurs in a capitalist culture there are two ways in which it can incorporated. Firstly, the difference can be commodified and used as a mechanism to sell products, for example the creation of an industry of support products: bought stim toys to replace those autistic people create themselves. The more usual response is to label the aspect of difference as being negative relative to the typical. There are two benefits for doing so to maintain the capitalist status quo. Firstly, labelling autism as problematic means that a pool of unused labour can be kept at no cost to business. This pool can be drawn on when needed, in high employment situations but when not needed can be kept at no financial costs as the unemployed individuals are deemed to be unemployed because of personal deficiencies (in this case autism related). Secondly labelling autism as problematic means that autistic individuals can be kept away from roles in which their different thinking may upset existing structures. Being relatively immune to peer pressure and thinking creatively autistic people could otherwise challenge inequalities in businesses and society. Therefore, this approach explains why autism is portrayed as a problem in society because doing so benefits capitalism. There is nothing inherent in autism which leads to problems. Problems results from societal responses and autistic people are disadvantaged because capitalism focuses on efficiencies and productivity as well as autistic people being deliberately disadvantaged because they have the capacity to undermine the precarious model and belief systems keeping the capitalist system afloat.

## Research Site

This site for study was chosen for several reasons: sufficient diversity in its student intake and programmes of study; the potential for insider research; and the desire for research to have benefits to the participant group. The benefits of insider research are that greater depth of understanding can be gained. Having some context and contacts means the researcher is able to drill deeper into the organisation and expedite some data collection as a result. Parades (1977) and Zinn (1979) both also point to the problems of outsider research which this study aims to mitigate, i.e. that outsider researchers may be consciously lied to or unconsciously misled and not be aware of this because of their lack of contextual knowledge. However, Preedy and Riches (1988, p221) describe ‘problems of tempering the truth in the knowledge that fruitful professional relationships…continue after the research had been completed’ so that insider researchers may have skewed responses. However, whilst an insider to the organisation the researcher does not work with or within the main services considered here.

This research considered the needs of people with a specific disability and Fox, Martin and Green (2007) lay out the key criteria the British Council of Disabled People (BCDP) use to characterize emancipatory research. They argue that research must attempt to leave people in a better position after it has been completed. As a researcher this was important: research must serve a function beyond my desire to explore an issue and develop myself. If the research takes people’s time or engages them it should also attempt to lead to change. Of all five potential sites the one which was chosen was the one most open to engage with the research and its outputs and use it in a positive way. This potential was gauged both from the researcher’s implicit understanding of each organisation from having spent so much time there and from the responses, or lack of, gained when making initial soundings to each potential organisation prior to starting.

The chosen university is situated in the North of England and is a member of the Russell Group of research-intensive universities. At the start of this study, in 2016, it had 15,400 EU and 3,107 overseas undergraduate students based in five main faculties (Anonymised, 2018). A sixth faculty in Greece was not included in this study. There are two city centre based main sites to the university with a small number of medical related and engineering courses based elsewhere in the city.

According to the insitution, (Anonymised 2018) of the 17% of students classed as overseas the largest country represented was China, which was home to 43% of this group. Undergraduate students were 51% female and 92% were under 21 years of age, with a further 6% age 21-24. At undergraduate level 20% achieve a first class and 55% achieve a 2:1. Of the 88% of home graduates who responded to the Destination of Leavers of Higher Education Survey in 2017 53.6% were in full time employment and 24.4% were in full time education six months post-graduation.

## Participants

### 3.3.1 Phase One Participant Pool

Once organisational context was chosen it was important to establish who was included in the pool of potential participants. This phase was concerned with gathering data to compare autistic students and neurotypical students. Therefore, all undergraduate students were within the participant pool.

In order to attract participants to take part in the questionnaire several routes were used. Whilst the survey was open to all students it was important to disproportionately attract students who had autism in order to facilitate comparison. Therefore, contact was made with the faculty Disability Liaison Officers (DLO). DLOs are responsible for ensuring any student learning plans resulting from their assessment with the DDSS are carried out and also act as general liaison points. DLOs were split into two groups: primary and secondary contacts, depending on the nature of their contact with students. There were 58 and 19 in the groups respectively. All DLOs were contacted by email at least once and the primary group at least twice about this research. Where DLOs were amenable face to face contact was arranged and six meetings were held in this way. The meetings were both to gain contextual information about their academic area and to gain support for disseminating the questionnaire and encouraging participation. Consequently, the questionnaire was disseminated through eight different DLOs directly through their student lists and the researcher was able to speak at four penultimate year lectures advertising the research in September 2016. Several individual students were also introduced to the research by their DLOs and asked if they wanted to participate. In addition, the Dyslexia and Disability Service sent details of the research to all students who they had registered as having a diagnosis of ASC once in June 2017 and once in November 2017.

Potential participants were also targeted through social media. Online forums are considered to be good for and popular with autistic individuals because they do not require non-verbal communication. Raskind, Margalit and Higgins, 2006 highlight that difficulties in interpreting others’ communication is equally common for all users. Because of this, autistic students are more likely to socialise in this way. Permission was gained from three separate online groups to advertise the research: Neurodiverse UK Facebook group; [www.wrongplanet.net](http://www.wrongplanet.net); and Neurodiverse UK. Neurodiverse UK is a social discussion forum for people who are on the spectrum and those who are interested in neurodiversity. Wrongplanet is a website which incorporates discussion forums and is aimed only at those on the spectrum, though it is physically open to all. The final group was a closed Facebook subgroup of Neurodiverse UK which was only for autistic women.

As well as these efforts to oversample neurodiverse individuals in the participants general advertising was undertaken to encourage participation by all students. As well as speaking to groups of penultimate year students the questionnaire link and advert was emailed out through the volunteers’ link run by the university itself three times between July 2016 and September 2017. This is sent to all students of the university who have not unsubscribed. All students are auto enrolled at registration. The actual number of students who remain on this email list is unknown to the administrators of the list.

Table 1: Fieldwork Schedule

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Phase | Date Range | Number of Participants | Number of Usable Data Sets | Incentive |
| 1: Questionnaire | 14th May 2017 to 11th March 2018 | 253 | 147 | Prize draw for £20 voucher[[5]](#footnote-5) |
| 2: Interviews with autistic students | 1st August 2017 to 27th April 2018 | 16 | 14 | £10 cash |
| 3: Interviews with matched samples | 15th March 2018 to 10th May 2018 | 4 | 4 | £10 cash |
| 4: Interviews with staff members | 30th June 2017 to 25th July 2018 | 6 | 6 | No incentive |

### 3.3.2 Phase Two Participant Pool

Phase two involved in-depth interviews and was specifically for autistic students. Consequently, the participant pool for this phase was narrower. Having a diagnosis of autism was not the inclusion criterion used however. Whilst there are binary differences in disability as legally defined autism is a spectrum condition. In addition, crip theory looks at the fluidity and intersectionality of disability in relation to aspects of the self, such as cultural interpretation of impairment and how impairment and disability have performative aspects within a specific context (Garland-Thomson, 2011, 2015; McRuer, 2006). For these reasons the inclusion criterion used was whether one believed oneself to have autism.

Another criterion at this phase was stage of study. The experiences of penultimate year students were the most appropriate to gather. The rationale was two-fold. Firstly, students who had arrived at the university recently and were still in their first year might not yet have experienced any university interventions around employability and were also less likely to have actively considered employability themselves. Secondly final year students would be actively involved in job search at this time therefore their views on support they had received in the past might be coloured by their current success in job search. Final year students may also experience an issue in common with graduates, i.e. that they may experience hindsight bias as illustrated by Schkade and Kilbourne, (1991). Hindsight bias is the process by which people exaggerate the scale of the difference they have experienced between their expectations and what they received when they think back through time about this. For these reasons a secondary criterion used was that participants be in their penultimate year.

Given prevalence rates previously described it is probable that there are between 173 and 206 autistic undergraduate students, diagnosed or not, studying at the university. It is also fair to assume these would be roughly evenly distributed amongst the three levels of undergraduate study. Figures held by the university’s Disability and Dyslexia Support Service show a total of 149 autistic students registered in the academic year 2016-2017 (personal communication, 22nd February 2017). Therefore, it is probable there is a pool of potential penultimate year student participants, on the spectrum of between 50 and 67 people.

In the phase one questionnaire forty-nine autistic people agreed to be interviewed. However, some of these did not meet the inclusion criteria: they were not penultimate year students or had incomplete information meaning they could not be contacted. After data cleaning seventeen were eligible. Of this group, fourteen students agreed to participate when emailed and were subsequently interviewed.

Self-selection methods can lead to unrepresentative samples, and Hayfield and Huxley, (2015) discuss how this sample bias is a common and perhaps intrinsic feature in research with socially excluded or dispersed groups because of the difficulties in making contact with these individuals. In addition, Guest, Bunce and Johnson’s experiment with data saturation (2006) established that in qualitative studies, eleven interviews usually led to exhaustive data and this figure had been reached by using the sample available from the phase one research. However, in this case oversampling females relative to diagnosis rates was seen as important because autistic females are currently underrepresented in the literature.

Even though there is believed to be an overrepresentation of autistic males this is probably the result of cultural factors and differences in aetiology leading to reduced diagnoses rather than fewer autistic females. Indeed large differences in reported ratios suggest the actual figures are unknown. For example, Baio, (2014) reports the ratio as 4:1 overall and 10:1 for high functioning whereas Mattila et al. (2011) report the high functioning ratio as 17:10. The idea of different aetiology is contested by models of autism as a presentation of an extreme expression of male behaviour though (see Baron-Cohen et al., 2011). Despite this positioning the idea that females attempt to mask their impairment effects by copying others is supported by the later diagnosis of females as this mechanism breaks down (see Van Wijngaarden-Cremers et al., 2014, for review) and a range of authors present evidence to show it is simply under-diagnosed in females because the presentation varies in relation to males (Attwood 2006; Dworzynski et al. 2012; Kopp and Gillberg 1992).

Many authors argue that the perception of autism as a male condition means females are significantly absent in research (e.g. Goldman 2013; Kirkovski et al. 2013; Krahn and Fenton 2012). All groups within the autism community: autistic adults, family members of autistic children and professionals argue that the lack of research on autistic females is the main issue to be addressed in future research (Pellicano et al., 2014). Females have become what Bazelon, (2007) calls ‘research orphans.’ He suggests this is because historically it has been too difficult to find large enough samples. For these reasons it is important to ensure females do feature in this research. Therefore, snowball sampling was also used.

Snowball sampling is a technique in which participants are referred to the researcher by previous participants. Biernacki and Waldorf (1981) and Noy (2008) both outline its benefits for accessing participants in ‘low visibility’ groups and obtaining insights into hidden populations. Therefore snowballing was encouraged. When participants had concluded an interview, they were asked to tell anyone they knew who might meet the criteria. Subsequently two participants approached the researcher, indicated a friend had contacted them and both took part directly at the interview phase without completing the phase one questionnaire. Ultimately of the sixteen interviewees at this phase six were female.

Because of the nature of the condition particular care was taken to make participants comfortable in data collection. This meant using a range of media. Five interviews were conducted by Skype, one by phone and nine face to face in a private office within the university. Finally, one was conducted face to face in a room booked in a public library close to the participant’s home.

### 3.3.3 Phase Three Participant Pool

At phase three the participants were systematically sampled as matched controls to the participants in phase two. The pool drawn upon was the participants from phase one who had indicated that they did not believe themselves to have autism, did not have a diagnosis of autism, studied at the university concerned and were in their penultimate year. Matching was made in a three-stage process on the subject of study being undertaken, gender and as a final filter, age. Practically the process involved generating lists of potential participants matching on subject. From within each list, where possible a gender match was made. If there were multiple potential matches, then age was considered as a final factor.

Given that the inclusion criterion for phase two participation was belief one had autism then it seems rational that the inclusion criterion as a control participant would be that one did not believe oneself to have autism. However, these are not polar opposites. Believing oneself to have autism is an important first step exclusion criterion. Some people might not believe this if they had never considered the idea or were unaware of autism. For these reasons it was important to check that autism is not present in control participants. NICE guidelines (2012) state professionals’ judgements are more important when interpreting diagnostic tests than the objective outputs. Whilst the researcher is a Chartered Psychologist she is not trained in autism diagnosis and so it would not be appropriate or ethical to attempt to diagnose. As an alternative the Autism Spectrum Quotient (AQ) was used (Baron-Cohen et al. 2001). The AQ is a self-report screening tool which has fifty items on a 4-point Likert scale. Each item is scored as a 0 or 1. Scores equal to or greater than 26 are regarded as consistent with the presence of autism (Woodbury-Smith et al. 2005). The AQ, whilst not a diagnostic tool shows high discriminative validity, differentiating between those with and without autism in more than 80% of cases (see Allison, Auyeung and Baron-Cohen, 2012).

### 3.3.4 Phases Two and Three Actual Participants

There were sixteen phase two participants and four control participants. However, one of the phase two participants was transcribed and coded but not included in analysis, because they did not study at the university being studied, despite saying so in early checks. In addition, technical issues meant data was lost for another phase two participant. However some notes remained which informed the analysis. Of the remaining fourteen main participants four had previously studied at another higher education institute, two of whom were mature students and already had another undergraduate degree. Another participant had decided in year two to change courses. These points are noted because whilst not typical of most undergraduate students they may reflect aspects of being an autistic student. It was considered data saturation was achieved after these participants were interviewed as no new data was being revealed at this point. The original intention was to match each autistic student with a neurotypical control participant, using the criteria of gender, and subject of study, and then if possible age. However, this proved difficult: few of the stage one participants who could have acted as controls responded to requests for later participation despite agreeing this in stage one. It was not deemed ethical to attempt to secure matched controls through other routes because it could have compromised the identity of autistic participants within their peer group.

Many researchers argue sample size should be dictated by saturation (e.g. Mason, 2010; Glaser and Strauss, 1967). However, the practicalities of when it has been achieved are contentious. Morse (1995) outlines the problems of researchers being unable to prove saturation whilst Charmaz suggested inexperienced researchers might make the claim too soon because they do not recognise nuance in the data. She also acknowledges saturation can be more rapidly achieved by studies with ‘modest claims’ (2006, p114): a feature of this study which has narrow parameters of inclusion. Ritchie et al. in outlining factors impacting sample size recognise the pragmatic as well as theoretical: ‘the heterogeneity of the population; the number of selection criteria; the extent to which 'nesting' of criteria is needed; groups of special interest that require intensive study; multiple samples within one study; types of data collection methods used; and the budget and resources available’ (2003, p84). Dey (1999) also argues that new understandings can always emerge but that researchers need to consider the pragmatics of how much can be analysed. In choosing to stop data collection at fifteen participants this study is informed by Guest et al.’s finding that where a sample has high homogeneity ‘a sample of six interviews may [be] sufficient to enable development of meaningful themes and useful interpretations’ (2006, p78) along with Bertaux’s (1981) argument that fifteen is the fewest participants one should ever use. At this point a sample of six females was included within the overall sample of fifteen meeting both of these criteria.

Of the fifteen participants fitting the criteria eleven stated they had used or had contact with the Disability and Dyslexia Support Service. Checks with the DDSS (personal communication, 25th July 2018) suggested that a 73% rate such as this was consistent with their understanding of usage rates. Given the expected participant pool this group represents somewhere between 22 and 30% of all potential participants. Of these eight were male, six of whom had diagnoses on the day of interview, the other two believed themselves to have autism and had been told by others, including medical professionals they probably did. Six were female and all had diagnoses on the day of interview.

### 3.3.5 Phase Four Participants

Phase four was concerned with exploring/ explaining issues which arise from phases one to three output and for contextualising any findings. Focused selection of participants took place. Individuals were approached to take part in informal unstructured interviews based on their job roles. Participants were therefore Disability Liaison Officers, specialist Careers Advisers focusing on disability and staff from the Disability and Dyslexia Support Service, as mentioned in describing phase one participants and how these were accessed.

## Research Design Overview

Before exploring the data collection methods and analysis in depth the overarching research design principles are considered. Oliver (1992, 2002) criticises the positivist and realist perspectives of most disability research, arguing that the resulting descriptions are insufficiently nuanced to capture the real experiences of disabled people or to impact lives. Consequently, this study looks at disability as a socio-political issue and privileges the participants’ own narratives. The research is undertaken in an interpretivist paradigm, considering personal experiences and establishing the truth of these specific participants’ experiences. As a theoretical grounding, a literature review preceded the study design. This review was ongoing throughout the data collection and analysis phases to ensure that more recent related research was considered. This review guided the data collection, interpretation and analysis phases of the research.

Figure 2 illustrates the overarching research design and mechanisms for gathering data. It can be seen from this image that data collection did not always follow a neat timeline. Sometimes data was made available during polite conversations about the research and outside of the context of a formal interview. For example, a DLO might provide some information about their beliefs or approaches to working with students. Whilst this data was not formally analysed it did inform the sense making of data which was formally collected. Griffiths sees the use of data from informal interactions as ‘a betrayal of trust and an abuse of access’ (1985, p210). However, this research adopts a position in line with researchers such as Pollard (1985); Scott (1985) and Mercer (2007) in using this material because it was produced in the public domain the researcher was in no position of responsibility or power in relation to the data provider or within the institution.

Synthesis:

Findings

Recommendations

Conclusions

Synthesis:

Findings

RecomendationsConclusions

Figure 2: Flowchart of research design

## Data Collection Methods

### 3.5.1 Phase One: Questionnaire Design

Questionnaires conducted asynchronously are an unobtrusive method which is easy to administer. In line with the overall principles of this research, this questionnaire supplemented the closed questions with open ended questions to tap into personal beliefs and richer data. This phase of the research complemented the main data collection methods. As the questionnaire phase was to be used in part to encourage participation in phases two and three it was important to draw participants in. So the principles established by Goodwin’s (2010) in reviewing survey methods were followed. These included starting with the most interesting questions, moving from simpler to more difficult questions and finishing with interesting questions. Goodwin showed all of these techniques improved response rates. Traditionally Likert scales were used in questionnaire of this type to give rapid answer choices for participants. However, these bring issues, for example, Chen et al. (cited in Fiske et al., 2010) demonstrated the scale midpoint is used disproportionately by some ethnic groups. For this reason, an interview hosting platform was chosen, (Qualtrics) which allowed the use of more complex data recording, for example asking participants to distribute percentages according to different answers. In addition, Krosnick et al. (2002) demonstrated that providing a neutral response option for participants led to increased numbers of participants reporting no opinion when they did in fact have an opinion. For this reason, the N/A option was not given for participants to choose. There was no ethical issue with not providing this response option however, because the only forced choice answers were those concerned with ensuring the participant gave informed consent.

The questionnaire comprised five blocks of questions. Each block was presented on a new page for the participant. Forced choice was used on the first block of questions to establish that the potential participant understood. These were preceded by information about the study and the main question in this block was ‘I confirm that I have read and understood the preceding information provided about the project Experiences of Employability Interventions in Higher Education.**’** If participants chose ‘no’, the survey terminated. If participants chose ‘I would like more information before participating’ they were filtered to a page containing researcher’s contact details and given the opportunity to provide their contact details so the researcher could contact them. One participant chose ‘no’ and one chose the further information option, giving their details at this phase. The researcher emailed using the supplied address but was no response was elicited.

Block two contained demographic questions. These questions served three purposes: firstly, they ensured that participants met the inclusion criteria for this phase of the study; secondly the data could assist in later matching of controls for phases two and three; finally, with sufficient respondents the responses could allow comparison between different groups. Demographic data collected included: age; gender identification; degree subject; year of study and home address postcode on application to study. This final question would allow participants’ widening participation status to be measured and was included as a rough proxy for social class. In the event insufficient participants included this information to use it in analysis but the intent was to explore identity in a multifaceted way and potentially looking at the intersectionality of autistic and class identities.

The third question block contained the core questions of interest and so explored perceptions of the support that participants wanted whilst at university. The questions were broken down to look employability, academic and social support. Participants were asked to consider these aspects in terms of relative importance to them and then in terms of how well they felt the university, their course and the student union addressed their support needs, therefore covering all four of the research questions for this study. The basic structure of each question was the same with participants using slider arrows to indicate the relative importance of each item. In each case the default position was changed from the midpoint set by the Qualtrics system to zero. This helped to prevent anchoring influences: Tourangeau, Rips and Rasinski, (2000) report that individuals are influenced by a figure they see if it has no relationship to the question. Harvey, Billings and Nilan, (1985) highlight the problems with reverse coding items in that unnatural links are made. It is easier for participants to answer the same questions in the same style. For this reason, it would be sensible to have the six questions about desired and received support to be structured similarly. However, Harvey et al. (1985) also highlight that such changes can act as a check on whether participants are really reading the questions though. For this reason, the questions were alternated to keep the participants’ attention and raise awareness that the questions were different to each other. Three were structured in one way and three in another. Hees, Moyson and Roeyers’ (2015) finding that autistic students did not distinguish between the three domains of student life, i.e. education, daily living and, social life was the basis for exploring perceptions wider than just employability in these questions. Breaking down the questions to consider the responsibility of different areas of the university resulted from a consideration of how services were already delivered. Whilst this aligned with how the students had likely experienced services being delivered it did constrain their responses. For this reason, open text questions were placed throughout to allow participants to make any other comments or explanations they felt were relevant. In addition, open text questions were used in this section to gather suggestions from participants as to how services and support could or should be delivered.

The penultimate question block looked at diagnosis and service use in order to categorise students. Depending on numbers in each group different levels of analysis were possible. For example, with only small numbers of respondents comparisons could only be made between autistic and non-autistic. With larger numbers an analysis could be conducted between autistic females, relative to non-autistic disabled females, for example. Participants were asked both whether they had received diagnoses for specific conditions and whether they, or other people believed that they had particular conditions. The information was presented in a table and the most common diagnosis categories for students at this university were included, (autism, ADHD, dyslexia, dyspraxia) along with generic categories of physical disability and other learning difficulty. Participants were also asked about whom they had disclosed to and which, employability services they had accessed, if any. The fixed responses available about services were created from preliminary discussions with careers and employability staff about which services were available. An additional question in this block asked about disclosure. This question was modified from disclosure scales used in LGBT research by Ragins and Cornwell (2001). Other research with autistic individuals uses bimodal scales when investigating disclosure (e.g. Johnson and Joshi, 2016) but as HE is a unique environment with both social and work-related contacts it was thought important to give more options.

The final question block had the practical questions necessary to administer phases two and three. It gave details of how the incentive would be allocated; a £20 gift voucher was given as a prize and participants could join the prize draw for this. This section also collected personal contact details from those participants who either wanted to take part in the draw or were happy to take part in phases two or three.

The questionnaire was piloted with a small group of students, of which diagnosis status was not known. Participants completed the questionnaire in the presence of the researcher (with computer screens not visible) and were asked to comment on any difficulties experienced. There were no specific problems raised in this field trial and so the questionnaire was formally launched, and this initial data set was incorporated into the larger data set collected.

### 3.5.2 Phases Two and Three: Interview Design

Interviews were the primary method for data collection in this study. Interviews were used because they are useful for eliciting thick descriptions. This is particularly important for data collection with autistic students because it is necessary to gather the contextual information to step inside their worldview and perceptions. Interviews allow researchers to clarify issues and probe to gather additional information. Interviews remain a major feature of qualitative research. Their use can be limited by poor interviewing though. In this case the researcher is experienced in a range of different types of interviewing including selection interviews; guidance interviews and research interviews. The design of interview schedules for phases two and three will be considered together as they mirrored each other in most parts, to facilitate comparison. The areas of difference concerned discussion about diagnosis and this will be explored after first describing the philosophy of the design and the areas of similarity in the schedules. A primary aim of these interviews was to generate rich data. Therefore a key principle in schedule design was to acknowledge that levelling of questioning may be required, i.e. a main question could be posed but if there was little information forthcoming a series of prompt questions may be applied. Further to this the schedule was used only as a springboard to discussion and it was not incumbent on the interviewer to get answers to all questions produced.

The interview design was iterative during the main phase. Mindful that opportunities to engage with phase two participants should not be wasted two pilot interviews were conducted with neurotypical students to establish the questions had no glaring problems. Whilst their experience of the interview schedule would likely differ from neurodiverse students it was felt appropriate to work with these students as part of the pilot so no rich data from the target population was lost because of bad question design. No questions were changed as a result of these pilots and the data generated was not transcribed or included in the study. Once data collection was underway in the main phase minor changes were made to the questions posed. Changes made will be discussed in the following sections as part of the description of the specific block they were part of.

Question design began from the research questions: how do autistic students experience employability interventions; what difficulties do they face in building employability; how do they conceptualise employability and their future employment prospects; and what are their views on how universities should assist them in relation to employability? The development of specific questions was in themed blocks. The first block included introductory or scene setting questions. The main reason for these questions was to help in rapport building as a mechanism for facilitating deeper exploration in later phases. Because anchoring can influence participants the small talk a researcher uses needs to be planned explicitly. If this is not done a form of item priming can occur, i.e. asking particular questions make some factors more salient to the interviewee (Salancik, 1984). Questions in this block were therefore about degree subject, why it was chosen, how long that interest had been felt, etc. The second block of questions was broadly about future career prospects, how the individual imagined they would be and what their best and worst imagined futures would be. This was the section that was most impacted through iterative changes. The idea of considering future selves drew on work by a range of researchers who consider aspirations to be critical to future employment and who use the notion of imagined self to explore different personal aspirations (e.g. Hart, 2016; Nussbaum, 2002). These questions used Oyserman and Markus (1990) argumentation that people have a range of ‘possible selves’ which they aspire to or concern them and cause fear. Therefore participants were asked about different versions of themselves. Phase two participants needed many prompts for these questions and early prompts required some visualisation ‘where do you live? Do you work with people? Is pay important? Do you need to have status? Do you want responsibility? Is work life balance important.’’ Imagining themselves in a concrete future role was difficult for some participants. Therefore over different presentations of the interview these questions morphed into more explicit questions about aspirations or beliefs about the future self, e.g. ‘Is it likely you’ll work in a team when you graduate?’

The next block of questions drew on the work of Cai and Richdale (2016) whose work with higher education autistic students led to them drawing out six core areas of difficulty. The first two were pertinent in this research and so questions were mapped onto them. The first of these two concerned the impact of core autism impairment effects, in particular social-communication difficulties and need for structure, routine and sensory sensitivities. The second concerned co-morbid conditions and two in particular were explored: difficulties in executive function especially, concentration/distraction; and issues with fine motor skills. When using these questions in phase two they were framed in the context of autism, e.g. ‘one of the symptoms of autism is difficulties with social interactions and communication. Is this something which has impacted your career so far?’ When the questions were used in phase three this framing was removed, for example the same question would be ‘one of the things we’re exploring is how social interactions and communication impact career. Is this something that has impacted your career?’

The third question block concerned employability services which had been accessed. This section of question was one in which many leads were followed and questioning differed between participants. In this section a starter question concerned the services which had already been accessed. Questioning then followed that line and focused on how they have found that service, whether it was useful, and how they chose it. The fourth block focused on help or services the participant would like to have in relation to employability. The first iteration of these questions was highly explicit about this being university led services for employability in line with Hees, Moyson and Roeyers (2015) finding that autistic students did not distinguish between the three domains of student life, i.e. education, daily living and, social life. However, as this did not seem to be an issue with these particular students’ later iterations of the interview schedule were looser.

Finally a separate block of questions was asked of phase two and phase three participants. Phase two participants were asked about their experiences of diagnosis and to what extent autism formed part of their identity. Ability to engage with an identity is dependent on having some understanding of that identity (Beart, Hardy and Buchan, 2005). Therefore these participants were asked about their perceptions of their own identity. Later iterations asked about how autism had been presented to them at diagnosis and later, to establish if that was a negative or positive framing. A specific question was asked about age of diagnosis, for those who had a diagnosis. This was included because previous studies have shown that this is related to sense of ownership of, or identity with the autism label (Johnson and Joshi, 2016). As a pattern of diagnosis ages based on gender appeared through early interviews, further questions were added to later interviewees as part of the iterative process which asked about earlier diagnoses or rationales for their autism impairment effects which would account for females’ relatively later diagnosis. Participants in phase three did not receive this line of questions.

Interviews were recorded, with participant permission, on two separate devices and transcribed in full. Participants used the numbers allocated in phase one in place of names to ensure confidentiality. The two participants not involved in phase one were allocated numbers at the start of the interview. Whilst some researchers call for data to be returned to participants for editing (e.g. Shils (1959/1980; Walker, (1993) this was not undertaken in this case. Asking participants to review what they have said puts a work burden on them and may also lead them to self-analyse: something that can lead to unasked for self-knowledge. Platt’s (1981) position has been adopted. Platt argues participants should not provide their own analysis, only raw data with the spoken words on the day are regarded as the complete data set to be analysed.

### 3.5.3 Phase Four: Contextualising Interview Design

The final phase of data collection involved DLOs and other staff. There was no fixed interview schedule prior to meeting; simply general themes as they had emerged from data analysis of phases one to three as prompt points. This was to allow the interviewee to lead the process: identifying what they felt was relevant in relation to each theme and allowing a jumping off point to gather contextual information. The aim of this data collection point was to clarify and elucidate any comments made in the early phases. For example, when a phase two participant discussed having many mentors and each one not staying long in role, the DDSS interviewee was able to clarify that there were three different types of mentors given and this was a planned part of delivery. This additional depth allowed greater understanding for the researcher of the gap between service as it was delivered and experienced. The DDSS staff member interviewee was interviewed twice: once prior to the other data collection phases to ensure phrasing was correct and to give context. The second interview was to clarify any points of confusion. The first interview did involve some pre-determined questions about service delivery. In addition, some questions built on the work by Johnson and Joshi, (2016) who asked organisations whether: neurological/developmental disability included explicitly in the definition of disability; whether awareness of autism and other neurological conditions was promoted as part of diversity training and whether specific resource groups provided for autistic individuals or other neurological conditions. Other interviewees in this phase were interviewed once and provided subject or school specific context to data provided by early participants.

## Data Analysis and Synthesis

This project employed mixed methods and the two elements of data gathered will be considered separately here. The initial data collection was mostly quantitative and so the analysis process involved the use of statistical techniques to assess the similarities and differences in data between those who were self-classified as on the autistic spectrum and those who did not. These took the form of a series of Mann-Whitney U tests and considered a range of aspects of student life: for example, whether one group was more likely to take part in particular employability activities or whether one group was more likely to believe they had received appropriate support. The probability level for statistical analysis was set at 0.05 and because a significant number of tests were employed it is probable that at least one type two error is present: a consideration borne in mind in the analysis and interpretation. The qualitative data gathered in this first phase were analysed using thematic analysis techniques as below.

The next project phase generated a large quantity of qualitative data. When there is such volume of data it can easily become repetitive and unfocused if care is not employed (Merriam, 1998). To attempt to mitigate this risk, qualitative data was analysed and synthesised in an ongoing thematic analysis process in line Braun and Clarke’s (2012 and 2013) steps.

