# Being and becoming: Transition from higher education for emerging adults on the autism spectrum

Jonathan Vincent, BA (Hons.) (Queen's University, Belfast), M.Ed. (University of Cambridge)

April 2017

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy.

Department of Educational Research, Lancaster University, UK.

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This thesis results entirely from my own work and has not been offered previously for any other degree or diploma.

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# Abstract

This thesis uncovers the experiences of transition from higher education for emerging adults - students and recent graduates - on the autism spectrum and explores their aspirations for the future. Evidence suggests that the number of students disclosing an autism spectrum diagnosis to their higher education institution in the UK has greatly increased in recent years and whilst there is a growing body of evidence which investigates the pre-induction needs of this population, there is a paucity of research which explores their experience in making the transition from higher education. A sample of twenty-one emerging adults (n=10 students and n=11 recent graduates) on the autism spectrum participated in the study where qualitative methods, including semi-structured interviews and visual life-maps, were utilised to develop an in-depth and contextualised understanding of post-graduate transition from eight higher education institutions across England.

This study makes an original contribution to the field by offering a theorisation of transition for emerging adults on the autism spectrum as a complex phenomenon experienced across practical, psychological and philosophical domains. Three broad aspirational destinations – occupational, relational and personal – were identified for this population, with successful transition to each being affected by both distal and proximal capacities and resources. By understanding autism in terms of neurodiversity rather than deficits, this study demonstrates the enabling effects contextual factors can have with respect to the differences experienced by autistic people making the transition from higher education. The findings from this thesis have implications for higher education, employers and service-providers regarding policy and practice, particularly with respect to improving transitional support for emerging adults on the autism spectrum making the transition from the transition from university.

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## Publications derived from work on the Doctoral Programme

Vincent, J., Potts, M., Fletcher, D., Hodges, S., Howells, J., Mitchell, A., Mallon, B. & Ledger, T. (2017). 'I think autism is like running on Windows while everyone else is a Mac': using a participatory action research approach with students on the autistic spectrum to rearticulate autism and the lived experience of university. *Educational Action Research*, *25*(2), 300-315.

Vincent, J. (2016) Transition from secondary to higher education: an evaluation of a pre-entry transition programme for students on the autistic spectrum. *The Journal of Inclusive Practice in Further and Higher Education*, 7 (1), 53-63.

Nixon, J., Buckley, A. Cheng, A., Dymoke, S., Spiro, J. & Vincent, J. (2016) 'The 'questionableness' of things: opening up the conversation' in McNiff, J. (ed) *Value and Virtue in Practice-Based Research*. 100-117. London: Routledge

Vincent, J. (2015). Developing REAL inclusive teaching and learning at university for autistic students through dialogue: a participatory action research project. *Good Autism Practice (GAP)*, *16*(2), 41-47.

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# Chapter 1 Introduction

Very little is known about the experiences of transition from higher education for emerging adults (Arnett, 2014) on the autism spectrum or their aspirations for the future. This thesis will make an original contribution to this field in seeking to uncover the relationships, contingencies, and potentialities involved in this phenomenon. By drawing on insider accounts it will identify what autistic students and recent graduates considered to be enabling with respect to successful transition and for actualising their aspirations. Before I embark on an empirical examination of these issues, however, it is important to establish some pertinent background information, including the makeup of the autistic student population in higher education, what is already known about their destinations beyond university, and how the term 'emerging adulthood' applies. Moreover, this brief chapter will more fully outline the gap in the research literature along with the scope and aims of this current study. Finally, the overall structure of the thesis will be outlined to clarify how, conceptually and practically, the research developed.

## 1.1 Autistic population in higher education

The autism spectrum is a set of conditions reflected by the wide range of terms used to describe it (as will be examined in some depth in Chapter 2). Within higher education, students may define themselves or be defined by practitioners and policy-makers as having an autism spectrum disorder (ASD), an autism spectrum condition (ASC), Asperger's syndrome (AS), or High Functioning Autism (HFA). The variety of terms used is indicative of the complexity of the autism diagnosis and the different ways that individuals choose to describe their condition. Throughout this thesis the term 'students / graduates on the autism spectrum' or 'autistic students / graduates' will be used in keeping with identityfirst language (e.g., 'autistic person') as preferred by self-advocates (Kenny et al, 2016). Whilst this broad term is less sensitive to the particular diagnostic labels ascribed to individuals by clinicians, it offers a means of referring to the autism diagnosis that is both inclusive and reflects how the majority of participants in this study described themselves. Another term that is applied to the participants throughout this thesis is Arnett's (2014:xii) concept of 'emerging adulthood'. It has particular import for this study for two main reasons. Firstly, in practical terms, emerging adulthood extends from (roughly) ages 18 to 29, which is the range that the participants in this study fall into. Secondly, and more significantly, the term signals 'the age of identity explorations, the age of instability, the self-focused age, the age of feeling in-between, and the age of possibilities' and is thus more sensitive to the proximal as well as distal factors related to being and becoming.

Whilst emerging adults on the autism spectrum are less likely than their peers to go to university (NAS, 2017b), there is evidence to suggest that the population of autistic students in higher education is actually increasing. Obviously students on the spectrum have always attended university, indeed Hans Asperger (1944) used the term 'little professors' to describe the children that he observed and some suggest that such eminent academics as Sir Isaac Newton and Ludwig

Wittgenstein were in fact autistic (Fitzgerald, 2000). However, it is only relatively recently that data has begun to be collected regarding the participation of specific groups of disabled students in higher education. When the Universities and Colleges Admissions Service (UCAS) first introduced its disability coding system in 2003 it used the term Autistic spectrum disorder/Asperger's syndrome and recorded disclosure from 165 students (Madriaga et al, 2008); whereas today the diagnostic label that is utilised is broader and 'social / communication impairment such as Asperger's syndrome / other autistic spectrum disorder' also captures those who identify as having autism spectrum conditions (ASC) and High Functioning Autism (HFA). According to the Higher Education Statistical Agency (2015) the most recent data reports 2400 students on the autism spectrum that disclosed a diagnosis to their institution; such figures reflect a 300% rise just since 2012.

Whether these figures signal an increase in real terms in the numbers of autistic students attending higher education or just an increase in those disclosing their diagnoses is debateable. Whichever it is, the actual figures are likely to be much higher still as some students choose not to disclose their autism diagnosis at all for fear of discrimination or from a desire to start a new chapter in life without the label. Moreover, where the autism diagnosis is combined in the UCAS coding system with one or more co-occurring conditions, such as depression or dyspraxia, the clarity of the statistical evidence is reduced as the 'autism' diagnosis is subsumed into a 'two or more disabilities' code. Given that the autistic population generally has higher co-occurrence rates of sleep disorders, seizures, mental health conditions, and gastrointestinal disorders (Doshi-Velez et

al, 2014) this seems to muddy the waters somewhat. A final complicating factor, according to White, Ollendick, & Bray (2011), is that up to 1.9% of university students could be on the autism spectrum but have never been diagnosed at all. Thus, given this shift in the numbers of students disclosing their autism diagnoses and the likelihood of a much larger population still there is an imperative on higher education institutions to consider how they provide for these students' success.

Dillenburger et al. (2016) report that retention and achievement trends in the data for autistic students in higher education are only just emerging. However, over the 2 years that data were available (2010/2011 and 2011/2012), there was an increase in the relative proportion of students with autism who completed university successfully (0.23% vs 0.31%, respectively). Despite this positive trend in academic outcomes, other evidence suggests that disabled graduates have consistently lower rates of employment than their non-disabled peers and graduates on the autism spectrum specifically have the highest unemployment rates of all disability types (Association of Graduate Careers Advisory Services, 2015). Recent government figures indicate that only 3.9% of neurotypical graduates were unemployed six months after completing their course by comparison to 21.5% of autistic graduates (BIS, 2016). Unfortunately this evidence also falls within the wider social context of autistic unemployment, where the most recent figures suggest that up to 84% of adults on the autism spectrum are not in full-time employment, a statistic that has not changed in over a decade (NAS, 2017b). It seems clear that such a disparity between autistic

university students' academic capability and their postgraduate progression outcomes signals a gap in transition provision at this stage of the life course.

## 1.2 The gap in the research literature

As suggested at the outset, this study responds directly to a gap in the research literature. In May 2015 transitional and vocational issues were specifically identified at the International Meeting for Autism Research as an area where research is lacking (Nicholas et al., 2017). Whilst there is a small body of research which has focused on life outcomes for autistic adults in terms of employment, service-use, and living arrangements (Henninger and Lounds-Taylor, 2013) with a steady increase in the number of publications focused on the transition to employment in autism since the 1980s (Lopez and Keenan, 2014), this evidence-base is still limited and has tended to focus on quantitative data rather than perspectival accounts. Henninger and Lounds-Taylor (2013) identify three distinct 'eras' in outcomes research among autistic populations; they show how in the early 2000s studies were based on vague "good" to "very poor" ratings before moving to more reliable ordinal rating scales based on Howlin et al.'s (2004) work. However, in the third 'era' researchers have begun to perceive the benefit of investigating autistic adults' outcomes in relation to their subjective experiences; by doing so research is able to provide a more complete and multidimensional picture of adult transitional experiences. According to this typology, by drawing on first-hand accounts, this thesis fits into the final of the three branches of outcomes research.

With respect to the transitional experience for autistic students from higher education to adult outcomes, there is a further and more specific gap. Although transitions into and within higher education more generally have received a great deal of research interest over the last number of decades, particularly as participation has become more widely encouraged (Ingram et al., 2009), studies have tended to focus on the skills, behaviours, and identities of students as they begin tertiary education or develop as learners (Kift, 2009; Yorke, 2004). This trend is also reflected in the small but burgeoning body of research literature among autistic university populations which has centred on their experiences of induction, practical learning adjustments, and the social aspects of higher education (Van Hees et al., 2014; Barnhill, 2014; Adreon and Durocher, 2007; Pillay and Bhat, 2012; Zager and Alpern, 2010; Camarena and Sarigiani, 2009). Very few studies have investigated the needs of adults on the higher ability end of the autism spectrum (Hendricks & Wehman, 2009) and fewer still that examine transition from higher education or aspirations for the future. In fact based on a search of the literature, only one study specific to autistic students' transition from higher education was identified (Walker, 2012) and this was an evaluation of an employment course, rather than an investigation exploring the phenomenon itself or individuals' experiences of it. According to Dillenburger et al. (2014) this lack of research on educational trajectories among autistic populations is worrying.

However, as well as responding to a gap in the literature, this research is also timely. Within the higher education policy context, graduate progression has recently become a government priority. In 2016 the Conservative government

published its Higher Education White Paper, entitled 'Success as a Knowledge Economy: Teaching Excellence, Social Mobility and Student Choice' (BIS, 2016); as part of these proposals it is intended that universities' success will be assessed through a Teaching Excellence Framework based on their rates of graduate employment, as well as other metrics. Whilst serious concerns have been raised regarding the shift towards universities being measured on the basis of their role as producers of economic progress (Neary, 2016), it does signal a welcome review of how well institutions are responding to the transition and progression requirements of *all* their students (Finn, 2016). As, has already been established, autistic students are among the most academically capable in higher education yet are clearly encountering barriers as they make the transition from university to employment and adult life.

#### 1.3 Research aim and research questions

In seeking to respond directly to the identified gap in the literature and current policy emphasis on postgraduate progression, the overarching research aim of this qualitative study was to investigate the experiences of transition from higher education and future aspirations among emerging adults on the autism spectrum. Alongside attempting to uncover perspectival accounts of the phenomenon, it also sought to investigate perceived enabling and disabling mechanisms with respect to realising these future outcomes. The thesis was underpinned by the following research questions:

#### Research questions:

- a) How is the transition from higher education *conceptualised* by students and recent graduates on the autism spectrum?
- b) How is the transition from higher education *experienced* by students and recent graduates on the autism spectrum?
- c) What is perceived as *enabling* with respect to making the transition from higher education?
- d) What *aspirations* beyond higher education do students and recent graduates on the autism spectrum have?
- e) What is perceived as *enabling* with respect to autistic students and recent graduates on the autism spectrum *realising their aspirations*?

The research questions are both descriptive and exploratory in nature, seeking initially to provide an accurate description of transition from higher education and participants' aspirations for the future. Alongside this, they endeavour to understand the causal mechanisms involved in transition and the actualisation of aspirations by obtaining 'insider' perspectives derived from social actors' (autistic students and recent graduates) accounts and experiences (Blaikie, 2007).

## 1.4 Organisation of the thesis

This thesis is structured into eight chapters. Following Chapter 1, which has outlined the gap in the research field and the scope of this study, Chapter 2 reviews the literature. I provide an overview of the salient concepts that underpin this thesis, including an analysis of the autism spectrum, from clinical, social constructionist, and neurodiversity perspectives. Given the centrality and contestability of the autism diagnosis I chart how it has developed historically and identify a range of autistic traits relevant for understanding the experience of transition for this population. From there I go on to consider the life course as a sociological tool and appraise both traditional life course theories which reflect linear trajectories and more postmodern or 'liquid' ones based on choice, reflexivity and individualism. The Literature Review next presents a conceptual framework for understanding transition in higher education and relates this to the current research related to autistic students' experiences. The final section outlines the literature surrounding the concept of aspirations and considers the importance of capacities or resources required for actualising aspirations (Appadurai, 2004).

Chapter 3 outlines the critical realist position that underpins this study and locates my epistemological and ontological discussion within the wider methodological debates. In seeking a *via media* between interpretivism and positivism, I suggest that qualitative research can retain an 'ontological realism' whilst accepting a form of 'epistemological constructivism' garnered through perspectival understandings of the world (Bhaskar, 1975; Maxwell, 2012). I outline the qualitative methods that I utilised in this study including semistructured interviews and life maps and appraise each in relation to their suitability and usefulness for data collection among my sample of twenty-one autistic students and recent graduates. The chapter offers insight into the ethical issues that were considered important including participant confidentiality, future harm and reciprocity as well as my own positionality as a researcher in

the process. The final sections of this chapter outline the data analysis procedure and consider issues of reliability and validity.

Chapters 4 through 6 form the main findings of the thesis and outline three distinct sets of qualitative results. The first presents the experience of transition *from* higher education and identifies prominent themes derived from the participants' accounts. Chapter five presents my findings related to transition *to* various aspirational destinations, which centre on occupational, relational and personal goals and imagined future selves. The final findings chapter uncovers the resources and capacities that participants considered to be enabling for achieving a successful transition and actualising (or beginning to actualise) their aspirations. Chapter 7 forms the basis of my discussion of participants' experience of transitions, aspirations and enabling resources as outlined in the previous three chapters. Here I ground my theorisation in the literature and seek to identify how the twenty-one autistic participants' accounts shed new light on the issues.

Finally, Chapter 8 offers my main conclusions regarding the experience of transition from higher education and to aspirational destinations for emerging adults on the autism spectrum. I identify a number of limitations within the data collection procedure and the extent to which the sample recruited can be considered representative. This is followed by a range of implications that the findings of this study could have for improving policy and practice at a national level, within the higher education sector, and across industry and employers. I

suggest that students' capacity to aspire is enhanced both through their participation in developing policy but also as an outcome of these changes.

## **Chapter 2**

## **Literature Review**

In order to analyse transition from higher education for students on the autistic spectrum, it is necessary to establish the conceptual parameters of the discussion. The following section will critically assess the diagnostic label of autism; examine theories of transition; outline the proposed theoretical framework based on life course theory and postmodern interpretations of becoming; and finally contextualise these within the current discourse regarding transition for students on the autism spectrum.

### 2.1 Understanding the autism spectrum

The National Autistic Society (2017a) define autism as a lifelong developmental disability which affects how an individual communicates and relates to others, processes information, and makes 'sense of the world'. It seeks to enhance scientific knowledge and understanding about autism, as well as recognise the strengths of people on the autism spectrum and provide support, services and advocacy. This organisation is highlighted here, not because it offers the definitive description of autism, but because it exemplifies the neurodiversity view of autism, which is located between two prominent discourses in the field. The first tends to perceive autism as a medical condition which can be better understood through scientific research into the neurobiological differences and levels of cognitive functioning. Research of this kind has greatly informed the diagnostic process, specific interventions and much of the social and educational

support used by practitioners. At the opposite end of the discursive spectrum is the social constructionist model of autism. From this perspective autism, and by contradistinction 'normality', are considered to be ideologically constructed with the aim of managing and excluding disabled people from the mainstream of social institutions (Runswick-Cole et al., 2016; Terzi, 2008).

Both of these models are significant for understanding about autism, however, it is the neurodiversity model that offers most insight for this study. The neurodiversity model welcomes an increase in scientific knowledge about autism but favours natural diversity as a means of discussing different levels and kinds of neurological functioning and advocates for more emphasis on the lived experiences of autistic people. It encourages a more holistic approach to discussing autism, where an individual's strengths, personal preferences and disposition are considered alongside particular impairments. The neurodiversity model offers an important means of examining some of the specific neurological differences identified by scientists, psychologists and clinicians but uses these productively to garner greater insight into developing positive attitudes and effective adjustments. This model of autism will be especially useful for identifying the particular challenges and capabilities involved in transition across the life course for students on the autism spectrum.

All three models will be briefly outlined herein with a view to understanding their different uses in gaining an understanding of how transition is experienced by individuals on the autism spectrum.

#### 2.1.1 Clinical markers of autism

The term, 'autism' was initially coined by Bleuler (1911), a Swiss psychiatrist, to describe a subset of symptoms in schizophrenia; however, it was Leo Kanner (1943) who first used the term to describe the specific syndrome he termed 'infantile autism'. In his paper, 'Autistic Disturbances of Affective Contact', he presented detailed descriptions of 11 children (eight boys and three girls, aged five to eleven) and on this basis offered his overarching account of the condition. Kanner defined autism as being cut off from the world of people and believed that the children he observed lacked the predisposition to be social. In his original diagnostic description, he did not include communication problems as an essential feature of autism although Kanner did observe that three of the subjects did not speak at all and that the others had language problems including echolalia, idiosyncratic speech patterns and extremely literal language. At around the same time another Austrian, Hans Asperger (1944), was independently using the term autism to describe the condition 'autistic personality disorder' for a group of boys with severe social impairment and motor problems. Asperger described them as 'little professors' on account of their verbal precocity but noted how they tended toward social isolation and revolved almost all of their activities around their esoteric special interests. However, Asperger's study received little interest in the Anglo-American literature until Wing's study in Camberwell, London (Wing 1981) and as a result Kanner's autism is generally considered 'classic autism'.

Following Kanner's identification of autism in 1944 there was a strong movement to theorise autism as the earliest manifestation of childhood psychosis or schizophrenia and it was not until the 1970s that this was scientifically dispelled (Volkmar and McPartland, 2014). By the end of the decade psychologists and clinicians recognised the need to update Kanner's definition with more formal diagnostic guidelines and by 1980 'infantile autism' was included for the first time in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental of Disorders (DSM-III). This shift marked a development from considering autism in theoretical terms towards one based on observable features. The DSM descriptors have since been updated on two further occasions in 1994 and again in 2013. In the DSM-IV (1994) infantile autism was broadened to 'autistic spectrum disorder' and included Asperger's syndrome as a distinct condition on this spectrum. This new description outlined sixteen detailed criteria for diagnosis which broadly reflected the 'triad of impairments' in terms of difficulties with reciprocal social interaction, social communication, and restricted patterns of behaviour or social imagination (Wing and Gould, 1979).

The polythetic nature of an autistic continuum or spectrum is generally understood as a useful tool for reflecting the wide diversity and varying degrees to which the impairments are presented by different individuals (Wing, 1988). It both emphasises the individualised nature of autism spectrum conditions and offers clinicians a means of identifying different levels of functioning. A range of diagnostic instruments and assessments has been developed specifically to assess the broader autism phenotype, including psychometric tests for

intelligence, executive functioning, and adaptive skills (Baron-Cohen et al., 2001; Torralva et al., 2013). The result has been a demarcation between 'high functioning' and 'low functioning', where the former refers to individuals with autism who have an average or above average IQ (>70), a high degree of independence, but have difficulties with socialising; and the latter refers to individuals who experience a significant lack of independence, co-occurring intellectual disabilities as well as substantial problems in socialising (Baio, 2012). Asperger's Syndrome is frequently associated with the high functioning end of the autism spectrum (Spek et al, 2010; Boucher, 2009) and whilst there is much overlap (Ehlers et al., 1997), there also appears to be some distinctive traits between the conditions, for example individuals with Asperger's Syndrome do not, by diagnostic definition, exhibit characteristic autistic delays and anomalies in spoken language (Soulières et al., 2011).

The most recent edition of the DSM published in 2013 (American Psychiatric Association, 2013:1) describes the symptomatic characteristics in the following terms,

People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age. In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items.

It is clear that the latest DSM-V built on much that had previously been established but also includes a number of significant changes, among them redefining the diagnostic parameters of the autism spectrum. Previously separate diagnostic labels, including "classic" autism, autistic disorder, Asperger's syndrome, Pervasive Developmental Disorder Not Otherwise 24 Specified (PDD-NOS) were all used to delineate differences along the spectrum; in the new DSM-V these were collapsed into one umbrella category, Autistic Spectrum Disorders. It is worth noting, however, that whilst the DSM V is most widely used by psychologists and clinicians in the UK, the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) devised by the World Health Organisation (2016) as a diagnostic tool for epidemiology, health management and clinical purposes, continues to recognise Asperger's Syndrome as a distinct developmental disorder. Such clinical divergence signals the extent to which positivist claims to objectivity based on scientific categorisation might be challenged. A final and significant change included reframing the 'triad of impairments' as a 'dyad of impairments' where restricted and repetitive behaviours were preserved but social and communicative difficulties were merged into one single domain (Mandy et al, 2012). These impairment domains have particular implications for transitions, specifically around adjusting to change, sensory processing and encountering new social environments. Each of these specific autistic traits will be outlined and appraised according to the research literature.

#### Resistance to change

In his original description, Kanner recognised in the children he observed difficulties in dealing with change in the non-social world and termed this 'resistance to change'. He noted that the children were

... governed by an anxiously obsessive desire for the maintenance of sameness that nobody but the child himself may disrupt on rare occasions. Change of routine, of furniture arrangement, of a pattern, of the order in which everyday acts are carried out, can drive him to despair. (1943:245)

Kanner also identified a range of self-stimulatory behaviours such as hand flapping and body rocking as attempts on the child's part to maintain sameness and consistency in the social world. Today the American Psychiatric Association (2013) describes these as 'restrictive and repetitive behaviours' which can take many forms, including stereotyped movements, tics, compulsions, circumscribed interests, and rigid adherence to routines and rituals. Kloosterman et al. (2013) present evidence of co-occurrence between ASD and OCD and other studies also outline outcomes including over-arousal in response to novelty, enhanced habit formation, increased perception of environmental changes, and abnormal anxiety (Dillon, 2007; Boucher 2009). What is clear is that the need for sameness is one diagnostic trait of the autism definition that has remained largely unchanged and that transition between different physical environments can be challenging. This experience can be just as intense for adults as it is for children, who in Kanner's case were driven to despair.

#### Sensory processing difficulties

Many of the feelings of anxiety, despair, and the increase in 'restrictive and repetitive behaviours' stem from an individual's 'attempt to introduce order into their chaotic world' (Wing 2001:99), particularly in relation to sensory stimuli. Robertson and Simmons (2015) relate evidence of sensory issues in autism spectrum disorders from both first-hand perspectives (Grandin, 1986; Williams, 1996) and second-hand perspectives (Smith & Sharp, 2013; Bogdashina, 2016). Harrison and Hare (2004) describe atypical reactions in all five sensory modalities as well as kinaesthetic and proprioceptive sensation. Some of the common sensory issues include hyper-reactivity to stimuli including bright lights, loud noises, and strong odours; hypo-reactivity e.g. extremely low sensitivity to certain sensations such as touch and sound; visual-spatial distortions, e.g. depth may be wrongly perceived or still objects perceived as moving; multi- and cross-channel perception, e.g. the perception of sound accompanied by perceptions of colour or taste, akin to synaesthesia; difficulties in identifying and processing different sources of sensory stimulation; or sensory overloads where stimuli cause extreme physical and emotional distress.

The participants included in Robertson and Simmons' (2015:578) study described the effects of these negative sensory experiences as including nausea ("[if there's a] strong kind of sensory smell of a food ... it makes me feel physically sick") and physical pain ("[with] light hugs ... it gets to the point where my body tenses to the point of being painful") to becoming immobile ("[with] high-frequency and low-frequency noises ... I'll just become like a statue"). Moreover, where stimuli were considered outside of their control this tended to increase levels of distress among individuals with autism (Ashburner et al., 2013; Dickie et al., 2009). It is obvious how such intense sensory experiences could have implications for transition, especially where one is moving from a known environment to another, which is unknown. This could have particular import for the transition from higher education where many autistic students have no clear sense of where or what they will do next, which might therefore increase levels of anxiety.

#### Social interaction difficulties

Social interaction is another area of difficulty in relation to transition for many individuals on the autism spectrum. As has been outlined, social and communication impairments are a key diagnostic marker of ASD and many individuals, who may be considered 'low functioning' exhibit characteristic delays and anomalies in spoken language. Boucher (2009) suggests that these can affect language in all modalities (written, spoken, signed etc.), might include echolalia and idiosyncratic language, and are frequently characterised by problems of comprehension and meaning. However, for individuals who are considered 'high functioning' or with Asperger's syndrome, spoken language is frequently less problematic and in fact Soulieres et al (2011) suggest that it is often a strength, as evidenced by results from verbal subtests.

What appears to be more challenging across the whole of the autism spectrum is difficulty with nonverbal communication and pragmatic language (Barnhill, 2014). This, according to Baron-Cohen (2008), is based on 'mindblindness' or delays in the development of theory of mind, where individuals on the autism spectrum struggle to empathise or imagine another's thoughts and feelings. Difficulties with understanding someone else's behaviour based on nonverbal cues such as body language can be challenging and some autistic people find other people's behaviour confusing and unpredictable, even frightening. Thus, many autistic individuals seek to avoid social situations, especially with individuals that they do not know well, in order to minimize the risk of such reactions. Such a reaction has obvious consequences for transitions, especially where this involves interacting with people in contexts that have not previously been encountered.

A further theory developed to better understand social difficulties in autism is executive function, which can be broadly defined as one's ability to shift between mental sets in the processing of information (Hill, 2004). This effects one's capacity to organise, monitor and plan, that is to stop doing one thing (disengage attention from current stimulus), switch do something else (mental flexibility), and start on something new (generating a new focus of attention and planning how this might be achieved). Happe et al. (2006) identify various components of executive function for autistic people and conclude that cognitive flexibility and planning have been shown to be late in development and reliably impaired across the spectrum. This 'stuck-in-set' behaviour (Hill, 2004) can have implications for social interactions where an individual is utterly absorbed on one activity and finds it difficult to disengage in order to begin something entirely unrelated, such as a conversation or social activity. Whilst this sort behavioural inflexibility is not unique to autism (Pennington & Ozonoff, 1996) and has been observed more generally in what Baron-Cohen (2002) terms the 'extreme male brain', it nonetheless makes difficult anything other than the 'most systematic and predictable forms of change' (Boucher 2009:184), thus having significant implications for transitioning between different activities.

To conclude, psychologists and clinicians (Ozonoff and Griffith, 2000; Wing et al, 2011) aver that whilst there has been a focus on etiological trends, neurobiological differences and systems of classification, these have been useful

for informing clinical work, policy planning, and identifying additional entitlements to services. Using the knowledge gained through scientific studies practitioners have developed specific strategies, adjustments and provisions that enable communication, increase independence, and support greater inclusion into communities for individuals on the autism spectrum. Many of these provisions are hugely significant for improving the quality of life for autistic individuals and their families; for example Becker-Cottrill et al (2003) outline the usefulness of a behavioural support approach used among families to create positive home environments. In terms of transition, based on a deeper understanding of the cognitive, social and behavioural impairments related to autism, schools, higher education institutions, employers, and local as well as national governments have introduced policies and practices that seek to respond specifically to the needs of autistic young people and adults. Many of these specific provisions will be outlined in more detail in the following sections.

#### 2.1.2 The social construction of autism

The social constructivist model rejects the scientific characterisation of autism as a disease and even as an epidemic, based on the rise in number of diagnoses and belief in causal environmental factors (Runswick-Cole et al, 2016; Timimi, Gardner, and McCabe, 2011). It builds explicitly on the social model of disability and locates the 'problem' of autism not with individuals or their impairments but in social and political infrastructures (Pellicano & Stears, 2011; Baker, 2011). Proponents reject the binary distinctions between normality and abnormality, which they consider to be ideologically constructed by clinicians, psychologists, academics and the media to manage and exclude them from society (Terzi 2008). Social constructionists seek to problematise the scientific 'facts' outlined above and to uncover the damaging implications these can have for autistic people (Milton, 2014; Mallett and Runswick-Cole, 2012; Timimi, Gardner, and McCabe, 2011).

Given that the scientific and medical community's understanding of autism has changed so dramatically throughout the last seventy years this provides evidence that 'knowledge' about autism and classification systems like the DSM descriptors are simply human constructions and on this basis open to interpretation, change and misuse (Volkmar and McPartland, 2014). The absence of consensus is exemplified clearly by the disputed place of Asperger's syndrome on the autism spectrum according to different models of classification. Moreover, there is considerable scientific debate surrounding dominant theories including executive dysfunction, theory of mind deficit, and weak central coherence theory (Frith, 2003; Volkmar et al., 2013). Thus the positivist epistemology upon which the scientific or medical model of autism is based might be called into question. Waltz (2005) develops this point assiduously by demonstrating how the 'core narrative' of autism is in fact founded on a relatively small set of well-known case studies, (Kanner 1943; Asperger, 1944; and Bettelheim, 1967) and that whilst there is some evidence of systematic data collection, 'many texts are written in a format more closely approximating a fictive narrative than a medical text' (Waltz, 2005:433). Concurrently, Duffy and Dorner (2011:201) also question the objectivity of the scientific knowledge arguing how 'diagnoses of autism are essentially storytelling in character... narratives that seek to explain

contrasts between the normal and the abnormal, sameness and difference, thesis and antithesis'.

Importantly, however, the medical language used to describe autism or autistic people has significant and at times negative implications for how it is perceived more broadly in society. Autism has been described by clinicians as a 'devastating developmental disorder' (Happé, 1999:216), a 'neurological abnormality' (Frith, 2003:1) and a biological deficiency that 'strikes each victim differently' (Cuninghame, 1988). The American Psychological Association (2013) uses terms such as 'disorder, 'deficit', 'inappropriate' to describe autism and the associated behaviours and, whilst these are intended to be used descriptively, the emphasis takes on a pejorative and judgmental tone. It is argued that where labels are used to locate the problem with the 'other', it reaffirms the 'natural attitude' for the applier in their own perceptions (Said, 1978). A striking example of this can be found in Wellman's characterisation of autism (1990, cited in Baron-Cohen 1997:59),

Imagine a hypothetical being who knows nothing of internal mental states ... Such a being might be able to remember, know, and learn, but it would possess no understanding of these activities. The social world, the world of self and others, would be an impoverished place for such a creature.

Duffy and Dorner (2011) claim that such language posits an unbridgeable gulf between the 'normal' person, whom *we* can understand and with whom *we* can easily relate to, and neurologically deficient autistic people, for whom *we* must stretch our imaginations to comprehend owing to *their* deep strangeness. The consequence of language and rhetoric of this kind is a view of autism as

abnormal, biologically deviant and tragic and as something that ought to be treated and cured, where possible. Social constructivists argue the opposite,

If you do not believe there is a disability, if you do not believe there is anything that needs to be 'cured' or genetically prevented—that disability is indeed little more than a social construction—then you will likewise be freed from the need for a cure. (Cheu, 2004: 209)

Based on such a reading they posit a view of autism that is epistemologically opposed to that of the scientific community and resistant to hegemonic medical discourses, treatments and interventions. In the words of Oliver (1996:37) 'physiotherapy, occupational therapy, speech therapy, clinical psychology – each one [is] geared to the same aim – the restoration of normality' and, on this basis, ought to be resisted. Thus, according to this position, where medical professionals, educational practitioners, parents and employers attempt to manage autistic students' transitions to make them fit the 'norm' they are perpetuating this hegemonic structure.

