

***'Another door into a new world waiting to be explored': a psycho-social  
investigation into the transition experiences of young adults with autism using the  
Grid Elaboration Method***

Jane Park

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Tavistock and Portman NHS Foundation Trust

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## Abstract

Transition research tends to consider the experiences of 'typically developing' pupils and focusses on the primary to secondary school transition. Accounts that specifically focus on the views of pupils with autism also tend to rely heavily on the accounts of parents and staff. This study aimed to explore the transition experiences of young adults on the autism spectrum from the perspective of the young people themselves, having an exploratory and emancipatory purpose.

Four young people with diagnoses of autism (three male, one female) aged between 18 and 22 years old, enrolled on further education training courses in two colleges in two different outer London boroughs, were recruited to the study. A qualitative methodology was used, involving a psycho-social method of data collection which comprised of individual interviews applying the free association Grid Elaboration Method (Joffe & Elsey, 2014) and thematic analysis of the data. Each participant was interviewed about their experiences of transition. Interview transcripts were analysed using thematic analysis following guidance from Braun and Clarke (2006). Researcher field notes were used to support the analysis. Six themes emerged from the data: Resilience, Growth and Development, Relationships, Mental Wellbeing, Agency and Understanding Difference. Strengths and limitations of the study, in addition to further applied implications of the findings for professionals working with young adults with autism, were identified.

The study highlighted the importance of eliciting the views of young people with autism in order to facilitate positive transition experiences, which are likely to influence future outcomes for young people with autism.



## Confidentiality

All sensitive information has been anonymised throughout the document and this thesis contains no personally identifiable information.



## List of abbreviations

APA	American Psychological Association
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
DSM-5	Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition
EP	Educational Psychologist
FAS	'Finished at School' programme
FE	Further Education
GEM	Free association Grid Elaboration Method
HFA	High-functioning autism
ICD-10	International Classification of Diseases-Tenth Edition
IPA	Interpretive Phenomenological Analysis
IRISS	Institute for Research and Innovation in Social Sciences
LEA	Local Education Authority
NAS	National Autistic Society
NASEN	National Association for Special Educational Needs
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
SDT	Self-determination theory
SEN	Special Educational Needs
SLCN	Speech, language and communication needs
TEP	Trainee Educational Psychologist
WHO	World Health Organisation



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## Chapter 1: Introduction

*'It can be easy in many current practices to draw upon theoretical resources that engage only secondarily with the nature of the experiences of the children with whom we work. However, I also argue that any understanding which as professionals we might have of a child's difficulties, and therefore the appropriateness of our advice, may well be dependent on our ability to have some insight or understanding into the child's experience, in particular their experience of intense feelings.'* (Billington, 2006, p.3)

### 1.1 Chapter introduction

This research offers what is to the best of my knowledge the first study of its kind, empowering young people with autism who are enrolled on further education courses at mainstream colleges to have a voice about their transition experiences. I begin by outlining the aims and objectives of this study and the rationale behind writing in the first person. I continue by foregrounding my epistemological and ontological position with the aim of illuminating the philosophical underpinnings of the methodological decisions I made, which are more fully explored in Chapter 3. Next, I situate the present study in a personal context by providing a brief outline of the journey which stimulated my interest in carrying out a piece of Doctoral level research into the transition experiences of young people on the autism spectrum. This is followed by definitions of key terms of reference, 'autism' and 'transition'. I move on to situate this study in relation to UK government policy and to give an overview of transition research with young people on the autism spectrum. The chapter concludes by outlining the structure of the rest of the thesis followed by a brief summary.

## 1.2 Research aims and objectives

The aim of this piece of research is to explore and articulate the transition experiences of young people on the autism spectrum who are enrolled in further education at mainstream college. I have broken down this overarching aim into the following more specific research objectives:

1. I intend for this piece of research to be emancipatory since, in the UK literature, accounts of the views of young people with autism on their transition experiences are clearly underrepresented. As described by Edwards and Holland (2013, p. 20) 'from an emancipatory perspective, the aim of conducting research is to enable the voices of marginalised groups to be heard on their own terms'. This is the definition of 'emancipatory research' that I adopted for the purposes of this study. Perfitt (2013) argues that, because of its impact on an individual's ability to engage in social communication, young people with autism face significant challenges regarding issues of agency, autonomy and independence in relation to their experiences of transition. One way to be truly emancipatory in research is to use creative ways to elicit the richness of individual views and experiences, from which helpful suggestions may arise, while remaining mindful and appreciative of the uniqueness of each young person's individual experiences as a whole; the '*gestalt*'. Hollway and Jefferson (2008, p.307) describe *gestalt* as follows: 'As well as the transcripts from both interviews, we have our memories of meetings with that person; the notes we took after the first meeting and subsequent interviews and also, where more than one family member was interviewed, what was said about our participant by others. But this definition refers only to an external reality.'

Maybe the gestalt principle is best understood also as the internal capacity for holding those data together in the mind.'

2. Another objective for this research is to explore and gain insight into the viewpoints and unique emotional experiences of young adults with autism who have experienced a number of educational transitions and have transitioned into further education and/or training.

3. Billington (2013) writes of what he sees as an evolution in process, which is leading to the development of 'critical' research methodologies that aspire to redefine the power relations in research, and which promote the inclusion of young people themselves in the research process. In relation to the inclusion of young people with autism, Milton, Mills and Pellicano (2012, p.2651) describe the need for 'mechanisms that both place the perspectives of autistic people 'at the centre of the autism conversation' (Ne'eman 2011) and are attentive to the diversity of voices within the autism community. Such mechanisms must also be truly participatory (see Pellicano *et al.* 2011; Ne'eman 2011), actively seeking to overcome the power differentials that exist between autistic people and established authorities.' Taking inspiration from Billington (2013) and Milton, Mills and Pellicano (2012) the third objective is to consider the value, both actual and potential, of applying a novel research method to the field of autism research, with the hope of shifting the inherent power imbalance to a more equitable position.

### 1.3 Writing in the first person

Traditionally, scientific research has tended to be written in the passive voice or in the third person to emphasise objectivity and create distance from the arguments

being put forward, avoiding the use of the first person apart from in reflective or reflexive aspects. However, Foster and Parker (1995) argue that one way to acknowledge the creative and active role of the researcher is to use the first person. As transparency and openness about the researcher's relationship to the production of knowledge is key to my ontological position, outlined in section 1.4 below, I made the decision to write in the first person throughout.

## 1.4 Epistemology and ontology

### 1.4.1 Epistemology

Epistemology refers to the assumptions we make about what it is possible for us to know and how this knowledge can be obtained, which frames one's interaction with what is being researched. Both for the purposes of this research and in my professional life I take the epistemological standpoint that young people with autism are experts in their own lives and can and should be active and autonomous agents in relation to the production of knowledge, at the same time positioning myself as someone who believes professionals have much to learn from young people with autism. I took the decision to ascribe to a constructivist epistemological position to guide the research for several reasons. A constructivist paradigm acknowledges that each individual constructs his or her own reality, so there can be multiple perspectives, with the emphasis being on the viewpoints of the participants. In relation to the present study, I take the view that constructivism means, as researchers, we need to be aware of our own experiences, backgrounds and cultural context, and recognise those of our participants. As Burr (2003) demonstrates, a constructivist epistemological position proposes that 'knowledge' and 'reality' are constructed in the intersubjective interaction between researcher and participant.

As Guba and Lincoln (1994, p.111) describe, a constructivist epistemology posits that findings are created as the research investigation proceeds, and that the researcher and participant ('investigator and investigatee') are interactively linked.

#### 1.4.2 Ontology

'Ontology' refers to the stance of the researcher to the world and to their participants. For the purposes of this study I have taken up a relativist ontological position, which takes the view that knowledge is value-laden and emerges through individual interpretation. Though psychology has historically sought to ensure that the research process and analysis is 'value-free' and not unduly influenced by the researcher's biases, research from a relativist ontological position acknowledges that it is impossible to remove the influence of the researcher from the process, and in fact, this adds to the richness of the findings rather than detracts from it. This is congruent both with the psycho-social method of data collection used in this study and with thematic analysis of the data. In their article for *The Psychologist*, Braun and Clarke (2013, p.122) take the position that 'qualities such as subjectivity do not produce bias that undermines the research, but are essential to good qualitative research practice.' However, it is essential that the researcher maintains a reflexive stance throughout and acknowledges the role that their previous experiences, background, preferences and assumptions has on the participant and the construction of knowledge (Mays & Pope, 2000). This was facilitated in the current study by the use of a reflective research diary, which is discussed in more detail in Chapters 3 and 5.

### 1.5 The research origins: a personal context

In research from a positivist tradition, a focus on the background and emotions of the researcher would be regarded as unwarranted interference in the research process. However, as Woods (1996) points out, in psycho-social approaches influenced by feminism and post-modernism, the background of the researcher is seen as inextricably linked to the production of knowledge, and the research findings inevitably constitute a production based on the interplay between the researcher's perspective and that of their participants. Therefore, in the interests of transparency and openness about my relationship to the field of study I would like to offer a brief insight into the life experiences which led me to undertake this piece of research. I wish to communicate awareness that my own experiences with working with young people on the autism spectrum are likely to have influenced the way that I designed the research and interpreted the findings.

I moved to London in 2000 and began to work as a peripatetic music teacher in a number of mainstream primary and secondary schools around London. Here I encountered several children and young people on the autism spectrum and I became curious about how to engage with these children most effectively. As my curiosity grew, and I recognised the sense of enjoyment I got from working and engaging with young people on the autism spectrum, I took the decision to seek a position in a pioneering special school for primary aged children with autism. At the time there were only fifteen children in the school, many of whom were non-verbal. Working with this cohort of amazing individuals brought me great pleasure and I have fond, vivid memories of my time there.

I left the school to have my first child, and, after a period of being a full-time mother, I began working part-time as a Personal Assistant to a young boy with autism and his family. It was from within the family system that I developed a deeper understanding of the pressures on a family raising a child with autism, most memorably the demands on them emotionally, physically and financially, largely in the name of accessing the most appropriate educational provision for their son. It was this combination of experiences that inspired me to train as an educational psychologist (EP).

While studying for a degree in psychology and raising my growing young family I carried on working part-time for a local charity's 'respite' scheme, which enabled me to work with young people with a range of disabilities across the age range (5 to 19 years) and their families. So many of the young people with autism with whom I was working struggled with the post-18 transition into the next stage of their lives. It was almost as if they disappeared after their nineteenth birthday. I wished to develop an increasing appreciation of the opportunities and challenges these young people face as they move into adulthood and, having successfully gained a place on the EP training course at the Tavistock, to consider the potential implications of this on EP practice. It was inevitable that, when afforded the opportunity, I would take the chance to carry out a formal piece of research into this area.

As I began to prepare my research protocol I saw that the views of young people with autism had received scant attention in the literature, which seemed to be related to perceived difficulties in accessing their views. It appeared that the

views of professionals and of parents were prioritised over the young people themselves. I was passionate about finding a way to get a real sense of their experiences of transition and to find an effective way to facilitate their voice in the process. This is captured perfectly by Milton, Mills and Pellicano (2012, p.2650): ‘While nonautistic [*sic*] parents and professionals might claim that they are best placed to speak for autistic individuals, especially those who find it difficult to speak for themselves, this cannot be accepted on face value. We believe that human dignity requires us to make every effort to access the views and perspectives of autistic people.’

## 1.6 Terms of reference: ‘autism’ and ‘transition’

### 1.6.1 Autism

The present study focuses on one particular diagnostic category of Special Educational Needs (SEN), namely autism. Autism is commonly referred to as an Autism Spectrum ‘Condition’ (ASC) or ‘Disorder’ (ASD) (Wing & Gould, 1979; Frith, 1991; Roth, 2010). As Roth (2010) demonstrates, clinicians or specialists tend to use the term ‘autism spectrum disorders’ in the context of diagnosis and clinical practice, while individuals on the autism spectrum tend to favour the more neutral term ‘autism spectrum conditions’ (ASC). Since the National Autistic Society (NAS) advocates the use of ‘people-first’ language, I decided to adopt ‘young people on the autism spectrum’ or ‘young people with autism’ as my main terms of reference.

From a narrow diagnostic viewpoint autism is often constructed as a ‘lifelong developmental disability’, defined in the tenth revision of the World Health Organisation’s (WHO) International Classification of Diseases (ICD-10; WHO, 1992) by the following: (1) qualitative impairments in reciprocal social interaction, (2)

qualitative impairments in communication and (3) restricted, repetitive and stereotyped patterns of behaviour, interests and activities. Autism is defined in the fifth edition of the Diagnostic and Statistical Manual (DSM-5; American Psychiatric Association, 2013) by two core domains: (1) persistent deficits in social communication and social interaction across multiple contexts and (2) restricted, repetitive patterns of behaviour, interests or activities. The changes to the diagnostic criteria for an ASC in DSM-5 represent a significant shift in how autism is conceptualised: the diagnostic label 'ASD' now incorporates those who may already have had an established diagnosis of Asperger syndrome or pervasive developmental disorder not otherwise specified (PDD-NOS), while sensory sensitivities are included for the first time as part of the possible range of criteria. However, as the NAS (2014) explains, although DSM-5 is influential, the main set of diagnostic criteria used in the UK is the ICD-10 and it would seem that there have been no major changes to the way that autism spectrum conditions are diagnosed and understood in the UK since DSM-5's introduction.

As Billington (2013, p.176) writes, initial training for child or educational psychologists in the UK and beyond continues to be organised around diagnostically-oriented studies of disorders or difficulties such as autism, and are thus at risk of losing sight of the young person, who 'disappears under the weight of their diagnostic label'. For Billington (2013, p.176) this results in a 'chasm between professionalized discourses of particular psychopathologies and critically informed discourses of experience.' However, Billington (2013, p.176) takes the position that the development and application of critical methods in both research and professional practice 'has created opportunities for discourses which seek to resist

and challenge such fragmented models of the child, their human qualities and intelligences.'

Billington (2006) demonstrates the ways in which 'insider' accounts provide professionals with a valuable source of information when developing practices. Dann (2011) highlights how the growing body of autobiographical accounts of people with autism has enabled discussion to shift from being centred around autism as a 'difficulty' or 'disability' to an understanding of autism as a 'difference' in cognitive style (Grandin, 1995; Jackson, 2002; Mitchell, 2005; Williams, 1996). 'Worldly accounts' such as these provide valuable insights into the lived experiences of individuals with autism, despite their methodological limitations. Billington (2006, p.1) writes with an aim of creating 'narratives of autistic experience that are not restricted by a primary consideration of impairments or deficits but rather related to ideas about 'assets' as a means of developing professional practice'. Providing further support for alternatives to the 'deficit' model of autism, Silberman (2015) writes of the growing positive movement of 'neurodiversity', reframing autism in terms of 'people who think differently' and mapping out a broader model for acceptance, understanding, and full participation in society for people with autism. This is, essentially, the Social Model of Disability, which recognises that the world needs to adjust so that people with autism can fit in (Findlay, 2016). This philosophy has been influential in shaping my ontological position.

### 1.6.2 Transition

In the autism research literature 'transition' can refer to, for example, moving between activities or steps of activities or between areas of a

nursery/school/college, at the 'micro' level (Attwood, 1998). However, for the purposes of this study, the term 'transition' is used to describe major moves between educational provisions at the 'macro' level (Attwood, 1998), such as from school to further education (FE) college, and between different academic years.

Underpinning the behaviour of children and young people with autism is the 'triad of impairments' (Wing & Gould, 1979; Wing, 1993) which refers to difficulties with social interaction, social communication and imagination. The triad of impairments provides a framework for understanding how autism may affect an individual, since as autism is a spectrum condition there is wide variation in how these difficulties are manifested. According to the NAS (2014), ASC affect people in different ways; while some may live relatively independently, others may require a lifetime of specialist support. As Hannah and Topping (2012) explain, young people with autism may experience difficulties in managing changes of routine, which can lead to raised anxiety levels. For this reason, the careful management and planning of transitions is of particular relevance to young people with autism.

### 1.7 Relevant government policy and the UK national context

The focus of this study is on the experience of young adults with autism in the UK.

When considering policy frameworks, implications and outcomes, the UK experience is the primary field of study.

#### 1.7.1 UK policy context

This research is situated in the UK national context of the recent introduction of a new Children and Families Act (Department for Education, 2014 a) and updated Special Educational Needs and Disabilities (SEND) Code of Practice: 0-25 Years

(Department for Education, 2014 b). Key points from these recent legislative changes which are having an impact on the lives and well-being of young people on the autism spectrum and their families include the introduction of a single assessment process and an Education, Health and Care (EHC) Plan to support children, young people and their families from birth to 25 years, replacing statements of special educational needs. Further key changes include the requirement of health services and local authorities to jointly commission and plan services for children, young people and families and the right to a personal budget for the support that children, young people and their families receive. A clear, easy-to-read 'local offer' of services available to children and families is now required to be published by local authorities, and the involvement of families and children in discussions and decisions relating to their care and education has been prioritised. Recent legislative changes are also having an impact on the context in which EPs practice; for example, prior to the new Children and Families Act (2014), EPs and trainee EPs (TEPs) broadly worked with the 0-19 age range. The extension to 25 represents an important change to the role of EPs and TEPs, providing many opportunities to extend both the EP role and service delivery in relation to supporting the transition to adulthood for young people.

According to data from the NHS (2012) recent estimates suggests that there are approximately 700,000 people in England with an ASC, of whom around 100,000 are children and young people. The most recent available data from the Office of National Statistics, released in 2013 though apparently dating from 2004, suggests a prevalence rate in the UK of 1% with around 82% of those with a diagnosis of ASC being male (Office of National Statistics, 2013).

In 2014 the UK coalition government raised the compulsory education participation age; young people in England are now required to continue in education or training until at least their eighteenth birthday. This has had significant implications for young people with autism who, research suggests, are more likely at age 18 to be out of education, training or employment than their peers (Knapp, Romeo & Beecham, 2009). According to statistics from the Department for Education (2011) there are over 43,000 children with autism in mainstream schools, compared with just 10,440 learners with autism in mainstream further education.

### 1.7.2 Impact of government policy on the lives of young people with autism

Current research suggests that young people on the autism spectrum potentially face a range of issues as they transition into adulthood, such as unemployment, social isolation, lack of independence, mental health needs and general fears for the future (Hewitt, 2011; IRISS, 2014; Wehman, Schall, Carr, Targett, West & Cifu, 2014). According to Ambitious about Autism<sup>1</sup> and their 'Employ Autism' campaign, just 15% of adults with autism are currently in full time paid employment, which the organisation attributes to a lack of support and opportunity for young people with autism to transition successfully into the workplace (Ambitious about Autism, 2015).

In recent years, there has been a growing focus on the mental health and wellbeing of young people with autism, a trend which has been linked with the person-centred focus of the new SEND Code of Practice (Department for Education, 2014 b). Person-centred approaches are guided by the principle that everyone involved in working with children, young people and their families in assessment and

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<sup>1</sup> Founded in 1997, Ambitious about Autism is a UK-based registered charity for children and young people with autism, with the aims of providing services, raising awareness and understanding and campaigning for change.

planning processes should focus on the child or young person as an individual, enabling children and young people to express their views, wishes and feelings and supporting them to contribute to decision-making processes. Mercieca and Mercieca (2014) posit that listening to young people is an integral part of the role of the EP. In relation to transition planning, the involvement of young people at the heart of the experience is becoming more widely practiced and understood.

In 2009, the introduction of the Autism Act imposed various statutory duties on local authorities in relation to their delivery of social services (Department of Health, 2009), though not their education function. In 2010 the Department of Health published its national strategy for adults with autism in England, 'Fulfilling and Rewarding Lives', in which the Autism Act is described as a 'groundbreaking piece of legislation [which] signalled a commitment from the government to transforming the way public services support adults with autism' (Department of Health 2010, p.4). 'Think Autism', an update of the strategy, was published in 2014. Its reported priorities include improving the experience of the move from school to college and into adulthood for young people and their parents/carers, moving towards leading fulfilling lives. Knapp *et al.* (2009) conducted a study which sought to estimate the economic cost of ASC in the UK, providing an indication of the economic impact of the levels of educational attainment and relatively low employment rates for young adults with ASC.

The Equality Act 2010 is clear that all education providers must make 'reasonable adjustments' to ensure disabled learners are not discriminated against. However, despite government policy and guidance concerning the inclusion and

involvement of young people with autism in the development of provision (e.g. Department of Health 2001a; 2007), there is little evidence to suggest that young people with autism have 'had much of a voice in service development or, indeed, the shaping of their own individual service and support arrangements' (Institute for Applied Health and Social Policy, Kings College and the Judith Trust, 2002, p.30). Exceptions to this include the Finished at School Programme (FaS Programme) which was a two year Department for Education-funded project led by Ambitious about Autism in partnership with the Association of Colleges and the National Association for Special Educational Needs (NASEN), operating from April 2013 until March 2015 with the stated aim of improving the transition from school to college and community life for young people with autism. One of the stated primary success factors of the FaS Programme was that it identified 'approaches used to listen to learners and secure their active involvement in making decisions about their future' (FaS Programme, 2015, p.9). It is clear that empowering young people with autism to have an active voice about their experiences is of vital importance in facilitating positive future outcomes.

Having situated this research in the UK national context of government policy, with consideration given to the impact of policy on the lived experiences of young people with autism and to the importance of their voices in the transition planning process, I will now go on to explore how these related issues are represented in the existing body of transition research with a particular focus on eliciting the views of young people with autism.

## 1.8 Eliciting the views of young people with autism

The importance of enabling the voices and views of children and young people to be heard and prioritised is well understood (Ashton, 2008). However, the views of young adults on the autism spectrum in relation to their experiences of transition to further education in the UK have received surprisingly limited exploration. Existing studies which focus on eliciting the views of children and young people with autism are primarily focused on accessing the views of children who are moving from primary to secondary education (Horsley, 2014). Much research in relation to the challenges faced by young people with ASC at key transition points which aims to elicit any views at all largely focuses on parental perspectives; evidence suggests that, when the perspectives of the young people at the heart of the experience have been sought, their views tend to be mediated by their parents and/or teaching staff (Jindal-Snape, Douglas, Topping, Kerr & Smith, 2006; Humphrey & Lewis, 2008; Horsley, 2014; Fortuna, 2014). Therefore, there remains a relatively limited body of qualitative research that aims to elicit the perspectives of young people with autism. Those studies which more directly access the views of young adults have brought about positive change for young people with autism by enabling professionals to develop a deeper understanding of the systems, practices and support which they particularly value. These include support in developing social skills, learning to travel to college independently and receiving empathy and understanding from staff who have accessed autism awareness training, thus demonstrating the rich value which can be gained by accessing young people's views (Browning, Osborne & Reed, 2009; Beardon, Martin & Woolsey, 2009; Mitchell & Beresford, 2014).