Whilst thematic analysis cannot be regarded as a methodology because it can be used without any epistemological assumptions it is a method which suits this research. It fits in an interpretivist framework and allows the inclusion of a range of data: in this case from the interviews and from the questionnaires. It has the benefit of allowing the exploration of themes across the whole data set leading to more explicit recommendations for this organisation and for future research. This method allows for the consideration of both semantic and latent codes and so does not require participants to be self-aware; it allows for the emergence of new themes and is relatively fast and easy to use.

The formal process of data analysis began during data collection; transcription and familiarisation were an ongoing process. Analysis continued by identifying key phrases, words and themes and separating these into new spreadsheets with first round codes. When new codes were identified in this way a conscious attempt was made to see if they were present in the other interviews as analysis continued. Fragmenting data in this way forced consideration of detail and allowed the collation of similar themes into specific spreadsheets for comparison. The next phase of data analysis involved considering these themes independently of content assessing crossover. Next the codes themselves were checked for similarity to see if they could be merged into broader second order codes. At this point context was checked and data were considered both in the spreadsheets where it had been fragmented and also in the synthesised whole interview which allowed the holistic interview to be considered. A final check through all transcripts was then undertaken to assess whether any of these second order codes were present and had been missed during earlier analysis. Finally, the second order codes were either: recoded within other codes; dropped because they were of insufficient research interest; or transformed into themes for later analysis.

Table 2: Coding Table

|  |  |  |
| --- | --- | --- |
| **Final Themes** | **Second Round Codes** | **First Round Codes** |
| Gender | Gender | Diagnosis Gatekeeper to Resources |
| Gender Differences |
| Adjustments | Adjustments | Positive Help |
| Lack of Adjustment – Work and Work Placement |
| Negative Effect of Adjustments |
| Identity | The ‘other’/ identity | Attempts to Fit in |
| Comfortable with children |
| Identity |
| Language Learning |
| Loneliness |
| Personal Agency |
| Rejecting Label |
| Not typical of AS | Stereotypes |
| Impairment effect related | Symptom related | Concentration Problems |
| Hidden Curriculum |
| Literal Interpretation of Instructions |
| Misunderstanding Condition |
| Problems on Course |
| Structure |
| Study Problems |
| Study Skills Strategy |
| Framework for Support | Remedial approach  /Person-environment fit approach/ Needs to be reflexive | Accidental Employability Development |
| Consciously Building Skills |
| Gravitating to Work with Others with Autism |
| Lack of Knowledge about Career ‘Rules’ |
| Needing Careers Support |
| Negatives of Condition/ Lack of Consideration of Positives |
| Open to Opportunities |
| Preparedness for Work |
| Reliance on Hot Knowledge |
| Wanting/Accepting Help |
| Support needed | Neurodiverse adviser/ training for advisers |
| AS specific advice |
| Future plans | Worst Imagined Future/ effects of disclosure | Disclosure of Condition |
| Worst Imagined Future |
| Need to Tackle Views on Autism |

Table 3: Removed Codes

|  |  |  |
| --- | --- | --- |
| **Final Themes** | **Second Round Codes** | **First Round Codes** |
| Remove | Remove: only important to one participant | Age/ Maturity |
| Remove: few responses, not key | Imagined Self |
| Recoded | Recode: Worst Imagined Future | Work Motivator |
| Recode: Negatives of Condition/ Lack of Consideration of Positives | Strengths |
| Recode: Negatives of Condition/ Lack of Consideration of Positives | Positives |

## Ethical Considerations

Exploring ethical considerations is vital to good research. To practise ethically, a researcher must be flexible and open-minded and not restrict themselves only to meeting an ethics committee’s requirements or following one specific ethical code. In Kohlbergian terms, creating or subscribing to a rigid code of ethics can be viewed as the product of an immature stage of moral development: a stage incompatible with dealing with emerging ethical issues in real world research. Nevertheless such codes can act as a starting point for more in-depth reflective consideration of ethical issues. For this reason, two separate codes have been selected and their requirements are met: that of the British Educational Researchers’ Association BERA (2011) and that of the British Psychological Society BPS (2014). This section now describes both the ethical considerations made prior to beginning the research as well as some of the emerging ethical issues dealt with during the research process.

Hammersley (2009) argues that ethics’ committees have no particular justification for their claim to expertise arguing that the lack of consensus over ethics means there can be no possibility of expertise. He describes such committees as less knowledgeable about and less able to regulate the research activity than the researchers themselves as the committee’s understanding cannot be as complete. He complains that typically committees’ procedures do not check that the researcher has reflected on the ethical implications of the work which they are to undertake, simply that they have answered the questions appropriately. He argues this is an inappropriate level of control as researchers are challenged about what they might do whereas in all other areas, including law and teaching people are only challenged about what they have actually done. There is also evidence that ethics committees are inconsistent over time and institutions (e.g. Ceci et al., 1985; Rownow et al., 1993). This is not a moot point as real ethical dilemmas existed in this research as a result of this tension. For example, previous research has shown that some individuals with an autism diagnosis can find the ‘person with …’ terminology offensive because it suggests that autism is a negative thing and because it undermines their sense of identity (e.g. Kapp et al., 2012; and Kenny et al., 2015). So ‘autistic person’ is preferred as a term rather than ‘person with autistic spectrum disorder’. However the ‘person with …’ terminology is in common use and regarded as the most politically correct form of description by clinicians (Kenny et al., 2015) and therefore more acceptable to neurotypical populations. The ethics committee is likely to be neurotypical, as was the supervisor of this research. A compromise was reached to meet the requirements of these groups which, it was believed would not alienate potential participants. Therefore the descriptor used on advertising and the Participant Information Sheet was to name the condition in the medical terms, and invite people ‘who identify themselves as having Autism Spectrum Disorder including Asperger’s Syndrome.’ The ethical application for the research was approved on 4th July 2016 by the institutional review board of the University of Sheffield (Appendix 3).

A range of ethical issues were considered at design stage. A basic premise of involvement is that participants should provide informed consent. To ensure participants were sufficiently informed to be able to consent a two-step process was included in each phase of the research. The first step was to provide an information sheet which outlined the research aims, objectives, confidentiality, right to withdraw and details of whom to contact to access further information. In phase one this was provided as part of the questionnaire and participants had to confirm they had read this before progressing and seeing the questions. In phases two to four participants received printed or electronic copies to read at their own speed. At all phases a follow up question was asked to ensure the information was understood. At phase one a direct question addressed this and if participants responded that they wanted more information they were routed to a specific page with the researcher’s contact details on to ask their questions. At this stage they were prevented from accessing the questionnaire. In phases two to four the interviewer directly asked what the participants’ understanding of the research was and corrected any misunderstandings and answered further questions. In phase one informed voluntary consent was indicated additionally by ticking a box. In phases two to four consent was indicated by the completion of a consent form (Appendices 1a and 1b).

Participant data were anonymised at the earliest opportunity in order to maximise confidentiality. In phase one all questions could be completed anonymously, and the data required to administer the prize draw element were separated. Where participants in phase one had given contact details for the purpose of participating in later phases their data were allocated to a participant number and stored with no identifying details. Phases two and three used these participant numbers. Two participants were not involved at phase one and were allocated participant numbers at the interview. Signed consent forms were stored separately to other data so that in the event data were discovered identity could not be reconstructed. Paper records were kept in a locked desk drawer in the researcher’s office and electronic data kept in a password protected folder on a computer to which only the researcher has access with a backup on a password protected data drive kept on the researcher’s person. All data was stored collected and stored within the standards of the General Data Protection Legislation (Information Commissioner's Office, 2018)

Protection from harm was also considered both in relation to physical and emotional harm. Researcher safety is an ethical concern. The interviews took place in a private room but safety measures were implemented: other people were made aware the interview was taking place, (only though not the purpose of it); the rooms used had windows in the doors; and other people were on hand and could be alerted in the event of an incident. The questionnaire design and interview schedules were designed with consideration for potential emotional upset and no questions were asked which were likely to cause distress or concern. The researcher had no reason to believe the topic itself was likely to create distress. Nevertheless, contact details of appropriate support services were gathered prior to interviewing to ensure referral could be made if necessary.

Details of the DDSS were made ready for self-referral following completion of the self-administered autism check by phase three participants. As this measure could have potentially revealed the possibility of a person being autistic the researcher was ready to provide details of the DDSS so that the individual concerned could contact them in the event of their self-assessed score being beyond the threshold levels set to indicate likely autism.

Research uses time and resources and there should be an ethical expectation that participants’ time is not wasted. Whilst a primary aim for this research is for the researcher’s personal development, it is not ethical that this should be the only outcome. Alderson and Morrow, (2006) argue that research should not be for pure knowledge generation: that the research questions should be important to wider society; appropriate methods should be used to ensure those questions can be answered; and ultimately the research can be used to effect some change. These issues have been considered in relation to organisational context chosen but are also relevant in relation to how the research is reported. In order to act ethically it is important that the organisation receives feedback in a form which is appropriate for their understanding. To do this a short summary report with recommendations will be produced for the DDSS. In addition, where possible research should be emancipatory. The BCDP (n.d. as cited in Fox, Martin and Green, 2007) characterises emancipatory research by seven core principles, including that there is control by disabled people. The nature of this research means there have to be some compromises here. The aim of producing a piece of personal research for a doctorate mean that it is not possible to have genuine control by the people whose needs are being researched in this case. However, where possible the viewpoints of such individuals are sought, as in the example of naming given above. Another relevant concept to consider is that of accountability. In part this can be achieved by ensuring that findings are disseminated in appropriate formats and locations. To achieve this, summary documents will be provided to the participants who indicated they would like to receive one, as well as posted to the groups in which the research was originally advertised. The most relevant of the BCDP’s principles to consider ethical is that of empowerment. By this they mean that research should try to leave people in a better position than that which they were in prior to the research. As a researcher this is crucial and to me, research must serve a function. If it takes people’s time, or engages them it should also lead to change. To attempt to effect that change I will endeavour to present this research to practitioners, as well as researchers, through conferences such as the BERA Annual Conference and the British Psychological Society Annual Conference.

Moving on from looking at design stage ethical considerations, ethical issues at data collection and data analysis points will now be described. Ongoing consent is the most obvious ethical issue at data collection. The manual for research ethic committees is clear that ‘consent is a process, not a single event’ continuing ‘the ethical standards which must be met to ensure the validity of the consent might be far more stringent than the legal ones’ (Farsides 2003, p11). In most interviews continued consent can be ascertained by body language, verbal and non-verbal behaviours as well as the content of particular responses. Autistic participants, can have behaviours, language and intonation that differs from neurotypical people. Autistic people are less likely to express emotion in traditional ways and may not give the same cues if they are uncomfortable or reticent. For these reasons, it was important throughout the interviews to remind participants of their voluntary involvement and be especially diligent for any signs of discomfiture. In addition, prior to beginning the process advice was sought from acquaintances who have autism as to any signs the interviewer should familiarise themselves with. In the event there were no signs of distress or withdrawal of consent observed; rather, several participants remarked that they had enjoyed being involved in the process. Another ethical issue presented though: one participant appeared particularly keen to please and features of their speech, along with the content of anecdotes they reported from their life suggested that they may subvert their own views to present what they perceived was important to the researcher. The interviewer followed Powney and Watts’s (1987) caution that interviewers should not reveal their own position or views as these may distract the interviewee, or encourages acquiescence. This participant appeared to find it difficult to know what response was desired. In this case, it was ethical to remind the participant regularly there were no correct answers and that the research was genuinely looking for their views.

Another ethical issue arose during data collection. Some participants reported during their interview that they wished for resources which the interviewer knew were already available to them. Informing them during the interview itself may have affected the participants’ responses. However, it was important that participants were informed of their existence. To manage this issue the interviewer took notes simultaneously (with the interviewees’ consent) and went back over any of these issues after the interview was completed.

## Limitations of the Study

All research has some limitations and this section considers the limitations specific to this work rather than generally exploring the issues raised by qualitative research. The limitations will be explored in relation to potential bias and how it has been mitigated and then in relation to the design decisions made.

Whilst work in an interpretivist paradigm does not claim to be objective attempts should still be made to reduce, or if possible, remove bias from the process. This has been discussed at some length in the preceding section on trustworthiness and the discussions around ensuring the researcher is sufficiently self-aware to account for her own potential biases will not be repeated here. Other potential sources of bias create limitations as well though. One such bias is termed ‘construct bias’. This refers to the social, ecological, cultural and other contexts which may impact the design of the research. Adair (2006) describes this as particularly problematic where there is less indigenization of the discipline. Education research is typically more diverse than other forms and more likely to adopt paradigms which allow for differing constructs to be surfaced. In this research participants are not a subgroup in the nature of a specific cultural group, but they do represent a subset of students, whether or not they have any sense of shared identity or culture. It would be possible to overemphasise the similarity of these participants because of the way in which the research questions have been conceptualised and constructed though. Cheung et al. (2011) caution against overly focusing on the uniqueness of a culture when investigating specific cultural groups. To mitigate that risk here, controls have been employed in the form of neurotypical students. Whilst direct comparisons are not possible or desired this additional data helps the researcher contextualise the findings which they might otherwise consider as differences when they are in fact facets of many students’ lives.

Problems with conceptualisation may also occur because themes which arise from the autistic participants may not be easily understandable to the neurotypical researcher. For example, a participant describing how they visit busy, noisy venues was not initially logical to the researcher given the same participant describing their introversion. However, the researcher immersed herself in autistic culture and practices as much as possible to help understand these seeming contradictions. In so doing she could then understand the phenomenon of disassociation which can occur in some autistic people meaning they find it easier to be in a more troubling environment yet engage in this safety mechanism than to be in a midway environment. Whilst a neurotypical researcher can never truly think like an autistic person a range of tactics were employed to get as close as possible, such as reading life stories and electronic boards by neurodiverse individuals. The researcher also attempted by mitigate this issue by actively reflecting on pertinent academic discussions, for example that the dominant view is that that psychological constructs are universal, but they may manifest themselves differently in different cultures (see Berry et al., 2002).

Several of the research decisions made create limitations and will be explored here, including: restricted sample size; that this was insider research; the unit of analysis chosen and finally researcher characteristics. Whilst the latter is not technically a research decision in that the researcher cannot change; they did choose the research topic knowing their personal characteristics.

Restricted sample size is an issue of great concern in quantitative studies as it is linked to reduced power in the study and increased margin of error. In many respects the concept is not relevant in qualitative work where depth and richness is the objective rather than generalisability. However, there were potential risks in this work that only some autistic students were represented when the focus was on all, in this specific environment. To reduce this risk, specific attention was paid to ensure that both male and female participants were involved. In addition, diagnosis was not a prerequisite for inclusion: this may reduce the gender disparity but also help to mitigate reduced involvement by students who are working-class. Middle class children are more likely to receive a diagnosis despite no noticeable difference in actual experience of the condition.

A conscious decision was made to conduct this research as an insider researcher, relative to the organisation in which it was conducted. A range of problems have been identified with insider research: common understandings lead to questions being left unasked (Hockey, 1993); sensitive topics are left unbroached (Preedy and Riches, 1988); shared prior knowledge, norms and beliefs are not surfaced or are assumed (Powney and Watts, 1987, Kanuha, 2000, Platt, 1981); and assumptions are left unchallenged (Hockey, 1993). However, there are also benefits of insider research, for example Shah (2004, p556) argues that ‘a social insider is better positioned as a researcher because of his/her knowledge of the relevant patterns of social interaction required for gaining access and making meaning.’ For this reason, the benefits of this type of approach outweigh the disadvantages. The limitations still need to be addressed, however. So, the interview schedule was designed to be explicit, and the researcher’s self-reflection ensured that she entered interviews mindful of these potential problems. Conscious attempts were made to create an environment in which dialogue was open and explicit and specific attempts were made to check understanding of participants’ statements by reflecting back and explicitly clarifying what was stated or being inferred.

Another research decision leads to potential limitations: the unit of analysis chosen. In this case a specific organisation was chosen as one level of analysis and the rationale for the choice has been discussed in the organisational context section. At another level individuals were considered as a unit of analysis. This choice results from the researcher’s cultural context and is in line with most Western research in which the idea of the individual is dominant (e.g. Kitzinger, 1987; Sampson, 1985). So doing means that other potential levels of analysis are left unexplored: notably in this context the family as a unit. It is not pragmatically or theoretically possible to use multiple analytic lenses and explore the data through alternate levels of analysis. However, the point was borne in mind during analysis and it is suggested other researchers may wish to further explore this given there were multiple references to family and in particular parental advice and wishes in the data generated. The context used here was to consider these interactions as advice giving to an individual. However, a researcher from another cultural context may equally well view the individual student as simply part of a family unit and explore the data differently.

Finally, researcher characteristics may have created limitations. Whilst as an individual these cannot be changed research could be chosen which maximises the strength of one’s individual position. A range of personal characteristics have been shown to impact interviewees such as gender, age and personality (e.g. Bryman, 2008; Denscombe, 2007). However, even when these aspects ‘match’ the interviewee it is not a consistent picture. This leads Merton to argues that ‘as situations involving different values arise, different statuses are activated and the lines of separation shift’ (1972, p28). This results in matching characteristics changing over the course of an interview or other data collection phase. Indeed Kelleher and Hillier, (1996, p86) argue this can ‘fluctuate during the course of one interview’ and as Merton (1972) argues having characteristics in common is not in and of itself sufficient to understand another. Merton argues that people are so individual and so different that if one similarity is found it only highlights a multitude of other differences. Despite this if the researcher was like the participants in some significant way, for example, autistic then they would note it here.

## Summary

To summarise, this chapter provided a description of the practical and theoretical elements of the study’s research methodology. It outlined the rationale for using the this specific university as a site for study explaining it has: sufficient diversity in its student intake and programmes of study; the potential for insider research; and the desire for research to have benefits to the participant group as well as the fact that there was a potential for effecting change with the research at this site. Background information on the site was given along with preliminary information on the organisation’s approach to disability generally and autism specifically from consideration of key university documents. Information on the participant pool and actual participants was given showing throughout inferential statistics that it was probable the final participants represented approximately one quarter to one third of all potential participants. A rationale was given for oversampling females in relation to their usual absence from research and agreement in the autism community that this is a major issue to be addressed (Pellicano et al., 2014). An explanation was given of the practicalities of research involvement with questionnaires, interviews and contextualisation interviews being used. A rationale was given for thematic analysis being the main data analysis method employed and an explanation given of the practical steps involved in this process.

A discussion explored potential ethical issues in the research and described the ethical principles employed. Ethical issues explored included: consideration of the nomenclature used; confidentiality; ongoing consent; anonymity; protection from harm and the need to have positive outcomes from the research. In addition, processes for giving access to resources known to the researcher, but not the participant, was discussed.

A recognition was made of potential limitations of the study specifically. These related to potential bias and how it has been mitigated as well as in relation to the design decisions made. These included: restricted sample size; that this was insider research; the unit of analysis chosen and finally researcher characteristics. Explanations were given as to how these limitations have been mitigated.

# Chapter 4: Summary of Findings



## Introduction and Overview

Findings from phase one (questionnaire) will be presented in two parts: the quantitative data will form subsection 4.2 presented according to the appropriate structural protocols. The qualitative data from this phase will form subsection 4.3. Findings from phase two to four (interviews) are presented in subsection 4.4. The findings here are presented as themes which come from phase two interviews and which are informed by data from phase three and phase four interviews. It may be worth recalling that phase three interviews are with neurotypical students and were conducted as a check on whether phase two data were common to other students or was specific to them being an autistic HE student. Phase four interviews were with staff members as a mechanism to check on practical details in order to fully understand phase two interviews. For example, asking staff members what a particular intervention mentioned by a phase two participant was established for or what it involved.

## Quantitative Survey Findings

Mann Whitney U tests were used to consider whether there were significant differences in responses between autistic and non-disabled student populations. No significant differences were found on any of the variables. Both groups were similar in: their use of employability services; access to volunteering, extra-curricular activities, volunteering and paid work. They had similar ideas about how much the university, their course and the student union should place emphasis on supporting them in terms of developing employability, supporting academic progression and supporting them socially. In addition, there was no significant difference in the extent to which they felt they were supported in these areas by these different sections of the university. Full records of the statistical outputs are available in Appendix 7: Statistical Analyses of Phase One Quantitative Data.

## Qualitative Survey Findings

The number of participants completing the questionnaire element of the research is greater than the interview element and so some consideration of commonality of themes present in the free text elements here is relevant as additional themes may be illustrated by this data. Whilst responding to the free text questions was optional as King (2000) argues the very act of not communicating indicates something, for example that this issue is not of import. Missing data in this way should not be considered gaps in knowledge, just a different mechanism of communication. For this reason, broad comparisons with numbers of participants in each group will be detailed when reporting themes in this section. The rationale for this is takes into account principles of qualitative research: trust and honesty in qualitative research comes from thorough examination of the data, reporting actual numbers does not add to this; the extent to which something is interesting or worthy of consideration in qualitative research is not impacted by the presence or absence of large numbers of people saying it; data are not directly comparable between groups because responses are free text. However, whilst ultimately ‘counting responses misses the point of qualitative research’ (Pyett, 2003, p1174) in this context it is illustrative to see whether proportionally autistic students were more or less likely to comment on a specific issue than their neurotypical peers as this gives a sense as to whether that issue has different level of import for them.

As these open text questions were optional different numbers of participants contributed to each. Each question focused on problems the student faced and so, as expected, most responses were about areas for the university to develop. They were asked to consider the areas of employability development, academic development and social development. However, responses did not always conform to those questions and in particular employability was mentioned in responses to each question by at least some students. Autistic and neurotypical students shared some common requirements for employability development support. Both groups explicitly mentioned the need for transition skill support, such as CV preparation or practice interviews (mentioned by 37% autistic people and 32% non-autistic people). In addition, accessing work experience support was seen as important (mentioned by 22% autistic people and 12% non-autistic people). For those autistic students there was additional commentary about the need for careers support which was targeted to autistic people. Having autistic staff was seen as desirable; for example, wanting to have ‘*a careers advisor who [is] themselves Neurodivergent, who understand [sic] our limitations and potential rather than the regular careers advice*.’ Similarly, whilst both groups thought mentors would assist them academically (18% of non-autistic people raised this as well as most autistic respondents), autistic people specifically requested the mentors themselves be a ‘*neurodiverse mentor*’ and also called for ‘*more careers service events featuring neurodivergent and disabled people explicitly talking about these experiences*.’ The need for advice specific to people on the spectrum was repeated in open text questions about employability, academic support and social support. For example, in describing her move from one institution to another, one respondent found improvements for most students but not the neurodiverse. She described how ‘*[e]mployability as a whole was not a thing addressed at all while I was at the University of Cambridge. At the University of [redacted] it [employability] is addressed but clearly not aimed at people like me and so just feels more alienating and like further confirmation that career success and steady employment are not meant for people like me*.’

Exclusion and isolation was a theme which ran through all of the open text responses for autistic students. However, this theme was also present in some neurotypical students but only when reflecting on social activities. This was present in 13% of the responses by neurotypical students. For these students, exclusion was created by lack of religious tolerance and by a culture of ‘*heavy drinking*.’ Among autistic students, societies were seen as ‘*hard to crack*’ and these students commented on the potential benefits of resources such as a ‘*list of the societies that are inclusive and that I would fit in better at*.’ Interestingly three separate open text responses suggested the idea of an autism group, seemingly unaware one already existed. However, that at least one non-autistic commented on the need for an ‘*introvert club*’ shows some common needs and other students may benefit from more diverse socialising. Less dissatisfaction with social activities was evident among neurotypical students. 32% of these responses focused on their high degree of satisfaction rather than problems, despite the negative framing of the question. In contrast, all responses from autistic students mentioned difficulties in accessing clubs, societies and social activities. Three responses focused on the need to train other students, with one suggesting *‘[i]nclusion officers in all societies who have training on neurodivergence and how to be inclusive of neurodivergent people*.’ The idea of training was also mentioned in relation to staff, with requests for ‘*some form of awareness for teachers regarding autism and autistic students*’ and a call to tackle the ‘*widespread stigma*’ and the way in which ‘*the 'condition' is still viewed as similar to a mental disorder rather than a slightly different wiring in the brain*’

Some aspects of basic communication were raised by both groups. The problem of some academic staff being unapproachable was mentioned by both groups who acknowledged that this left them feeling unable to ask questions. One autistic student described how it would be helpful if they were ‘*able to raise questions through seminars.’* Their experiences with academic staff had led to them not understanding that this was a central purpose of seminars.

Managing expectations was a difficulty identified by autistic students but was not mentioned by their neurotypical peers. Their ability to handle problems like staff inaccessibility set the two groups apart. One student described how they ‘*want[ed] to investigate going part time so that [they would] have more time to develop employability.*’ They also said that they did not ‘*have enough time and energy to do employability work at the same time as full time degree work*’ and that they were ‘*scared because [they] need to work to live and [they are] unemployable*.’ Another described how they wanted to reduce the pressure and there was a need to ‘*Just let me have some time to live … I have a dream of startig [sic] a family, I can't meet anyone or improve myself when I don't have when. - I need more time to learn about my passions and what employers want, not only what university wants*.’ In these narratives employability development is seen as just another pressure in an already stressful situation one autistic male student described how ‘*I was so engrossed in accommodating all the changes in my life, fulfilling all the sudden adult responsibilities, that there was absolutely no space in my life to wonder if I was employable*.’

## Qualitative Interview Findings

In this section themes are drawn from the interview data. Their relationship to the original research questions is illustrated in Table 3: Relationship between original research questions and emergent themes. The themes of ‘future plans’ and ‘identity’ addressed the question of how autistic students conceptualise employability and their future employment prospects. The themes of: ‘adjustments’; ‘impairment effect related issues’; ‘gender’ and ‘identity’ addressed the question of what difficulties autistic students face in building employability. The themes of ‘identity’; ‘gender’; and ‘framework for support’ addressed the question of how autistic students experience employability interventions.

Table 4: Relationship between original research questions and emergent themes

|  |  |
| --- | --- |
| Original Research Question | Theme from the Data |
| 3. How do autistic students experience employability interventions? | Identity |
| 1. How do autistic students conceptualise employability and their future employment prospects? |
| Future Plans |
| 2. What difficulties do autistic students face in building employability? |
| Adjustments |
| Impairment effect related issues |
|
| Gender |
| 3. How do autistic students experience employability interventions? |
| Framework for Support |
| 4. What are autistic students’ views on how universities should assist them in relation to employability? |
|

As previously detailed interview data were analysed and synthesised in an ongoing process in line with Braun and Clarke’s (2012 and 2013) steps. Familiarisation was undertaken as an ongoing process. First round codes were extracted post-interview and these codes were then consciously looked for in later interview familiarisation/transcription. This resulted in forty-one initial codes. Codes were reanalysed for similarity and whether they could be subsumed into broader second order codes. Three initial codes were recoded: ‘work motivator’ into ‘worst imagined future’; and both ‘strengths’ and ‘positives’ into ‘negatives of condition/lack of consideration of positives.’ Two codes were removed. The code ‘age/maturity’ was recognised as important to one participant but did not appear in other transcripts. Similarly, ‘imagined self’ was removed as it appeared in few transcripts and was not a strong presence in those. The next round of coding led to eight themes being extracted. The final round of coding led to four of these being subsumed into the final six presented here (‘support needed’ and ‘remedial approach’ were subsumed into the theme ‘framework for support’: ‘everyone’s atypical’ was subsumed under ‘identity’).

Findings from phase one and phases two to four have been presented here in separate sections, but it is noted that the outcomes of phase one must have influenced coding in the later phases subconsciously and overlap is to be expected. Consequently, they have provided some ‘a priori’ ideas for codes to look for even if that was not the coder’s intent. Data from phase one is revisited in this section when there are obvious connections to draw. The original research questions provide a framework for the themes established though some themes cross the research questions. Consequently, each emergent theme is explored separately in this section, rather than in direct relation to the research questions. The themes of ‘future plans’ and ‘identity’ address the question of how autistic students conceptualise employability and their future employment prospects. The themes of: ‘adjustments’; ‘impairment effect related issues’; ‘gender’ and ‘identity’ address the question of what difficulties autistic students face in building employability. The themes of ‘identity’; ‘gender’; and ‘framework for support’ address the question of how autistic students experience employability interventions.

### 4.4.1 Theme 1: Gender

Autistic women reported a range of additional issues relative to the male autistic participants. Some participants were aware of a gender component to their difficulty but for the majority this was reported simply as difficulties in accessing resources which the researcher’s unique viewpoint allowed the gender component to be revealed. The context for these observations came mainly from discussions about accessing resources and how lack of diagnosis represented a primary barrier to receiving adjustments and support. From the first few interviews the emerging code appeared to be around diagnosis being a gatekeeper for resources. However, continued data collection showed that only female students were reporting issues with accessing a diagnosis. The benefits of both a formal diagnosis and a label were described by multiple participants. A female participant explained

*It explains why I act in such a way. Why I still act a certain way, and it has helped me now. Because, as soon as you say to someone now, in an academic environment, ‘Oh I’m autistic’ then they immediately go ‘Well right then, what can I do to help you?’…which is exactly what I need because I learn in a very specific way. So, it’s definitely helped. It’s helped a lot.*

A male participant described his rationale for getting a diagnosis as ‘[I] *was looking for something that would help. It helped me to get benefits. I could access resources*’ and compared that to before the diagnosis when in relation to support ‘*I had nothing*.’ A male participant explained

*Having a diagnosis has been useful. It’s given me access to support I wouldn’t necessarily have had at school and university. Those things are very important.*

The benefits of a diagnosis weres not always funding related. Several participants described the effects of having an explanation (revisited in the identity theme) but all participants spoke of the benefits of a label. Another female participant with a longer standing diagnosis explained the benefits for her in having a name and label she could use

*It mattered at the time because I was trying to get funding. So that was a practical thing…it mattered because it was then, um, beyond all doubt, sort of thing, and it gave me, not an excuse but an explanation for things. So it meant that people couldn’t tell me that I just had to get over things anymore because I could just pull out this trump card when I’d say ‘what I really have to do this little ritual’ and before people would just say ‘you don’t have to do it’ and I would say ‘but I feel like I have to do it’…and they would go ‘no you don’t, no you don’t. Don’t be so stupid’ and now I can say, even though it’s exactly the same process, ‘I say I feel like I have to do it because I have Asperger’s and everybody goes ‘okay then if it’s because of Asperger’s then of course you do have to do it.’ When of course, all along it’s the same process, the same need, but then people are more respectful of it if it’s got a reason they can name*.