#### 2.1.3 A *via media*: the neurodiversity model

The neurodiversity model might be viewed as a third way between the antagonistic scientific and social constructivist models of autism. The term 'neurodiversity' is relatively new and was first coined by the autistic sociologist Judy Singer (1999) who suggests that diversity is both the norm and the foundation of any flourishing natural system. Her conception of autism as a natural neurological variation was intended to resist deficit constructions and represent a new addition to the familiar political categories of class, gender or race. Whilst this thesis focuses on its usefulness for understanding the full 33

breadth of the autism spectrum, the current scope of the term also includes those diagnosed with neurological or neurodevelopmental disorders such as attention deficit-hyperactivity disorder, bipolar disorder, developmental dyspraxia, dyslexia, epilepsy, and Tourette's syndrome (Fenton and Krahn, 2009).

According to the neurodiversity model, rather than perceiving autism or brainbased differences as simply socially constructed, it makes use of neuroscience to stress the natural difference from non-autistic (often called neurotypical) experience and identity (Ortega, 2009). As Kapp et al. (2013:2) note,

While neurodiversity proponents tend to adopt a form of the social model of disability, distinguishing between a biological, underlying condition or way of being (autism) and disability rooted substantially in inaccessible social and political infrastructures, they essentialize autism as caused by biological factors and celebrate it as a part of natural human variation.

Within this model, scientific studies are seen as relevant and valuable as these offer a language to articulate different neurological functionalities in the context of public infrastructures built around a presumption of neurotypicality (Baker 2011). This model has not only had a significant impact on how society views autism but interestingly, it has also shifted some of the clinical and academic discourse. For example, Baron-Cohen (2015:1758), one of the most eminent psychologists in the field, outlines how a categorical view of autism became more and more difficult to defend and has since adopted a more dimensional approach that 'considers the same behaviours and impairments in terms of individual differences'. This positive emphasis is a fundamental principle of the neurodiversity movement where psychologists and neurologists are actively encouraged to acknowledge the strengths of people with autism, not only the

limitations. Soulieres et al. (2011:56) outline some autistic strengths as 'flexible co-ordination of attentional control, working memory, rule inference and integration, high-level abstraction, and goal-hierarchy management' and Van Hees et al.'s (2014:1684) study observes competences among students including,

their different way of processing information also gives rise to some exceptional skills and talents, such as a 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 etc.

The recognition of autistic capabilities and skills alongside neurological differences is an important departure from the deficits-based discourse that prevailed in the clinical and scientific discourse for many decades.

However, autistic people also experience a range of difficulties across the various core domains related to transition, including managing change, experience of sensory stimuli or social interactions. Acknowledgement of these has implications for how best to respond; some high-functioning autistic advocates resist treatments and interventions informed by scientific studies arguing that difficulties are often contextual and tend to be the result of the interaction between an ableist society and individual differences or impairments (Williams 1996; Sinclair, 2005; Robertson, 2009). This position, however, is by no means echoed across the whole of the autistic community. Whilst no proponent of the neurodiversity model advocates for a world without autistic people or even a cure, many are not opposed to the interventions or treatments which might ameliorate some of the challenges experienced by autistic people. Ortega (2009) offers various examples of prominent autistic advocates who support the use of therapies, including Singer, who coined the term neurodiversity, and Fernando

Cotta, president of the Brazilian Autistic Pride movement. Others, and especially parents, advocate for increased acceptance, accommodations, and supports and are generally very welcoming of research, therapies, and services that help individuals improve their quality of life (Nicolaidis 2012; Humphrey and Lewis, 2008; Baker, 2011; Ortega, 2009). Therefore, in terms of support for transition, a neurodiversity approach acknowledges the particular neurological differences around communication, social interactions, sensory experiences and routines but seeks to identify positive interventions that enable success while celebrating diversity.

It is clear that the autistic diagnosis is contestable and to some extent all three models outlined have merit. The clinical view of autism provides detailed knowledge about the neurological differences that can be experienced by autistic people, especially when involved in transitions and as such enables practitioners to better know how individuals function. The social constructivist position provides a critical perspective that holds the medical profession and researchers to account and challenges them to question what and why they are researching and who it is benefitting most. And finally, the neurodiversity model offers a means of making use of scientific knowledge to better enable inclusion across the life course. This study is clearly positioned within the final of the three models, that of neurodiversity. I thus, recognise that transition from higher education for an autistic population and their aspirations for the future may be experienced differently to neurotypical students but at the same time I am mindful that these neurological differences can also be potential strengths, which when identified may lead to more inclusive practice.

# 2.2 The life course as a sociological tool

#### 2.2.1 Linear constructions of the life course based on objective markers

This thesis makes use of the life course as a sociological tool (Mayer, 2009; Elder et al, 2003). Since its conception during the interwar period of the twentieth century until the 1990s the life course was frequently considered in normative terms with specific emphasis on economic status and work and tended to focus on 'predictable' and linear passages of youth into adult life (Mayer & Müller 1986; Kohli, 1985). These linear life stages are often presented as the straightforward participation of individuals across education and training; entry into the labour market; growing up in families; partnership formations and parenthood; and regional mobility (Heinz and Marshall 2003). To this end life stages were often specific to age and were 'produced' by institutions and structural opportunities (Sheehy 1996; Sampson and Laub 1993; Kohli, 2007) and analysis has focused on the connection between individual lives and the historical and socio-economic context in which these lives unfold (Rydzewska and Pirrie, 2016). With respect to education, life course theory tended to emphasise the transition from school to work as *the* primary transition (Ecclestone, Biesta, and Hughes 2009) reiterating a linear teleological model of development that typically took the immature unemployable child as its starting point and positioned the independent employable adult as the 'ultimate goal' (Cohen and Ainley 2000:80). More recently, Chadderton and Colley (2012) show how young people's transition from school-leavers to members of the labour market is still vaunted by policy-makers as the main policy objective and prime solution to social exclusion.

With respect to autistic populations, a normative life course is emphasised in much of the current research literature with an unproblematic focus on transitions including primary to secondary education; compulsory schooling to employment; secondary education to higher education; child to adult serviceuser (Henninger and Lounds-Taylor, 2013; Seltzer et al., 2000). Such linear demarcations may be due to the identification by clinicians of developmental, and therefore normative, delays or impairments in social, cognitive or communicative functioning among autistic people. At a policy level across England and Wales, there is also clear evidence of the construction of transition for autistic according to a traditionally structured life course. The Autism Act (2009), Think Autism (DWP, 2014) and more recent publications including, Progress Report on Think Autism: the updated strategy for adults with autism in England (DWP, 2016) and Improving Lives: The Work, Health and Disability Green *Paper* (DWP, 2017), tend to treat transitions between life stages as necessarily normative by focussing on preparing children and young people for adulthood and employment. Some suggest that such application of a linear life course to autistic populations might be underpinned more by the desire among service providers, academics and policy-makers to design, implement, and evaluate structured programmes than how disabled individuals actually experience these transitions (Will, 1983; Kohler, 1996). By contrast, an individualised and differential life course offers a more sensitised means of considering the life course as an analytic tool among autistic populations.

## 2.2.2 The 'liquid' life course of late modernity

By the 1990s a differential life course sociology emerged following a dramatic shift in global relations. Gallacher et al. (2009) cite globalisation, new technologies, science-based innovation, organisational restructuring, and the search for competitive advantage as precipitating such a sociological sea change. They refer to writers such as Giddens (1990), Beck (1992) and Bauman (2000) who emphasise a late modern shift towards heightened reflexivity, greater individualisation, and the interrogation of, heretofore, 'objective' demographic markers. Specifically, Bauman asserts that the 'modern' age would be better defined as 'liquid' where the liquidising powers have moved from the 'system' to 'society', from 'politics' to 'life policies' (Bauman, 2000:7). This process of 'disembedding without re-embedding' (Bauman and Tester, 2013: 89) results in new forms of personal alienation and community fragmentation where individuals experience 'precariousness, instability, vulnerability [as] the most widespread (as well as the most painfully felt) features of contemporary life conditions' (Bauman, 2000:160); a position that fits appositely with Beck's (1992) construction of the 'risk society'.

This analysis of society has implications for conceptions of young people and in particular transitions between life stages. Rather than seeing transition in terms of specific junctures that happen at assigned times throughout life, change is understood as a constant, whether it is experienced directly and personally or indirectly as part of the contexts of everyday life. According to Gallacher et al (2009:2) 'transition is a fundamental feature of life in late modernity...each social routine or institution, every relationship and practice, is fluid and open to change; there are no fixed points on today's social compass.' Thus, society no longer determines transitional patterns throughout life, instead,

'[e]verything, so to speak, is now down to the individual. It is up to the individual to find out what she or he is capable of doing, to stretch that capacity to the utmost, and to pick the ends to which that capacity could be applied best – that is, to the greatest conceivable satisfaction.' (Bauman, 2000: 62)

This emphasis on individualisation among late modernists was instrumental in developing the notion of the 'choice biography', where modern (young) people experience a much wider range of options from which to personally construct their life course and so determine their own transitions (Beck, 1992). As such 'the normal biography' becomes the 'elective biography', the 'reflexive biography', the 'do-it-yourself biography' (Beck and Beck-Gernsheim 2009:25). For autistic individuals, who frequently seek routine and sameness in order to bring structure to a chaotic world (Wing, 2000) it could be posited that such a precarious life course would be significantly more challenging.

Du Bois-Reymond (1998) was among the first to demonstrate the useful application of such choice biographies in her longitudinal study into postadolescents' life choices. Her participants presented high levels of flexibility and freedom with many leaving education 'undecided' about the future and prepared to defer their life's goals until late into adulthood. Such findings concur with Arnett's (2014) influential concept of 'emerging adulthood' where young people report enjoying a period of freedom and independence beyond adolescence before they commit themselves to adult responsibility. Both of these influential studies point towards an understanding of the life course that is elective and non-linear but also self-referential in nature.

Frequently young people's outcomes, aspirations and expectations are only explicable on the basis of previous decisions, resources and experiences and rest on mutuality and interdependence with others (Ecclestone, Biesta, and Hughes, 2009). Valentine and Skelton (2007) cite examples of young people being dependent on their families for longer as evidence in this regard and there is certainly evidence that parents play a significant and sustained role in the lives of autistic young people (Seltzer et al; 2000; Strnadová and Evans, 2012; Morningstar et al., 1995). Thus, there is increasing acknowledgment that young people are not a universal category and that their transitions need to be understood within the diverse and ecological context of peers, family, communities (Jones, 2004; Osgood, 2005). Moreover, sociological evidence suggests that this phenomenon is particularly prevalent among young people in central and western European countries where mass education, welfare societies, secularization and political, cultural and sexual liberation mitigates some of the risks involved in such arrangements (Brannen and Nilsen, 2005).

That notwithstanding, it is important to note that whilst the late modern thesis has been recognised as offering a useful alternative lens through which to analyse the life course and transitions (Bynner, 2005; Worth, 2009; Ecclestone, Biesta, and Hughes 2009; *inter alia*), some find its claims of detraditonalization and reflexivity as overstated (Evans 2002; Brannen and Nilsen 2005). For example, Hörschelmann (2011) argues strongly that ethnocentric reappraisals of

the term retain a misleading sense of historical order and cultural hierarchy and fail to acknowledge the extent to which 'risk' and unpredictability have been ever-present features of life in societies past and present. Moreover, Furlong (2009) argues that the mere existence of complexity does not necessarily result in the emergence of 'choice biographies', as du Bois Reymond (1998) and others suggest. By contrast they aver the opposite, that levels of complexity may in fact signify a lack of choice and a vulnerability to the adverse effects of flexible labour markets. Thus, it is clear that life course theory and transitions thereof continue to offer significant lines of intellectual discussion but remain conceptually and theoretically open to new constructions and applications.

#### 2.3 Transitions from higher education for students on the autism spectrum

This section of the chapter seeks to apply what has been already established regarding the neurological differences and strengths experienced by autistic people, particularly in relation to transition, within one specific stage of the life course. It focuses on how autistic emerging adults prepare for and embark on a new trajectory when making the transition from higher education. However, as was noted in Chapter 1, there is a significant gap in the literature regarding this transition. To date, the majority of transition research literature related to autistic populations has focused on children and adolescents (Lounds et al., 2007; Dettmer et al., 2000; Hendricks & Wehman, 2009); those with more significant learning disabilities (Strnadová and Evans, 2012; Hasazi et al., 1985); and the trajectory from school to work (Wehman et al., 2014; Mawhood and Howlin, 1999). Where it has focused on individuals with higher levels of

functioning, including Asperger's syndrome, the literature has centred on the transition into university or college (Van Hees et al 2014; Barnhill, 2014; Martin 2008; Adreon and Durocher, 2007; Pillay and Bhat, 2012). As a consequence, my review is based on a more conceptual analysis of how the transition *from* higher education might be constructed and experienced based on literature that relates more generally to transition for disabled and specifically autistic populations. Three broad themes were identified which include transition as the capacity to participate; transition as a change in status; and transition as becoming.

Transition among disabled populations is significantly lacking in theory (Worth, 2009). It has tended to be focused on planning rather than consideration of the phenomenon and is thus conceived of as 'an outcome-oriented process encompassing a broad array of services and experiences that lead to employment' (Will, 1983:2). More recently Sloper et al. (2011:1) also recognised the emphasis in transition discourse for disabled young people as 'the transfer of responsibility from children's to adult services in health, social care and education'. Such conceptions of transition, also reflected in the UK policy context, signal the linear 'movement from childhood into adulthood' (ibid) which encompasses a range of processes including leaving home, continuing education, entering employment, taking more responsibility for life choices, and establishing oneself as an autonomous individual. In seeking to better theorise transition for disabled groups Halpern (1994:117) cites the Division of Career Development and Transition's definition:

Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post-secondary education,

maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult agency services, and natural supports within the community.

Analysis of this indicates at least two themes: firstly a change of status from adolescent to emerging adult (Arnett, 2014); and secondly, the development of one's practical capacity to participate in the various identified processes. These two aspects are clearly interlinked and appear contingent, in that when one is enabled to participate in various identified adult processes, they inevitably begin to see themselves in these terms and their status is changed, both in their own eyes and in those of others. Gale and Parker (2014) also outline a typology of transition for neurotypical first year university students and similarly identify processes of induction and identity development as present in the phenomenon. Consequently, I will assess these themes in this order, first examining how transition from higher education for autistic students might be conceptualised as preparation for participation, before addressing the potential this transition also has with respect to a change in identity status.

## 2.3.1 Transition as preparation for participation

Transition as preparation for participation has traditionally focused on the experience of induction, mapping the process of inculcation into the requisite ways of knowing and learning at tertiary level or within a particular discipline (Kift, 2009). Much of this literature characterises transition as problematic; it is variously described as stressful (Fisher and Hood, 1987; Bland et al., 2012), complex, difficult, tumultuous (Krause and Coates, 2008) and a time of 44

significant vulnerability (Osgood et al, 2010). With regard to this, Gale and Parker (2014) note that a student's failure to achieve successful transition is frequently characterised as a 'dysfunction' to be overcome by individual effort combined with institutional provision and ameliorative reform (Cohen and Ainley 2000: 80). Such a conception of transition as preparation for participation resonates strongly with Kohler's (1996) Taxonomy for Transition Programming; in it she focuses on five areas of preparation including student-focused planning, student development, interagency and interdisciplinary collaboration, family involvement, and programme structure.

With specific reference to the transition from higher education, the literature largely emphasises the role institutions play in preparing all students for participation in the labour market through the development of employability skills. Transition is again constructed as preparation for participation but here, 'graduate attributes...require that the receptive student be shaped to fit an institutional concept of work-readiness (Daniels and Brooker, 2014:68;). Preparing the 'work-ready graduate' has been central to higher education discourse since the educational reforms adopted as part of the Bologna Process, yet successive governments have failed to explain differences in employment outcomes between graduates from particular demographic groups (Finn, 2016; Holmes, 2015; Chadderton and Colley, 2012). The most recent Higher Education White Paper, entitled 'Success as a Knowledge Economy: Teaching Excellence, Social Mobility and Student Choice' (BIS, 2016) is further evidence of this prevailing emphasis which fits appositely with traditional linear life course theory and assumes that graduates will follow a structured path from education to employment and so on.

#### 2.3.2 Transition as preparation for participation for autistic students

As has been established, the research literature has only recently begun to focus explicitly on autistic university students' experiences of transition. Of the studies specific to the issue, most concentrate on transition as preparation for participation as a student by investigating the barriers, challenges and adjustments relevant for successful adjustment to university (Van Hees et al 2014; Barnhill, 2014; Martin, 2008; Adreon and Durocher, 2007; Pillay and Bhat, 2012; Zager and Alpern, 2010; Camarena and Sarigiani, 2009). In keeping with the wider transition literature, researchers also tend to frame transition for autistic students as problematic, based on their social and communication impairments. Rydzewska (2012), for example, specifically identifies autistic young people as 'vulnerable' and many other studies emphasise students' potential for isolation, reduced mental health, high levels of anxiety and a sense of otherness in higher education (Van Hees et al 2014; Strnadová and Evans, 2012; Zager and Alpern, 2010; Camarena and Sarigiani, 2009).

Similarly, all the studies above signal the need for significant input at an institutional level and suggest that having the right provision and adjustments in place is necessary for students' success. In fact Beresford et al. (2013:3) warn that for emerging adults on the autism spectrum,

A 'poor transition' is likely to lead to reduced support and unmet needs which may have prolonged and cumulative consequences for the young people's education attainment, health and welfare.

Given the potential negative long-term effects, transition planning is therefore considered crucial at this stage and involves the participation and coordination of education practitioners, adult services, and support from within the community (Sloper et al., 2011; Halpern, 1994). However, given the complexity of the autism spectrum and the extent to which it affects different people across different domains – social, emotional, sensory, and cognitively – and in different contexts, it is necessary for the planning to be sensitive to the needs of the individual. Will (1983) indicates three distinct forms of transition programming for disabled young people completing education and whilst it is not specific to autism or higher education, still has relevance. She suggests that planning could include (a) movement from education either without services or with only those that are available to the population at large; (b) could include provision of timelimited services that are designed to lead to independent employment and terminate when this has been achieved; and (c) the provision of ongoing services for those individuals who require more robust support.

Currently little or nothing is known about the levels of support that autistic students might require in preparing them for participation in life after university, which suggests that most fall into Will's (1983) first category of receiving no specialist support. However, it can be assumed that as many of the challenges that students experience in making the transition *into* higher education are applicable beyond this context that some of what is known about these induction experiences might also be relevant for understanding better the

transition *from* higher education. For example, many autistic students report anxiety about encountering new physical environments and meeting new people (Van Hees et al, 2014) and indicate the usefulness of being able to experience settings 'in action' by visiting, speaking with others, and acclimatising to the sensory environment (Mitchell and Beresford, 2014; Camarena and Sarigiani, 2009; Chown & Beavan, 2012). In one of the few specific studies into transition among emerging adults on the autism spectrum, Giarelli et al. (2013) also found that accommodations that were often identified as enabling were having an individualized, flexible routine; having an orientation program and workplace preparation; and others being prepared in terms of attitudes and implementation of adjustments. It stands to reason that these measures of transition programming would be equally beneficial in preparing autistic students for participation after university in employment, living in a new city, or embarking on a different trajectory.

There is some evidence to support this drawn from the literature outlining autistic people's experience of the workplace (Ohl et al, 2017; Wehman et al. 2014; Lopez and Keenan, 2014; Booth, 2016; Hendrickx, 2008). Such research suggests that whilst autistic people may have particular talents including attention to detail, honesty, integrity, focus, diligence, taking pride in their work, the ability to handle large amounts of data and talents in specialised areas; unfortunately, difficulties with social skills often lead to employment failures despite task-related qualifications or performance (Griffiths et al. 2012; Lounds-Taylor and Seltzer, 2011). Difficulties with subtle social interactions may make it difficult to manage office politics and many of the negative attitudes experienced

in adolescence can persist with workplace bullying and manipulation resulting in reduced mental health (Simone and Grandin, 2010; NAS, 2017b). This evidence seems to accord with the most recent figures that show that autistic graduates have the highest rates of unemployment of all disabled students leaving higher education (AGCAS, 2015). Similar gloomy findings are reported by the NAS (2017b) that 84% of adults on the autism spectrum are not in full-time employment and Roux et al. (2013) who suggest that 53.4% had never worked for pay outside the home and had the lowest employability rate among disability groups. They further show that of those that were in employment, they earned significantly lower than average wages for young adults in comparison groups and held jobs that clustered within fewer occupational types.

As previously mentioned, the raft of national policies including the Autism Act (2009), Think Autism (DWP, 2014), Progress Report on Think Autism: the updated strategy for adults with autism in England (DWP, 2016) and the current Green Paper under review, Improving Lives: The Work, Health and Disability (DWP, 2017), all emphasise the need to support autistic people making transition towards full participation in society. Such disability-specific legislation (the only of its kind in England) could give the impression that services or support for autistic people enjoys high levels of resourcing but in fact the NAS (2017b) notes that the budget for the Work and Health Programme is planned to be reduced by 2019/20 to just one fifth of the current budget. The outcome of this, they argue, will be a reduction in services, support provision, and independence for many autistic people. Such a loss of services, can according to Rydzewska (2012), further protract and complicate the process of transition to

independent living and participation in employment for emerging adults on the autism spectrum.

Unfortunately, when applied to those autistic emerging adults who have accessed higher education, this picture is even more bleak. Despite legislation, such as the Children and Families Act 2014, many local services automatically preclude those who have gained access to higher education or full-time employment. In fact, there is a tendency in government policy to focus on transition up to the level of Further Education but make the assumption that if an autistic individual has the capacity to get to university that they must be capable of navigating their own transition to adulthood. Thus, whilst they may benefit from either time-limited or indeed ongoing services, autistic university students often make the transition from education either without services or with only those that are available to the population at large (van Schalkwyk and Volkmar 2017).

#### 2.3.3 Transition as a change in status

The second theme derived from the literature posits that transition involves a change in status. However, rather than practical preparation, it is more dependent on non-reversible psychological progression and is strongly associated with developmental psychology and life span studies (Oyserman et al, 2004; Rydzewska and Pirrie, 2016). Erikson (1959/1994) is often considered to be the first to have argued that developing a coherent identity is integral for achieving personal adjustment and well-being. Taking a psychological life span

approach, he proposed that development takes place over eight stages and built on Freud's 'ego identity' to theorise that individuals' identity is developed in relation to a series of crises where one must choose between a range of meaningful alternatives, ultimately resulting in 'identity achievement' or 'identity diffusion'. Erikson's notion of the 'late adolescent identity crisis' was marked by growing occupational and ideological commitment, where young people, faced with imminent adult tasks, such as getting a job and becoming a citizen, were required to 'synthesize childhood identifications in such a way that he can both establish a reciprocal relationship with his society and maintain a feeling of continuity within himself [sic]' (Marcia, 1966:551). It is clear to see how, from its earliest theoretical stages, identity development was considered as a transitional crisis between various possibilities.

Halpern (1992:203) referred to transition of this kind as 'a period of floundering' that occurs for at least the first several years after leaving education as adolescents attempt to assume a variety of adult roles in their communities. These roles might include movement between sixth-form pupil to university student; from adolescent to adult; from undergraduate learner to member of the labour-force. Whilst some recognise this fluctuating as evidence for non-traditional 'liquid' life course where adult identities emerge slowly and variously over time (Ecclestone et al, 2010), others perceive the transition from youth to full adult status as variously unfolding in a more linear way (Heinz and Marshall 2003; Mayer & Müller 1986; Kohli, 1985).

Clearly, transition as a change in status does not take place in a vacuum but is heavily influenced by social, ideological and interpersonal identity domains (Luyckx et al 2008). Such a view concurs with Hörschelmann (2011) and Warin and Muldoon (2009) who also favour theoretical approaches to identity which recognise the interweaving of the psychic, social, and cultural. Even Elder (1994), recognised as one the central figures in life course theory, identifies this interconnectivity in his concept of 'linked lives', suggesting that identities are relational achievements rather than individual choices. Consistent with this, Rydzewska and Pirrie (2016) suggest that transition must be understood in both distal and proximal terms, in order to fully appreciate the depth of the experience. Finn (2016) exemplifies this in her interesting and related analysis of the nature and location of the social networks into which female graduates are (re)embedded following university; she demonstrates how this population's capacity to navigate information and advice, as well as different employment trajectories, is often deeply affected by complex relational dimensions. Such relational, and thus proximal, transitions are probably nowhere more clearly expressed than when young people are beginning to explore and commit to certain identities and identify longer term trajectories at school, university and post-education.

#### 2.3.4 Transition as change in status for autistic students

As has been established, descriptions of autism and its neurological variances rely heavily on medical descriptions, which tend towards a normative view of psychological development. As aforementioned, research literature and wider government policy tend to reflect a relatively unproblematic demarcation between childhood and adulthood identity statuses. In legal terms, adulthood marks a transition from children's to adult services in health, social care and education and more significantly the transfer of responsibility for autistic individuals from parental support to self-advocacy. This change of status is largely echoed in England by the Department of Health's Strategy for Adults with Autism (2010a), and the National Institute for Clinical Excellence (NICE) guidelines on services for adults with autism (2012) as well as the policies previously mentioned. Whilst such policies place a legal responsibility on various institutions to provide better support for adults on the autism spectrum they are underpinned by a temporal and necessarily linear construction of the life course.

There is currently no evidence related to how autistic university students or recent graduates respond to the change in their status from learner to worker or adolescent to adult; however, Kapp et al. (2013) suggest that the transition between adolescence and adulthood can be a particularly difficult period in the lives of high-functioning individuals with autism spectrum disorders. These emerging adults are often required to make important decisions about their lives, yet may not have developed a full understanding of their own strengths and weaknesses, or how to advocate for services to meet their needs (Huntley, 2013; Beresford et al., 2013; Rydzewska, 2012). Moreover, the demands of social relationships, employment, and independent living may be exacerbated for those on the autism spectrum who may struggle with executive function, working memory and initiating action (Hill, 2004; Van Hees et al 2014).

Beresford et al.'s (2013:156) study gathered qualitative data from among 36 parents and 20 individuals with high-functioning autism or Asperger's syndrome making the transition between adolescence and adulthood to find that parents typically felt that 'achieving adulthood' would not follow a 'normal' trajectory. Parents in the study portrayed a view of 'incomplete' adulthood, based on the belief that their son or daughter would continue to need parental assistance well into adulthood, particularly regarding the management of finances, living independently or making major decisions.

Young autistic adults in Beresford et al.'s (2013) study were more positive regarding their transition to adulthood and identified six indicators associated with this identity including: independent travel; developing and engaging in new leisure interests and activities; employment; financial independence; moving away from the family home; and changing and developing social relationships. Consistent with findings from Szatmari et al. (1989), the young people reported some successes across these aspects of adulthood, specifically around independent travel and engaging in leisure activities, however, like their parents, many also recognised the need for support and the significant role that their parents play. Only a small minority were living independently and 15 of the 20 viewed such a move as something for the future. As one respondent from Beresford et al.'s study (2013:149) put it:

Um, I don't intend to move out until like my twenties, mid-twenties, late twenties/early thirties...I'm not sure I'm ready to, to stand on my own two feet yet, cos once you leave the nest, it's basically you versus the world and if you're not ready, it's gonna all come up to you and overwhelm you.

This sort of statement accords with Luyckx et al.'s (2008) assertion that transition as a change in identity and status is heavily influenced by social, ideological and interpersonal domains where individuals are engaged in ongoing exploration. Moreover, whilst Beresford et al.'s (2013) study does provide some indication of the sorts of experiences that emerging adults on the autism spectrum may encounter, it is not possible to know for sure whether these would also reflect those on the cusp of completing higher education.

Relationships are often a significant indicator of a change in status and some young autistic adolescents view finding a life partner and sustaining a relationship as indicative of adulthood (Huntley, 2013). Evidence shows that those with low-functioning autism may experience more romantic loneliness than those considered high-functioning, however, particular autistic traits such as attention to detail and a need for sameness can become strengths for maintaining a committed relationship (Kapp et al., 2013). Developing social relationships are also viewed as problematic and autistic individuals at this stage can experience a sense of social alienation and loss of belonging (Simmeborn-Fleischer, 2012). Reports show that adolescents and young adults with highfunctioning autism / Asperger's syndrome are more likely to be victimised by peers and are consequently more likely to suffer from anxiety, depression, suicidal ideation, and avoidant behaviours (Shtayermman, 2007). Experiences such as these frequently result in greater levels of social isolation and dependency, which ultimately limit the potential for young people to develop their identities and develop their status as adults.

It is clear how transition as preparation to participate and transition as change in status are interlinked and contingent to some extent. The literature makes it clear that achieving adult status – living independently, having meaningful relationships, being employed, and having financial stability – can be challenging for anyone at this stage of life but that for emerging adults on the autism spectrum this can be problematic and often requires a more robust level of support and enhanced set of resources. Elder's (1994) interconnective theory of 'linked lives' has particular resonance here as parents play a significant and sustained role at this stage of the life course. The evidence-base is weak with respect to autistic university students' experiences of identity or status development; however, it is likely that many of the difficulties acknowledged would also be present among this population.

#### 2.3.5 Transition as becoming

The final conception of transition is identified within Gale and Parker's (2014) typology which they present as a process of 'becoming'. It is characterised as an iterative where individuals experience process 'ongoing changes, transformations and the back-and-forward movements' (Gale and Parker 2014:744). Where transition as preparation for participation and transition as change in status both draw on traditional views of the life course, normative psychological development and linear transition, this model resonates much more strongly with late modern life course. Quinn (2010:123) argues that, given the flexibility and uncertainty experienced in 'liquid modernity', transition is a perpetual process that is never complete; 'we are all always lost in transition, not

just in the sense of moving from one task or context to another, but as a condition of our subjectivity'. Moreover, transition as becoming has an emphasis on futurity, which might incorporate 'a multiplicity of futures and ways of understandings the self' (Worth 2009:1058).

Much of the research in this field has been greatly influenced by Deleuze and Guattari's seminal work *A Thousand Plateaus* (1988), which offered a rhizomatic analysis of becoming based on resistance, flux and change. Deleuze and Guattari's concept of becoming seeks to unsettle binary conceptions such as autistic or 'normal', success or failure etc. as Goodley (2007:154) puts it,

The question, therefore, is not which subject to become but how to escape the forces of subjectification that block flows of desire and territorialize the subject with rigid segmentarities.

In rejecting binary and complete concepts, the individual is freed to 'engage with places of immanence, to create action and results rather than establish transcendentals, not being, but always becoming as a line of flight' (Goodley 2007:155). Thus, according to Deleuzo-Guattarian postmodernist theory 'becoming' is based on an inherent instability, where everything is continually transitioning through states without heading towards any particular outcome.

'A becoming is neither one nor two, nor the relation of the two; it is the inbetween, the border or the line of flight... Becoming is the movement by which the line frees itself from the point, and renders the point indiscernible: the rhizome, the opposite of aborescence; breaks away from aborescence' (Deleuze and Guatarri 1988:342).

As opposed to linear and 'arboreal' logic, Deleuze and Guatarri (1988) introduced the concept of the rhizome – an acentred, non-hierarchical, open system, ruptured by lines of becoming, which go off in all and any direction.

These lines of becoming have 'neither beginning nor end, departure nor arrival, origin nor destination' and so reject the notion of a pre-traced destiny, be it divine, anagogic, historical, economic, structural, hereditary or syntagmatic.

According to Petrescu (2007) the 'line' is the metaphoric basis of all of Deleuzo-Guattarian thinking because the 'line', as opposed to the 'point', is a dynamic element. The line is thus understood as a useful metaphor to map the dynamic and entangled nature of the social field in terms of affects, politics, desire and power; for this endeavour Deleuze and Guattari draw heavily on the notion of cartography. They juxtapose tracings and maps averring that tracings are like the leaves of a tree, which are found within a naturally developing hierarchical system; whereas a map, concomitant with the rhizome,

...is open and connectable in all of its dimensions; it is detachable, reversible, susceptible to constant modification. It can be torn, reversed, adapted to any kind of mounting, reworked by an individual, group or social formation. It can be drawn on a wall, conceived as a work of art, constructed as a political action or as a meditation...A map has multiple entryways as opposed to the tracing, which always comes back "to the same". The map has to do with performance, whereas the tracing always involves an alleged "competence" (Deleuze and Guatarri 1988:12).

Interestingly, Deleuze and Guattari exemplify their concept of becoming as a map with reference to the work of French psychiatrist and educator, Deligny (1976), who lived with a group of autistic children and observed the way they moved around their surroundings. Pinchevski (2011:48) cites how he mapped the 'customary lines' of routine activities but also the 'wandering lines' (lignes d'erre) 'where the halts, returns, hesitations, and loops respond to invitations at once real and imaginary, decoded, opening into constellations and not closed into a system'. While for Deligny (1976:342), 'the maps do not say much, they only can show that we unknow what is the human, as well as what is the common' but for Deleuze and Guattari the customary and wandering lines are perceived as analogous to their own speculations on 'lines of flight' which present new and significant ways of being and sharing with 'the other' (Pinchevski, 2011; Petrescu, 2007).