In his article for *The Psychologist* magazine, Jarrett (2014) interviewed a research assistant from the University of Connecticut, Allison Shefcyk, who was diagnosed with an ASC aged three. Shefcyk is quoted as saying 'Much of current research is developed under what professionals believe parents need and want, but rarely ask us [people with autism] directly for our opinions; even when formulating research and policy that has a direct impact on our lives...speaking for yourself and others with the hope that they can have a better tomorrow is a wonderful thing that must be cultivated for people with autism' (Jarrett, 2014, p.748). By speaking directly to young adults on the autism spectrum about their experiences of transition I hoped to gain a deeper understanding of those experiences, with a view to informing the practice of professionals working with such young people.

### 1.9 Transition research with participants who are on the autism spectrum

As Dann (2011) explains, much previous transition research tends to consider the experiences of 'typically developing' pupils (Ashton, 2008; Jindal-Snape & Foggie, 2008; Rice, Frederickson & Seymour, 2006; Lucey & Reay, 2000) and pupils with a range of special educational needs (Maras & Aveling, 2006). In relation to transitions for young people with autism, the literature has largely concentrated on the transition from primary to secondary school (Jindal-Snape *et al.*, 2006; Dann, 2011; Hannah & Topping, 2013; Fortuna, 2014; Horsley, 2014). Links have been made between transition issues affecting both typically developing children and those with an SEN; for example, in their quantitative study of a set of typically-developing year 6 pupils in mainstream education, Rice, Frederickson and Seymour (2011) assessed pupil concerns about transition to secondary school, concluding that the effective negotiation of transition points will impact on future success.

Rice, Frederickson and Seymour identify the top five 'stress factors' for these children as homework, bullying, remembering equipment, size of school and changing class. Linking with this, Dann (2011) demonstrates how the experiences of pupils with ASCs are likely to reflect the experiences of those who are typically developing and with other types of SEN. Perfitt (2013) outlines a range of considerations when planning transitions for pupils with speech, language and communication needs, which in this study included consideration of young people with ASC. Her findings support Dann (2011) and Rice, Frederickson and Seymour (2011) 'suggesting there is little difference in the stress factors between pupils in [special school] and pupils in mainstream school during transitions' (Perfitt, 2013, p.191).

There exists a growing body of research which seeks to learn how best to support young people with autism at transition points, though the voices of the young people at the heart of the experience is surprisingly under-represented. Regarding the transition from school to further education there exists a limited range of research, which is reviewed and summarised in Chown and Beavan (2012) and relates primarily to developing an understanding of the supports which work. Chown and Beavan (2012, p.478) refer to a 'surge' of young people on the autism spectrum entering further education, which supports the findings of Ambitious about Autism's 'Finished at School' report (Ambitious about Autism, 2015). Surprisingly, Chown and Beavan (2012) make no reference to research which elicits the views of young people with autism. Published after Chown and Beavan (2012), Mitchell and Beresford's 2014 study is, to the best of my knowledge, the only one which reports the views and experiences of the transition experiences of young

people with autism in the UK. Mitchell and Beresford (2014) explored the process of transfer from school to a FE college from the perspective of the experiences of young people with 'HFA[high functioning autism]/Asperger syndrome' through thematic analysis of semi-structured interviews. The focus of their study is on exploring young people's lived experiences of transition and how their experiences may add to and develop our understanding of how best to work alongside, listen to and support these young people.

### 1.10 Thesis structure

This thesis is structured conventionally. Following this introduction Chapter 2 provides a review of the literature associated with the transition experiences of young people on the autism spectrum in the UK context, with critical reflection on the methods used to gain their perspectives. Chapter 3 details the methodology and introduces the reader to the psycho-social method that I used for data collection, the free association Grid Elaboration Method (Joffe & Elsey, 2014). Chapter 3 also details how I approached the research design, ethical considerations and the stages of thematic analysis which were applied. In Chapter 4 I present the findings, first by introducing the reader to my participants in the form of brief pen portraits and then showing the themes that emerged from the data, supported by extracts from the transcripts. Chapter 5 is a discussion of the themes in relation to the research question and gives my summary and conclusions of the research, with a review of outcomes set against the research aims given above. Following identification of the original research contributions made by this thesis, with particular focus on the role of the EP, I conclude with consideration of the limitations of this study and suggestions for further areas for research.

### 1.11 Chapter summary

This piece of research aims to find out about the experiences of young people on the autism spectrum aged 18 years plus, having transitioned into further education or training, from the perspective of the young people themselves. Few published papers address the area of eliciting young people with autism's accounts of their unique and individual experiences of transition. Very little recent work has looked specifically at the transition experiences of pupils with autism from the perspective of having transitioned into further education. It is important to address this gap in the research due to the acknowledged issues these young adults face as they transition into adulthood (Hewitt, 2011; Institute for Research and Innovation in Social Sciences (IRISS), 2014, Galler, 2014; Wehman *et al.*, 2014; NAS, 2014; Mitchell & Beresford, 2014). Since accounts which feature the voices and experiences of this group of young people are scarce, it is my intention that this research will facilitate an opportunity for a range of professionals to learn from first-person accounts of the transition experiences of young adults with autism.



## Chapter 2: Literature Review

### 2.1 Chapter introduction

The purpose of this chapter is to present the comprehensive literature review which I undertook prior to commencing the study. The aim is to:

- describe the findings of previous research in order to support understanding of current issues and establish what is already known.
- critically appraise relevant research and consider methodological implications both for the research findings and for my own study.
- justify the unique aim, objectives, research question and rationale of this research study.

In undertaking this literature review I aimed to establish a clear understanding of what is already known about the transition experiences of young people with autism. This review was then used to shape the research question and to explore which methodological approach would be most appropriate to answer the research question. Given my relativist ontological and constructivist epistemological positions outlined in Chapter 1, I was drawn to paying particular heed to research approaches which address the methodological challenges of carrying out inclusive research with young adults on the autism spectrum and those which focus on eliciting and promoting their views and experiences. Though my primary terms of reference are 'young people with autism' or 'young people on the autism spectrum', when writing about other researchers' work I have reported their findings in the terms used by the original paper, which include high-functioning autism (HFA), Asperger syndrome (AS), ASD and ASC.

## 2.2 The process of the literature review

This section is intended to make the process of this literature review as clear as possible. Information concerning past and contemporary studies on the topics of eliciting the views and transition experiences of young people on the autism spectrum were located through various means, including the use of formal databases, outlined below:

- JSTOR
- PsycINFO (accessed through EBSCO Host)
- Psychnet
- Pubmed
- ScienceDirect
- Google Scholar
- ERIC

Being mindful of the potential limitations of using databases alone, I also located relevant information through a range of relevant research organisations:

- Autism Education Trust
- Centre for Research in Autism Education
- EThOS
- National Autistic Society Autism Data
- Research Autism
- National Autistic Society Information Centre and Library

Academic literature, including text books and specialist journals, were also searched manually by means of networking backwards from the bibliographies of work that had recently been published. Websites relating to issues which impact young people with autism, such as those operated by the Department of Education, the Department of Health and the National Autistic Society, identified a range of information regarding relevant national policy. I set up automatic alerts on EBSCO Host which emailed me each time a potentially relevant paper was added to the database, enabling me to stay as informed as possible about the very latest additions to the body of research.

### 2.3 Search terms

I used a range of search terms to reflect the different terminology that may be used in relation to accessing the views of young people with autism. I ran the same searches across all the databases and research organisations listed above in order to identify as exhaustive and comprehensive a collection of relevant research and information as possible. Search terms encompassed the following, using AND and OR and including truncation where necessary:

Autism, autistic, Asperger, Asperger syndrome, Autistic Spectrum Disorder, Autistic Spectrum Condition
Transition, college, education, further education, adulthood
Views, voice, experiences, lived experiences, eliciting experiences, eliciting views
Visual methods, visuals, visual support
Youth, adolescents, adolescence, teenage, young adult

## 2.4 Inclusion/exclusion criteria

As my area of interest is located in the experiences of young people on the autism spectrum in relation to the UK education system, literature from other countries was excluded. Therefore this review was limited to work published in the English language and to material published in the United Kingdom. I gave this substantial thought, as in the process of researching for this literature review I came across several interesting and potentially relevant studies published in the USA and other countries including South Korea and Belgium. However, I decided it was important to focus on maintaining the relevance of my research to the UK national context. As unpublished dissertations/theses have not been peer reviewed in the same fashion as published journal articles they were excluded from the literature review, though I carried out hand-searches of bibliographies/reference lists for further papers to potentially include. Other 'limiters' included the year of publication (2000-2015) to allow for inclusion of research published in the last 15-16 years, though the vast majority of research cited in this chapter is from the last ten years; a reflection perhaps of the exciting pace at which the field of autism research is evolving.

The search strategy produced potential papers, and applying the inclusion and exclusion criteria ensured only relevant papers were selected. The next inclusion criteria was 'quality' and therefore I applied criteria to establish the quality of each piece of information using checklists from the Critical Appraisal Skills Program (CASP; a completed example CASP is included as Appendix A). This process enabled me to focus this literature review on a manageable set of high-quality research that is directly relevant to the UK context. Finally, these papers were synthesised into

categories (i.e. 'transition experiences' and 'accessing the views of young people with autism') to provide the structure for the review, including papers which both agreed with or challenged prior findings. A summary of the research that I included in this review is included as Appendix B.

## 2.5 Involving young adults on the autism spectrum in research

The reviewed literature provides a number of examples of research which takes the view that young people on the autism spectrum are the most suitable individuals to ask if knowledge is to be gained concerning their viewpoints and experiences (Connor, 2000; Williams & Hanke, 2007; Beardon *et al.*, 2009; Tobias, 2009; Moxon & Gates, 2010; Dann, 2011; Hill, 2014; McLaughlin & Rafferty, 2014; Shepherd, 2015). The first-person 'insider' perspective of young people with autism has been highlighted as a particular standpoint on which to focus when looking at the development of services for people with autism (Billington, 2006; Raghavan, 2004; Beardon *et al.*, 2009, Moxon & Gates, 2010; Perfitt, 2013; Hill, 2014; Mitchell & Beresford, 2014; Shepherd, 2015). Writing of the experiences of young people with autism when transitioning from child and adolescent into adult mental health services, Raghavan (2004) makes the important point that research facilitating the involvement of young people with autism has the potential to make a helpful contribution to the development of a knowledge base about the life experiences of people on the autism spectrum. Raghavan writes that 'there is a need for more self-reports and stories of the complex journeys undertaken through a variety of services' (Raghavan, 2004, p.9). This reflects the evident shift towards 'critical' research methodologies that is currently in evidence, in relation to the most valid methods for eliciting the views of children and young people with

autism, as demonstrated by Billington (2013). Moreover, in comparatively recent times, practitioner researchers have begun to take the view that young people on the autism spectrum are capable of insight, and of expressing their experiences (Connor, 2000; Williams & Hanke, 2007; Humphrey & Lewis, 2008; Tobias, 2009; McLoughlin & Rafferty, 2014; Hill, 2014; Shepherd, 2015). As a consequence of these changes relating to research approaches, there has been an increasing interest in prioritising the involvement of young people with autism in the research process.

## 2.6 Researching transition experiences

This literature review uncovered a limited body of relevant, largely recent, research that aimed to find out about the transition experiences of young people with autism across the age range. This body of research may be divided into two broad areas: studies that anticipate future transitions (Fortuna, 2014; Mitchell & Beresford, 2014; Hill, 2014) and research that looks at both pre- and, retrospectively, post- transition experiences (Jindal-Snape *et al.*, 2006; Browning *et al.*, 2009; Dann, 2011; Hannah & Topping, 2013; Horsley, 2014; Mandy, Murin, Baykaner, Staunton, Cobb, Hellriegel & Skuse, 2015; Perfitt, 2013; Shepherd, 2015). Though Hill's 2014 study did not explicitly aim to research views on future transitions, views and experiences were raised by participants organically through the research process and feature as a theme.

Though all the studies considered here aimed to gather data on the transition experiences of young people with autism, researchers adopted a range of ways to approach the gathering of data, depending on their ontological and

epistemological standpoints and their research questions. This will be explored in greater detail in the sections which follow.

### 2.6.1 Primary to secondary transition

The majority of identified transition studies looked at experiences of the move from primary to secondary school from a range of perspectives (Jindal-Snape *et al.*, 2006; Dann, 2011; Hannah & Topping, 2013; Horsley, 2014; Fortuna, 2014).

Horsley (2014) carried out a small-scale qualitative study into the transition experiences of a sample of eight boys and two girls moving from primary to secondary school, also incorporating the views of their families, using Likert scale-style questionnaires; in all cases it was their mothers who completed the parent questionnaires. The aim was to identify what parents and pupils worry about on transition to secondary school and was motivated by the researcher's observations of heightened parental anxiety in the autumn term, with a focus on developing appropriate support for parents. The children participating took part in a transition programme. Prior to the move, the group were reported to be most anxious about having property stolen. Parents were most anxious about their children making friends and managing the level of homework. Horsley (2009) notes that the use of a questionnaire leads to a loss of richness of data in which individual experience is lost. The indications which can be gained through this methodological approach are broad, but limited by the predefined range of questions they ask which, as stated by Joffe and Elsey (2014, p.181) 'do not necessarily reflect issues of subjective salience to the respondent'. In her conclusion, Horsley (2014, p.75) notes that 'interviews

would yield richer data' and indicates a need to facilitate and listen to the views of individuals at the heart of an experience in as rich and detailed a way as possible.

Though this study focussed on the premise that transitions in general are more difficult for pupils with autism, a view challenged by Mandy *et al.* (2015) as explored further on in this review, Horsley (2014) notes that major transitions can cause anxiety for any pupil and that families of children without SEN also find transition difficult. This supports studies by Perfitt (2013) and by Rice, Frederickson and Seymour (2010) in which the researchers suggest there is little difference in the stress factors experienced by pupils without SEN and pupils in mainstream school during transitions. Horsley (2014) found that the anxieties expressed by parents prior to the move to secondary education contrasted with those expressed by their children. Parents were reportedly more anxious about the transition than pupils, which supports the findings of Fortuna (2014). Fortuna (2014) found discrepancies between parental views of their child's difficulties and the child's own view, noting that two of his participants were gauged more accurately by primary school staff than by their parents. Fortuna (2014) also identified that the parental perspective on their child's difficulties can be skewed by their own worries and anxieties about their child's transition. While parental views are undoubtedly important and worthy of study, McLaughlin and Rafferty (2014) express the view that it is vital to separate out parental and young people's views in order to gain the clearest possible understanding of the issues which young people themselves report.

### 2.6.2 Secondary to secondary transition

Perfitt's 2013 study looks at a very select area of transition research, that of the impact of transitions on a self-selecting convenience sample of fifteen pupils aged 11-14 years (14 males, 1 female) with speech, language and communication needs (SLCN), specific language impairments and autism, moving from one secondary school to another following the closure of the specialist provision they were previously attending. Perfitt (2013) used an adapted version of the Pictorial Measure of School Stress and Wellbeing (Murray & Harrison, 2009, cited in Perfitt, 2013) using visual prompts such as drawings and visual scales to obtain qualitative information on pupil views about the closure of their school, thus providing a voice for their perceptions, experiences and attitudes in relation to the transition process. By scaffolding the interviews using visual supports, Perfitt (2013, p.190) hoped to overcome her participants' communication difficulties. The aim of this study was to identify a range of stress factors, examine whether any subgroups are particularly affected, and suggest practical strategies to support students through transition. Perfitt (2013) found that pupil responses were highly individualised, arguing that this demonstrates the importance of maintaining 'awareness of individual pupils' stress factors throughout transitions', as these are 'lived through by individuals in everyday life' (Humphrey and Symes, 2010, p.83, cited in Perfitt, 2013, p.191). Though Perfitt (2013, p.189) is clear that generalisability from her study is not possible, she expresses the hope that 'this insight may help improve future transitions', demonstrating the importance and relevance of student views to the development of appropriate support and provision. Perfitt (2013) notes that, though a wealth of general transition research exists, little research that specifically considers the views

and needs of pupils with SLCN including autism currently exists. This is despite the knowledge that transitions may be particularly challenging for young people with autism to manage 'due to the increased anxiety that they feel in new and changing situations' (Perfitt, 2013, p.189). Perfitt (2013) believes that 'necessary steps should be taken to include the view of all pupils if we are to include the voices of all pupils in an increasingly diverse education population', a view also espoused by researchers such as Whitehurst (2007).

### 2.6.3 Leaving school

This review identified one study which looked at pupils with autism's experiences of leaving school at the end of compulsory education. Browning *et al.* (2009) carried out a qualitative study looking at differences in perceived stress and coping between adolescents with and without autism at the point of leaving secondary education. Browning *et al.* (2009) used a scripted set of seven questions to gain the views of seventeen young people with ASD or Asperger syndrome and a further seven young people without any diagnosis, using content analysis to analyse the data. The paper was written before policy changes shifting the age of compulsory education up to 18 years of age came into being, so the sample reflects the policy of the time when young people could leave education or training at 16. From their own literature review, Browning *et al.* (2009) identified that there has been 'little focus on obtaining the views of individuals with ASD on these issues' and argue for the usefulness of involving the target population when investigating factors which directly affect them (Browning *et al.*, 2009, p.35); however, it should be noted that the review cites research from 1991-1995 which could be argued is somewhat dated given the pace at which autism research has developed in recent times. Browning *et*

*al.* (2009) found that their participants with ASD indicated worries about 'specific objects and social relations' (Browning *et al.*, 2009, p.36), which supports Horsley (2009) and Humphrey and Lewis (2008), whose interviews with young people with autism indicated high levels of concern around social issues, including bullying. It is understandable, given the focus of the study, that Browning *et al.* (2009) constructed a set of questions that largely focussed on causes of and feelings about 'stress' and 'worries', with six of the seven questions centred around 'what' and 'how' questions. However, it could be argued that there are assumptions inherent in the design of the questions which may have constrained the participants' responses and may have provoked more problem-oriented responses, rather than starting from accounts of their individual experiences. Though understanding stressors and sources of worry is undoubtedly important, one result of documenting stressors is that there is reduced scope for exploration of protective factors and individual differences. As Joffe and Elsey (2014, p.182) explain, Hollway and Jefferson (2012) criticize the traditional semi-structured interview for its use of the '*how? when? and why?*' question-and-answer format arguing that it can produce intellectualized data which may conceal or constrain access to more emotive and experiential data. Finally, in their analysis, Browning *et al.* (2009) quantify their data into the total number of units of information provided by each group of participants, which leads to the inevitable loss of the richness and value of individual narratives.

#### 2.6.4 Transition to Further Education

This literature review suggests that very little information exists about the transition experiences of young people with autism once they reach further education. Of all the studies identified just two looked at the transition experiences of young people

with autism in relation to the move to further education (Mitchell & Beresford, 2014; Shepherd, 2015). Mitchell and Beresford's 2014 paper is adapted from one element of a larger project on transition and young people with ASC in England. The project had a particular focus on those with a diagnosis of high-functioning autism or Asperger syndrome due to expressed concerns about unmet needs among this particular population. Mitchell and Beresford (2014) carried out semi-structured interviews with a sample of 18 young people aged between 15 and 21 years old, some of whom were on the cusp of leaving school and some who were already in or had recent experiences of Further Education (FE). The interviews were carried out in the homes of interviewees according to a researcher-led agenda using pre-prepared 'topic guides' focusing on both anticipating the move to FE and experiences of those who had made the move. Thematic analysis highlighted a range of practical and administrative support which was felt to be helpful, including the need for emotional support which the researchers report was highly valued and tended to be provided by parents, typically mothers, who were the primary source of emotional support (Mitchell & Beresford, 2014, p.159). The researchers chose to adopt what could be positioned as a more 'solution-focussed' perspective, focusing on the 'systems and practices' which support a successful transition rather than revisiting the 'well-documented difficulties' that young people on the autism spectrum face (Mitchell & Beresford, 2014, p.165). However, it could be argued that the use of a topic guide for the semi-structured interview means that the kinds of knowledge which could be elicited from participants was predominantly researcher-led, potentially limiting opportunities to illuminate the unique preoccupations and experiences of each individual participant. The research also looks at some

participants' feelings prior to the move to further education, while others had already transitioned, and therefore the findings do not focus in on post-transition experiences; it is left to the reader to work out which views belong to those anticipating the move and which represent the views of those who had already transitioned.

In her study of the lived experiences of young people with ASD and learning difficulties transitioning from special schools into Further Education, Shepherd (2015) reports on the development of appropriate research methods for accessing the views of her participants and describes a novel methodological approach to eliciting these young peoples' views. The author made use of collages, video, walking interviews and card sorts as well as opportunities to build a trusting relationship and alliance with each participant in order to find out about their experiences of transition. Shepherd (2015, p.258) takes the position that sharing the process with her participants and having them lead the research begins to 'readjust the power relationship'. In their exploration of eight qualitative studies which purport to give a voice to young people with Asperger's Syndrome [*sic*] McLaughlin and Rafferty (2014, p.63) raise the concern that the data in at least half of these studies was analysed 'mainly as it related to the diagnostic criteria for AS'. As with the studies identified by McLaughlin and Rafferty (2014), it could be argued that Shepherd's analysis as reported in her paper also tends to look to these young people's experiences through the lens of diagnostic criteria, relating themes to typically 'autistic' behaviours; for example when one participant, 'Jake', uses some of the researchers words in his reply to a question, Shepherd frames this as 'echolalia', leading me to wonder whether in a 'neuro-typical' participant this would have been

identified in the same way. Shepherd acknowledges both the usefulness and limitations of the use of collages, card-sort activities and scaffolding the conversations with participants, all of which use pre-determined choices. Though the use of visual tools seems to support those with autism to articulate their views effectively, given the heterogeneity of the population being studied, this loss of individual experience and richness is, I feel, significant. Equally, I argue that it would be valuable to take a similar approach utilizing visually-oriented methods to the study of young people who are higher functioning, since as Mitchell and Beresford (2014) highlight, this cohort of young people is at risk of having unmet needs following transition to further education.

### 2.7 Eliciting the views of children, parents/carers and staff

Several studies were identified which gained the views of parents alongside young people (Hannah & Topping, 2013; Horsley, 2014; Mandy *et al.*, 2015; Mitchell & Beresford, 2014; Tobias, 2009). Findings from the literature review show that, importantly, it is not only the child or young person who is affected by the psychological impact of going through a major transition. Evidence from a number of studies suggests that parental anxieties are both higher than those of their children both pre- and post-transition, and focus on different areas. Two studies, Fortuna (2014) and Jindal-Snape *et al.* (2006) also gained the views of staff as well as parents and young people and found that the views expressed on the transition experiences of the pupils differed substantially from those of staff and parents. The findings from Mandy *et al.* (2015) challenge the assumption that transition leads to an escalation of difficulties for children with autism. Though Mandy *et al.* (2015, p.2) found no evidence of a marked escalation of difficulties across the transition from primary to

secondary school, they observed high levels of psychopathology at baseline; that is prior to transition, which in some cases was under-recognised.