That is not to say having a diagnosis automatically leads to appropriate treatment as will be discussed further in relation to the themes two, four and five. Data from the open text questions in phase one illustrated some difficulties in having the adjustments required accommodated:

*I would have appreciated the lecturers respecting the one of two concessions to my disabilities that the university granted me, the right to ask for additional time on my assignments. I even had one lecturer say to me that she never read the disability notes attached to students' assignments and that she thought it was a terrible idea that we were allowed to ask for more time as it would just make us used to being able to ask for it*

Despite this all participants reported some benefits from having a diagnosis so differential access to diagnosis reflects an additional burden for female participants. All female participants explicitly labelled the process as difficult themselves or described a process which was difficult. In contrast, no males described difficulties in accessing diagnosis and when it was mentioned it was in an off-hand way as if it were something that would obviously be received if required. Male participants described diagnoses as a straightforward process, for example,

*there were a couple of times when I was taken out of school and taken to a doctor’s office…The actual diagnosis was the first time I heard the name Asperger’s Syndrome and I went on and did my own sort of reading and stuff about it and stuff just sort of clicked into place after that.*

Another male participant described requesting a diagnosis ‘*more out of curiosity*’ suggesting no difficulty in accessing. The ease of this process for this participant was interesting given he reported no particular need for support and that ‘*the DSS have helped me to apply for a Disability Allowance but I haven’t got round to using it yet.’* In contrast, four female participants reported misdiagnoses before their autism diagnosis, and all reported other difficulties in accessing diagnosis. One female with a relatively easy process was referred to CAMHS because of anxiety and after the case was escalated to a clinical psychologist. Asperger’s Syndrome was diagnosed. Even she reported several years of wait. Other women reported:

*I’d been since I was thirteen diagnosed with an ever-changing anxiety, OCD, whatever and I just think nobody wanted to say ‘God we’ve been doing this wrong for five years*’

and another described receiving a series of diagnoses: ADHD as a child, later autism, that diagnosis was repealed when she was sectioned with depression, before being diagnosed with Asperger’s Syndrome and finally with classic autism again. A third believed her difficulties in accessing diagnosis stemmed from professionals’ understanding of the condition focusing on males’ presentation. She explained

*…when I was diagnosed people were more aware of how autism presents in boys. So the things that a typical autistic boy would do, wouldn’t apply to me.*

Differential presentation of impairment effects only partially explains differences in diagnosis experiences though. A male participant who described himself as highly atypical of autistic people and listed several diagnostic impairment effects he did not have explained his diagnosis at age ten as:

*A specialist just happened to come into the school and saw me and said [clicks fingers] ‘he needs to be assessed’ [laughs]. So when we went over had the assessment, [it] got sent to the school and that was that.*

### 4.4.2 Theme 2: Adjustments

Finding one looked at differential access to diagnosis and how diagnosis was key in allowing access to adjustments and resources. The subsequent adjustments were the focus for finding two. This theme explores positive adjustments, those which were absent but needed and finally those which were counterproductive.

A range of adjustments and services which had been made were viewed positively by recipients, including those who did not actually use the services available. Participant three described the reassurance of knowing

*I can make an appointment if I want to and just knowing that the option is there to go and talk to is great, even if I don’t need to go and do it.*

The pre-entry sessions for autistic people were seen as beneficial for social and information purposes and participant eight praised support she had received throughout explaining ‘*all the help I’ve received, I’ve like used, or I’m glad to know it’s there if I do need to use it, so far.’* Several participants named personal mentors as ‘*very useful, very useful’;* or described support they have been given. Higher education was generally described as being beneficial and more likely to accommodate their needs. One participant argued

*universities are a much better place to be autistic than a school or anything like that…because they’re willing to accept people being different.*

Not all students who could have benefited from services were aware of them though. Participant nine responded positively to hearing about an autistic specific pre-entry session but had not received details ahead of time. Staff members reported some systematic problems in cascading information from the DDSS to individual departments, meaning students may wait a long time without adjustments in place. However, participants themselves mostly discussed lack of adjustments in the context of work placements or work experience they had found themselves. No student reported problems with a university organised placement and staff interviews showed creative planning had gone into gaining work experience for individuals who could not self-access. For example, the Taste of Work programme was used as a type of sheltered placement following a one-to-one staff preparation for one student. Self-accessed placements were more problematic. Participant five reported

*I kept getting kicked out of placements…My behaviourisms apparently weren’t appropriate enough.*

When asked whether she raised the issue of lack of support and reasonable adjustment she responded *‘yeah, yeah [at] several points, I still lost my job.’*  Participants did not always feel confident in requesting adjustments and some reported fear they would never work because of stark messages given about the importance of work experience and so tolerated work which was harmful to them. Participant twelve recalled taking a job where she had to interact with the public because she was so worried about not having work experience:

*I remember one occasion I was just quite overwhelmed so I pretended I was sick really so I could get let home I mean I was fine I was just overwhelmed.*

Knowing that she had to do the work meant

*I couldn’t sleep, and I remember getting up worrying that I had to go and meet new people.*

For this participant the effect of trying to work in an unsuitable role had long-term effects

*I think it’s probably had an impact, especially anxiety and stresses and interpersonal issues and just even like relating to other people a bit.*

Participant four who had extensive work experience and was a mature student explained his views on appropriate workplaces for learning arguing *‘you need to work with a person you trust from whom you can learn everything from.’*  The benefits of situated learning were described by several participants in the terminology of having a supportive person or a friend in the workplace. Staff interviews revealed case examples of students who had workplace mentors who had eased transition and solved problems on the ground.

No participant reported employers making adjustments to accommodate differences after they were struggling. However, this does not mean it did not happen, only that it wasn’t as salient in their minds when discussing work or work experience. Participant four talked about problems being associated with other staff rather than the environment explaining ‘*My problem wasn’t with the…it was to do with being isolated from the other staff. You didn’t really get to know other staff. The longest friend I’ve ever had said that he was autistic as well*.’ Several reported making changes themselves though to deal with the extra strain involved. Participant fifteen reported making adjustments herself

*I’ve learnt from that that there are strategies when used from school as a child for example that could really, really help me in work … [I stopped using them] Because I thought that if I don’t use them, I’m more grown up and independent and I thought that that’s how you be an adult and that those strategies are like childish.*

She had previously refrained from using them believing they would be frowned upon in the workplace and explained she felt she needed explicit permission to use techniques such as wearing noise cancelling headphones or stimming to control anxiety.

Several participants explicitly talked about the need to educate employers in particular about the strengths of autism and about discrimination which was built into their recruitment processes. Participant nine expressed her experiences as:

*I think when people get to know me, they [her strengths] become evident...there are things which make me attractive to employers. Like, I’m very academically driven, the fact that a lot of the ways recruiting works aren’t angled to me…[they] are going to highlight me weaknesses rather than my strengths.*

Participant seven felt this lack of understanding was inherent in the university as well with employers. She explained:

*I think it would be good, the university and not just the university, schools, employment and people would have a reconsideration of what autism is and what the potential strengths and the potential shortcomings and try to understand how these people may be an asset rather than a detriment.*

Participant four laid out how he previously felt out of place and felt he was at fault. He now believes:

*…other people are the problem. So, the extent to which you can create an environment in which you feel comfortable and, to an extent, feel successful, you know, for the greater part of my life...I’ve always felt like a complete failure.*

He argued lack of desire to understand his position by employers resulted in his feelings of inadequacy, which he felt were not objectively realistic. He wanted to give specific advice to the university:

*If you work with employers you really need to get them to see the value in working with someone with autism. That they are bringing things specific and special to that environment which an employer would find valuable.*

The notion of positive positioning of autism is revisited in theme five about framework for support.

Whilst participants did not explicitly say at this stage the university had failed to make adjustments, several students described failures in the adjustment process but did not recognise them as such. For example, participant eight described an adjustment which should have occurred:

*… they’re supposed to have it so that one of the PhD students come up to one of the rooms I’m in and ask if I need any extra help, but that didn’t happen the last few times so I’m going to have to kind of ask why and try and get it sorted.*

Even whilst recounting a failure of service which had gone on for weeks, she praised the idea of any attempt at adjustment, indicating her low expectations. For many students the adjustments they received increased feelings of isolation and difference from other students as they often involved studying alone. Participant four described his loneliness from working alone and the benefits of an autism social group he attended outside the university to counteract this:

*There is never more than five or six…I think small groups are great…We were all sat on tables and our group was quite nice and that was one, two, three, four and sometimes a visitor would come and that is quite a nice size.*

Some participants described adjustments impacting their learning and therefore long-term employability. Participant one described his experience of doing a group project alone as an adjustment:

*… that doesn’t prepare me, it’s worse, it doesn’t prepare me for the real world.*

He argued that the adjustment was not appropriate as it did not scaffold his own learning in the task, only that removed the requirement that he do it.

Whilst other participants had reported finding the buddy system beneficial participant nine found that whilst:

*I never met up with my buddy because it was just another social interaction I had to have in fresher’s week.*

He clarified:

*…it’s best for me to just push through these first few weeks when it’s difficult to find my way around because it’s still easier than having to rely on a person.*

Freshers’ week was referred to by four participants as a time of great stress and emotional burden due to meeting new people. Two participants referred to feeling ‘burned out’ by this period and described concern about similar processes if joining a graduate scheme.

Practical adjustments were also problematic for some participants. In particular, the notion that adjusting an overcrowded environment was to supply one with no other people or stimuli was challenged. Three participants described problems with seemingly silent rooms. Participant sixteen clarified the issues:

…*some of the lights, then they become really overwhelming again because there is no background noise to drown them out and it makes it quite difficult to concentrate and keep track of time because I can use noise to keep track of time. Like if you hear, the long buzzing of the lights, it’s easier to drift off and daydream because there’s nothing to break it up.*

She was critical of the superficial nature of the adjustment and argued that the university should consider the core of what was wrong with a situation rather than make individual adjustments. She reasoned:

*I just think it’s silly to have adjustments for exams because the problems that people with autism have with exams, they’re problems that are inherent in exams. It’s the exams in the first place, it’s the going and sitting in room and writing down all this knowledge, with no outside help, in a really artificial situation that’s a problem and you can’t, you know you can do all these little things to fix it and you’re not fixing the core problem. There’s things like that where they’re not actually addressing the core problem, just trying to sort of plaster over it. But I still think the adjustments are useful and everything but you’re better off using that time and energy to come up with a better assessment system.*

In this section problems with adjustments were discussed. Participants themselves have described failure of organisations to understand autism as a specific cause of this. Failure to request, or organisations failure to provide appropriate adjustments has also been illustrated. A third issue has been evident that adjustments are being made without consideration of the perspective of the person receiving them. Autistic people are less likely to complain about failures in service due to a combination of past experiences, comorbid anxiety and difficulties in understanding how to raise concerns or fear of losing existing adjustments if they complain they are unsuitable. Participant sixteen explained eloquently:

*It’s impacted my ability to access things I’m entitled to at university. So to access disability services and so on because it all relies on your ability to go up and ask them for help with doing things. For example, I had to ask them, I was supposed to get some software, they were going to pay for the software but I had to order it and talk to a person on the telephone and so on who distributed the software and things and that meant I couldn’t get it. I had a lot of problems with it, with trying to talk to people and trying to organise that sort of thing. So that impacted me.*

### 4.4.3 Theme 3: Identity

Theme three draws together different aspects of the data related to personal identity and how that impacts behaviour. The effects of adjustments on loneliness was touched on in theme two and loneliness is explored more fully here. Different techniques and approaches adopted to attempt to fit in with other people are then considered with specific consideration of language learning and working with children. Identity itself is then explored with focus on the importance of retaining personal agency for identity and a discussion about autistic labels and their use.

Two thirds of participants described loneliness as a problem associated with being autistic. Participant one described how he became more isolated over time:

*… I wasn’t really making friends as such, as I say, so as I say, I became more and more isolated. That became particularly key, you know, in the second year when most people had made their friends, as I say, and then they kind of, they finally get, they kind of move out of halls and you know, as I say, they kind of move out with the friends they’ve made and, you know … (drifts off).*

Participant four described similar experiences explaining ‘...*one of the biggest problems for people on the spectrum for me is that sense of isolation.’* Participant twelve acted as a student representative and found this common amongst autistic student. She explained:

*a lot of autistic students were struggling in the uni accommodation because having issues socially, just being social with other students or just being in that environment.*

Two participants reported different experiences, however. Participant eleven described how he had met friends through pursuing genuine interests in societies and now has ‘*a fantastic group of friends who every single one is good.’* Participant twelve’s experience were less positive as she described self-isolation rather than loneliness. The notion of self-isolation as distinct from isolation fits with the reported experiences of other participants though who put self-blamed for their isolation.

Participant four spoke fluent English on entering university but described how

*Nobody was trying to exclude me or anything like that but I kind of felt like I don’t have that level of communication. I was too shy to ask questions or to be like ‘I’m a foreigner, I don’t understand.’ Then after my first year, when I went to my first excavation. I had a chance to meet people in a more intimate setting. Then I had the chance to actually socialise. Because, one on one is much better for me, it’s easier.*

Participant seven was more explicit in self-blaming explaining ‘*I felt a bit as if it was my fault for not socialising enough.’* She explained she had actively tried to learn techniques to make friends. Three participants described making conscious decisions about accepting loneliness. Participant nine outlined how

*I’m more academically than socially driven anyway. So, a lot of me doesn’t worry if I’m doing alright socially, if I’m doing alright academically*.

Similarly, participant eight explained:

*I’ve had quite a lot of trouble with making friends, erm, so I sort of struggling to make friends and that then really upset me, it was like, it affected my ability to focus on what I was supposed to be doing in the university because I was getting upset by that*.

For these students, loneliness was framed as a necessary part of studying, but one which was only problematic if it impacted their longer term academic or career goals. Not all participants took this position. Participant thirteen had been successful in building relationships and was prepared to miss opportunities which would help his employability so that he did not risk those friendships. He described his fears that

*I feel as if I come back from a year’s placement with a lot of new people even in my classes and in my lectures because I would have shifted a year and I wouldn’t have as many people to talk to. I wouldn’t have as many people who have like been in my circumstances.*

Equal numbers of participants were up front about their autism when meeting people as attempted to hide it attempting to fit in. Participant three demonstrated some ambivalent feelings about autism, describing both that he did not ‘*really think about Asperger’s Syndrome*’ and that he consciously changed behaviours so that he did not appear autistic. He described problems with concentrating because he did not want to stim in a situation as ‘*it’s inappropriate to be flapping around*.’ He used derogatory language around autistic behaviours several times and at points attempted to distance himself from the condition. He described in a pleasurable reverie how he ‘*used to find soft things and brush them along my upper lip’* something he stopped when ‘*I realised how weird it looked*.’ His attempts to manage without a stimming tool were not always successful though and he described how without it:

*…people will get annoyed… [when he is] shaking my leg and that does annoy people around me and they’ll be like ‘****stop****’*

He was the participant who described the most conscious attempts to fit in with his peers explaining

*I’ve spent a lot of time practising, practising and learning to play football, for instance. So I’ve been sort of honing the skills wherever I can*.

He proudly explained how if told of his autism friends would say ‘*oh, I’d never have guessed*’ describing other autistic people as being ‘*far down the spectrum*’ and explained ‘*I’ve just decided to handle it by, um [stumbles over words] mitigate it as much as possible*.’ His friendship with other autistic students had led to some reflection on these behaviours. He explained:

*I have a few friends who have been diagnosed with Asperger’s Syndrome and they all have different ways of dealing with it. Whereas they sort of embraced that and they’ve used that as part of their identity and so it’s quite, not necessarily obvious, but it’s quite, if they say it, it makes sense and it’s part of* ***my*** *identity, I’m not trying to necessarily trying to fit in because I like being unique but I try and learn social cues and I’ve worked really hard to fit in more socially.*

Participant sixteen also mentioned autism was core to identity but described the need to hide it. She explained

*I’m not bothered about it but I know other people, other people have told me to hide it in the past or it will hurt me to get diagnosed with it and I know other people who have got diagnosed too, hide them and it is like an admittance, whatever.*

Seven participants described anxiety about interacting, from revealing their autism or generally not fitting in because of it. Participant seven described hyperfocusing on English speaking skills as a reason not to interact:

*I was very socially anxious to go there and make mistakes. Even if it was the very simplest mistake, things like a simple grammatical error that a native would do. It just drove me insane.*

Participant sevendescribed hiding her autism so as to ‘*Not, making other people see me as lesser than.’* She described ‘*trying to overcompensate.’* Participant nine had another rationale for not disclosing, being concerned that it became *‘a lot of questions.’*

Participant eleven attempted to fit in by never *‘disagreeing with people in a group.’*

As well as the fear of being recognised as autistic a minority of participants spoke about anxiety associated with not knowing what was expected of them. Participant thirteen asked the interviewer several times about her expectations of what he should answer during the interview and described his difficulties in social interactions stating ‘*I don’t know what to think. I don’t know what they want me to think.’*  He described difficulties in knowing if he should do work experience because he had heard conflicting things and did not know how to fit the dual expectations of tutors and his parents.

For those participants worried about fitting in, and actively making efforts to meet expectations the effort involved in this process was described as high. Participant seven described a previous workplace where staff were

*…more withdrawn, more intellectual. So my being withdrawn and not necessarily joining in with all that fun was not necessarily viewed as something bad. I was perceived as being more intelligent. Whereas where I’m working now, I’m kind of having to face the same reality that I was facing before, you know: why do you avoid? Why don’t you join in? So, I just think that it’s more fitting to my personality.*

Reducing the difference between the expectations of others and her ability to engage was cited as the reason she was shifting focus *‘thinking about computing’* even though *‘it’s quite unrelated’* because *‘I noticed that I had the least problems fitting in.’* The effort involved in fitting in with employees at her work of choice was too great. Other participants described the efforts involved in interactions at university. Participant eight explained:

*Like when I did start to make friend I started to feel more, like tired, and worn out by it and more, anxious and so less strong anxiety in the moment but more anxiety over the day.*

She described concerns about being ‘found out’ as autistic when the effort of fitting in was too great*.* She found relief in having found a small group of friends explaining:

*It’s like saying ‘I don’t really need any more friends’ and it’s like saying that ‘I don’t have to force myself to try and make more friends in the XXXX class.’*

Some participants developed strategies to hide their discomfort. Three female participants described focusing on working with children to avoid the problems associated with adult communication. Participant sixteen was attracted to this type of work because:

*Children, you can talk to them and that’s easy. They’re not judging…*

All three acknowledged that this type of work was poorly paid and did not fit with their undergraduate studies but used it as a way of earning money which did not overload them. Unfortunately, they are unlikely to be building the skills and experiences necessary for graduate level careers. Language learning was another common tactic, with a third of participants mentioning their skills in other languages. Not all participants were asked about their proficiency in foreign language as this is an emergent finding, therefore the figure may be higher. Those mentioning alternate languages had functional use of three to six different languages. This contrasts with the British Council’s (2017) finding that only 25% of UK residents speak even one additional language. Participant sixteen explained

*I could just talk more [in non-native language]. That I wasn’t as afraid of making mistakes I think because I was instantly recognisable as being a non-native speaker of German…I’m sort of allowed to struggle more I don’t find it embarrassing to get it wrong so I’m happy to try and fail. Whereas I’m not happy to try and fail in English.*

Participant six supplied a similar rationale for language learning, again seeing it as easier to communicate in a foreign language:

*It’s good that if you make mistakes, or if you use the language unnaturally. People will put it down to ‘oh you’re foreign’ and it’s not your native language… problems in your communication are much more forgivable.*

Participant seven described the enjoyment of being correct when using foreign languages:

*I like the structure. It’s like complex systems which I can learn perfectly. It’s something like, you have a map essentially. In social interactions you don’t really have a map of anything. You just have to guess and even if you guess people will say to you ‘no you’ve done it wrong.’ With no justifications. At least with languages and with sciences, you can be certain: You will study it. You will get it.*

Despite the obvious employability benefits of language knowledge this participant clarified ‘*it’s not so much in order to communicate, to be honest. Just my personal interest in systems.’* The participant reported being fluent in six languages because of hyperfixations on language learning and did not see these skills as marketable, not wanting to communicate generally. This descriptor of language learning as distinct from communication was present in other explanations of learning languages. Participant six explained ‘*I like learning Korean...it is all very logical, and I quite like that aspect of it.’* When such fixations resulted in employability skills was not always recognised by the participants themselves. The phenomenon was backed up by DDSS staff interviews, who described how some autistic students began with a deep interest in Japanese culture because of the formality, with clear social rules, which subsequently led to Japanese language learning.

For those participants who were actively using their language skills they represented an opportunity to not feel like the ‘other.’ They were not different because of their autism when using foreign languages.

The extent to which autism was regarded as core to identity differed and was related to positivity about the condition. For a third of participants autism was described as central to their identity. Participant eleven explained ‘*I don’t think of it as something that defines me but as a part of who I am.’* Participant sixteen explained:

*It is a major part of my identity. It was actually quite scary when I first realised what Asperger’s was and I looked at all the list of symptoms and stuff and I just thought, everything I do, all my interests and my behaviours and stuff they can all be summed up by this list of symptoms it made me think ‘who am I outside of this’…it is not something I have. It is not something you can take away from me ‘cause there wouldn’t be anything of me left without it.*

For the majority of the remaining participants autism was considered as a smaller part of who they were. Participant thirteen explained:

*I was also thinking ‘it’s not the entirety of me because I’m not the same as everyone else who is autistic.’*

Only one participant argued that autism was not a core component to their identity. Participant fifteen explained:

*what I think about autism and diagnosis and the thing is I’m me, I’m [name] I’ve got lots of things going on but that’s not this, this, this or this but I’m me.*

Other participants picked up the notion that autism was something that one had, rather than who one was. Participant nine explained:

*when I hear like ‘person with autism’ I just imagine a person with a little bag of autism with them that they can put down at any time, but autistic person or Asperger’s or Aspie or whatever seem to, they’re a part of you the same as you’d say sort of like you’d say brunette rather than you’d say a person with brown hair*.

She argued that the ‘person with’ language ‘*says a lot about other people’s attitudes towards it*,’ i.e. viewing it as a negative. Something participant sixteen reiterated:

*I don’t like anything that says ‘person with…something.’ I especially don’t like the ‘suffers from.’ It is people who think they are being polite but you only say person with if it is a fault. It’s this idea that there’s no naughty child. There’s a child that does naughty behaviours, but you wouldn’t say there’s no good child, only a child who does good things. Again you say a beautiful person, and intelligent person if it is something you see as positive you don’t use that person first language. You don’t say a person with intelligence because intelligence is seen as positive. It shows you that they see it as a negative thing because what they’re trying to say is ‘it doesn’t matter that they’ve got this thing because, look they’re a person anyway.’ It’s just a problem that they have, they’re still a person. They’re trying to prove you’re a person without it and they shouldn’t have to.*

Such detailed explanations were presented by four different participants: all of whom had expressed positivity about autism and some degree of exploration of the political issues associated with the condition. This raised consciousness about the condition reflected more positive self-image as well. Participant eleven:

*I’d say I was autistic …I know a lot of people who are autistic don’t like the ‘person with…’ language and as something I really don’t like it’s a person who suffers from…like I say, someone who is autistic doesn’t want to be told they are suffering with autism when it is so integral to who they are.*

For those participants who were negative or ambivalent about the condition, there was an associated negativity towards it. Participant seven described they were not ‘*really at peace with the diagnosis. You know, I didn’t really believe it’* explaining it took some time to come to terms with it. This was a common theme, participant one explained ‘*I kind of sort of well went into denial of it.’* He explained that the denial was not related to not believing the diagnosis, but fear of how he might be labelled by society.

*It was something I was kind of wary of when I was younger: if I tell people I have Asperger’s then do they see a person, or do they see a label.*

However, over time he

*stopped worrying about that. I don’t have a problem of saying I have Asperger’s Syndrome.*

Ambivalence about the diagnosis was always described in relation to the negative effects and stereotyping it might bring for participants, rather than actual disbelief or lack of acceptance. Participant fifteen clarified:

*When I was younger, I kind of loved it and hated it. I loved it because I knew I was very different but couldn’t understand why and I couldn’t understand why people couldn’t understand me.*

This ambivalence was present in more than half of the transcripts and existed even for those who had personally sought the diagnosis. Participant twelve in common with other participants, distanced herself from other autistic people explaining ‘*I think I’m really on the high end of it.’* Participant thirteen took a similar position arguing:

*I’m not like a typical [autistic person]. I’m a lot more extraverted than other people. I have a lot more interests or a lot weaker specific interests than people that I know.*

At the same time, she had argued for the use of the term ‘aspie’ as descriptor because

*it’s something that tends to be clicked straight away by people who understand or completely ignored by people who don’t. It’s a good way of gauging who gets it or not*

demonstrating more positive feelings and associations with the label if talking to people who have a good understanding of autism.Participant fifteen described a similar shift in personal acceptance and behaviour depending on whom she was with describing her use of terminology changing:

*…sometimes I will say ‘I’m autistic’ because autism is part of who I am. It’s part of my identity. But sometimes, it depends on who I’m talking to. If it’s someone who is like trying to, like tell me off for something that I’m doing that’s part of autism. Then I’m say I’m [name] with autism. Because then I like to separate it and say I’m just being me but I’ve got autism.*

Whatever personal positions individuals adopted relative to autism the fear of the label being used to discriminate against them was common. Participant thirteen explained:

*[laughs] I’ve now been branded like a cow, carry this label around and present to everyone.*

Participant nine described the decision not to disclose to a work experience provider:

*The sort of advice always was to declare it. But, I know that there’s, as pessimistic as it sounds, it is not an attractive feature for potential employers. While they might be disability friendly they probably have some assumptions about what that label will mean as an employer.*

Interviews with DDSS staff revealed case examples of students choosing not to disclose to anyone after diagnosis and choosing only to go onto be assessed on the basis that the information was confidential, and they could choose whether to have it on their records. Participant sixteen described the low-level difficulties this desire to hide the condition led to:

*The biggest problem with the physical aspect of it is that you can’t behave the way you want to because of societal rules and social norms and so on. So like, for example, I always like to sit perched, I don’t like to sit with my feet on the floor. I like to sit on the edge of things. I don’t like to sit down normally and then I always have to sit down normally, whenever I’m not at home or anytime I go out and then it makes me uncomfortable the whole time I’m doing it and it just adds a negative edge to whatever I’m doing all the time...*

Deciding to actively disclose and whether to attempt to hide autistic elements of identity was associated with a fear of being restricted or branded as a result. Participant four described how:

*people have this idea that people on the spectrum like repetitive tasks. But sameness and repetition are not the same thing.*

He drew out the distinction between methodical and repetitive work with a range of examples and expressed a concern that a misunderstanding of the desire for stability as part of the condition might lead employers to provide very boring mundane and repetitive work. Participant nine articulated her concerns that employers may focus on specific elements of the condition and ignore others:

*You know, the stereotypes are like very logical very methodical which aren’t like huge creative strengths and thinking differently and all of those things which are important to creative careers but aren’t the first assumptions people have about people with autism.*

Interestingly, participant nine framed this stereotyping as a weakness of neurotypical thinking arguing:

*I suppose typical is something that a lot of, that is quite a neurotypical idea. Like most of the people I’ve met who are autistic are like completely different but because you have this one similar like diagnosis people want you to have particular traits.*

### 4.4.4 Theme 4: Future Plans

Disclosure of an autism diagnosis was considered in theme three as it relates to identity. Participants future plans were also strongly tied up with disclosure issues, in this case disclosure to employers. The prompt questions for discussion about future selves were impacted most by iterative changes as participants found it difficult to imagine alternate future selves. For later participants the questions focused more on probabilities of what they would do, which participants found easier to conceptualise. All participants drew their responses back to factual elements of their futures, and specific concerns, of which disclosure was one.

It is worth drawing out some specific responses from phase one open text questionnaire responses here as they articulate some beliefs about lack of autism understanding. The anonymous autistic respondents argued there should be explicit attempts to tackle misunderstandings about autism by ‘*some form of awareness for teachers regarding autism and autistic students*’ (anonymous 1) to deal with ‘*widespread stigma and the 'condition' is still viewed as similar to a mental disorder rather than a slightly different wiring in the brain*’ (anonymous 2) alongside ‘*More acknowledgement of different, non-neurotypical learning styles*’ (anonymous 3). These responses help to contextualise some of the reasons why phase two participants may be concerned about disclosure and how it may impact their long-term career success. The idea of labelling was explored in the identity section: participant three provides a neat summary of most autistic people’s position:

*I really don’t like using labels, umm, they’re, ah, I could do a whole rant. I’ll keep it short. I just don’t like the fact that our society has evolved around labels. I really don’t like that.*

All except one participant expressed concern that disclosing their autism would impact their employment chances. Participant seven explained:

*It is definitely not wise to tell your employer, because there is a lot of discrimination going on and I’m almost certain I wouldn’t get hired.*

Participant thirteen explained his rationale for how the discrimination would occur:

*I feel as if I’d be disadvantaged [if disclosing]. They may see me as a weaker candidate for having a disability. Or they may see ‘oh one of the points that he has to bring himself up is that he is disabled.’*

That this position was one held more widely than the individuals interviewed was suggested by several participants. Participant sixteen explained advice she had received:

*Other people have told me to hide it in the past or it will hurt me to get diagnosed with it and I know other people who have got diagnosed too, hide them*

For some participants fear of discrimination in the job market initially prevented them from progressing a full diagnosis and acceptance that discrimination would occur was high, though tempered disclosure was sometimes undertaken, when the participant felt they could not hide the condition with participants waiting to receive a contract before disclosing. Witnessing discrimination impacted the likelihood of future disclosure. Participant seven explained:

*If you are ambitious at all then, I wouldn’t [disclose]. If you just want to get by and coast then, maybe.*

Participant five explained she does disclose but is accepting that it might mean being rejected, seeing disclosure as a short cut to an eventual job loss which is inevitable if the organisation is discriminatory:

*If they’re turning me down purely based on that then I don’t know. It saves me, it saves both of us time though I guess. If they don’t turn me down, they can sack me, so I tell them.*

This individual was inured to discrimination explaining within a minute that ‘*I’ve never really found it [discrimination in selection] to be that much of a problem’* and that:

*I’ve lost a job because of my autism… You know, you’re going to get companies like that. But, I’m not going to lie, there’s no point hiding it.*

Whilst this participant was unaware of her legal rights, believing for example ‘*I think legally I have to declare it now anyway’* most participants named specific legislation which should protect them from discrimination. Only one participant mentioning the law expressed confidence the legislation was effective. Participant three explained that whilst he never had disclosed when applying for work, he believed:

*only good things can come from disclosing it. I think, if they were to say we’re not going to give you the job because of it then that’s discrimination so it is not like it can negatively affect the application.*

Participant seven’s response was typical of the remaining participants

*I mean the law exists, but the employers have so much power so what an employee do… I honestly don’t believe the law is working.*

Four participants mentioned disclosing later so that the job was finalised. Staff interviews in phase four revealed similar approaches occurring when prospective students applied to university in the first place. For example, a family attending open day asked about support available but were adamant no identifying details would be given until the student was safely registered. Participant sixteen described being tactical in waiting to disclose:

*Sometimes I deliberately don’t tell people, things like job interviews and so on but not really for any other environment only somewhere I can see it directly hurting me. I don’t have any problem with people knowing in general, but I do recognise that it has negative stereotypes associated with it there are some environments where I shouldn’t be it, like in a job interview. So, once I had a job, I wouldn’t be afraid to say it. Problem is I wouldn’t say it at an interview.*

Being unemployed was cited as the most fearful future by all participants. This is picked up in theme five (impairment effect related issues) in relation to lack of personal agency. There was consensus this was the worst destination possible. Participant eleven:

*that [worst case scenario] would be having no job I suppose. If I were to go through all of this and have no job, then that would be terrible.*

Participant seven described how:

*I don’t think I can be unemployed. I am too stressed when I am in the process of trying to find a job. I think it is because I take it a bit personally.*

Bearing the strength of feeling in mind about this it is understandable fewer are prepared to take the gamble they see as disclosing autism to an employer.