The discourse surrounding transition as becoming has also been greatly influenced by the feminist theory of Elizabeth Grosz (1998:38). Positively developing the ideas of Darwin, Nietzsche, Bergson and Deleuze she argues that,

unless we develop concepts of time and duration which welcome and privilege the future, which openly accept the rich virtualities and divergent resonances of the present, we will remain closed to understanding the complex processes of becoming that engender and constitute both life and matter.

For Grosz, duration fractures the past and the present and opens them up to what is virtual in them, to what in them differs from the actual, to what in them can bring forth the new. Hence becoming is the operation of self-differentiation, which is actualised only in the 'uncontainability and unpredictability of the future' (2005; 2004:261). A good example of the application of Grosz's theories of time and futurity can be found in Worth's (2009) study of the transitions of visually impaired young people, in it she argues that what is real and what is possible in the future both co-exist in time and are only separated by the process of realisation, therefore, opening up a nexus of 'becomings' all at once.

For Gale and Parker (2014), by contrast to other models of transition, the unsettling and unpredictable nature of becoming is considered in productive and

positive terms, rather than something that must be overcome or ameliorated. It allows for flexibility, changes, transformations, and the back-and-forward movements between identities and roles. Transition understood as becoming deconstructs the prevalent binaries of success and failure, reconfiguring the transitional experiences of students whose non-normative accounts could be considered 'deviant', 'deficient', 'unruly' and 'inadequate' (Colley 2007: 430; Quinn 2010:126). In this sense transition as becoming emphasises diversity and difference and foregrounds the lived experiences of students in all their rhizomatic compositions. Where education systems, structures and procedures perpetuate the fetishisation of the certain time frames and activities and so disregard the multiplicities of student lives, transition practices are often much less effective (Gale and Parker, 2014; Quinn, 2010).

It is clear that transition as becoming requires greater theorisation. There is a danger that such a rhizomatic conception like this can emphasise the multiplicitous, non-teleological and ungrounded abyss of becoming at the expense of the real social and material structures experienced by young people (Neimanis, 2006; Gutman and Akerman, 2008). Others including Hardgrove et al. (2015) and Ansell et al. (2014) also warn against theories of transition, that offer only a partial perspective which is insensitive to the transactional relationship between present and future needs, aspirations, and subjective attitudes, values and preferences. However, becoming also has the potential to extend discussion of transition far beyond a linear (or aborescent) process of change over time to something much more nuanced and sensitive to the fluidity of the individual's lived experience. Given that this study relates to the aspirations of autistic

students making the transition out of higher education and therefore into the 'unknown future', the concept of becoming is viewed as having particular resonance and worth.

## 2.3.6 Transition as becoming for autistic students

This is an area of the literature which is almost entirely unexplored. While there have been a small number of studies which investigate the concept of transition as becoming for other groups of disabled learners, for example Worth's (2009) study among a visually impaired youth population, so far this issue has not been fully considered in relation to those on the autism spectrum. Consequently, it is only possible to theorise; however, it seems possible to interpret transition as becoming for young autistic adults in at least two ways: first, as a theoretical transition where rigid segmentarities and binary conceptions of autism are deterritorialised; and second, in practical terms as individuals map out their 'wandering lines' with respect to life choices and biographies.

Van der Palen (2014) explores Braidotti's notion of the posthuman in relation to autism and offers some insight into this first approach to transition as becoming for autistic individuals. He presents the notion of 'becoming-autistic' where binary terms (autistic / non-autistic; normal / abnormal) are questioned and deconstructed; this is a process of transition both for the autistic individual but also more broadly for society. He writes,

What needs to occur is a becoming-autistic of the autistic, as well as a becoming-autistic of all non-autistics: becoming-autistic is a becoming, not a state, which undoes identity and counteridentity and instead

instantiates "a block of alliance" between the two, in the middle, but always in the direction of the minoritarian...Becoming-autistic is not a move towards normality and normativity on the autistic's part. Instead, it is the embrace of the disorder with which the condition confronts the autistic. (2014:111)

In this way the concept of autism is itself problematized through a rhizomatic analysis and lines of becoming catalyse new divergent virtualities. Where 'autistic' denotes binary distinctions, 'becoming-autistic' demands hybridity between the autistic and the non-autistic and as such, rather than being reterritorialised in a new whole it takes on a 'becoming-with', a coalition based on 'affinity' rather than identity (Haraway, 1991:150). To an extent this 'becoming-autistic' is evident in the neurodiversity movement where there is an appeal to diversity, rather than the creation of a counter-identity; the term itself serves to 'open a space where respect is distributed equally to all human beings in all their differences' (Van der Palen, 2012:110).

The second approach to interpreting transition as becoming relates to the rhizomatic and non-linear way emerging adults on the autism spectrum negotiate their life trajectories. Evidence shows that this population has the highest level of part-time work and post-graduate education out of all disabled graduates (AGCAS, 2015); this could suggest that, like their neurotypical peers, they are increasingly opting to extend adolescence and explore various avenues before committing to one particular 'biography' or career in adulthood (du Bois-Reymond, 1998; Brannen and Nilsen, 2005). However, like Furlong (2009) suggests, there is a danger of misinterpreting the complex experiences of autistic individuals in emerging adulthood as 'choice biographies', thus underplaying the structural barriers that they face in terms of employment, independent living

and future aspirations. It is hoped that this study will offer some additional insight into the varied lines of becoming that autistic students leaving higher education may seek to follow and the capacities that enable these aspirations.

## 2.4 The capacity to aspire

## 2.4.1 Aspirations and 'possible selves'

Aspirations relate to an individual's desired or imagined future, often conceptualised in terms of educational, relational, financial and vocational outcomes (Sirin et al., 2004). The construct of aspirations finds its roots in psychological research originally designed to investigate anger; based on these historical antecedents, Quaglia and Cobb (1996:130) suggest an integrated schema for conceptualizing aspirations, which they describe as,

the ability to identify and set goals for the future, while being inspired in the present to work toward those goals.

They emphasise two key aspects within aspirations: inspiration and ambitions. Inspiration reflects the view that individuals aspire to activities that will be exciting and enjoyable on the basis of what they find intrinsically valuable in the present. Ambitions, on the other hand, are more functional and reflect certain activities designated as important for achieving future goals. This way of viewing aspirations is useful as it acknowledges the 'connections between current and future lives' (Ansell et al., 2014:387) in combining the motivational components of the present (inspiration) with the goal-oriented future (ambitions).

The term aspiration is not, however, without its detractors. Some, including Hardgrove et al. (2015) criticise its use claiming that it can appear vague and

lack specificity. They suggest that aspirations, characterised as future dreams, 'fails to draw a compelling link between future goals or outcomes and young people's agentive efforts to work towards them'. Like Oyserman & Markus (1990), they prefer the term 'possible selves' to articulate the imagined, possible outcomes grounded in past experiences and present circumstances. Sarojini-Hart (2013) also critiques a view of aspiration as being simply 'imagining' the future; in contrast, like Quaglia and Cobb (1996), she conceptualises aspiration as goaloriented and concerning the future of the self or the agency of the self in relation to goals concerning others.

It is clear that, like transitions, aspirations are dynamic and multidimensional and can be encouraged, informed, guided or manipulated by relationships past, present and future. Consistent with Finn (2016), Sarojini-Hart (2013) finds that aspirations are frequently 'peopled' with others and imagined futures are 'relational', 'connected to others', and reflect a sense of reciprocal obligation into the future. As a result, planning and decision-making about the future becomes less of a 'cognitive process wherein sovereign rational individuals weigh up options' and takes on more 'non-rational and also non-conscious aspects' as aspirations are influenced by a host of personal and social attitudes, values, preferences, memories, affects and emotions (Ansell et al., 2014:390; Holmes, 2015). Thus, one's capacity to aspire is 'always formed in interaction and in the thick of social life' (Appadurai, 2004: 67), where present and future needs and pressures are complexly bound to wider contexts that are social, cultural, political and economic. Appadurai (2004:76) articulates the 'capacity to aspire' as having the personal and social resources needed to read one's own map into the future. He suggests that having aspirations is not exclusive to more affluent or powerful groups, however, like Sarojini-Hart's (2013) analysis suggests, those with the least power in society tend to have 'a more brittle horizon of aspirations' (Appadurai 2004:69). For these groups barriers experienced in the sedimented traditions of the past have implications for their capacity to realise aspirations into the future. Appadurai argues that it is essential to develop the 'navigational capacity' to recognise intermediary aspirational paths or 'nodes' and offers four principles for achieving this. The first involves what Kamler and Comber (2005:5) describe as 'contesting deficit assumptions', where a new consensus is produced that identifies, supports and reports processes through which norms surrounding disadvantaged groups are challenged. The second principle recommends emancipatory and community-based educational efforts to better understand and navigate normative contexts. The third suggests the development of methodologies for identifying and contextualising people's immediate desires in relation to broader norms and narratives. The final principle supports the 'exercise of voice' through which 'the sinews of aspiration as a cultural capacity are built and strengthened, and conversely, it is through exercising the capacity to aspire that the exercise of voice by the poor will be extended' (Appadurai, 2004:83). Sellar and Gale (2011:130) demonstrate the usefulness of Appadurai's (2004) principles for enhancing students' capacity to narrate their experiences of university,

Aspiration-focused student equity efforts might be conceived in terms of resourcing students to imagine alternative futures in open-ended ways, exposing current institutional forms to critique and creating opportunities for the production of new forms of sociality within and beyond university.

It is thus through recognising the socially- and historically-located experiences of those most marginalised that society and institutions may begin to develop greater epistemological equity and corresponding capacity to aspire.

## 2.4.2 Autistic students' aspirations

Whilst there are no qualitative studies available which specifically investigate the aspirations of autistic university students or graduates as they make the transition from higher education, Huntley (2013), Giarelli et al. (2013) and Beresford et al. (2013) offer some insight through their qualitative studies among emerging adult populations on the autism spectrum and their parents. Their evidence shows that young autistic adults have aspirations in some of the following areas: education, careers, socialising, and independence. On the whole, Huntley (2013) found that young adults were more positive than their parents regarding the future and both report that they have high aspirations with respect to ongoing or further education, a point also supported by evidence of graduate destinations (AGCAS, 2015). Beresford et al.'s (2013) findings concur with this,

I'm there [at college] to study basically, I'm there to study and to get my, get my A' Levels so that I can move on to university, get a degree, get a doctorate and become a scientist. I'm quite tough on that path basically.

The young autistic adults identify aspirations towards developing careers, which included working with animals, becoming a champion computer-gamer, graphic design, music production and driving (Huntley, 2013). Consistent with Giarelli et al.'s (2013) findings, young autistic adults also indicated their aspirations for

greater independence, with almost all hoping to live on their own at some stage in the future.

I think I might like to live with some other people I guess... I'm generally distant to sort of talk to someone because... I like sort of my alone time... but it would be good to... have some flat mates as well. (Huntley, 2013:82)

This statement is also suggestive of young adults' aspirations for more developed social networks and friendships, however, parents tended to perceive this as more important than they did. Interestingly in Huntley's (2013) study almost all of the parents had aspirations that included the desire for their son or daughter to be happy, yet this affective aspiration was not reported by any of the young adults themselves.

Both Huntley's (2013) and Giarelli et al.'s (2013) studies identified some external and internal barriers to achieving aspirations. External factors included financial barriers and extended dependency on parents, concerns about finding work in the current economic climate and a lack of understanding among other people. In terms of internal factors specific autistic behaviours and neurological differences related to autism were identified as significant in autistic participants' realising their aspirations. Both Giarelli et al. (2013) and Huntley, (2013) identify challenges associated with interpersonal difficulties, restricted interests, repetitive behaviours and vulnerability to others as being problematic. In Huntley's study young adults relate how they were often misunderstood or targeted by others, whereas their parents report a lack of judgment in social situations and inappropriate behaviour. Moreover, both Huntley (2013) and Giarelli et al. (2013) found that cognitive capacity played a part in the potential actualisation of aspirations. Often those with higher levels of cognitive

functioning had more sophisticated thinking about the future; and by comparison those with lower IQ were less able to articulate this. Whilst the evidence-base is small it is clear in suggesting that emerging adults on the autism spectrum have varied capacities to aspire, plan for the future and can articulate what they perceive is enabling in this transitional process.

# Chapter 3 Methodology

This chapter details my philosophical position with respect to this study, outlining the centrality of critical realism and a qualitative methodology for responding to the research questions. It offers explanation and reflection on the use of semi-structured interviews and life maps as the research tools used for uncovering the lived experiences and future aspirations of autistic participants making the transition from higher education. I provide details of the sample recruited to take part in the study and describe the ethical protocol adopted to safeguard them throughout the process. The final sections outline my positionality as a researcher, the attempts made to generate valid claims based on a reliable research strategy, and the data analysis procedure as framed within a critical realist paradigm.

# 3.1 Methodological Orientation

This study is underpinned by particular ontological and epistemological assumptions, which reflect my own methodological orientation towards social research. Ontology is concerned with 'being' and what is; where epistemology centres on the study of knowledge and addresses questions of what can be known (Converse, 2012). With respect to research, these issues have their roots in Cartesian dualism which assumes a clear distinction between the physical and the mental, between the body and the soul, between the objective and the subjective, and between 'things' and 'meanings' (Pring 2015). Based on differing positions in relation to these metaphysical issues, contrasting research

paradigms in postitivism and interpretivism have developed; this study, however, takes a critical realist position (Bhaskar, 1975:xxvii), which serves as a middle road between these opposing schools of thought.

Traditionally positivist approaches have emphasised the ontological position that there is an 'objective reality' made up of physical, social and psychological 'objects' that exist independently of the subject, or researcher. Pring (2015) suggests that this has led to the epistemic assumption that these different 'objects' can be observed and understood by researchers through experiments and that their conclusions can be repeated and verified under similar conditions resulting in a body of knowledge that reflects the world as it really is. The correspondence theory of truth, that posits the 'possibility of directly and unproblematically mapping symbolic representations on to the facts in the world in a one-to-one fashion' (Kamberelis & Dimitriadis 2005:29), fits appositely with this view of knowledge and thus regards it as entirely neutral and separate from power relations or contextual dimensions. This 'naïve positivism' (Denzin and Lincoln, 2013) is frequently associated with quantitative and scientific research methods. Such a position is demonstrated in the Literature Review, where much of the clinical research on autism is based on ontological and epistemological assumptions that uncritically suggest that there is such an 'object' as autism which can be investigated and known in an unproblematic sense. This approach has been useful for gaining better understanding about the aetiological trends and biological markers for the condition and is welcomed by most medical practitioners as well as some autistic people and their families.

Not all, however, share such a positivist stance and, by contrast, interpretive approaches tend to reject comprehensive explanations of the origins of knowledge in favour of a hermeneutic-dialectic process (Delanty, 1997; Pring, 2015). Drawing on social constructionist epistemologies, this perspective suggests that all 'objects' in the world are constructed and do not exist independently of the researcher, consequently knowledge is created through interactions between the researcher and the phenomena researched rather than discovered as objective truth (ibid). The interpretive paradigm proposes that the very distinction between objective and subjective knowledge is invalid, given that all knowledge is perspectival. Accordingly, research is no longer focused on the representational mirroring of an objective reality and its verification but about human interaction, communication and dialogue (Kamberelis & Dimitriadis 2005). The 'interpretive turn' in research was reflected by an emphasis on qualitative methods, through which knowledge might emerge from embodied, rich and messy experiences of being-in-the-world; it is not on this basis considered to be 'better' or 'truer' than its predecessors, but simply more informed' (Guba and Lincoln 1989:17). This epistemological shift has been identified in disciplines including history, anthropology, psychology. sociolinguistics and sociology (Riessman, 2002) and as such the post-modern concept of identity began to be understood as a life-long process of construction and reconstruction; a continuous rewriting of one's identity and thus process of becoming (Brockmeier 2000; Deleuze and Guatarri, 1988). The strength of the interpretive position is clear for some within the autistic community who reject a form of objective knowledge that they perceive to be hegemonic and oppressive, preferring to view autism as socially constructed.

However, like those who adopt a neurodiversity model of autism, I sought a third way between the entrenched dichotomy of positivism and interpretivism. Without doubt positivist approaches have been useful for understanding the neurological differences experienced by autistic people and through experimental research have garnered much knowledge about these lived realities. In relation to transition for autistic people, experimental quantitative studies have provided useful information regarding societal expectations, typical transition indicators, and life course patterns (e.g. Allen et al, 2013; Daniels and Brooker, 2014). However, positivist approaches also present limitations for capturing the complexity of human behaviour and respond less well to the challenge of conceptualising life transitions in nondeterministic ways (Hörschelmann 2011).

By contrast, a critical realist stance offers 'double inclusivesness' (Bhaskar and Danermark, 2006:278) by retaining an 'ontological realism' in suggesting that there is a real world that exists independently of our perceptions, theories, and constructions but also accepting a form of 'epistemological constructivism' garnered through our perspectival understanding of the world (Bhaskar, 1975; Maxwell, 2012). Hence, it is critical insofar as it rejects a correspondence theory of truth but realist in that it posits that phenomena really exist within our 'life world' (Putnam, 1990). In this way, then, critical realists build on symbolic interactionism (Blumer, 1969) by holding that mental states and attributes, which include meanings, intentions, and aspirations, form part of our real world

whilst they might not be 'objectively' knowable. In his seminal text, The Logic of Scientific Discovery, Bhaskar (1975:177), puts it well:

Science is explanatory, not simply descriptive. Explanation is achieved by reference to enduring mechanisms. Such mechanisms exist as the powers of things and act independently of the conditions that enable us to identify them. Thus there is a direct link between the dynamic realist thesis that the things and causal structures of nature not only exist but act independently of men and the conception of science as a social activity *sui generis* in which both the facts and the conjunctions that, when attainable, provide the empirical grounds for causal laws are seen as social products.

Therefore, in terms of social research, a critical realist seeks to build theory and explain causal structures and their properties on the bases of constant reflections, immanent critique, and iterative abstraction (Yeung, 1997:57). Schwandt (2007) avers that this paradigmatic position really reflects how most people behave – we generally act as if objects, mechanisms, and structures in the world, for example, society, transition, or autism, really do exist as independent from our experience of them. Maxwell (2012) claims that, on this basis, qualitative researchers frequently adopt – if only implicitly – a realist stance based on the fundamental assumptions underlying their study and the methods utilised within the strategy. Bhaskar and Danermark (2006:282) demonstrate the usefulness of critical realism, specifically for disability research, by offering an analysis of the phenomenon of disability within a 'necessarily laminated system' experienced on biological, psychological, socio-economic, cultural, and normative levels.

Thus, for this thesis, critical realism offers a means of taking a realist position with respect to the condition autism and its implications for transition and aspirations. It suggests that it is possible to gain some social-scientific knowledge of autism, transitions, and aspirations when examined within such a laminated system; at the same time critical realism allows space for epistemological interpretivism, where knowledge of these 'realities' is provisional rather than representational (Scott, 2005). For Sayer (2000:18):

While realism shares with interpretive social science the view that social phenomena are concept-dependent and have to be understood, unlike interpretivism it argues that this does not rule out causal explanation, a) because material change in society has to be explained too, and b) because reasons can also be causes, in that they prompt us to do things, think differently.

Such a realist focus on relationships, contingencies and potentialities has import here, given its focus on autistic participants' transitions and aspirations within wider social structures; moreover, its critical aspect has emancipatory potential for affecting change (Bhaskar, 1986; Hammersley, 1996).

To engage in this form of critical abstraction, I adopted a qualitative research design for this investigation. Creswell (2007:13) metaphorically describes this methodology as '...an intricate fabric composed of minute threads, many colors, different textures, and various blends of material'; in doing so he reiterates the perspectival nature of such approaches and, for this study, signals a means of describing the embodied *realities* of autistic individuals making the transition from higher education. From a critical realist perspective, qualitative methods such as interviews and life-maps offer a means of gaining an in-depth understanding of individuals' experiences in order to abstract the causal mechanisms which affect them and on the basis of these 'social facts' (Erikson, 1977) seek to affect change. Such an approach has obvious implications for how and why certain data was collected and particularly the way in which it was

analysed (Yeung, 1997; Miles and Huberman, 1994). Each of these issues will be explored herein.

# 3.2 Research methods

Two qualitative methods were used in conjunction to draw out the lived experiences of the students making the transition from university: semistructured interviews and life maps. Both of these methods of data collection lent themselves to participants' deep reflection on the particular phenomenon under investigation and allowed for a flexible and adaptable approach to gathering data. The semi-structured interviews were broadly employed to probe participants' experience of transition from higher education; and the life maps, together with semi-structured questions, were utilised to uncover their aspirations beyond university and the expected trajectory of their lives.

#### 3.2.1 Semi-structured interviews

Semi-structured interviews are considered a credible and powerful research method today. In particular they offered much for this study given their potential for capturing the fluidity and unpredictability of life courses, whilst attending to moments of rupture, uncertainty, tension and confusion (Hörschelmann, 2011). In order to facilitate this process, I devised two separate interview schedules: one for current students and another for recent graduates on the autism spectrum (Appendices 5 and 6). The questions developed were slightly different for those participants who were 'in the midst of transition' from university and those who had, to some extent, completed certain aspects of the transition process; in doing so I sought to capture how transition and aspirations might be differently constructed and experienced once one has made the transition from higher education or is at least part way through it. To provide clarity and structure, each schedule was divided into three sections in order to explore (a) the participants' experience of completing their university course; (b) their plans regarding the immediate future or current status; and (c) their longer-term aspirations and expectations for the future. Moreover, in doing so I was directly attempting to uncover some of the enabling and disabling mechanisms which impact on the participants' movement between these different life stages. The semi-structured nature of the interview schedule ensured that certain aspects of transition could be probed in depth allowing for some direct comparison between participants; however, it also retained the flexibility required to explore various 'lines of flight' (Deleuze and Guatarri, 1988).

Out of the 21 interviews conducted, fourteen were face to face. Most of the interviews took place in a private office at my own higher education institution although on four occasions these were conducted at different locations identified by the participants themselves. It was not always possible for interviews to take place in person as the sample was drawn from institutions across the United Kingdom and so a video interview using Skype® was conducted with five participants. However, as social communication, especially with individuals with whom they are unfamiliar, can cause anxiety for some autistic people, communication through email was also offered. Only one participant chose to

conduct it via Skype. Whilst there are some drawbacks with qualitative data collection where the interaction is not face to face, particularly with respect to the teasing out of meaning in responses (Ratislavova and Ratislav, 2014), it was judged that the benefits of having a more diverse sample outweighed these disadvantages. All twenty interviews conducted in person or via Skype were audio recorded (Cohen et al., 2011) and ranged in length with the shortest interview at 37 minutes and the longest at 2 hours 2 minutes; with the mean interview length across the sample at 1 hour and 21 minutes.

#### 3.2.2 Life maps

Where data collection took place face to face, this was facilitated by the use of life maps as a secondary and complementary method. Fourteen of the twenty-one participants engaged in aspects of this. Life maps are a visual form of data collection situated within a participatory diagramming tradition where an individual traces significant events, junctures and transitions across their life (Bushfield 2010; Hodge, 2005). Worth (2011) describes life maps as an organisational tool which can support narrative research, especially where this involves uncovering personal and specific aspects of life experience. Visual data collection methods of this kind have been used to study self-identity since the 1970s (Ziller and Smith, 1977) and Alexander et al. (2007) identify a range of diagramming approaches including maps, transects, sketches, cartoons, piecharts, flow-diagrams and matrices. According to Kesby (2000) techniques and materials should feel comfortable to those handling them and so resources often include flip chart paper, marker pens, post-it notes and coloured sticky dots. The process of generating visual data in this study typically followed a particular sequence: brainstorming aspirations using Post-It<sub>®</sub> notes, identifying priorities, exploring relationships, discussing what would enable their realisation and then constructing a visual artefact that represented these different aspects.

As a research method, the life map complemented the final two sections of the semi-structured interview where participants were invited to reflect on their short and long term aspirations for the future. To avoid condensing the complex multiplicities of lived experiences into linear and formalised representations (Kothari and Wathen 2017), I encouraged participants to consider different aspects of life and aspirations as widely as possible including family, career, further study, travel, relationships etc. Participants used different coloured postit notes to think broadly about their 'possible selves' (Hardgrove et al., 2015), which were in turn discussed to uncover their decisions, priorities, and predictions. According to Alexander et al. (2007:116) when 'diagrams are interviewed... this process often produces the richest material'. Moreover, such an approach offers a degree of 'member checking' where the depth and quality of my understanding is improved by checking it against the interpretation of the participant (Cahill and Torre, 2010). Figure 3.1 offers an example of a life map constructed by a participant in their final year of an undergraduate degree. On the left of the picture are short term aspirations which include examples such as learn to drive, relocate part-time job and move out of family home; on the other side are longer term aspirations which include doing a PhD, getting a job at a university; in the centre is how this participant chose to visualise her future trajectory, whilst she did so in linear form, this was not the case for all.

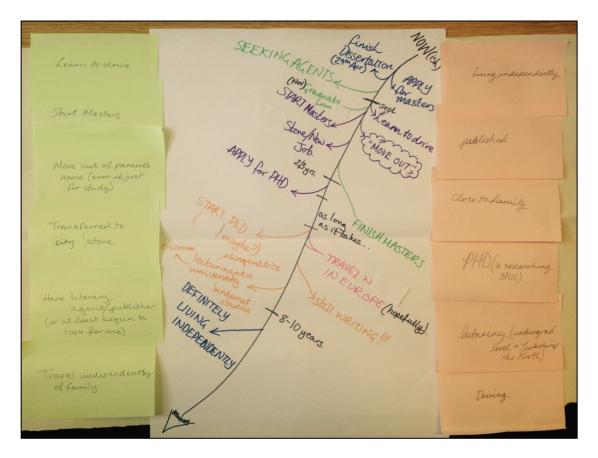


Figure 3.1. Example of life map used with undergraduate student

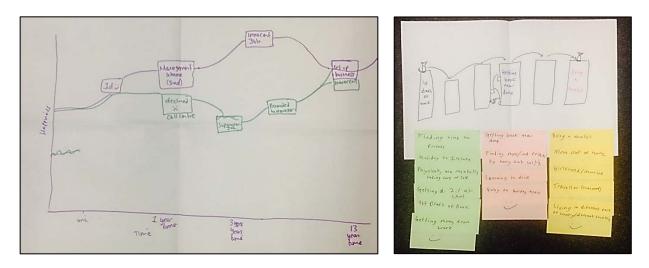


Figure 3.2: Life map - UG student

Figure 3.3: Life map - Graduate

By contrast, Figure 3.2 shows life visualised as a graph based on levels of happiness attained over time and Figure 3.3 illustrates life as a series of obstacles that one can fall off or use to jump between.

One of the benefits of using life maps in this way is that unlike traditional research methods, which tend to have a fixed 'product' in mind, diagrams are open, flexible and can be adapted as ideas and understandings develop. Kesby (2000) suggests that given the more open nature of visual methods participants 'have less inhibitions about changing and adapting the diagram as they go along'. Such flexibility allows the individual to construct their map in whatever way is most meaningful to them and so is in keeping with the Deleuzo-Guattarian (1988) conception of cartography based on 'becoming', where the map is considered concomitant with the rhizome. However, perhaps most importantly, the data derived from the life map has two dimensions: the information included in the map; but also the perceptions of the map-makers about themselves and their place in society. Figure 3.3 is a good example of this as the cat jumping between obstacles depicts the precarious nature of the future and the practical and intellectual agility required to be successful. Moreover, this agentic understanding accords with what Appadurai (2004) would term the 'capacity to aspire', where an individual possesses the 'navigational capacity' to read their own map into the future.

That notwithstanding, whilst diagramming is an increasingly popular form of data collection among marginalised populations, choosing it cannot guarantee a positive response. Table 3.1 shows the breakdown of the different methods that

were adopted as part of the data collection process among the twenty-one participants.

Life map + Post-it notes +	Post-it notes + interview	Interview
interview		
6	8	7

Table 3.1 – Actual data collection

Rather than insisting that participants created a drawn life map as outlined in Figures 1 and 3 above, I explained its purpose and how it might help think about their next transitional steps in a visual format; not all participants felt able to participate in this activity with 8 preferring to simply use the Post-It notes as the basis of further discussion. On reflection, it might be the case that drawing a life map diagram in this way was considered patronising; it could have been as a result of not perceiving the usefulness of the task; or that for certain individuals who struggle with imaginative thinking, especially about the future (Boucher, 2009; Huntley, 2013) this task might have been too challenging. Matthew stated, for example,

Sometimes you can't picture what your life will be like and you just have to wait and see what happens...

For whatever reason, I felt it important to be sensitive and respect each participant's autonomy rather than force a particular method and so marginalise the individual. The seven participants that used neither Post-it Notes nor visual life maps were those who participated via Skype or email and so this option was not available.

# 3.3 Research sample

The inclusion criteria for participation in the study was individuals with a formal diagnosis of an autistic spectrum condition (including Asperger's syndrome); students in their final year of higher education (BA / Post-graduate); or those who have graduated from a higher education institution within the last three years. It was considered that by incorporating those who have recently graduated as well as current university students that this would offer a longitudinal layer of experience with respect to enabling mechanisms for realising aspirations following the transition out of university. The potential population for this study, however, is very small. The Higher Education Statistical Agency (2015) reports just over 2,400 students with autism spectrum conditions in UK universities, which when disaggregated based on the inclusion criteria leaves a very limited sample to draw on.

Combined with this, people on the autism spectrum often find it difficult interacting with individuals they do not know, many are wary of disclosing or discussing their diagnosis, and some find it challenging engaging in unfamiliar contexts where the benefits or outcomes are unclear (Hill, 2004). Thus, recruiting participants from this 'hard to reach' population relied heavily on purposive sampling among established networks and pre-existing connections. A blog (Appendix 3) was deemed an appropriate way to recruit participants given its accessibility in terms of information and its capacity to be shared on social media. This was shared across local networks, on Twitter, and on a UK-wide JISC mailing list, 'Autism Practitioners in HE' (<u>Austismpractioners@jiscmail.ac.uk</u>). In

total 21 participants met the inclusion criteria and were recruited to take part in the study (see Table 3.2 below).

There is much debate around the ideal sample size for qualitative studies. Polkinghorne (1988) and Creswell (2007) recommend that researchers interview between five and twenty-five participants, whilst Ragin (2012, cited in Baker and Edwards, 2012:5) suggests that it ought to be '20 for an M.A. thesis and 50 for a Ph.D. dissertation'. For this study, rather than attempting to identify a particular sample size at the planning stage, the number of participants involved was determined on the basis of saturation. Such a concept, whilst difficult to define explicitly (Guest, et al., 2006), centres on the notion of commonality where the researcher collects data until that which is being found is so repetitive that there is no need to continue. Doucet and Charmaz (cited in Baker and Edwards, 2012) each suggest that reaching saturation - and so knowing 'how many' in a study – is only made possible by the researcher's familiarity with their epistemic communities. For this study, the researcher was in a particularly privileged position, having worked and researched with autistic university students previously (Vincent et al, 2016; Vincent, 2015); such access provided insight into the population and allowed for a better understanding of when saturation had been achieved.