While gaining the views of parents and staff is undoubtedly important it may also be problematic. Connor (2000) and McLaughlin and Rafferty (2014) refer to the potential strength and insight which may be gained by including a perspective additional to that of the young person, for example that of a parent or of a key staff member, but only when their data is presented separately after analysis (Connor, 2000) or when it is differentiated within the results section (Hay & Winn, 2005, cited in McLaughlin & Rafferty, 2014) since this enables comparisons to be drawn between different perspectives and gives due value to the unique perspectives of the young people at the heart of the research. Of the studies cited above, only Horsley (2014) differentiated pupil and adult data, enabling the researcher to identify clear differences between the child and parent responses.

Identifying a gap in the research literature Tobias (2009) applied a focus group methodology to examine parental and student perspectives on current support practices at secondary school for young people with ASD, with a focus on identifying what was most helpful and what else could be provided. Focus groups were used as the researchers felt that being in a group situation with familiar peers would support participants to feel more at ease than in individual interviews (Costley, 2000, cited in Tobias, 2009). Questions asked in the focus group were constructed by the researcher drawing on elements of Personal Construct Psychology (Kelly, 1955, cited in Tobias, 2009). However, by adopting a focus group approach, the researcher makes several prior assumptions about the relationships

between participants, and the richness of individual experience is inevitably lost. Given individual differences between all young people on the autism spectrum, it is not possible to be clear that individual views are fairly represented in this piece of research. Tobias (2009) identifies a number of key aspects of support which were evaluated positively by participants, supported by vignettes from the focus groups, including: targeted support at key transition points, the provision of mentors for students, availability of quiet, calmer spaces to reduce anxiety, good communication between staff and parents, good staff knowledge of ASD and of individual students, individual tailor-made support, a welcoming school ethos and thoroughness. Possibilities for further support included developing enhanced self-confidence and self-awareness, developing a sense of belonging and social inclusion, to develop greater independence and organisational ability and to develop life-skills for the 'real world'. However, the analysis presented in the paper is heavily weighted towards parental views, with 22 vignettes reported from parental accounts as opposed to three views presented as a homogeneous 'group view' and just four identified as 'student' views, with no clear sense of individual differences or of the unique experiences of each participant. It is not clear the extent to which the views belong to the young people and/or to their parents; as described by McLaughlin and Rafferty (2014, p.65) 'it seems as though the potential richness of this data has been lost and instead a perception given of the parent and child as having the same lived experience'.

Hannah and Topping (2013, p.11) researched the perspectives of students with autism transitioning from primary to secondary school, with the aim of informing the development of tailored intervention to support the 'specific needs of

this group' and to inform policy and practice. Drawing on ecological theories of human development (Bronfenbrenner, 1978, cited in Hannah & Topping, 2013) and of resilience (Luthar, 2006, cited in Hannah & Topping, 2013) in order to theoretically conceptualise educational transitions, the researchers interviewed nine male participants in Year 7 and their families at three different time points in order to trace participants' feelings prior to and following transition, to identify transition supports which were felt to have been helpful and to identify gaps in effective transition planning. Data collection at the three time points involved 1) a pre-transfer questionnaire, 2) a post-transfer group activity and 3) a post-transfer interview. Noting prior research by Topping (2011) which identifies that teachers and pupils have different perspectives on primary to secondary transition, Hannah and Topping (2013) chose to compare the views of the young people and their parents, highlighting the importance of seeking the views of key stakeholders. This broadly supports Horsley (2009) and Fortuna (2014). Hannah and Topping (2013) take an interactionist perspective, noting risk and protective or resilience factors both within the individual and in the environment, demonstrating how transition experiences are inherently psycho-social.

The researchers report that interviews were not recorded, but 'contemporaneous notes were recorded, while maintaining the flow of the interview' (Hannah & Topping, 2013, p.7), which for me raises questions about the fidelity of the views represented here, leading me to be curious about the scale of impact on the richness of the data and the potential for misrepresentation due to the lack of context, tone of voice, inflections and articulation in the absence of a recording of the exact words used by participants. Though the researchers

acknowledge 'the potential threat to the reliability of this recording method' they do not address the issue of equity for participants as, using this method of recording data there is no way of checking back to the original transcripts (Hannah & Topping, 2013, p.7). Findings include identification of key support mechanisms which were felt to help ease the move to secondary school including preparation of students (e.g. learning about the school, getting to know teachers and visiting the new school), information and friendships, plus reports of feelings of fear and anxiety mixed with excitement, which the researchers relate to the psycho-social work of Lucey and Reay (2000). Students reported a combination of positive and negative feelings prior to transition, and post-transition there were more positive experiences reported by pupils than negative, which supports Horsley (2009) and Perfitt (2013). Though the findings broadly mirror those of Jindal-Snape *et al.* (2006), Fortuna (2014) and Mandy *et al.* (2015) it is clear from reading the findings that qualitative differences between parental concerns and pupil concerns exist. Hannah and Topping (2013) advocate the use of a similar qualitative psycho-social methodology to that of Lucey and Reay (2000, p.194) who looked at the adaptive function of anxiety in a cohort of 'typically-developing' children transitioning from Year 6 into Year 7, framing anxiety as 'fearful excitement'. Hannah and Topping (2013) wonder whether anxiety serves a similar function for students with ASD and make the case for further research which investigates their feelings, expectations and experiences of transition. Hannah and Topping (2013) also call for similar transition research in different educational contexts.

Fortuna (2014, p.178) used a mixed-methods approach to research the social and emotional functioning of five Year 6 children transitioning into Year 7, that is,

from primary to secondary school, noting previous research by Dillon and Underwood (2012) which identified that the transition process for children with ASD can be 'especially fraught'. Fortuna (2014, p.178) highlights the potential implications for young people with autism transitioning from primary to secondary school, arguing that they have 'a greater likelihood of suffering anxiety, mental health problems and school exclusions than their neurotypical school counterparts'. Fortuna (2014, p.179) cites Dann (2011), in whose study five out of six participants reported incidents of bullying at secondary school, arguing that bullying is likely to have an impact on pupils' ability to establish socio-emotional resiliency strategies, while later concluding that socio-emotional wellbeing 'seems to be the chief factor for the young person with ASD to be content in their new setting'. Fortuna (2014) used a range of approaches to data collection, including Likert-style scaled questionnaires, the Strengths and Difficulties Questionnaire and 'pupil diaries' which are actually 'Rate My Day' scales collecting primarily quantitative data, though students were welcome to add additional commentary if they wished. This may have been more convenient to gather and enables quantitative comparison across the data set, though arguably at the cost of the richness of individual experience. Quantitative data informed the development of semi-structured interviews with the pupils. Fortuna's data showed a positive change in the social and emotional wellbeing of four of the students following transition and a negative change in the other participant. Notably, the two pupils showing the greatest positive change in their emotional wellbeing transitioned together and were in many of the same lessons at their new school. This supports Mandy *et al.* (2015) who found no evidence for a marked escalation of difficulties during the transition from primary to secondary

school; rather they identified higher levels of psychopathology and maladaptation prior to transition which persisted during the change. Rather than focus exclusively on the views and experiences of the pupils themselves, Fortuna (2014) chose to explore the experiences of 'key stakeholders' in order to 'seek insights' from parents, staff and the children themselves. However, it could be argued that the research questions prioritise the adult views, focussing primarily on parental and staff perceptions. Hill (2014, p.80) raises concerns that, though the aim of triangulation is an admirable one, published articles which triangulate the views of young people with those of parents and school staff tend to give precedence to the adult contributors, with 'the voices of young people being markedly overshadowed or absent'.

Jindal-Snape *et al.* (2006) looked at the perceptions of transition arrangements of a convenience sample of five children with autism transitioning from mainstream primary to secondary education, contrasting their views with those of other stakeholders including parents/carers, teaching staff, the school educational psychologist and the current speech and language therapist. The researchers found a wide and variable range of transition arrangements, identifying that the children showed more positive attitudes to the transition process and to their new school, expressing a wish for 'real inclusion' in school activities and an appreciation of transition arrangements. Parents/carers tended to be much more negative. Their evaluation of the transition process identified a higher number of problems and concerns than professional stakeholders, with delays to placement decisions being raised as a factor bringing uncertainty and stress to parents/carers. As in Mitchell and Beresford (2014), Jindal-Snape *et al.* (2006) adopted a 'solution-

focussed' approach to interviews, helpfully enabling views on 'what works' to emerge from the data. Though by adopting an 'intensive case study methodology' Jindal-Snape *et al.* (2006, p.19) admirably attempt to bring the children's views into the research and draw attention to key differences in perspective, it could be argued that their paper is still very much dominated by the perspectives of key adult stakeholders.

## 2.8 Focussing exclusively on the views of children and young people with autism

Few studies identified in this review focus exclusively on accessing the views of young people themselves. Of those which do, topics focussed on include exploring the inclusion process for pupils with 'AS' (Humphrey & Lewis, 2008), features of educational provisions (Williams & Hanke, 2007), experiences of stress and coping (Browning *et al.*, 2009), general experiences of education and 'what is life like for you?' (Hill, 2014; Moxon & Gates, 2001; McLaughlin and Rafferty, 2014), experiences in further and higher education (Beardon *et al.*, 2009) and experiences of transition to further education (Shepherd, 2015). A range of methodological approaches to data collection of young people's views is in evidence. In the following section I will critically explore some of these studies in greater depth in order to demonstrate the strengths and limitations of these approaches to eliciting the views of young people with autism and how the methodology impacts on the kind of knowledge which can be gained.

Methodological approaches to eliciting the views of young people with autism identified through the process of this literature review encompass the use of semi-structured interviews (Shepherd, 2015; Mitchell & Beresford, 2014; McLaughlin

& Rafferty, 2014; Hannah & Topping, 2013; Humphrey & Lewis, 2008), structured interviews (Jindal-Snape *et al.*, 2006), group/focus group interviews (Hannah & Topping, 2013; Tobias, 2009), questionnaires (Hannah & Topping, 2013), self-report schedules (Connor, 2000), diaries (Fortuna, 2014; Humphrey & Lewis (2008), card sorts (Shepherd, 2015), standardized psychometric measures (Mandy *et al.*, 2015; Fortuna, 2014; Perfitt, 2013) and novel approaches using visual supports such as photo elicitation (Hill, 2014), Talking Mats (Shepherd, 2015) and techniques from Personal Construct Psychology (Tobias, 2009; Williams & Hanke, 2007).

### 2.8.1 Exploring lived experiences using questionnaires

Beardon *et al.* (2009) carried out a mid-to-large scale 'emancipatory' study in the UK as part of a larger 'ASPECT' study of experiences in further and higher education, linked to the University of Sheffield. The ASPECT consultancy study explored local authority service provision for 238 adults with AS or HFA in the United Kingdom. The aim of this study was to gain the views of young people with 'AS/HFA' in order to inform future good practice, with suggestions arising from the data. Beardon *et al.* (2009) used a questionnaire with a mixture of closed and open-ended questions, receiving 238 responses of which 229 were 'valid'. Of those, 135 students identified challenges at college or university, including expressed difficulties with social interaction, managing the social environment, other people's understanding of HFA/AS and the course structures/curriculum requirements. Of these, 54 students accessed some level of support. However, the experiences of the 94 students who did not report challenges are left under-explored in this paper. The researchers attempt to extract both internal and external attributions to the experiences reported by participants, such as student reluctance to accept support or going

through the process of familiarization and confidence in the setting. The researchers acknowledge some of the limitations to their data gathering method from a highly heterogeneous sample, making a case for individualisation of support as not all the suggestions arising from the data will apply to all young people with HFA/AS. Their methodology enabled a large data set to be gathered, though the cost is a loss of richness and the absence of individual narratives and unique experience. The researchers conclude that 'participants were clear about wanting to be appreciated for themselves rather than modified to fit in' (Beardon *et al.*, 2009, p.37).

### 2.8.2 Using semi-structured interviews to gain the views of young people with autism

Of all the papers surveyed which focus on gaining the views of young people with autism, by far the most popular methodology is the semi-structured interview. Earlier papers use straightforward semi-structured interviews to find out about day-to-day issues (Connor, 2000), experiences of transition from primary to secondary school (Jindal-Snape *et al.*, 2006) and the experiences of pupils on the autism spectrum in mainstream secondary schools in north-west England (Humphrey & Lewis, 2008). However, the use of semi-structured interviews raises several issues of concern relating to the production of knowledge and to the balance of power between researcher and participant. In the following section I will explore the strengths and limitations of some of these studies in greater depth.

In their study Humphrey and Lewis (2008) used Interpretive Phenomenological Analysis (IPA) to explore the views of twenty pupils with 'AS' (high-functioning autism and Asperger syndrome) in the 11-17 age range about mainstream education and to document their everyday experiences of learning and

participation in order to develop a deeper understanding of the inclusion process for pupils with 'AS'. Data was collected via semi-structured interviews and pupil diaries, though of the twenty participants only nine completed the diaries. Humphrey and Lewis (2008, p.28) encouraged the use of drawings as an alternative data source as these 'enable expression of thoughts and feelings that are difficult to articulate in words', thus signposting the potential value of future methodological developments which aim to facilitate this kind of knowledge. Though this piece of research is an apt demonstration of the valuable knowledge and understanding which can be fruitfully gained by interviewing young people with ASC about their lived experiences, it could be argued that the researcher's data was analysed through the lens of the diagnostic criteria for autism, for example referring to the 'characteristics of AS'. This may reveal some implicit assumptions on the part of the researchers. By imposing diagnostic criteria onto the analysis, the researchers risk attributing an individual's experience to an aspect of their diagnosis, leading to a prioritising of the 'label' over the personal experience. As stated by McLaughlin and Rafferty (2014, p.65) 'perhaps withholding our assumptions may help to further our understanding of 'having' AS in adolescence instead of simply confirming the diagnostic criteria'. Humphrey and Lewis's (2008) paper is also based upon and frequently cites Carrington and Graham (2001), which is not only a study from the USA (which I have noted above poses challenges when generalising to the UK cultural context) but is a paper which McLaughlin and Rafferty (2014, p.65) note appears to have 'over-represented the voice of the parent in comparison to the voice of the child'. Humphrey and Lewis (2008, p.43) conclude by citing the perceived need for more qualitative research in the field of autism 'to achieve an in-depth exploration of the real-life experiences of

these individuals from their own perspective'. It is important that future research builds upon the strengths and limitations of past research in order that it can be as mindful of issues of power and equity as possible.

### 2.8.3 Using visual methods to elicit views of young people with autism

This literature review identified a number of studies which take a creative and novel approach to research with young people on the autism spectrum, using visual supports such as photo elicitation (Hill, 2014), Talking Mats, card sorts and photos (Shepherd, 2015) and drawn techniques from Personal Construct Psychology (Williams & Hanke, 2007).

Hill (2014) explored the lived experiences of mainstream secondary school of six young people on the autism spectrum, using Interpretative Phenomenological Analysis as her chosen method of data analysis. The researcher addressed the concern that, within the existing research base, the voices of young people with autism have 'often been missing or overshadowed' and that 'there is a dearth of research focusing on outcomes for young people with ASD' by supporting her participants to take photographs of aspects of school life which were important to them, which then formed the basis of further discussion (Hill, 2014, p.790). In doing so, Hill supported her participants not only to participate fully in the research process but to 'set the agenda for discussion and to take the lead in discussing issues of importance to themselves' (Hill, 2014, p.81). As with Shepherd (2015), Hill's (2014, p.81) participants were supported to capture their own visual images, thus ensuring that the material to prompt further discussion reflected factors of importance to them, rather than what was perceived to be significant from an

outsider's perspective. Hill (2014) also notes that using photographs to scaffold discussions with young people on the autism spectrum took pressure off the potential intensity of them being the central point of attention. Hill (2014) identified three themes for the group as a whole: 'anxiety', 'sanctuary' and 'young people as active agents', though the researcher notes that there was considerable variation within shared themes. Despite the equity of Hill's approach, the author describes concerns that her participants 'might focus their attention on items of idiosyncratic or obsessive interests' (Hill, 2014, p.82) which led the researcher to consider imposing a caveat around the number of photos which could be taken around any one aspect of her participants' experience. Though Hill (2014) chose not to impose the caveat, it could be argued that, as with Shepherd (2015), this reveals something of the researcher's prior assumptions about their participant group which are grounded in diagnostic criteria. However, the researcher concludes that this study is an apt demonstration not only of the insightfulness and capacity for competent reflection shown by young people with autism but also the importance of focussing on their individual and unique strengths, needs and interests, rather than looking solely at their experience through an 'ASD lens' (Hill, 2014, p.87).

Williams and Hanke (2007) adapted a technique from Personal Construct Psychology called *Drawing the Ideal Self* (Moran, 2001) in order to seek the views of fifteen pupils with autism attending a mainstream school on what they felt were the most important features of school provision. They identified a range of environmental features such as the design and layout of the school building and the way it was equipped was important to many children, as was the ethos of the school and the personal characteristics of staff members such as 'ready to teach' and 'nice,

but don't let you get away with everything'. As with other research which employs an element of visual support (Hill, 2014; Shepherd, 2015) Williams and Hanke (2007) note not only the ideological shifts which have led to the involvement of young people in making decisions about issues which affect them directly but the value of the insights which 'insider accounts' can bring. The researchers describe how retrospective accounts that look back upon childhood experiences from the adult perspective can result in further valuable insight. Williams and Hanke (2007, p.53) highlight the limitations of research methods such as semi-structured interviews and questionnaires, in which the researcher 'denotes the constructs or elements that are deemed meaningful for the pupils to consider rather than the pupils generating these themselves' and call for research methods 'which genuinely provide a vehicle to gain a true picture of pupils' views without pre-determining what these might be'.

### 2.9 Strengths and limitations of the literature review

This literature review provides a comprehensive picture of the extent of research relating to the transition experiences of young people with autism by summarizing and critiquing a range of methodologies and creative approaches to the eliciting of views of young people with autism and by critiquing the existing limited body of knowledge relating to the transition experiences of young people on the autism spectrum. The review is necessarily 'niche' given the limitations to the scope and depth which is possible given the size and parameters of this piece of work, and I wish to acknowledge several other limitations to this review. The research I have presented here is drawn solely from the UK literature, which may present challenges to potential wider audiences seeking to apply findings from different social, cultural and political contexts. Given my ontological and epistemological

perspectives on this body of research, the locus of my critique is oriented in favour of those approaches which prioritise the voice and views of young people and which acknowledge and attempt to overcome some of the imbalances of power relations inherent in all research methods, in different ways and to varying extents. This inevitably leads to a presentation of one particular view of the research, influenced by my personal ontology, where other perspectives are both possible and valid.

## 2.10 Recommendations

This literature review has highlighted that several gaps in the UK research literature exist, as do a number of methodological issues. It is beyond the scope of this review to grapple with either the challenges of generalising from qualitative research to the wider UK population, or the implications of these challenges on any attempt to draw together what the existing body of research tells us or how this may inform practice. Rather, I have focussed on pulling together what existing research tells us about the research process itself. What I believe are the most salient concerns are summarised below:

- No published study exists which looks exclusively at the transition experiences of young people with autism following their transition into further education.
- Despite the valuable insights which insider accounts can generate, there is a very limited body of research which focusses on gaining the views of young people on the 'higher functioning' end of the autism spectrum, who are at risk of having unmet needs (Mitchell & Beresford, 2014).

- Though the views of parents and staff are undoubtedly of value, much prior transition research has prioritised the views of such 'key stakeholders' over the young people themselves, which has been criticised by McLaughlin and Rafferty (2014). This highlights a gap in the literature in which the knowledge gained does not fully reflect the unique perspective of each individual and is researcher-dominated rather than participant-led.
- There has been a recent call for more inclusive 'critical' educational psychology research which takes a perspective on the experiences of young people with autism that is not centred around diagnostic criteria or a 'deficit model' and which re-balances the power relations between researcher and participant (Billington, 2013; McLaughlin & Rafferty, 2014; Hill, 2015).
- Research with young people with autism has tended to be dominated by the researcher's agenda, for example through the use of questionnaires and structured interviews, which is arguably at risk of presupposing the lines the young people should be thinking along.

This literature review demonstrates that, while some research has been carried out to elicit the views of young adults with autism on their Further Education experiences, no single study yet exists which elicits the views of young people on the autism spectrum about their experiences of transition from the perspective of already having transitioned into Further Education. Joffe and Elsey (2014, p.182) highlight that, despite its importance, there remains 'a paucity of research focused on apprehending the rich contents of emotionally laden thought. The lack of appropriate methodologies for conducting such research may explain this

deficiency.’ The present study aims to address these concerns by exclusively researching the transition experiences of young people with autism following their transition to further education, leading to the research question: ‘what are the transition experiences of young people on the autism spectrum?’

Studies by researchers such as Hill (2014) and McLaughlin and Rafferty (2014) highlight the vital importance of involving young people with autism in research which is directly relevant to issues which affect them, and the insights that such research can bring about which make valuable contributions to the knowledge base. The present study will be guided by a psycho-social method using the free association Grid Elaboration Method (GEM; Joffe & Elsey, 2014). This is congruent with a relativist ontological position, in which the role of the researcher in relation to the production of knowledge is foregrounded, and with a constructivist epistemology, in which knowledge is understood to be created in the interactions between researcher and participant (Guba & Lincoln, 1994). By using the GEM to elicit the views on the unique transition experiences of a number of young adults with autism currently attending Further Education, I hope to address some of the power imbalances inherent in existing research methods with a focus on discovering more about my participants’ thoughts, feelings and emotional experiences. In doing so I hope to continue to shift the inherent power imbalance to a more equitable position.

### 2.11 Chapter summary

The aims of this literature review were to establish a clear understanding of what is already known about the transition experiences of young people with autism and to

critically appraise any methodological implications both for the research findings and for my own study. This review was then used to shape the research question and to establish which methodological approach would be most appropriate to answer the research question.



## Chapter 3: Methodology

### 3.1 Chapter introduction

This chapter provides details of the research methodology I selected for this study and explores how it guided data collection and analysis. Having restated the purpose of this research, I briefly describe the process of negotiating the research with my placement provider. Next I provide some essential background to 'psycho-social' research methodologies. Then I explore the development and application of a psycho-social method of qualitative data collection, consisting of in-depth interviews using the free association Grid Elaboration Method (Joffe & Elsey, 2014). The subsequent sections of this chapter describe participant recruitment procedures and sampling. I move on to describe in depth the approach I used in the analysis and interpretation of my empirical data, with a view to highlighting the consideration I gave to 'validity' and 'reliability' issues in qualitative research. Ethical considerations were of the highest priority and detailed description of these is provided.

### 3.2 Purpose of the research

This piece of research aimed to find out about the experiences of young people on the autism spectrum aged 18 years plus having transitioned into further education or training, from the perspective of the young people themselves. Young people with autism have the right to express their opinions and for their opinions to be heard. This piece of exploratory and emancipatory research study aimed to build on previous research into transition experiences of young people with autism with a view to considering the potential implications of the findings on the continued development of EP practice.