Despite the difficulties which participants described having faced, autism related issues were only mentioned by two participants as being central to their fears. Both described having had bad issues in workplaces previously and it is probable their experiences made these issues more salient. Participant nine worried about:

*…something that would make me miserable. Working every day in something that, sort of, a restaurant, waiting tables, having to do hours and hours of sort of interaction that I know that having to do that stuff, five, seven days a week. I know I just couldn’t do it.*

She recognised that:

*…if I’m unemployed that’s a huge financial worry. But I don’t imagine I’d be able to hold down a job that’s like working in a restaurant very long anyway.*

She had previously held a job which required a lot of customer contact and described how

*I managed sort of two weeks in WH Smiths…during the Christmas rush, two weeks was all I can do before I said no, absolutely not.*

Participant sixteen described how it:

*…would be important to me would be not having to, jobs that didn’t require a lot of emotional energy. I don’t mind jobs that require other types of energy. I don’t mind a job that takes up a lot of time, for example, but I don’t want, I don’t want to have to deal with people face to face a lot of the time.*

She clarified:

*Making small talks is the thing I find most difficult. But again, I don’t mind engaging with people, and they’re people I know well and get along with. I don’t mind working in a team or something like that with people I like but I couldn’t do like a customer facing role, that sort of thing.*

The extrinsic measures of employment success (status, promotion, pay, benefits) were rarely mentioned as being drivers. Only participant sixteen mentioned pay and this was in the context of giving personal agency, rather than as a status marker. This issue is picked up in the next section. For most participants their measures of a positive future were about using their degree, having work of intrinsic value and avoiding penury. Participant three explained:

*I think as long as I’m not struggling to make ends meet…I’d rather be in a place where I’m happy and I’m enjoying myself rather than have a slog to get through. I’m not superfussed. I don’t want to be rich or anything. I just want to enjoy what I’m doing really.*

Participant ten prioritised ‘*the contents, the intrinsic value of the work is more important than the pay.’*

The work having meaning was mentioned by most participants. Participant three described his worst-case scenario as:

*I’m stuck in some kind of telemarketing doing something just for forty hours a week doing something that I hate…doing something menial that I don’t care about.*

Similarly, participant five described ‘*Not doing anything that’s in my opinion, worthwhile, or in my field of subject’ and* participant seven argued ‘*my life would be more meaningful if I was getting something out of it apart from money.’* Being bored in work was described more often than impairment effect related issues as a problem. This is an important point given the common misunderstanding that desire for predictability or systematicity in work by autistic people meant they wanted repetitious work. Participant six described his fear that he ‘*would be doing a boring job’* and participant ten explained ‘*the worst thing…a job that‘s really easy and repetitive and I’m just stuck in it for a long time.’* However, even jobs which were regarded as highly undesirable were perceived as preferable to unemployment and participants were prepared to tolerate poor work. Participant six explained ‘*if I’m unemployed that knocks onto all your future and other aspects of your life.’* He described:

*a job in summer one time which was extremely tedious, but it was, at least I was doing something, and it gave me regularity with what I was doing with my time.*

Participant thirteen described his tolerance level for mundanity:

*having no job would be worse than having a boring job but, um, I can stick to being the mundane guy. I’m alright with just doing admin, because, I can it’s a good place for me to just keep concentrating and doing the tasks that no one else wants to do.*

Participant eight rationalised the benefits of taking poor work ‘*If I have a job then I have, at least, there is, I have some independence.’* This point is explored further in relation to agency in the next section on impairment effect related issues.

### 4.4.5 Theme 5: Impairment Effect Related Issues

Lack of personal agency was threaded through the interviews. Desire for control and using rituals to create feelings of control are core indicators of autism. Despite this when talking about past experiences participants frequently spoke of themselves as an object without agency, for example, participant one ‘*they didn’t really know what to do with me’* and when asked their own opinions it was not uncommon to give other people’s: participant nine automatically discussed his parents’ views ‘*that in the past my parents have been quite hesitant about whether I ought to.’* Participant one had reflected on this restriction himself explaining:

*you’re a bit different but at the same time, as I say, you know, you know, you’re not special and you’re not going to be Mozart or whatever…at the same time I grew up thinking that the world wasn’t open to me, that things were limited.*

He described outside forces leading him to a particular career:

*in reality, I was trying to force a square peg into a round hole. Yeah, it’s like I felt like I had to be a writer because there’s nothing else for me.*

Interviews with staff revealed case examples of autistic students who had never had any personal agency: never leaving home without a parent until the week before starting university; discussing even minor decisions with parents and deferring to their decisions automatically with no belief they, as Western culture suggests, should ultimately make decisions for themselves as adults. No participants described this as problematic though and indeed alluded to parents as having been useful sources of information and guidance. Problems with lack of agency were related usually to more immediate control of environment though. The square pegs metaphor was also used and subverted by participant four who explained it in relation to personal progression to having responsibility for self, independent of others:

*I think it was square pegs into round holes. I’ve tried to create a round hole for myself, no, a square hole.*

As a mature student he had considerable life experience to reflect on and described his philosophy

*I think if you’re on the spectrum…you need to find your own niche. You need to find something, that is unique to you. Now that could be in work, but it might not be. It is a bit of a problem.*

Other students had reached similar reflexive positions and described a fear of lack of future personal agency. Fear of unemployment was frequently related to loss of control. Participant eleven described:

*Being unemployed means no control over what I’m doing or where I’m going. I’d find that a bit unnerving.*

Whilst participant five explained that unemployment was worse than even the worst job because of:

*…independence: I like to be able to know that I earn the money that I use. I couldn’t live off benefits. As it is I’m refusing to apply for benefits that I’m probably entitled to, because I want to live off my own means. I couldn’t… I don’t want to be unemployed, I can’t, I’ve done it, I will not do it again, no.*

Interviews with DDSS staff revealed it was not uncommon for eligible students to not use services from a desire to be independent and feel in control. Participant seven articulated similar concerns about unemployment:

*I tend to have high anxiety when I don’t have employment and I’ve never claimed benefits or anything like that. I am very afraid I’ll be in a position where I have to claim benefits, or I have to go back to my mum and be like ‘mum help me’ because I’m quite proud of myself for being able to manage without having to fall back onto help.*

The fear of having to return to the family home was mentioned explicitly by several participants. Participant thirteen explained why unemployment was so bad in direct relation to returning home ‘*No job you can’t do anything. You can’t. You are at home and everything.’*

Personal agency was sometimes reported as mechanism for controlling uncertainty and therefore anxiety. Participant eleven described why control was important:

*I like to be sure about what is happening and if I am the person making those decisions it makes me feel more certain*

and participant sixteen described how unemployment would ‘*set me back’* because she would be out of control. Having rituals or controlled behaviours is a common feature of autism, one which was explained several times by different participants. Five participants spontaneously described how having agency in other ways meant they did not have to use those more immediate forms of control such as stimming or ritualised behaviours. Participant eight explained that it was this form of control which meant he was attracted to particular work:

*Yeah, yeah that is one of the things that I think did draw me was…it is mostly working by yourself, or in small groups.*

Participant eleven described working in an environment which appeared superficially highly inappropriate for an autistic person: crowded and loud. He explained that generally ‘*I do not like large groups of people’* and described specific instances

*…freshers’ fair is one that comes to mind. Where everyone is in the Octagon Centre all closely packed. So, avoid that, and nightclubs.*

Despite this he worked as a technician in a nightclub explaining the difference:

*I work in a nightclub, but I would never go to one, as the crowd. Just in a working position, when it’s a working position there is, for me, a distance from the crowd, but it’s very noisy and a lot of people.*

He explained that personal control was the difference:

*One of the things I like about that role is that I can choose where I go within it…there is always a fence or a pole and space and I can move around within it. If I feel I don’t really want to be near people, then I can always go backstage…*

Participant sixteen explained:

*I like, like order in certain things but it’s usually things I can control anyway. I like, um, I like walking the same route to work every day, even though I could do a different one, even when it’s too cold weather and it’s snowing and it’s not, not a nice walk and stuff. I still go on the same route and don’t take a bus and things because I like that routine, but, then I sort of, because I’ve got that control over that aspect. I don’t need as much control over other things like in studying and in work and so on.*

She described this desire for control as overwhelming explaining:

*For other people, it’s more of a decision that they want to be in control, for me it’s more of a compulsion. So if for example, other people might like to take the same route to work, they might like to take that walk, but if circumstances forced them not to, they could, they’d be okay with that I think, whereas for me, even if there’s a lot of things trying to force me not to, like roadworks or like heavy snow. Even when there was heavy snow I still went and did it even though I didn’t want to walk that far in the snow, I didn’t like it. I had to do it anyway because it was more important to me to be in control than it was for me to be comfortable or warm or any of those things.*

She went on to describe how career choice was linked to desire for personal agency through the mechanism of pay. She explained her main driver in work was ‘*pay…I want a lot of money.’* This was explained as a mechanism for having security and control in relation to future agency:

*I prefer having money than having things you can buy with money. Say I have ten pounds and I could buy a dress, or a book or a film with it. I’d rather not buy any of them and have the potential to buy any of them because I’d rather not have lost that potential. So I like, I like the idea that I can do things with money, although I often don’t, I don’t do the things I can afford to do with money because I prefer to be able to do a different thing at a later date so I just keep deferring gratification with it because I find that gratifying in and of itself*

Whilst maintaining concentration is an issue for many autistic children (Patten and Watson, 2011) it was reported by only four participants as affecting their learning. Participant two explains:

*I generally follow, follow the lectures. Occasionally my mind would wander. I’m not entirely sure if I was that good at taking notes in lectures. I was usually writing down everything. I thought, I need to write down everything. I’m not entirely sure why l don’t jot down the most salient points.*

Participant three described affected concentration only ‘*if I’m in a situation where concentration is required and it’s inappropriate to be flapping around’* explaining the inability to stim has a negative effect. For participant nine it represents a major challenge:

*I stru…some rooms it’s not bad, other rooms it’s a sensory hell, but you know, because there’s a lot of stuff to regulate as well as the information to take in which will normally result in either poor notes or very hyperfocused notes and like no sort of engagement with the actual lecture, erm, but no but there a lot of buildings I’m in are fairly near building sites. Which a lot of university buildings are, so you try to keep my headphones on as long as I can until the lecture starts and put them back on as quickly as I can before I leave, because those are the really loud points where everybody is sort of moving around and getting themselves ready to write or leave. Once they’re sort of settled it’s just the noise outside that I’ve got to kind of regulate.*

Participant sixteen was distracted by her own thought processes rather than external stimuli:

*I don’t, I don’t easily get distracted by external things say if people are shouting outside or something it doesn’t usually stop me from being able to work but internal things: if I’m struggling to understand a point I can’t let go of it and move on and listen to what the teacher is saying, or whatever. I have to keep thinking about it until it’s sorted so I distract myself by following a train of thought for a long period of time and I miss things like that.*

She has learnt some skills for stopping her own distraction though:

*I think, the only sort of things I can do sometimes is if, if I catch myself early enough on and realise I’m not going to be able to make sense of something at the time then I can make a note of it and then I can go figure it out later but realise I don’t usually realise how long it will take me to think something through so I don’t catch it early enough.*

Consequently, in all these cases learning can be impacted because focus is lost. Being unfocused may explain some aspects of another phenomenon mentioned, i.e. the hidden curriculum. However, the problem of hidden curriculum was widespread amongst participants distraction alone cannot explain it.

What I have named the hidden curriculum is the phenomenon reported by two thirds of participants in which the individual did not understand something which they believed the rest of their peers did understand and they were uncertain how that knowledge had been gained. Participant one’s description epitomised the difficulties:

*I was reading, I was doing the reading, but they knew things and I don’t, as I say. It was taking me a long time and I, they sort of knew things already and I thought of, I didn’t, they seemed to know things together. It took its toll.*

He stressed:

*…and I didn’t know, know what there was. Others seemed to have been told things or they knew, and I didn’t know about other things…I didn’t know how to, do, I didn’t know lots of things*

and he was confused about how:

t*hey had ideas which, well as I say, I don’t know where they, why, it was things that we weren’t* ***told*** *to do.*

In part this problem may have arisen through missed cues caused by distraction, however the type of difficulties suggests some student interaction was occurring without these individuals. Participant sixteen explained:

*I don’t always understand where people are coming from with points and everybody seems to come up with the same ideas, for a lot of things and I don’t understand. What I can’t understand is how they’ve all come up with such similar ideas and I haven’t, because if it was something, if there was some hint about it then … there must be some trigger for coming up with an idea and what I don’t understand is if everyone else has got it why hasn’t the same trigger worked on me and things like that. Why have I got something different from it? Because the same experiences should produce the same effect.*

A staff member interview revealed their course relied on students learning from each other and recognised this may be an issue for autistic students who may miss the richness of the informal aspect of learning. Differences in thinking approaches may also play a part in the hidden curriculum. Participant ten gave examples of things he had not known:

*In a way, they don’t talk explicit about how they do it [decision making]. I learnt that if a cow has heart condition, you don’t treat it because most people don’t have the cost to treat it so they don’t. So you just say poor prognosis without saying why.*

This participant found difficulty in recognising what level of directness and honesty was necessary and beneficial in different circumstances. This example illustrates his problem with understanding the depth of communication which needs to used, in any circumstance.

The hidden curriculum was not just a feature of taught components of the university experience. It was reported as an issue in understanding what was required in extracurricular activities too. Participant fifteen described her distress at seeing:

*…the majority of actors I’ve ever met, in fact every actor I’ve ever met, it’s like a rule that nobody’s ever told them, but it’s a rule that they write on their script if a director’s told them.*

For her, a text was a revered object and should be treated as such. She did not see the practical link between having the notation immediately in front of her when rehearsing or recognise that this drove the writing behaviour. As excellent memory recall is a common feature of autism it is probable, she did not need the written prompt so did not see why others did. With the assistance of her mentor participant fifteen actively tried to find such rules and understand them and explained:

*Now I’m very good at knowing how to do things that I’ve never been taught how to do like socialising and joining societies and things. [in the beginning] I didn’t do any of that because I didn’t know how to do any of that because nobody tells you how to do it.*

This was something participant twelve felt was lacking for them:

*Having someone to work with you keep on keeping on can be quite helpful otherwise it’s all too vague and abstract.*

Dwelling on the insignificant was also a feature associated with the hidden curriculum. Participant one described how he had got focused on expressions he did not understand and so did not take responsibility for his own employability. He described how:

*I think I had a kind of a, (3 second pause) I guess I had a rather foolish attitude (2 second pause). It’s like I’d sort of be, like I’d see, sort of, American expressions like ‘hit the ground running’ and ‘team player’ and the like and it’s like (12 second pause)* *(Asks interviewer as a question) What* ***does*** *it mean?*

Even after recognising his attention had been inappropriately focused on these terms, and with a considerable time gap he was still distracted by this insignificant detail. For some participants they recognised that the gaps in their knowledge meant they were not preparing well for their careers. Participant thirteen described inertia in accessing work experience as ‘*I feel as if everyone else is just getting their CVs and covering letters written by everyone else.’* They did not recognise how to present themselves and assumed that other students were receiving additional help with this. There may be some intersectional elements to this issue. Participant twelve (a first- generation entrant) described problems common to other widening participation students:

*I’m sure other people must have been aware. It may be that other people had a better support network going in, like parents saying ‘let’s get you signed up’ but I didn’t have any of that because I was living alone before I started uni. So, I think for someone in my position it was quite difficult because I just didn’t have a clue*

lack of understanding of what was required meant they did not take the practical steps necessary to build employability.

A level of literalness in interpreting guidance and instructions also impacted career decision making and academic success. When instructions had been given as absolute and recognised by neurotypical students as hyperbole autistic students had accepted them as factual. This extended from choosing subjects and careers to practically tackling tasks. Participant fifteen described how she had taken English, maths and science for understanding at A level despite wanting to study drama. She explained:

*when I was at secondary school they went on and on and on about English maths and science and in order to go to university you have to do English maths and science.*

Even while friends had taken other A levels she had held the literal position that these were the only three subjects with which you could access university. The truth was only revealed to her when a tutor helped her with her UCAS application and remarked on the odd combination and lack of link to her subject of interest. Participant sixteen described this literality impacting how she approached tasks:

*One of the things is knowing what people want. Like in history we were once told to do some research, so I did, I spent loads, I spent loads, ages doing and they didn’t say write it down, and I got in trouble and they did write it but never said it, they never said write it down and I’d done it.*

Similarly, participant thirteen explained why she had missed deadlines for work experience arguing ‘*they were basically saying apply now or you won’t get anything ever’* after that immediate period was past, she accepted there was no opportunity to access any so did not bother. These misunderstandings demonstrate the importance of clear and accurate guidance being given and highlight the potential problems when information is provided off the cuff.

Interviews with faculty-based staff members suggested there was a three-week vulnerability for students between arriving and getting their support plan set up. Staff from DDSS described structural problems causing some delays for some students. Even after adjustments were made however participants raised a number of issues impacting their immediate learning as well as their longer-term employability even after adjustments had been made. The noise and other stimuli of lecture theatres were reported to be problematic by five participants. In particular the changeover period was most stressful. Participant eight explained:

*I find the beginning of lectures when people are still talking distressing when it is a lot of people talking in one room.*

She described:

*…what’s usually the worst is if I get there early and there will be a few people there early but also people trying to leave because it is the end of the lecture before and that can be like a really horrible experience.*

Another participant (eleven) found he could cope if familiar with spaces but:

*If it’s somewhere very, very new where I haven’t been to before and it’s quite large then I can find that quite difficult.*

Participant nine reflected:

*I notice that I, that if I’m getting distracted then my fine motor skills are worse, and I can look back at notes and see that my notes are not as neat because I was too busy thinking about other things.*

Again, it was lectures which proved most problematic, but any large environment could be difficult. Participant eight explained that

n*oise is the main one. But when I become very stressed, I can become very sensitive to touch and even if I’m in a situation when I’m not stressed out, so like if I’m in a crowd and somebody accidentally bumps into me that will really bother me. Or, if someone, for example, sometimes when I get upset people will offer to hug me and I don’t know. Sometimes I’m okay with that and sometimes it will make me feel a lot worse as well, and also heat sensitivity I get quite a lot. I have a problem with overheating sometimes, so when I’m stressed, I’ll feel like really hot and not be able to cope with it*

Participant fifteen argued

*Lectures as a whole are a nightmare. There’s too many people which is too many distractions which is too much noise. I use noise cancelling headphones and ear defenders but it’s still too, too much, too, too much sensory overload.*

She found

*the bigger the group the harder it is, because if there is a lecture with a hundred students in it then that’s a hundred distractions, one hundred different hairstyle, one hundred different lunchbags in their backpacks and a hundred different smells and it can all be too much. So, so quite often, at university I had to have a lot of breaks from lectures, into smaller quiet rooms*

Being in sensory overload then made it difficult to interact with peers which was already a problematic area. Communicating with peers was a problem reported by all participants. Participant six explained he struggled to recognise how to communicate and described his adjustments ‘*if people perceive me as rude. Which people often do.’* In response he would ‘*overcompensate by being polite to the point to which no actual information gets conveyed’* failing to recognise how to strike the right balance. He displayed genuine concern within the interview as he did not understand how his style of language impacted. He explained

*I’ve had people assuming that I don’t like them or I think they’re stupid because I talk to them in a particular way. But I don’t actually. I haven’t actually said anything that means that. They’ve just assumed it for some reason.*

He reported situations which showed he did not understand social rules such as announcing your departure before leaving

*I’ve had things where I’ve just left a situation and people assume it’s because I’m cross but it’s not it’s because I’ve got something else to do. And I’ve had to be like ‘no I’ve got to do this’ but I haven’t actually explained it, kind of thing.*

Other participants reported similar gaps in their knowledge of what might otherwise be regarded as normal communication and how this impacted relationship building. For example, participant eight reported her difficulties with groupwork

*like me who just like to get things done and not mess around or anything then I think it could be alright but I know in groupwork there is always people who say there are people who just talk*

demonstrating a lack of knowledge about the social aspects that impact successful collaboration, suggesting that explicit teaching of how to build relationships was required. When possible some participants were attempting to avoid communication participant nine reported

*In lectures, obviously I can just take in the knowledge and just leave afterwards but seminars are definitely the place where those social communication deficits are pretty obvious*

and participant fifteen reported relief that

*mostly the assignments were written on our own so I didn’t have to try and, try and cope, with social situations which I find very difficult actually.*

However, four participants reported improvements in their own communication which they believed to be beneficial for their long-term outcomes. Participant thirteen explained

*it’s not really conscious at the time, but now looking back I’ve understood that I’ve had to learn a lot more, and work a lot more to communicate easier with people.*

Whilst the process was difficult, he recognised the progress he had made in learning meta skills in his first year: ‘*At first it was quite a stressful process, I feel as if I’m a lot more comfortable now because I’ve done it, I’ve managed. I’ve got through it.’*

As well as difficulties with peers, communication issues caused problems in engaging with staff and therefore the material as well. Participant twelve described how not understanding how to access services led to her having to repeat the year:

*I guess, when I started uni I didn’t know how to access support services at all so I didn’t really engage with it…all so I ended up having to repeat the year and it was during the process of applying to repeat it that I was told about services.*

Communicating with tutors was caused by environmental issues, as well as lack of willingness by the tutors. Participant five described:

*Other struggles would be like you, you have a tutor who you can go talk to but it’s not like you can go up at the end of class and say I’m really struggling with this. You’ve got to get out, people are coming in, it’s a lot of people.*

The difficulties with the physical environment inhibited help seeking. Equally she found:

*I ask to meet up with my tutor, but she never had time. I do need a lot more one-to-one support than sort of your average student does. Sometimes it’s just reassurance that yeah, you are on the right track. But, I, it’s difficult for me to see, to tell that on my own.*

Participant seven argued that whilst ‘*I still did get support… I would think that a lot more one-to-ones and pastoral care should be provided.’* For her lack of effective relationships with her peers compounded the problems with staff. She explained:

*A lot of the things were harder because I’d have to make sure I’d make all of the notes myself. If I had any questions and I couldn’t get hold of a professor, then I just didn’t know. Like if a class was being cancelled. I didn’t know about any of this.*

For two thirds of participants recognising how to study at this level posed problems. In particular difficulties were found with identifying the most relevant information and staying focused. Difficulties, already mentioned, in accessing support services compounded these problems. Participant five explained:

*It’s hard because what’s relevant? How do I know what’s relevant, what I should look at? Just tell me which bit. So that’s a struggle.*

Participant one’s approach was common:

*I thought I’d better write down everything to be on the safe side…I was usually writing down everything. I thought, I need to write down everything. I’m not entirely sure why l don’t jot down the most salient points.*

This note taking issue was further impacted by a difficulty in reading quickly as he was unable to identify the most pertinent points in written text either. He explained:

*I’m a much slower reader and um, and, as I say, on average it did take me three times as long to read and understand something as the other students and things and so when you times that by everything it was so much harder for me to do it. As I say, I was sort of working around the clock, and as I say, in isolation and I think, I think, it took its toll.*

Some students were able to source outside help. Participant fifteen explained:

*I didn’t know what to do or the process of writing assignments because I hadn’t ever been taught that. I went to my best friend … she and a lecturer from the Open University helped me write my first assignment and showed me how I go about writing assignments at university level*

The lack of clarity around expectations was difficult she argued:

*In school, and at sixth form it’s all about the way in which the education system wants you to learn...Whereas at university level it wasn’t about ‘this is how you do it, this is what you must do’…so in some ways that was hard because if [redacted]…hadn’t helped me to understand how to write assignments I’d probably have still failed.*

Participant four described why he believed an autistic way of learning was more time consuming, because it was more intensive:

*I’m basically autodidactic and I suspect that a lot of people that are on the spectrum are, and that is something that needs to be taken into account. You know if you think differently everything that you do, and the way that you learn, and your life, has to be done differently. One of the things I first, it’s a bit like learning a language. If I go to a foreign country, I always like to try to speak some of the language. One of the things I don’t do is try to translate. So, I’m not listening to your words and translating it back. I try to be it, to absorb it and obviously if I went to Russia it would be hopeless, but you would live it. I have never done anything in my life, even as an autodidact without living it, becoming obsessed by it.*

In addition to more direct explanations of what is being required in assessments most participants spoke about the need for more structure overall. Participant seven explained:

*in an anxious situation anyway...Then the need for structure becomes more intense, almost overwhelming. You need to wake up, do your morning routine. So, yeah …yeah if anyone tries to intervene, I can become very cranky. So, people around me just learn to, I’ll not be okay with it.*

Participant six explained the need to have structure all the time:

*I quite like having tasks. One of the things I find is that if I don’t have anything to do other than my degree, I have too much unstructured time… I found that quite stressful, because I didn’t know what I should be doing and I couldn’t really think of something I could, I couldn’t really enforce upon myself regularity of what to do. Because there weren’t clear options. I quite like being at university because you have all of these, modules which are clear assessments and you’ve got one for this time and this time. Having lots of projects which have got clear deadlines and that sort of thing. I kind of like that sort of structure.*

These issues mirrored comments from the open text questionnaire. One anonymous respondent explained:

*I have found general, compulsory events such as Think-Create or State of [redacted] more harmful than helpful. I did talk to organisers about my disability, and they did their best to try and calm my anxieties prior to the event. However, as the events were designed to be unstructured to allow groups to come up with ideas unrestricted, I found it so stressful that it was detrimental. It was where I first came across the opportunity of 'networking', and the event in general made me more fearful of working in similar environments. I don't blame the organisers for this, but I wish there was some more specific services to help those on the spectrum, as we often have different needs and concerns. I would appreciate 'training' in communicating in work environments etc.*

For all bar one participant, second year study was described as a stressful and time intensive experience. The intensive nature of the academic components meant most could not begin to think in concrete ways about their employability. Participant thirteen explained:

*The hardest transition I’ve had in my studies in the past kind of decade or whatever, has been moving from first year to second year in university.*

In part this was more stressful because:

*You move onto second year and it’s like ‘all of this counts’ and I’m trying to understand where my priorities lie and when*.

It is worth noting that one student had left his studies at the end of year two because of the pressure experienced, despite acceptable performance. Open text responses from phase one corroborated thisidea. Anonymous respondents there explained:

*I want to investigate going part time so that I have more time to develop employability. I don't have enough time and energy to do employability work at the same time as full-time degree work. I am scared because I need to work to live and I am unemployable*

and

*I was so engrossed in accommodating all the changes in my life, fulfilling all the sudden adult responsibilities, that there was absolutely no space in my life to wonder if I was employable.*

A staff interview revealed that at least one autistic student had made such a transition to part time study as a reasonable adjustment as they were finding difficulty coping with a full-time course. However, this was not a common, or publicised, possible adjustment.

### 4.4.6 Theme 6: Framework for Support

The final theme draws together the specifics of what the autistic students are doing to develop their employability and prepare for work and how that aligns with what staff are doing to support them. In this section the following are explored: how autistic students currently prepare themselves; what difficulties they currently face, conscious or unconscious; and their recommendations for effective support systems.

All participants stated that they welcomed help with developing their employability and building skills. Whilst this may seem like an obvious statement, it matches what neurotypical students say they require. Both groups say they need support. Despite this both underuse the services. When discussing services, it was often in the context of real need. For example, participant one described needing help because ‘*otherwise you’re out in the real world and you haven’t got skills or experience to get a job.’* The discrepancy between the claimed need to use service and actual take up can be explained in several ways. Throughout the interviews more than half of participants alluded to being overwhelmed timewise and struggling to structure their activities to include everything. This could contribute to experiences such as participant six who described

*Because I think the careers service do a lot of things, don’t they? But I’ve not done any of those. I wasn’t really paying attention to it, until reasonably recently. So, I wasn’t really thinking about it like ‘you’ve got to do all of these different things.’*

This type of response was common to the control participants who also mentioned not ‘*getting round to it*’ (participant seventeen) and that they ‘*will make an [careers] appointment’*’ (participant nineteen). However, for several autistic participants including those who had used services so far, a feeling that the staff might not be sufficiently tuned to their experiences also impacted. Participant five described this in the context of staff in the past being unable to see what the problems were for her:

*I asked for help from my teachers. I didn’t get the help. I didn’t get the grades that I deserved, because I worked harder than anyone else. I was an A grade expected student but the most I ever got was Cs. Every single teacher kind of went, we don’t know why. It was just because no matter how much I asked for help I wasn’t really getting it, what I needed.*

The need or desire for autistic or autism trained staff will be revisited later in this section. Another common response which marked a difference from control participants was that autistic students reported wanting an element of compulsion to the careers interventions, struggling with time management meant they would value in-built guidance and support sessions as part of the curriculum. Participant one described:

*I didn’t really you know help myself much either, I didn’t a…I couldn’t ask and I was behind, I couldn’t…(drifts off) As I say, I possibly, you know, sort of, sort of, a more proper active intervention from the university, you know might have made a difference. I’m not sure…*

Later in the interview he was able to articulate more clearly what he felt was required:

*Well as I say, yeah, a with a wiser head, I would say what would be good for me, possibly, like a compulsory session with a you know, you know a careers adviser. That’s particularly important for people with Asperger’s Syndrome. As I say, especially as, if it is, if, when the person doesn’t have any specific sort of goals or sort of or unrealistic, or in my head, I was going to become a bestselling author [waits for reaction]. So, as I say there are viable career ambitions, career goals out there.*

Specific forms of interaction were described as needed as well. Participant thirteen described their biggest development need as:

*…peer communication and if there is something about my behaviour, they don’t like they should tell me about it and so I could correct it.*

Participant eight thought it would be helpful ‘*if, they could actually take you to see the places where you could work’* and participant nine recognised strengths from her autism but wanted help with selling them in that way explaining:

*I don’t know how I’d spin them without sounding like I was pleading. Like ‘oh no, please believe me. I have got strengths.’*

For most participants it was a more general sense that they did not know how to progress which they wanted help with. Participant twelve described how:

*I sort of know what I want to do but I just sort of need some help in getting to that point, because I’m sort of directionless and aimless and I need help kind of working out what I can do or what I can benefit from to reach that point in terms of personal and skills development.*

Even when following guidance given several participants mentioned the need to know the next steps for them in a structured way. Participant fifteen described how

*I do go onto prospects.ac.uk and look up different jobs on there. I rely heavily on opportunities coming up with people I know, and I don’t really know how I would go about expanding on that.*

This is not to say no participants recognised the active steps they should engage in. Four participants described specific areas they were working on to become more employable. Participant five described attempting to develop her communication skills

*I have lot of experience doing it and I know I’ve got a lot more to learn, but yeah, I am trying to focus on parts of my life so I can expand that side of it.*

Participant seven focused on acclimatising herself to situations where she felt uncomfortable

*I need quite a lot of structure. I have consciously tried to fit myself into unstructured situations to try to get away from that need and life has not been that easy.*

Participant six had an unusually extensive range of relevant experiences which would facilitate long-term employability. He described a conscious tactic

*The other thing I did was look up what other people did. Because I was originally one year and then I did a year in China, so I could see what people in the year above me were doing. So, I was looking at what people who were generally good at managing their life were doing and copied what they were doing. So, I sort of applied for the same things. And, I’ve got a job now at the same time, so, I’ve got this one friend who was president of my society, that I’m now president of. I also went to the G20 thing and also did the same job as me. So I thought, ‘she’s doing well: I’m going to copy what she’s doing.’*

He was unusual in seeing these specific activities as being employability building. He explained:

*I mean, there are things I’ve done which with hindsight people quite like to see but then lots of those things was with an eye to employability. I mean, applying to lots of different schemes which, like the sort of G20 thing, and doing certain things in the department. Doing certain things which make it look like you aren’t just studying. Which is with an eye towards the future, getting a job.*

More often any employability development had been more accidental though. Accidental employability development usually resulted from following interests and university societies played an important role in this. Participant eleven (an electronic engineering student) described:

*I just followed my hobbies really. One of my hobbies is doing a lot of theatrical, theatrical lights and sound. So, whilst pursuing that I got involved in about six separate societies.* [He now has paid work as a night club technician].