Access to this epistemic community was also fundamental for recruitment. Due to the issues outlined above, 15 of the twenty-one participants were previously known to me through one higher education institution and other autism networks in the local area. Such close recruitment has a number of potential

Participant	Sex	Age	Diagnosis	Final Gra	Graduate Subject		Highest	Year of	HE institution type	University
				Year			Qual	comp		location
Grace	ы	20	AS, OCD, Dyspraxia	۲	Business		BA	2016	Post-1992	North of England
John	¥	20	AS	7	History		BA	2016	Post-1992	North of England
Eliza	E2.	21	AS	7	English La	English Language and Linguistics	BA	2016	Post-1992	North of England
Tom	¥	22	AS	7	Creative Writing	Vriting	MA	2016	Post-1992 (same)	North of England
Winston	W	22	ASD	7	History		MA	2016	Post-1992 / Russell Group	North of England
Arthur	W	20	AS, Depression	7	Creative Writing	Vriting	BA	2017	Post-1992	North of England
Theo	W	20	AS, Ataxia	2	Theology	Theology and Religious Studies	BA	2017	Post-1992	North of England
Lewis	M	20	AS, Depression	2	Creative Writing	Vriting	BA	2017	Post-1992	North of England
Matthew	W	21	AS, Anxiety	2	Youth and	Youth and Childhood Studies	BA	2017	Post-1992	North of England
Adam	M	21	AS, dyspraxia, depression	7	Business		BA	2017	Post-1992	North of England
Robert	W	25	AS, Depression	7	Digital media	dia	PGcert	2014	Post-1992 (same)	North West Eng
Timothy	W	22	ASD	>	Mathematics	tics	BA	2014	Post-1992	South of England
Alice	ц	23	AS	>	Primary Education	ducation	BA	2014	Post-1992	North of England
Max	¥	22	AS	7	Creative V	Creative Writing and Media studies	BA	2014	Post-1992	North of England
Poppy	ш.	21	AS	2	SEN & inclusion	lusion	BA	2015	Post-1992	Midlands
Ezra	W	25	AS	7	Mathematics	tics	DhD	2015	Oxbridge / Russell Group	South/North Eng

Lily	щ	22	AS	7	International Relations and Politics	BA	2015	Russell Group	North of England
Dave	×	25	AS	2	Creative Writing	BA	2013	Post-1992	North of England
İzzy	ц.	22	AS	7	Creative Writing	BA	2014	Post-1992	North of England
Martin	×	26	ASD	2	Education Studies	BA	2015	Post-1992	North of England
Kieran	×	26	AS, IBS, dyspraxia, depression	2	Business	PGCert	2015	Post-1992 / Post-1992	South of England

Table 3.2: Research sample details

shortcomings, including the claim that participants may have felt obliged to take part or might skew their data for fear of damaging the relationship (Cohen et al., 2011). However, by using the recruitment blog I was able to allow space for participants to make their decision about involvement without undue personal pressure. Moreover, my robust ethics procedure and the critical accounts presented by some of the participants both offer assurances that participants were comfortable with the arrangements and were able to outline their views in an honest way. In fact, I believe that because I was already known to many of the participants, this generated richer data by alleviating some of the stress involved in the research process (Duncombe and Jessop, 2002).

Miles and Huberman (1994) also claim that close purposive sampling of this kind might not necessarily be representative of the wider (university) population. Whilst this was not the aim of my study, the sample included 15 males and only 6 females. This approximately reflects the traditional male:female gender distribution of 4:1 in the autism community (Elsabbagh et al., 2012) but some studies show that female autistic students' university enrolments could be as high as 47% (Dillenburger et al., 2016). This being so, the sample here may overrepresent male experiences of transition from university and aspirations beyond and should therefore be considered with this in mind.

Moreover, only eight higher education institutions in England were represented in the sample, with the majority in the North of England (see Table 3.2). Today few observers would dispute that the UK university system is a differentiated rather than a unitary one with differences in student outcomes and experiences

depending on the type of higher education institution (Oxbridge, Russell Group, Million+, Cathedrals Group etc.) and potentially location (Boliver, 2015). Whilst it was beyond the scope of this thesis to compare the transitional experience of emerging autistic adults across these different institutional clusters or locations, it is worth noting that the majority (n=18) of those interviewed were recruited from Post-1992 universities and which, therefore, may limit the range of potential experiences. Additionally, my sample does not include the accounts of students from every academic discipline, with the majority (n=18) studying in the arts, humanities and social sciences. This is notable as many studies show that autistic university students are more often drawn to STEM subjects including science, engineering and mathematics (Wei et al., 2014; Lee, 2014; Chen, 2009).

As noted above, although I was not attempting to recruit a representative sample *per se*, I did want to recruit participants from different courses and institutions in order to offer greater diversity. Through the blog and the autism practitioners mailing list mentioned above I added a further six participants, which included two from Russell Group universities and two that studied Physics and Mathematics, respectively. The low recruitment numbers here may demonstrate the difficulty in accessing autistic individuals' experiences without the kinds of pre-existing networks outlined above. It might also indicate that those autistic university students studying STEM subjects compared to those studying Creative Writing, for example, may be less comfortable with the verbal expression demanded from interviews and were therefore dissuaded from taking part; however, accessing why individuals do not take part in studies is always

speculative. For future research, recruiting a sample from a wider range of disciplines, university-types, and backgrounds would be preferable for gaining a deeper understanding of the complex nature of postgraduate transition.

# 3.4 Ethical approach

Any piece of research involves consideration of a range of ethical issues, including a commitment to minimising harm, protecting privacy, respecting autonomy, offering reciprocity and treating people equitably (Hammersley and Traianou, 2012). As part of the preparation, research procedure, and dissemination of findings such concerns were foregrounded and actions taken to mitigate any harm for the participants. One of the principal means of ensuring ethical conduct was through the institutional ethical approval that was sought prior to the commencement of the research [UREC reference RS2015 54 -Appendix 1]. As part of this process a consent form and participant information sheet (PIS) were developed to provide participants with full details regarding the aims and objectives of the research, the primary data collection methods, how their data will be used, and what will be required of them as participants (see Appendix 2). The PIS also explained what the participants could expect from me in terms of assuring their privacy, the security of information stored, and evidence of due process by providing my contact details and those of my doctoral supervisor (Cohen et al. 2011). All the PIS information was also available via the online recruitment blog, which also served as an adjustment for those autistic participants for whom organisation can be problematic (MacLeod et al, 2014). Having an online version meant that information could be more easily accessed and used as the basis of discussion with parents, friends or mentors before deciding whether to take part. To maximise participants' understanding of the research, the PIS and consent form were both shared on three occasions: firstly through the online recruitment blog; again when participants had agreed to take part; and finally each were viewed and discussed in person prior to the commencement of the interview. Such provision offered me assurance that the participants had made informed decisions about their involvement (Nind and Vinha, 2014).

The issue of harm with respect to non-experimental studies is sometimes glossed over without too much consideration; however, for this study I was aware that the topics discussed and the format used to explore these could potentially cause distress or emotional upset for the participant. For example, there was no guarantee that all of the participants' experiences of transition would necessarily be positive and that discussing these would not cause some degree of psychological harm. This issue came to the fore in the interview with Izzy, when she was discussing job interviews and the barriers she thought might be preventing her from being successful; on reflecting she described her experience at one interview which led her to become visibly upset,

(Izzy) ... they told me that a couple of things that were good but a couple of things that were also bad about it. And then they just said flat-out that maybe I should consider another career.

(JV) Why do you think they said that?

(Izzy) I don't know. They thought, I guess, they thought I didn't have the right qualities of having a career in being a TA and they just pretty much told me that I shouldn't be a TA. So... that was rough. I was just blank with

shock at that moment when they said that, well I didn't even get an interview that day, I was just... I just walked out.

(JV) That sounds really hard.

(Izzy) Yeah...[visibly upset]... that was rough. I was in a bit of a funk after that, afterwards. It was rough but I'm still trying. It's hard you know... I guess I was kind of... humiliated. It was... [visibly upset]... it was awful. I'm still trying but I'm a bit of a sceptic.

Whilst it would have been possible (and, perhaps for some, more ethical) to have ended the interview at this point as Izzy was upset, I took the decision to continue with the interview but shift it in a different direction. Had it been terminated on this negative note there would have been no opportunity to have considered some of the more positive aspects of her experience, thus perhaps causing more harm. In fact, by the end of the interview Izzy was able to provide a different and more positive example, which to some extent validates my decision:

Let's see what did they say? They said that I was one of the strongest candidates, they loved my confidence and coming across as confident and professional and such. At the end of the interview they said I hope that wasn't too bad and I said believe me I've had worse!

However, in another interview, this time with Timothy, the interview was terminated prematurely; in this instance it was at the participant's request and due to his increased levels of stress. Sensitive to body language and non-verbal cues of the participant, I could see that he was becoming distressed. In the first instance a break was offered but shortly after this the interview was ended quite abruptly. The excerpt below gives a sense of the interaction:

(JV) So, do you feel happy with your life at the minute?(P) I feel frustrated with the jobs but... who wouldn't? Can we stop now?(JV) Of course.

Being able to 'read' the situation is essential for making ethical decisions regarding the research process and involves a great deal of reflection-in-action (Schön, 1984). In the former case, because I had known Izzy for at least three years, and there was an established level of trust and rapport, deciding to continue seemed like the right decision although this was not the case for Timothy and so it was important to respect his wishes.

Another aspect of harm that must be considered is future harm. For some autistic people, especially those who are anxious about discussing their diagnosis with others, anonymity is a primary concern with respect to research (Huws and Jones, 2008). With this in mind, measures were taken to protect the anonymity of participants, including the use of pseudonyms both in transcripts and in the final thesis. Moreover, consistent with Arksey and Knight (1999), explicit permissions to use direct quotations in later publications and published works were also sought. By doing so I sought to protect the participants from future harm that could come as a result of being identifiable. Secondly, the interview transcripts were reviewed by the participants before analysis; by engaging in memberchecking of this kind they could have confidence that their information had been handled in an ethical and confidential manner as well as signalling their ownership of the data (Punch, 2013). Finally, participants were assured that they could withdraw from the study at any point and were offered a 'two week cooling off period' following the interview during which their data could be entirely removed. Whilst no participant did withdraw, such adjustments provided time for them to reflect on their involvement after the event and reinforced their agency in the research process.

In terms of reciprocity, participants did not receive any financial reimbursement for sharing their experiences; however, it was clear that simply having the opportunity to discuss the experience was useful for some, as is evident from this email response from one participant:

Thank you very much for the opportunity to take part in the research, it was interesting to think through my experiences so far. It has also helped me be a bit more prepared for starting my Masters as made me stop and think of some of the challenges I had for my undergrad and prepare for them in advance this time round. (Lily)

Similarly, another participant wrote:

Talking to you was therapeutic for me and it has allowed me to reflect on myself and think clearly about how to go forward in my life, so it was a great success overall! (Robert)

Effort was also made to follow up some of the issues discussed in the interview; for example, signposting participants to postgraduate internships for disabled students, sharing information about free financial education or career planning, and enquiring about 'what happened next' after the interview. Such engagement with the participants, it is hoped, demonstrated an ethic of care and signalled that I was interested in them as human beings rather than simply sources of data (Cooper, 1991).

# 3.5 Reflexivity and positionality of researcher

Positionality is an important factor in any piece of research but particularly for qualitative studies. In this sense it leads from the previous section as an ethical issue, as it required me to consider the 'politics of position' (Smith 1993:305)

bound up in the processes of recruitment, data collection, analysis, discussion and dissemination. In phenomenological terms, according to Heidegger researchers are 'thrown into' a world of phenomena including relationships, objects, and language; and thus this 'being-in-the-world' is always 'in-relation-to' making it essentially temporal and perspectival. Therefore, for this thesis, it was imperative for me to acknowledge my own position as a neurotypical, male, middle-class, member of academic staff at a university, and volunteer at a social group for autistic students, not because these are necessarily barriers to uncovering more about the experiences and structures of transition for autistic participants but because these factors undoubtedly influenced the research.

Throughout the data collection and especially the analysis process I attempted to 'bracket' or suspend my own personal biases, preconceptions and assumptions and attempt to listen to participants 'freshly, as if for the first time' (Husserl, 1931). However, this is seldom perfectly achieved (Moustakas, 1994) and undoubtedly my own worldview will have influenced the questions asked and analytical codes and themes identified but it is hoped that by outlining in some detail the process undertaken that this is mitigated to some extent (Miles and Huberman, 1994).

Moreover, my position as an academic researcher and university lecturer no doubt had implications for relational asymmetries in this research. Frequently the researcher holds a more dominant position in an interview as they direct questions, interrogate answers and interpret the data in the moment and this can, at times, be more pronounced for studies among disabled populations (Nind

and Vinha, 2014). Consequently, effort was made to deconstruct psychological barriers and democratise the encounter, where possible. In the first instance the interview was described as 'more of a chat', which indicated to the participants its non-threatening and dialogic nature; secondly, where life-maps were utilised, this served to equalise the dynamic as participants were able to lead on the activity, thus placing them in a position of control. Interestingly there were instances where the power dynamic was in fact entirely reversed and I came under scrutiny from the participants. This extract, again from Izzy, shows this quite appositely,

(Izzy) I guess what I would want life to be if I can put it bluntly is: as close to 'normal' as possible. That's just what many people who have something that impairs them wants; to live a normal life, to hell with disabilities (JV) So what things would you consider being part of normal life?

(Izzy) The same thing you consider a normal life. What do *you* think a normal life is, tell me?

(JV) Well I don't know it will depend on different people and what different people want. Some people might want to be single their whole life and go travel the world, never have a home or whatever...

(Izzy) Yeah but that's some people, what about most people? What would most people think is a normal life?

(JV) Maybe I suppose having a family, living by themselves or with someone else, maybe?

(Izzy) So that is most people, what do *you* think is a normal life? What's *your* life, what do *you* think is normal about *your* life? What do *you* think is life in general; it's a very broad term.

(JV) It is. I like how you are turning this interview back on me!

Here the implied demarcations between researcher and researched, autistic and neurotypical, normal and abnormal, us and others are made explicit by the participant with the interview techniques inverted and directed back towards the researcher. It is clear from the exchange how I feel uncomfortable with answering the question about what is considered 'normal' for my own life. Such encounters identify both the challenge involved in having to extemporarily articulate issues surrounding one's self-conception and the need to guard against 'othering' positions that can be subconsciously adopted.

# 3.6 Reliability and validity

The concepts of reliability and validity are traditionally rooted in positivist and scientific traditions within the natural and human sciences (Guba and Lincoln, 1989). Within these disciplines there exists an epistemic assumption, based on the correspondence theory of truth, that particular 'objects' can be observed by researchers and that their conclusions can be repeated and verified under similar conditions. This is often labelled 'external reliability' and emphasises the consistency, dependability, and replicability of the study to prove that the findings are independent of merely accidental circumstances (Kirk and Miller, 1986, cited in Silverman, 2006). Within interpretive and phenomenological traditions researchers typically eschew such claims to reliability or replicability (Guba and Lincoln, 1989; Golafshani, 2003); however, for critical realists, through the continual dialectic between 'ontological realism' and 'epistemological constructivism', the concept has more traction (Sayer, 2000).

Reliability can therefore, in theory, be achieved where the qualitative research strategy is sufficiently detailed that others might be able to replicate it for themselves (Le Compte and Preissle, 1993, cited in Cohen et al., 2011; Silverman, 2006). It is hoped that this study achieved some degree of reliability by identifying clear research questions, offering transparency regarding the study design, recognising my positionality as a variable, and attempting to specify analytic constructs based on thorough analysis. However, given the perspectival nature of qualitative studies, I do not suppose that others would necessarily generate the same findings but suggest the possibility of comparing, refining and validating conceptual constructs through use of the same strategy (Miles, Huberman and Saldaña 2013). For Guba and Lincoln (1989) such a position is construed as 'dependability' and relates specifically to the internal validity of the research which they understand as the confidence that the researcher can have that the explanations and conclusions drawn can be sustained by the data (Cohen et al., 2011).

Building on the critical realist stance, Miles, Huberman and Saldaña (2013:293) suggest that, although not universally accepted, when a reliable research approach is followed it is possible to arrive at valid claims,

The phenomenologist chuckles, reinforced in the idea that there is no single reality to get "right"—but cannot escape a sneaky feeling that, in fact, reasonable conclusions are out there somewhere.

They argue that qualitative research can lead to plausible social facts but in order to test and confirm these researchers must confront the issue of validity. Whilst qualitative researchers may disagree whether such claims point to 'realities' or 'meanings', approaches from across the spectrum tend to identify the same elements of validity, including context-rich meanings (Geertz, 1973), data linked to the categories of prior or emerging theory, (Charmaz, 2014) and systematic and coherent findings which engage with negative and rival evidence. Yeung

(1997) offers grounded theory as a qualitative approach that fits within a critical realist stance as it aims at developing concepts and abstractions at a level that supports their transferability to other populations and contexts (Glaser, 2002). Accordingly, the claims that are drawn from the accounts and social mechanisms identified in this study, it is believed, are based on plausible conclusions and a reliable research strategy.

In this study, one of the strengths in terms of validity is the development of theoretical constructs which are derived directly from the data (Patton, 2001; Yeung, 1997). Specific effort was made to gain an authentic understanding of autistic participants' experiences of transition from higher education and aspirations for the future through semi-structured interviews and life-maps. Using open questions with some degree of flexibility built in allowed the participants to speak at length about their experiences and at times to direct the encounter according to what was most significant for them. One way of confirming the internal validity of the research was by recording and transcribing the participants' interviews verbatim and foregrounding these in the thesis. The following findings chapters and appendices provide evidence of context-rich accounts and so aimed to increase the dependability of the study. It is, however, recognised that, as a human researcher, I was the instrument used for understanding and interpreting this phenomenon and so 'validity, then, should be seen as a matter of degree rather than an absolute state' (Gronlund, 1981, cited in Cohen et al., 2011:179). To provide some degree of internal validity the causal mechanisms identified at the level of abstraction were then tested against these accounts and the wider theoretical literature to assess their

applicability (Yeung, 1997). Thus to conclude, whilst claims to absolute knowledge and reality are rejected, the outcomes of this study are considered valid and point towards a material reality for my autistic participants based on causal relationships in society and which ultimately 'prompt us to do things, [and to] think differently' (Sayer, 2000:18).

### 3.7 Data analysis

The final section in this chapter deals with the data analysis strategy and aims to outline in as transparent a way possible how the findings outlined in the following chapter were arrived at. Once again, foregrounding the critical realist paradigm adopted is relevant for making sense of this process. In the first instance, the realist method for data analysis, and so theory construction, is neither purely deductive, nor purely inductive but rather operates simultaneously in a dialectic in which the researcher aims to achieve 'a harmonious synchronization between deductive abstraction and inductive grounding of generative mechanisms' (Yeung 1997:63). Throughout the data analysis process I engaged in this deductive-inductive dialectic which guided my abstraction and theoretical construction based on data grounded in the real life experiences of the participants as social actors. From this perspective it was possible to see this process as a theory-building activity based on 'knowledge of real structures or mechanisms which give rise to or govern the flux of real phenomena of social and economic life' (Lawson, 1989: 69).

More specifically, the objective of data analysis in this study was to describe participants' (real) experiences of transition from higher education and their aspirations for the future but also to identify the (real) enabling and disabling mechanisms which affect these in practice. Thus, I was constantly moving from descriptions of the phenomenon to descriptions of what produces or is a condition for it; this iterative process Bhaskar (1986) calls retroduction. In order to aid the transparency of the process and the plausibility of my abstractions, a structured approach was required to data analysis. Miles and Huberman's (1994:12) interactive framework (Figure 4) was used to guide the data analysis process; in it they divide data analysis into three distinct stages: data reduction, data display, and conclusions and verification.

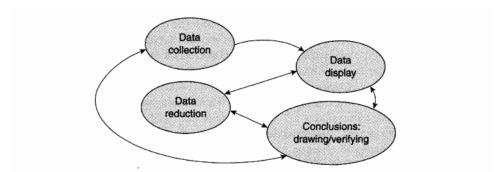


Figure 3.4 Miles and Huberman's (1994) interactive framework

Whilst Miles and Huberman (1994) understand qualitative methodology as largely residing within the interpretive tradition, they orientate themselves according to a critical realist stance in seeking to 'transcend' subjective phenomena by building theories to account for the real world. In broad terms, the procedure included the transcription of all data collected; the identification of 'codes' assigned to representative statements drawn from the interviews and life-maps; visual memoing; and the identification of axial relationships and metacodes. In the final stages causal mechanisms were isolated and theories deduced based on this thorough inductive data analysis process.

#### 3.7.1 Transcription

Having completed the collection of data based on twenty-one semi-structured interviews these were electronically transcribed verbatim. It is recognised that, given the inherently interpretative nature of interviews, it is not possible to produce a transcript that reflects the research interaction in its fullness (Kvale, 2007; Miles, Huberman and Saldaña, 2013). Indeed it was difficult to capture in a written transcript the participants' or researcher's body language, the subtle shift in dynamic generated by a particular question, the emotions that underlie the experience etc., however, getting as close to this was the aim. Transcripts were member-checked to ensure that the experience, as I observed it, matched that of the participants and each was given the opportunity to comment, amend or challenge how the encounter had been represented before analysis took place. The life-maps drawn by some of the participants were not transcribed in terms of their content, as these had largely served as a scaffold for discussion in the interviews; however, the composition of each was considered with a view to better understanding how some autistic students and recent graduates configure their future trajectories. Furthermore, as only six of the participants opted to draw a life map, this data was considered supplementary rather than central and was used to increase the internal validity by a means of triangulation in conjunction with the written transcripts.

#### 3.7.2 Data reduction and initial coding

Having transcribed the interviews and checked these with participants, my next step was to immerse myself in the data through reading and re-reading the transcripts. One outcome of this process was what Miles and Huberman (1994) term 'data reduction'. This involves reducing the mass of qualitative data interview transcripts, field notes, observations etc. – down to what is considered most relevant; in doing so it 'sharpens, sorts, focuses, discards and organizes data in such a way that 'final' conclusions can be drawn and verified' (Miles and Huberman 1994:11). In phenomenological terms, the objective here is to distil the mass of data without significant loss of context in order to draw out the 'essence' or meaning from participants' descriptions. One example where data was 'reduced' was from the initial stages of the interview: each began with a question asking the participant to discuss the university course they were doing or had just completed and why they decided to study it; the intention with this was not to generate important data but to put the participant at ease and create a relaxed atmosphere at the outset. Another example is where participants discussed at length issues or experiences that were of particular interest to them but that significantly diverged from the research question asked; to illustrate this, in one interview a participant spent around five minutes discussing the different forms of Manga animation and their various interpretations. For Miles and Huberman (1994), as data collection proceeds, additional episodes of reduction occur through coding, writing memos, teasing out themes and assigning tentative clusters and is only finally complete once the study is written.

Although it is recognised that coding and analysis are not synonymous, coding is a crucial aspect of analysis and was identified as the next step in the process. A code is understood as a label that 'symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data' (Saldaña, 2014:3). Codes can be descriptive, what Glaser (2002) calls in vivo codes, and which tend to use words derived directly from the text. These might identify some of the surface-level aspects of the phenomenon or provide details about the experience. In this study descriptive codes were noted, for example, to identify the different diagnostic labels used by participants (Aspergers, autism, high functioning autism etc.), the kinds of transition support that had been offered at different institutions, the different employment sectors that participants had applied to or had experience in, and particular aspirations that participants had for the future. However, at other times with a code I was seeking to distil the core meaning of the participants' account. Alongside initial coding I also engaged in memoing as a parallel activity. For Lempert (2007:245) memos aim to 'conceptualize the data in narrative form' and can include written reflections, diagrams, and conceptualising concepts.

#### 3.7.3 From codes to categories

I found that given the iterative nature of reading, coding, re-reading, coding, my analysis became quite substantial. In order to avoid data fragmentation and decontextualisation following over-coding (Ereaut, 2002; Welsh, 2002) I inputted the codes from each transcript into a spreadsheet. By going back to the data and the codes in this way I was able to develop a more sophisticated inferential analysis leading to more abstracted categories. Recoding of this kind offered opportunity for further data reduction by identifying the salient features in the data for generating categories and grasping meaning (Saldaña, 2014). It also provided the means for more axial coding, where connections and deviations between incidents were sought. Richards and Morse (2007:157) suggest that,

'categorising is how we get 'up' from the diversity of data to the shapes of the data, the sorts of things represented. Concepts are how we get up to more general, higher-level, and more abstract constructs'

Visual memoing was again important at this stage of the analysis for two main reasons: firstly it aided the classification of categories and; secondly helped identify possible causal relationships or mechanisms based on the participants' experience of transition from higher education. The organisation and presentation of codes and categories in the form of tables and visual memoing aligns with Miles and Huberman's (1994) second component of the analysis procedure: data display and helped identify inferential relationships necessary for abstraction.

As the dataset generated from the twenty-one interviews was considered large and there was thus a higher margin for human error, I felt it necessary to make use of a Computer Assisted Qualitative Data AnalysiS (CAQDAS) package to manage the data and coding process more effectively and so NVivo® (Version 10) was utilised. CAQDAS packages have been used effectively to support qualitative data analysis in a range of approaches including grounded theory (Charmaz, 2006), interpretive phenomenological analysis (Smith, Flowers, & Larkin, 2009), framework analysis (Lewis and Richie, 2003), and qualitative 103 content analysis (Mayring, 2000). Gibbs (2013) suggests that whilst CAQDAS programmes do not 'do' the analysis, what they offer is the capacity to organise and display large datasets more effectively than is usually possible through manual management. NVivo® was another useful device for forcing me to consider how the various categories were grouped and related to each other. As NVivo® requires one to pre-assign categories (or nodes as they are termed in the programme) this required me to get to a stage of abstraction where I was confident of the general shape of the data. The main benefit with NVivo® was the opportunity to view all the data chunks from the twenty-one participants under the particular categories at the same time, thus aiding higher-level abstraction and the generation of themes and theories.

Another benefit of NVivo® is its capacity to identify the frequency of particular codes mentioned across the sample, within subsets and by individuals. Such counting activities in qualitative research might be viewed with suspicion by some, as Krane *et al.* (1997, p.214) suggest:

Placing a frequency count after a category of experiences is tantamount to saying how important it is; thus value is derived by number. In many cases, rare experiences are no less meaningful, useful, or important than common ones. In some cases, the rare experience may be the most enlightening one.

They make a strong case for discounting frequency as a measure of meaning; however, others such as Frankfort-Nachimas and Nachimas (1996) suggest that considering the incidence of particular codes can actually assist analysis. In fact quantifying codes across a number of different cases is the central activity in the identification of any theme or pattern and numerical data can often confirm instances and verify – or at least provide some substance for – the claims that are

being made (Miles, Huberman and Saldaña, 2013). Some of the codes with the highest frequency in this study related to employment; independent living; and experiences of job interviews and while these did not specifically lead to the development of themes, their frequency indicated their potential significance and suggested important avenues for exploration.

### 3.7.4 Theorisation of data

The final stages of data analysis are conceptualisation and theorisation. These are based on the various steps that have gone before but broadly develop out of reflection, focused coding, writing, re-reading, making connections, collapsing codes and beginning to generate theories and abstract possible causes. Table 3.3 outlines the overarching categories that were derived from this process; these were housed under three distinct headings: transition *from* higher education; transition *to* occupational aspirations and transition *to* relational and personal aspirations.

Transition from higher	Transition to occupational	Transition to relational /
education	aspirations	personal aspirations
Source of anxiety &	Disheartened by the	Desire for romantic
avoidance	recruitment process	relationships
Positive departure	Scepticism / loss of trust in	Desire for independence
	employers	
Loss of independence and	Naivety regarding	Desire to be 'normal'
momentum	employment	

### Identity development Pursuing the dream

### Table 3.3 Overarching categories

Analysing these categories, I attempted to ascend from the minutiae of empirical data to a broader conceptual perspective. From a critical realist perspective this aims at attempting to construct knowledge of real structures or mechanisms which can account for the 'how' and 'why' of the phenomena under study (Bhaskar, 1986). As will be outlined in the following chapter, three conceptual domains were identified with respect to the experience of transition: practical, psychological, and philosophical which represent a set of fluid and nested experiences captured by the range of codes, categories and themes. Moreover, I sought to uncover some of the causal mechanisms – both proximal and distal – that enabled participants' transitions *from* higher education and *to* their various aspirational destinations. The following chapter will outline these and seek to verify my theoretical abstraction by foregrounding participants' first-hand accounts of the phenomenon.

## **Chapter 4**

# Findings: Transition from higher education

The findings in this thesis are subdivided into three distinct chapters. The first outlines the different experiences of transition *from* higher education as reported by the participants; the following chapter presents the findings with respect to the participants transition *to* their different occupational, relational and personal destinations; and the final chapter offers insight from the participants' accounts regarding the resources and capacities that were considered enabling for actualising their different aspirations. The demarcation between transition *from* higher education and transition *to* aspirational destinations is suggestive of the dynamic nature of transitions as an ongoing process – moving from, between, and to new experiences and identities. Whilst it would have been possible to have conceptualised these distinct transitions as simply one wider process of transition, disaggregating them in this way, I believe, offers a more authentic analysis.

In terms of the transition *from* higher education, four broad themes were derived from the twenty-one participants' accounts. These included: transition as a positive departure; transition as loss; transition as a source of anxiety; and transition as identity development. Table 4.1 below outlines the different analytic categories that made up these themes.

#### Theme

Categories

Transition as a source of anxiety &

avoidance	
	Anxiety
	Fear of uncertain future
	Overwhelmed by experience
	Out of my control
	Avoidance activities
Transition as a positive departure	
	Optimistic
	Excited about potential future
	Sense of pride
	Feeling in control
	Organised / mapped out
Transition as loss	
	Loss of independence
	Loss of relationships
	Loss of momentum
	Loss of identity
Transition as identity development	
	From adolescent to adult
	Member of the workforce
	Developed self-concept

Table 4.1 Themes: transition from higher education

## 4.1 Transition as a source of anxiety and avoidance

A significant theme across all twenty-one of the participants' accounts was transition as a source of anxiety. Participants used words such as 'distracted dread', stressed, terrified, nervous, anxious, strange, odd, worry, panic, fear, crisis, apprehensive, not in control, and scared to describe their experiences of preparing to leave university. Part of the explanation for this, according to the accounts, was that heightened levels of anxiety is simply a characteristic of what it means to be autistic 'because you have all the extra worries that no one else has' (Izzy). As well as what any neurotypical final year student may be experiencing, additional worries related to social and communication demands, organisational requirements, or managing highly sensory environments can make this experience more challenging. This excerpt from John, a history graduate, shows how anxiety has been a consistent emotion throughout many of his transitions made across the life course.

his transitions made across the life course,

(John) I've always been... it's just that kind of anxiety that I've always had moving onto something different. I had anxiety before I went to school, I had anxiety before I went to secondary school, I had anxiety before coming to university, I have this anxiety now that I need to go out and get a job.

(JV) And how did that manifest itself for you?

(John) Worry in the pit of my stomach, focusing on other things, trying not to think about it too much because I know it will just worry me stress me more.

John's experience identifies two important issues related to anxiety: firstly, it is

frequently exacerbated by transition to new contexts; and secondly, it can lead to

avoidance activities. Both of these were also identified by other participants; for

example, Lily discussed why 'fear of the unknown' is so problematic for her,

I think it's the unknown. Like not knowing what's going to happen and then thinking the worst sometimes I guess; its more not anything that is actually there it's the not knowing... (Lily)

I'd say it's the fear of the unknown because you don't know what is going to happen, you don't know if you're going to succeed or fail. I think that plays a big part of it. (Izzy)

For both Lily and Izzy it was the inability to be able to predict what might happen next that was challenging, especially where this may lead to uncertain or undesired outcomes. For Theo and Dave education provided a known 'structure', which when removed generated anxiety 'you've got that security in learning...and then once that security goes you don't know what you'll be doing'. Hence, the unknown nature of transition from university to whatever might be next appears to make this more difficult than previous life course transitions. In beginning school, moving between primary and secondary education, and even coming to university, whilst there is a level of unpredictability, these destinations can be known: one can visit the school or campus, sit in the lecture theatre, meet the teachers or lecturers, talk to current students, and so conceptualise one's identity and place in that context; however, when one is faced with an unknown future, few, if any, practical and psychological provisions can be made to support this transition.

For some of the participants, where levels of anxiety were significantly heightened in the final months of university, their mechanism for coping was to avoid engaging in the transition process at all. Like John's comment above suggests, cognitive space was simply given over to focusing on 'other things', which might include final year exams, dissertations, or assignments. Lily reports that it was only 'after I handed my dissertation in that I was like, right that's it, what on earth do I do now?' These types of displacement activities appear to be psychological strategies used to manage the experience, especially where there is difficulty accepting that significant change must take place.

It's one of those things where I don't acknowledge that it's a big transition...So it's kind of one of those things where I don't accept it until it's right there. (Alice)

I have been constantly worried about the future, mainly death but also life and what it might hold...I think it is much easier to worry about the future than to be in the present. I think it's easier to get focused on, for me, to be

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pessimistic and go into a place where you are thinking 'what am I going to do with my life?' rather than just being there and being in it...I am always working against myself, I am always trying to reach a place where I am selfdestructing because when I am self-destructing I do not need to take on responsibility, it's everyone else's responsibility to look after me and I constantly have to fight that urge because I know that deep down I don't want to be that and I would rather be functioning and doing well. (Lewis)

I kind of tried not to think about it because I just didn't know what was going to happen. Yeah, so I just avoided it as much as possible. (Lily)

I don't recognise stuff in my future until there is something that I can do, there's no point trying to worry because if I start to worry it will spiral out of control, so yeah I do tend to... if there is something in the immediate and something that I can do then I'll try to focus my attention on that and anything after will have to wait. (John)

It is obvious from the extracts above and final year Creative Writing student Lewis' in particular, that thinking about the future can be deeply troubling at a psychological and even existential level. He described it as an inner struggle between doing what he knows will help and 'self-destructing' in order to have a valid reason for not having to engage in the process. It is obvious that by disengaging psychologically and practically from the transition process, it will in fact potentially make it even more challenging by further increasing levels of anxiety; however, it seems also that control plays a central role in this experience. The unknown future is by definition outside of one's control, to some extent, compared to the present which is populated with concrete tasks, real objects, and achievable goals. All of these things are known and understandable and can thus be managed at a psychological level; however, John's statement suggests that having control of the present can allay some anxiety and the risk involved in loosening his grasp of the present is too great as to do so may mean that everything – the present and future – 'spirals out of control'.