### 3.3 Research question

As outlined in Chapter 2 the research question this study aimed to address stemmed from the literature review and is as follows: 'what are the transition experiences of young people on the autism spectrum?' Holding in mind suggestions made by Hollway and Jefferson (2012, p.155) my research question is constructed to be deliberately broad and open-ended with the intention of understanding these young people's experiences 'through their own meaning-frame'.

### 3.4 Negotiating the research

This piece of research was negotiated between the Principal EP of my EPS placement and me. I was grateful that my primary area of interest tapped in to one of the on-going priorities of my placement service. I was mindful of the need for this research to focus on 'real world' problems and that the timeframe for completion was relatively short. I wanted to focus on an issue that was relevant to both local and national contexts and directly relevant to the work of EPs/TEPs. I was also mindful of the need for my research to be of benefit to the service in which I was working. All of these factors, in tandem with my personal interests as outlined in Chapter 1.5, led me to focus on accessing the views and experiences of young people on the autism spectrum in post-18 education and/or training, in line with the shifts in the role of the EP and the associated potential for new opportunities brought about by the introduction of the new SEND Code of Practice (2014).

### 3.5 Participants and recruitment procedures

Due to the scale of the study and the in-depth nature of the interviews, I kept the number of participants to a small and manageable number. Though Joffe and Elsey (2014, pp. 178-179) describe sample sizes of between 40 and 144 participants, it

should be noted that their sample sizes relate to research studies which draw upon a large and broad population, using *a priori* sampling procedures. Given the specialist population under investigation and the in-depth nature of my study it was necessary to make adaptations to the sample size in order to realistically reflect the overall sample size. This is more in line with the narrative interview approach as described by Joffe and Elsey (2014, p.179) in which there is inevitably a tendency towards smaller participant numbers. I recruited four young people aged between 18 years and 22 years of age who identified themselves as being on the 'high functioning' end of the autism spectrum. Though I was not aiming for representativeness in my sample, it is interesting to note that three participants were 'White British' and one was 'Black Other', which is a broad reflection of the demographic of the locality of the research. One female and three males were recruited, broadly reflecting the gender balance of diagnoses of ASC in the UK. The proportion of males as opposed to females diagnosed with autism varies across studies, but always shows a greater proportion of males. Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum and Charman (2006) found a male to female ratio of 3:1 across the autism spectrum in their sample, though it should be noted that autism spectrum disorders are under-diagnosed in females, which is discussed in Gould and Ashton-Smith (2011).

Inclusion and exclusion criteria were as follows:

- Participants will have a diagnosis of autism.
- Participants will express a positive interest in being interviewed.
- Participants will have sufficient language skills to be able to access the interview process.

- Participants will be enrolled in further education and/or training at a Further Education college.
- Participants should have attended school until the end of compulsory education. This is because young people who may have experienced a break in their school-based education will not have had the same experience of transition as others.
- Participants should not be or ever have been children Looked-After or care leavers, since evidence suggests that these groups of young people are likely to experience significantly different issues around post-18 transition (Guishard-Pine, Hamilton & McCall, 2007).

All four participants had continuously attended schools and colleges either in the borough in which I was on placement or in neighbouring boroughs, and all were enrolled on and attending a mainstream training course at one of two Further Education colleges in the local area. I used purposive sampling (Robson, 2011) since, in this mode of sampling, participants share experience of a particular event; in this piece of research they are all young people on the autism spectrum aged 18 and over (i.e. above compulsory school age) who have transitioned in to further education or training.

In advance of contacting the local FE College I prepared an information sheet (Appendix C) and consent form (Appendix D) following guidance produced by Loyd (2012) in relation to obtaining consent from young people with autism. Loyd (2012) describes the process of obtaining fully informed consent from participants for her own study investigating the participation of young people with autism in drama

education. Loyd (2012, p.41) places particular emphasis on both using effective, often visually-oriented, modes of communication and on giving opportunities to potential participants 'to say 'no' in different ways, different contexts and to different people on different occasions'. I hoped to pilot the information sheet and consent form with young people with similar needs in order to ensure it fulfilled its function. However, due to the perpetual constraints of time, it was not possible to do so. In lieu of this I asked experienced members of the Educational Psychology service in which I was on placement, all of whom had substantial experience of working with young people with autism, whether or not they felt that the information sheet and consent form were clear, and whether 'transition' was a term with which my participants would be familiar, or whether further clarification of the focus of my research would be necessary. The unanimous response was that 'transition' would be a familiar term to my participant group and that further explanation of the term or of the consent forms, beyond going through them together in accordance with guidance produced by Loyd (2012) would not be necessary.

In the first instance I approached the Head of Learner Support at the local FE college, who was interested in my research and was prepared to support me to identify and recruit suitable participants. Having obtained consent to recruit participants from the management team, the Head of Learner Support introduced me to a Speech Therapist in the college, who agreed to assist me in approaching a number of potential participants. I felt that it was helpful to have a familiar known staff member to mediate the first contact between myself and potential participants. Three students who met the inclusion criteria were identified. They

were invited by the college by text message (as text messaging is an established way of communicating with students within the college) to come and meet me at a set time and a familiar location, if they were interested in participating and wished to find out more about what participation would involve. All three attended and expressed an interest in taking part, so following guidance provided by Loyd (2012) I gave them an information sheet (Appendix C) and a consent form (Appendix D) to take away and I encouraged them to share this information with whoever they wished to, for example parents and/or support staff, in order to ensure as far as possible that they would be making a fully informed decision whether to participate.

My fourth participant was recruited by speculatively contacting lecturing colleagues in another FE College, who consented to take part in the research and who identified one potentially suitable young person. As before, it was helpful for this initial contact to be mediated by someone familiar to the young person. I was mindful of the risk of the participant feeling coerced into taking part, so again following guidance from Loyd (2012) I ensured that they had sufficient opportunity to read through the information sheet and consent form and to give consideration to the implications of taking part, to ensure they were giving fully informed consent.

### 3.6 An overview of a psycho-social methodological approach

Psycho-social research is an 'umbrella' term which encompasses what Lucey (2004, p.54) calls 'a significant and growing body of contemporary work in varying disciplines including sociology, social psychology, cultural studies, anthropology and critical psychology that engages with psychoanalysis in order to extend research and writing on a diverse range of subjects'. Given the limitations of this study there is not

room to explore the entire range of psycho-social research which spans all of these social science disciplines. Rather, my aim in this section is to elaborate on and describe the psycho-social method of data collection and analysis used in this study.

As psycho-social research methods emphasise theoretical intersubjectivity and how it affects the production and analysis of data, careful examination of the researcher's relationships to their subjects and objects of study is required. As Hollway (2009, p.3) explains, 'the situation in which a string of words emerges to represent experience is always intersubjective (even when there is no one present to hear them, there are other imagined recipients, present in the speaker/writer's imagination). Thus the relation between participant and researcher needs to remain central.' As described by Clarke and Hoggett (2009, p.7), psycho-social research methods have emerged in relatively recent times, with the 'reflexive practitioner' at the heart of their aims. Clarke and Hoggett (2009, p.7) describe the idea of the reflexive practitioner as involving 'sustained and critical self-reflection on our methods and practice, to recognise our emotional involvement in the project.' Therefore, psycho-social methods not only recognise and acknowledge facets of the researcher's own biography but make use of them as a reflexive tool alongside the use of the researcher's emotional responses. This is congruent with a constructivist epistemology, in which Guba and Lincoln (1994, p.113) contend that 'knowledge [is] created in interaction among investigator and respondent'.

As outlined by Hollway (2006), methods play an active role in the production of knowledge and how phenomena are framed, construed, organised and understood. Psycho-social research offers a methodological framework for the

exploration of experience, eliciting ‘participants’ experience in a form dictated as little as possible by the protocol of questions’ (Hollway, 2015, p.43). As Marshall and Rossman (1999) describe, psycho-social research shares several characteristics with other qualitative methods such as IPA and grounded theory, which correspond to those of this study; for example:

- Focus on everyday life experiences
- Valuing participants' perspectives
- Enquiry as interactive process between researcher and respondents
- Primarily descriptive and relying on people's words

Despite this common ground, it should be noted that different methods will have very different effects on the production of knowledge; they are conducted in different ways and generate different kinds of data. The psycho-social method of data collection used in the present study, the free association Grid Elaboration Method (GEM; Joffe & Else, 2014) can be differentiated from other qualitative approaches for several reasons, which will be explored in the following section.

### 3.6.1 The free association Grid Elaboration Method

The free association GEM is a visually-oriented method based in the principles of free association<sup>2</sup> in which data collection begins with and stems from each individual participant’s unique associations to the topic of study. A recently established tool from psycho-social research, the GEM is strongly influenced by Hollway and Jefferson’s Free Association Narrative Interview (FANI) method, in which

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<sup>2</sup> Commonly associated with the clinical work of psychoanalyst Sigmund Freud, in ‘free association’ the ‘patient’ says whatever comes to mind without exercising any selectivity or censorship (De Mijoller, 2005, p.616).

participants are asked to 'tell me about' the topic in question, using a pre-prepared interview schedule (Hollway & Jefferson, 2000; 2008; 2012). However the GEM extends beyond such structured interviewing, recognising and transcending the possible risks within the FANI (and of other semi-structured interviewing techniques) of constraining interviewees by the assumptions inherent within pre-prepared interview questions.

As Joffe and Elsey (2014) describe, in the GEM, participants are presented with a blank grid comprising four boxes on an A4 sheet of paper. They are then asked to represent with a word, image or phrase their 'associations' to a given topic, that is, their first responses or 'associations'. Therefore, factors that immediately occur to the participant in association to the issue under study are recorded on the grid before dialogue with the researcher begins. These are limited to one per box, so that once the grid is complete there are four 'salient' associations. The researcher then enquires about these unique associations in turn, encouraging participants to elaborate in as much detail as possible until the point at which they indicate that they have no more to add. At this point, the researcher guides the participant through the next box in the same way until all four boxes have been explored. In this way, researcher interference with the data collection process is minimised and all data originates from the 'subjective stance of participants' (Joffe & Elsey, 2014, p.178). Joffe and Elsey (2014, p.181) also suggest that the use of the grid frees participants 'from the need to restrain their expression to a coherent, linear dialogue or detailed narrative'.

As Joffe and Elsey (2014, p.181) explain, the GEM 'provides a means of eliciting material that is subjectively relevant to respondents, without presuppositions as to what they should think or even concerning the lines they should be thinking along'. The use of free association in the GEM is intended to ensure that the material to be explored in the interview which follows directly stems from each participant's unique experiences and adequately reflects the 'emotional underpinning of participants' remembered experiences' (Hollway, 2015, p.44). The use of the GEM acknowledges of the position of the researcher in relation to the production of knowledge and in its active use of researcher reflexivity, which is congruent with a constructivist epistemology. Reflexivity takes the form of consideration of the affective response of the researcher to the interview process through the use of reflective field notes as a valuable means of supporting data analysis. I made use of a reflective research diary and of the field notes I took immediately following each interview to support consideration of the interpersonal dynamics between my participants and I, and of the impact of my emotional responses to the data on the process of data analysis.

### 3.6.2 Reflective field notes and research diary

According to Fox, Martin and Green (2007, p.148) the research diary 'is a comprehensive record of the research process and contains a reflection on that process' and as such is integral to the research process. I kept a detailed reflective research diary including thoughts, feelings and notes detailing the research journey with the intention of foregrounding reflexivity and making transparent my position as researcher in relation to the processes of interpretation being applied to the data. This also contributed to a full and transparent 'audit trail', encompassing the data,

details of the analysis and my research diary plus field notes, thus enabling me to trace the process by which I came to my interpretation and justify each step in order to increase confidence in the credibility of my findings (Robson, 2011).

As Hollway (2015, p.86) describes, 'the capacity to reflect on emotional experience as we encounter participants in the field and later through the data (including with the help of other minds) is central to the psychoanalytically informed account of researchers' knowing that draws on Wilfred Bion's theory of thinking'. As Hollway (2011, p.95) explains: 'In qualitative data analysis, transcript has tended to become reified as the only reliable expression of participants' accounts and the only valid form of evidence. I have tried to convey its limitations and illustrate alternatives that are guided by the principle of preserving emotional experience and using researcher subjectivity and imagination as an instrument of psychoanalytically-informed knowing.' Immediately following each interview I took some time to write detailed and extensive field notes, in which I recorded my feelings about the interview and reflections on what I felt were the most pertinent or salient points of the interview. I tried to notice my emotional responses to what was happening in the 'there-and-then' of the interview and reflected on why I may have asked one question and not another, or picked up on something at the potential expense of another area. This enabled me to be critically curious about how my research practices may have implications for the evidence produced.

Holding in mind the perspective of Hollway and Jefferson (2012), alongside the thematic analysis I wanted to give consideration to the *gestalt*; that is, I developed and retained an understanding of my participants' individual narratives in

order to understand particular parts of them. According to Hollway and Jefferson (2012) meanings can only be understood in relation to a larger whole, and I was mindful of what can be lost from the data when it is fragmented into themes. Keeping reflective field notes supported me to address this, as it enabled me to keep each participant alive in my mind as an individual and to have a written record of my feelings and thoughts at the time of the interviews, which I could return to during data analysis and throughout the writing of the thesis. To illustrate this process I have included a brief anonymised extract from my field notes following one interview:

*'Being different' and 'difference' felt like pervasive themes... 'perseverance' and 'overcoming challenges' and adversity. Challenges of adolescence. Learning to love to socialise? Participant spoke freely about difficult experiences and equally was clear about what had been helpful. Actually felt quite draining to attend to everything. [Participant] spoke with determination; I felt a little intimidated when listening to [their] difficult experiences.*

This extract demonstrates one way in which field notes supported the process of data analysis. I was able to refer back to my notes which was helpful in enabling me to attend to some of the more challenging or painful material being raised, and to keep the *gestalt* of each individual alive in my mind.

### 3.7 Data collection

As outlined in section 3.6 I used the free association Grid Elaboration Method (GEM; Joffe & Elsey, 2014) to collect data. The completed and anonymised GEM grids are included in Appendix E. Interviews were carried out on a one-to-one basis. I

provided participants with a blank GEM grid containing the following written instructions:

*I am interested in what you associate with experiences of transition. Please express what you associate by using images and/or words. Please put one image/word/phrase in each box. Sometimes a really simple drawing or word can be a good way of portraying your thoughts and feelings. (Instructions adapted from Joffe & Elsey, 2014).*

It was important to establish with each participant that there were no right or wrong answers, and that there was space for each participant to respond to the GEM grid in whatever ways felt important and appropriate for them. There was some variation in the way each participant responded to the GEM grid; some chose to write a few words or a phrase while another drew sketches. Rather than see this as an obstacle to the collection of useful data I was encouraged by this, viewing it as a demonstration of how flexible and responsive a data-collecting tool the GEM could be in meeting the individual needs of my participants. Copies of my participants' completed GEM grids are included as Appendix E.

The next step in the GEM was to ask my participants to elaborate on their associations. Once they had filled in the four boxes, I asked participants to elaborate on each box in sequence, following the order in which they completed each box, so as to trace the order of their associations. Using this approach ensured that the material to be explored was deeply connected to the unique and personal experience of each participant. Following completion of the GEM grid, the opening question for each interview was 'can you tell me more about this?' Participants were

encouraged to take up the freedom to say whatever came to their mind in an attempt to elicit narratives that were structured and defined by implicit and emotive motivations. Rather than applying a set of pre-defined questions, as in many forms of semi-structured interview, interviews took the form of me guiding my participants through their initial four associations to the subject of 'transitions' in order to encourage a fuller exploration of their unique experiences. I used techniques espoused by Hollway and Jefferson (2008; 2012) and Joffe and Elsey (2014) such as encouragement, parroting (using the participant's own words to encourage further detail) and asking participants to 'tell me more about XYZ' until the point at which they indicated to me that they had no more to say about their association. These principles were adopted in order to empower my participants and to facilitate exploration of constructs that were personally meaningful to each participant. This also enabled me to clarify the participants' understanding of the questions being asked and clarify their thinking, for example through summarising and reflecting back my understanding of what I thought they were telling me.

The GEM offered a means of collecting data through visually structuring individual interviews in which the material to be explored was generated by each participant's unique and personal associations to 'experiences of transition'. The GEM grid functioned as a visual tool, which research suggested would be helpful when interviewing young people with autism; for example, Preece (2002), Hill (2014), Perfitt (2013) and Shepherd (2015) argue that visually mediated methods strengthen the communication abilities of young people with autism.

### 3.8 Data analysis

A range of approaches to analysing qualitative data are available and selection of an appropriate method should not only consider the research questions to be answered, but the ontological and epistemological position of the study. I therefore reviewed a range of possible approaches to qualitative data analysis including Interpretive Phenomenological Analysis (IPA; Smith, 1996) and discourse analysis (Potter & Wetherall, 1987). Though I have experience of working with IPA at an undergraduate level, as this research study is not located within a phenomenological epistemology it would have been inappropriate to adopt IPA as a method of analysis.

I decided to analyse my data using thematic analysis following Braun and Clarke's model (2006) since this was the most transparent mode of analysis available to me, allowing me freedom to work with the themes while enabling a clear audit trail to be established which foregrounds the process of data analysis. Thematic analysis can be applied across a range of theoretical frameworks, across a small data set and, as shown by Joffe and Elsey (2014), is compatible with a psycho-social method of data collection.

### 3.9 Qualitative research and quality: establishing trustworthiness

Issues of the 'validity' and 'reliability' of elicited narratives as a research method have been addressed by qualitative researchers in a range of ways. In their 2014 paper, Joffe and Elsey demonstrate the internal validity of their findings when applying the GEM, using highly-correlated inter-rater reliability to demonstrate the consistency and reliability of their findings. However given the small sample size of the present study and the idiographic focus of the process of data analysis involving

the use of field notes as described in chapter 3 section 6.2 I felt that drawing on inter-rater reliability as a way to demonstrate reliability was not appropriate. Instead I drew on Hollway and Jefferson (2012), who advocate for a focus on the 'credibility' of qualitative research. Credibility refers to the extent to which the analysis reflects what the participants had to say. Hollway and Jefferson (2012) propose that the concept of trustworthiness is more appropriate for evaluating qualitative research, in which a study is considered to be trustworthy if its credibility is clearly established. Hollway and Jefferson (2012) demonstrate the range of ways in which interpretations of data are robust and supported by evidence, which is established through transparency and the acknowledgement of researcher subjectivity in the production of knowledge. As Hollway and Jefferson (2012, p.162) explain, 'we cannot claim that subjective involvement is always a danger or always a positive resource, only that it depends on how the researcher, given the structures within which she works, is able to use this knowledge'. It is hoped that foregrounding the use of researcher subjectivity at each stage in the research process will contribute to the overall transparency and subsequent credibility of the analysis.

Guba and Lincoln's (1994, p.114) quality criteria for qualitative research within a constructivist paradigm takes the form of trustworthiness, which itself can be broken down into credibility, dependability, transferability and confirmability. When viewed together, these criteria ensure the rigour of qualitative findings (Guba and Lincoln, 1994; Schwandt, Lincoln and Guba, 2007). Guba and Lincoln (1994) position credibility in terms of whether or not the findings represent plausible information drawn from participants' original data and are understood to be a fair interpretation of participants' views. According to Anney (2014, p.278),

‘dependability involves participants evaluating the findings and the interpretation and recommendations of the study to make sure that they are all supported by the data received from the informants of the study’. Anney (2014, p.278) suggests that transferability of a study’s findings is facilitated by the combination of provision of ‘a detailed description of the enquiry’ and through purposive sampling. Bowen (2009, p.307) relates confirmability to the presence of an audit trail, which ‘offers visible evidence—from process and product—that the researcher did not simply find what he or she set out to find’. In this study it is hoped that the use of purposive sampling (section 3.5), providing a clear description of the process of data analysis using MAXQDA, foregrounding researcher reflexivity in the form of a reflective research journal and detailed field notes, inclusion of the completed GEM grids (Appendix E), an example page from an annotated interview transcript (Appendix F) and feeding back the research findings in a participant-friendly summary (Appendix G) plus receiving and incorporating participant feedback on the findings (Chapter 3 section 9.1 and Chapter 5 section 9) will contribute to the confirmability, credibility and dependability of this piece of research.

### 3.9.1 Participant feedback on findings

As suggested by Humphrey and Lewis (2008), in order to increase the social validity and credibility of the research, following the process of interpretation of the data, I made available a participant-friendly summary of my findings (Appendix G). At the end of each interview and as evidenced in the consent form (Appendix D) I established with each participant whether or not they would be happy for me to contact them again to share the findings, with the aim of ensuring transparency about the research process for my participants and to aid the reader in

consideration of the credibility of the findings. Further discussion of the feedback my participants gave will be made in Chapter 5.

### 3.10 Ethical considerations

In order to ensure that my participants were not exposed to any harm, I carefully considered ethical considerations in line with the BPS Code of Ethics and Conduct (BPS, 2011) and sought formal ethical approval from the Tavistock and Portman NHS Foundation Trust Research Ethics Committee (please see Appendix H).

Autism manifests differently across individuals but, as outlined in Chapter 1 section 6, the condition is broadly characterised by a 'triad of impairments' in social interaction, social communication and social imagination (Wing & Gould, 1979; Wing, 1993). Since I recruited participants from a vulnerable group and asked them to speak about potentially emotive experiences, their safety and well-being was considered as the utmost priority. Following Loyd's (2012) recommendations, as outlined in section 3.5 of this chapter, I presented potential participants with several opportunities to say 'yes' or 'no' to participating in the research, presented in different ways, by different people and in different contexts (Loyd, 2012, p.136). This took the form of an initial meeting to discuss the possibility of taking part in the research in which I went through the Information Sheet (Appendix C) and Consent Form (Appendix D) with each participant on a 1:1 basis, offering space for questions or clarification. At this point I did not ask anyone to sign the forms, but encouraged them to take them away, read them in their own time and share them with anyone they felt they wanted to. Though I sought informed consent directly from the young people, given their age and capacity to make their own choices, I encouraged them

to talk through the information sheet and consent form with their parents/guardians or a preferred staff member at the FE College in order to protect the interests and wellbeing of my participants. The dual aims of this were to protect against the young people acquiescing to participating in the research and to enable them to understand fully what participating in the research study would entail.

Being mindful of the potential ways in which changes to routine and unpredictability could be anxiety-provoking for my participants, I did whatever I could to ensure that all my participants were fully informed of the arrangements for each interview. College staff were helpful and supportive and booked rooms for me which were broadly familiar to my participants. We met in the reception area. Participants were provided with a bottle of water as a small token of thanks for participating and to ensure they were comfortable while speaking with me. All rooms used had windows on the doors and I signed in and out of the building as a visitor.