He found societies as a more interesting way of developing transferable skills because whilst transferable skills were taught on course:

*I feel much more less engaged with when they’re done on the course though and much more on learning them through the societies that I do. So I’m on the committee for media, particularly the radio aspect, as well as all the technical roles I’m doing so I’m always doing those and those because I enjoy them I get fully involved with them and I’m happy to work with as many people as needed and that teamwork. In the course though sometimes because the groups are set for us and the things we’re to look at are set for us and therefore it is set how we do it I feel less engaged with it and therefore less engaged with the group.*

Participant thirteen was cynical about students using societies to build skills though explaining:

*I feel as if everybody else is doing things just to put on there and I feel as if I can’t do the things I’m interested in, just for that sake.*

He described great enjoyment from being involved in societies explaining:

*[giggles with enjoyment throughout] I have never had so much opportunity to do extra-curricular activities, loads of stuff, as when I’ve come to here. When I come to this uni, I spent a large amount of time working in societies, trying to just learn whatever I can beyond the course and meet as many people as I could. Um, I went to work as a technician at the union. I’ve been to work as a technician for the theatre. I’ve been going to all sorts of dancing lessons, helping out with like newspapers, video editing, every possible thing I can find. I thought I need to do this because I’m not going to get the chance to do all of this again.*

When asked if he thought it built employability, he responded:

*I thought of it a lot more as ‘I’m enjoying this activity’ because it seems like if people join the society and think I’m like going to put this on my CV, or go into a committee or do this jobs, assign project and like oh yeah, put this on my CV and I was thinking ‘I actually like to do this.’ No I was just there because I wanted to know about it before.*

Similarly, participant nine recognised some extracurricular activities could help her, but separated them into for ‘fun’ and those ‘for employability’:

*…if it was going onto my blog, it would just be a hobby, if it is going to an anthology and they have specific guidelines that becomes more of a job but it’s never really a job if I enjoy it.*

The compartmentalisation of activities by autistic participants meant that many reported beneficial activities which they themselves did not recognise worthy of mentioning in a recruitment context. Participant nine described spending ‘*Most of the time it is just charities in [redacted: names university city]’* but when asked if that were to aid future employability, she was surprised at the question responding:

*I’d never really thought about it in terms of employability and since I’ve started doing it I’ve never applied for jobs so it’s never been something that’s on my CV as work experience. I suppose it might be beneficial, but it was never started with an intention towards attractive in the workplace.*

Failing to see employability benefits in specific activities does not imply participants were not open to opportunities. Surprisingly, given the autistic trait to being conservative relative to new opportunities the majority of participants expressed willingness and even desire to make quite drastic lifestyle changes to secure appropriate graduate work. Participant four described this as ‘*the whole thing about autism is it’s about making things work.’* Whilst participant five had chosen a career she was overly focused on it. She explained:

*If I still want to do CBT by that point [post-graduation], then fantastic. If not then and I’ve changed my mind then I want to focus on something else then at least I’ve got the foundation behind me because with psychology as a base for anything I want to do.*

Whilst she liked having the security of knowing a specific potential destination from her degree she also wanted ‘*to see what else is out there. I don’t want to limit myself in case I’m passing something up which I might enjoy more.’* There was sense from most participants that they could be flexible. Participant nine explained she just needed ‘*enough to live on sort of without having to worry is a fine place for me. I don’t really need more than that’* and participant eleven had ‘*No idea’* where he would work *‘anywhere that would take me I guess. Obviously, it would be ideal if it were near home or [redacted: names university city] but anywhere, I guess.’* Participant sixteen described how practical issues had led to degree choice and that ‘*I just sort of ended up accidentally doing English literature: a series of random events.’*

The participants were not directly asked if they felt prepared for entering the graduate labour market. However, six participants mentioned not feeling ready. Participant one described how he ended up focusing on an inappropriate career because he and his advisers were *‘thinking about the condition in isolation.’* He had grave concerns that he would not be prepared for work by the end of this course but felt that ‘*for me the problem goes deeper than the university. It’s, you know, my education, from you know day one.’* Participant six epitomised most of the respondents who felt unready though when he explained

*I think I should probably pay more attention than…to careers and those sorts of things and future. It’s just that there are so many choices and a lot of the processes are so different and you have to get your head around one process. Then apply it to one situation and then you’ve got to manage that.*

Despite the problems described by participants throughout the interviews only two were genuinely concerned it would impact them accessing or keeping work. Participant eight explained ‘*I’m worried that might affect my chances of getting a job when I’m old’* talking about discrimination she may face. Participant twelve described problems stemming from the condition impacting employment. She was worried about:

*…keeping employment. Like when I’m at work I do it to a high standard because I want to and I do it well so it’s not like I’m lazy with my work that I’m doing it’s the initial getting up and going there and that is stressful for me for some reason so it makes it more difficult to stay in employment. But I’ve never had a problem with employers not doing the job properly. I’m either doing it well or not doing it at all.*

Whilst it was positive that some participants felt confident about their future prospects this finding is out of line with research on autistic graduates which shows only 36% in full time employment relative to 58% of their non-disabled peers (AGCAS 2015, 2017) and so demonstrates some lack of awareness of the difficulties which they may face for which they are not prepared.

In building employability there are three main issues that participants were facing: needing support which they were not currently receiving; being unable to frame their autism in positive ways and not understanding career ‘rules’ which might otherwise be regarded as an example of the hidden curriculum discussed earlier.

An interview with careers service staff revealed a belief that ‘*very, very few students on the spectrum get to us*.’ However, no significant difference in take up of careers services was found in phase one between autistic and non-autistic students. It may be that careers staff aren’t always aware their clients are autistic. The same interview revealed a belief that ‘*many of them won’t disclose they have a diagnosis*.’ Given that careers staff do not have access to the individualised learning plans which are sent from DDSS to academic departments, they will only know a student is autistic if individuals disclose to the service. As the service runs a triage system disclosure can feel more difficult for service users, for example the appropriate time. In addition, as already explored in themes three and four, disclosure is a problematic area. If students do not fully understand the role of careers or its distinction from a job agency, then they may choose not to disclose for fear of discrimination. As already discussed in this section participants felt that careers support would be helpful, including some participants describing the need for careers intervention even pre-entry: Participant five:

*I think there should be more support given to autistics about the wider side: outside of university. I know it’s hard but universities should make more of an effort to speak to individuals at their college or school or whatever to see what their long-term plans are. We struggle out, we struggle to make out a career plan or whatever, we do need help, even before we come. So more help.*

What was apparent from interviews with several students is that they either were not aware of services or did not understand how they worked. Participant three explained:

*I avoided the careers module. Because frankly people were taking it because they thought it was an easy option and I’d rather do more maths.*

Participant nine did not know one was open to her responding:

*I definitively would sign up for one. I don’t know if we have one, but if there was one I’d definitely sign up for it. If we did, and that was advertised I’d definitely be interested.*

There was also confusion about who ran services or what they were for. Participant ten who asked, ‘*What sort of services are available, because I don’t think there was anything like that?’* when asked if he had been to the careers service then described how:

*…the 301 service[[6]](#footnote-6) is really really good. Kind of skills services, so they look through your CV or do a mock interview and they have a database of jobs that’s very useful. That’s a good service.*

For participants who had used any careers services the help given was not found to be sufficiently individualised or in-depth. For example, Participant four described his difficulty with job interviews:

*But I would say, with hindsight, weird things, or ask weird questions…I mean not trying to be provocative or anything but interested in the answer. Needless to say, I didn’t get the job.*

Longer appointments in which a relationship was built up would help to alleviate this problem, encourage disclosure and allow autistic students to articulate their issues. Participant sixteen explained:

*I just don’t think other people can, not that other people can’t give you careers advice but I don’t think you can turn up and talk to somebody for ten minutes or half an hour or whatever and then they know what you should do with your life. I think people who know you well can suggest things. They’re more likely to get it right. But there’s so many aspects of each job and each person’s personality you can’t possibly match them all up, correctly. Like I can say I really like science and somebody can say ‘you should be a doctor’ it does all seem to make perfect sense because I like science, I want to earn a lot of money, things like that. It does work out neatly but it doesn’t take into account all the things that I don’t like. Like doing tricky fine motor skills things, like stitch up a wound or give and injection. I wouldn’t like that sort of thing and somebody who knew me really well could suggest that a bit better but something like fine motor skills that wouldn’t come up in a half hour interview or whatever so I just think it’s a fault in how the system is set up.*

She however argued that for effective progression in relation to careers it required reflection by the person alongside a long-standing relationship with someone who could facilitate that growth:

*If you were a reflective person I think possibly that could work with me but I don’t know, I don’t think that would work for everybody because there is just so much that you don’t say. There’s so much people’s character that you pick up from how they physically move and their expressions and so on and how they react in different situations. If you don’t see someone in different situations, then you can’t. You don’t know how they’ll react in different situations in other places and even people who are very reflective you still write a narrative in your head for why you behave the way you have and so on and it has to fit with your own positive view of yourself as a person like if you’re a person who is very cowardly and you do cowardly things, like, I don’t know, running away from an accident instead of helping or something then later on you rewrite that in your head that it was a sensible thing to do and normally I wouldn’t do that and it was just that one occasion. So you can’t really be objective about yourself because you do have to fit it into your own view of yourself.*

Not all participants explicitly wanted the longer-term careers coaching or careers counselling articulated by participant sixteen and discussed the desire to be told more explicitly what they should be doing. For example, participant thirteen expressed a need to be told how to structure his CV:

*A lot of the case is just the ‘write this thing in this way’ because I’m still struggling to write my CV, even though it’s a simple, one-page, two-page document.*

Even when expressing the desire to be told ‘facts’ the individuals would have benefited more from a longer-term coaching/counselling relationship. Careers services have to balance long-term work and information delivery. For autistic students the longer-term counselling is more important than for other students. Participant twelve described:

*I mean I know at university level you’re supposed to be self-driven and lead yourself and everything and that’s fair enough and everything it is higher education, but I just think at the same time if it was possible to have a bit more focus on that. I mean I know as part of my degree I did a work placement and there was a few sessions we looked at job skills or career skills looking at some of the tools the careers centre has on their website but that is where you can identify where you have strengths and areas where you have weaknesses which was useful if somewhat depressing. You’d categorise them into areas you were very strong in or areas you were very interested in but not very strong in or something you weren’t that good at but would like to move better at and something you weren’t interested in and weren’t very good at, at all, so, there was working on identifying it but then there was nothing to tell you how to develop it or what to do.*

Participant thirteen who had expressed the desire to be **told** how to structure things went on to explain:

*It’s the case of not knowing exactly where I’m going. If I’m writing a CV what words am I supposed to be putting in there and who exactly am I supposed to be sending it to at what time. It’s a process that I’m not familiar with. It’s very common, but I’m not familiar with and I’m struggling to go through those steps towards getting a job that I’m not really sure that I want.*

This statement demonstrates a person in need of in-depth career counselling: working to achieve something they are not sure they even want. For some participants it was clear they had been put off by the first steps of a triage system and did not know how to access other services. Participant twelve described

*Yeah I went to the career service but I didn’t find it particularly helpful because they just directed me to some online tools and I was like ‘oh okay.’*

She was not aware of other available services or where to go next, when she found these unhelpful. For autistic people communicating bluntly what they need or want at the first steps of a triage system mean that their underlying issues are not identified and consequently they receive only information services, not guidance services as a result. The front-line staff are not aware of their diagnosis and so take their stated need, for example, knowing how to structure a CV, at face value and so refer them to CV layout resources. When staff are aware of difficulties it does not mean they are always able to give the time and resources to structure career learning. An interview with a careers professional revealed autistic students had previously struggled with attending noisy and stressful networking sessions. Such participation should, ideally be at the culmination of a series of preparatory activities so the individually is psychologically prepared for the event. In this instance an appropriate adjustment might mean quite substantial investment of staff time in scaffolding the learning and skill development necessary to participate in such an activity. Simply avoiding such networking events as an alternative would mean that autistic students would miss an important route into work. It is also worth recognising that the interaction with the careers adviser themselves means a new relationship to negotiate: one which deters some autistic students from engaging with face to face services. Participant nine was sceptical that the difficulties of engaging with new people would be worthwhile:

*I’d be quite hesitant to because the, a lot of the jobs, I mean I access the careers services online, rather than in person because that’s a whole other social interaction, and I’d be sceptical like the sort of jobs I’d find that would, you know, to find employers who are disability friendly like, where I stand a good as a chance as other people going to the same job.*

She explained her preference for receiving online guidance:

*I think, definitely I’m much better at communicating in text, than verbally. So, I think the chances of me getting my point across and being able to communicate effectively are far higher for written communication, than spoken.*

Participant sixteen:

*I haven’t been to the careers service at university. I mean I’ve had careers advice earlier on but they weren’t much help. Most of the help I’ve got is from online, things like Prospects and stuff online…*

She explained using that resource:

*…partly because when you’re talking to people they have their own ideas and then they sort of try and force it on what they think you should do which is the experience I had with careers advice earlier. They didn’t know me well enough and they focused on superficial things that I said and tried to use them as a sort of guide for my whole life basically.*

This participant expresses the need to be seen holistically and not viewed through a small part of her identity. As previously discussed, this had been an issue for participant one and his advisers who were only thinking about autism as a driver for career choice ‘*thinking about the condition in isolation.’*  Having very short careers interactions contributes to this issue: there is insufficient time to explore the individual holistically and the autism is salient in the helper’s mind and so can influence discussions.

A specific area where autistic students would benefit from careers support is in learning how to draw out and frame the positives associated with autism. For four participants they could not articulate any positives associated with the condition and when asked participant fifteen could only begin to describe problems

*I don’t like change. I have massive, massive issues with change and because of that I’m very limited with jobs.*

Those participants who attempted to distance themselves from the condition (discussed in theme three: identity) also identified no positives when asked. That positives had never been discussed or considered was apparent in some interviews. Participant ten explained:

*I don’t really know what the costs and benefits might be. If that kind of information was available to us, or available to us, that would be really, really, good.*

Those participants who expressed strong autistic identities were, in contrast, able to describe a range of strengths. However, in no cases were participants able to frame these well for recruitment purposes. Participant thirteen explained ‘*it’s something I benefit from’* but could not articulate how it might be beneficial. Participant twelve explained the benefits of being objective

*Um, I guess I can stay quite calm and objective when other people are not able to. So that can have advantages if there is actually a crisis happening to and you need a calm reaction.*

However*,* like all respondents, he immediately moved to focus on disadvantages

*Where that can be a disadvantage is where people are actually wanting an emotional reaction and you’re having to actually force it out a bit. Or I feel I need to otherwise the other person gets upset.*

Logical thinking was a positive described by several participants, along with being highly prepared or organised. For example, participant eleven explained:

*…logical thinking that comes out of it and passions for very specific things are very helpful…I’m quite organised in how I do things that has helped me so much in project planning and schoolwork…*

However, even with well thought out ideas of how autism helps, participants still struggled to present these strengths in ways which might be meaningful for recruiters. Participant three:

*In a way yes, I’m quite pleased, I think I’ve been associated with, people say I’ve had, I’ve got a good intelligence and I’ve got a knack for things like numbers and for languages, which, which I know don’t often go together but things can just sort of appear to me and it’s really nice. There are lots of different, the way I think is apparently, I’ve spoken to a few people, and I’m pretty sure the way I, I, my thought process works different. People, and I’ve spoken to a lot of people who have said they think in a sort of logical ladder type way, whereas I think I’m more like shooting stars flying around and occasionally I’ll grab one, and it’ll, which sometimes means I’ll tell you something that doesn’t have any real relevance or doesn’t seem to have any relevance to what is going on but it also means that quite often information will just come to me and I won’t necessarily know where it’s come from but it’s handy at the time. I think, it’s quite nice, it’s good for pub quizzes. Quite often I’ll just blurt out something I didn’t know that I knew. It’s, I think, it’s probably made me more intelligent than perhaps I would have been if it were not for the Asperger’s Syndrome.*

Diverse ways of thinking are beneficial for most organisations, but this student needed help with building a workable example to use in a recruitment interview. Her discussion of it here was difficult to follow. When asked about strengths four participants raised the issue of combatting negative images of the condition. Participant twelve described how:

*There was someone in the same group work I was doing in Uni who was doing the same placement as me who had a tendency, they had a tendency to refer to people who were ‘suffering from autism’ or ‘suffering from Asperger’s’ so I had to correct them quite a bit on that because I don’t think. I mean I think, I have come across some people who have said they do suffer as a result of their condition but overall I don’t think it is right to say suffering from it when some of the things that make it difficult are the external things, if that makes sense.*

Participant seven argued ‘*It has definitely been presented as a bad thing, and not very helpful.’* She explained:

*to an extent, it presented as a mental disorder and in my view, a disorder is like having bipolar, or Alzheimer’s like I said. If it is not something really detrimental and it is just a different way of seeing things in a different way. But being perfectly able to do everything.*

Participant thirteen similarly felt terminology created negative images:

*…’person who suffers from autism’…I feel as if it’s…I don’t really know how to say. It sounds like it’s got a lot of gravitas to it. It’s got a lot of weight to it, a lot of assumptions of pure negativity.*

For participant sixteen the negatives were associated with being different rather than autism per se:

*I see it as a very positive thing and one of the other things I’ve noticed is that there aren’t any clear negatives with Asperger’s or autism. In the media people who have it are usually shown as being these savants, like geniuses and so on and so on and they…It’s not that it’s like there’s a particular negative stereotype associated with people with Asperger’s or autistic people like that but it’s just a general not liking people who are not normal otherwise it’s all portrayed quite positively usually and the downsides aren’t often acknowledged.*

However, whether the negativity is specifically associated with autism or simply a result of fear of difference is a moot point if the effect on autistic people in employment is the same.

In theme five the notion of hidden curriculum in relation to academic content was explored. A similar issue was present when participants talked about employability. Several participants articulated the idea that other students knew things they did not. Participant one described:

*I don’t think I had the self-confidence to try and learn other skills and I didn’t know, know what there was. Others seemed to have been told things or they knew and I didn’t know about other things.*

Participant thirteen described how:

*…it is stressing deciding where to go and what to do because it seems like the big unknown. Because I don’t really know how I’m supposed to be selling myself and how legitimate that whole case is supposed to be.*

Participant four framed this knowledge gap as relating to differing ways of thinking or of valuing things. He explained:

*But I have learned that other people think the same as that but they don’t think the same as me. So, respecting other people’s values is quite important, even if you don’t understand them, even if, might I say, you find them a little bit silly.*

In common with all students some participants were evidently missing pieces of careers knowledge which would have helped. Participant eight described her career choice:

*I originally wanted to be a doctor. Er, as more symptoms of my autism became apparent because I didn’t start showing symptoms until er, quite late, quite late teenager. It became quite apparent that I probably wasn’t meant to be a doctor, like I wouldn’t be very good with it so, erm. I figured I’d like to do research instead and I think physics research just stood out to be a bit more … [tails off in her own thoughts]*

It was apparent she was unaware that lower empathy was beneficial in some areas of medicine such as surgery or pathology, as she continued to describe how ‘*sometimes [I] struggle to give the right level of empathy.’* Similarly, participant thirteen explained how ‘*I just do want to find a course I enjoy and then when I get to module choices it’s just choose the modules I enjoy’* seemingly unaware this impacted his employability. In contrast participant sixteen reflected a subgroup who objectively assessed the most useful degree for employment:

*…better for me, not just for employability, but also for other things, better for me to go to a better university and do English literature than go to a worse university and do history, even though I liked it more.*

She described how she chose her course as ‘*a very cynical process.’*

Autistic participants differed markedly from non-autistic participants in that they relied heavily on hot knowledge, something common to working-class students (see Ball and Vincent, 1998). Hot knowledge is information gathered from from informal sources such as social interactions om contrast to official sources such as statistics or reports. For example, participant three described ‘*I do tend to talk to my parents, quite an easy point of call because they’ve had careers.’* Despite neither working in similar areas to his career interest or having careers training he preferred:

…w*hen it came to writing a CV instead of listening to what the teachers at school were saying, I’d talk to dad. I’d work on it on my own and work out what I had to do. I wasn’t interested in sitting and listening in a formal scenario to someone telling me how to do it.*

Participant five’s career was made on the basis that she was:

*…talking to my therapist she said you know what you’d be really really really good at this and I think I would as well.*

Participant thirteen took advice from:

*…my teachers, I remember in college they were warning me off maths…someone recommended going into engineering.*

In describing useful careers advice, it was the personal connection which was focused on as making it useful. Participant sixteen explained:

*I think a longer series of interviews would definitely help a lot more. I think a solution would be having a lecturer give careers advice if they could or somebody who knew you quite well, through the university. So they’ve got to be aware of there’s things that you don’t say but which they should be aware of. So you might say you want work in a really high flying job and you might say you can cope with stress, somebody who’s actually watched you work for a year might know you can’t so they can advise you against that. Whereas if you just have a lot of interviews you just keep saying ‘I can do this, I can do this’ so they would never actually get a picture of what you can and couldn’t do.*

The rationale for not going to professional careers staff was given as ‘*It’s that, um, people don’t understand well enough to help, things like that.’* When participants were prepared to use official services, it was on the strength of hot knowledge as participant five explained:

*So, there is a careers adviser at the university which I’m going to book an appointment within the future. Cos my friend used them and they’re really really good.*

Participants were explicit about some of the things they would find beneficial in an employability development programme. A minority mentioned an element of compulsion about the activities so that autistic students would recognise the importance of them. This call should be contextualised in the earlier finding that many participants were already struggling to manage the workloads they experienced though. Participant one described these sessions as:

*…compulsory sessions with a careers adviser, someone who’s going to kind of help you realise there are jobs that I can help you do, you know, and that’s how their skills can be utilised. To get me out of that, you know, that cloud cuckoo land.*

Compulsion was also mentioned in the responses from open text comments in phase one

*I think active and early intervention from the university (compulsory interviews with a careers adviser, detailed guidance on ‘real world’ expectations outside the university and organised social interaction within an Asperger's support group)*

When discussing how current autistic students’ employability needs were not being met at the start of this section, the specific activities desired by phase two participants were described. The open text questionnaire responses from phase one corroborated many of those ideas. The importance of specific sessions focused on autistic students’ needs was a common message. One anonymous participant explained ‘*I've found that employability advice for people with ASD is definitely lacking. I decided to change my career in light of my diagnosis’* another explained that:

*There was no specific advice available from my University, especially around moving career/transferrable skills from the course, so I had to go to the NAS[[7]](#footnote-7) for specific help.*

A third explained:

*At the University of [redacted] it [employability] is addressed but clearly not aimed at people like me and so just feels more alienating and like further confirmation that career success and steady employment are not meant for people like me.*

In addition, there was much more focus on specifically supporting linking with employers directly. The anonymous comments (each from a different respondent) suggested ‘*help in finding work suited to me needs and preferences as a student with ASD’; ‘pointing me toward companies and employers who are inclusive’* and *‘a lot more emphasis paid to which jobs are realistic for us to be able to do.’* The notion that only certain recruiters would be accepting of autistic candidates was a frequent implication in responses. One respondent explained:

*I know a lot of companies like Microsoft are looking into hiring more people on the spectrum and it would be nice to get a compiled list of disability-friendly companies. All too often, I know before I even go to an interview that my disability sabotages my chances and it would be nice to have knowledge of which companies are most understanding and accessible.*

There were also several mentions that the university should be directly responsible for promoting autistic applicants, for example, one anonymous respondent argued they should ‘*raise the issue with employers that ASD is not a hinder of employability.’*

The findings have demonstrated that person-fit theories of careers support are not appropriate for autistic students. Participants have indicated that the typical aspects of career matched on are not those areas of most importance to them and they are more concerned about being successful in their attempts to enter some work than in finding the ‘perfect’ role. In addition, participant four’s reflections on how autism has been helpful to him in the past demonstrate some common features of autistic graduates’ careers: either they are out of work completely or they do very well. Participant four explained that it was his autism which made his career so unpredictable:

*I’ve been a senior manager three times and gone from that to supply teacher, rock bottom. What I’ve found is I would succeed when the need was very often so extreme that very different thinking was required.*

For this reason, a chaos-based approach to career planning would be more suitable for these specific students: an issue picked up in the discussion. Finally, a common theme through phases one and two was that staff generally needed training in autism awareness, or preferably were autistic themselves and so genuinely understood the issues. Participant fifteen’s experience epitomised the type of problem experienced:

*I attempted to go to the careers adviser…who was really nice but it didn’t really help…I don’t think they had much experience with autistic people and that has, that has, like put me off from seeking career advice, because she was suggesting things like ‘Oh you can take your CV into shops’…I don’t want somebody that I don’t know to contact me because I would not be very good at coping with that…So like I know that the majority of people would quite happily give their CVs to shops and like for summer work, or things … they need training. They need, they need to know that I’m not just being difficult and not wanting to work. I do want to work. I* ***very*** *much want to work, but I can’t just work anywhere.*

Participant five felt that this training needed to extend to written resources as well. She argued:

*I think they should invest money in making their written materials more autistic friendly, more learning difficulty friendly. They should actually get someone who has that disadvantage themselves to go through any new material and give feedback. I know it’s been written by professors with an academic background or careers and they know but the people couldn’t always read it.*

Open text questionnaire responses called for the same resources:

*a careers advisor who are themselves Neurodivergent, who understand our limitations and potential rather than the regular careers advice*.

Calls were also made for other contributors to employability programmes to be autistic. One anonymous respondent stated, ‘*I would like a neurodiverse mentor.*’ Another called for:

*More guidance on how to navigate job seeking and employment while neurodivergent/disabled, ideally from people with these experiences themselves, potentially some kind of anonymous webchat service or online mentor scheme. Also, more careers service events featuring neurodivergent and disabled people explicitly talking about these experiences*.

Being in touch with professionals who were autistic and hearing directly from them was seen as of great import.

# Chapter 5: Discussion

The key themes are now grouped into emergent analytical categories, distinct from how they were previously organised. Table 4 demonstrates the relationships between the original research questions, emergent themes and analytic categories. This new structure reflects the voice of participants whose messages did not fit neatly into the prescribed questions of this research. Five analytical categories draw together threads and connections from the previous themes. These focus on: the effects of previous treatment on current thoughts and behaviours; impairment effect related issues and their effects; managing identity and disclosure; dealing with a hidden curriculum; and creating appropriate services. The secondary level analysis involves the use of theoretical frameworks as introduced in chapter two. In addition, a new theoretical perspective is explored, feminist theory, to focus on the gender related findings which were not anticipated. The discussion acknowledges previous research with autistic people and other marginalised groups to enhance and extend understanding of these themes.

|  |  |  |
| --- | --- | --- |
| Original Research Question | Theme from the Data | Analytical Category |
| 3. How do autistic students experience employability interventions? | Identity | 3. Managing identity and disclosure |
| 1. How do autistic students conceptualise employability and their future employment prospects? |
| Future Plans |
| 2. What difficulties do autistic students face in building employability? |
| Adjustments |
| Impairment effect related issues | 2. Impairment effect related issues and their effects |
| 4. Hidden curriculum |
| Gender | 1.Effects of previous treatment |
| 3. How do autistic students experience employability interventions? |
| Framework for Support | 3. Managing identity and disclosure |
| 4. What are autistic students’ views on how universities should assist them in relation to employability? | 4. Hidden curriculum |
| 5.Creating appropriate services |

Table 5: Relationship between original research questions, emergent themes and analytical categories used



## Analytic Category 1: Effects of Previous Treatment

This first analytic category explores the effect that participants’ previous experiences has on their current and future expectations. The issue of gender differences in treatment was not anticipated from the research questions posed. It emerged as an important theme and so new literature is considered here in relation to this. In the theme 4.4.1 clear gender-based patterns of diagnosis were revealed. Because diagnosis was also shown to be a gatekeeper for accessing services and adjustments this meant a disproportionate impact on the female students who had received later diagnoses, and whose diagnoses had been preceded by other inaccurate diagnoses. The lack of service and adjustment were described as affecting mental wellness and achievement by female participants. That females experienced more problems in the past is consistent with other literature which demonstrates that autistic girls have more difficulty making and maintaining friendships (Kirkovski et al., 2013) and have more social problems than boys generally (Holtmann et al., 2007). The longitudinal study of Howlin et al. (2004) found autistic females are less likely to be in higher education, or paid employment and are more likely to be socially isolated. Themes such as these prompted Shefcyk to describe autistic females as ‘*twice excluded: once from the neurotypical female population and once again from the ASD community*’ (2015, p132). A plethora of research shows diagnosis occurs later for girls than boys (e.g. Begeer et al., 2012; Giarelli et al., 2010; Shattuck et al., 2009). Many female participants in this study had been referred for mood or anxiety disorders. This is consistent with patterns of diagnosis for other women (Bashe and Kirby, 2005; Kopp and Gillberg, 1997; Kopp et al., 2009). Women are also sometimes diagnosed after a misdiagnosis of anorexia nervosa, a condition related to the taste hypersensitivity, which autistic people often experience (Nilsson et al., 1999). Mood disorder presentations and diagnosis may result from either a simple misdiagnosis or they may be comorbid conditions which stemming from lack of adjustment and support for autistic females. In either case they have been disadvantaged. There is evidence to demonstrate that autistic teenage girls are more likely to internalise problems than either autistic teenage boys, or neurotypical girls (Solomon et al., 2012). This can be a precursor to mood disorders. In addition, Simone et al. (2010) found autistic women are judged more harshly for lack of tact than autistic men are, even when the recipient is aware of the autism. Society expects women and girls to be more nurturing, mindful of others’ emotions and tactful. This creates an extra level of pressure which interacts with the difficulties in getting diagnosis creating a harsher environment. There are several hypotheses to explain lower and later diagnoses rates for females relative to males. Firstly, it is suggested there are phenotypic differences in presentation such as improved superficial social and communication skills, fewer special interests and differential displays of aggression, using more subtle forms (Gillberg and Coleman, 2000; Kirkovski et al., 2013). A range of authors argue that these differences result from differential gender socialisation (Goldman, 2013; Krahn and Fenton, 2012; Thompson et al., 2003). Secondly autism is perceived by the general public, practitioners and researchers as a male disorder (Goldman, 2013; Kirkovski et al., 2013; Krahn and Fenton, 2012). This has the effect of misattributing the difficulties girls experience as a result of autism as related to anxiety, depression or eating disorders; more stereotypically female conditions. Finally, girls develop unique coping strategies to mask their problems. For example, they may consciously mimic peers’ behaviours (Attwood 2006). This hypothesis has not been empirically tested but derives from Attwood’s clinical accounts (2006, 2007) and case studies by Kopp and Gillberg (1992). This strategy of imitation obscures difficulties but is only successful for known, familiar environments where rehearsal has already occurred. (Attwood, 2007). The long-term effects of such behaviours produce extra pressure and can lead to significant differences when females move into new environments such as leaving home and going to university because they lack pre-prepared strategies.