#### 4.2. Transition as a positive departure

The second theme, transition as a positive departure, relates how some of the participants' perceived leaving higher education in optimistic terms. Many participants used words like 'incredibly excited', 'happy', 'fun' and 'mostly optimistic' to describe the experience. Both Adam and Lewis described feeling 'ready to go into the world...I feel much more prepared to talk to employers, meet people, try to organise myself and Eliza's comment suggests how getting to this point in university is analogous with finishing a marathon, 'I'm looking forward to it...you know when it's just you can see the finish line and you really want to get it'. Such comments indicate a positive desire for transition and signal the temporal nature of the phenomenon in perceiving it as a juncture point between the completion of one life stage and the beginning of another. However, whilst some participants related excitement about the future this was generally balanced against other emotions. Theo, Arthur, Matthew, and Max all described a 'sort of a mix of being excited and a bit apprehensive... the mix of feeling quite sad to leave but excited' and Winston commented that he felt 'probably more good than bad, more excited than anxious'.

Very often, perceiving transition as a positive departure was catalysed by having a clear sense of what might be next. Where participants in their final year had identified or organised a job, course or valued activity, understood the process and felt in control this tended to mitigate anxieties. As Poppy suggests, 'I'm feeling alright about it now 'cause I've kind of got the gist of what's going on.' In this sense then, transition appears to shift from being a primarily emotional issue to a practical one as the two statements below attest,

Well I always had my heart set on working in schools. So I wasn't really concerned about that. I just put all of my efforts into getting ready for my third year and getting the degree and then trying to figure out things from there. (Izzy)

I guess quite early in 3rd year, I was definitely planning on doing a masters it was just where; so I started looking through the options (Winston)

For others, where there was a clear alignment between what they had been

studying and what was next, this also made the transition more manageable, as

Tom, who was studying a MA in creative writing, reports,

It hasn't been that bad since it's basically doing what I was doing when I was at University except I'm not at university since what I'm doing is watching anime, reading manga, reading books, I'm writing, I'm making videos. So I'm just doing my every day routine really, it's just removed the university from it.

These experiences portray the mixed, but potentially positive, emotions that transition from university may generate and indicate a level of contingency between practical readiness and psychological responses to the phenomenon.

## 4.3 Transition as loss

The third theme identifies transition in terms of loss. In particular participants perceived it as loss of independence, loss of friendships, and loss of momentum. Whilst on first reading such a list could be interpreted in negative terms – as loss often is – however, it is also indicative of the fulfilling experiences, meaningful

relationships, and positive trajectories that students on the cusp of transition had worked hard to achieve and were thus scared to lose. For many of the participants the greatest loss experienced as part of the transition was of independence, particularly were this was precipitated by having to move back into the family home.

Yeah so I didn't want to go back home because I liked how independent uni made me and the feeling that you could go out when you wanted and cook what you wanted and then to go back to where I used to live...It felt restricting. (Poppy)

One of the things that I didn't want to happen was to move back home because I was concerned that if I did I would lose the independence that I had built up whilst at university... I think to be independent at university took a lot of work even like learning to cook for myself took a lot of effort and things like that and remembering I had to eat and things like that and I think I've picked up a lot from that which was quite a struggle, so I kind of feel like I made that transition and I'm much better, I'm more responsible for myself I think but sometimes it's quite hard not to just slip back into just easily forgetting it all again. (Lily)

Anxiety comes from the prospect of not getting a job because I don't want to go home... I'm doing a tonne of stuff in uni right now – a job, internship, trying to get my grades, alongside hobbies...it's nice to have the independence and I don't want my mum and dad breathing down my neck. (Arthur)

I have enjoyed my experience of term-time independent living as a student and feel competent in that context... I have noticed this even during weekends at home that made me feel "homesick" for my university accommodation. (Ezra)

Loss in this context again relates to control. Whilst at university the participants were able to make simple but significant decisions about their own lives. To some being able to decide what or when to eat, what to wear, or how to fill a day may seem trivial but for this group often these skills represent years of hard work developing practical and organisational methods and processes. Feeling 'competent' in the university context was important to them and they felt positive about how they had developed and matured; in this respect they no longer felt like the 'child' they had been when they began their university course. However, this is just what appears to concern them most about returning to the family home; participants saw this shift as a loss of independence and control and so 'restrictive'.

Another aspect of loss experienced as part of the transition from university was a perceived reduction in momentum. Over the three or more years of university participants had been focused on learning academic skills, garnering knowledge, and applying their understanding in various fields so the prospect of finishing their education or returning home reflected a stalling or even cessation of this progressive development. One participant, Martin, who had completed a Foundation Degree and then a Bachelor's degree said, '...sitting back now and talking about it I feel lost'. So much time and energy had been expended on getting to this end point so for some the transition led to a sense of frustration as Max put it,

I felt like I spent all that time learning all this stuff at university and now you've just gone back to being a 17-year-old... in many ways it felt like I hadn't left – I had a kind of a groundhog day feeling about it in the sense that I had come home, the house hadn't changed a huge amount, the people's lives – friends that I hadn't seen as intensely as I had – their lives hadn't changed, they were still doing the same things. It was almost as if the three years at uni hadn't happened.

Such losses of independence and momentum as part of the transition process were challenging for many of the participants and link to a shift in identity status.

### 4.4 Transition as identity development

Participants made a clear connection between finishing university and its implications for their personal identities. Like the previous theme, this also relates to returning to the family home and reflects anxiety about how they perceived themselves or were perceived by others. For many of the participants, leaving university signalled the socially-acknowledged transition to adulthood, validated by having 'a place to live and a job'. For Grace the primary reason that she went to university was to gain the necessary skills to establish herself as an independent and self-sufficient adult and so to fail in this endeavour was contrary to everything that she and others had worked for.

The last worst scenario is me living at home for a year 'cause I've moved away from home to gain independence, to get a job, to show my parents I can cope on my own and there's me going for the three years, them paying my accommodation to me going I can't handle it, to not getting a job, I don't have the skills, I need to come home to get more - it's kind of contradicting the whole reason I've gone to uni, I've got my own life and can do what I want... although I'll have a first degree and I might have a job, I might be becoming a little closer to being independent but I wouldn't be independent if I was living at home (Grace)

For Grace particularly, her identity is wrapped up in her parents' perception of her and making a successful transition to adulthood is about proving to them that she can cope with life; in doing so she puts huge pressure on herself to be successful from the point of graduation. Others felt more relaxed about their 'inbetween' identities, as Max puts it, 'I'm not a child, I'm not a teenager or anything – I'm an adult with responsibilities but I still have things done for me that I had done when I was a kid'. In this sense making the transition to adulthood is determined on the basis of readiness and when it feels like the right time, rather than any linear life course marker. For example, Eliza, who lived at home throughout her degree, suggests,

Well it's just getting to a stage when I'm getting a bit too independent. I probably can't live in this house too much longer not in the sense like... not that I want to move out but it's going to need to happen at some point... there is a point when you just want to leave the nest as it where and I think I'm coming to that now. It will be hard and it will be stressful and scary but I'm aware that it is stressful and scary for everyone. It's a step that it's going to need to be taken at some point.

For most participants living independently was important but related to this was their identity as a member of the workforce. For example, John sums up the importance of a professional identity within a wider frame of reference when he states,

I know that I would feel the next level of fulfilment if I have a job, if I'm getting paid and I'm enjoying it... Knowing that I've been able to get a job would be sort of be another level, almost, on the checklist of life for me.

It is clear here how making the transition to an adult identity is conceptualised in linear terms with a range of criteria which can be checked off one by one. This generally accords with the participants' view of the life course, often preferring a sequential understanding to one that can diverge in multiple directions.

The final way transition from university was understood with respect to identity relates to psychological development or improved self-concept. Participants reported a shift in how they viewed themselves as they moved into and through this stage; their comments often referred to confidence, control, and emotional stability.

Simply put, I'm a lot less lonely. I have...managed to meet a lot of new people and that has provided a kind of fresh perspective on things...I feel

better equipped than I was when I came into university...both the skills that I have learned here, the ability to socialise, jump on opportunities, managing myself'... (Lewis)

I'm a lot more confident...I wouldn't have been able to have this Skype conversation without being absolutely terrified and even then things like I couldn't get a bus without panicking, even if it was one that I got all the time, it would still be a huge deal. Where now I'm a lot better, particularly with having been abroad and having to get on with it, that's made a massive difference, it's made me a lot more confident and less anxious – well I wouldn't say I'm less anxious but just better dealing with it maybe. And I think just having a better ability to know that if things do go wrong that I can deal with it, whereas before I thought the world would end pretty much. Yeah, so that's helped...I don't know that it would ever necessarily happen – but if I got to stage where I didn't get anxious doing things, I would feel like, yes I've achieved it kind of thing. (Lily)

The psychological dimension of transition is clearly as important as the practical one and in many respects interacts contingently. As Lily's comments suggest, her capacity to complete practical tasks such as get a bus or have a conversation with a stranger (which are frequently necessary conditions for successful transition to employment or independent living) are dependent on the psychological resources she has for managing emotions like anxiety. She does not suggest that she has fully made her transition to 'adult-in-control' and signals scepticism that this will ever happen. One might question, however, whether any individual ever feels fully in control of their anxieties, suggesting that this psychological isthmus is more symptomatic of what it means to be human than what it means to be autistic.

Other participants also recognised a similar positive shift in their personal identities, including being 'more self-aware, more mature, a lot more mature'

(Robert) or more 'able to push myself and go further than I have before, to test my boundaries and do things I'm not comfortable with' (John). One participant, Martin, reflected on his identity since completing his education, 'I just feel like I'm a completely different person. If you met me two years ago my confidence wasn't there like it is now and that has developed'. Whilst some participants clearly experienced frustration and anxiety as a response to their imminent or actual circumstances following graduation, almost all related a feeling of improved self-concept and psychological development.

## **Chapter 5**

## Findings: Transition to aspirational destinations

As outlined at the beginning of the previous chapter, I separated the experience of transition into two distinct stages; the first outlined participants' transition *from* higher education and this chapter will outline participants' transition *to* their different aspirational destinations. Treating them separately in this way signals my own theoretical position, based on the participants' accounts, that transition *from* one stage in the life course is qualitatively different to transition *into* another. Disaggregating the participants' experiences in this way, I argue, provides opportunity for more authentic and detailed analysis. This chapter outlines the occupational, relational, and personal aspirations that were considered desirable and how participants conceptualised their transitions to these.

### 5.1 Aspirational destinations

Participants identified a range of future selves that they perceived as possible following higher education. Based on analysis these were grouped into occupational, relational, and personal aspirations.

### 5.2 Occupational aspirations

The theme of occupational aspirations will be discussed first and at length, largely due to the fact that this was identified by all the twenty-one participants as most significant to them. Nineteen identified gaining full-time paid employment as their primary goal following university. They reported aspirations to work in a variety of fields including business, primary education, international development, arts, youth work, finance, retail, design, heritage, and higher education. Three participants aspired to be self-employed writers and/or produce video material for YouTube. However, whilst these are useful for signalling participants' future occupational goals they do not uncover how they conceptualised making the transition to these.

Whilst the participants who had recently graduated generally had more experience of applying for jobs and working, a large number of final year students also had experience of part-time work and had applied for jobs or postgraduate courses and so were also able to reflect on these experiences. Table 5.1 below outlines the four themes based on the experience of transition to occupational aspirations. These include: disheartened by the recruitment process; scepticism and loss of trust in employers; naivety about the job market; and pursuing the dream. Each of these will be outlined in detail before the factors that enabled or prevented successful transition are explored.

Theme	Categories
Disheartened by the process	
	Lack of opportunities
	Job insecurity
	'Always coming up short'
	Out of your control
Scepticism / loss of trust in employers	
	Negative previous experiences
	Expectation / acceptance of discrimination
	Application and interview barriers
	Fear of disclosure
Naivety regarding employment	

	Lack of understanding regarding job
	market
	Unrealistic expectations
	Rigid planning
Pursuing the dream	
	More than a 9 to 5 job
	Individual pathway
	Risk-optimism

Table 5.1 - Transition to occupational aspirations

### 5.2.1 Disheartened by a lack of job opportunities

There are two main categories which inform this overarching theme, a lack of job opportunities and 'always coming up short'. Both relate to the participants' experiences in a precarious and challenging job market often resulting in frustration and despair.

The EU's fucked, I'm fucked, the world's fucked. Help! So much has happened in the last couple of years which has really destabilised my idea about having a stable income, a stable living as a guarantee...I'm a little worried that someone who is autistic and doesn't fit the 'box' will have a harder time getting a commercial job. (Lewis)

Such despair was unfortunately grounded in reality for some of the recent graduates; according to Kieran, 'I think it was about 2000 jobs I applied for before I got my [current] job'. Others also related similar experiences, (Max) states, 'I've worked out that by the time I got my current job I'd fired off over 100 applications and had about 10 or 15 interviews out of those in various places' and Lily concurs, 'I think since I got back I've maybe applied for like seventy...I'm trying to do about five or six applications per day but nothing so far'. It seems unsurprising that with such high levels of activity and low levels of success participants would feel frustrated and demoralised.

Participants also reported that 'the recruitment process itself can be quite degrading' (Grace), particularly with respect to psychometric testing and the interview processes. Often the application form, where the participants could take their time and access support in preparation, was considered manageable; however, where they were required to process information quickly and in real-time, this was much more difficult. Grace relates the specific difficulties with psychometric testing,

I've been invited to go and do the psychometric testing – the maths, English and numeracy – but because I can't process things as well and can't retain as much memory I can't remember half my GCSE maths and I can't do mathematical problems as quick as other people and I just get really confused and blank, I really and can't do them. So I don't get any further in grad jobs really because I don't have the mental capability...

While it is obvious that psychometric testing is designed to be rigorous and challenging, for Grace, the experience left her disheartened and questioning her intellectual capacity. Similarly for others, the interview procedure is recognised as requiring the ability to think quickly and creatively which can be difficult for some autistic graduates. Participants described their experiences of job interviews as 'horrendous' and 'nerve-wracking', especially where it 'takes some time to figure out what they're wanting and I might answer the wrong thing to what they've asked' (Poppy). For some, interviews bring out their 'socially awkward side' evidenced by 'saying or doing wrong stuff' (Winston) or being 'terrible at selling myself' (Robert). It is clear, therefore, that alongside a lack of job opportunities, recruitment processes also create barriers and lead to a sense of frustration.

This emotion is also captured by the category 'always coming up short' as it signals not just the lack of prospects but the particular feeling that opportunities are consistently just beyond one's grasp. This excerpt from the interview with Izzy typifies this emotion quite acutely.

Well I've got eight years' experience under my belt. I'm getting several interviews a year and I'm always coming up short, it's very difficult trying to get a job... I have no idea they always give the same reasons, like the whole experience thing but I know that's a load of bull, because they're just using that as an easy excuse rather than saying 'we don't want you' because when I try to find reason they just say the same thing and whenever they say it's because of the inexperience I know that there's something more behind it but they never reveal what is more. So it's annoying when you're trying to get a job and you know that you're coming up short and that you're doing something wrong but they're not telling you what. I was hoping that one day I would figure it out but to this day I don't know what it is!

For Izzy, as was also the case for other participants, there is a feeling that employers are being disingenuous in their feedback and not sharing the real reasons that she and others are 'coming up short'. Such oblique feedback (for example, suggesting that eight years' experience is not enough) is challenging for participants that often benefit from straightforward answers based on concrete facts and does not offer any insight into how to improve. The result is that autistic participants end up feeling disheartened by the process as they know that there is clearly a barrier to their getting the job they aspire to but have no access to the conditions attached to their lack of success.

Where these three aspects – a lack of opportunities, challenging recruitment processes, and unconstructive feedback – are compounded the outcome for many of the participants was simply to abandon their initial aspirations and

apply for non-graduate temporary jobs. Two participants (one with a degree in mathematics) reported doing 'kitchen portering' at local pubs, others like Izzy were 'earning some money on the side, being a cashier at Kentucky Fried Chicken'. Lily who has a First Class degree from a Russell Group university stated,

...it's quite frustrating as lots of the jobs here are things like waitressing and my coordination is so bad that it would be a disaster – so that's, yeah, it's frustrating.

Two participants were in specialist disability programmes to support them into paid work and one had applied for an entry level administration job with a large national retailer. Various participants like Kieran recalled having to work jobs, 'most of them would be part time and that would be it for a while and then you go back to trying to look for something else' or else jobs that were 'zero contract hour' (Poppy). The ultimate outcome is a sense of feeling 'frustrated with the jobs but... who wouldn't?' (Timothy).

#### 5.2.2 Scepticism and loss of trust

A second theme derived from participants' accounts was scepticism and loss of trust. Lewis reports how he heard 'horror stories about companies who treat autistic people like dirt' and as was alluded to in Izzy's comment above, sometimes interactions with employers appear disingenuous, so it might not be surprising that such experiences might result in a degree of scepticism regarding recruitment activities. For some of the participants, previous negative experiences related to non-autistic-friendly interview processes, difficult interactions with managers, or the suspicion that they had been taken advantage of; these in turn affected their trust in employers and ability to secure a job. In some cases participants were not paid for work that they had completed and in others they faced social and communication difficulties interacting with potential employers or responding to pressures exerted by them. Robert's experience offers insight into this:

I went for the interview and got the job at the interview which is weird – but he didn't give me any time to think about it. In hindsight there was a lot of iffy things – he just sort of said, here's the job, do you want to start tomorrow? And I was like – I didn't know what to do so I just sort of said yeah and emm...and then I mean I came in – it sort of happened so fast that I couldn't think about all the problems, all the potential problems.

Robert recognised, in hindsight, that he felt helpless in the situation and under pressure to agree to join the company even though he had not been given any time to consider the offer. Another participant discussed a similar experience with a 'sales job...the company was very corrupt, unfortunately, and my partner saw through some of the things that were going wrong, so I only stayed there a day'. When pressed in both cases as to what was considered 'iffy' or 'corrupt' in Robert's case it was that he was requested to bring and use his own computer to work; he claims 'I actually think a big reason I got the job is because I had a computer and I had the software already...I probably wouldn't have had if I'd said no to that' and in Kieran's case 'they were asking me to pay for uniform'. Whilst it is not clear whether these are simply standard company policies or not, it is the case that the two participants felt that they were being taken advantage of and the result was a loss of trust in employers.

Part of the participants' scepticism definitely emerges from past negative experiences; however, another part also emerges from fear of how they believe they will be treated. In some cases participants had disclosed their autism diagnosis to their employer (as in Robert's case above) but in others they were so sceptical that they would receive fair treatment or positive reactions that this information was sometimes never shared. Those like Dave were 'concerned whether [employers] would actually take someone who is autistic' and Grace, who was applying for graduate employment programmes concurred,

I've applied for jobs and not disclosed that I'm disabled because if I say I'm disabled they'll think I'm not worthy... well I am worthy but they'll think that I can't do as much because I'm different. A lot of organisations don't like employing disabled people and don't like diversity and it could be a form of discrimination against me – they'd rather go for someone who isn't disabled who has the same qualifications, the same grades...

Furthermore, Alice, who worked as a qualified teacher, sums up her reasons for

not disclosing her diagnosis,

(Alice) I never told any of the people...most of my lecturers didn't know, none of the people on my placements knew, none of the people at my school last year knew.

(JV) And why?

(Alice) Just because, even more so in teaching, because they have been taught that autism is this... you say autism and they are immediately going to think she can't communicate properly and see that and especially by the time I got 3rd year I was like 'I can communicate just as well as anyone else, I can do better than a lot of people on my course, I'm not having your perception of autism hold me back.'

It is clear from these examples that participants were fearful that disclosure would lead to workplace discrimination and othering attitudes from potential employers and co-workers. Their perceptions indicate the damaging effect of deficit discourses of autism prevalent in society that focus on autistic people's difficulties rather than potential strengths. Moreover, Grace's use of the term 'worthy' points, at one level, to the social value that is placed on the ability to communicate and interact according to neurotypical norms but at a more profound level about her sense of self-worth which is contingent on how others, but particularly employers, perceive her.

#### 5.2.3 Naivety regarding employment activities

The third theme in this section, naivety regarding employment, has some crossovers with issues regarding disclosure. Naivety here might be considered as an under-appreciation of the 'rules of the game' when it comes to employment; for example, the behaviours, skills and traits that many employers view as significant when recruiting, how a particular profession is situated in its sector, and what knowledge that is advantageous to demonstrate. Some of these may be particularly challenging for autistic graduates, particularly where they rely on reading non-verbal cues or decoding complex social situations. With respect to how disclosure of a diagnosis might be perceived, the previous section demonstrated that many were sceptical and expected a negative response from employers; however this was not the case for all. Izzy relates her experience of disclosure in a very different – and perhaps naïve – way when she explains,

I don't really see how something like [having autism] can make a difference whether you get a job or not, it's discrimination otherwise. I don't personally, I really don't see how a differently wired brain can make any difference...

there is this little section dedicated to disability, whether its physical or mental and I always tick the learning difficulties one and at one point mum and dad considered that that was the reason I was being turned down and they said 'maybe you should say that you don't have a disability' and as soon as they said that I immediately said 'absolutely not!...

Withholding information is the same as hiding things and when you hide the truth. If you withhold information you are hiding something. Personally I don't see the difference that's why I'm always honest when I tell people that I'm autistic. For Izzy, she did not see how being autistic could 'make any difference' which was markedly different from others' position and could reflect naivety about employers' attitudes in a fast-moving, neurotypical job market. While her parents perceived her honesty in this matter as a barrier to her success and encouraged economy with the truth, she rejected such an approach and felt strongly that her diagnosis was not something to be ashamed of or kept hidden. For Izzy, disclosing her diagnosis to employers was as much about her honouring their 'right to the truth' as their honouring her 'right to work'. From a clinical position, Izzy's actions might be viewed as evidence of deficits in social communication and a lack of sophisticated understanding of the subtleties involved in applying for jobs; but when perceived from an autistic (or, perhaps, more ethical) perspective, her naïve honesty could be viewed as a potential strength and a virtue much more admirable than actively misleading an employer.

Further evidence of naivety relates to how participants positioned themselves within the job sector. Whilst some expressed a clear grasp of how they might make the transition to employment and the necessary steps required to achieve it, others expressed less sophisticated strategies. The extract below from the interview with Timothy, who had graduated with a mathematics degree and wanted to complete the Association of Accounting Technician qualification to work in accountancy, offers insight into the possible mismatch between occupational aspirations and the level of understanding required for these to be actualised.

(JV) So what does AAT stand for? I've not heard of it.

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(Timothy) I don't know what it stands for but...there are different levels. Actually I did write it down but I forgot what it was. (IV) And what is involved in it? (Timothy) I think it's just in a year but you've got different levels, so I think it was level 2 you needed. (JV) And where can you do that AAT qualification? (Timothy) I know you can do it in [the city] but there are a lot of places you can do it. I think it costs about £200 but that may not be right. But to do it at university would be £1000. (IV) But you've decided that you want to be an accountant – is there any particular area of accountancy that you would like to work in? (Timothy) I'm not sure about that. There are a couple of businesses that do accountancy that I've looked at. (JV) Have you got any work experience in accountancy firms? (Timothy) No no. (JV) Is that something that you would like to do? (Timothy) I could do yes. I have done work experience in a data company but that's when I was about 15.

(JV) And what about since graduating, have you got any work experience? (Timothy) No.

In this case Timothy indicates his aspiration to work in accountancy yet he does

not seem to fully understand what is involved in this or have developed any clear

plans about how to go about realising it. Similarly Matthew indicated a level of

naivety with respect to the steps he would have to take following his degree.

When asked about whether he had any thoughts about what sorts of jobs he

would be interested in pursuing following graduation, he stated,

(Matthew) Not really. I'd have to go to speak to the careers service first...I'd have potential to get a correctly qualified job and stuff like that.

(JV) What sort of thing would be a qualified job?

(Matthew) I don't really know.

[...]

(JV) You mentioned that you would like a 'fairly successful job' what sort of thing might that be?

(Matthew) I'll have to think about that...I'm not sure I'll have to speak to careers...actually a PhD is another possibility that I might do.

(JV) What sort of thing do you think you would study if you did a PhD?

(Matthew) Em.... Em... probably... uh... maybe something different...I don't know.

Although based on their qualifications, both participants have the requisite academic capacity to be successful in a variety of fields; however, their naïve grasp of the job market is likely to be problematic when faced with an interview panel that demands a sophisticated understanding of the sector.

#### 5.2.4 Pursuing the dream

Whilst most of the participants did aspire to gaining full-time paid employment a number eschewed this structured linear pattern in favour of a more unconventional trajectory. Alice reported leaving her job as a qualified primary school teacher to pursue a career in an arts-based business, despite her parents' attempts to dissuade her and Dave, Arthur, Lewis and Tom each described a desire to be self-employed and write for a living.

I just thought after a few months of thinking in the summer I decided to actually try to be a writer and that was around August time... So that's a bit of a job I put on myself – I'm not getting anything out of it at the minute but we'll see. (Dave)

I got an email from my writer friend, because I'd sent him the first half of my book and the only thing he said was 'this is good keep going', that was it, that was all I needed hear. I needed write when he told me that, so from that point on I decided, well I'll be a novelist, that's what I want to aim for, to be a novelist. (Lewis)

There are two things that I wanted to do and I'm working on both of them. So first is being an author and the other is a YouTuber, yes professional YouTuber...(Tom)

All of these participants sought to engage in occupational activity that is somewhat precarious and relies on the practical and financial support of others, particularly parents, to actualise. Given the lack of stability and the fact that financial return is something that is only predicted for the future, rather than realised in the present, I understand this to be a 'valued occupation', rather than employment. However, it is unlikely that the participants would not see it this way. When asked how confident he was about the possibility of making a living from being a writer and YouTuber, Tom responded: 'I'm rather confident, I'd say 80%', suggesting that for him this aspiration is employment rather than simply a valued occupation. Quite contrastingly, both Arthur and Lewis were more realistic about the difficulty in being financially successful as a writer. The latter indicated that his 'dream job' on leaving university would be working in a bookshop, writing alongside this and slowly building up a reputation in the 'writing scene'. When pressed about his long-term aspirations he stated that contract writing would be the ideal but it did not necessarily have to be this – 'if it ends up being something else, so be it.'

Interestingly, many of the participants in my sample reported writing as a significant aspiration in life although for most this creative activity was viewed within their wider life course and regulated in relation to their other aspirations.

Writing is just something I see as a pastime for fun, it's not something I see myself as making a permanent career out of it. Like a couple of times my mum has dropped that suggestion but the way I see it, being a writer is a bit of a hit and miss thing... (Izzy)

Whether writing is viewed as either a full-time employment aspiration or a valued pastime, what is clear, is that there exists for many a strong desire to communicate with others and express a particular worldview in a creative way that others can understand and engage with. Lewis explains, 'the writing is necessary...the writing is something that I cannot do without and if I wasn't able to write and express myself the negative emotions that would stew in that space would be incredibly damaging'.

Another occupational aspiration that accords with pursuing the dream is further study. Five participants had already completed further postgraduate study and a further eleven identified it as a future aspiration. Many desired to continue their education at Masters or doctoral level based around their specialist areas of interest. For Theo it was to improve his job prospects but as Arthur suggests, postgraduate education was desirable because the environment and demands are known and can allow for greater levels of 'individual flexibility'.

I like learning; I also like not having to worry about a lot of things that happen outside of the education system. I mean there is a lot of support in education, a lot of things that I would lose access to if I was outside of it like mentoring and things like that... (Arthur)

However, it could also be the case that such an aspiration might simply be a means of delaying longer-term decisions regarding employment. Lily suggests this when she states,

I just couldn't see anything after finishing, whereas now I feel that after I finish my Masters something will come up as it has this time round.

By remaining in higher education this provides her with at least one more year of security and additional time to reflect before she engages in the transition proper to whatever might be next. Postgraduate study thus appears to offer a dual opportunity: to continue with studying an area of particular interest whilst staying within the secure bounds of what is known to the students.

#### 5.3 Relational and personal aspirations

The final set of aspirations identified in participants' accounts related to future relationships and personal goals as outlined by Table 5.2 below.

Theme	Categories
Relational	
	Having / developing romantic relationship
	Having family of my own
	Having / developing friendships
	Maintaining relationship with parents / family
Personal	
	Living independently
	Be able to travel
	Being financially stable
	Being healthy
	'Normality'

Table 5.2: Transition to relational and personal aspirations

By contrast to other topics, discussion and reflection on these aspirations was much more limited. Whilst having and maintaining romantic and family relationships was clearly important to many of the participants, it was frequently positioned as secondary to the immediate concerns of employment and living independently. When asked about these sorts of aspirations, Theo responded,

I've never really thought about friends, family or relationships since moving up here since it's always been focused on the work really.

That relational and personal aspirations did not register as a high priority might, for some, verify clinical descriptions of this population as lacking in emotional capacities. However, another interpretation might simply be that this sort of abstract personal reflection is simply less accessible in terms of the imaginative thinking spontaneously required of in an interview. Moreover, it seems likely that there is also a connection here between the shift in identify status from child / adolescent under the care and control of family to independent emerging adult (section 4.4) where participants desired to explore this life stage of their own 134

accord and thus distance themselves somewhat from their families. Some aspects of this complex relational balance are also explored more comprehensively in section 6.1 on parental involvement.

#### 5.3.1 Romantic relationships

Seven out of the 21 participants interviewed were in long-term romantic relationships and identified this aspect of their life as meaningful; of the others many reported that 'to be able to fall in love with someone', 'be in a stable relationship' or 'see whether I can make a relationship work' was something that they would want for the future. Matthew stated that having a girlfriend was his primary aspiration following university; however, he was also unsure about what exactly might be good about being in a relationship or how he would go about realising this in practice. For Arthur, almost all of his postgraduate aspirations hinged entirely on being able to live independently with his girlfriend:

My relationship has been very good for me. It's grounded me; it's given me a good sort of home support; it's helped me deal with my mental health issues; and it's also sort of given me a place away from home that I sort of feel is home and I'm quite comfortable.

It is clear here that he sees his romantic relationship and its development after university as central to his personal, social, and emotional flourishing thereafter. Some reported their desire for this but current lack of success: 'A relationship, yes because I've never been in one, I've never had a girlfriend. I fancy people but never had anyone fancy me back' (Winston). Conversely, others specifically reported that romantic relationships were not a priority for them: The relationship thing...if it happens it happens I'm not really bothered... I think I maybe wanted at one point but I think that's because I thought I needed to want it. (Eliza) I don't actually see myself actually having a relationship (Theo) if I'm able to maintain a full-time job that's got the same kind of salary as everyone else, enough to live on your own and such, maybe I would consider jumping into the dating pool but right now having a boyfriend is the last thing on my mind... It's just something I don't even think about. (Grace)

These statements indicate the dynamic decision-making process involved where individuals negotiate their personal and relational aspirations with respect to wider societal pressures and expectations.

### 5.3.2 Family relationships and friendships

Another relational aspiration for the participants was maintaining relationships, particularly with family and parents following the transition from university. Family were identified by some as being part of an emotional and practical 'support network' to assist with coping with adult life. Moreover, many other aspirations, such as independence, travel, financial security were dependent on these relationships and most participants sought to sustain these into the future. However, for others family relationships were recognised as being more challenging, particularly where parents were considered interfering or did not understand them. Eliza's excerpt relates the struggle that some experience and the reactions that this might generate,

I mean there are things like issues with my mum but I do still love them and it's not like the moment I get independence I'm never going to see them again. So unless something really bad happens I don't think I'll be... I have no intention of severing all ties with the craziness that is my family. (Eliza)

By contrast to the sometimes complicated dynamic experienced in the family 136

setup evidenced by Eliza, many participants recognised the important role that having friends played throughout their time at university and aspired to maintain these relationships beyond the course. Lewis, Arthur, Max, and Winston all signalled a strong desire to 'keep in touch' with others but identified the difficulties that can come with this when people 'drift away' to home or other parts of the country. This aspiration is tied into the sense of transition as loss (section 4.3) as often participants had a sense that whilst they wanted to continue meaningful and positive friendships they did not feel that it would be possible given the practical, social and communicative demands.