At the end of each interview I debriefed my participants. This was a relatively informal procedure involving checking out with my participants how they had experienced the process, what the next steps were and that I would like to meet with them again at some point in the future to share a summary of my findings. All agreed to be contacted again for this purpose. All were given space to raise any questions they might have and an opportunity to talk about how they felt the interview went.

As part of the ethical considerations for this piece of research I was mindful of my own safety and well-being. I ensured that others were informed about where I

would be and when. I was also mindful of the potential demands of my own emotional responses to my participants' stories. It was important to recognise that I may also have found some issues arising out of the research difficult or painful. One way of managing this was to ensure I had time at the end of each interview to make detailed field notes around the experience of each interview, which functioned as a self-debrief.

### 3.10.1 Audio recording and data security

I was clear that I would make audio recordings of the interviews, and that these recordings would only be used to facilitate the data collection process and would be kept safe and secure. I ensured from the first contact that my research participants were aware of their right to withdraw from research participation at any time (BPS Code of Ethics and Conduct, 2011, p.14). Data security is concerned with the safe storage of interview recordings and transcripts. It is necessary to store data in a way that ensures that no one other than those approved of (i.e. researcher and supervisor) can access to the data. I audio-recorded the interviews using a small voice recorder. I explained to all my participants that as soon as I had transferred the recordings to a personal password-protected computer, and made a back-up copy on an encrypted memory stick, that I would delete the files from the voice recorder.

### 3.10.2 Confidentiality and anonymity

My participants were advised both verbally and in writing on the consent form (Appendix D) that 'All personal information provided by yourself will remain confidential and no information that identifies you will be made publicly available; however, absolute confidentiality cannot be guaranteed as research staff will see the finished project and the transcripts. You may choose to use a pseudonym if you

prefer.’ One participant expressed the view that he would prefer to use his own name, though he was happy to defer the final decision to me. Though I was effectively going against his wishes, I chose to use pseudonyms for all four participants, as given the small sample size and level of personal information provided in the pen portraits in Chapter 4 I felt that identifying one participant by their real name could compromise the anonymity of the others. It should also be noted that, following Perfitt (2013), to maintain confidentiality and prevent identification, any language or syntactic idiosyncrasies in participant responses have not been included in quotations. Interpretations of responses were checked in the interview by repeating or paraphrasing during interviews.

### 3.11 Thematic Analysis

Braun and Clarke (2006, p.10) attempt to define a theme as that which ‘captures something important about the data in relation to the research question’. Where other methodologies, such as content analysis, determine the strength or validity of a theme in terms of its frequency across the data set (which does not fit well with the aims of a psycho-social approach), thematic analysis enables the researcher to attend to both the frequency of the emergence of themes and to consider the subtler nuances expressed by participants. Thematic analysis also enables understanding of the individual narrative of each participant, thus supporting a psycho-social approach which seeks to attend to the *gestalt* and to participant associations.

It is important to acknowledge and foreground the inevitable but often-hidden level of researcher subjectivity at this point in the analysis. As Braun and

Clarke (2006, p.13) explain, researcher judgement is necessary to determine what a theme is, and further to this, 'researchers cannot free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum'. Braun and Clarke (2006, p.79) describe thematic analysis as 'a method for identifying, analysing [*sic*] and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic'. The authors also describe a common misconception of the approach: it is not about themes 'emerging' from the data, which positions thematic analysis as 'a passive account of the process of analysis and denies the active role the researcher always plays in identifying patterns/themes' (Braun & Clarke, 2006, p.80). Braun and Clarke (2006, p.80) cite Ely, Vinz, Downing and Anzul (1997, pp.205-6) in saying 'if themes 'reside' anywhere, they reside in our heads from thinking about our data and creating links as we understand them'. Since a key aspect of both a constructivist epistemology and of a relativist ontology involves foregrounding and acknowledging the role of the researcher in relation to the production of knowledge, this is an important distinction to be held in mind.

As well as applying an inductive approach to themes, I decided that the analysis would be at the semantic level. Though psycho-social approaches most obviously fit with analysis at a latent level, as Braun and Clarke (2006) explain, analysis at the semantic level allows for participants' descriptions to emerge and provides a rich account of their constructions, rather than going beyond description into more interpretative work. This seemed to be more congruent with the exploratory and emancipatory aims of the study and with a constructivist

epistemology. According to Braun and Clarke (2006), in analysis at the semantic level, themes that emerge are seen to represent what is created via the research process.

In their 2006 paper, Braun and Clarke outline a six-phase process of thematic analysis, which I used to guide my analysis. The six-phase process is as follows:

**Phase 1:** Familiarising yourself with your data

**Phase 2:** Generating initial codes

**Phase 3:** Searching for themes

**Phase 4:** Reviewing themes

**Phase 5:** Defining and naming themes

**Phase 6:** Producing the report

*Phase 1: Familiarising yourself with your data*

The process of familiarisation begins with getting to know your data set. My data set comprised the four participant interviews. I chose to transcribe the interviews myself by listening to the audio recordings using a playback device on my computer. At this stage Hollway (2009) advocates delaying the move towards coding and fragmenting the interview until the researcher feels that he or she is familiar with the whole and is able to set extracts in that context. The process of interview transcription facilitated an important level of processing, enabling me to become familiar with the data and to begin to note key themes and ideas, as espoused by Hollway and Jefferson (2000). Hollway and Jefferson (2000, p.69) note that, through

the process of transcription as well as repeatedly listening to an interview and reading the transcript, they came to feel 'inhabited by that person in the sense that our imagination was full of him or her'. As espoused by Hollway and Jefferson (2000), researchers need to understand the whole of the participant's narrative in order to understand particular parts of it. According to Hollway and Jefferson (2008), meanings can best be understood in relation to a larger whole, whether it be a sentence in the interview, the whole narrative or the culture in which that person resides. As Braun and Clarke (2006) highlight, some researchers argue that the process of transcription should be seen as 'a key phase of data analysis within interpretative qualitative methodology' (Bird, 2005, p.227, cited in Braun & Clarke, 2006, p.17), and recognised as an interpretative act, where meanings begin to be created. As I listened to the recordings and transcribed them, I made notes in my research diary of any responses or emotions about what happened and how I conducted the interview. Once I had fully transcribed the interviews I printed them out and listened to them again several times, making notes on the paper transcripts to remind me of important details such as tone of voice, longer pauses, and other aspects of communication such as laughs and words which were emphasised or spoken louder than usual. Though these could have been indicated in the typed transcripts by, for example, use of capitals or italics, adding this information by hand enabled me to attend to and record the details with due attention to their subtleties, and to produce a set of orthographic transcripts which are rigorous and thorough (Braun & Clarke, 2006). An example page from an annotated transcript can be found in Appendix F.

### *Phase 2: Generating initial codes*

In accordance with my relativist ontological position, codes were generated inductively in response to the data set with the aim of linking the themes to the data, also relating to the broad and exploratory research question. Unlike Joffe and Eley (2014) who developed their thematic analysis when using the GEM on the basis of both inductive codes grounded in the content of the data, and more deductive codes devised from theory and relevant past research, I chose to ground my analysis on purely inductive codes. This is because I was interested in seeing whether subsequent links could be made to the existing body of research identified in my literature review without imposing a deductive coding-frame onto the data set. Coding at this stage involved labelling elements of the data which were not fully synthesised until later in the analytic process. I used the software programme MAXQDA Version 11 as a tool for organising my data and to support the process of analysis. Memos, colour codes and active notations in MAXQDA were used extensively to aid the thinking process during coding; an extract from the analysis of Stephen's data demonstrating the use of memos and colour codes is included as Appendix I. A table outlining the coded segments and their relation to themes and subthemes is included as Appendix J, which is located on the attached CD-ROM.

### *Phase 3: Searching for themes*

This stage involved analysing the coded data across the whole data set and constructing themes; that is, identifying meaningful patterns which were relevant to the research questions, while always remaining mindful of the participants' *gestalt*. Sub-themes also emerged through the analysis of data; again, no pre-existing coding

frame was used and the analysis was fully data driven, thus ensuring as far as possible that the analysis would mirror the participant-led process of data collection. At this point, a thematic 'map' was drawn out on paper using sticky 'post-it' notes to enable the relationships and overlaps between themes and sub-themes to be represented. This helped me to identify areas in which themes were too similar and needed to be refined, or where themes were more distinct and needed to be separated out. The analysis also utilised the technique of negative case analysis whereby efforts were taken to identify extracts that challenged a particular idea or theme (Mays & Pope, 2000); this helped me to remain open to considering my data from different angles.

#### *Phase 4: Reviewing themes*

This phase enabled me to step back and take a meta-perspective on the themes, to check that they adequately represented the coded data extracts within them and to consider the themes in relation to the interviews as a whole. I continued to use manual forms of data analysis such as print outs of extracts and sticky notes, in order to cross-check the themes which I had constructed in relation to the transcripts as a whole.

#### *Phase 5: Defining and naming themes*

As Braun and Clarke (2006, p.22) explain, the fifth phase involves naming the themes in order to identify 'the "essence" of what each theme is about (as well as the themes overall), and determining what aspect of the data each theme captures'. I ensured that all four participants were represented in my chosen extracts and that this reflected the scale of their individual contributions. To ensure that the themes were relevant to my research question, I wrote a brief description of each theme

which I would use in the 'Findings' chapter to illustrate the findings, also functioning as part of the 'audit trail' with the aim of being clear about the processes involved in arriving at my analysis of the data. The final part of this phase involved naming the themes in such a way to capture their essence and arouse the interest of the reader.

#### *Phase 6: Producing the report*

The final phase involved writing the themes into a coherent narrative which adequately told the stories within my participants' data, which is presented in Chapter 4.

#### **3.12 Chapter summary**

This chapter detailed the research methodology I selected for this study and explained the process of data collection using the free association Grid Elaboration Method (Joffe & Elsey, 2014) and of thematic analysis of the data. Credibility was discussed as an indication of the quality and rigour of qualitative research, including consideration of trustworthiness, dependability, transferability and confirmability. Ethical considerations were described.



## Chapter 4: Findings

### 4.1 Chapter introduction

This chapter begins by providing biographical information about the four young people who took part in this study, in the form of pen portraits. This is followed by an in-depth exploration of the six themes which were constructed during the interview, transcription and thematic analysis process, supported and illuminated by extracts and vignettes from the participants' accounts.

### 4.2 Pen portraits and approaches to the GEM grid

I interviewed four young adults with autism aged between 18 and 22 years of age; three males and one female. Three participants attended one FE College and the other participant attended a different FE College, both located in outer London boroughs. Three of my participants agreed to be interviewed in their college building. Using the college building as the venue for interviews was largely pragmatic; as my participants were all enrolled on different courses on different days I needed to locate a quiet, confidential space which would also enable me to adapt to their varied timetables. I hoped that staying within the familiar boundaries of their college would support my participants to feel as at-ease as possible. My fourth participant chose to be interviewed in a small studio in the local community with which he was familiar. This provided a private space for the interview recording to take place and ensured he felt comfortable. The length of interviews ranged from 21 minutes to 80 minutes.

To aid the reader in appreciating the individual context and background of each participant, brief pen portraits of the participants, which also outline their

unique responses to being given the GEM grid to complete, are outlined in Table 4.1

below:

*Table 4.1: Pen portraits of participants*

<b>Pseudonym</b>	Stephen
<b>Description</b>	Stephen is a friendly 22 year old male who is currently enrolled on an NVQ Level 3 in health and social care. Having attended a mainstream primary school, Stephen transitioned into a specialist ASD provision for secondary schooling where he stayed until 16. Aged 16, Stephen briefly transitioned to a different further education college before settling at the college which he is now attending. Here he enrolled on the Health and Social Care programme. As well as studying, Stephen has a part-time job and often contributes to staff and student development by giving presentations on autism awareness at the college, for which he was nominated for and received an award. He is looking forward to developing a career in the 'helping professions'.
<b>Approach to GEM grid</b>	Stephen wrote lengthy aphoristic-style statements in the boxes of the grid. Initially he wrote straight across the boxes and ended up writing three statements

<b>Pseudonym</b>	Ben
<b>Description</b>	Ben is a shy 21 year old male in his fourth year of attending FE college. Ben went to a mainstream primary school then attended an ASD specialist provision for a time, transitioning back into mainstream education in Year 8 until the end of Year 11. Having successfully completed the Skills for Work and Life training, Ben enrolled on a mainstream catering course and is part of a team who have won awards for their high standards of cookery. Ben enjoys sports and has a small but close group of friends at the college who he has known since school. He is working towards his Level 2 qualification and following completion he plans to investigate developing his computing and IT skills with a view to having a future career in this field.
<b>Approach to GEM grid</b>	Ben chose to write just a few words in each box. He began with emotions or feeling states ('happy and scared') and moved around the grid to name the experience ('new start')

<b>Pseudonym</b>	Samantha
<b>Description</b>	Samantha is a trendy 18 year old female in her third year of attending the local FE college. Samantha attended mainstream schools until the end of Year 11, at which point she transitioned to college. She has always been interested in working with children and is currently studying for her NVQ Level 2 in childcare, which she loves, and hopes to develop a career in this area.
<b>Approach to GEM grid</b>	Samantha drew sketches of stick people in her boxes, each representing a feeling or emotion. During the interview she expressed the view that the stick people represented her.

<b>Pseudonym</b>	Jamie
<b>Description</b>	Jamie is an outgoing 18 year old male in his second year of FE college. Jamie attended mainstream schools until achieving his GCSE results in Year 11, when he moved to college and enrolled on a Music Technology course. He is a talented performer and already works as a freelance guitarist, music producer, sound technician and sound engineer. Jamie plans to go to university to further his skills and develop a career in music.
<b>Approach to GEM grid</b>	Jamie wrote about his different life stages in the four boxes, starting from early years through primary to high school and finally FE college. He picked out what he saw as the most salient points and elaborated in them in the interview.

It can be seen from the pen portraits that there was some variation in the length of time my participants had been attending FE college with two slightly older participants having left secondary school six years earlier having attended their current college for three or four years already; the younger two were in their second or third year of college. These variations were held in mind during the analysis of the data and in the development of the themes, outlined below.

### 4.3 Overview of Themes

In this section I describe in detail the six overarching themes which emerged from the data, which are: Resilience, Growth and Development, Relationships, Mental Wellbeing, Agency and Understanding Difference. As discussed in Chapter 3 these findings should not be read as a passive account of the process of analysis but should acknowledge the active role the researcher always plays in identifying patterns/themes (Braun & Clarke, 2006, p.80). These themes relate to areas of psychological relevance in relation to young people with autism's experiences of transition from the perspective of having already transitioned into further education and/or training. As evidenced by the exploration of the findings throughout this chapter, the themes and sub-themes are inter-related and have multi-directional influence. Table 4.1 is a thematic map representing the six overarching themes, in which data from all four participants will have contributed. The same table also depicts the related sub themes, to which not all participants will have made contributions.

*Table 4.1: Thematic map*

<b>Themes</b>	<b>Sub-Themes</b>
Resilience	Positive attitudes
	Overcoming challenges
Growth and Development	Learning from experience
	Making a positive contribution
Relationships	
Mental Wellbeing	
Agency	External constraints on agency
	Knowing yourself
Understanding Difference	

Figure 4.1 is a simplified visual representation of the six overarching themes which I put together for inclusion in the participant-friendly research summary (Appendix G).

*Figure 4.1: Simplified visual thematic map for inclusion in participant-friendly research summary*



It should be noted that Stephen and Jamie's narratives dominate because of the length of their interviews and the rich detail both young men were able to articulate. However, throughout the process of thematic analysis I was mindful of giving equitable voice to Samantha and Ben, which I hope will be adequately portrayed in Chapters 4 and 5.

#### 4.4 Theme 1: Resilience

For all four participants, the idea of resilience was a recurrent theme, including through overcoming fears and challenging experiences. Stephen began his interview with some passionately articulated words of encouragement, which related to personal experiences of being discouraged from pursuing further education:

*'Don't let people... don't let people say you can't do it. Don't waste a human mind'* (Stephen, line 95)

Over the course of the interview it became apparent that Stephen had gone through some difficult experiences as he moved from high school to his first FE College, and his words of encouragement were rooted in his own capacity to overcome challenges and demonstrate resilience:

*'And there are some people who said that I couldn't do this...but I've proved them wrong.'* (Stephen, line 13)

*'Perseverance. That's my favourite word in our language, cos it has so much meaning behind it. I just, I just love that word.'* (Stephen, lines 194-195)

Stephen spoke about uncertainty when thinking about future transitions but again demonstrated a resilient mind-set:

*'Think of the next stage in life as a door. You're not sure where it will lead you but it is a good starting point. Take a little peek at it, see if you like it. If you don't like it then you try something else.'* (Stephen, lines 89-91)

Jamie spoke to me about his difficulties at high school which led to him not attending school for a period, and how the desire to get on the FE course he badly wanted motivated him to achieve the grades he needed:

*'I had my meeting to talk about coming on to the course that I'm on now, and I just explained my passion to him and everything and he turned round and he went 'ok, you know, I'll have you on my course. If you get a C in English' ...so I was like right, I need to get on this course, I need this C. So I've gone to me teacher and I've*

*sat down with her and I'm like 'look. Here's what's happening, here's what's going down. I need a C in English. I'm gonna knuckle down, I'm gonna get this right'. I wanted to stay behind and do more work, after school... The point is that I got into the habit of like doing English work and doing lots of it and I got me C in the end and it was like 'yes. I'm on me course, I'm loving life, everything's cool.'* (Jamie, lines 217-245)

Jamie also spoke about his feelings of having changed through his time at high school, much of which was a difficult experience for him, and how good he felt on leaving school and transitioning to college:

*'All that negative energy just went out of the window, and it's gone. The point was that I was changed by the end. In that five years, I mean, the worst five years of my life but I took out my exam results and my music, which was cool, and now we're in the good life, we're all confident, we're all loving what we're doing with music and networking and things like that.'* (Jamie, lines 250-254)

Within the broad theme of Resilience two further sub-themes emerged; 'Positive Attitudes' and 'Overcoming Challenges', both of which relate and contribute to an overall understanding of the main theme.

#### 4.4.1 Positive Attitudes

Though, as will be demonstrated, my participants individually described feelings of anxiety, being scared or being worried at transition points to varying extents, when asked about their experiences of having a new start at college three participants described how they approached their most recent transitions with a positive attitude:

*'The next stage in life is another door into a new world waiting to be explored. That is, basically, what transition means.'* (Stephen, lines 85-86)

*'it's... it's exciting, kind of exciting...you know, working with new people, a new classroom, and like learning your way around'* (Ben, lines 209-211)

*'My new school is a new start...I make new friends, stuff like that really.'*  
(Ben, lines 201-202)

*'Happy. Cos you're making new friends, meeting new people, new experiences.'* (Samantha, line 23)

Stephen gave some further advice about what had been helpful to him, notably speaking about 'them' and 'their life' rather than directly about himself:

*'You just need to just reassure them that everything will be Ok, just give them a little boost of confidence for transitioning into a new stage of their life.'* (Stephen, lines 108-110)

#### 4.4.2 Overcoming Challenges

Stephen acknowledged 'scary' feelings while communicating a sense of transition as being a challenge to be overcome:

*'I think that entering into a new world of something that you're not sure about is scary, but if you think about it, if you think of that concept, that it's just another door going into a new world of your life, the next stage of your life, everybody has to go through it.'* (Stephen, lines 91-94)

Stephen outlined some coping strategies that he used to support him through periods of anxiety and challenging times:

*'just, something simple like going out for ten minutes for fresh air, or you know taking deep breaths just...and also maybe doing a little bit of exercise, that also might help as well. That certainly has helped me, I recommend that it would help anyone. And also maybe using, I dunno, maybe a certain toy or object to squeeze like a stress ball or something.'* (Stephen, lines 169-173)

Jamie was also able to reflect back on the challenges he had overcome in order to get where he is today:

*'I've learnt things like that, from all this high school experience and primary school experience. So it's all good. Like I say, it's been a journey and there have been positives and negatives as always. One I nearly ended me own life but anyway, it's all good and I look up to the stars and I don't think about it anymore.'* (Jamie, lines 410-413)

Another challenge to be overcome was present in the attitudes of others, even family members in Stephen's case:

*'Even people in my family said oh Stephen, he's autistic, he'll never be able to do that, and now here I am, about to finish a Level 3 course! and thinking about doing a University level course.'* (Stephen, lines 184-186)

On transitioning to FE college Jamie benefitted from access to professional support over time to enable him to adjust to the new college context, which was felt to be overwhelming to begin with, despite college staff being supportive and encouraging:

*'I must have had two months of counselling, two or three months, met this guy called [names counsellor] and he just explained everything. And it was like, legend. Absolute legend... it was like, I'm a changed man now, now I can work with this, I can work in this positive situation.'* (Jamie, lines 357-361)

#### 4.5 Theme 2: Growth and Development

For all four participants, the idea of transitions offering the possibility of growth and development in a range of ways was a recurrent theme, including through having new experiences, learning new academic and life skills and growing independence.