These issues are not simply historical for autistic female HE students because discrimination experienced in the past impacts expectations of treatment in the future. A range of subthemes in the themes speak to this point. Students of both genders described explicitly and implicitly ways in which they accepted some level of discrimination and inadequate adjustment. Lack of adjustment specifically will be revisited later in this chapter. Examples of acceptance came in a range of forms: participants described how their university experience was better than previous education and therefore should not be something they complained about; they described adjustments which were helpful but glossed over those which were not implemented; they did not request adjustment in self-accessed work and work placements, instead accepting being dismissed or leaving roles. In addition, a range of failures in the university adjustment process was described as being inappropriate or incomplete yet participants did not raise these issues, instead being grateful for what did work for them. Finally, the need to educate others (other students, staff and employers) was mentioned multiple times but never with a sense of personal agency. Lack of personal autonomy and agency in this regard was marked. This was something described as if out of their hands and not something which they as individuals should either advocate for or begin to do.

There are a number of practical reasons why autistic students might not complain about inadequate treatment or self-advocate. Autism is comorbid with depression (Ghaziuddin et al., 2002); and anxiety (Kim et al., 2000; White et al., 2009). Even without these comorbidities autistic students have heightened levels of anxiety (Van Bergeijk et al., 2008). These factors may inhibit practical ability to effect changes. However, there was no sense in the data that participants felt unable to advocate for themselves. It was clear participants did not feel they deserved or should aspire to more. This acceptance of external pressures represented an adaptation rather than a defeat, what Hart describes as a response to the outside pressures. She argues these changed aspirations are

*often born out of unequal power relations that constrain humans to mould themselves in ways that suit perceived expectations of normalcy and acceptability* (2016, p4).

Reeve (2004) uses the social relational model of disability to explain the undermining effect of long-term negative treatment. She describes how the personal experience of oppression leads to a longer-term impact on psycho-social wellbeing and therefore impacts both what disabled people can do and be. Such experiences have been shown to impact the self-efficacy levels individuals experience as well as their ability to imagine their future ‘possible selves’ (Oyserman and Markus, 1990). Moreover, participants demonstrated little sense of personal power or control over their own lives. Their acceptance of worse treatment is at odds with natural justice, as Fraser describes how:

…*justice requires social arrangements that permit all to participate as peers in social life. On the view of justice as participatory parity, overcoming injustice means dismantling institutionalized obstacles that prevent some people from participating on a par with others, as full partners in social interaction* (2009, p17).

For these participants justice is not currently being served. Some do not recognise the extent of discrimination; others recognise but accept the discrimination, simply being happy for the better circumstances they now find themselves in, relative to past treatment.

One of the theoretical frameworks explored in chapter two, social constructivist theory, is pertinent here. In addition, it is worth exploring the explanatory power of feminist theory in this part of the analysis. The latter was not considered at the start of the study because the absence of females from previous literature was considered to be an artefact from research occurring in medical domains which traditionally exclude women. However, the gender element has been shown to be of great importance in these themes and so intersectional aspects of autism need to be considered. Social constructivism takes a societal level approach, exploring how societal expectations impact individuals’ expectations and desires. As such this is a potential explanatory framework for how the students in this study interact with, and have low expectations of, university services and employers. Social constructivism explains that they have been trained to expect little. In particular, disability theory, a subset of social constructivism looks at the extent to which impairment is viewed as a deficit in the individual which causes problems, rather than a societal deficit which is not accommodating. It should be noted that there was one exception in the data, with one participant advocating for organisational change regarding exams. She reasoned:

*... the problems that people with autism have with exams, they’re problems that are inherent in exams…they’re not actually addressing the core problem, just trying to sort of plaster over it…you’re better off using that time and energy to come up with a better assessment system.*

The call mirrors the arguments of Sharp and Earle (2000) who, critical of adjustments made for disabled students, call for re-examination of assessment to make them appropriate to real life problems. On a superficial level this quote may appear as an exception invalidating the use of disability theory to explain the themes. However, it should be noted that the participant did not take any action about these arguments. Generally she accepted what she had been given, even if unsuitable. For example, elsewhere in the interview she explained how she did not receive the services she required and was eligible for but did not complain because it was her fault, she was unable to speak on the phone explaining:

*I had to ask them, I was supposed to get some software, they were going to pay for the software but I had to order it and talk to a person on the telephone and so on who distributed the software and things and that meant I couldn’t get it.*

A feminist perspective on these themes can also be taken and can be complementary to the social constructivist theory. Feminist theory states that women and girls are systematically subordinated in all domains, including healthcare and education. Consequently, this theory would predict, as was shown, that they would be treated less effectively by the both systems: being diagnosed later and receiving different treatment to males. Feminist theory can be used to explain the differential socialisation of girls relative to boys by drawing out the ways in which women are socialised to be caring and subservient under patriarchy. Finally, feminist theory can also explain how the typical male presentation of autism has come to be the definitive diagnostic form, disadvantaging girls and advantaging boys. Intersectional feminism looks specifically at how gender affects and is affected by other factors which are used to cause inequality such as race, age as well as disability through social and cultural forces.

## Analytic Category 2: Impairment effect Related Issues and Their Effects

The second analytic category looks at the impact of impairment effects of autism and how this affects the individual. The two greatest effects are be explored. These are loneliness and the need for practical adjustments. They are discussed in the context of social identity and social constructivist theory respectively.

Loneliness was a thread which ran through much of the interview and questionnaire data. Exclusion and isolation was a theme running through all the autistic students’ open text responses in the questionnaire. Whilst present for some neurotypical students, it only appeared in their responses when they were reflecting on social activities. It appeared in the autistic students’ interviews both as explicit statements about loneliness and also implicitly when participants discussed difficulties with communicating and concern that the autism label might lead to discrimination and negative labelling. In line with findings by Johnson and Joshi (2016) it was found some individuals found organizational support stigmatizing so did not access services which were available to them. Finding that loneliness was a major issue is not surprising given that Bauminger et al. (2003) drew out how at school level autistic children are not taught skills to engage but rather more effective partners are swapped in to assist them to have friends temporarily in the form of more experienced conversation partners, adults etc. They argued that the lack of initiation of interactions relative to other children (disabled and typically developing) means autistic children fail to learn from interaction opportunities as well. Creating structure in the creation of social relationships is helpful for autistic individuals (Sofronoff, Dark and Stone, 2011) and they experience lower depression and self-esteem problems when given opportunities to develop relationships in structured ways (Bauminger et al., 2004).

Social identity theory explains how self-identity and sense of self is constructed by reference to other people and by one’s interactions with those others. Failure by autistic students to make friends and develop deep relationships with others can be understood in the context of in-group, out-group difference. Social identity theory explains that stereotyping is a normal cognitive process. Therefore, if a particular aspect of identity is salient (autism) this will naturally lead to stereotyping by those of a different identity (neurotypical). Tajfel (1978) the originator of the theory argued that group members of an in-group will deliberately seek out and accentuate negative aspects of an out-group as a mechanism to enhance their own self-image. Some autistic students have adopted this position: better to subvert that aspect of identity in order to make friends. The difficulty is that as Bauminger et al. (2003) demonstrated the autistic students have not developed the necessary skills to ‘pass’ as neurotypical. Teaching basic interpersonal communication and skills in conversation initiation and reading intention in others may be beneficial.

In chapter four the need for a range of other practical forms of support or adjustment were also identified in the data. These related to dealing with sensory overload, recognising what is relevant in the curriculum, being able to maintain concentration (this only impacted four participants though) and time management, in particular being able to deal with the impact of the intensive nature of their academic courses. In addition, the notion of personal agency as a mechanism for controlling anxiety was raised and can act as an overarching theme for discussing this category of data. These impairment effect related issues should have been dealt with in conjunction with the Dyslexia and Disability Support Service. That so many participants had incomplete or inappropriate adjustments indicates that the students themselves did not have a sense of ownership over the assessment process or the requested adjustments and/or did not feel able to complain if the adjustments were not helpful. Potential reasons for this have been discussed in the previous section in relation to lack of a sense of personal authority or agency because the students themselves are grateful for any adjustments, believing themselves to the be source of difficulties rather than the environment. The finding that students are not using the best strategies available to them is in line with the research of Cai and Richdale with autistic HE students in Australia who found students did not always use available strategies for fear of appearing rude. They report that ‘*a lecturer or tutor…can think ‘Oh that student’s spaced out’’* when in actual fact they’re reducing the stimuli’ (2016, p35). That autistic students do not feel able to negotiate the most relevant adjustments for themselves is problematic beyond the educational sphere. Knight and Yorke (2002) argue that self-efficacy is critical to employability and that fixed ideas of self and intelligence lead to a learned helplessness and a negative impact on employability. They argue that employability is much more than learning transferable skills. That autistic students are lacking in a sense of self-efficacy or agency fits in the framework of social constructivist theory as previously discussed. This is a learnt behaviour and response, resulting from social pressures.

## Analytic Category 3: Managing Identity/Disclosure

The third analytic category considers how participants managed their identity and chose whether to disclose their condition to others. This is considered in relation to personal agency which was a feature threaded through the interviews. Desire for control and using rituals to create feelings of control are core indicators of autism and this relates both to how participants manage their identity now and whether they will choose to disclose in the future. In contrast to MacLeod et al.’s (2013) findings most autistic students in this study felt that autism was core to their personal identity (for many as a positive aspect). However all except one believed that disclosing that identity was likely to have negative impacts in the workplace and more broadly. A range of mechanisms were identified which participants used to hide their autism, and therefore identity. These included: working with children; actively building neurotypical interests and learning languages to hide autistic difficulties by speaking in the secondary language so that difficulties appeared as if related to being a non-native speaker. On a more day-to-day basis half of participants were immediately upfront about their autism whilst half made conscious attempts to hide it. Attempts to hide it were problematic and correlated with anxiety, high cognitive load and negative ideas about autism. All of these findings can be considered from a Bourdieusian perspective. Both higher education and graduate employment can be regarded as fields in Bourdieusian terms. Within these fields autistic students are attempting to operate by the rules of the game, as dictated by the powerful agents in these fields. In both fields being neurotypical is more highly desired. Any form of genuine creativity or divergence of thinking is potentially dangerous to the status quo which Bourdieu describes. As such, autistic people represent a threat to the status quo. Alternate thinking patterns and lower responsiveness to social influence are intrinsic features to autism. Consequently, autistic people are more likely to be critical of existing power structures, being unchecked by standard mechanisms for suppressing dissent such as social disapproval. From a Bourdieusian perspective then it is imperative to the status quo to prevent autistic people having genuine power or authority. They must be disenfranchised to prevent harmful criticism. One mechanism is to encourage the internalisation of negative messages about autism and pressure autistic people to adopt neurotypical ways of thinking and behaving. A highly contentious, though popular process is the Applied Behaviour Analysis ‘therapy’ (ABA) which Autism Speaks (2019) describes as aiming to ‘*increase behaviors that are helpful and decrease behaviors that are harmful*.’ Whilst the charity implies that the harm being decreased is for the individual, or more probably their family (for whom the charity speaks) that is not the only reading. Taking a Bourdieusian perspective the ‘harm’ which can be done is to the iniquitous status quo: allowing natural behaviours could ultimately lead to challenge of inequity. Kelly and Barnes-Holmes (2013) demonstrated that such treatments are correlated with negativity about autism. They assessed ABA tutors’ implicit attitudes and compared them with a control group of mainstream teachers. They found the ABA staff held negative biases towards autistic children and more positive biases towards neurotypical children. This is in line with the ABA theory that autism impairment effects should be eradicated. The study also used psychopathy scales to assess how staff felt about the children they worked with. Those who had higher empathy levels, i.e. saw the children as individuals had corresponding feelings of ‘guilt and inadequacy in their professional roles’ (Kelly and Barnes-Holmes, 2013, p26).

Given the negative perspectives participants described having been subjected to, it should not be surprising that all bar one believed that disclosure of the condition would lead them open to discrimination and be overall a negative experience. Several participants also reported professionals or family members similarly advising them not to disclose. This study did not set out to investigate the effects of disclosure and in an educational context participants reported, generally, improved treatment after disclosing. However, this is not to suggest that disclosure would be a beneficial during the job application process and it remains to be tested whether the anticipated discrimination would occur. There are both psychological and social costs when revealing stigmatising information (Baldridge and Swift, 2013; Colella, 2001) and as previously discussed autism is usually framed negatively and so is stigmatising. These issues may be particularly heightened in autism as the potential deleterious effects of this in the workplace are related to some of the skills which graduate recruiters describe as most relevant, in particular communication skills.

Disclosure is complex in autism as it is ‘episodically visible’ (Liveneh et al., 2014). The impact of this is that an active disclosure is required. However hiding the condition forever is likely to be impossible, or certainly cause high cognitive load. Whilst research has not been completed looking at discrimination against autistic individuals specifically, there is extensive literature on workplace discrimination against disabled people generally. Even when there affirmative action strategies in place there can still be negative outcomes for individuals disclosing. For example, they may be perceived as less competent (Heilman, Block, and Lucas, 1992), receive smaller salary increases (Heilman, Block, and Stathatos, 1997) or worse performance evaluations (Garcia, Erskine, Hawn, and Casmay, 1981). Disclosure may also create a backlash against the individuals and has been shown to be linked to anxiety, lower self-esteem and feelings of stigmatisation (Colella, 2001; Stone and Colella, 1996). Because of the difficulties in reading other people which comes with autism it is likely that autistic students will find it more difficult to accurately assess the effects of a disclosure and how a recruiter might respond. In an ideal world employers could be trained not to discriminate. However, more immediate and focused actions are necessary for current autistic students. These might include actively engaging with autistic students about disclosure and looking at the potential outcomes of disclosing or not, as well as tactics for disclosing which involve positive presentation. However services should also be mindful that autistic students may be undiagnosed or choose not to disclose to the university (Janiga and Costenbader, 2002).

If students choose not to disclose then this will impact their working environment and add an extra level of pressure. They will potentially lose personal agency and be unable to engage in comforting rituals or easily withdraw from difficult situations. The need for personal agency and control were a recurring motif in the interviews, spoken about in relation to day to day practices as well as in relation to managing career as a whole. Therefore, losing this control may have deleterious effects on mental wellbeing. In addition, suppression of identity, in this way, has been shown to be highly correlated with anxiety and depression in other stigmatised groups, for example gay and lesbian people (Griffith and Hebl, 2002; Major and O’Brien, 2005; Ragins et al., 2007) and it is reasonable to generalise these themes, to some extent.

## Analytic Category 4: Hidden Curriculum

The penultimate analytic category explores the perception from many participants that there some elements of curriculum were hidden. Chapter four discusses this in relation to academic curriculum as well as career ‘rules’ which they might be expected to adhere to. Consequently, whilst many participants had engaged in activities which would enhance their overall employability, they did not themselves always recognise it as such and had only gained relevant experiences ‘accidentally.’ This lack of understanding of what is employers ask of applicants, alongside the difficulties noted in being able to frame their autism positively means that autistic students are less well placed to understand how to meet the employers’ existing requirements nor to market their existing strengths to recruiters. In addition, employability development was seen as an added pressure, by many, on what they were already experiencing as an overloaded schedule. Some participants mentioned employability related services they had accessed but did not recognise them as such, confusing them with study skills support. The notion of hidden curriculum was corroborated in discussion with staff members who also recognised there were key aspects of courses which required interaction with peers which autistic students might miss.

That existing employability development programmes might fail to meet the needs of autistic students is not surprising. Without direct consideration of what they might miss or fail to notice, trainers and training designers are unlikely to consider autistic people specifically, particularly given that these roles require great communication skills and extravert personalities meaning role holders are less likely to be autistic. Lowden et al. (2011) argues systematic evaluation of employability programmes’ long-term impact is rare and they rely on anecdotal evidence instead. Whilst there has been a deliberate attempt to evaluate services since 2011, there is still little, as yet, published in the area. This means that this issue may be a problem for a larger group of students as well. Whilst the neurotypical matched sample who were interviewed did not raise this issue they were specifically selected as matches and so may not represent the widest neurotypical pool. Focusing an intervention to support understanding of the academic curriculum or employability rules on autistic students consequently might not benefit everyone who needs it. In addition, many autistic people are undiagnosed or, as previously discussed, reticent about disclosing.

Having an implicit curriculum or rules for employability was touched on in chapter two when exploring the concept of employability and can be understood through a Bourdieusian analysis. In the literature review the notion that the concept of employability was deliberately vague, and abstract was explored. This can be understood as beneficial for maintaining the status quo. Understanding the employability ‘rules’ is a form of capital in Bourdieu’s terms. It is something which more powerful members of society have, and weaker ones do not. For example, middle-class parents will inform their children of the need to engage in specific activities to be employable; working-class parents will emphasise the need to focus on education and not be distracted by extra-curricular activities. In addition, the ‘rules’ of employability require of individuals to have capital to access opportunities even if the individuals become aware of the need to engage with those activities. For example, to take part in skill building extra-curricular social activities; accessing internships; and building connections all rely on having different forms of capital in the first place: social, financial and cultural. Bourdieu would consider this in relation to class and lack of financial capital. Autistic students, of whatever class, are a further victim of this inequity, lacking capital in the form of informal knowledge, communication and networking skills. Their lack of awareness of the career rules and ability to access relevant activities mirrors those of working-class students and for some students the two identities will intersect leaving them doubly disadvantaged. When the concept of employability is crystallised it still remains oblique and inaccurate. For example, overemphasising teamwork (Booth, 2016) which is something middle-class neurotypical students can easily demonstrate and ignoring other job elements central to many jobs such as emotion suppression (Eurofound, 2016) which working-class and autistic students have more experience.

It is possible that discussions about these issues could be incorporated into employability programmes. Social justice is part of the occupational standards (UKCES, 2014) and code of practice (CDI, 2014) for careers professionals. However currently this does not usually manifest in specific discussions about discrimination, transition or habitus. Indeed whilst once a graduate profession with a requirement to hold a postgraduate qualification in careers guidance, employability interventions and careers work has increasingly been de-skilled and is delivered by people with business backgrounds or staff who are trained, though not educated in careers issues. NVQs at levels two or three have replaced the level six Postgraduate Certificate in Careers Guidance as the standard qualification for careers advisers. Such discussions would not undo the systemic barriers experienced by minority students though they would raise their awareness and having appropriately qualified staff in senior positions would mean they were able to advocate for supportive curriculum changes and programmes. Currently the Careers Service is not integrated into other learning and teaching structures and therefore not always able to contribute to discussions on employability development interventions or curriculum issues.

Introducing awareness raising activities about career rules is a relatively minor fix. There are some basic level sessions which may benefit autistic students and other minority groups to make up for some of the missing social capital, for example sessions on cultural behaviour such as dress, how to approach a potential contact or how to address different people could be beneficial for any non-typical student. In addition, autistic students specifically would benefit from input about the need to spin their achievements if they want to be successful in recruitment processes alongside neurotypical people. Autistic people are more likely to engage in ‘brutal honesty’ (Powell, 2017) consequently they do not necessarily recognise the need to spin their experience or skills; being open about their weaknesses and failing to emphasise their strengths. Autistic students also need to be shown that a significant number of other people ‘fake good’ (a form of lying) on parts of the application process. Such as faking good on personality measures (Arthur et al., 2009, Donovan et al., 2003; Griffith et al., 2007) as well as on cognitive parts of tests (Donovan and Dwight, 2014). This type of faking is important because self-report measures have grown in popularity and have replaced cognitive ability testing to some degree (Oswald and Hough, 2008).  Such behaviours advantage fakers as it is possible to increase one’s score by up to one standard deviation in this way (Allinger and Dwight, 2000). Depending on the fakers’ genuine scores such an increase could be recorded as a movement from being average to being in the top third of applicants. Such specific sessions for particular groups do have precedents with 77% of higher education careers services have specific initiatives for students with a disability or physical/mental health condition (AGCAS, 2018 as cited in Green, 2019)

The more major issue is the overarching principle of judging all students against specific external criteria which consequently creates a negative frame; a frame which as previously discussed, is one which replicates the status quo and so discriminates against non-traditional students. This university is not unusual in framing individual students in this deficit way but in so doing contributes to perpetuating the smokescreen that employability is a dispassionate equitable concept. That this approach is endemic is shown by the endorsement of the careers service practice of sending out a deficit framework career diagnostic tool to final year students. This practice resulted in the endorsement of an award from the Association of Graduate Careers Advisory Services (Anonymised, 2015).

One of the ways in which this deficit approach perpetuates the status quo is by placing the blame for failures in the economic system to provide adequate work onto individuals. Taking a macro level or Bourdieusian approach to this we see individuals then feel responsible, perceiving deficits in themselves rather than deficits in the system. The associated shame consequently prevents them from advocating for changes. In psychological terms the deficit approach can be conceptualised in relation to self-efficacy theory and research. Academic success has repeatedly been shown to be linked to self-efficacy (e.g. Lane, Lane, and Kyprianou 2004; McLaughlin, Moutray, and Muldoon 2007). Knight and Yorke (2002) argue that self-efficacy is critical to employability with fixed ideas of self and intelligence leading to a learned helplessness and subsequent negative impact on employability. Focusing on gaps leads to a negative cycle in which self-efficacy is reduced, impacting sense of employability, which impacts likelihood of employment, which then impacts self-efficacy.

Figure 3: Model of relationship between self-efficacy, employment and employability

This model can be critiqued on a theoretical level using social learning theory (Bandura 1977) because identifying development areas against any explicit set of criteria can be beneficial for learning. However, this benefit can only be realised if the criteria are both explicit and achievable and there is scaffolding to assist the individual to develop. That employability as a concept is diffuse and shifting has already been explored. In addition, the scaffolding required for development is great. Bandura explains that

*The less individuals believe in themselves, the more they need explicit, proximal, and frequent feedback of progress that provides repeated affirmations of their growing capabilities* (1997, p217).

Unfortunately, employability interventions rarely have the resources to work alongside students as they develop and provide that ongoing feedback, consequently individuals are simply left with a sense of deficit. This feeling of deficit is problematic not just in direct relation to employability but also in relation to mental wellness: this link between lack of employment and mental wellness was explored in chapter two. In addition, there is a potential primary impact between sense of self-efficacy and mental wellness which is independent of the mediating effect of actual employment if we consider Social Identity Theory. When autism is portrayed as a condition of deficit, as is the case relative to the concept of employability then autistic individuals are left with potential cognitive dissonance. Breakwell (1978) considers differences in self-identity and external criteria as resulting in two things: if self-identity is positive and group identity negative then the individual may lower self-esteem, or they may engage in collective action to change the views of the group. As already explored the effects of framing employability as a personal responsibility are that autistic individuals are unlikely to engage in collective action and such unity was not demonstrated in individuals in this study.

An alternative approach would be to adopt a strengths-based approach. For example, when working directly with autistic students’ advisers could emphasise specific strengths: that autistic people are more rational and clear decision makers (e.g. Farmer, Baron-Cohen and Skylark, 2017). They benefit from:

*…strong memory, focus precision and an eye for detail, dedication, the ability of putting one’s mind to a subject, analytical skills, remarkable powers of observation* (Van Hees et al., 2015).

In addition, there are myriad benefits from divergent thinking which both Dillon (2007) and Morrison, Sansosti, and Hadley (2009) argue are beneficial for academic life and the workplace but are only regarded as problematic for employers because they can result in challenge to the status quo. It could be argued that such an approach would leave students overconfident and lacking in skills which employers have stated they require. This is only problematic if accepting the rules and structure of the status quo. It assumes that employers are requesting what is best for the workplace, rather than what is best for their self-interests. It also assumes that the status quo is beneficial for individuals and for society. Nussbaum (2002) takes an alternate perspective. She describes the capabilities approach. This explores what someone is able to do and to be. She argues capability, rather than functioning, should therefore be the political goal. Her work is gender-related but can be applied to other disadvantaged groups, being grounded in Marx’s work. She argues that at a societal and organisational level questions should be explored about opportunities such as: can a person become X, if not what opportunities and liberties impact that capability and what resources are necessary to allow full capability. Capability in this approach is not fulfilling some capitalist requirement to work in a specific way in a specific organisation. Rather it is about having full personal capability as a human, rather than a worker and for each individual to have their senses ‘cultivated by appropriate education, by leisure for play and self-expression, by valuable association with others’ (p130). In this tradition a full re-evaluation of broader education is necessary with a move away from its employment focus.

## Analytic Category 5: Creating Appropriate Services

The final analytic category moves beyond the discussion of hidden curriculum and discusses the services autistic students requested and additional those from which they may benefit. In this section, how to frame services so that they encourage reflexivity and acknowledge chaotic effects in the labour market are explored. The discussion then turns to look at how employability services should incorporate the views and needs of autistic people in the long-term and consider how they access support naturally from known sources.

Phase one findings demonstrated that autistic students were equally as likely as neurotypical students to use support services and be working towards activities which enhanced their employability. They were also equally as likely to believe the university provided good support. However, for all students, active use of careers services was low and for autistic students as well as other atypical students the need for support with employability development is higher if they are to attempt to compete for graduate jobs against neurotypical students. Whilst comparator figures are not available for students at this university in recent months there has been a growing awareness of the need for increased support. In January 2019 The Universities Minister Chris Skidmore called on universities to do more to support disabled students. This call focused on increased support for disabled students to enter HE rather than on improving graduate destinations, despite there being a 30.9% employment gap between autistic students/ students with a social impairment and non-disabled students for 2016 graduates (AGCAS, 2018 as cited in Coney and Allen, 2019). It is sometimes argued that degree level study improves employment chances of disabled people. The House of Commons (Powell, 2018) briefing paper shows employment rates for disabled graduates of 71.7% in contrast to 45.6% for disabled people with only level two qualifications. However, this comparison does not illustrate the benefits of a degree. These are not the same groups. Not all people with level two qualifications are capable of degree level study and the difference in intelligence, skills or behaviours may account for the differential employment rates. There is no evidence the degree itself has an impact.

One pertinent finding from this research is that some autistic students were highly literal in their interpretation of careers advice and displayed an absolutist approach to career decision making. When careers interactions are triaged for efficiency many enquiries will be dealt with through simple information giving. A specific question is asked, and a specific response is given. This is an efficient way of providing resources as staff who provide information, as opposed to guidance, require fewer qualifications and are typically cheaper to hire. This is problematic if an individual is literal or absolutist in their approach though. If someone is not already being reflexive, in considering career, they are unlikely to ask the right questions, or even recognise that there are alternatives. Even seemingly basic level employability tasks such as creating a CV require reflection as it requires one to be aware of another’s needs and perceptions (Beck and Beck-Gernsheim, 2002). An unqualified triage receptionist may not perceive the real need and see this as an information requirement. For an autistic student more support is needed to encourage the level of reflection necessary and active teaching of reflection may be necessary. Not all research agrees that reflection can be taught. Boud and Walker (1998) criticise the idea that any teacher can facilitate reflection, arguing that teacher as well as learner inexperience causes problems. They argue that reflection cannot be easily embedded into a curriculum and that it is badly understood in universities, with problems such as an expectation that students can reflect on demand, and that reflection equates to learning. They concluded this results in inappropriate disclosure and excessive use of teacher power. However, Boud and Walker’s work looks at teacher, not careers adviser led reflection, which is reasonable given that is how the services are most often delivered. Most HE staff have not been formally trained in reflection themselves, indeed 35% do not have teaching qualification, the most recent iteration now incorporates reflective practice (HESA, 2019b). In contrast, traditionally trained careers advisers do have this training and experience. Reflection is core to guidance. Where it becomes problematic, is when a service offered by careers specialists is scaled up using non-specialists who do not have the training. This has occurred with reflection in the curriculum, with attempts to enforce it by attaching assessment to the reflection. Boud, Cohen and Sampson (1999) argue that the process of assessment is in direct competition with the nature of reflection. Therefore, it is not possible to provide this necessary reflection support cheaply embedded in existing learning activities. It must be done by trained professionals, on a one-to-one basis with the individuals concerned. To allow this employability should be considered as part of the students’ individual learning plans and appropriate interventions included. This also needs to occur on an ongoing basis.

Thomlinson finds ‘*Reflective thinking should not just occur before or after the action but if possible, also in the midst of it*’ (1999, p408). This means one off disjointed meetings with careers advisers are insufficient. That ongoing support is given also fits with the finding that participants requested longer interventions where they could build up a relationship with the staff member and in turn the staff member could find out genuinely about the student. Autistic students need to have a programme of interactions during which they can explore their ongoing learning in relation to career and employability.

It should be noted that autistic people are not necessarily worse at reflection than their neurotypical peers, simply that this needs to be better guided towards relevant issues or triggered appropriately. Indeed, the personal stories of autistic people in Prince-Hughes’s book often describe great *personal* introspection. Darius, one participant describes how ‘*I have always found that level of reflexivity quite normal, but all the doctors I saw during childhood used to be astounded by my apparently abnormal level of introspection*’ (2002, p13). Another participant, Jim, talks about the cost- benefit analyses he conducted as a child on himself after applying ethnographic techniques to himself to establish why he was so different from his peers.