#### **5.3.3 Being independent**

The loss of independence has already been identified within the transition *from* higher education as a challenging aspect of emerging adulthood (section 4.3), so it is not surprising that gaining independence was a prominent future goal for many of the participants. Having a 'place of my own' was important for many. Alongside this practical competences like being 'able to maintain our own house, know how to pay bills, keep up mortgages' were recognised as significant markers of independence and identified as the potential catalyst for the actualisation of other aspirations.

...in an ideal perfect world I'd have my own place... I mean it's great that I don't have to manage the house or anything but I think...as scary as it would be to live on my own and have to do all that management I think it's better for me to live on my own. Because it will force me to be more social, it'll force me to do more adventurous things. (Robert)

Matthew, who lives at home, particularly wanted to gain independence in terms of simple tasks like cooking for himself and managing his own money. For him 137 this aspiration was related to being 'less worried about needing a carer' when he is older and his parents are unable to support him as much. This was also reflected in Adam's account who believed that being self-sufficient was important as his parents 'aren't going to be around forever'.

Whilst gaining independence was considered a 'challenge' and 'scary' for some, for others it was something they felt prepared for and relished its reification. For some, like Arthur, the aspiration to live independently of his parents was so strong that he discussed gaining any reasonable form of employment after graduation and much of his anxiety regarding the next months seemed to stem from not achieving this. Again, given the limited data generated around this issue, it seems to be the case that some participants struggled to imagine what living entirely independently might be like and so descriptions were often brief and functional.

#### 5.3.4 Being 'normal'

Interestingly Adam's discussion of independence spilled over into the next category. Being independent was a matter of rejecting the 'traditional, stereotypical autist who lives with their parents all their life and their parents have to do everything for them'; by contrast he and others, like Izzy, wanted 'essentially just the normal things, just a normal life really'. This longer excerpt from Izzy's interview captures the essence of this aspiration:

I guess what I would want life to be if I can put it bluntly is: as close to 'normal' as possible...We want something... or at least I want something and I like to think that people in general on the spectrum think that too, we want something that's as close to the social norm as possible. So we

want the same things that everyone else wants in life, we want to be able to maintain our own house, know how to pay bills, keep up mortgages, we want to be able to fall in love with someone that we want to spend the rest of our lives with, we want to kids, maybe get a pet dog or cat, we want to be able to go out and about and have fun with people, or even go out and have parties in such, go to christenings, have grandchildren, we want to do the same thing as everyone else – to live a life, it may not be a great one or it may be, it may have things which make people consider us weird or sometimes we do things we can't control or that they don't understand because there's always going to be people who don't understand no matter how hard they try, even I don't understand autism and I've got it! But what we want in life is something that's as close as possible to what everyone else has, something that people like you take for granted, we want to be able to maintain relationships, raise a family!

Interestingly, Izzy identifies that the personal aspiration to have a life 'as close to 'normal' as possible' is recognised as something that other participants on the spectrum may also want but feel unable or unwilling to voice. However, what is powerful about her comment is the deconstruction of 'autistic' aspirations as distinct from neurotypical aspirations; they are, for her, the same as anyone else's and quite simply, 'to live a life'. Lewis also discusses a desire to have 'control of my mind' in which he explains that he would like to be able to manage his emotions and reactions to stress; quite simply, he states 'I would like to feel peaceful one day'.

## **Chapter 6**

# **Findings: Enabling resources and capacities**

It has so far been established that emerging adults on the autism spectrum in this study had varying experiences in making the transition *from* higher education and *to* different occupational, personal and relational aspirations. Participants' accounts identified various proximal and distal resources and capacities which affected how successfully they were able to manage these transitions and actualise (or begin to actualise) their aspirations. There were four resources in particular that impacted, both positively and negatively, on the success of transition for the participants; these included parental involvement, autistic characteristics, institutional support, and external social support. These reflect how transition is not a phenomenon that takes place in a vacuum but is always in relation to other people, institutions, or wider social structures. Each factor will be outlined in turn to uncover the extent to which it could be considered an enabling and/or disabling mechanism leading to different outcomes for this group.

### 6.1 Parental involvement

One's family can often be a significant source of practical and emotional support throughout any point in life but can be a particularly useful resource when engaging in significant life course transitions. Participants identified parents, as providing both practical assistance and emotional support as they made the transition from higher education and towards their aspirations. My mum is very good at going 'have you done this? Have you done that?' sort of thing... so the things that I wouldn't even have thought about, she will or go 'you need to look at this'. (Lily)

I talk to me mum about lots of things, a lot of things like university-wise and obviously what I want to do. (Theo)

...my mum and dad were accustomed to helping me with upcoming changes, they planned in advance and helped me ... just sort of organising things so that it was less of a hassle and I didn't get stressed about it. (Izzy)

Family, family for that one, So I ended up... I had to do that nervous thing of making phonecalls, I had to like arrange to meet them. (Winston)

I think it's more about just knowing that the support systems are there if I need them and not feeling like oh no I need to do it on my own because I'm an adult and I need to do adult things – but actually know that not everybody does know what they're doing. (Eliza)

From each of these excerpts organising oneself, interacting with strangers, and managing change are all issues that participants identified as challenging for them in making their respective transitions. Many of these were identified in the Literature Review as some of the core characteristics of the autism spectrum and, as a lifelong condition, persist into adulthood. In each case parents are recognised as an important resource for providing hands-on support in helping to plan, structure and explore options for the future.

With respect to participants' transition to their adult aspirations, and particularly gaining employment, parents were again viewed as a useful source of practical assistance in the process,

[Mum] would often look on the websites and send me them quite often, different types of jobs that were quite varied. (Poppy)

For some participants, their parents were also able to provide contacts or insider information from within their own workplace for their children which enabled them to successfully gain employment.

It came about because my mum and dad work in the office where it was advertised. They found out about it and managed to get hold of a copy of the application for me. (Max)

Moreover, participants frequently recognised their parents' ongoing involvement and practical support as necessary for actualising some of their other capacities and aspirations; for example, living independently or being financially stable were particularly contingent on their parents' ongoing support and assistance.

Alongside practical support, parents also provided much-needed emotional and psychological support. Most participants felt assured that their 'family is always there to support me' (Winston); such confidence is indicative of the safety-net that the parental role provides once the 'structure' of education has been removed. Parents were also identified as a useful sounding board and 'willing to talk' about emotional issues experienced throughout the transitional process. In making the transition to their aspirations, many parents actively encouraged their children to seek paid employment but were also supportive of more unconventional routes and valued occupations. For example, in the cases of Dave, Lewis, and Tom who each aimed at becoming authors, their parents played a significant role in enabling them to realise this aspiration, as Tom's comment reveals,

My mum is very supportive of my being an author; she thinks I'm quite good since I gave her stuff that I wrote... So she is supportive of me being an author although she is not as supportive about me being a YouTuber because she doesn't know if I'm good enough to do so, so what she has said is that she wants me to show her the videos before I put them online just so then she could see if I'm actually good at it or not.

This excerpt offers insight into the positive psychological impact that this maternal relationship has for validating Tom's aspirations to become a novelist and online video producer. Interestingly, her support is conditional on her assurance that it is of a quality that she believes could lead to success. However, crucially her request to see his videos before he publishes them to YouTube might also indicate her parental desire to safeguard him from vulnerability among an anonymous online community and signals an infantilising view of Tom who is in need of protection. Likewise for Dave, he suggested that his parents 'know writing is what I want to do but it's just they do worry about the financial needs' which is consistent with the complex inter-relationship between practical and emotional support derived from parents.

However, parental support did not always generate positive relationships. Just as many participants were attempting to make sense, practically and psychologically, of what the transition to adulthood means so too were their parents it seems. This at times led to tension and even the threat of long-term separation. The following excerpts from Tom and Ezra, both of whom had studied at post-graduate level, offer insight into the breakdown of family relationships amidst this transitional period.

[My dad] was saying that I lack perspective and I can't see things from other people's perspectives, so I was thinking no that is him; he complains that I talk about videogames, anime or manga but he drones on and on about sport and if you point that out he just throws a tantrum; he was saying all of these things like 'I'm not good at communicating' which I wouldn't say I'm the best but I don't only talk to people through barking orders. He is a hypocrite where everyone has to do things by his rules but they don't apply to him...It is slowly escalated throughout my life because when I was younger I just sort of did what he said when he barks orders because I was a child sort of thing but where I have grown older sort of things I have got disillusioned about the way that he acts and if he does something stupid I'm going to call him out on it. (Tom)

Living with my family is less enjoyable...because their requests for favours regularly interrupt my work and other routines in unscheduled ways, and I find my parents' judgmental reaction to my eating habits overbearing, especially given that they supply me with my meals and then complain they are obesogenic. I have privately considered breaking off ties from them once I have completed moving my possessions into a longterm home. (Ezra)

In both cases the participants find that their parents are judgmental and undermining of them as individuals, resulting in fractious relationships. In the case of Tom, he specifically positions himself as an adult by contradistinction to 'when I was younger' and relates how this shift in identity has increased his level of agency within the family; however, at the same time it has increased tensions with his father who continues to treat him as a child. Whilst Tom is still prepared to live at home, largely due to the positive relationship he has with his mother and the fact that he is financially dependent on his parents, Ezra suggests that he may disassociate himself from his parents altogether. These relational tensions have obvious implications for future aspirations and reflect the difficulties in establishing adult identities in the family context.

Moreover, for some their diagnosis and their parents' relationship to it is a specific issue. Martin and Eliza both relate their experience of parents who struggled to make the conceptual transition in their own minds from their identity as an autistic child to that of an autistic adult.

My mum couldn't move on from how I used to be and I was still seen as 'Martin is autistic, this, this and this'... she would say 'oh yeah he's still like

this' and that person would view me as still being autistic or doing something when I hadn't. (Martin)

My mum's like she's read all the books and because she's read all the books about types of autism she thinks she's kind of got it and maybe she has but she hasn't got mine – the way it affects everyone is different...I think my mum...[inaudible]... my dad was like, okay you have a thing, if you've got any questions or you need a hug just find me I'm fine with it and I know that you need it. My mum has been much more like you have it, now let's move on and it's like 'nope, that's not how it works'. (Eliza)

Both participants suggest that there is a lack of parental understanding which has a negative impact on transition. For Eliza, who only received her autism diagnosis at age 16, she felt that her mother had pathologised her but not understood her fully as an individual and expressed an emotional distance that has developed between them by comparison to the relationship she has with her father. For Martin, his diagnosis was an ongoing source of tension within his relationship with his mother, particularly where he felt that many of the diagnostic criteria were no longer relevant to his experience as an emerging adult.

#### 6.2 Institutional support

Participants noted the positive role that institutions could play in supporting them make the practical transition from higher education and into occupational aspirations. Both Lewis and Adam recognised that the sort of support that was available for the transition *into* university – a structured induction programme, peer support, and guidance from the learning support team – would also be useful for the transition *from* university. Lewis, in particular, believes that he will need support to help him learn a new set of skills that will enable him in the

'daily and yearly motions of what's involved in living in society'; this might involve having support that extends beyond the end of the degree programme and into his emerging independent adulthood. Various aspects of life were identified as requiring ongoing additional support: maintaining social relationships, applying for jobs, accessing funding, and managing money.

The Careers service and Disability Support Services within universities were both highlighted as useful, particularly where they were able to offer guidance that extended the participants' understanding of the job sector or as Max put it, helped him see 'that I could go into all of these different things'. For both Robert and Arthur, the Careers service actually provided internships through which they were able to 'understand how to work in the real world cause I'd never done that before and what I'm actually capable of and what I'm not' (Robert). Many of the participants also had mentors with whom they were able to discuss plans following graduation; for Grace their role offered psychological reassurance, 'a kind of hope from other people'. Moreover, where Careers service and Disability Support Services collaborated in providing autism-specific preemployment provision, this was recognised as being particularly useful; six participants from the twenty-one made use of this sort of university-level provision.

I was on the [employment course at the university for students on the autism spectrum], so that was really helpful just for things like building up a CV and that kind of thing which I hadn't really put much thought into either and then I did speak to Careers and they gave me a mentor as they have a scheme where they have people who have already graduated who can mentor you, so I got so me somebody who worked for the UN so that was very much helpful (Lily).

Finally, participants also recognised the role that academic staff can play in identifying and negotiating future steps. Eliza, Lewis and Poppy all drew on the support of their course lecturers to provide additional guidance and assurance that 'she would help me if I needed any references or where to look when it came to jobs' (Poppy).

However, alongside these positive accounts of institutional support that enabled participants' successful transition, there were also instances were provision and guidance was lacking. Participants' described how Careers professionals did not always understand the particular needs that they had as autistic students and made an assumption that the same information or approach provided for neurotypical students would also be suitable for them. For Lily, she felt that Careers staff assumed, 'well you've got good grades, you've got work experience so you're employable' which I thought 'yes I'm employable but I don't know how to get a job'. Even when she was provided with specific support she felt that they bypassed some of the more basic information like 'this is where you should be looking for jobs or these are the kinds of jobs you should be looking for at this stage'. Poppy had a similar experience towards the end of her degree, where Careers staff 'basically gave me a long list of websites that I could look at but not tell me what kinds of jobs I might be suitable for or how to apply for them'. Finally, Robert suggests that had Careers staff been more aware of his needs, the transition process could have been more successful,

...if I'd had a plan coming in and coming out cause then they could have said, well 'you should apply for this job even before you leave university' then maybe I could have developed it and hopped into another job from there – that could have happened but that didn't happen for me. Likewise Theo suggested that Careers services must understand that 'if you have Asperger's you're not like everyone else, you can't just go and get a job wherever, you'd have to have a lot of help.' Such experiences indicate the important role that Careers and Disability Services at universities can play in enabling successful transition but also suggest that where there is a lack of understanding about autism and appropriate training this can in fact be a barrier for many autistic students.

### 6.3 Autistic characteristics

Participants viewed their autism diagnosis and certain personality traits as both enabling and disabling with respect to making the transition from higher education and into the next stage of life. Just as the neurodiversity model established in Chapter 2 suggests, the condition can be understood in terms of real embodied difficulties but also strengths and specific capacities. It is this latter category that I begin with in outlining how participants perceived their diagnoses as offering something additional for their participation in employment and adult life.

Participants' strengths can be subdivided into functional and affective capacities. In terms of functional or practical aptitudes participants recognised in themselves dedication, 'attention to detail' and the 'ability to stick at a project'. In particular having a 'strong working memory' was considered important for success in employment, specifically where routine activities were part of the job. Just as with the difficulties that autistic people can face, strengths are also contextual and Alice makes a strong point when she suggests,

I've got a really good memory but in teaching it doesn't matter if you know all the kids' birthdays or can recite the register...but where I am now it's really useful.

For her, being in a work environment that maximises her capabilities is important for developing a more positive self-concept and validating her differences. Others identified being organised as a particular strength and felt capable of managing their time effectively, and juggling multiple tasks 'in a kind of orderly calm fashion'. Grace, a final year business student, also indicated her capacity to be organised,

Well people with AS are very organised, with excessive worrying they often get things done. Cause I'm always thinking about work, I'm always thinking I've got to do this tomorrow and thinking about what needs to be done, because I'm generally a perfectionist it means that it has to be great, it has to be on point.

Clearly being organised and desiring perfection are skills that any employer would find beneficial and would potentially make working life a success. However, Grace's comment also provides insight into how these skills have been nurtured and are used as a coping mechanism to alleviate her anxiety about making mistakes or being perceived by others as inadequate.

The affective capacities that are beneficial for making the transition into employment were honesty, empathy and resilience. As Izzy put it, 'honesty is who we are...if I know something about being autistic it's that we can't tell a lie to save our own lives'. Whilst honesty was tied earlier in the chapter to the potential for naivety, it might also be considered a strength in the workplace where employees can be trusted implicitly. Another affective capacity that autistic participants related was empathy.

Most of the jobs that I've been applying for have been working with people with special needs themselves so I could probably empathise more than most people who have just learned about it from a book and I think they quite like that and the people that I have been working with have quite liked, feel more comfortable, with that. (Poppy)

I think maybe if I encounter another child who has a similar sort of difficulty then I will be able to empathise with them and talk with to them about it if they need to. (John)

I am quite good at working with younger people and that is something that I have done a lot of in my life...my dad ran and I worked with him on a programme for children with siblings who were very, very ill indeed in a hospice group, potentially terminally ill or always in and out of hospital. (Arthur)

Ironically, lack of empathy is one of the deficits that clinicians have long identified as a marker of autism spectrum conditions; however, in this case the three participants recognise their capacity to put themselves in another person's position and intuit what might be challenging, problematic, or difficult and seek to find a solution for them.

The final affective strength that enabled participants' successful transition was positive psychological thinking and personal resilience in difficult circumstances. Like many others, Lily related how transitions often made her feel very anxious but rather than ceding to her emotion urge to withdraw she faced them head on by engaging in 'extreme transitions' like living for extended periods of time in Africa and North America:

I do find it stressful but I kind of find it easier if I do it in extremes – if I know that I'm going to have to move anyway I might as well do it as thoroughly as I can; that's how I feel about it cause it's not going to change the level of stress and actually I find the more extreme...was actually easier

because you're not expected to know how things work, so there's actually more help. So sometimes that's easier.

For Lily, extreme transitions, where the whole culture is new, are actually considered easier because the expectations that one would know how to act, what to say, where to go etc. are lower and therefore the autistic social and communication differences are less prominent. Enacting what would be a significant transition for anyone but particularly for an individual on the autism spectrum, she represents a great deal of positive psychological thinking and personal resilience. Others also recognised the benefit of counselling, keeping diaries, and adopting positive mindsets. Lewis, Dave and Robert in particular all noted how 'dealing with intrusive thoughts' (Lewis) and becoming more reflective and learning 'to be better to yourself, not beat yourself up about a lot of stuff' (Dave) was an important personal resource. Such positive psychology enabled them to 'push through' particularly where they had been unable to gain employment and felt disheartened by how life had so far unfolded.

Whilst participants did recognise various strengths as part of their autism diagnosis, there were also difficulties which they identified specifically with respect to the transition to their occupational aspirations. Four main themes emerged from across the accounts: social interactions, sensory environments, need for routine, and stress. Each of the four themes can be taken as independent factors; however, it is more likely that these are inter-related, particularly where difficult social interactions and overwhelming sensory environments generate heightened levels of stress and thus the need for routines to manage the experience. It is clear that where these challenges were compounded,

particularly with the transition to employment in terms of recruitment activities, working environments, and unpredictable social interactions, this was recognised as being much more difficult.

Analysis of the participants' accounts identified two challenges associated with social interactions in the workplace. The first relates to the difficulties autistic students and graduates had in decoding social etiquette and interactions; this had obvious implications for being successful at interview, as was established to some extent in the first theme in this chapter (5.3.1), but also for being successful in a particular sector where significant social demands are made of employees. Given the reliance on social interactions in the recruitment process, some participants felt particularly disadvantaged by their diagnosis. Robert described it as 'a "Catch 22" situation' where 'I find it so difficult to do things that other people do like interviews and socialising' and so was unable to find employment and thus unlock other positive aspects of life that he desired, like living independently. For another graduate participant, Ezra, his preferred employment trajectory had to be adjusted on the basis of the high social demands of working in academia,

I planned to stay in an academic study of physics. However, during my time as a PhD student I found academia made demands that I found unfeasible or uncomfortable. These included succinct exposition requirements in papers and conferences, the social etiquette of an academic department, and "networking" at conferences in the hopes of finding a postdoctoral supervisor.

For Ezra, who had a first degree from Oxbridge and a PhD from a Russell Group University, the actual 'work' of being a physicist was not the difficulty; rather it was the informal and extempore social interactions that form such an important 152 additional dimension that caused him distress. Other graduate participants also resisted 'social situations that I don't feel comfortable in' (Winston) and were thus also limited in their employment options.

Another element of social interactions is the requirement to engage in practical social activities, for example making phone-calls, answering emails, and making friends in the workplace. Tom noted his particular issue with responding to emails:

I sort of have a similar problem with emails because when I'm writing an email I think what is the best response, so then I keep on writing it, editing it, editing it, and so after a month has passed the person is no longer expecting email at this point so I just delete the email.

In this case Tom is paralysed to an extent by the expectation on him to respond in a socially appropriate way and the result is his eventual abdication from the process. This provides an interesting counter-factual to the perception an employer may have of his being rude, anti-social or unable to communicate; as in fact he has taken much time in writing, thinking and editing the email but in the elapsed period it has lost its relevance. Similarly, other participants discussed their feelings about making phone-calls,

No I hate making phone-calls. It's just the nerves of talking to someone not being able to see them in person. I find it easier being able to type to somebody because you can think about what you're going to say whereas if you said it you said in a phone call – and not being able to see their face. Yes I hate it, I hate making phone calls. (Winston)

For Winston social interactions are difficult enough when he can see an individual and attempt to decode the non-verbal messages involved but with a phone-call this is almost impossible and thus heightens his anxiety. It is clear, again, how specific challenges like this might have implications for successful employment, especially where industries rely heavily on telecommunication. The final aspect of social interactions that participants reported was developing positive workplace relationships. Some felt 'unsure how I will make friends in the workplace', particularly where they felt overwhelmed by the social demands involved and the change in dynamics experienced at university. The outcome was often to simply withdraw; Lewis relates,

'sometimes I become so emotionally distraught that I lose the ability to speak...it's like a clogged pipeline; people keep asking questions and trying to get information out of me and the more that is asked the less easy it is – it's sort of like a hole closes until its nothing and I am completely shut out from the world'.

Similarly, Alice recalls 'I did not speak the entire summer'; in both cases, such communicative challenges have obvious implications for successful transition to and within the workplace and serve to socially isolate participants.

The second difficulty identified in participants' accounts related specifically to their diagnosis is experiencing overwhelming sensory environments. Izzy, Adam and Eliza all discussed experiencing sensory overloads, where they process sight, sound, touch, etc. in a way that impacts on their employment. For some information from just one sense was processed all at once which made it difficult to register and decode others' speech; Izzy relates how 'I hear everything at once and then I don't really hear one of my co-workers talking to me'. Whilst this sensory disconnect might be perceived as a 'quirk' by colleagues and easily laughed off, it could also be extremely distressing for the individual, which is more often the case when this develops into a sensory overload. Adam reported how when stress, anxiety and pressure build he is at risk of a 'meltdown' which he described as 'explosive; it's nought to rage in like less than thirty seconds – kabumph! It's like a nuclear bomb going off...screaming, shouting, running around rampaging, bang my head off brick walls, hitting myself...just basically a complete overload of emotion'. Eliza also provides an insightful example of how she experienced a sensory overload whilst working part-time for a large retailer.

Yeah my mood will change dramatically in the space of about a minute. I noticed it - because sometimes you don't always notice it but you feel the physical evidence of it... I just felt this wave of absolute rage coming over me and was like oh dear this isn't good. It's weird because you're kind of partially conscious of what happening because at that point I was like 'shit I'm going to have a meltdown and it's going to be on the shop-floor, great... I just literally walked past my colleague and said 'I'm having a meltdown I'll be out in the back, tell the manager'. Because I had like a mini one which didn't involve any emotion but just like crying and a kind of managed to bottle it back up. I was stressed about having it at work and being embarrassed because even though I shouldn't be embarrassed about it the people there don't necessarily understand and so I didn't want to have that as well as everything else. So I went into the back had the mini meltdown, dried my tears and then went back onto the shopfloor, my eyes were a bit puffy but I managed to disguise it and managed to do the rest of my shift...It's sensory thing in the way that I get a pounding headache but that doesn't tend to happen until after the big emotional blowout so like I have this huge fit of rage that is followed by absolute exhaustion.

Eliza's experience provides a vivid description of the psychological, physical, and social distress that high levels of sensory arousal can generate and whilst her manager was aware of her condition and very supportive, other employers might not be so understanding.

The final two autism-specific difficulties that participants identified with the transition to employment relate to stress and routine. Some described employment experiences as 'really stressful' where 'pressure' from managers

and workload meant that they lacked confidence in 'coping with all the demands and stuff' of a workplace. A number of participants also acknowledged their difficulties with transition and the desire for routine. According to Kieran, 'my boss says that I'm not very good at accepting change' and Alice reported 'I took a long time settling in...I was really emotional when I first started just about everything because it was such a big change'; for both the practical element of being in a new environment with new people and new social expectations was very challenging and the outcome was to establish specific routines to manage this: 'I need to see students at specific times, have lunch at specific times, use the bathroom at specific times' (Kieran).

However, when viewed from a neurodiversity perspective, such autistic differences may be understood in terms of context rather than deficits. Where the social demands are high and unpredictable and the sensory environment makes processing and decoding these interactions more challenging, it is not surprising that emerging adults on the autism spectrum may find this environment very stressful and desire highly regulated routines where they can control and manage the situation. Unfortunately for these same individuals, employers might perceive these differences and adjustments as rude, isolationist or inefficient and thus negatively impact on their transition to and success within particular occupations, which feeds back into the 'horror stories where employers treat autistic people like dirt' earlier expressed by Lewis.

## 6.4 External support, adjustments, and opportunities

Given the challenges that can be faced in making the transition from higher education, and particularly to employment, participants recognised different forms of external support, specific adjustments, and additional opportunities as enabling. Support that assisted practical preparation for application-writing, interview success, and coping with the workplace were all identified as positive. Participants received support of this kind from a range of external sources, including local government-funded services, the National Autistic Society and other disability-specific employment agencies.

Frequently the support focused on 'the practicalities' of finding a job. As the previous chapter demonstrated (5.3.4), most graduates struggled to comprehend how and where they might access relevant job opportunities whilst in higher education; so once this structure has been removed this task can be even more challenging. Timothy described how he worked with his job coach, 'I would show him something and he would say that's good or not'. Another role was 'helping with the interview training and things you could put on your CV, helping to make yourself look better to employees and stuff' (Max). Practical support often focused on helping participants consider in a structured way what and how to communicate at interview; for example Kieran recalls how his mentor at the National Autistic Society

wrote out a list of some strengths and weaknesses that I had and she helped me to prepare for interviews...What I did when I was successful at interviews is that I actually had that sheet that the NAS had prepared with me so I can talk about where my strengths lie and so if an employer did ask 'we hear you have a disability' (I have five) but you know if you can sort of portray it in a positive light. As disclosure was identified as a particular difficulty, external support of this kind assisted participants in preparing the best way to disclose if it was their decision to do so. However, provision like this also provided psychological support for some; Robert reported how his job coach helped him 'approach things better from the autism point of view...mainly helped to think about things' and Kieran also described how this helped him to 'try to keep a positive stance'. Such psychological support, in terms of keeping perspective, managing rejection, and sustaining momentum was recognised as particularly enabling for these individuals. Adam identified positive external support at a more distal level in terms of government policy and public engagement regarding employment for autistic people. He cited organisations that have actively set about recruiting 1% of its workforce from among the autistic population;

'before they were like we're not taking him on, he's autistic – not a very good team player sort of thing – whereas now people with severe autism are being taken on because they can do the job in question, sometimes better than their neurotypical counterparts'.

He reflects that whilst there is still 'stigma' associated with autism, society is beginning to adapt from a view of 'autistics as useless or retarded' to one where their unique skills, capabilities and talents are recognised.

Unfortunately, this support was not always available and was often dependent on geographical location and perceived level of need. Some participants experienced what was described earlier in the chapter as a 'Catch 22' situation (6.3). They were 'too employable' for government-funded social care support 'but then I was applying for other jobs and not getting anything' (Lily). Izzy's experience also offers particular insight into the current situation, (JV) What about any other organisations that might offer support, not just the job centre but something maybe more specific? Have you ever accessed anything like that?

(Izzy) If there is I haven't heard of it. I have been to a bunch of job fairs and stuff with regards to the disability area but really there is not really much they can do because essentially when you leave university you just get the same support as everyone else, you go to the job centre, you talk to a bunch of pencil pushers...the way I see it the minute you leave, the minute an Aspie or someone on the spectrum at least leaves University, that's it you're on your own; no support, no disabled students allowances, no special helpers to write notes for you, no teaching assistants, it's just you and a harsh world that doesn't go easy on you just because your brain is different. They just see us as another adult, another adult who is a little bit quirky, a little bit weird, and can't really understand why the chicken would cross the road...I have no idea. I just don't know how Aspie adults get help because it's not there. How can I ask for the help when I don't know what I can get the help for. As far as I know there is no help for that. There is plenty of help for children and teenagers and students but what about the ones who are still trying to figure out what they're doing with their lives, what about the adults, what about the ones who can can't really understand how to have a family of your own, you know marriage, jobs, kids - you don't get taught that in school or by people who are specialist in Asperger's, it's still very new, there's still a lot of things they don't understand or are still trying to understand.

Izzy's description outlines the fundamental assumption made by the government and employers that underpins the main issue for this population, that those on the autism spectrum that are high functioning enough to get to university and successfully complete a degree do not require any additional support. She depicts quite vividly the contrast between the enhanced level of support received throughout education, where needs are understood and adjustments made and the sense of abandonment experienced in the transition to employment and adult life. She positions emerging adults on the autism spectrum as potentially vulnerable and falling between the gaps.

# **Chapter 7**

# Discussion

### 7.1 Introduction

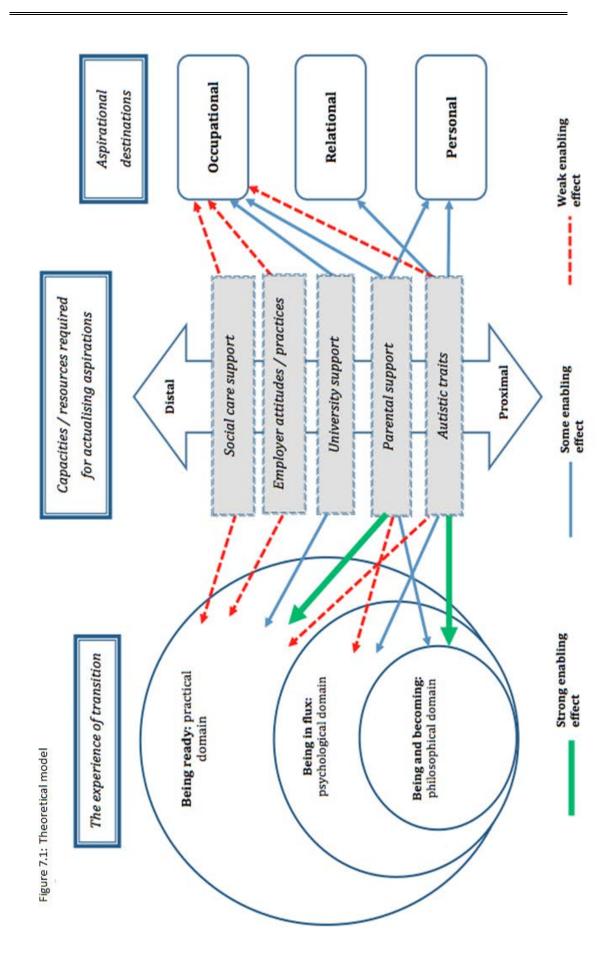
A number of themes related to transition *from* higher education, transition *to* aspirational destinations, and the proximal and distal factors identified as enabling, were identified from the twenty-one participants' accounts in the previous three chapters. This present chapter seeks more specifically to theorise the inter-related meanings of participants' transitional journeys from higher education and the mechanisms utilised in actualising their different aspirations. In doing so I return both to the initial research questions to consider how the findings respond to these and to the wider literature to assess the extent to which they align with what has already been established in the field. My research questions were as follows:

- a) How was the transition from higher education *conceptualised* by students and recent graduates on the autism spectrum?
- b) How was the transition from higher education *experienced* by students and recent graduates on the autism spectrum?
- c) What was perceived as *enabling* with respect to making the transition from higher education?
- d) What *aspirations* beyond higher education did students and recent graduates on the autism spectrum have?
- e) What was perceived as enabling with respect to autistic students and recent graduates on the autism spectrum *realising their aspirations*?