For Stephen, the idea of 'transition' led him to reflect on development from being a child into a teenager:

*'The thing is, when you transition, for example when you transition from a child into a teenager, think about it, you...there is no...rule book in terms of, you know, when you're a child you need to follow certain rules. When you're a teenager, you experience the world differently and the same if you're an adult, you take matters into your own hands when you turn into an adult. But when let's just start from child to teenager here; their bodies change, their moods change, and new clothes, new social customs, new friends.'* (Stephen, lines 110-115)

Stephen also described the importance of learning practical life skills such as interpreting a bus timetable and managing the journey into college had been for his personal growth when planning the transition from high school to college:

*'They always made sure that we figured out a bus timetable and knew where we were going and looked on a map to make sure that we knew where we were going before we left. They did it on buses, they didn't do it as much on trains. I think,*

*you know, they should introduce it on trains maybe a little bit? Several times we went down the hill to the library to look at books and stuff like that as part of independent training. We got the bus and stuff. But they didn't expose us to the trains and the tube. Very rarely; I mean we only ever went on the tube or the train occasionally but I think they should have, not just buses but they should have just got us used to other types of public transport as well.'* (Stephen, lines 147-158)

Ben associated transition with 'learning' including developing his academic and practical skills:

Jane: *So if we move on to the next box, you've written 'learning'. So, can you tell me a bit about that?*

Ben: *I... so, I like, learnt...going to school to learn new things... and new skills.*

Jane: *Mmm. What kind of new skills have you been able to learn?*

Ben: *Like, Maths and English and learning cooking at the moment.*

Jane: *mmm. So that's a real combination of sort of academic subjects like Maths and English and really practical things like cooking?*

Ben: *yeah* (Ben, lines 96-103)

Later, Ben associated 'transition' with learning how to manage and understand his emotional responses and developing his social skills:

Jane: *what about, what other skills have you been able to learn from making a transition into college?*

Ben: *like, learning how to feel and what to do in situations.*

Jane: *mm, that's really interesting. Can you tell me a bit more about that?*

Ben: *instead of, like, feeling scared, I just...feel a bit nervous.*

Jane: *ok. I'm wondering if that's a different feeling or a different way of thinking about the feeling?*

Ben: *I think it's a different way. (Ben, lines 104-111)*

All four participants had plans for the future which they were looking forward to, with varying degrees of confidence and certainty. Ben anticipated getting a job, though possibly not in catering, despite this being his area of study. Jamie had plans to go to university and has his heart set on one in particular. Stephen was looking forward to further study and then job hunting and Samantha wanted to complete her Level 3 qualification and then work in childcare:

*'I probably will get a job somewhere. I probably won't do level 3, just probably think I'll maybe get a job.'* (Ben, line 223)

*'With university I've applied for five. [Names university] is the one. If I don't get into [name] I don't know...that's actually a fixed sort of autism set of mind, that's the one I want to go for. But I know that's the one I want to go for, I know that.'*

(Jamie, lines 383-389)

*'In terms of what I want to do after this, I'd like to work in the field of people who have special needs. Young teenagers and young adults and maybe adults'*

(Stephen, lines 317-318)

*'In terms of what I want to do for employment, something similar to what the support staff do here, and maybe doing some kind of therapy work to help people*

*who struggle with, with the worry of what they want to feel or do with life, stuff like that. I would love to help people who need extra help.'* (Stephen, lines 393-396)

*'In a couple of years' time I'll give up this job, I'll keep it while I'm looking for another job, once I get a better offer of a job that I actually want to work in I will give up this job... I'd like to work for people with special needs, I like to support them, I love it, I do.'* (Stephen, lines 16-18)

Jane: *what are your thoughts when you're looking ahead to your next transition?*

Samantha: *Excited. Yeah...looking forward to it.* (Samantha, line 104)

Ben also talked about having experienced a feeling of readiness to 'move on' from school to college and confidence in his belief that he would be able to make new friends:

*'Happy to move on... happy that I made friends at the school before... and happy I'll make new ones at the next one.'* (Ben, lines 39-47)

Despite having been enrolled on a second-choice course, Ben was still keen to pursue computing and described having the confidence to try something new:

*'I might try something a bit different... maybe computers or something.'* (Ben, lines 227-229)

As with the *Resilience* theme, two further sub-themes emerged within *Growth and Development*, which are Learning from Experience and Making a Positive Contribution, both of which relate and contribute to an overall understanding of the main theme.

#### 4.5.1 Learning from experience

Ben described feelings of excitement around the transition to college, tempered by 'scared' feelings which subsided with experience:

Ben: *It's exciting...kind of exciting, you know, working with new people, a new classroom, and like learning your way around.*

Jane: *Yeah? And, what's that like to begin with?*

Ben: *er, it's a bit scary to start off with but you tend to get used to it and you get less and less scared.* (Ben, lines 209-214)

Jamie's first association to 'transitions' was to consider his earliest experiences of growth and development through experience, from the point of view of learning the value of eye contact and gaining retrospective insight into his own personal functioning through access to psycho-education:

*'I never looked people in the eyes, I never used to do this [demonstrates looking from his eyes to mine] it was always like that [looks down] and I would always talk like this, wouldn't look at anyone, none of that rubbish. I don't know, I felt intimidated when people looked at me, I think that's what it was. I know now from the mind management book that it was just a part of my brain recognising threat, so I tried to avoid the threat.'* (Jamie, lines 52-57)

*'The psychology's the big bit though, for me cos I've had to go back and understand all why I was like this, to form this new, it's like I was a flower, I was like, evolved into this, not this perfect image but the person I wanted to be and the person that I am now so, it's all good.'* (Jamie, lines 267-270)

#### 4.5.2 Making a positive contribution

For Stephen, moving to college afforded the opportunity for him to become fully involved in the pastoral life of the college, especially in helping staff and students learn about people who are 'different':

*'There have been hundreds of times when I've done presentations on people who are different so, through personal experience I can give people these ideas, and it feels good to help the community, it really does.'* (Stephen, lines 177-179)

Stephen's contributions to the college community led to personal growth, self-pride and a sense of belonging:

*'I have made a massive improvement not only in myself but I think I've also helped, I myself have helped this college raise awareness for people who are different. Because this orange lanyard that you see is the role of the Student Executive which is responsible for making sure that every student in this college is comfortable and happy with what they're doing. So basically if they have any problem, they just come to me. So this has also made me quite popular here as well, but as I said earlier I do autism talks in this college as well, that's also made me quite popular.'* (Stephen, lines 320-325)

#### 4.6 Theme 3: Relationships

Relationships with staff were a recurrent theme for all four participants. These were mainly seen as positive, helpful relationships, a significant protective factor in overcoming the 'scared' or 'anxious' feelings which were experienced at transition points. For Samantha, the feeling of being excited about making a new transition was also associated with meeting new people and being understood by staff:

*'Excited! at college, like, meeting new people, teachers understanding you, if you need help you go to them, not to be scared to ask for help.'* (Samantha, lines 93-96)

Ben also described the importance of forming new friendships in mediating feelings of anxiety about having a new start:

*'When I left school, and like, joined different ones I was happy, like, I made new friends and stuff, and, like, scared, it's like a new school and new teachers.'* (Ben, lines 31-32)

*'[Making friends was] a bit hard at first but, I got to know them. It just got easier.'* (Ben, lines 57-59)

For two participants, having friends transitioning with them was felt to be a helpful protective factor in supporting a successful transition:

*'On the first day I was a little bit scared but I knew a few people who, that started the course so that helped a bit'* (Samantha, lines 73-74)

*'Some of them [my friends] like went to the same school so I already had friends there.'* (Ben, line 54)

Two participants reported feelings of sadness and loss when leaving behind friends and known teachers on transitioning from one school to another:

*'Well, I mean, at the time, no, I didn't have any friends. I was very sad, very very sad. I'm not going to say the 'D' word but I was very sad.'* (Jamie, lines 210-211)

*'When you're moving school and you're upset cos you don't wanna leave...missing friends and teachers.'*(Samantha, lines 6-8)

*'I don't know... I didn't speak to anyone from school after that so that was a bit upsetting.'* (Samantha, line 17)

Relationships with teaching and support staff were reported by all four participants as being key to successful transitions and experiences at college:

*'I don't think [the work] is that difficult, to be honest with you. But, I couldn't do it without the help that Learner Support has given me. I don't need to have as much help as most people. What the support team do for me is they just make sure that I understand things, if it's too complex they specify it for me. They might take notes down and give me handouts to help me with my work, erm...that's about it really.'* (Stephen, lines 410-416)

*'You get to know them [teachers] a little bit more so that when you do go into the lesson you're not scared. Or afraid that if you say something wrong that they will take it the wrong way or something so, when you go in there on the first day it's actually fine to say things.'* (Samantha, lines 118-121)

*'There weren't no-one having a go at me, it was just like, encouraging me to do work, cos, in that other school they didn't, they just expected me to do work where in this one, they actually helped me. Made sure I understood what I was doing.'* (Samantha, lines 32-34)

*'Just, having someone there to help when I need it. Like, if I didn't, just to repeat stuff. If I didn't hear the teacher. If I get stuck with my work I ask for help.'*

(Ben, lines 181-185)

At the same time breakdowns in staff-student relationships had a negative impact on one participant's educational experiences:

*'It was fine like moving from primary school to school, to high school. But the difference is the communication with the teachers, they didn't...I was in a base most of the time but they didn't know how to speak to me, how to break it down really.'*

(Samantha, lines 58-60)

*'In high school I was confused a lot, like teachers were saying things to me that I didn't understand, they didn't break it down. And I didn't understand a lot of things. I got upset quite a lot.'* (Samantha, lines 48-50)

Support to build friendships was appreciated by two participants. Jamie described the process of being taken out of class by a specialist teacher to join a speech and language group, which enabled him to build friendships within the group, while Samantha described accessing 'ice-breaker' activities on her first day after moving to college which helped her to make friends:

*'So I've walked out she's taken me into this room and there's, again, new people; what is going on?! it's like, some sort of awkward meeting sort of thing. We sat down and we learnt about speech and language and like all about eye contact and communicating and things like that, and, I'll never, I'm so thankful for that because I actually realised how important eye contact and things like that were. So, I*

*learnt that and I engaged with people who were not necessarily autistic but had their own speech problems, like I always remember my friend [name removed]...we was just having a laugh and, it formed a friendship and er, met this guy called [name removed] who I still see now and then we used to play football and all that and it was like I'd finally got on like a friendship group if you like... cos we had literally sat in this room and had a teacher and we're expressing each other's, like, who we are and what we like and that and at the time I used to love football so it was all football, we used to just talk about football and things like that was, it was new it was cool, erm, so yeah, erm, it was good.'* (Jamie, lines 109-122)

*'They helped us like get to know like new people and play games, like, tell two things that are true about you and one thing that, like, you're lying, and we had to play games like that to get to know each other. And the teachers are friendly so, it was fine.'* (Samantha, lines 74-76)

For Stephen, the experience of forming friendships at college was not straightforward at first:

*'I interacted with the students of course, there were a couple of people, only a couple of people who actually allowed me to be friends with them and there are, you know, there were some of them that didn't even want to be seen near me because they thought that I was...that I was...just...stupid, and they didn't think that I'd be able to have a proper conversation with them.'* (Stephen, lines 55-59)

For Stephen, being enrolled on an unsuitable course had a significant impact on the quality of his peer relationships:

*'I tried doing childcare at [names college] but the course was full so I went onto a skills for working life course which didn't last very long because...I don't like using this word, but...the people in my class were a bit too disabled, you know? Well, I, well, if you, to put it more basic, I helped the staff members with the students instead of working with the students. That's how...more severe they were than me. I couldn't really have a conversation with the students because they were, they were not really with it. I wasn't really on the right course so I stopped doing that.'*

(Stephen, lines 26-31)

#### 4.7 Theme 4: Mental wellbeing

All four participants spoke about issues relating to their mental wellbeing. Stephen highlighted the importance and value of having access to tailored support:

*'When I first started here, because the start of enrolment when everyone starts a new course there may be some certain changes to the timetable and things like that, but I first started here I got really really anxious about those changes and I used to get really strange panic attacks and things like that about it. This college is very good at supporting people with those different needs. And loads of people who need extra time, they offer very good support services. This college is probably one of the best colleges I've ever been to or ever seen in terms of supporting people who are different.'* (Stephen, lines 201-207)

Stephen described his struggle and frustration at not being able to secure appropriate support while enrolled on a course in a different FE college:

*'At the time [names college] didn't have a very good reputation for support with students who had learning difficulties. And the number of times that I tried to*

*explain to the staff members and to the students in my class that I needed extra help...endless, seriously. I tried so hard to ask for help and their idea of help was to bring in a, they finally did, they brought in a learning assistant, but that assistant was a bit like an assistant when you go into school who helps every single person in the class; I needed somebody to just be assigned to help me.'* (Stephen, lines 37-42)

Stephen also described the longer term impact of mental health difficulties experienced at an earlier stage in his life:

*'I did have anxiety, quite bad anxiety when I was younger. And at school, and outside of school of course when I left, I still received therapy and counselling for my anxiety. And basically what they did was they gave me coping strategies. And I still follow those coping strategies today.'* (Stephen, lines 163-166)

Samantha's transition from primary to secondary school was characterised by confusion, which manifested itself in emotional outbursts and challenging behaviour:

*'I didn't understand a lot of things. I got upset quite a lot... I was very emotional and a little bit violent because of it because I didn't know how to show my expressions.'* (Samantha, lines 49-54)

Ben expressed feelings of being 'scared' at times of transition:

*'I was like scared to be starting somewhere new'* (Ben, line 62)

Ensuring access to appropriate mental health support was important in supporting one participant's wellbeing following a difficult transition to secondary school:

*'I had a couple of counselling sessions, I remember the first was in Year 7 cos I used to have a mentor, like a school mentor and er, well, it sort of goes that I used to have these dreams about this suicide stuff cos I, I was, at the time I was pretty much done with life, I thought I'd seen it all.'* (Jamie, lines 323-325)

Two participants reported experiencing incidents of bullying at different points, which they associated with transition. For Jamie this was at the transition point from primary to secondary school, though his experience of bullying continued throughout secondary school:

*'When I was in Year 6 I'd like learnt all these new skills and everything and I felt like I had become a more confident person and er, and again with the psychology what's happened is like, obviously, I had become a new person and other people felt threatened by it. Their like, their er, establishment in the triangle, I've forgotten what that's called, it's like a triangle and it's got alpha and, hierarchy, that's the word, hierarchy, so I was obviously building me way up and people felt threatened so they try to like poke me back down by saying like my football team are shit or something like that.'* (Jamie, lines 124-134)

Stephen related painful experiences of bullying at the hands of his peers which occurred following his transition to his first college placement, which broke down:

*'There were tons of people in my class who thought I was a stupid retard who couldn't do anything and why did I need extra help, why was she helping me the most? Why didn't I understand the work and all of that. And this girl that came up to me in the canteen while I was getting my lunch and she told me something that I*

*would never forget. And, I did the right thing, I told her to, basically I told her to sod off. And...just walked away and ignored her. Because she told me that she thought my condition was stupid. I was like...I just said "can you please get out of my face", I just said that. Then she tripped me up and I dropped my lunch and then everybody in the whole canteen laughed at me.'* (Stephen, lines 41-48)

Stephen described the lack of empathy and understanding of security staff at the college, whose handling of the incident in the canteen escalated the difficulties Stephen was experiencing:

*'The security guards didn't help either, they thought I was being really rude, so they dragged me away and they told me off. And then I obviously didn't like being touched at the time so I was you know being really really difficult with them and they didn't understand that and you know these were security guards, for flip's sake! Show a bit of sympathy, you know! I mean I was only a child at the time, I was 16. And I, I went back into the class but let's just say the majority of the time, I spent half my life trying to be in the bathroom than I did in the classroom.'* (Stephen, lines 48-54)

Jamie also powerfully described the pervasive impact of being bullied on his social and emotional development following his transition to high school:

*'So that's where I was extremely bullied and then all this lovely opening up to people and things like that, that just went all out the window, my autism just like kicked in there and it was like, just straight through like protection, cos I can't open up to people cos I'll just get the piss taken out of me, cos I mean, I was taken the piss out of just for sitting like this [sits normally] it just doesn't make sense. It just doesn't*

*make sense. So, that made me feel like I didn't have any friends which was upsetting and I was actually quite lonely because at break and lunchtime I had no one to really play with or anything like that cos I would just be taken the piss out of.'* (Jamie, lines 178-181)

Stephen alluded to past difficult experiences at his previous college and expressed the view that being slightly older was advantageous:

*'I think there's...there's a benefit to being a slightly older student as well because you...you sort of... have come away from the age where bullying and all of that is an issue any more, when you're 18 or over you sort of forget all the bullying and start to just ignore them and just carry on. So I think that age has helped me a little bit in terms of that.'* (Stephen, lines 238-241)

Jamie described experiencing difficulties adjusting to the newly supportive college environment:

*'It's a weird one because, you think of this ... I've come into school every day, been taken the piss out of non-stop and I've sort of got used to that environment. Sounds very sad, but I got used to it and all that and then I'd actually left and then all of a sudden I'm at college, and I'm like in a positive environment, just in general, just positive, it's like 'what?!' and my brain couldn't recognise that, so I all of a sudden I was like fighting away, I was like I need to get out of these situations, it wasn't the fact that I wanted to leave college and like not go to college any more cos I loved my course, it was just, all these people being nice to me, what is going on?!'* (Jamie, lines 349-356)

#### 4.8 Theme 5: Agency

Agency was a recurrent theme which emerged across the data set. Stephen described how learning new skills at college and having access to reasonable adjustments had contributed to his growing sense of autonomy and independence:

*'I can work on my own initiative now. And also because of my condition, I couldn't work in a noisy environment, so I used to go to the library to do my work.'*

(Stephen, lines 443-444)

Stephen described the availability of a range of supports at college to cater for different needs and develop the agency of students:

*'I like the fact that college and the other campuses of [names college], they're very good at preparing their students for the next stage, and for the outside world. The skills for working life upstairs, for example, prepares students who want to go into employment or into another course here in the college, erm, the [names provision] centre gets the students used to doing practical and independent skills for if they want to do stuff by themselves'* (Stephen, lines 305-309)

Stephen described the value of gaining insight into what underpins the difficulties they experience through access to supportive staff:

*'I was a visual learner but also an auditory learner as well, so a visual and auditory learner. So, I learn best by looking and listening. But also, I don't learn on my own initiative. So, in work and employment it's completely different, you have to work on your own initiative, but when you're a student, as a student I am not a person who works on my own initiative, I prefer working in teams, I prefer working when other people support you and do the work with you. I can do independent work*

*now but back then when I requested it, working on my own initiative was something of a mystery.'* (Stephen, lines 435-441)

Two further sub-themes emerged from the data set; External constraints on agency and Knowing yourself.

#### 4.8.1 External constraints on agency

Ben and Stephen described how their choice of college course had been limited by availability of places, though both young men had tried to make the best of the courses they got places on:

Jane: *so what led you to choose cooking rather than computers?*

Ben: *er well, there wasn't enough, erm, I did apply for computing, but the teacher said there wasn't enough room. There were places in cooking so, I did cooking.*

Jane: *and so, what kind of skills have you learned in your cooking lessons?*

Ben: *like, how to chop vegetables quickly and how to cook dishes and stuff.*

Jane: *so it's been a good experience?*

Ben: *yeah.* (Ben, lines 232-238)

*'Basically when I started I didn't have a nice experience at [names college]. I tried maybe doing something else. The only course that was available was business studies. So I tried doing business studies; it didn't work. The students in the class were the type of teenagers who were um...who didn't want to be in the class and they weren't interested in the subject; I mean, I didn't want to do that subject but at least I showed an interest.'* (Stephen, lines 31-35)

Stephen described feelings of frustration at the level of independent skills and training he had access to at high school in preparation for his transition to college:

*'There should have been an even balance between us being indoors and being outdoors and there wasn't an even balance. We only ever went outside when I was at [names school], we only ever went outside twice. Twice a week.'* (Stephen, lines 132-134)

#### 4.8.2 Knowing yourself

Stephen and Jamie described how they have developed an understanding of their own strengths and areas of challenge and what works for them, which supported them to make a successful transition into FE College:

*'I like the fact that, here, they do offer support and they do offer ways in which you can help the students learn. Such as maybe doing powerpoint slides, visual clues you know, pictures, books, handouts. All of these things really do help. I am a visual learner so it really does help me.'* (Stephen, lines 286-289)

Jamie has struggled with 'socialising', 'eye contact' and needing 'everything in order'. He described at various points in the interview how psycho-education in the form of information provided by counsellors, trained staff and by popular psychology books enabled him and his family to understand why he felt how he felt, in turn enabling him to manage more effectively:

*'I love trains, and since a while I was really obsessed with it, and, I'm not as obsessed but back in the day I had, bloody, Thomas the Tank Engine, got all the stuff, things like that, and erm I used to go round and play with them and my mum would*

*go 'Jamie, what are you doing?' I had no answer. I was just, no answer, used to just [demonstrates not having an answer, lips shut] no answer. I got really frustrated with it cos I couldn't actually explain what I was doing. So...they brought in someone who...was aware of the 'spectrum' and they said you've gotta explain to him what he's doing, so, my Nan and my mum went 'Jamie, you're playing with your toys' and that used to spark off something where I could then explain what I was doing.'*

(Jamie, lines 42-50)

*'I read this book and I think "oh that's why I done that! Oh that's why I was like that! It all makes sense" sort of thing' (Jamie, lines 59-60)*

Stephen also described securing the kind of support he believed he needed by having the agency to approach the Learner Support team himself before his course began, having had negative experiences of accessing support in the past:

*'When I first started here a couple of years ago, I went to the Learner Support team and asked for support myself. I told them even before the course had started when I was just showing interest, I said to them look, this is really important that I get learning support, cos otherwise I won't be able to know what I'm supposed to be doing. So could you please help me and find some support for me? So I had to fill in this form, and that got done like, a month before college was due to start anyway, so when I, when I first started, support was already put in place.'* (Stephen, lines 421-427)

#### 4.9 Theme 6: Understanding Difference

For Jamie and Stephen in particular, feelings about being understood and misunderstood were powerfully represented through their accounts. Stephen spoke

powerfully about his experiences of being judged and his sense of injustice about this:

*'When I was younger everybody didn't understand, I was a stupid retard who didn't understand anything, even people in my family said oh Stephen, he's autistic, he'll never be able to do that.'* (Stephen, lines 182-184)

*'You shouldn't judge people by their looks or their needs.'* (Stephen, lines 96-97)

Stephen also described the skills and strengths of people who *'may be different'*:

*'Just because they may be different doesn't mean that they're no less of a person and their minds tend to be, with people that need extra time, with people that have learning difficulties, their minds actually tend to be much more creative and much more detailed than people who don't have extra time.'* (Stephen, lines 97-100)

Stephen spoke of the fears that parents may experience following their child's diagnosis:

*'This is the same with parents who get a diagnosis that their child has a condition, there's a certain humiliation in there where they think that people might look at them differently, and they're scared for their, for that child's safety.'* (Stephen, lines 125-127)

Stephen was clear that staff should be the ones to learn and make adaptations to accommodate the needs of *'people who are different'*:

*'I don't think anyone should let anyone else define who they are. I think that we should just learn to work with these people who are different.'* (Stephen, lines 277-279)

At the same time, Stephen felt that 'these people' should be pushed out of their comfort zone in order to develop their social skills, highlighting the risk of social exclusion:

*'We've gotta expose these people who have...difficulties in interaction, expose them to doing practical activities and expose them to social interaction activities that include social interaction, otherwise they'll just become a recluse in their bedroom playing video games.'* (Stephen, lines 246-248)

Part of the transition planning that Stephen experienced at high school was to support students to go out into the local community with increasing independence. Stephen's view was that this was not adequate, attributing the school's perceived overprotectiveness to their concerns about the students' anxiety levels and subsequent 'peculiar' behaviour, also locating the difficulty in a lack of understanding on the part of the wider public:

*'I think that at [names school] there was a certain humiliation, where they didn't actually feel that if they got us too exposed to the outside world we would get too anxious. And then if we started acting peculiarly, people would start to question why we were behaving like that, because not everybody understands.'* (Stephen, lines 128-130)

Jamie's account included rich first-person descriptions of some of the difficulties he has experienced over time, which have had an impact on his capacity to manage transitions from primary to high school and also into the part-time workplace:

*'If there's too many people in a room, say so, this is 1 on 1, that's fine, if there's 2 people, ok that's fine, 3 people, ok, I can manage. 4 plus? It's too many people now. My brain is trying to recognise each individual person and what to say etc and at the time 2 or more people, no, I just walk away, it's just too many people. It's the fear of, just too many people in a room. It's just threat, walking away from threat.'* (Jamie, lines 84-89)

*"Everything in order": a great way to describe that is if we have that [moves music stand], that [bag] and that [coat], so, that's in a line right? now if this goes here [moves music stand out of line] I'll be ripping my hair out, what is going on, why is that not like that?! Aaaahhh! Like all like that, I'd go mental, cos I used to have all my trains in order, everything was in order, trains, er, what else, like, chips, everything was in order so if something was moved it was like 'what is going on here?!'* (Jamie, lines 94-99)

Jamie explained about an experience in the workplace where he had a part-time job where his reluctance to get involved with conversations between other team members was interpreted as poor team work, and which cost him his job. It was Jamie's view that raising his autism to the attention of his employer at the start would have led him to be negatively judged, and that it should be his personal right to tell people or not to:

*'I didn't actually tell them that I was autistic in the first place. So, it was a weird one but, for me, autism is a thing where I don't tell someone until I'm ready, and when only I'm ready. And no one speaks about it and if people do speak about it it's, "why are you talking about this now?" It was a weird one because I think if I did explain it and I put it in the disability section of the job application I think they would have actually judged me for it'* (Jamie, lines 292-297)

Later, Jamie conceded that he would tell potential employers about his autism in future, but expressed a wish to have some control over how the information that he is autistic would be used:

*'I've learnt from my mistake now and all I do for that is I literally put in the application I am autistic, I am on the spectrum, but I always tell whatever general manager or whatever, 'we don't talk about it. You just know. And if I act differently to every other employee then you know why and that's it.'* (Jamie, lines 300-303)

#### 4.10 Chapter summary

I began this chapter by outlining demographic information about my participants in the form of brief pen portraits, including information about each participant's approach to data collection via the GEM grid. I then outlined the six themes which emerged through the process of thematic analysis, with supporting evidence provided by excerpts and vignettes from the interview transcripts. In Chapter 5 I will apply and reflect on these findings in order to answer the research question 'what are the transition experiences of young people on the autism spectrum?'