These narratives demonstrate that reflection is occurring, but it is not always appropriately focused for employability: that autistic people may self-analyse rather than exploring the perceptions and needs of other as is required to present oneself appropriately as meeting those needs and therefore employable. This assumes that being employable in an existing system is the desired outcome and as currently practised it is this level of personal reflexivity which can be harmful to the individual: introspecting on why they do not fit into a system. However if outwardly focused it could have impact on structures and systems. In many ways autistic people are not vulnerable to the structural factors Bourdieu describes as holding the status quo. They are likely to step outside of the ‘game’ and question the pre-existing rules which stem only from arbitrary rules benefitting the ruling classes. Autistic people’s relative imperviousness to some aspects of socialisation, notably peer pressure is often construed as negative: they do not conform with what society requires. However, it is through people who do not conform that societal changes occur. In exploring reflection, reflexivity and how this can be directed with autistic people it is important that this does not take the form of analysing own deficits in a current system. Rather considering deficits in a current system and how to respond could be a more appropriate focus. In some respects, this was already seen in the findings, for example, participants reported wanting meaningful work, rather than well paid work which capitalism assumes is the driver. However, this finding needs contextualising. It represented a difference between the autistic participants and matched controls. However, there is external evidence that the need for authenticity in work is a generational difference and so might be seen in a wider sample of neurotypical students of this age as well (Sullivan et al., 2009). Participants were open to experiences, quite prepared to move geographically or explore other types of work. This was an interesting finding given the autistic preference for continuity over change. However, this can be understood in the context of personal agency and control: a central theme through all interviews. As long as the individual is in control then they can engage in dramatic changes. Another related finding was that participants wanted holistic assistance, not focused on specific aspects of their condition. This does not map onto the current practice of deficit-based employability programmes but does fit with chaos-based interventions which focus on reflexivity and personal preparedness. Both approaches are now explored. These relate to research question four which investigates what autistic students want from university regarding employability support. Whilst participants have not discussed particular models in their responses, it is worth exploring how different theoretical and practical approaches to supporting employability could potentially meet the needs they describe.

Both Cranmer (2006) and Mason et al. (2003) argue there is no evidence that teaching employability skills impacts employability. One explanation already explored is that the skills identified are actually a smokescreen to improve the likelihood of middle-class students succeeding and thereby perpetuating the status quo. Another consideration is that programmes build on person-environment models of career so are outdated. Person-environment fit models operate on the assumption that particular personalities fit with particular occupations or environments. In these approaches, attempts are made to assess the individual’s personality and preferences, through inventories or self-reflection and then consider how these might fit with different environments. Holland’s (1966) highly influential matching model is used extensively in career counselling as is the DOTS model of Law and Watts (1977). The latter gives a practical framework for working with clients and so is popular. It describes four phases to focus on: self-awareness (S); opportunity awareness (O); decision making (D) and transition (T). All of these models assume stability though. This assumption is pervasive in career research. Arthur and Rousseau (1996) found that 74% of articles on careers assumed environmental stability, 76% had an intrafirm focus and 81% had hierarchical assumptions. Lack of personal stability in personality and organisational stability are both challenged as problems with these approaches. In addition, there is evidence that people cannot collect and process all the information they need consciously (e.g. Simon, 1957; Claxton, 2006). Using such models appears superficially sensible. It maps onto employers’ practices. Job selection involves an element of deciding whether people fit into an organisation (Huffcutt et al., 2001) but at the same time employers claim to want employees to stand out (Parmentier, Fischer, and Reuber, 2013). A major issue with these models is that the underlying assumptions of them have not been shown. They all assume that congruence between individual and environment leads to greater satisfaction. Arnold (2010) argues that congruence between person and environment is neither strongly correlated with achievement nor satisfaction. In addition, Muchinsky and Monahan (1987) present evidence for complementary congruence, i.e. that people are more satisfied in roles where they are significantly different to the majority of other role-holders. Regardless of these criticisms employers use such systems and so those supporting employability do need to consider them. However this can be done with a critical perspective and one role of careers advisers is to build relationships with and influence employers. Hill (2014) argues we know too little about how selection processes impact autistic people and suggests that they are screened out in early parts of the process which depend on emotional intelligence, organisational skill or flexibility.

An alternative model for career interventions is chaos-based and allows for greater levels of personal as well as organisational difference, therefore, making it suitable for neurodiverse participants. Numerous researchers describe changes to the employment landscape (e.g. Sullivan and Baruch, 2009) laying out the impact of being in what Benett and Lemoine, (2014) describe as a VUCA world, i.e. one which is volatile, uncertain, complex and ambiguous. In this world autistic people need to be prepared for change as it is a feature of their lives. Conceptualisations of career have evolved to fit with this new environment. Hawkins describes how ‘There’s no such thing as a career path. It’s crazy paving and you have to lay it yourself’ (1999 p1) and definitions of career have changed to focus on change, such as Arthur et al.’s definition that career is ‘*The evolving sequence of a person’s work experiences over time.*’ (1989, p8) or Collin and Watts’ definition of ‘*The individual’s development in learning and work throughout life.*’ (1996, p386). It is into this environment various chaos-based models of career development have emerged and have proved beneficial. Mackay, Bright and Pryor (2005) found chaos-based career counselling was more highly rated as effective by clients than matching based counselling or a control participant on a waiting list.

Central to chaos-based approaches is reflexivity. Something Threadgold and Nilan describe as ‘the ‘new’ cultural capital’ (2009, p63). An example is Planned Happenstance. This model argues that career counselling should focus on developing an exploration mindset, being ready for any eventualities (Mitchell and Krumboltz, 1996). On a practical level this means an employability intervention should focus on encouraging the acceptance of change and uncertainty as normal, developing a range of skills to be ready for different situations and recognising it as normal and even desirable to have one’s career influenced by random events. Reflection is key to this as one is required to continually self-assess and commit to ongoing personal development. One should also learn how to actively plan for periods of instability or unemployment. Reflexivity as well as reflection is required though, as the individual needs to survey the environment to assess opportunities. Sen (2009) encourages reflexivity in another form: in order to become the rational agent which economic theory would have us be. He argues individuals need to become aware of the deep and pervasive effect that society has on the way in which people think about themselves and behave. Whilst the same sort of reflexive practice may occur the intended outcome differs from chaos-based interventions as Sen would support societal change as result of this reflection and encourage individuals to engage in advocating for change. The chaos-based approach is more concerned with the individual being able to achieve success in their own terms within the existing society rather than working to change it. Bourdieu’s reflexivity describes the process by which people consciously override their habitus, e.g. this could be done through careers education. He argues the ability to be reflexive comes as a response to adversity: it is a process of adaptation and that the challenges of unfamiliar situations lead to ‘gaps between expectation and experience’ (Elder-Vass, 2007, p329) allowing the ability to be reflexive to develop. Theoretically the increasing need for reflexivity to adapt to the changing job market means that habitus should become less important over time. However, Sweetman argues that

‘...reflexive orientation towards the contemporary environment may itself be regarded as a form of habitus, itself the outcome of an ***adaption to***...the changing nature of the social terrain.’ (2003, p 543)

again fitting back with chaos-based career interventions: preparation for the new terrain. Whether increasing reflexivity allows people to operate within an environment or develop the consciousness to change that environment is perhaps the active choice of the individual themselves. As previously discussed, autistic people are perhaps well placed to engage in the subversive questioning and behaviours which can lead to change, particularly if they manage to use the same reflexive approach to access powerful positions in the first place.

In instituting a chaos-based employability approach for autistic people their unique strengths and weaknesses still need to be considered. An example would be about preparing autistic people for adapting how they present in the workplace. Fugate et al. describe employability as a ‘*form of work specific active adaptability*’ (2004 p16). Hall and Mirvis (1995) argue that this adaptability specifically requires individuals to manage multiple identities whilst Chan (2000) argues the requirement to be malleable and to change to fit the employment requirements is a feature of modern work. Given that the findings focused on the need for personal control this may prove a problematic element, essentially pretending to be different people. Ashford and Taylor (1990) describe the ways in which employees adapt to fit the work environment as: understanding their environment and status within it; having the internal characteristics necessary for adaptability; and being willing to change behaviours, cognition and affect. Whilst participants in this study demonstrated willingness to make major changes to access work they enjoyed this does not imply they would be prepared to make these day to day changes necessary in a given workplace. Indeed this is counter to the findings regarding managing their own identity discussed in analytic category three. Therefore this is likely to require a good deal of preparation prior to graduation.

It is also worth drawing in other potential issues here. As previously discussed, autistic students have intersectional identities. The intersection of gender and autism was previously explored. Class and autism may also be intersecting aspects of self which were not explored in this study and would benefit from future consideration. Working class people have been shown to be more able to be reflexive in career planning with middle-class youths less able to imagine any alternate options (Laughland-Booÿ, Mayall and Skrbiš, 2015). Similarly, research shows greater reflexive awareness amongst those from working-class backgrounds who went to university. Findings also suggest that reflection can be taught. Reflection forms part of the curriculum for both nurses and social workers, two groups who also showed greater reflexivity (Reay, Crozier and Clayton, 2009 and Huppatz, 2010).

Whilst the initial reflection and reflexivity required can be incorporated into the support given whilst at university, autistic graduates may still need some help once in the workplace in dealing with the adaptations required of them. If they are prepared to disclose, then this can form part of the formal adjustments requested and advocates from the university could support with this induction process. However, as explored in this chapter most participants were highly wary of disclosure and did not plan to do so with employers at least in the early stages. This is something which careers advisers could work on with students: exploring the benefits of asking for adjustments versus making adjustments oneself. In the long-term autistic employees may have difficulties if adjustments are not made. For example, Burke et al., 2010 point to the need to modify traditional on-the-job training for autistic employees so that long instructions and modelling are not used, as these are less effective than other forms of training. Some elements which could potentially cause problems could be dealt with during HE though. For example, the concept of social decorum and what is required is identified by Vogeley et al. (2013) as being problematic would need to be discussed and addressed as this is central to getting and keeping a job. Whether preparation ahead of time would be sufficient has not been tested with autistic participants, although research has investigated how personality types impact receptiveness to self-reflection. Berzonsky and Adams (1999) identified different levels of receptiveness to feedback: those with an information orientation seek out and use information. Those with a normative orientation conform to others’ expectations and those with avoidant orientation avoid self-reflection. Those who have information orientation are more likely to be prepared for, and successful in their careers as a result (e.g. Ashforth, 2001; Cheek and Jones, 2001). Therefore, this remains an area for future exploration.

Another finding relevant to creating appropriate services is that participants from phases one and two requested more involvement of neurodiverse staff generally and the availability of neurodiverse mentors and advisers. Initially this might be understood through Social Identity theory: that autistic students identify more with other autistic people as part of the same in-group and so would rather spend time with them or regard them as more able than people from an out group. However, a simpler explanation is that participants expect other autistic people to be more able to understand their perspectives or advocate better for them. Despite Hans Asperger originally labelling his charges as ‘little professors’ for their traits (Asperger, 1938, as cited in Silberman, 2015), the presence of autistic academic staff in UK HE is fifty times lower than should be expected. No figures are available for associated or administrative staff but HESA (2019a) records show that that of the 97% of full-time academic staff employed in 2017-18 who responded to questions about disability only 4% believed they had any disability and fewer than 0.02% believed they had any social or communication impairment (including autism). The figures in the general population of people diagnosed with a disability are 16.7% (Department for Work and Pensions, 2019) and 1% for autism alone without other communication or social impairments (APA, 2013). Therefore, when participants requested autism specific careers help from neurodiverse staff it is reasonable to assume that the primarily neurotypical staff in HE are not correctly gauging what it is they require at the moment. A range of students have been shown to use services less because they feel unrepresented by staff diversity including mature, part time and widening participation students (e.g. Redmond, 2006; Stevenson and Clegg, 2011). Therefore, it is tenable similar patterns occur for autistic students.

That autistic students feel comfortable with staff is important given the finding that they are more likely to rely on hot knowledge. Hot knowledge is that which comes from trusted individuals rather than statistics or formal data sources. Autistic students were seen to rely on family and supporters as advocates. This fits with Barnhill’s (2016) finding that American autistic HE students’ families were more likely to live closer to their university, they were more likely to live at home and academic success was correlated with proximity to family. Barnhill reported that many American HEIs regard parental support as beneficial. This contrasts with the findings in this cohort where staff members reported attempting to wean students off parental support and in one case deciding not to speak with family at all. Family and friends play an important role for autistic students and attempts to make students independent of their families should be considered further. The requirement to be independent is an example of what in Bourdieusian terms would be regarded as doxa: a learned unconscious belief which is understood as a self-evident universal. However this position is not universal. Firstly, a considerable corpus of literature exists from occupational psychology to show that people do not make decisions on purely rational grounds and that in particular working-class students prefer ‘hot knowledge’ from trusted people rather than the ‘cold knowledge’ provided by statistics (see Ball and Vincent, 1998). Secondly the notion of ‘Individualism and collectivism has emerged as the most important dimension on which cross-cultural differences in values have been described.’ (Speilberger, 2008 p459). The findings from staff members demonstrated an individualist approach which assumes autistic students, and indeed all students should be distancing themselves from parents and moving towards complete independence. This is both primarily a middle-class perception of familial relationships and responsibilities and a highly Western one. If outside forces do not match the cultural perspective on individualism/collectivism it affects task performance (Inyegar, 2010) and also can cause distress (Harkin and Huber, 2004). Autistic students are more likely to have a collectivist attitude to decision making and appropriate knowledge sources. Both Kenny et al. (2015) and Langan,(2011) argue that parents of autistic people have to wage battle against social and political forces to gain medical and educational interventions for their children (Sousa, 2011, p220): something many participants described and something which is likely to impact their trust in authority figures and belief in their parents’ judgement. As such attempts to force autistic students who are culturally collectivist into individualistic behaviour patterns can be regarded as symbolic violence.

## Summary

In this chapter several theoretical frameworks were used to explore different aspects of the findings. These included three already laid out in the literature review: Social Identity theory, Social Constructionist theory and elements of Bourdieusian theory. As with existing literature Social Identity theory or Social Constructionist theory could be used to explain the practicalities of how structural inequity described by Bourdieu is created and maintained. In addition, feminist theory was used to elucidate the impacts which resulted from participants intersectional identities. Figure 4 demonstrates how these theories are interrelated in this chapter. It was not possible within this research to explore intersectional identities in any depth. However, given the relevance of gender found, further exploration about the gender-autism intersection is advisable. Additionally, given the themes regarding hidden curriculum and theoretical links between this and social class, some future investigation into the the intersectional aspects of class and autism are worthy of future exploration.

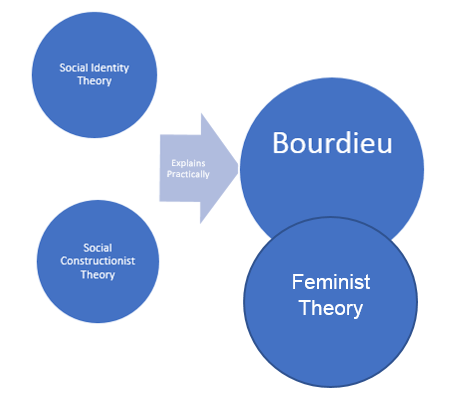


Figure 4: Model showing interrelationship between theories used in discussion

This chapter portrayed the experiences of a sample of autistic higher education students. In summary, the prior discussion demonstrates the continued effects of stigma around autism and for female participants the ongoing effects of failure to diagnose in early childhood and misdiagnosis. It explored issues that result from managing identity and choosing to disclose and the impacts of structural elements of the curriculum and employability services including using a deficit model of employability.

# Chapter 6: Conclusions

The purpose of this research was to explore with a sample of autistic students their experiences of employability through their studies. The conclusions from this study stem both from addressing the initial research questions and from emergent findings from the interviews. Therefore conclusions fit within five broad categories: the effects of previous treatment on current thoughts and behaviours; impairment effect related issues and their effects; managing identity and disclosure; dealing with a hidden curriculum; and creating appropriate services. Then follows a brief discussion of the main conclusions drawn from this study and of the implications these have for future study, for practice and for individual autistic students. These discussions are followed by a summary of the discussion regarding rigour and trustworthiness of the research which occurred in chapter three and comments on areas of vulnerability when using the research outcomes. The chapter closes with the researcher’s final reflections on the work.



## Summary of Findings, Analysis and Conclusions

The first major finding of this research is that previous experiences during diagnosis and engagement with services have implications for future expectations and tolerance of discrimination against the self. This issue was explored in relation to differential treatment experienced by female relative to male autistic students and in relation to both genders being accepting of negative treatment. A conclusion that can be drawn from this theme is that autistic people are likely to be more wary of formal services than neurotypical students and not expect to receive the help that they need. A practical implication stemming from this is that services need to repair previous damage done and to develop long-term meaningful relationships in which there is trust. A secondary practical implication is that students need to be supported to recognise their legal rights and to self-advocate. A final implication from this finding is that HEIs need to be mindful of the increased risk to autistic students of mental health problems because of their previous experiences, in particular female students, and should put in place appropriate risk management strategies.

The second major theme looked at issues which sprang from autistic impairment effects and adjustments to manage them. The greatest of these was increased loneliness. Loneliness was a thread which ran through much of the data, both in interviews and the questionnaire and related to exclusion and isolation. This was explored in relation to adjustments having negative effects and distancing autistic students from their peers and the finding that autistic students did not always use the services they needed because they felt stigmatised or distanced them from peers. A conclusion that can be drawn from this is that autistic students have not always been able to develop the necessary skills to create and sustain deep friendships. An implication from this finding is that students might benefit from active training in interpersonal communications and opportunities to discuss practical tips. Whilst it is acknowledged that a support group is available which allows students to meet up with autistic peers, it should be recognised that this does not necessarily lead to the necessary skill development or ability to build relationships with neurotypical people and so may be only a short-term fix. A recommendation is that relationship building is included as a focused activity available to autistic students, ideally run by autistic people themselves (linking with theme five). Another element of the theme regarding adjustments was that they were not always received or beneficial to recipients when they were delivered. Despite this they were unlikely to complain or ask for reassessments. A conclusion from this is that autistic students adopt a position that they should be grateful for any adjustments are received and that complaining may jeopardise existing adjustments. Therefore a recommendation is that it is important to build strong trusting relationships between individual students and DDSS; and that the DDSS actively explores whether adjustments are working with students. A further recommendation is that students are actively informed of their legal rights regarding adjustments and periodically reminded of them so that they feel secure in raising issues.

The third major theme concerned how autistic students manage their identities and their reticence to disclose autism in employment situations. A critical factor in the discussion about how this occurred was whether individuals felt their personal agency was retained. For participants in this study autism was regarded as a major part of personal identity and passing as neurotypical was something which they attempted but led to a problematically high cognitive load. Disclosure was discussed in relation to potential discrimination. The analysis used Bourdieusian perspectives to consider how the negative framing of autism was beneficial for maintaining the status quo as it prevented difficult questions being asked by autistic people who approach problems in different ways. One conclusion is that despite the difficulties caused by simulating neurotypical behaviour, most autistic students attempt this at least part of the time. Another finding is that there is significant fear by autistic students that they will be discriminated against if they disclose their condition. Given that there are potential negative outcomes to disclosing (discrimination) and not disclosing (lack of adaptations) it is recommended that explicit conversations are had with students about this issue so that they can make an informed choice. A further recommendation is that HEIs should work with employers to reduce stigma about autism and understand the benefits associated with autism to reduce potential discrimination.

The penultimate theme was that for many participants there was a sense that there was a hidden curriculum both academically and relative to what was required of them to be employable. This theme was analysed in relation to Bourdieusian principles and the idea that the concept of employability and the skills articulated as being imperative for employability represent a mechanism for maintaining the status quo and are a smokescreen to justify inequity rather than real aspects of working life. A conclusion from this is that this theme can offer support to Bourdieusian ideas about the subtle ways in which power is transferred in society. There are several potential recommendations stemming from this. Firstly, active discussions can be had with autistic students about social equity and what they can do to mitigate some of the barriers faced, whilst reminding them that unemployment should not be regarded as personal failure because there are powerful systemic, structural factors. Secondly, appropriately qualified careers staff should be involved with curriculum design to ensure that such issues are present for all students whether diagnosed as autistic or not. Relevant training for careers staff would be at professional level, most likely post graduate and involve critical exploration of issues of social equity and power, for example as is covered on a PGDip or Masters in Careers Guidance. Skills training alone would not insufficient. Thirdly basic awareness raising sessions should be run for autistic students to help them understand hidden aspects of curriculum and employability concerning aspects such as networking, dress, interpersonal communication. Fourthly attempts should be made to actively reject deficit models of employability and consider the need for raising self-efficacy. On a practical level this could mean adopting a strengths-based approach to career and supporting individual autistic students over an extended period of time to scaffold necessary employability learning. This leads to another recommendation: that employability development is included, as standard, as part of a disabled student’s learning plan so that there is a coherent university-wide approach to support and development. This means active communication between the DDSS and Careers Service, and specific adjustments and responsibilities relative to employability on the Individual Learning Plan.

The final theme analysed concerned what was needed from employability services. This looked at the need to reframe services away from person-environment approaches to work towards more reflexive approaches which acknowledge the chaotic patterns of workplaces, recruitment and business development. It also explored the ways in which autistic students currently access support and information through hot knowledge, and discussed how their preferences should be respected as cultural aspects of practice rather than deficits relative to a middle-class Western assumption about decision making. The primary conclusions drawn from this analysis was that autistic people’s development needs are often stymied by neurotypical understandings of success. A recommendation from this is that HEIs should actively seek to hire autistic people who can contribute to strategic and structural planning of services and curricula. A second recommendation is that careers services should consider chaos-based approaches to counselling and employability development. Thirdly autistic students should be encouraged to direct their reflexivity to external targets, not just inwardly, to explore what others may require from them in the workplace. A fourth recommendation is that autistic students are involved in decision making regarding rules which impact them: with a deliberate attempt to gain representation via a student representative or specific feedback sessions from autistic students to the university.

## Moving Forwards

In this section recommendations are offered stemming from the themes, analysis and conclusions drawn from this research. These are grouped for different stakeholders: for future researchers; for university staff and for individual autistic students.

### Legislation and Policy: Making it Work

Before exploring explicit recommendations from this research, it is worth considering existing policy and legislation and how this can be harnessed to improve outcomes for autistic graduates. There is a range of legislation and policy which impacts autistic people in the UK which could potentially strengthen their rights. However, as previously discussed autistic students are not always aware of these or able to use them effectively. The Human Rights Act (1998) affords general rights to all people. The UN Convention on the Rights of Persons with Disabilities (2006) focuses specifically on disabled people reaffirming those rights. The UK Government are signatories to this document which explicitly emphasises that all human rights and freedoms apply to disabled people and that adaptations should be made in order to support individuals to exercise their rights. These ideas are enshrined in UK law through two key pieces of legislation which are important for autistic people. Firstly the Equality Act (2010) which provides protection from discrimination, victimisation or harassment in the workplace, education and wider society. The act helps disabled people because it requires that reasonable adjustments are put into place to support them in accessing employment and services and because it prevents questioning about disability issues as part of the recruitment process. However, as shown through this research, the act is poorly understood by those who should benefit from it, with one participant even believing it required her to declare a disability: the exact opposite of its intent. In addition, the Equality Act only applies in relation to disability where there has been a specific diagnosis. Accessing diagnoses has historically proven difficult and many autistic people have not received them until adulthood, if at all. This prevents them being protecting by this act. The Autism Act (2009) goes some way to mitigate this problem. It requires local authorities to have strategies in place for diagnosing and supporting autistic people and so should put in place the mechanisms for adult diagnoses. However, the act is not working at the moment. This research shows that most female participants were not diagnosed until late adolescence despite the act having been in place since their early childhood. To date, more than ten years after the act, not all local authorities even have an adult diagnosis service and many autistic people are still not served (National Autistic Society, 2000). However, there is a significant upsurge in research activity regarding autism, activism by autistic people, campaign groups as well as increasing awareness of autism by the general public. Historically it is changes in culture which lead to significant changes in social justice issues. The legislation is rarely the catalyst and these pieces of legislation are too cumbersome and expensive to enforce fully. Their strength comes in being used as test cases which can then be used to gain public support and move towards a more inclusive culture.

### Recommendations for future study

Given the tight focus of this research on one HEI at one point in time it is recommended that further studies be conducted to explore the generalisability of these themes to students at other types of institutions and in other geographical domains. In so doing the following should be considered:

* The intersectional aspects of identity which may impact on experience. In this study both social class and gender were touched on as potential moderators or exacerbators of autism related issues. Future studies may wish to classify participants according to differing aspects of their identity such as this.
* In this study participants were self-identifying, though almost all also had a formal diagnosis. Future studies may wish to consider individuals who would not reach the diagnostic threshold but who display autistic characteristics and explore the difference between those who disclose early, late, or not at all to the HEI. In extending this research in this way the Broad Autistic Phenotype Questionnaire (BAPQ) may be used as it can measure autistic characteristics. It has been found to be effective in assessing broad autistic phenotype (BAP) in the general population (Ingersoll et al., 2011; Sasson et al., 2013). Participants reported strong reliance on family support and advocacy. However this may be inadequate because family members of autistic people often have similar traits: difficulties with communication; rigid personalities etc (Hurley et al., 2007; Landa et al., 1992; Piven et al., 1997).

### 6.2.3 Recommendations for practice

Administrators of employability programmes and services for students more generally should consider the following recommendations:

* Allocating fixed staff contacts for autistic students and meeting regularly so that they are able to build up long-term trusting relationships.
* Providing whole course planned employability programmes which consider the individual holistically as part of their Individual Learning Plan.
* Work with autistic students so they recognise their legal rights to adjustments and feel secure in self-advocating.
* Developing risk management strategies for autistic students who have increased risk of mental illness.
* Ensuring that access to careers services and employability initiatives are covered in autistic students’ individual learning plans.
* Delivering a range of specific sessions for autistic students which might include: active training in interpersonal communications and relationship building; discussions about disclosure, boundaries between ‘spinning’ skills and being dishonest and social inequity; and considerations of the specific factors which may prevent them accessing work such as knowledge of appropriate dress or communication. Booth (2016) recommends training for everyone on working together so that it gets to people who are not aware they are autistic and so that it is not perceived as remedial. However, this recommendation needs to be considered in relation to resources as well.
* The DDSS actively exploring how adjustments are/ are not working for individuals at fixed points in time.
* Working with employers to reduce stigma about the condition and understand the benefits associated with autism to reduce potential discrimination.
* Involving appropriately qualified careers staff in curriculum design and service planning.
* Actively rejecting deficit models of employability and focusing on raising sense of self-efficacy and strengths. On a practical level this could mean adopting a strengths-based approach to career and supporting individual autistic students over an extended period of time to scaffold the employability learning necessary.
* Actively encouraging applications by autistic people for university posts, in particular for mentoring/ buddying services where they have been specifically requested.
* Considering implementing chaos-based approaches to counselling and employability development.
* Careers staff exploring existing neurotypical rules.
* Ensuring autistic students’ voices are heard in decision making regarding rules which impact them: creating formal university-wide structures to ensure representations and an ethos of welcoming informal feedback.
* Provide training and education for all students on diversity issues.

### 6.2.3 Recommendations for autistic students

* Ensure you understand your own legal rights to adjustment and regarding discrimination.
* Ensure you take the time to explore the hidden rules of employability and how these might impact you. Use the Careers Service to find out more and to develop. Be aware that you can access the Careers Service post-graduation.
* Consider employability development as part of your overall learning whilst at university and actively plan for this starting in year one.
* Acknowledge that achieving employment involves elements within your control as well as forces which are outside of your control. If you are not successful, do not blame yourself.
* Take opportunities to actively develop skills such as how to build relationships or prepare for face-to-face and online interviews.
* Consider the strengths which you have and decide how much you want to ‘spin’ these when seeking work.
* Take advantage of opportunities to see employers’ premises ahead of time or familiarise yourself with an organisation, for example, taking part in Insight Days.

## Revisiting Assumptions

Assumptions underpinning this research were presented in chapter one. These were the product of the researcher’s background and experience as Programme Director and previously as a Head of Employability Services. The first assumption was that there was no academic difference between autistic and non-autistic students’ performance. This was not explicitly tested in the research, but the theme held true according to students’ self-perceptions of academic support needed. The second assumption related to financial and opportunity costs associated with university participation. It was assumed that all students intend to recoup those costs in improved work quality and value at the end of the study period and so wish to be employable at course end. This assumption was revealed to be partially correct. Whilst all students expressed a desire to be employable, what that meant for the different groups had subtle differences. What was critical in employability terms for the autistic students was that their jobs allowed them to be independent and to have personal autonomy. With the exception of one student, graduate level salary was of low import for autistic students. They focused on qualitative aspects of the work. The third assumption was that all students are motivated to succeed in their studies. This was not tested in the study but there is no evidence to undermine this assumption. The fourth assumption was that all students are capable of understanding instructions and guidance and are motivated to listen to that advice and guidance if they see it as credible. This assumption was partially upheld. Whilst autistic students were no less likely to seek out advice or to listen to that advice, for some participants there was an issue with literal interpretations of advice which means that this assumption is not completely correct. The final assumption was that autistic students are no less likely than their peers to want to work generally or in graduate roles specifically. This assumption was found to be correct. Indeed there was evidence to demonstrate that for this group having work was more important than for neurotypical students as it was related to a desire for personal autonomy.

## Potential Limitations to this Study

Trustworthiness of the research was explored in relation to Whittemore et al.’s (2001) key criteria: credibility, dependability, confirmability and transferability. In this way, rigour was demonstrated by describing the procedures used to establish and enhance each of these features.

Credibility is concerned with whether the research provides an accurate representation of the lived experience of participants. One mechanism for ensuring this is for self-reflection by the researcher. To facilitate this a research diary was maintained throughout and used to restimulate memory when transcribing, coding or exploring themes. Another mechanism for ensuring credibility was ensuring the methodological tools matched the research questions posed and were therefore able to yield relevant data. In addition, generating data from multiple sources as well as using multiple data collection methods meant a richer picture was gained. Discrepant findings and negative instances were explored at length in analysis, in so doing challenging the researcher’s potentially biased expectations. Finally, as a principle, refuting rather than corroborating evidence was sought, in both data collection and analysis.

With regard to transferability no claim was made for generalisability from this research. Rather, consideration has been made as to whether these findings can potentially have meaning for others and for understanding the broader social experience. The likelihood of transferability was increased by ensuring the organisational context chosen was as ‘average’ as possible. In addition, sufficient detail has been given to allow readers to assess the similarity for other contexts.

Dependability of the findings and analysis was demonstrated by having clear rationales and an accurate audit trail of decisions. Where inconsistencies occurred, active attempts were made to understand when and why. Finally, confirmability in this work was established by transparency about data collection, coding and analysis.

It is not beneficial for the reader to revisit the limitations explored through the methodology chapter. These included discussions about paradigm dependent limitations; the impact of the researcher not being autistic affecting understanding; restricted sample size; insider research; the unit of analysis chosen; and researcher characteristics. However, some unanticipated factors arose during the research:

1. The intersectional nature of identity became apparent as relevant during this study in relation to both class and gender. This was not considered either in the initial selection of participants, beyond attempting to oversample females, nor in the interview schedules developed. The relatively small sample used means that it is possible that other aspects of identity have not surfaced as relevant here but might do so if the research used a larger participant group. Whilst this could not have been anticipated ahead of time it does lead to recommendations for future work which explores other aspects of identity.
2. Autism is a spectrum condition and diagnosis occurs at an arbitrary cut-off point. This research did not explore participants’ placement on the spectrum. However, this may have effects on their experiences, particularly in relation to impairment effect related problems. Given such a small sample pool to draw from initially it could be problematic to consider this as a factor. However, a multi-site study could have addressed this issue as it would have increased the size of the participant pool.