My research questions aimed at uncovering the experience of transition and the enabling and/or disabling mechanisms that impact on this phenomenon and are informed by a critical realist paradigm, as noted in Chapter 3. This position accepts that any claims are epistemologically constructed through individuals' perspectival engagement with the world and are, therefore, inherently fallible (Bhaskar, 1975; Maxwell, 2012); however, it also retains an 'ontological realism' in suggesting that their experiences point to real phenomena. Accordingly, through the abstraction of participants' individual and subjective accounts I have attempted to uncover something tangible about their experiences of transition and the enabling factors which have the greatest effects. The dialectic achieved between deductive abstraction and inductive grounding of generative mechanisms (Yeung, 1997) allowed me to posit tentative theoretical explanations about transition from higher education and its outcomes for my participants. Figure 7.1 (below) outlines my theoretical model grounded in the participants' perspectival accounts (Sayer, 2000) and identifies three interrelated sections.

The first offers a theoretical explanation of the experience of transition from higher education and into something new; it outlines three domains – *practical: being ready; psychological: being in flux;* and *philosophical: being and becoming* – which are nested together within the wider transitional experience. This resonates with the typology identified in the literature review where transition was conceptualised as transition as preparation for participation (Halpern, 1994); transition as change of status (Ecclestone, et al, 2010); alongside Gale and Parker's (2014) transition as becoming but offers a more nuanced model

sensitive to the experiences of autistic university students and recent graduates. The middle column identifies distal and proximal capacities and resources that enable successful transition and the actualisation of aspirations: social care support; employer attitudes and practices; institutional provision; parental support; and individual autistic and personality traits. These move from the most distal or external to the most proximal and thus internal effects. The final section indicates the three aspirational destinations for the participants, occupational, relational, and personal and again indicates where these are contingent on the distal and proximal capacities and resources. As my research questions sought to uncover what was enabling for participants, and so gain understanding of 'real structures or mechanisms which give rise to or govern the flux of real phenomena of social and economic life' (Lawson, 1989: 69), I have theorised that social, institutional, parental and individual capacities and resources can produce both strong and weak effects for enabling transition across the different domains and achieving, or working towards, the different aspirational destinations. The different coloured lines represent the extent to which each resource/capacity was enabling represented by a thick green line to signal *strong* enabling effect; a solid thin blue line to represent *some* enabling effect; and a broken red line to symbolise *weak* enabling effect. I will now take each of these parts of my theoretical model and offer further explanation regarding its conceptualisation and implications in relation to the wider literature and policy setting.



# 7.2 Nested transitions: practical, psychological and philosophical

#### 7.2.1 The practical domain: being ready

In my findings I disaggregated the transitional phenomenon into transition from higher education and transition to valued aspirations. I have theorised, based on my participants' accounts, that across both of these stages transition is experienced within three nested domains: the practical, psychological, and philosophical. To take the practical domain first, I posit that transition is an essentially practical activity that is explicit and experienced by all; hence it forms the largest of the domains. The practical elements in the transition *from* higher education are evidenced by participants' practical apprehensions related to where they would live next, what job they might do, how they would apply for it or be successful at interview, how they might sustain a meaningful lifestyle, or how they would maintain relationships that they had worked hard to establish during their time at university. Consistent with Huntley (2013), Giarelli et al. (2013) and Beresford, et al. (2013), practical independence is a key feature of what it means to be an emerging autistic adult and thus losing or having to reestablish practical routines and levels of independence at this stage of the life course was considered a practical transition in many regards.

In the transition *to* valued aspirations participants also identified challenges of a practical nature. These included searching for relevant jobs, participating in interviews, completing functional tasks like making phone calls and responding to emails, and managing their time effectively, which concurs with other studies

related to autistic individuals' employment experiences (Lopez and Keenan, 2014; Hulburtt and Chalmers, 2004). Such theorisation also fits with Quaglia and Cobb's (1996) schema of aspirations where 'ambition' reflects the functional activities designated for achieving future goals. Whilst some participants demonstrated capacity and skill in this area, for others the practical elements of transition from higher education and into employment were challenging, particularly where they experienced difficulties with executive function that affected their capacity to plan and organise tasks (Hill, 2004; Ozonoff and Griffith, 2000).

A growing body of literature recognises the importance of supporting the practical transition into university by providing opportunities for autistic students to visit campuses, meet with staff, offer early entry to accommodation and various other adjustments (Vincent, 2017; Vincent, 2016; Van Hees et al 2014; Barnhill, 2014; Chown & Beavan, 2012; Zager and Alpern, 2010; Camarena and Sarigiani, 2009; *inter alia*). However, this study has indicated the need for greater provision for the practical transition *from* university and *into* employment and independent adulthood. It is thus imperative on the higher education sector generally, and disability practitioners, careers advisors, employers, and those supporting autistic students specifically, to be more aware of this population's particular needs and provide support that scaffolds activity within this practical transitional domain.

#### 7.2.2 The psychological domain: being in flux

The second domain is the psychological; this relates to the emotional journey and affective development that takes place throughout this period of transition. Given the variable nature of psychological states, it is summed up by the term 'being in flux', which also reflects Arnett's (2014:xii) concept of 'emerging adulthood'. The related themes outlined in the findings (emboldened / underlined in Table 7.1 below) indicate the centrality of participants' psychological responses in their experience of transition:

Transition <i>from</i> higher education	Transition <i>to</i> occupational aspirations	Transition <i>to</i> relational / personal aspirations
Source of anxiety & avoidance	<u><b>Disheartened</b></u> by the recruitment process	<u>Desire</u> for positive relationships
Positive departure	<u>Scepticism / loss of trust</u> in employers	<u>Desire for independence</u>
Loss of independence and momentum	Naivety regarding employment	<u>Desire to be 'normal'</u>
momentum	employment	

**Identity development** 

Table 7.1 - Transition to relational and personal aspirations

As identified in the findings, participants reported a range of different emotions throughout their transitions from higher education and particularly into employment; these included excitement, anxiety, loss, frustration, confidence,

Pursuing the dream

despondence, fear, pride, and scepticism among others. They also related how, at times, they experienced multiple emotions at once; for example, leaving university filled some participants with both a sense of fear and excitement. Whilst fluctuations in psychological states is common for anyone experiencing significant changes in life and particularly among students at this juncture of the life course (Torres et al, 2009), I suggest that the autistic population's emotional experience is amplified by factors related to their condition.

On the whole, among my participants, there was a strong representation of negative emotions. Anxiety and fear about an unknown future were particularly prevalent and fit with other research findings in this area (Rydzewska, 2012; Giarelli et al., 2013; Nolan and Gleeson, 2016). One possible explanation for this could be the likely co-occurrence of other affective disorders that run alongside the autism diagnosis. Berney (2004) suggests that anxiety states such as social phobia, generalised anxiety disorders, and panic disorders can compound with autistic impairments to exacerbate the anxiety involved in making the transition to employment. Moreover, frequently the psychological and practical domains are concomitant, which is why the former is nested within the latter in my theoretical model. Where practical issues of the transition have not been thoroughly considered or attended to, for example preparation for interview or adjustments to the workplace environment, this can lead to heightened levels of anxiety (Edmonds and Beardon, 2008; Simone and Grandin, 2010). As was clear with the theme 'transition as a source of anxiety and avoidance' (4.2.1) where students were making a transition to something as yet undecided and thus

entirely unknown, it was impossible to make any practical preparations for this and so the psychological strain experienced was therefore greatly increased.

Like Gale and Parker's (2014) typology, the psychological domain in my model also recognises how transitional experiences can lead to identity development. The findings in this study show how participants saw themselves as fluctuating between adult, child, student, worker, and autistic identities. Such shifts in identity accord with wider life course theories (Ecclestone et al, 2010; Finn, 2016; Daniels and Brooker, 2014) and suggest that this period of transition can be psychologically unsettling. The over-arching identity that participants wanted to achieve was being an independent adult in control of their own life; this was often evidenced in the via negative through the loss of independence experienced following graduation (4.2.1) and the desire to break away from family restraints at times (4.2.3). This is consistent with Giarelli and Fisher's (2013) findings which show difficulties for adolescents on the autism spectrum with matching their self-image to the expectations of others. Moreover, frequently participants' achievement of particular identities, for example 'independent adult' or 'member of the workforce' was understood in direct correspondence to occupational, relational and personal aspirations and was often dependent on other practical issues such as their living arrangements, relative job success, and autistic / personality traits (Huntley, 2013; Beresford, et al., 2013; Kapp et al. 2013). It is clear that identity development is internally complex and contingent on many other factors making it difficult to assess if and when has been successfully achieved.

#### 7.2.3 The philosophical domain: being and becoming

The final transitional domain in my theoretical model is nested at its core and relates to the postmodernist concept of becoming. As established in Chapter 2, according to Deleuzo-Guattarian theory (1988:432), 'becoming is the movement by which the line frees itself from the point' and signals a departure from the linear logic. According to my findings there was some evidence of this form of transition, where individuals eschewed the 'arboreal' trajectory expected of them by society: leave university, gain paid employment and move out of their family home. By contrast, participants like Dave and Tom embarked on a different transition to become something more, to nurture those aspects of life that allow them to flourish, and to pursue the 'good life'. Alice also demonstrated her capacity to develop her own 'reflexive biography' (Beck and Beck-Gernsheim, 2009) by leaving a career in teaching that she had trained in for three years to work in an arts business. By pursuing their individual desires it could be posited that these three participants rejected the social norms for a more rhizomatic transition which preferences subjectivity and personal autonomy.

It is symbolic that this philosophical domain is represented as the smallest and nested most deeply within the others, as becoming here denotes something that is essential to our human experience yet least frequently accessed. Indeed not all participants even viewed the possibility of 'a multiplicity of futures and ways of understandings the self' (Worth 2009:1058) in positive terms and the findings suggest a desire among some to achieve quite the opposite. Izzy's comments about her personal aspirations are a good example of this as she stated that what she (and also believed what other autistic emerging adults) wanted was simply to be 'normal' and have what everyone else has – a job, a family, opportunities, friends and so on. By contrast to a rhizomatic life, a sequential life course following a traditional (or 'normal') trajectory was preferred by the majority. That notwithstanding there is certainly still indicative evidence that for a small portion of this sample, transition to a state of being and becoming that allows for individual 'lines of flight' was important.

#### 7.3 Capacities and resources that enable successful transition

My findings in chapters 4-6 demonstrate that participants' successful practical, psychological, and philosophical transition from higher education and towards particular aspirations was frequently dependent on different capacities and resources. The most significant of these were parental support, employer attitudes and practices, higher education institution provision, specific autistic traits, and social care provision. As my theoretical model suggests these capacities and resources were both distal and proximal in nature; for example social care and employer attitudes/practices have potential to be enabling at a wider and more abstracted level, whereas parental support and individual autistic traits tended to impact on individuals' success at an internal level. Such interconnectivity is suggestive of Elder's concept of (1994) 'linked lives', where transitions across the life course and considerations of the future are 'peopled' with others and 'relational' (Finn, 2016; Sarojini-Hart, 2013). For Appadurai (2004:76), personal and social resources such as these are crucial for reading

one's map into the future and thus actualising the 'capacity to aspire'. However, rather than examining each individual capacity and resource and its relationship to transition or aspirational destinations, I will outline those for which the enabling effect was particularly strong or weak, indicated by thick green or dashed red line in Figure 7.1. The first of these is autistic traits.

#### 7.3.1 Proximal resources: autistic differences

Autistic differences are without doubt the most proximal of the resources and capacities under examination. They refer to participants' internal experience of their autism spectrum condition and the specific strengths which they are able to utilise in actualising successful transition and future aspirations, alongside difficulties which make aspects of this experience more challenging. As the findings suggest some of the participants recognised capacities which can generate success. These tended to be more applicable to those already in a workplace and included functional capacities like managing time effectively, being organised and having a strong working memory as well as affective capacities including honesty, empathy and resilience. Findings here are consistent with other studies (Van Hees et al., 2014; Soulieres et al., 2011; Edmonds and Beardon, 2008) which also suggest that when applied within an appropriate context autistic differences could be viewed as capabilities.

However, as my theoretical model suggests autistic traits were more often perceived by participants as having a weak enabling effect, particularly with respect to successful practical transition from higher education and their

actualisation of occupational aspirations. Whilst organisation was acknowledged as a strength for some, most recognised the essential role that was required of parents and others in managing their transition from higher education and to employment, thus denoting this capacity as more limited at times and consistent with clinical descriptions of difficulties with executive function (Hill, 2004; Edmonds and Beardon, 2008). Such organisational challenges have particular import given the level of practical organisation required in developing proactive career behaviours, which Claes and Ruiz-Quintanilla (1998) describe as: career planning, career consultation, networking, gathering information on potential career opportunities, and proactive skill development. Accordingly, various participants noted their difficulties with knowing where to find relevant careers information, how to conduct themselves at interview, and networking as a means of gaining advantage in the labour market.

Moreover, participants identified social interactions as challenging in developing successful workplace relationships (Soulières et al., 2011; Barnhill, 2014), the impact of the sensory environment was noted as a specific barrier for some (Robertson and Simmons, 2015; Harrison and Hare, 2004; Bogdashina, 2003), as was the need for routine (Ozonoff and Griffith, 2000), alongside increased levels of stress (Ashburner et al., 2013; Dickie et al., 2009). These autistic traits have obvious implications for successful transition from higher education and to occupational aspirations and concur with other employment-focused studies among autistic populations (Lopez and Keenan, 2014; Griffiths et al., 2011; Simone and Grandin, 2010).

However, in keeping with the neurodiversity model established in Chapter 2, I posit that to view participants' autistic difficulties with organisation, social interactions, sensory processing, management of stress, and a need for routine as mere confirmation of autistic 'deficits' essentialises the individuals as problematic and underrepresents wider issues. By contrast, there is evidence that many of these embodied difficulties are often contextual (Williams, 1996; Sinclair, 2005; Robertson, 2009) and relate more specifically to employer attitudes and practices. For example, where social demands are high and unpredictable and the sensory environment makes processing and decoding these interactions more challenging (as in some workplaces), it is not surprising that autistic individuals may find this very stressful and desire highly regulated routines where they can control and manage the situation (Giarelli and Fisher, 2013). So, if it can be accepted that autistic traits have a weak enabling effect but, crucially, can be exacerbated or limited depending on the context, this leads to discussion of the next distal capacity and resource in this study: wider external support.

#### 7.3.2 Distal resources: government-funded support, employers & HEIs

My findings suggest that local government services for emerging university students and graduates on the autism spectrum have a distinctly weak enabling effect. Several studies suggest that this group can experience independence in adulthood and success within the workplace given appropriate vocational supports (Bertilsdotter-Rosqvist, 2012; Howlin & Mawhood, 1996; Wehman, 1996). However, despite the number of legislative and policy documents drafted by successive British governments to enable successful transition, autistic people at the higher end of the spectrum continue to experience a gap in services (Neary et al, 2015; Sloper et al, 2011; Hurlbutt & Chalmers, 2004). Specifically, participants described themselves as falling into a 'Catch 22' situation where they were too high functioning to access specialist support for autistic adults but not able to actualise many of their aspirations for paid employment and independent living.

As Figure 7.1 suggests, employer attitudes and practices have particularly weak enabling effect for practical preparation and the realisation of occupational aspirations. Participants reported experiences of poor recruitment practices and fears around discrimination based on disclosure of their autism diagnoses. This is despite legislation (Equality Act, 2010; Autism Act, 2009 etc.) and an Access To *Work* scheme that ought specifically to protect and support them practically in successfully achieving these. Similar experiences have been reported by other studies (Ohl et al., 2017; Krieger et al., 2012) and Van Wieren et al., (2012) found that in the United States, allegations of discrimination by autistic people were more likely to have been made against employers from educational, information, and arts and entertainment industries. Surprisingly, this trend is confirmed among the small sample involved in this study, where Izzy, Alice, Lewis, and Robert all experienced workplace discrimination in educational and arts industries respectively. It is clear that discriminatory attitudes and behaviours of this kind further serve to weaken the enabling effect that government-funded social care support has for this group.

Another distal resource that has a relatively weak enabling effect for this group is higher education institutions. This is evidenced by a recent report which shows that autistic graduates have the highest rates of unemployment of all disabled students leaving higher education (AGCAS, 2015). Whilst the findings in my study suggest that there is some good practice, including specialist preemployment programmes at two institutions and some staff that went out of their way to offer additional guidance and opportunities, generally this positive experience was inconsistent. Institutions have both an opportunity and responsibility to offer autistic students not just induction into the norms, procedures and expectations of university but also to provide 'outduction' experiences (Morgan, 2013) that enable them to be successful in the next stage of their life course; currently this is not happening across the sector and this group are thus disabled from achieving their full horizon of aspirations (Appadurai, 2004).

There is clearly a dynamic relationship between proximal capacities such as participants' autistic traits and more distal resources including local services and institutional transition provision. The outcome, based on my theorisation, is that the context-dependent difficulties that autistic students and graduates experience make the transition *from* higher education and *to* their aspirational destinations more challenging and are therefore a weak enabling resource; however, the distal resources which ought to compensate and enable them are either non-existent or inconsistent, thus compounding the effects between all three (Figure 7.1).

#### 7.3.3 Proximal resources: parental support

The previous section suggested the weak enabling effects that a lack of social and institutional support can have for successful practical transition and achievement of occupational aspirations. In stark contrast, my findings posit that parents had a very strong enabling effect in supporting their children in being practically ready at this juncture of the life course. It is likely that parents are having to compensate for the lack of services available elsewhere by assisting them in being organised, planning for the future, and facilitating their next steps towards adulthood. Moreover, as was recognised within the findings, parents' involvement was often a catalyst for the achievement of other personal aspirations, including independent living and travel. The importance of ongoing parental support for this group is consistent with other findings in the literature (Huntley, 2013; Beresford et al, 2013; Morningstar et al., 1995) and resonates with Kohler's (1996) Taxonomy for Transition Programming, which highlights family involvement as being among the most significant factors for successful transition.

However, the evidence in this study also showed that parents could at times have a weak enabling effect, particularly in relation to participants' psychological transition and development of an adult identity. A number of individuals interviewed recognised tensions related to how they were treated or perceived in the family home; in one instance Ezra suggested that he had considered cutting off all further ties with his family following his imminent employment and shift to independent living. Several participants reported how their parents continued to view them on the same terms as they had done so as a child and seemed unable to allow them the space to flourish and grow into an independent adult. An interesting example of this is Tom's mother who, despite being recognised as supportive and a positive resource, required that he show her any materials he intended to publish online as part of his occupational aspiration to be a YouTuber. Such infantilising activity, despite Tom's academic credentials (MA in Creative Writing), is demonstrative of his mother's lack of trust in his capacity to manage his own affairs within his chosen field. Such practices are consistent with Huntley's (2013) study among emerging autistic adults which also found that parents frequently lack of confidence in their children, even as adults.

It could be the case that due to the vital and sustained role that parents have played (and continue to play) throughout their child's life, as primary care-givers and providers, it is difficult for them to make this conceptual transition themselves and to see their child as a potentially independent adult. Given the paucity of research in this field there is limited evidence to support this, however, Vincent (2016), which focused on evaluation of an induction programme at a UK university for autistic students, also found that parents struggled to 'let go' of their son's or daughter's adolescent identity when moving onto this next stage of the life course.

#### 7.3.4 Enabling transition to becoming

It has already been established that particular neurological differences associated with autism had a weakening effect on enabling practical transition 177

and particularly achieving occupational aspirations; however, the findings suggest that they had a strong enabling effect when applied to pursuing individual and rhizomatic trajectories. Given that my theoretical model (Figure 7.1) posits that the philosophical transition relates to a deep understanding of oneself based on what might represent the good life, it is not surprising that this most proximal resource, autistic traits, would have a significant impact. It might, in this way, represent the highest form of participants' navigational capacity to aspire (Appadurai, 2004) as they are able to read their 'own map into the future' rather than being restricted by societal conventions.

Assessing the pathways of individuals such as Dave and Tom, who eschewed the traditional labour market for individualised and creative routes as authors and/or YouTuber content creators, it could be suggested that they have embarked on risk-intensive trajectories. This is maintained by Pacer (2013) who outlines the significant challenges that authors face today in publishing original literary work or Perry (2016) who maintains that only those YouTube creators who are able to incorporate brand management strategies to maximise advantage in audience growth and revenue are likely to be successful. For Pacer (2013) and Perry (2016), whilst they do not suggest that being successful in these creative industries is impossible, it is certainly difficult and requires 'hard work, diligence, and perhaps a bit of luck' (*ibid* 2016:52). When asked, Tom felt he was 80% sure that he would be successful as an author and YouTuber and did not view his decision to pursue this as too great a risk.

Some, however, would regard Dave and Tom's approaches as signalling the kind of social naivety with respect to employment often prevalent in autistic populations (Berney, 2004). Accordingly, they simply do not understand the risks involved in the pathways that they are choosing and present a degree of 'optimism bias' which assumes more favourable outcomes for oneself than for others (Lapsley and Hill, 2010). One explanation for this is cognitive egocentrism understood as maladaptive development based on personal fable ideation and the 'reckless behaviour' that it encourages. Lapsley and Hill (2010) suggest that such cognitive egocentrism accounts view invulnerability as a lamentable feature of development in its capacity to impair judgment in critical situations. According to this interpretation, Dave and Tom's actions would certainly appear to reflect a combination of social naivety and optimism bias and far from enabling them, these apparent autistic traits might in fact increase levels of risk across the life course.

However, studies into optimism bias show that optimistic updating is largely mediated by the medial prefrontal cortex (Sharot et al., 2011). Given that autism spectrum conditions are associated with hypoactivity in this region (Gilbert et al., 2008), it is suggested that these individuals are indeed less susceptible to emotional biases in decision making than typically developing adults (Harris et al., 2013; de Martino et al., 2008). In fact, Kuzmanovic et al. (2016) found that adults with high functioning autism spectrum conditions were significantly less biased when updating self-referential beliefs. These findings indicate a reduction in emotional biases and increase in rational consistency in decision making processes as a positive autistic trait. It could therefore be claimed that Dave and Tom were simply following a logical trajectory; for example Tom had studied Creative Writing at undergraduate level and was just in the process of completing his Master's degree in the same subject, so it is not unreasonable for him to pursue this career whilst living at home, despite its inherent risks.

Moreover, alongside the potentially positive autistic trait of rational consistency, those participants like Dave and Tom who were supported in making a philosophical transition of being and becoming demonstrated other autistic resources that enabled them. Whilst clinical descriptions often suggest that dysfunctions in executive function (Hill, 2004) and theory of mind (Baron-Cohen, 1995) make it difficult for autistic people to engage in imaginative episodic future thinking (Lind et al, 2013); viewed differently, it could be argued that this restricted thinking about the future is evidence of exclusivity, where one identifies and validates one future self over others (Markus & Wurf, 1987). In psychological terms exclusivity is often identified as a positive capacity that enables individuals to activate 'constructive episodic simulation' in working memory and so generate positive future behaviours (Shao et al., 2010).

Furthermore, where these future selves are considered accessible in an individual's memory, that is, that they can be conceptually conceived of and are considered within the range of what is possible, this will further strengthen their influence on behaviour. There is some evidence to suggest that whilst someone like Tom's thinking was restricted as he had no other trajectory planned beyond being an author / YouTuber, it was also exclusive and to some extent accessible.

Finally, as both Perry (2016) and Pacer (2013) suggest, despite the challenges of the creative industries, both continue to thrive with thousands of books and hours of lucrative video content being published each year; this might beg the question: why should Tom or Dave not be counted among those with the potential to be successful in this arena? To position them as socially naïve, unreasonably optimistic or restricted in their future thinking simply on the basis of their autistic diagnoses undermines their proximal capacities to think abstractly about their own lives, act rationally, and ultimately to aspire to engage in an occupation that they enjoy and have a talent for. According to Appadurai (2004), in order to develop 'navigational capacity' among disesteemed groups, deficit assumptions prevalent in society must be contested by providing processes through which norms and preconceptions are challenged. I suggest that these findings offer evidence that this is both necessary and possible for autistic students who seek to engage in non-conventional trajectories.

However, actualising these is not achieved in isolation as has already been established in previous sections. Indeed, parents played a significant role in enabling various aspects of this transition including the provision of practical, financial and emotional support. It is likely that by facilitating their child's more rhizomatic and individualised pathways, they were also seeking to manage the risks and potential threats involved, which can be seen in Tom's mother's intervention regarding the publication of his online material. There are very few longitudinal studies that examine parents' impact on trajectory development (Gray, 2006) but there is some resonance with other studies (Giarelli and Fisher, 2013; Beresford et al., 2013; Huntley, 2013) which also showed the desire that

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parents had to support their children in engaging in meaningful activities into adulthood.

# Chapter 8 Conclusions

The aim of this research was to understand more about the experiences of transition from higher education for emerging adults on the autism spectrum and to uncover their aspirations for the future. A further research aim was to investigate what they considered to be enabling with respect to achieving a successful transition and actualising their aspirations. Using a qualitative methodology, my study was underpinned by a critical realist paradigm, which asserts that an external world exists both independently of human consciousness and at the same time includes socially determined knowledge about reality. Such 'double inclusiveness' (Bhaskar and Danermark, 2006) offered the possibility of deriving deep levels of meaning about autism and transition based on the perspectival accounts from among my sample and from which I was able to identify underlying causal mechanisms that might be considered 'approximately true' (Maxwell, 2012:42).

Given the paucity of literature regarding transition from higher education for emerging adults on the autism spectrum, this thesis makes an original and important contribution to the field. It responds to the need for richer theorisation of transition (Worth, 2009) by identifying how this phenomenon can be experienced dynamically across different nested domains. It provides specific insight into the transitional experiences for an autistic emerging adult population and identifies the challenges that can be involved in this. Moreover, this thesis provides greater theorisation regarding the impact of enabling resources and capacities at both proximal and distal levels and signals the implications that these can have for practice.

# 8.1 Main conclusions

#### 8.1.1 A deeper understanding of transition

Firstly, my findings establish that transition is a complex phenomenon which can be experienced across practical, psychological and sometimes philosophical domains. The practical domain of transition is captured by the notion of 'being ready' and relates to how well participants were able to organise themselves in preparation for completing one and beginning another stage of life. The psychological domain involved the emotional flux that participants experienced in making the change from higher education to something new, as well as the iterative process of identity development. The final philosophical domain suggests how transition can engage an individual in deep reflection about what a flourishing life is and how it can be achieved through the process of becoming. By positing that these are nested within each other I indicate the multifaceted nature of transition and how these domains are often interdependent.

Moreover, this study demonstrates the dynamic nature of transition and how it necessarily involves *transition from* as well as *transition to*. Thus, in order to understand more about the *transition from* higher education, it was necessary also to uncover the valued aspirations that participants saw themselves making the *transition to*. Three broad aspirational destinations were identified – occupational, relational and personal – and indicate the 'capacity to aspire' that 184

autistic students and recent graduates have for their futures. Occupational and personal aspirations were considered the most significant for participants, particularly gaining paid employment and living independently; both of which are concomitant and reflect participants' desire to actualise their emerging adult identities within the psychological dimension.

Finally, my research indicates that transition across the three practical, psychological and philosophical domains is both linear and liquid. There is evidence that autistic populations can prefer transitions which follow a sequential or linear life course pattern, particularly within the practical and psychological domains: from child to university student, university student to member of the workforce, member of the workforce to independent adult. Such a sequential or linear trajectory is desirable as it both mitigates 'unknowns' in life which can be distressing and situates autistic emerging adults within typical or 'normal' modes of development. That notwithstanding there was also evidence that the psychological domain of transition is at times liquid and the same emerging adult identities and associated emotional states fluctuate depending on other contingent factors. Furthermore, there is also some evidence that transition for autistic populations can be philosophical insofar as exploring individual aspirations and rhizomatic trajectories was considered a possibility.

#### 8.1.2 Transition can be challenging

Significantly, this thesis confirms that transition from higher education can be challenging for emerging adults on the autism spectrum. Where the future is not certain or clearly mapped out, this can lead to high levels of anxiety, feeling overwhelmed, and ultimately avoidance. Whilst such emotional states do not affect the capacity to aspire per se they do have obvious implications for the capacity to realise these aspirations. This was specifically recognised with the practical (being ready) transition from higher education and to occupational aspirations. As many aspects of this transition require high levels of organisational skill, communicative ability, and emotional resilience, all of which can be difficult for this population, realising these aspirations was more challenging. Moreover, the psychological transition between identities was also difficult where these emerging adults felt that they were required to cede the independence and momentum that they had worked hard to establish during their time at university in order to adopt more dependant roles if they were not immediately successful at making the transition to independence.

#### 8.1.3 Enabling resources and capacities

The final contribution that this study makes to the field is the identification of a range of proximal and distal resources and capacities required successful transition. In attempting to uncover the causal mechanisms involved in transition, it uncovered a number of strong and weak enabling factors, including parental support, autistic differences, institutional support, employer attitudes and practices, and wider social support. My findings suggest that some autistic traits such as strong working memory, empathy and honesty can be positive and enabling; however, difficulties with social interaction, stress management, sensory processing and desire for routine can have weak enabling effects on

transition to employment. Following a neurodiversity model of autism, I suggest that both the strengths and the challenges that are present are contextual and can be nurtured or mitigated with appropriate support and workplace adjustments.

Another key conclusion is that negative employer attitudes and practices, a lack of resources located in government-funded service provision, and inconsistent institutional support at a distal level are not enabling. In particular, the transition to employment was recognised as being problematic and negative experiences of recruitment processes and working environments often impacted adversely on participants' psychological wellbeing and limited their capacity to aspire in this area. The findings indicate that the assumption that high functioning autistic people do not require additional support is fundamentally flawed. This is reflected in the Children and Families Act 2014 where disabled students capable of attending university are no longer provided for under the Code of Practice, and my findings suggest that this lack of provision creates barriers to successful transition to employment and independence. Moreover, when negative employer attitudes and practice, inconsistent institutional support, and a lack of social care provision are compounded together this creates a very precarious situation for autistic university students making the transition from higher education and towards employment and adulthood.

However, my study has also signalled the important role that parents play for emerging adults on the autism spectrum leaving university. Parents were generally recognised as having a strong enabling effect and very often 187 compensated for the lack of wider social support. Parents were frequently a significant resource in the actualisation of participants' aspirations, often through provision of both practical and emotional support. That said, this thesis also showed that such a sustained level of parental support can also reduce the enabling effect where it generates tension within the family and prevents autistic students and recent graduates from fully pursuing and achieving emerging adult identities. Such a finding is reflective of the complex and inter-dependent nature of this phenomenon.

#### 8.1.4 Capacity to aspire

Finally, it can be concluded from this research that autistic students and recent graduates do indeed have the capacity to aspire. They are often able to successfully navigate their transitions from higher education and towards the actualisation of their aspirational destinations when provided with the right enabling resources. Occupational aspirations were by far the most prominent across all the participants' accounts, signalling the importance that this has for enabling a change of identity status as well as recognition of its capacity to open up other future aspirations. Whilst personal and relational aspirations, including the desire for romantic relationships and better family dynamics, were not discussed in as much depth, it was clear that for many these were still important. The over-ridng aspirations, is indicative of a desire to negotiate their emerging status as autistic adults. Lastly, in articulating their aspirations, the participants in this study questioned some of the fundamental clinical assumptions about the

autism diagnosis that suggests a lack of imaginative thinking; by contrast they demonstrated their capacity to engage empathetically, creatively, and imaginatively with respect to the future.

# 8.2 Limitations

Whilst this study provides a range of meaningful conclusions, there are also a number of limitations which this section will briefly outline.

#### 8.2.1 Diversity of sample

Firstly, although the sample in this study was never intended to be representative of all autistic students or graduates, it might still have been more diverse. Of the twenty-one participants interviewed, the majority studied arts, humanities and social science subjects (n=18) and were male (n=15). This is notable as many studies show that autistic university students are more often drawn to STEM subjects including science, engineering and mathematics (Wei et al., 2014; Lee, 2014), thus for future research it would be advantageous to recruit a larger and more varied sample from across a wider range of academic disciplines and higher education institutions. Moreover, given the strong and weak enabling effects that other people have for the success of this population's transition, this study's focus on student and recent graduate's perspectives limits the bredth of possible insight. Further studies may also include the perspectives from other stakeholders, including parents, university careers practitioners, employers, and external service providers to provide a more holistic picture of the phenomenon and its underlying causal mechanisms.

## 8.2.2 Data collection limitations

This study utilised individual semi-structured interviews with the twenty-one participants and life maps with a subset of the sample. Where successfully utilised, these methods were generally satisfactory for ascertaining in-depth accounts of how some autistic emerging adults experienced transition and their aspirations for the future. However, as indicated in the Methodology Chapter, life maps had limited usefulness and did not generate the level of data anticipated. Whilst it is acknowledged that diagrammatic approaches can be extremely useful among some marginalised populations, they may have less value among high functioning autistic adults who, based on this study, tend to prefer clearer and more structured data collection methods. Moreover, a further drawback to both of these methods was that they were only able to provide a one-off snapshot of participants' experiences. Given the aspirational focus and the degree to which life can change for individuals during this stage of the life course, it would be beneficial for future research to study this phenomenon longitudinally over a number of years, in order to provide more detailed understandings of transition, the actualisation of aspirations, and the resources that enable this.