## Chapter 5: Discussion

### 5.1 Chapter introduction

In this chapter I summarise the findings of this study and discuss both how they relate to the research literature and to the research question. I relate the findings to three established psychological theories: Bronfenbrenner's (1977) ecological model of human development, Seligman's (2011) PERMA model of wellbeing and Deci and Ryan's (2000) self-determination theory (SDT). Implications for professionals working with young adults with autism and the contribution of this research to the knowledge base are discussed, as are the strengths and limitations of the study. Avenues for future research are identified. This is followed by a reflexive statement about the research process and a brief conclusion.

### 5.2 Summary of the research

This piece of research explored and articulated the transition experiences of young people on the autism who are enrolled in further education at a mainstream college. This study had three objectives, as described in Chapter 1, which have been met in the following ways:

1. To be emancipatory, in order to contribute to the limited but growing body of research in the UK literature which fully represents inclusive accounts of the richness of individual views of young people with autism on their transition experiences. I prioritised the narratives of young people on the autism spectrum and operated with the view that these young people are valid interpreters of their own experiences.

2. To gain insight into the viewpoints and unique emotional experiences of young adults with autism who had experienced a number of educational transitions and had transitioned into further education and/or training. Focussing exclusively on the accounts of young people with autism has deepened our understanding of, and offers insights that both support and challenge normalised versions of, the processes of transition.

3. To contribute to the development of 'critical' research methodologies (Billington, 2013) which aspire to redefine the power relations in research, and which promote the inclusion of young people themselves in the research process. Using the free association Grid Elaboration Method ensured that data collection stemmed from participants' unique associations to and preoccupations with the idea of 'transition', from the perspective of their unique lived experiences. Participants were offered a participant-friendly summary of findings in order to support their inclusion in the research process.

The research question this study addressed was: 'what are the transition experiences of young people on the autism spectrum?' In summary, though there was significant variation between individual participants in terms of their unique transition experiences, six discrete (though related) themes emerged from the data:

- *Resilience* in terms of building the necessary skills to help them successfully navigate through life. Participants commonly alluded to *overcoming challenges* and demonstrating a *positive attitude* to transition.
- The young people's experiences, while not always comfortable, led to *growth and development* through *learning from experience*, acquiring academic and

life skills, making plans for the future and through *making a positive contribution* to the community.

- This links to the theme of *relationships*, in which my participants described the importance of supportive staff and peer relations and some of the challenges in forming new friendships.
- *Mental wellbeing*, in which participants described the impact of anxiety, depression, confusion and stress on their transition experiences, also recounting painful incidents of bullying and of not being understood by teachers and college staff.
- *Agency*, whereby my participants spoke of how having access to appropriate tailored support enabled them to develop greater independence and autonomy; frustrations at *external constraints on agency* in some respects such as access to appropriate or desired college places and aspects of their training, and how *knowing yourself*, knowing what works for each individual and tailoring support accordingly, could enable the young people to manage the challenges of college life with increasing independence and autonomy.
- *Understanding difference*, in which participants described the impact of their experiences of being judged or misunderstood on their lives, and the value of being accepted and understood.

The findings from the research have been presented in the form of a thematic analysis and, in accordance with Braun and Clarke (2006), a discussion follows which

considers the findings in relation to the research question. The findings are also located in the context of existing research and psychological theory.

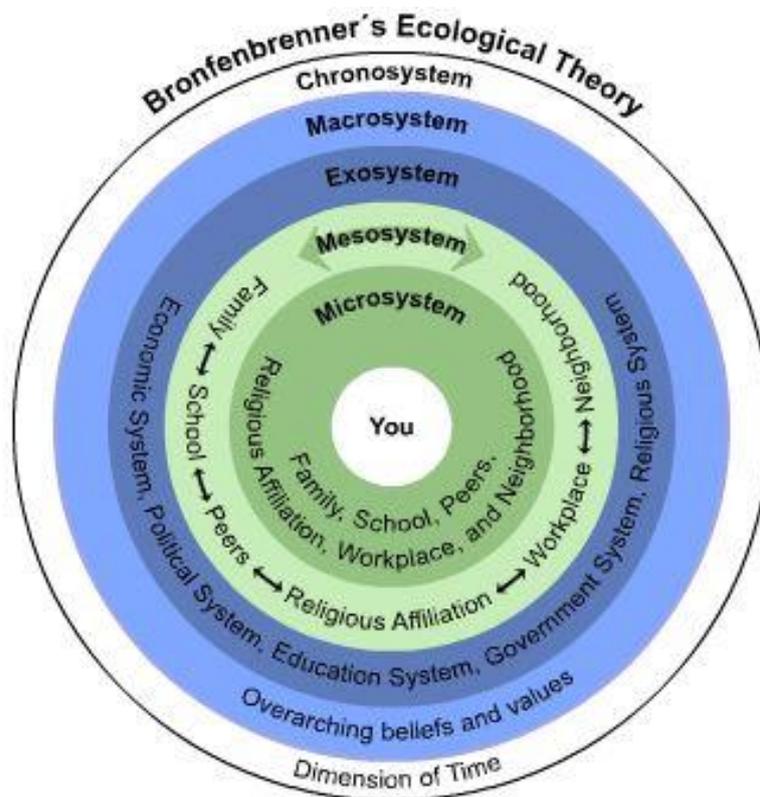
### 5.3 Research question: what are the transition experiences of young people on the autism spectrum?

Findings from this study highlight that all four young people who took part in the study had successfully transitioned into a mainstream college of further education and were preparing for their next transition into the workplace or to higher education, in relation to their expressed future aspirations. Research suggests that entry to further education and/or work training can be seen as objective markers of a successful transition to adulthood (Hendricks & Wehman, 2009). The findings of the current study capture something of how each young person managed the processes of change. Key protective factors facilitating a positive transition into further education which emerged from this analysis included the value of having healthy relationships with peers and with teaching and support staff, having a positive outlook and a resilient mind-set, accessing appropriate tailored support, learning practical and emotional life skills and for individuals with autism being understood in terms of their skills and strengths.

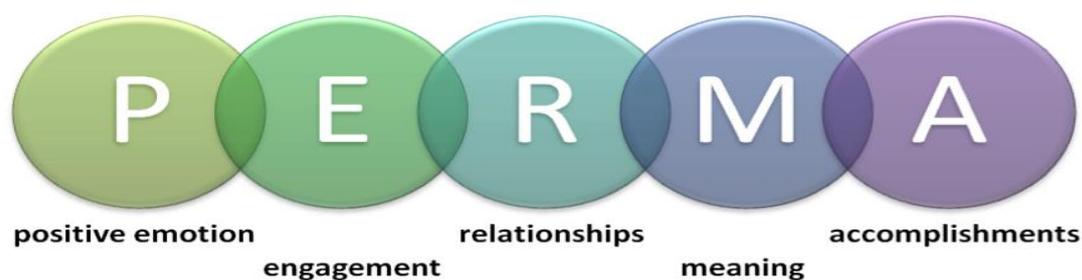
It may be tentatively surmised from these findings that a range of interlinked psychological and social factors, which cannot be extrapolated from one another and which operate together, are evident in relation to my participants' transition experiences. Bronfenbrenner's ecological model (1977) enables consideration of the systems around a young person which shape and influence their development such as those found within e.g. a family, school or college. As demonstrated in figure 5.1, Bronfenbrenner (1977) identifies bidirectional influences across broad levels, from

the young person's immediate environment and the relationships within it (the 'microsystem') through to the 'macrosystem' which enables consideration of wider cultural and political belief systems such as those at the government and local authority level. As espoused by Hannah and Topping (2013), Bronfenbrenner's 1977 ecological model provides a helpful framework for understanding the importance of the social context in which transitions take place, and the bidirectional influences between an individual and their environment.

*Figure 5.1 Bronfenbrenner's Ecological Theory*



I suggest that Seligman's 2011 multidimensional PERMA model of wellbeing may also be a helpful lens through which to view the findings which emerged in this study (figure 5.2).



*Figure 5.2 Seligman's 2011 PERMA model of wellbeing*

PERMA (Seligman, 2011) is an acronym that stands for what Seligman describes as five 'pillars' or core elements of positive human functioning which contribute to lasting wellbeing, and which people pursue for their own sake. 'Positive emotion' refers to subjective feelings of happiness and positive emotion, while 'Engagement' refers to the psychological connection between a person and activities or organisations. 'Relationships' includes feeling socially integrated, cared about and supported by others, and satisfied with one's social connections. 'Meaning' refers to being part of something larger than oneself, while 'Accomplishment' refers to the progress an individual makes progress toward goals, their feelings of competence and experience of a sense of achievement. According to Seligman (2011) these elements are subjective, meaning that different individuals value different aspects of PERMA and give different weight to individual elements.

I also propose that, with its links to the positive psychology movement (Seligman & Csikszentmihalyi, 2000), the application of Ryan and Deci's (2000) psychological theory of self-determination may provide insights into the developmental and socio-cultural processes which underpin these findings and which facilitate self-determination. Self-determination theory (SDT) focuses on three

innate psychological needs: competence, autonomy, and relatedness. According to Ryan and Deci (2000) these factors are essential for supporting optimal functioning, facilitating the process of natural development, and promoting social well-being, all of which can be related to the themes which emerged from the data in this study. Self-determination is important to people with autism since the theory emerged as a result of related social movements such as self-advocacy, self-determination, disability rights and the independent living movement (Ward, 1996). According to Ward (1988) SDT can be seen as a 'way of life' for all people, providing a framework for a better quality of living and offering mechanisms and processes to aid consideration of possibilities. For the purpose of this discussion I take the view that SDT is not simply a set of attitudes, skills and abilities, but represents a more complex construct that includes consideration of the environmental context. The application of this theoretical framework has been established in research literature concerning the academic and social functioning of children with autism in the USA though it has not yet been applied in the UK; however, it would seem to be suited to the exploratory and emancipatory aims of the current study.

### 5.3.1 Resilience (Theme 1)

Resilience is relatively well-established in the body of research relating to the transition experiences of young people with autism (Hannah & Topping, 2013; Jindal-Snape & Miller, 2008). Resilience has been defined as 'a dynamic process encompassing positive adaptation within the context of significant adversity', which is argued is due both to the attributes of the individual and to protective factors in the surrounding environment (Luthar, 2000, p.543). According to Rutter (1999, p.135) resilience 'does not constitute an individual trait or characteristic... resilience

involves a range of processes that bring together quite diverse mechanisms.’ Successful adaptation to the college environment may be due in part to students remaining resilient and coping with change (Jindal-Snape & Miller, 2008) but equally, successful transition to further education may be seen as an interactionist product of both internal factors, such as resilience, and external factors, such as availability of and access to appropriate support (Hannah and Topping, 2013). Waller (2001, cited in Hannah and Topping, 2013) proposes that research approaches which tap into subjective experience may reveal protective factors which are critical to understanding resilience. This perspective is supported by the findings of the current study. The present findings also support Jindal-Snape and Miller (2008), who argue that for some young people transition can be considered a ‘challenge of living’ and propose that there should be a greater focus on social and personal experiences at these times.

In SDT, resilience is connected to intrinsic motivation (Ryan & Deci, 2000). Intrinsic motivation refers to the ways in which people may be motivated from within, for example by interests, curiosity or their values. Research applying SDT suggests that having choice, acknowledgment of feelings, and opportunities for self-direction have been found to enhance intrinsic motivation because they allow people a greater feeling of mastery (Deci & Ryan, 1985, cited in Ryan & Deci, 2000). This may be related to the subthemes of *positive attitudes* and *overcoming challenges*, for example in Jamie’s account of how he was motivated to achieve academically by his desire to access a place on a particular course at an FE college. These subthemes could also be understood in terms of the ‘Accomplishment’ construct from Seligman’s (2011) PERMA model, for example in participants’

accounts of overcoming challenges at the transition to FE college and the different ways in which they conveyed a sense of accomplishment and achievement, and how this builds resilience. 'Achievement' may also be allied with mastery, which SDT suggests is a primary human need and one which is closely linked to well-being (Deci & Ryan, 2000).

### 5.3.2 Growth and development (Theme 2)

All four participants expressed a sense of looking forward to new opportunities and reporting positive feelings following transition to college, which supports the findings of Perfitt (2013), Hannah and Topping (2013) and Horsley (2009). Samantha and Ben articulated worries and fears prior to their transition to college about what it would be like, tempered by feelings of anticipation and excitement. Lucey and Reay's 2000 paper adopts a psycho-social perspective on the links between transition experiences of a cohort of children attending mainstream primary schools in the process of selecting a secondary school and their identity formation, and highlights the social psychological dimensions of transition. Drawing on the work of Klein and Winnicott, Lucey and Reay (2000, p.194) positively frame anxiety in terms of 'fearful excitement', positioning it as an integral and necessary force in transitional states, particularly those connected to change. According to Lucey and Reay (2000, p.194) 'fearful excitement' fulfils an adaptive function in supporting a young person to adjust to their new environment and new circumstances, this being crucial to the growth and development of the 'self'. All four of my participants reported that they were anticipating the next transition into work with positivity, with what Lucey and Reay (2000, p.194) call a 'tinge of optimism'. This

may be linked to the successful transition experiences my participants reported having had on moving to their current further educational setting.

In relation to the theme of *growth and development*, participants reported finding specific aspects of available help and support to be particularly valuable, including the development of social skills, learning to travel to college independently and managing the challenges of increasingly complex social situations. These findings align with previous research (Mitchell & Beresford, 2014; Chown & Beavan, 2010; Hendricks & Wehman, 2009). However, as Mitchell and Beresford (2014) highlight, the provision of support with the development of skills such as social skills or travel skills cannot be assumed, given that many young people on the autism spectrum will not automatically be eligible for statutory transition planning and support processes within special educational needs provision (Beresford *et al.*, 2013, cited in Mitchell & Beresford, 2014).

One sub-theme was *making a positive contribution*, which emerged primarily from Stephen and Jamie's data. For both young men, though in different ways, being in an inclusive college 'system' which enabled them to pursue their interests and ideals supported their mental wellbeing and their developing sense of agency; as demonstrated by the thematic map (figure 4.1), the themes have bidirectional influence and interconnect with each other. This may be understood in the context of Bronfenbrenner's (1977) ecological model (figure 5.1) and the interaction between an individual's personal world and their social networks. Within this social systems framework, participation in the community, in college life, is located in the wider institutional structures of the 'exo' system, as in the larger whole school or

college systems and the community in which they are in, and interacts with an individual's 'micro' and 'meso' systems. The subtheme of *making a positive contribution* may also be understood in the context of the 'Meaning' element from Seligman's (2011) PERMA model. Here, 'Meaning' is understood as a way of being in the world that connects oneself to something larger than one's more immediate needs and desires, such as Stephen's voluntary work in the college, Samantha's passion for working with children or Jamie's enjoyment of and participation in music performance. This also reflects the bidirectional interconnectedness of themes, for example the influence of relationships on what makes an activity meaningful, since in Seligman's (2011) model, feelings of integration with a community are closely linked to relationships.

### 5.3.3 Relationships (Theme 3)

The strong influence of family, friend and staff relationships found in the present study reflects those found in other literature (Mitchell & Beresford, 2014; Hill, 2014; Dann, 2011; Fortuna, 2014). The present findings highlight the helpfulness of peer relationships when transitioning from primary to secondary school and from secondary school to college, which is congruent with research by Dann (2011) that indicates that having friends who are also transitioning, or knowing a friend already at the next setting, can support successful transition and mediate feelings of anxiety. This also supports the findings of Fortuna (2014) who describes the mediating role of friendships and prior relationships in supporting a successful transition. Dann (2011, p.305) noted that students 'became increasingly concerned with friendships following transition', while Hannah and Topping (2013) relate the protective role of positive peer relationships to the resilience literature. The fostering of successful

relationships with peers is highlighted as good practice in the development of provision for young people with autism (Charman, Pellicano, Peacey L., Peacey, N., Forward & Dockrell, 2011).

In this study, establishing good working relationships with teaching and support staff in the college was reported to be an important protective factor. Samantha and Ben focussed more on friends and teaching staff as the go-to source of support, which differs from Mitchell and Beresford (2014) who found that the primary source of emotional support was the family, especially parents. Looking at support for students at the point of transition, research highlights the importance of staff building up a relationship with the student (Johnstone & Patrone, 2003). Research which features the voice of young people with autism has suggested ways to improve the transition process from primary to secondary school from a social and emotional perspective, including knowing some students who would be in the same class and being treated in a more mature fashion (Johnstone & Patrone, 2003). As this is congruent with the present findings, this tentatively suggests that it may be helpful to consider 'what works' in supporting children with autism at key transition points earlier in their education to see what can be applied to the post-secondary transition.

In relation to SDT, research has found that self-determination in friendship has been found to be positively correlated with social acceptance (Soenens & Vansteenkiste, 2005). Deci and Ryan (2002) describe 'relatedness' as one of the three basic psychological needs and as essential for adjustment and wellbeing, while in the PERMA model Seligman (2011) describes 'relationships' as being fundamental

to the promotion of lasting wellbeing. Samantha and Ben highlighted the value of having access to social activities within their new peer group after transitioning to college. Samantha described a range of 'ice-breaker' activities, facilitated by teaching staff. This supports research by Pietarinen (2000) who showed that teaching staff are seen as playing a significant role in facilitating social relationships.

Samantha and Ben both spoke of sad feelings and of loss on leaving high school and transitioning to college, particularly around friendships and the good teacher relationships which they had formed. Though their research was not specifically in relation to children with autism, Lucey and Reay (2000, p.195) describe the sense of loss associated with educational transition as being 'integral to the process of change'.

#### 5.3.4 Mental wellbeing (Theme 4)

The psychological wellbeing of young people with autism is an ongoing concern, with over 70% of this population reported to experience mental health problems (NAS, 2010). Three of my four participants related mental health difficulties which impacted on their transition experiences. For all three, these difficulties became manifest during their time in secondary school, and so accessing appropriate support in order to enable them to make the move into further education was vital. Experiences of support and the development of helpful coping strategies differed between participants; key sources of support included family and friends, leaving behind more difficult times, taking inspiration from music, access to psycho-education, drawing on known coping mechanisms and accessing professional counselling support.

Being slightly older than some of his college contemporaries, Stephen reported feeling that being older was advantageous as he felt 'older and wiser'. Jamie, however, was the youngest participant and though closer in proximity to some of the difficulties he had experienced while at school, was full of optimism for his academic and working future. Pietarinen, Soini and Pyhältö (2010) highlight how such perceived well-being regulates learning, which the authors relate to the three components of SDT: relatedness, competence and autonomy (Deci & Ryan, 2002).

Samantha and Ben both raised feelings of being 'scared' prior to making the transition to college, though from the perspective of already having transitioned successfully they also related feelings of being 'happy' and 'excited' in the present. In relation to the primary-to-secondary literature, Hannah and Topping (2013) discovered from their data the existence of individual differences in anxiety levels for autistic students at the point of transition. They noted in their study that five out of the eight students participating made reference to feeling frightened or nervous about their impending transition, though this was to secondary school rather than to FE college. Frederickson, Rice and Seymour (2011) highlight that, for most children, anxieties associated with transition are typically short-lived and significantly decline in intensity after the first term. Similar findings were also reflected for children with autism in transition research into parental perspectives by Dillon and Underwood (2012). This would seem to be supported by the present findings.

Notably, one participant, Jamie, identified that moving into the more sympathetic and supportive college environment was felt to be overwhelming. For Jamie, the novel feeling of being accepted and understood was overpowering and he

benefitted from access to professional support to enable him to adjust to this change. Though such a response to an empathetic and supportive college environment is not reflected in the present literature on transitions for young people with autism, it could be argued that Jamie's experience relates to the findings of Connor (2000, p.294), who concludes that 'one immediate implication from the responses of the young people themselves and their teachers is the need to recognise that social and other problems may be quite marked, even at the mild end of the autistic spectrum. One is reminded of the role of emotional sequelae from the possible mismatch in scholastic, social or behavioural demands in the mainstream setting and the particular style or needs of the individuals.'

Bronfenbrenner's 1977 ecological model encourages accommodation of the system to the individual. In relation to effective transition planning for young people with autism, this could be interpreted as a call for arrangements to reflect the unique needs of each individual, matching their profile and giving due consideration to how they may best be supported through the process of change and adjustment to a new environment and context.

#### 5.3.5 Agency (Theme 5)

Self-determination means that all people have the right to direct their futures, to have control over how they live their lives and to have authority over the resources that support them (Ryan & Deci, 2000). It could be argued that this links to the theme of *agency*, which emerged from my findings. In SDT, autonomy is defined as 'the universal urge to be causal agents of one's own life and act in harmony with one's integrated self' (Deci & Vansteenkiste, 2004, p.25). Pietarinen, Soini and

Pyhältö (2010) argue that 'active learning agency' supports the overall well-being of students, and can also be seen as a crucial aspect of resilience, as described by Jindal-Snape and Miller (2008). Hill (2014) writes of the importance of young people with autism seeing themselves as 'active agents' in their lives and more specifically in decisions which impact on them directly. According to Hill (2014) being active agents involves feeling supported, heard and understood, which is congruent with the findings of the present study and can be understood as a component of self-determination.