In addition, whilst this analysis aims to bring together findings from multifaceted and nuanced data, some caution should be applied when trying to generalise from it. Whilst the university which forms the case organisation is typical of a Russell Group institution, its services and practices will differ in many ways from other institutions. The research sample, whilst a significant proportion of potential respondents, was still small with fourteen autistic students’ interview data being used in the final analysis. Secondly the study itself may have attracted individuals who had particular views or experiences they wanted to explore or describe. Whilst this cannot be ruled out, there was no evidence for this being the case during the interviews, with participants making no particular attempts to lead the process, or to pursue particular topics of discussion. Neither did they display very strong feelings about specific issues. However, these factors should be borne in mind when drawing implications, as they represent the specific experiences of this study’s sample group.

## Researcher’s Final Reflections

Bourdieu encourages all researchers to engage in reflection and attempt to be reflexive when considering their own work in order to identify their own internalised structures and how these impact understanding, interpretation and analysis of findings. In this work I believe my own position as a woman from a working-class background has impacted what was visible to me. This positionality foregrounded class and gender issues when they were present. I recognise that aspects of my personality will have influenced data collection as well as data analysis. For example, my introvert personality may imperceptibly and subtly influence how I respond to participants different from me. I also recognise that having children who mirror the ages of most participants could affect my interactions with them and my feelings towards them. I recognise that I am not an impartial observer, being the mother of an autistic daughter influences me in ways which I cannot fully control. Whilst this potentially impacts my objectivity, I feel that it adds more than it subtracts from the research as it allows me the language and tools to better understand the lived experiences of autistic HE students.

In this research I have elicited the views and stories of both autistic and neurotypical students and have at times compared these. It is not usual to have a control group in interpretivist work of this type and I have been questioned about the value of this input when the research focuses on autistic students’ experiences. I stand by this decision for two reasons. Firstly, I have a strong belief in the need to produce work which generates practical outcomes. Consequently, I feel it is important to focus on what is unique to the experiences of autistic students relative to their neurotypical peers. The research can only cover so much and issues which are common to more students will, hopefully, be explored by other researchers. I feel it is of particular value to explore what unique experiences autistic students have so that when disseminating the messages about this group’s specific needs, they are not lost in a bigger message concerning all students. Secondly, I had some concerns about my own position as a middle aged neurotypical person in being able to recognise what was unique. I took on board Cheung et al.’s (2011) warnings regarding overly focusing on the uniqueness of a culture when investigating specific cultural groups. Employing neurotypical controls allowed me the context necessary to mitigate this risk.

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# Appendices

## Appendix 1a: Participant Consent Form for Interviews Pre April 2018

Participant Consent Form

|  |
| --- |
| Title of Research Project: Experiences of Employability Interventions in Higher Education Name of Researcher: **Laura Dean**  ParticipantIdentification Number for this project: Please initial box   1. I confirm that I have read and understand the information sheet  dated *27th July 2017* explaining the above research project and I have had the opportunity to ask questions about the project. 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. 3. If I wish to remove my data from the project I can do so until 1st January 2018. This can be done by contacting the lead researcher Laura Dean at [l.dean@sheffield.ac.uk](mailto:l.dean@sheffield.ac.uk) 4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. 5. I agree for the data collected from me to be used in future research 6. I agree to take part in the above research project. |
| Name of Participant Date Signature  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Lead Researcher Date Signature  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  *To be signed and dated in presence of the participant* |
| Copies: *Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form and the information sheet. A copy of the signed and dated consent form should be placed in the project’s main record (e.g. a site file), which must be kept in a secure location.* |

## Appendix 1b: Participant Consent Form for Interviews Post April 2018

Participant Consent Form

|  |
| --- |
| Title of Research Project: **Experiences of Employability Interventions in Higher Education** Name of Researcher: **Laura Dean**  ParticipantIdentification Number for this project: Please initial box   1. I confirm that I have read and understand the information sheet  dated *27th July 2017* explaining the above research project and I have had the opportunity to ask questions about the project. 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. 3. If I wish to remove my data from the project I can do so until 1st June 2018. This can be done by contacting the lead researcher Laura Dean at [l.dean@sheffield.ac.uk](mailto:l.dean@sheffield.ac.uk) 4. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. 5. I agree for the data collected from me to be used in future research 6. I agree to take part in the above research project. |
| Name of Participant Date Signature  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Lead Researcher Date Signature  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  *To be signed and dated in presence of the participant* |
| Copies: *Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form and the information sheet. A copy of the signed and dated consent form should be placed in the project’s main record (e.g. a site file), which must be kept in a secure location.* |

## Appendix 2: Participant Information Sheet

**Participant Information Sheet: Experiences of Employability Interventions in Higher Education**

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If you have any questions or would like more information you can contact the researcher Laura Dean at [l.dean@sheffield.ac.uk](mailto:l.dean@sheffield.ac.uk)

FAQs

**What is the project’s purpose?**

To evaluate the effectiveness of employability interventions for undergraduate students at three higher education institutions. In addition to compare group differences in the levels of support provided with a particular emphasis on individuals who identify themselves as having Autism Spectrum Disorder (ASD) including Asperger’s Syndrome. It is anticipated this research will inform the development of future equal opportunities practices to support the employability of graduates irrespective of background

**Why have I been chosen?**

You have been asked to take part because you are an undergraduate student at one of the three institutions being studied as part of this research. We are interested in developing a sample with a mix of participants including some who identify as having Autistic Spectrum Disorder. This will enable us to compare the kinds of support available to diverse students.

**What will happen to me if I take part?**

You will be interviewed about your experience of higher education and learning to be employable. This may be one interview of approximately half an hour or you may be asked to undertake a second interview in several months. It is up to you whether you want to take part in the second interview. If you are happy to be recorded then the interview will be audio recorded. If you’d rather not be recorded then notes will be taken during the interview. The audio recordings made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. You would be asked both open questions such as ‘what type of work experience have you engaged in?’ and closed questions such as ‘which subject are you studying.’ You can chose to answer or not answer any specific question. Due to the nature of the research process not all questions will be written out at the start as the interview will evolve. However if you would like a copy you may see all of the written questions before you begin. There is no expectation that you prepare for the interview or that you need to be especially knowledgeable about the subject or remember specific facts about services you may or may not have accessed.

**What are the possible disadvantages and risks of taking part?**

No disadvantages or risks are anticipated.

**What are the possible benefits of taking part?**

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will lead to more appropriate interventions for future students.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form) and you can still withdraw at any time without it affecting any benefits that you are entitled to in any way.

You do not have to give a reason.

**What if something goes wrong?**

If you are unhappy with the study or how you have been treated by researchers then you can contact

|  |  |
| --- | --- |
| **Researcher**  Laura Dean  B030 Management School  University of Sheffield  Conduit Road  Sheffield  S10 1FL  [l.dean@sheffield.ac.uk](mailto:l.dean@sheffield.ac.uk) | **Supervisor**  Caroline Sarojini Hart  8.03 Husband Building  University of Sheffield  388 Glossop Road  Sheffield  S10 2JA  [c.hart@sheffield.ac.uk](mailto:c.hart@sheffield.ac.uk) |

**Will my taking part in this project be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any reports or publications.

**What will happen to the results of the research project?**

The results will be used as part of the Doctorate in Education submission. In addition it is anticipated they will also form part of an academic journal paper or conference presentation.

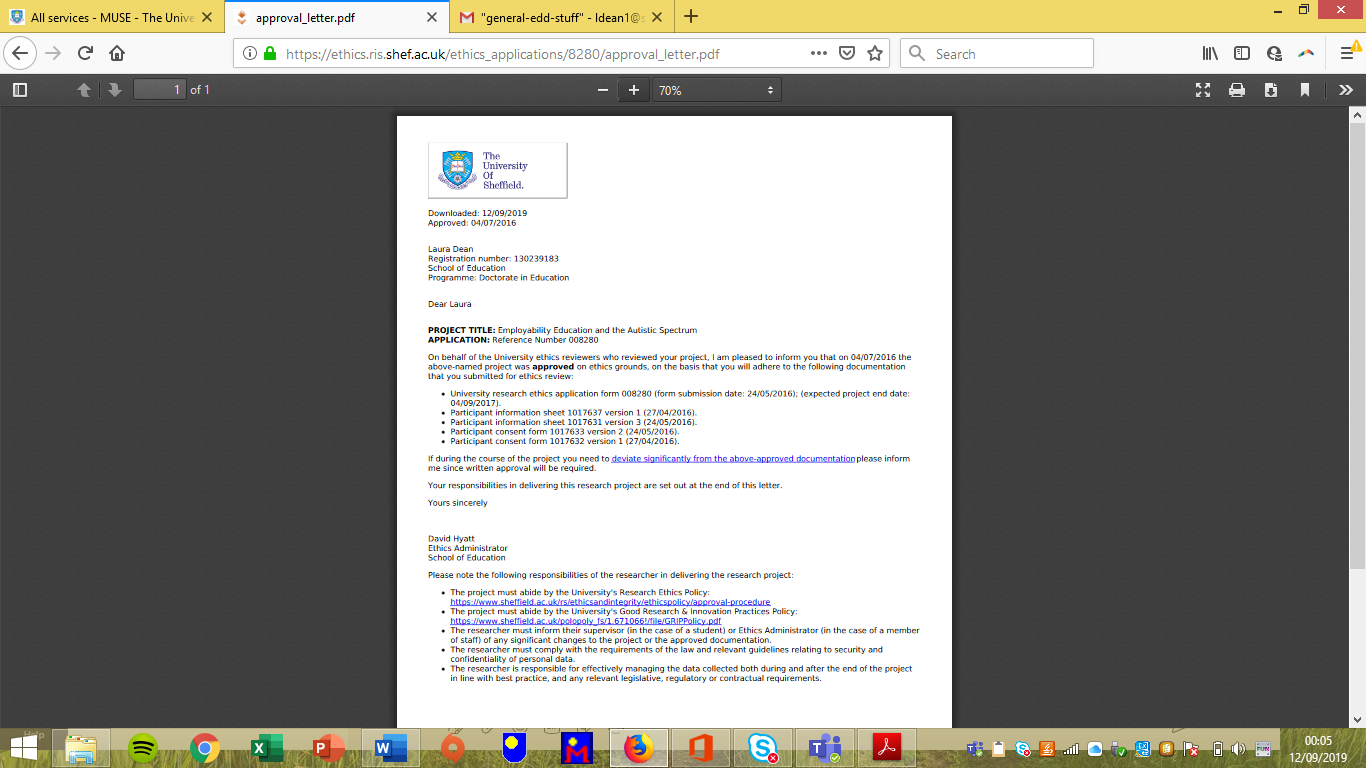
**Who is organising and funding the research?**

The research is self-funded by the researcher: Laura Dean

**Who has ethically reviewed the project?**

This project has been ethically approved via the Education department’s ethics review procedure of the University of Sheffield.

## Appendix 3: Ethical approval



## Appendix 4: Phase One Questions

**Consent Questions**

Thank you for your interest in this research. It looks at how people view interventions to help them become more employable. The research is particularly looking at differences in how individuals with autistic spectrum disorder (including Asperger’s Syndrome) experience these. In order to look at this effectively it is important to collect information both from those with an ASD diagnosis and from those who don’t (neurotypicals).

Therefore, the research is looking for participants both who have a diagnosis of autism and those who don’t. It also doesn’t matter whether you have experienced an employability intervention or not: we will be asking questions about these things as part of the study. You do however need to be a university student now.

The research forms part of my Doctorate in Education but it is intended that the outputs will also be published in an academic journal and/or presented at academic or practitioner conferences. If you chose to take part your data will be anonymised. As such once you have submitted your data it cannot be withdrawn because the researcher cannot identify your data from the rest.

I confirm that I have read and understood the preceding information provided about the project **Experiences of Employability Interventions in Higher Education.**

**Question 1a FORCED CHOICE QUESTION**

Yes I am happy to participate *– choosing this option routes them onto question 1b.*

No, I do not wish to participate *– choosing this option routes them to the end without asking any questions with a message saying thanks for looking.*

I would like more information before participating *– choosing this option routes them onto question 1c.*

**Question 1b (becomes visible if they chose yes on the last option) FORCED CHOICE QUESTION**

In continuing on to complete questions I acknowledge that my participation is voluntary and I am free to decline to take part and free to decline to answer any specific questions on the questionnaire.

 I am aware that due to the nature of data collection and the anonymity of the system I will not be able to request my data to be withdrawn from the project.

Yes

No *– choosing this option routes them onto question 1c.*

**Question 1c (becomes visible if they chose I would like more information on the last option)**

If you would like more information about the project before deciding whether to take part please fill in your contact details below (whichever method you prefer, post, email or phone) and we will be in touch to tell you more about the work. Filling in this box will take you to end of the survey. If you would like to continue onto complete the survey now please select 'yes I am happy to participate' on the last question.

**Demographic Questions**

2a Please fill in the age you are today



2b Which gender would you identify yourself as?

Male

Female

Other/ None

2c What is/was your main subject of your degree?



2d Which year of study are you? (Multiple answers are allowed)

1st year

2nd year

3rd year

4th year

Graduate *choosing this option makes question 2e visible*

Sandwich placement year

Left course without completing *choosing this option makes question 2f visible*

|  |  |
| --- | --- |
|  |  |

2e Did you complete your course?

Yes, I graduated from the course I joined

Partially I graduated with a different qualification after part fulfilling course requirements, e.g. Certificate or Diploma *choosing this option makes question 2h visible*

No, I did not finish my course and left without a qualification. *choosing this option makes question 2g visible*

2f For what reason or reasons did you leave your course?



2g For what reason or reasons did you not graduate from the course you joined?



2h What was the postcode of your home address when you applied to university?  
  


**Support Questions**

3a If the support your university as a whole gives is 100%, how much should be given for each area of support?



Ensuring you are employable at the end of your course



Ensuring you are academic successful on your course



Ensuring you are happy and able to engage in the social activities you want/ need to

Total



3b Thinking about your achieving your potential, to what extent do you feel/ did you feel supported by your university? *This question has sliding scales – participants pull the marker across from zero to their chosen amount.*

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | |  | | --- | |  | | | | | | | | | | |  |  |
|  |  |  | **010** | **20** | **30** | **40** | **50** | **60** | **70** | **80** | **90** | **100** |  |  |
| **Academic Potential** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Employability Potential** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Ability to have a pleasurable social life** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |

3c If the support your course gives you as a whole is 100%, how should this be divided up between these different areas of support?



Ensuring you are employable at the end of your course



Ensuring you are academic successful on your course



Ensuring you are happy and able to engage in the social activities you want/ need to

Total



3d Thinking about your achieving your potential, to what extent do you feel/ did you feel supported by your course? *This question has sliding scales – participants pull the marker across from zero to their chosen amount.*

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | |  | | --- | |  | | | | | | | | | | |  |  |
|  |  |  | **010** | **20** | **30** | **40** | **50** | **60** | **70** | **80** | **90** | **100** |  |  |
| **Academic Potential** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Employability Potential** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Ability to have a pleasurable social life** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |

3e If the support your Student Union gives you as a whole is 100%, how should this be divided up between these different areas of support?



Ensuring you are employable at the end of your course



Ensuring you are academic successful on your course



Ensuring you are happy and able to engage in the social activities you want/ need to

Total



3f Thinking about your achieving your potential, to what extent do you feel/ did you feel supported by your Student Union? *This question has sliding scales – participants pull the marker across from zero to their chosen amount.*

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | |  | | --- | |  | | | | | | | | | | |  |  |
|  |  |  | **010** | **20** | **30** | **40** | **50** | **60** | **70** | **80** | **90** | **100** |  |  |
| **Academic Potential** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Employability Potential** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Ability to have a pleasurable social life** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |

3g What  support would you like to help you with your employability and who would you like to provide that support?



3h What support would you like from your university to help you academically and who would you like to provide that support?



3i What support would you like from your university to help you socially and who would you like to provide that support?



**Diagnosis Questions**

4a Have you ever received a diagnosis of, or suspected you have any of these conditions? (You may make multiple selections) *ticking any box in this table makes question 4b appear*

|  |  |  | **Column Options** | |  |  |  | **Column Options** | |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | Have Received a Diagnosis | |  |  |  | Believe Myself to Have | |  |
|  |  |  | Diagnosed in last 2 years | Diagnosed over 2 years ago |  |  |  | I believe I have | Others (non-professionals) say I have |  |
| **Autism, or variant of (PDD, Asperger's Syndrome, etc.)** |  |  |  |  |  |  |  |  |  |  |
| **ADHD** |  |  |  |  |  |  |  |  |  |  |
| **Dyslexia** |  |  |  |  |  |  |  |  |  |  |
| **Dyspraxia** |  |  |  |  |  |  |  |  |  |  |
| **Other learning difficulty not mentioned** |  |  |  |  |  |  |  |  |  |  |
| **Physical disability** |  |  |  |  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |  |  |  |  |

4b Whilst at university, have you ever disclosed your diagnosis/ belief about your condition to anyone?

Only disability services

No one

Some people

Most people

Everyone

Not applicable

**Accessing Services Questions**

5a Whilst at university have you ever accessed any of the services to develop employability?

Careers interview

Used careers library

Drop in with careers service

Attended an optional employer talk

Attended an employer talk within a module

Joined an optional careers module

Participated in a compulsory careers module

5b Whilst at university have you ever taken part in the following:

Mentoring programme

Work shadowing (less than a week)

Work experience (paid)

Work experience (unpaid)

Paid job related to preferred career

Paid job not related to preferred career

Volunteering

Acting as a course rep, society treasurer, chair, etc.

**Practical Questions**

The next stage of the research is to talk to some people in more depth about their experiences. This interview will take approximately 40 minutes and can take place via Skype or face to face as you prefer. You will receive £10 as a gesture of goodwill for taking part.  If you would like to take part please leave your contact details below, i.e. name and email.  
  
  
If you just want to enter the draw to win £20 then please leave your email and tick the box to indicate you do not wish to be contacted.



Contact details should be used for:

Only for the purposes of the prize draw

For the prize draw and to be interviewed

Only to be interviewed.

Thank you for taking part in this survey.

## Appendix 5: Phase Two Interview Schedule

**Introductory Scene Setting Questions**

* Can you tell me about your university degree: what subject are you studying?
* Is that what you applied for to begin with?
* Have you always been interested in X?

**Imagined Career**

* I’d like you to think about the best possible career outcome you have for yourself after this degree. It might not be a particular job, but talk me through what you’d want in your career.
  + Prompts: where do you live; do you work with people; is pay important; do you need to have status; do you want responsibility; is work life balance important.
* And what is the worst case scenario?  What are you most worried or concerned may happen?
  + Prompts: is unemployment worse than a job you dislike (or vice versa); what is it which concerns you about that scenario; to what extent do you worry about this being a realistic future for you?

**Impact of Core ASC Issues**

* To what extent has your career so far been affected by:
  + Social-communication difficulties
  + Structure, routine and sensory sensitivities
  + Co-morbid conditions
  + Psychopathology
  + Executive function for example concentration/distraction
  + Fine motor skills

**Employability Services You’ve Used**

* Thinking back to your idealised self and worst case self, have you sought out help to navigate employment?  Is so what have you looked for?
* Who did you get help or guidance from?
* Why did you choose (that person/ that service)?
* Tell me about how useful have you found the help you’ve had so far

**Help You’d Like**

* In an ideal world there would be funding to provide a whole range of different services. Imagining money was no object for the university to begin with. What services or support would you have found useful?
* So now we’ll think a bit more realistically. With limited resources what do you think a university should focus on to support people with ASC to become employable?
* Is there anything which happens now which you think isn’t helping much?

**Basic Details (2 minutes)**

Ok before we close I just want to check some basic details. Correct me if I’ve got these things wrong:

* You have stated you are X years old?
* You define yourself as Y (gender here)
* You have/ have not previously had a diagnosis of autistic spectrum disorder?

**Diagnosis Process** (5 minutes)

* You identified as having ASC.  Can you tell me about the diagnosis process and when you were diagnosed?
* How did you feel about getting a diagnosis?
* Is ASC part of your identity: is it one of the ways in which you’d describe yourself?
* Is there a particular term you like to use or ones you don’t like? Here are terms other people have used. (*Show list*).
* Would you say you were typical of someone with ASD?
  + Prompt if needed: current diagnosis looks at whether your social interaction is atypical, your communication is different to other people and also says you will have repetitive or restricted interests and activities.

Thanks for your time, I appreciate you meeting with me. (Give £10 payment)

**Autism Terms to Show**

|  |  |
| --- | --- |
| Autistic spectrum disorder  Autistic spectrum condition  Autistic (person)  Aspie | Person with ASC  Person with Asperger’s Syndrome  Person who suffers with Autism  Person with Autism  Person with ASD |

## Appendix 6: Phase Three Interview Schedule

**Introductory Scene Setting Questions**

* Can you tell me about your university degree: what subject are you/ did you study
* Is that what you applied for to begin with?
* Have you always been interested in X?

**Imagined Career**

* I’d like you to think about the best possible career outcome you have for yourself after this degree. It might not be a particular job, but talk me through what you’d want in your career.
  + Prompts: where do you live; do you work with people; is pay important; do you need to have status; do you want responsibility; is work life balance important.
* And what is the worst case scenario?  What are you most worried or concerned may happen?
  + Prompts: is unemployment worse than a job you dislike (or vice versa); what is it which concerns you about that scenario; to what extent do you worry about this being a realistic future for you?

**Employability Services You’ve Used**

* Thinking back to your idealised self and worst case self, have you sought out help to navigate employment?  Is so what have you looked for?
* Who did you get help or guidance from?
* Why did you choose (that person/ that service)?
* Tell me about how useful have you found the help you’ve had so far

**Help You’d Like**

* In an ideal world there would be funding to provide a whole range of different services. Imagining money was no object for the university to begin with. What services or support would you have found useful?
* So now we’ll think a bit more realistically. With limited resources what do you think a university should focus on to support people with ASC to become employable?
* Is there anything which happens now which you think isn’t helping much?

**Basic Details**

Ok before we close, I just want to check some basic details. Correct me if I’ve got these things wrong:

* You have stated you are X years old?
* You define yourself as Y (gender here)
* You have not previously had a diagnosis of autistic spectrum disorder?

Thanks for your time, I appreciate you meeting with me. (Give £10 payment)

## 

## Appendix 7: Statistical Analyses of Phase One Quantitative Data

This appendix explains the key findings from the quantitative data gathered from the questionnaires used in phase one. Mann Whitney U tests were used to consider whether there was significant differences in responses between groups.

A Mann Whitney U test showed that autistic students are not significantly likely to be older than students reporting no disabilities or conditions (U=593.5, p>0.05). There was no significant difference in the scores for autistic students (M=40.77) and students with no disabilities (M=38.20).

A Mann Whitney U test showed that autistic students are equally likely to use employability services as students with no declared condition (U=641, p>0.05). There was no significant difference in the scores for autistic students (M=42.36) and students with no disabilities (M=39.65).

Man Whitney U tests demonstrated that autistic students are no more or less likely to undertake a range of activities that enhance their employability than students with no declared condition, such as paid work, work experience, volunteering or taking a position of responsibility, e.g. course rep, society chair. It is worth noting that use of all of these areas of employability development were very low for all students though. A mean of one indicates that all students in this group engage in this activity, a mean of zero mean that no students indicate in this activity. Whilst there are no significant differences here summary findings are reported for completeness.

* There was no significant difference in the scores for autistic students (M=40.59) and students with no disabilities (M=40.59) on participation in mentoring (U=682.5, p>0.05).
* There was no significant difference in the scores for autistic students (M=38) and students with no disabilities (M=40.87) on participation in work shadowing (U=612, p>0.05).
* There was no significant difference in the scores for autistic students (M=40.3, and M=41) and students with no disabilities (M=40.59, and M=40.27) on participation in paid and unpaid work experience, respectively (U=682.5 and U=675 respectively with, p>0.05 in both cases).
* There was no significant difference in the scores for autistic students (M=43.9, and M=41.1) and students with no disabilities (M=38.95, and M=40.23) on participation in work related or unrelated to their preferred career (U=602.5 and U=672.5 respectively with, p>0.05 in both cases).
* There was no significant difference in the scores for autistic students (M=35.7) and students with no disabilities (M=42.68) on participation in volunteering (U=567.5, p>0.05).
* There was no significant difference in the scores for autistic students (M=38.63) and students with no disabilities (M=39.89) on taking a position of responsibility such as society treasure or course representative (U=627, p>0.05).

Participants were asked about how they believed support should be focused at the university and course level as well as the support given by the student union. They were given the option to allocate 100% of support to developing employability, providing academic support and supporting them socially. A series of Mann Whitney U tests found there were no significant differences between autistic students and those with no disability in how they believed this support should be distributed in any of the nine areas. Summary findings are reported for completeness:

* There was no significant difference in the scores for autistic students (M=33.54), (M=37.14) and (M=38.54) and students with no disabilities (M=43.66), (M=42.03) and (M=41.39) on belief in how much university support ensuring employability, ensuring academic success and ensuring engagement in social activities, respectively (U=513.5, U=603.5 and U =638.5, all p>0.05).
* There was no significant difference in the scores for autistic students (M=42.85), (M=40.44) and (M=37.79) and students with no disabilities (M=38.75), (M=39.81) and (M=40.96) on belief in how much course level support ensuring employability, ensuring academic success and ensuring engagement in social activities, respectively (U=591.5, U=649.5 and U = 607, all p>0.05).
* There was no significant difference in the scores for autistic students (M=33.96), (M=34.83) and (M=39.79) and students with no disabilities (M=42.64), (M=42.25) and (M=40.09) on belief in how much student union support ensuring employability, ensuring academic success and ensuring engagement in social activities, respectively (U=515, U=536 and U=655, all p>0.05).

Similarly there were no significant differences in most areas of the level of support that was perceived as being given to them as individuals, by the university, course and student union in the three areas of employability development, academic development and social integration between the groups of autistic students and students with no disabilities. Again, for completeness summary statistics are presented though there are no significant differences found.

* There was no significant difference in the scores for autistic students (M=39.65), (M=42.02) and (M=35.51) and students with no disabilities (M=40.15), (M=39.81) and (M=40.64) on belief in how much university support they had received in ensuring employability, ensuring academic success and ensuring engagement in social activities, respectively (U=651.5, U=649.5 and U = 532.5, all p>0.05).
* There was no significant difference in the scores for autistic students (M=35.72), (M=40.96) and (M=33.61) and students with no disabilities (M=40.4), (M=38.85) and (M=40.49) on belief in how much support they had received from their course in ensuring employability, ensuring academic success and ensuring engagement in social activities, respectively (U=545.5, U=613 and U =486.5, all p>0.05).
* There was no significant difference in the scores for autistic students (M=33.67), (M=31.64) and (M=32.02) and students with no disabilities (M=37.59), (M=39.86) and (M=41.14) on belief in how much support they had received from the student union in ensuring employability, ensuring academic success and ensuring engagement in social activities, respectively (U=463.5, U=433.5 and U=451.5, all p>0.05).

An attempt was made to explore disclosure patterns. However, there were insufficient responses to the question about disclosure to conduct comparative statistics on the outputs. Absolute numbers are presented in figure five. They do not suggest any particular pattern.

Figure 5: Absolute numbers of students: patterns of disclosure of their condition.

## Appendix 8: Changes to Autism Definitions Over Time

#### DSM Definitions

The Diagnostic and Statistical Manual of Mental Disorders (DSM) has had many major rewrites since its inception. It is the tool used most widely internationally

DSM-II published in 1952 viewed autism as emotional disturbance and did not look at the effect on cognition. Autism was considered a form of childhood schizophrenia. Diagnosis was vague with no specific criterion given in the text.

DSM-III published in 1980 moved autism into its own diagnostic category. Three specific criteria were given to allow diagnosis: no interest in people, severe communication impairments, and strange responses to the environment. At this point autism was regarded as a developmental disorder and the link with schizophrenia was considered to be inaccurate. Critically these features must have been recognised before the child was two and a half, thereby discounting many forms of autism recognised today.

DSM-IIIR was published in 1987 and this involved a major change to the autism criteria. The early onset requirement was dropped from the diagnostic criteria. Sixteen specific criteria were introduced, of which eight needed to be met for diagnosis. In addition, another sub-category was added: pervasive developmental disorder-not otherwise specified (PDD-NOS). PDD-NOS was regarded as a milder form of the condition and this diagnosis was given to people who did not meet al.l of the other criteria.

DSM-IV was published in 1994 and the revised version DSM-IVR was published in 2000. Both presented autism as a spectrum condition. The two categories present in the previous version were expanded to five and included Asperger’s Syndrome, Childhood Disintegrative Disorder (CDD) and Rett Syndrome. It was believed that there may be genetic elements to each of the five sub-categories and so they needed to be distinct to facilitate research.

DSM-5 redefined autism as Autism Spectrum Disorder. Diagnosis now requires ‘persistent impairment in reciprocal social communication and social interaction’ and ‘restricted, repetitive patterns of behaviour.’ Both of these features needed to be present from childhood. Several subcategories were eliminated from the category, namely Asperger syndrome, PDD-NOS and classic autism, along with Rett Syndrome and CDD which had been introduced in the last version. A new diagnosis was introduced of Social Communication Disorder which was to be use when people had language and social impairments but not repetitive behaviours.

#### ICD Definitions

An alternative to the DSM is the International Classification of Diseases. This resource is broader than the DSM covering physical disorders as well. It was first published in 1948 with the tenth edition released in 1990. That edition grouped autism, Asperger syndrome, Rett syndrome, CDD and PDD-NOS under the category of Pervasive Developmental Disorders and so mapped onto the DSM-IV.

The latest 2018 eleventh version of the ICD mirrors DSM-5. Autism Spectrum Disorder is the main category and the subcategories have been eliminated. It differs from DSM diagnostic criteria in some respects, however. The ICD specifically differentiates between autism with intellectual disability and without. It also specifically emphasises that older people and women may mask autistic traits and this should be considered in diagnosis.

1. See appendix 10 for full lineage of the definitional terms. [↑](#footnote-ref-1)
2. <https://unistats.ac.uk/> [↑](#footnote-ref-2)
3. A range of employers have run specific campaigns to attract autistic individuals including Auticon, Microsoft, Procter & Gamble, Deutsche Bank, and Harry Spectres Chocolates. Others such as the military organisations have deployed autistic people in specific roles which use their talents such as code construction and breaking and pattern spotting in enemies’ manoeuvres. The employment agency Specialisterne is specifically for autistic people. [↑](#footnote-ref-3)
4. These search tools were: Star Plus at the University of Sheffield; Bring Me at the University of Leicester; and the unnamed total library search at the University of Leeds. [↑](#footnote-ref-4)
5. To ensure random prize allocation contact details were separated from the main question, allocated numbers and winners were chosen using the tools at <https://www.random.org/>. [↑](#footnote-ref-5)
6. The 301 Study Skills Centre provides online materials, face to face workshops and one to one appointments and covers all aspects of study skills issues. [↑](#footnote-ref-6)
7. National Autistic Society [↑](#footnote-ref-7)