## 8.3 Implications for policy and practice

This thesis foregrounded the voices of autistic participants in identifying a number of strong and weak enabling factors that affect the successful transition from higher education for them. This section of the chapter indicates how research-informed changes to policies, and practice (advice and guidance, resource development, and training) applicable to students, parents, employers, higher education practitioners, and service providers could have positive implications for transitional outcomes (see Table 8.1 below). While it is recognised that the findings have potential implications for all of these stakeholders, particular focus is placed on government-funded service providers, higher education institutions, and employers.

## 8.3.1 Implications for social policy

This study has identified a gap between what students on the autism spectrum require to be successful and what government-funded service providers are currently offering based on the aforementioned assumption that that autistic adults who are able to attend university do not require additional support. Such a position might serve to explain the low employment statistics among autistic adults in the UK, which suggest that up to 84% of adults on the autistic spectrum are not in full time paid employment (NAS, 2017; Dillenburger et al, 2014) and reflects a lack of understanding about the complex challenges that this population face in making the transition to work. It is suggested here that the statutary provision ought to be more robust and guaranteed for all individuals on the autism spectrum, including those considered high functioning in order to redress this issue. At a practical level, given the emphasis on transition to adulthood in the Autism Act (2009) and Progress Report on Think Autism (2016), it would be reasonable for government-funded support into independent adulthood to extend to this group too. It would benefit those autistic students completing higher education or who have recently graduated if there was specialist autism service provision which could assist with advocacy in the recruitment process, employment preparation, and greater support with the implementation of the Access to Work scheme. Apart from the potentially moral argument for this, there is also a financial one that suggests that better provision might be cost-effective in the long-term as independent adults in full-time employment are less likely to need to access social care services and more able to add to the economy (Knapp et al., 2009).

#### **8.3.2 Implications for higher education**

It is recognised that there is great diversity across UK higher education in terms of student satisfaction and outcomes (Boliver, 2015) and therefore it is difficult to draw implications for an entire sector. Concurrently, given the paucity of research literature related to autistic students' postgraduate transitions, it is impossible to suggest which kinds of universities might be recognised as leading the way in terms of practice. Whilst only eight institutions across England were represented in this study, evidence here suggests that practice was relatively inchoate and inconsistent and illustrates to some extent why this population are currently the least likely to gain postgraduate employment out of all disabled students (AGCAS, 2015). Such findings reflect the need for systemic policy change across the sector including the need for universities to take into account the whole transitional journey of autistic students; from induction to outduction (Morgan, 2013). As the issue of postgraduate transition for autistic students gains more purchase in the research literature, it will be increasingly possible for universities work collaboratively with researchers, practitioners, and autistic students to identify 'best practice'.

Suggestions might include autism-specific training and guidance for careers staff and other practitioners to ensure that they are informed about the specific needs that this group may have; access to a careers/transition mentor who could facilitate the wider transition to employment and other aspects of adulthood; and better laision between universities, local service providers and employers at this transitional stage. The outcomes, it is suggested, would be an increase in employment progression rates for students and more inclusive, autism-friendly institutions where staff are more informed about the how they can best support autistic students at this latter stage of their university journey.

#### 8.3.3 Implications for employers

Finally, the participants' accounts in this study suggest that recruitment and workplace policies and practices must be improved in order to enable autistic students to gain full-time graduate level employment. This might be achieved were employers to make their recruitment strategies and policies more autismfriendly. This could include, specifically recruiting autistic graduates; and developing more transparent and inclusive recruitment policies. Examples might include, giving additional time for psychometric testing; providing advance information about the interview procedure; offering clear, honest and constructive feedback; and allowing opportunities for autistic applicants to visit the workplace prior to interview. Moreover, there is scope to make the workplace setting more inclusive by making small adjustments to the sensory environment, such as providing dimmed lighting or a quiet space to work; creating structure to the working day or week; and providing a mentor who can support transition into work and development within the role. By making these relatively small adjustments companies have the potential to tap into an able and willing workforce who could offer a range of autistic skills, talents and capabilities as well as improve their own workplace culture.

		Research-informed:	nformed:		
Stakeholder	Policy development	Specialist advice	Resource	Training	Implications
group		and guidance	development		
Autistic students	-Involvement of development of policy and practice	- Receive autism-specific careers guidance across all three years - Focus on autistic strengths	<ul> <li>Access to careers mentor</li> <li>Opportunities to visit workplaces / live independently</li> </ul>	<ul> <li>Interview techniques</li> <li>Anxiety / stress management</li> <li>Success in the workplace</li> <li>Positive disclosure</li> </ul>	<ul> <li>Voices recognised as important</li> <li>Increased levels of employment</li> <li>Greater levels of confidence about future options / interviews etc.</li> <li>Fewer 'unknowns' which can generate anxiety</li> </ul>
Parents	-Involvementof developmentofpolicy and practice	<ul> <li>Receive support for son / daughter to be independent and find employment</li> </ul>			<ul> <li>Practical preasure relieved</li> <li>Improved transition to adult identity</li> <li>Voices recognised as important for informing change</li> </ul>
Employers	- Targeted recruitment of autistic graduates - Develop transparent / inclusive recruitment policies - Develop policies for making workplaces autism-friendly	- Specialist autism- friendly workplace guidance for HR / managers / colleagues	<ul> <li>Provide opportunities for autistic students to visit workplace prior to commencing</li> <li>Simple adjustments to work environment</li> <li>Mentor into and throughout career</li> </ul>	<ul> <li>Addressing</li> <li>recruitment</li> <li>discrimination and</li> <li>stereotyping</li> <li>Identifying workplace</li> <li>adjustments</li> </ul>	<ul> <li>Autism-friendly workplaces that are more diverse and recognise / celebrate autistic strengths</li> </ul>
Higher Education Institutions	<ul> <li>-Collaborate with students to develop policy to provide transitional support into and from higher education</li> <li>-Share good practice between HEIs</li> </ul>	- Autism-specific guidance provided for careers staff -Laision between HE and local service provider / employer	<ul> <li>Individual careers/ transition mentor assigned to student</li> <li>Facilitate</li> <li>opportunities to visit workplaces / live</li> <li>independently</li> </ul>	<ul> <li>Autism-specific guidance training provided for careers staff</li> <li>Training offered to academic staff</li> </ul>	<ul> <li>Increase in employment progression rates for autistic student populations</li> <li>Better informed and inclusive staff</li> <li>More autism-friendly institutions and policies</li> </ul>
Government- funded service providers	- More robust provision -Code of Practice include 'high functioning' autistic adults -Greater sensitivity to autistic adults' experiences	<ul> <li>Autism-specific careers guidance</li> <li>Options regarding living independently / money management</li> </ul>	<ul> <li>Wider range of resources available for autistic adults considered 'high functioning'</li> </ul>	<ul> <li>Support / advocacy with employment an implementation of Access to Work</li> <li>Support with independent living</li> </ul>	<ul> <li>Increased levels of employment for autistic adults</li> <li>Reduced pressure on other services / benefits in longterm</li> </ul>

Table 8.1

### 8.3.4 Implications for students and parents

It is obvious that if policy and practice as outlined above were to be implemented across national and local service provision, higher education institutions, and employers it would have positive implications for both autistic students and their parents. In particular such provision would enable successful transition to the more structured and linear aspects of the life course: employment and independent living and would ease the need for dependence on parents and the relational pressure that this can generate. Accordingly, I suggest that policy and practice development ought to be informed by those for whom it has the greatest impact – namely the students themselves. By legitimising their voices in this way, it both develops their capability to affect societal change but also, and perhaps more concretely, would increase their capacity to actualise their occupational aspirations. However, I would also suggest that by having a robust system of inclusive policies and practices in place, this may also allow space for autistic individuals' more philosophical transition to follow different trajectories and engage in activities that give their lives most meaning.

# 8.4 Closing comments

The Introduction and Literature Review chapters highlighted the paucity of research with respect to autistic students' transition from higher education. Therefore, the value of this thesis is both the purpose it serves as an exploratory study and the potential it has to promote positive social transformation through the findings. According to Bhaskar, research that is philosophically grounded in critical realism should lead to emancipatory knowledge, which consists in 'the *transformation*, in "self-emancipation" by the agent or agents concerned, from an unwanted to a wanted source of determination...that can only be effected in practice' (emphasis in original 1989:90). By bridging the gap between 'knowing' and 'doing', social scientific research such as this has the potential to empower participants by legitimising their voices and developing theory through the data generated from those voices (Egbo, 2005). This emphasis on emancipation through participants' voices aligns quite appositely with the way Appadurai (2004:186) connects individuals' capacity to aspire with the cultural capability to 'debate, contest, and oppose vital directions for collective social life'. He argues that for voice to take effect it must engage in examination and critique of social, political and economic issues and be expressed in actions and performances that have both proximal and distal impacts. It is, therefore, hoped that through the twenty-one participants' accounts and their theorisation, this thesis has offered new insight into the complex nature of transition for emerging adults on the autism spectrum making the transition from higher education and may serve to transform policy and practice in the future.

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# Appendices

#### **Appendix One – Ethical Approval**

STUDENT FORM RESEARCH ETHICS AT LANCASTER STUDENT FORM

Stage 1 Self-Assessment Form (Part A) - for Research Students

(To be completed by the student together with the supervisor in all cases; send signed original to Research Support)

Student name and email: Jonathan Vincent (j.vincent1@yorksj.ac.uk)

Supervisor name: Dr Jan McArthur Department: Education

Title of project: A future of possibilities: a qualitative study into the aspirations of students on the autistic spectrum making the transition from higher education

Proposed funding source (if applicable): N/A

- Please confirm that you have read the code of practice, '<u>Research Ethics at Lancaster: a</u> code of practice' and are willing to abide by it in relation to the current proposal? ? If no, please provide explanation on separate page
- Does your research project involve non-human vertebrates, cephalopods or decapod crustaceans? No If yes, have you contacted the Ethical Review Process Committee (ERP) via the University Secretary (Fiona Aiken)? ?
- 3a. Does your research project involve human participants i.e. including all types of interviews, questionnaires, focus groups, records relating to humans etc? Yes If yes, you must complete Part B unless your project is being reviewed by an ethics committee
- 3b. If the research involves human participants please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data Yes
- 3c. If the research involves human participants, are any of the following relevant:
  - No The involvement of vulnerable participants or groups, such as children, people with a learning disability or cognitive impairment, or persons in a dependent relationship
  - No The sensitivity of the research topic e.g. the participants' sexual, political or legal behaviour, or their experience of violence, abuse or exploitation
  - No The gender, ethnicity, language or cultural status of the participants
  - No Deception, trickery or other procedures that may contravene participants' full and informed consent, without timely and appropriate debriefing, or activities that cause stress, humiliation, anxiety or the infliction of more than minimal pain
  - No Access to records of personal or other confidential information, including genetic or other biological information, concerning identifiable individuals, without their knowledge or consent
  - No The use of intrusive interventions, including the administration of drugs, or other treatments, excessive physical exertion, or techniques such as hypnotherapy, without the participants' knowledge or consent
  - No Any other potential areas of ethical concern? (Please give brief description)

Although this study involves university students with Asperger's syndrome or High Functioning Autism, this population has average or above average IQ and few, if any would consider themselves 'vulnerable' or at risk \_\_\_\_\_ STUDENT FORM

#### STEDENT FORM

STUDENT FORM

4. Are any of the following potential areas of ethical concern relevant to your research?

No Could the funding source be considered controversial?

- No Does the research involve lone working or travel to areas where researchers may be at risk (eg countries that the FCO advises against travelling to)? If yes give details.
- No Does the research involve the use of human cells or tissues other than those established in laboratory cultures?

No Does the research involve non-human vertebrates? If yes, has the University Secretary signified her approval??

No Any other potential areas of ethical concern? (Please give brief description)

- Please select ONE appropriate option for this project, take any action indicated below and in all cases <u>submit the fully signed original self-assessment to RSO</u>.
- (a) Low risk, no potential concerns identified The research does NOT involve human participants, response to all parts of Q.4 is 'NO'. No further action required once this signed form has been submitted to RSO
- (b) Project will be reviewed by NHS ethics committee Part B/Stage 2 not usually required, liaise with RSO for further information. If Lancaster will be named as sponsor, contact RSO for details of the procedure
- (c) Project will be reviewed by other external ethics committee Please contact RSO for details of the information to submit with this form
- (d) Project routed to UREC via internal ethics committee SHM and Psychology only. Please follow specific guidance for your School or Department and submit this signed original self-assessment to RSO
- (e) Potential ethical concerns, review by UREC required Potential ethical concerns requiring review by UREC, please contact RSO to register your intention to submit a Stage 2 form and to discuss timescales
- (f) Potential ethical concerns but considered low risk, (a)-(e) above not ticked Research involves human participants and/or response to one or more parts of Q.4 is 'YES' but ethical risk is considered low. Provide further information by completing <u>PART B</u> and submitting with this <u>signed original</u> PART A to RSO

Student signature:		Date: 22.09.15	
Supervisor signature:		Date:	
Head of Department (or delegated representative)	Name:	Prof Paul Ashwin	
Signature:		Date:	

Research Support Office (RSO) ethics contact details: ethics@lance.aetdcar Dabbin Valabe --- 02000

#### Ethical research at Lancaster: STAGE 1 SELF-ASSESSMENT (PART B)

This form should be completed if you have selected option 5(f) in Part A of the stage I self-assessment form, or following discussion with RSO. The information provided will be reviewed by the Chair of the University Research Ethics Committee (UREC). If you cannot easily fit the information within the space below, consider whether a stage 2 form would be more appropriate.

Principal Investigator/ Student name: Jonathan Vincent

Sircel. 22.09.15

pFACT ID number (if applicable - staff only): N/A

6. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language): This study aims to understand more about the experience of transition out of higher education for university students with Asperger's syndrome (AS) and High Functioning Autism (HFA). Particularly, it is concerned with autistic students' future aspirations and what is perceived as being enabling and disabling in achieving these. The study aims to use the findings to better inform policy and practice in higher education and contribute to the growing theorisation around processes of transition across the life course for autistic people.

Please explain why you consider the ethical risk to be low, with particular reference to any areas of potential concern highlighted in Q.3 and Q.4 (PART A):

This piece of research will be conducted among a sample of adult undergraduate students and recent graduates with AS or HFA. Although this cohort have diagnosed social and communication impairments, they frequently demonstrate average or above average IQ (Whitby and Mancil, 2009) and few, if any, would consider themselves 'vulnerable' or at risk. Such a position fails to take into account the complexity of autism spectrum conditions and only serves to infantilise the individuals. Accordingly, it is argued that where information, written in plain English, is provided and explained to participants they are able to provide informed consent and thus any ethical risk is limited, if not entirely mitigated.

 If your research involves human participants, please summarise (as applicable) how participants will be recruited and consent obtained (copies of supporting documentation - information sheets, consent forms, questionnaires, interview schedules etc should be attached, if available\*).

Full supporting documentation attached Supporting documentation will be submitted if grant awarded Supporting documentation to be submitted later (please include details below)

Students will be recruited in two phases. The first will make use of the researcher's preexisting contacts at two higher education institutions in Yorkshire. A secondary phase of recruitment will be conducted using a national forum among other higher education practitioners supporting students on the autism spectrum. Detailed information will be provided and written consent obtained from all participants prior to the collection of any data. As the data collection will be structured around the diagrammatic method of life maps, the interviews will be semi-structured and largely narrative, thus no interview schedule is available at present.

9. If you have any other relevant information please provide details below:

Having just completed a three year-long participatory project among higher education students on the autistic spectrum at one HEI in Yorkshire, I have extensive research experience with this population. This previous project involved data collection, analysis, coauthorship and dissemination and offers evidence that students with Asperger's / HFA are capable of making informed and independent decisions regarding ethical consent - as well as many other aspects of the research process. From this I have garnered vital experience of negotiating ethical consent with participants as well as conducting ethical research with such a sample.

"Where supporting documentation is not available at the time this form is submitted it will usually need to be provided and approved before the project begins (or recruitment of participants begins, depending on the nature of the project). Please remember to allow sufficient time for approvals. Contact the Research Support Office for further details <u>ethics/itlonester at uk</u>.

# Appendix Two – Participant Information Sheet Participant Information Sheet



**Title of Project:** A future of possibilities: a qualitative study into the aspirations of students on the autistic spectrum making the transition from higher education

### Research Student: Jonathan Vincent

Full Address: *York St John University, Lord Mayor's Walk, York, YO31 7EX* Tel: 01904 876136 Email: j.vincent1@yorksj.ac.uk or *j.vincent@lancaster.ac.uk* 

### Supervisor: Dr Jan McArthur

County South, Lancaster University, LA1 4YD, UK Tel: +44 (0)1524 592290 Email: j.mcarthur@lancaster.ac.uk

# Date: 24.09.15

### Dear

I am carrying out research at Lancaster University into how students with High Functioning Autism or Asperger's syndrome experience the transition from university to whatever might be next for them. In particular I am interested in what individuals want to do or to be in the future, what helps them to achieve these, and what makes achieving their aspirations more difficult.

As a student currently in your third year of university, I am writing to see if you may be interested in being a part of this project, as a participant.

This will consist of me talking to you about:

- Your experiences of being a student in your final year of university;
- The sorts of support that are (or could be) in place to assist you as you make the transition to the next stage of your life;
- Where you see your life going in the future, both in the short term and the long term.

The interview will last around one hour and will take place in my office (TWOM02), where our conversation can be held in private. Before you decide if you wish to take part you need to understand why the research is being done and what it would involve for you. Please take time to read the information on the following pages very carefully. Talk to your friends or family if you wish and ask me if there is anything that is not clear or if you would like more information. You can contact me directly at <u>j.vincent1@yorksj.ac.uk</u> or <u>j.vincent@lancaster.ac.uk</u>.

Thank you for taking the time to read this and I look forward to hearing from you soon.

# What is the project about?

At the moment, there is very little information about how students with Asperger's syndrome or High Functioning Autism experience the transition out of university or about what they want to do when they graduate. I want to get students' insider perspectives in order to understand more about the successes and challenges of this experience as well as raise awareness and improve practice among staff at universities and employers.

# Why have you chosen me?

You have been invited to take part because your views and experiences are extremely important for understanding more about the transition out of university for students with Asperger's syndrome or High Functioning Autism. In order to make the support in the final year better and find out how we can enable you to achieve your aspirations, we need to ask the experts – the students themselves!

# What will I have to do?

The interivew will consist of me talking to you for around one hour. I would like to find out about your time at university and where you see your life going in the future.

We will also discuss your experiences of being a student in your final year of university and the sorts of support that are/were in place to assist you as you make/made this transition to the next stage of your life.

The interview can take place in my office (TWOM02) or at a different location if that would make you feel more comfortable. I would also be happy to conduct the interview by Skype or email if you would prefer.

# What will you do with the information I tell you?

All information collected in our interviews will be kept confidential. Your confidentiality, privacy and anonymity will be ensured in the collection, storage and publication of research material.

If your data is used, it will not identify you in any way or means. A pseudonym will be given to protect your identity in the research report and any identifying

information about you will be removed from the report. All pseudonyms will be securely stored and kept by myself.

The data (information from our interviews) may be kept for up to ten years after the successful completion of the PhD Viva as per Lancaster University requirements. Audio recordings will be deleted from portable media and stored on my personal laptop where it will be encrypted; where there is an interim period the recording device and data will be stored securely. You can request to view the field notes or listen to the audio at the end of the interview and any parts you are unhappy with will be deleted, or disregarded from the data. You have the right to request this data is destroyed at any time during the study as well as having full protection via the UK Data Protection Act. The completion of this study is estimated to be by August 2017 although data collection will be complete by November 2016.

The data may be used for future journal articles and conference presentations, however, the same levels of confidentiality, privacy and anonymity will be applied and the data may be required for up to ten years. After this period the data will be destroyed.

### Do I have to take part?

No, your participation is entirely voluntary. If you do not want to take part, then please let me know.

You can withdraw at any time during the study and there is absolutely no obligation on you to continue or penalty for withdrawing. Please note that you will have a two week 'cooling off period' after your interviews – within this time you withdraw and ask me to delete all of your information, however, after this point you can still withdraw but your data will remain in the study.

### Who can I contact for further information or with concerns?

If you would like further information on this project or the programme within which the research is being conducted please contact me:

# Jonathan Vincent - PhD researcher

Tel: 01904 876136 Email: <u>j.vincent1@yorksj.ac.uk</u> or <u>j.vincent@lancaster.ac.uk</u> Room: TWOM02, Temple Wing, York St John University, York, YO31 7EX

If you have any concerns about the project or my conduct as a researcher please contact:

**Professor Paul Ashwin – Head of Department** Tel: +44 (0)1524 594443 Email: <u>P.Ashwin@Lancaster.ac.uk</u> Room: County South, D32, Lancaster University, Lancaster, LA1 4YD, UK.

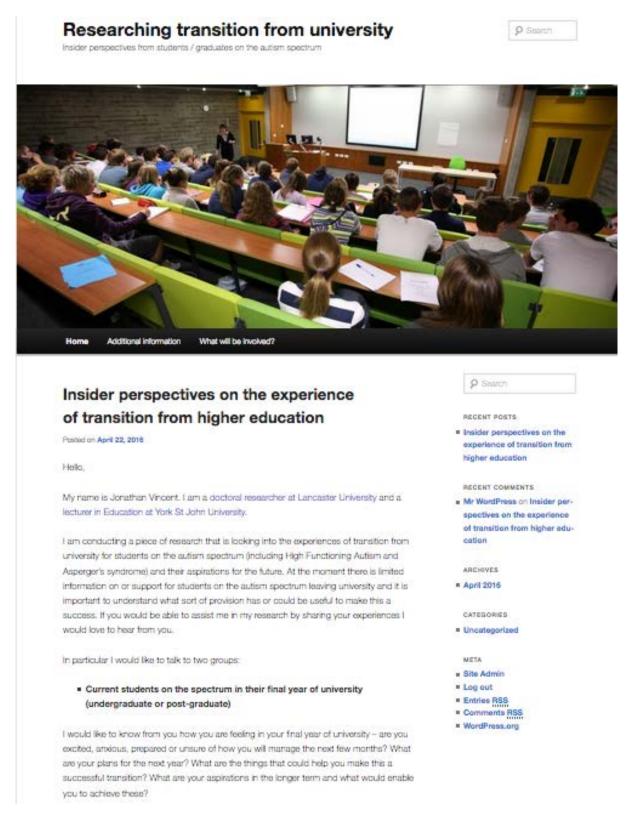
Thank you for reading this information sheet,

Weller Unerf

**Jonathan Vincent** 

# Appendix Three – Participant Information / recruitment blog (sample)

For full information visit: <u>http://blog.yorksj.ac.uk/transtionfromuniversity/</u>



# Researching transition from university

P Starch

Insider perspectives from students / graduates on the autism spectrum



# Additional information

Title of Project: A future of possibilities: a qualitative study into the aspirations of students on the autistic spectrum making the transition from higher education

#### **Research Student: Jonathan Vincent**

- . Full Address: York St John University, Lord Mayor's Walk, York, YO31 7EX
- Tel: 01904 876136

Edit

· Email: j.vincent1@yorksj.ac.uk or j.vincent@lancaster.ac.uk

#### Supervisor: Dr Jan McArthur

- · County South, Lancaster University, LA1 4YD, UK
- Tel: +44 (0)1524 592290
- · Email: j.mcarthur@lancaster.ac.uk

Ethical approval for this project has been granted by Lancaster University's ethics committee: [UREC reference RS2015/54]

#### Participant information sheet

1. What is the project about?



# What will be involved?

#### How will the interview take place?

I would ideally like to meet you in person to conduct the interview. The best place would be where I work at York St John University but if you are within travelling distance I can also come to somewhere more convenient for you.

However, if meeting in person is not possible I would be happy to conduct the interview using Skype, phone or for you to write responses via email.

I would also be happy to meet / skype with you during the summer months (June/July) after exams if that would be better.

#### How long will it take?

It is just one interview and most so far have lasted between 60-90 minutes.

#### Is there more information?

Yes, I can send you more information about consent, recording and data protection via email.

Ethical approval for this project has been granted by Lancaster University's ethics committee: [UREC reference RS2015/54]

# **Appendix Four – Consent Form**



**Title of Project:** A future of possibilities: a qualitative study into the aspirations of students on the autistic spectrum making the transition from higher education Name of Researcher: Jonathan Vincent

		Please tick if	
		you agree	
1.	I confirm that I have read and understand the information sheet dated 24.09.15 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		
2.	I understand that my participation in this research study		
	is voluntary. If for any reason I wish to withdraw during		
	the period of this study, I am free to do so without		
	providing any reason.		
3.	I consent to the interview being audio recorded.		
4.	I understand that my contributions to an interview will be part of the data collected for this study and my anonymity will ensured. I give consent for all my contributions to be included and/or quoted using a pseudonymin this study.		
5.	I understand that after the two week 'cooling off period' after my interview I can still withdraw but my information will remain in the study.		
6.	I understand that the information I provide will be used for a PhD research project and the combined results of the project may be published.		
7.	I understand that I have the right to review and comment on the information I have provided.		
8.	I agree to take part in the above study.		
Name of Participant: Signature:			
Date:			

# **Appendix Five – Interview questions (Students)**

# Data Collection procedure - life maps + semi-structured interviews

My PhD is trying to find out more about (1) how the period before finishing university is experienced; (2) what your aspirations are for next year; (3) and your plans for the longer term / future and the different things that might impact on how you achieve these. The point of this is to find out from as many people as possible so that we know more and can then (hopefully) change what universities / colleges do to support their students at this stage of their degree programme.

# Part 1 - transition from university

- Let's start with an easy one Just tell me first of all what course you are doing why did you choose that course in particular? Have you enjoyed it?
- As you know I'm particularly interested in the experiences of students with AS / HFA - Can you tell me a little bit about when you got your diagnosis of Aspergers/HFA – was that at school – what impact did that have for you – personally – and in education?
- [What about studying at university? Has being an autistic / AS student made a difference? Are there particular things that are challenging or has it given you any advantages or particular skills?]
- How do you tend to find transitions? How did you find the transition from school/college to university?
- In the next few months you are about to finish your undergraduate degree, How are you feeling about that? [Listen and probe emotional responses excitement / anxiety etc.]
- What does finishing university as an undergraduate mean to you?
- In what ways is your transition from university similar or different to when you made the transition from school to university? Do you feel different now- in what ways?
- What for you would a successful transition from university look like and what would help you to achieve it?

# (PINK) IMMEDIATE FUTURE - POST-IT NOTES

- **Talk me through your plans for the next year** what is next after university?
- Life is made up of lots of different important aspects friends, family, jobs etc. What for you would a happy or fulfilled life look like? Write these on different postit notes.
- What do you think you will be doing or where do you think you will be living etc.? [3 months, 6 months, year]

- How might things be different for you after you graduate? [Job, friends, parents, independence etc?]
- What sort of support have you received from the university (lecturers, mentors, Learning Support) or others (parents, friends etc.) to help you get ready for what might be after university?
- [Depending on previous answer] Is there any additional support or provision do you think would be useful?
- What could employers / others do to support you into a job?
- Is there anything that you think autistic graduates or people on the spectrum bring to a job that non-autistic people don't?
- When you made the transition from school / college you went from legally being a child at home to an adult at university how do you think about the transition from university to whatever is next are you at a different stage now?

# <u>(GREEN) LONGER TERM FUTURE - POST-IT NOTES</u> - life aspirations beyond university

Life is made up of lots of different important aspects – friends, family, jobs etc. What for you would a happy or fulfilled life look like? Write these on different postit notes. [DISCUSS THESE FIRST- WHEN WILL THEY HAPPEN – WHAT WILL IMPACT ON THEM ETC]

- Which for you is the most important today? Why?
- Are the different aspects of life interdependent do they cross over or rely on each other?
- Are there any that are realistic or idealistic (more just dreams)?

<u>LIFE MAP ACTIVITY USING BOTH SHORT / LONGER TERM PLANS</u>: Thinking about life in the future and all the different aspects of it – can you try to draw in form of diagram / map how you see your life progressing – we might think of this in short term (next year), medium term (5 years) and long term (30 years)?

- What is ahead in the next year? What would you like to be doing?
- What about the next 5 years?
- What about in 30 years from now what would life be like for you? What would you be doing?
- [Responding to what they write] What might the challenges be? What happens if things don't go to plan?
- [Responding to what they write] What would help you achieve all these?

• Are there any particular personal strengths or characteristics that you think might help you in achieving your goals?

### <u>FINISH</u>

- Those are all the questions that I have is there anything else you would like to say that we have not covered?
- Thank you so much for giving up your time to talk with me as I said, hopefully, with your insight we will be able to affect some change in universities.

# **Appendix Six- Interview questions (Graduates)**

# Data Collection procedure - life maps + semi-structured interviews

My PhD is trying to find out more about (1) how the period before finishing university is experienced; (2) what your aspirations were post-graduation; (3) and your plans for the longer term / future and the different things that might impact on how you achieve these. The point of this is to find out from as many people as possible so that we know more and can then (hopefully) change what universities / colleges do to support their students at this stage of their degree programme.

# Part 1 - transition from university

- Let's start with an easy one Just tell me first of all what course did why did you choose that course in particular? Did you enjoy it? When did you graduate?
- As you know I'm particularly interested in the experiences of students with AS / HFA - Can you tell me a little bit about when you got your diagnosis of Aspergers/ HFA – was that at school – what impact did that have for you – personally – and in education?
- How do you see your diagnosis / Aspergers is it a enabling or a barrier for you?
- [What about studying at university? Did being an autistic / AS student made a difference? Are there particular things that are challenging or has it given you any advantages or particular skills?]
- Can you tell me about your experience of university in the final year, when you were finishing your undergraduate degree, How did you feel about that? [Listen and probe emotional responses excitement / anxiety etc.]
- When you were leaving university, what did you want to be doing? What were your plans and aspirations?
- In retrospect, do you think these aspirations were realistic?
- What support did you receive from the university while studying? Was there any additional support to help with your transition out of university? Student support / lecturers / careers etc?
- Looking back, is there any support that you did not get but that might have been useful?
- Did others around you support you as you left full time education? In what ways?

# Part 2 - Since graduating

• Can you describe how you felt once you had graduated? Did you feel different?

- How did life change for you? Support, structure, friends, independence, relationships etc?
- What did you in the first 6 months after graduating? Did you get a job straight away? How did you feel about that?
- Can you tell me what you have been doing since you graduated, are you working at the moment?
- Is this what you thought you would be doing in your final year? Why / why not?
- Did you disclose your Aspergers diagnosis to employers? Why / why not? Have you found it a barrier or enabling? Are there any particular personal strengths or characteristics that you think having AS gives you?
- Outside of work are there other things that are important to you / that you do?
- Do you live with parent / independently? How do you find that?
- Is family still important for you at this stage in life? Will there come a time when you don't need them as much?
- When you were at school you were effectively a child, at uni you were legally an adult what would you call the stage you are at now?
- How did you find the transition from full time student to the stage you are at now –Do you feel like an adult yet?
- What has enabled / got in the way of making your plans / aspirations a reality? Are there things that have (or would have) helped you as you made the transition from student to 'independent adult'?
- Thinking back to yourself at university and now do you think that you have you changed? In what ways?

# <u>Part 3 - life aspirations beyond university</u> GREEN<u>POST-IT NOTES</u>:

• What are the things that you have done / achieved since graduating that you feel proud of – this can be any aspect of life (big or small).

# PINK POST-IT NOTES:

- What are the different things that you have not yet achieved or done but would want to?
- Having left university now and been in the 'real world', do you have a different perspective on future goals?
- Which of these are short or long term goals? Which might you achieve in the next year, 5 years, 20 years?
- What is the next step or steps for you now?
- What will need to happen in order to achieve them?
- What might prevent these from being achieved?

# LIFE MAP ACTIVITY USING BOTH SHORT / LONGER TERM PLANS: Thinking about life in the future and all the different aspects of it – can you try to draw in form of diagram / map how you see your life progressing – we might think of this in short term (next year), medium term (5 years) and long term (30 years)?

[Talk through the life map in combination with the Post-Its – how do they understand the transition(s) and what will help them to achieve these things?]

### <u>FINISH</u>

- Those are all the questions that I have is there anything else you would like to say that we have not covered?
- Thank you so much for giving up your time to talk with me as I said, hopefully, with your insight we will be able to affect some change in universities.