The sub-theme *external constraints on agency* is reflected in the fact that two participants, Ben and Stephen, reported not being able to access their first-choice courses. Though Ben wanted to do computer studies, he found that the course was fully subscribed and instead was given a place on a cookery course. Awareness of personal preferences and interests can be seen as a characteristic of self-determination (Deci & Ryan, 2000). Though he reported having enjoyed the college experience, Ben intended to pursue his original aims once his cookery course was complete. Stephen spoke frankly about his difficult experiences having been placed on an unsuitable college course. His associations to transition were driven by the theme of resilience, overcoming challenges and passionately-articulated pleas for understanding and acceptance of 'difference', again reflecting the interconnectedness of themes.

Previous research has highlighted that professional, parental and pupil/student concerns around transition differ in their intensity and in areas of concern (Mandy *et al.*, 2015; McLaughlin & Rafferty, 2014; Dann, 2011; Fortuna,

2014, Hannah & Topping, 2013; Jindal-Snape *et al.*, 2006), which it could be argued relates to the sub-theme of *external constraints on agency*. Stephen described the over-protectiveness of family members, for example speaking for him in meetings, and the limitations of his previous high school's transition planning, particularly in relation to the development of independence skills for young people moving on to further education or new settings. This aligns with findings in Mitchell and Beresford (2014) in relation to the perceived over-protectiveness of family members and their influence on post-school outcomes. In addition to existing findings, this study raised the potentially over-protective role of the school, particularly in relation to the development of life skills such as independent travel to college. Stephen's perception was that his school was concerned that the young people 'might start acting peculiarly', which he believed led the school to be over-cautious about the design of their independence training-package. At different points in the interview he made pleas for young people to take up the agency to speak for themselves.

Stephen was clear that he wanted less support than others. He wished to have support in certain situations, but in his interview, Stephen tended to distance himself from others who 'needed' support, referring to them as 'they' or 'them'. He found some support patronising and wished not to be compared with other autistic students either positively or negatively, preferring to be seen as an individual in his own right. This is congruent with Fabri, Andrews and Pukki (2016) whose similar findings are in relation to young people on the autism spectrum transitioning into university.

### 5.3.6 Understanding difference (Theme 6)

Hill (2014) and McLaughlin and Rafferty (2014) highlight the importance of focussing on the individual and unique strengths, needs and interests of each young person, rather than focussing on their difficulties through a diagnostic lens. Jamie spoke of his dilemmas about disclosing his diagnosis, alluding to a fear of negative treatment, a desire to have the right to choose who knows and who does not, and fear of preconceptions as his reasons for not disclosing. This relates to the results of Humphrey and Lewis (2008) whose participants related comparable findings relating to their desire to fit in and appear 'normal'. However, unlike Humphrey and Lewis's findings showing participants who celebrated their autism spoke positively about themselves, Stephen and Jamie expressed a preference for being discreet about their autism, which Stephen frequently referred to as 'my condition'. Both young men articulated a simple wish to be considered as individuals in their own right, regardless of their diagnosis.

For all four participants it was not clear the extent to which staff across the two different whole college 'systems' had accessed autism awareness training, though all participants reported favourably on the level of support and understanding in their current provision. However, Stephen's prior experiences of being misunderstood and poorly treated by security staff after transitioning into a different FE college suggests that the channels for communicating information about autism awareness were not as clearly defined as might be expected. This supports findings from Dillon and Underwood (2012) who promote the importance of autism awareness training at schools and FE colleges across all levels of staffing, while Connor (2000, p.294) points to 'staff awareness of the nature of ASD and Asperger

syndrome, and a whole school approach' as being critical in 'minimising the risk of unreasonable expectations' and of misunderstandings.

The theme of *understanding difference* may also be understood in terms of the 'Relationships' element from Seligman's 2011 PERMA model. Seligman (2011) proposes that positive relationships and a sense of feeling understood, with differences accepted, supports and deepens an individual's feelings of security, self-esteem and subsequently self-acceptance. This relates to Stephen and Jamie's accounts of being negatively judged and the impact of this on their feelings of anxiety and depression, and to all four participants' expressed sense of being accepted and understood by teaching and support staff at college, which contributes to their sense of wellbeing.

#### 5.4 Limitations of the study

When considering the findings of this piece of research it is important to give the fullest possible consideration of the limitations of the study, which will be brought to light in this section. While this study successfully promotes the experiences and views of young people on the autism spectrum, generalisability is not possible from this sample, nor was it an aim of the study, though tentative extrapolations may be made.

This study was based on retrospective accounts of transition, as all four participants were contributing to the research from the perspective of already having made a successful transition into further education and/or training. Difficulties with accuracy concerning retrospective accounts are understood in research generally (Mertens, 2010); however, that this study sought to access

participants' associations to 'transition' means that 'accuracy of recall' was not the primary aim.

This study was based on one interview per participant. Follow-up interviews may have provided an opportunity for participants to add further information about their transition experiences and may have supported them to emphasise those aspects which they felt were most salient.

Though all four participants gave fully informed consent to participate and expressed positive views about participation post-interview, one parent contacted me in September 2015, prior to the interview with their child, to express reservations about their child taking part. After exploring the parent's anxieties I was able to reassure the parent about the nature of the interview and about the ethical processes which were already in place and which were vital to the research process. Though the interview went ahead as agreed with the young person, reflections on this which are available to me through the use of a research diary remind me that I was guarded and careful with my lines of questioning in this one particular interview, in the light of expressed parental concerns. As with all my participants I set up as safe a context as possible for the interview, for example by establishing how they would let me know if they didn't want to answer a question. However, though data collection was led by my participant through the use of the GEM, throughout the interview I was mindful of the pressure I felt to keep to benign areas, as far as possible. I feel this had a significant impact on the depth of data I was able to access from this interview, which is likely to have affected my findings.

In the light of the use of a psychoanalytically-informed method of data collection, the choice not to apply psychoanalytic concepts in the data analysis could potentially be viewed as a limitation. However I wish to highlight that I made a clear and conscious choice to adopt only the elements of a psycho-social approach that sat comfortably with my constructivist epistemology, in which the emphasis was on the viewpoints of the participants. I felt that deductively applying psychoanalytic constructs to the data analysis would not have been an adequate fit with a constructivist epistemology.

Contemporary EP work is located in the context of austerity, led by a government whose policies of budget cuts and deficit reduction have arguably led to increased pressures on the most vulnerable members of society and on the services who serve them. As Goodman and Gregg (2010) show, vulnerable families are those who experience the most risk factors and are arguably the most likely families to be encountered in EP work. However, no data was collected on the socio-economic status of my participants, which might have provided further interesting context for my findings.

### 5.5 Recommendations for future research

While the present study shares similarities with wider autism research in its intention to promote the views of the young people themselves, it adds depth to the limited body of research into the transition experiences of young people with autism by providing insights from the lived experiences of four young people who have successfully transitioned into further education or training. Given the changes to the working practices of educational psychologists since the introduction of the new

SEND Code of Practice (2014) and the development of the EP role in relation to the post-18 age range, further research which explores the lived experiences of young people with autism and which enables insight into the protective factors which support successful transition may be helpful.

The approach to data collection adopted in this research, using the free association Grid Elaboration Method, may form the basis of further research which explores the lived experiences and associations of young people on the autism spectrum. The present study was based on retrospective accounts of transition. It may be fruitful to take a more longitudinal approach and to gather data using the GEM both prior to and following the transition to college in order to develop a deeper understanding of the transition experiences of young people on the autism spectrum.

Further research may also wish to use the GEM to explore the experiences and associations of young people on the autism spectrum who have transitioned into university. It is likely that these young people will be on the 'higher functioning' end of the autism spectrum; despite this, as articulated by Connor (2000) and Fabri, Andrews and Pukki (2016), autistic students can face multiple factors affecting their educational experience and it would be wrong to underestimate the actual or potential difficulties which may be experienced.

### 5.6 Contribution to knowledge and practice implications

This piece of exploratory and emancipatory research contributes to a small but growing body of qualitative research which exclusively aims to gain the views of young people with autism about their experiences of transition (Mitchell &

Beresford, 2014, Shepherd, 2015). It makes a contribution to knowledge and has practice implications in several ways. These findings suggest that peer relationships may be a protective factor in facilitating a positive transition. This is particularly salient when placed in the context of previous research that has highlighted that young people with autism tend to have access to limited social networks, fewer friends and lower levels of social support, and that positive interactions feed the development of peer relationships (Humphrey & Symes, 2011).

This study is an apt demonstration of ways in which EPs can take up an advocacy role when working with young adults on the autism spectrum and ensure that their voices are heard in relation to decisions which impact on their future and on their well-being. The use of the free association GEM with its integrated visual element shows how using 'light-touch' visual support can be helpful in enabling the views and voices of young people with autism to be expressed. Further to this, as described by Billington (2006, p.3), it is hoped that this study may helpfully empower EPs to draw upon existing skills in order to develop the EP role and engage with young people with autism in the 18-25 age range, particularly in relation to gaining insight into their experiences and their views.

Overall these findings lend further support to the importance of flexible and individualised transition planning for young people with autism and of having key stakeholders at the heart of decision making and planning (Tobias, 2009, Mitchell & Beresford, 2014). These findings support Connor's (2000) view that it is important not to underestimate the stress to which young people on the autism spectrum may be subject at times of major transition. It may be surmised that it is most important

to know what works for each individual and that drawing on what has made past transition experiences successful or otherwise may be helpful.

As espoused by Hill (2014), planning for life outcomes and preparation for post-16 provision needs to be considered as an important factor in the Key Stage 4 provision for young people on the autism spectrum. In line with the government agenda of person-centred planning it remains vital to hear from these young people's perspectives and, as Hill (2014) writes, to establish the kinds of support that is most useful to them and the type and extent of support desired. EPs are well positioned to have a key role in facilitating and representing the views of young people at the heart of decision making about their futures.

These findings indicate the potential of using psycho-education in order to enable young people with autism to know themselves and to provide insights into their unique strengths and areas of challenge. This study also highlights a potential role for the EP in challenging reified notions such as the 'learning styles' myth and perhaps supporting FE colleges to construct ever more helpful ways to think about how best to support their learners.

### 5.7 Reflections on the use of the free association Grid Elaboration Method as a research tool

As outlined in Chapter 4 and evidenced in Appendix E, all four participants approached the GEM grid in a different way. Stephen wrote lengthy, passionate statements in each box, Jamie outlined the stages of his life so far, Ben wrote two or three words and Samantha chose to draw brief sketches. As stated earlier, rather than see this as an obstacle to the collection of useful data I viewed this as a demonstration of how flexible and responsive a data-collecting tool the GEM could

be in meeting the individual needs of my participants. One implication was that my participants had autonomy and ownership of what was raised for discussion and could approach the task in whichever way felt most comfortable. I would argue that giving participants ownership of the process of data collection helps to reduce or minimize the power imbalance inherent in research and enables participants to have a greater degree of control over the process than would be the case in a semi-structured interview, for example.

Despite its many advantages, the use of the GEM in qualitative research has a number of disadvantages, which were considered during the conceptualisation of the research. Firstly, this approach can be time consuming, particularly when conducting research in a large geographical area or with a large sample of participants. Robson (2011) posits that interviews that exceed one hour can be demanding for participants, whilst interviews lasting less than thirty minutes can be limited in the wealth of information and data they offer. Two of my interviews lasted around twenty minutes and the scale of information and data being made available was inevitably limited. However it is my view that both of these participants felt that they had used the opportunity to give their views to the fullest possible extent and that they were satisfied with their contributions, as evidenced in Chapter 5 section 8. Verbosity should not be a barrier to participation in action research into issues which directly affect young people such as those who took part in the present study; rather, as espoused by Lewis and Norwich (2005) it is the responsibility of action researchers to consider the individual and exceptional needs of participants, and to design research and adapt methods accordingly.

## 5.8 Participant experiences of the research process

At the end of each interview I asked my participants to let me know what the experience of taking part in this piece of research had been like for them. Having already established rapport and a comfortable working relationship it is my view that my participants would have felt able to give frank and honest feedback in the one-to-one context. All four reported having had a positive experience, each reflecting their own response to the research process. Samantha appreciated the chance to represent her 'feelings' pictorially instead of being asked directly, while Ben came with the aim of 'getting his point across', which he reported having achieved. For Stephen, the research experience lent him a chance to be characteristically altruistic, while Jamie reported a sense of catharsis, of having gone on a 'memory tour'. Jamie was particularly keen for assurance of his privacy and confidentiality to be reiterated. These positions may helpfully be demonstrated by the following brief extracts:

### *Samantha*

Jane: *How was the experience of talking through that, for you?*

Samantha: *It was alright. It was good to show people's, like, feelings, if you get them to draw stuff instead of just asking them.*

### *Stephen*

Jane: *How has it been talking about those experiences? Not all of them were comfortable...*

Stephen: *No, it's fine, I mean... if somebody wants to know something in terms of, especially if it's for your doctorate as well then, I will give you as much info as you*

*need to help you with your degree, seriously, I'm not going to hide anything from you.*

*Ben*

*Jane: I wonder if you can say a little about the overall experience of taking part in this piece of research, what it's been like for you?*

*Ben: It's been good. I got my point across.*

*Jane: Yeah, you've done it very clearly. Do you think that, are you happy with what you've been able to say, that it's a fair representation of how you feel about transitions?*

*Ben: Yeah.*

*Jane: That's great. Wonderful. Is there anything else you would like to add?*

*Ben: Not that I can think of.*

*Jamie*

*Jane: How was that for you because I know there were some difficult things that you were taking about and, you know, are you Ok with all of that?*

*Jamie: Absolutely, I'm fine with it all, it's fine, I mean I'm not going to sit here and say it's all been lovely, it's been whatever, it's been a journey and it's been one where I've learnt things from...[edited to remove personal identifying details]... from all this high school experience and primary school experience. So it's all good. Like I say, it's been a journey and there have been positives and negatives as always. Once I nearly ended my own life but anyway, it's all good and I look up to the stars and I don't*

*think about it anymore. Unless of course I'm being interviewed about it now (Jamie laughs)...'*

### 5.9 Participant feedback

As explained in chapter 3 section 9.1 all four participants agreed to be contacted once the data had been analysed in order for me to share the findings and receive their feedback. Later in the academic year when the data had been analysed and findings were ready to be shared only two participants, Jamie and Stephen, took up the offer. The decision of Ben and Samantha not to receive a summary of the findings or feed back their views was fully respected. Due to the demands of his college course Jamie chose to give feedback by email, while Stephen and I met in person. Both young men recognised their own voices in the findings and reported being interested in discovering some of the ways in which other young people's experiences were congruent with theirs. Feedback in an email from Jamie was as follows:

*'The whole process for me was strangely weird and quite funny at the same time. Going through my 'transitions' and now looking back at them makes me realise how much I've grown as a person and how much less autistic I am now than I once was. Jane's conclusions are spot on and each of them are all connected to conclude, as she mentioned, a positive outcome.'*

Stephen and I met to discuss the summary. His written feedback was as follows:

*'This feedback is very impressive. Very useful and easy to read and understand. I see nothing wrong with this at all. Well done.'*

Stephen verbally clarified for me that this feedback was in relation to both the findings and the summary that I provided.

### 5.10 Concluding reflexive comments

This study is, to the best of my knowledge, the first qualitative investigation into the transition experiences of young adults with autism applying a psycho-social method of data collection. A constructivist epistemology was assumed in order to develop a deeper understanding of participants' experiences of transition and to make small steps towards prioritising a more inclusive account of the richness of the individual views of young people with autism, while accounting for the inevitable variability contained in their unique experiences. The study provides original insights into the first-hand transition experiences of young people on the autism spectrum in the post-18 age range. The study contributes to the field at doctoral level and will be of interest to other researchers and professionals working with this population of young people in the following ways:

- It makes small steps towards more inclusive research.
- It contributes to an understanding of the experiences of transition of young people with autism.
- It develops our understanding of what works and what young people with autism value when transitioning to further education or training;
- It raises further possibilities for the development of the EP role in relation to the 18-25 age range.

As explored in Chapter 3 section 5, reflexivity is central to the process of conducting qualitative research (Hollway & Jefferson, 2013; Braun & Clarke, 2013). To me, this

means that the researcher should give consideration to ways in which their views, social position and experience may have influenced the research process. Instead of being a limitation, these factors contribute to the construction of the research, so long as they are acknowledged, foregrounded and are congruent with the study's epistemological position. Given the constructivist epistemology of this study I aimed for reflexive awareness of my own experiences, background and cultural context, and those of my participants.

Politically I position myself as a feminist and am drawn to advocating for those whose voices have been marginalised or who may be vulnerable in society. I believe that this valence is likely to have influenced the collection and interpretation of the data. Throughout the research process I felt strongly loyal to my participants. Though it was my wish to prioritise their voices and communicate their experiences, it was also important to remind myself that I was only hearing one side. However I hope that in some way my identification with my participants may have contributed to a sense that it was safe to talk and that I would be able to hear and empathise with their experiences and handle them with due care.

I was aware both in the interviews and throughout the process of analysis of a pull within myself into seeing elements of the transition experiences being related to me in terms of resilience factors or strengths in their associations. My reflective research journal helped me to notice this and give it due attention, which in turn enabled me to notice more about the difficulties or more painful experiences that my participants articulated. In terms of my data analysis I am largely happy with what I found. Though there can be a pull to achieve a broader consensus on whether

an interpretation is 'correct' or not, for me this denies the importance of reflexive research. I have attempted to be open about my own investments in it and show something of my autobiographical inputs and how they relate to my engagement with young people with autism regarding their experiences of transition.

The research process has been challenging and emotional, though my passion for it has never wavered and I can say with honesty that I have truly enjoyed it. The emotional experience of the whole process, particularly when carrying out the interviews and offering/receiving feedback from my participants, has been important in maintaining my wish to ensure that this research is disseminated. I intend to seek out opportunities in the future to research and work to improve outcomes for young people with autism.



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## Appendix A: Example of the use of the CASP for Fortuna (2014)

**Author(s) and date:** Fortuna (2014)

**Title:** The social and emotional functioning of students with an autistic spectrum disorder during the transition between primary and secondary schools.

**Screening questions:**

1. Was there a clear statement of the aims of the research?

Yes

2. Is a qualitative methodology appropriate?

Yes

**Detailed questions:**

3. Was the research design appropriate to address the aims of the research?

Yes

4. Was the recruitment strategy appropriate to the aims of the research?

Yes

5. Was the data collected in way that addressed the research issue?

Yes

6. Has the relationship between researcher and participants been adequately considered?

Not clear from the paper.

7. Have ethical issues been taken into consideration?

No specific section on ethical considerations is evident. Consideration of participant wellbeing of participants is addressed e.g. using diaries to collect data as they are less intrusive than interviewing.

8. Was the data analysis sufficiently rigorous?

Process of qualitative data analysis is not fully transparent. Quotes from participants are used to illustrate the themes.

9. Is there a clear statement of findings?

Key themes are described in detail, illustrated by extracts from participant accounts.

10. How valuable is the research?

Valuable insights gained into what makes a successful transition process for students transitioning from primary to secondary school with an ASD.

## Appendix B: Summary of studies included in literature review

<b>Author(s)</b>	<b>Focus of study</b>	<b>Participants</b>	<b>Method of data collection</b>	<b>Method of data analysis</b>
Beardon, Martin and Woolsey (2009)	Exploration of the perceptions of adults with AS/HFA about challenges and support at college/university	238 adults (aged 16 and over) with AS/HFA	Questionnaire including a mix of open-ended and closed questions	Quantitative data: compiled into statistics Qualitative data: coding followed by themes
Browning, Osborne and Reed (2009)	Comparison of perceived stress and coping in adolescents with and without autism as they approach leaving school	17 young people (mean age= 15 years 0 months). Ten participants had ASD (8 male, 2 female); 6 males and both females had diagnosis of Asperger syndrome; 2 males diagnosed with autism. 7 young people without any diagnosis also included.	Scripted set of seven questions	Content analysis
Connor (2000)	Mainstream secondary school experiences of students with Asperger Syndrome	16 secondary school pupils with Asperger syndrome from Year 7-11 sampled from 9 separate mainstream secondary schools, and 9 SENCos.	Self-report schedule	Results presented quantitatively according to frequency of reference. SENCo data analysed for recurrent themes.

Dann (2011)	Exploring the views and experiences of 'key stakeholders' regarding inclusion into secondary education before and after transition	Six Year 6 pupils with ASC (5 boys and 1 girl); also 6 parents and 18 staff members	Two separate semi-structured interviews using Talking Mats, vignettes and questions	Thematic analysis using a phenomenological and inductive approach
Fortuna (2014)	Exploration of key stakeholders regarding students with ASD transitioning from primary to secondary school	Five Year 6 students with ASD (3 boys and 2 girls) moving into Year 7, their parents and school staff at their primary and secondary schools.	Mixed methods: Likert-style questionnaires, use of Strengths and Difficulties Questionnaire, completion of a diary of their school day and a semi-structured interview	Not clear from the paper
Hannah and Topping (2013)	Longitudinal investigation into the feelings, expectations and experiences of nine students and their parents during the transition from primary to secondary school	9 males with diagnosis of Asperger syndrome aged 11 years 3 months to 12 years 4 months ( <i>Mean</i> = 11 years 8.9 months; <i>SD</i> = 4.6 months) and their parents	Mixed methods: questionnaires, group interviews and individual semi-structured interviews	Content analysis for both quantitative and qualitative data
Hill (2014)	Exploration of the experiences of secondary school education from the perspective of young people with a diagnosis of ASD	Six young people with ASD attending two mainstream secondary schools	Semi-structured interviews supported by photo elicitation	Interpretive Phenomenological Analysis

Horsley (2014)	Comparison of parents and pupils concerns around the transition from primary to secondary school for pupils with autism	8 boys and 2 girls aged 11 years with autism, transitioning from primary to secondary phase, and their parents.	Likert-style questionnaires	Mean scores calculated, plus thematic analysis of the data
Humphrey and Lewis (2008)	Qualitative study of the views and experiences of pupils with autism in mainstream secondary schools	20 young people with Asperger syndrome and high-functioning autism attending four mainstream secondary schools	Semi-structured interviews and diaries	Interpretative Phenomenological Analysis
Jindal-Snape, Douglas, Topping, Kerr and Smith (2006)	Investigation of the perceptions of children and young people with autism, their parents and professionals on support arrangements on transition from primary to secondary school	Five children with ASD transitioning from mainstream primary to a mainstream secondary school, their parents and views of professionals	Structured interviews with parents, children and staff	Themes identified from interview responses followed by systematic content analysis using those themes
Mandy, Murin, Baykaner, Staunton, Cobb, Hellriegel and Skuse (2015)	Systematic investigation into the transition experiences of children with ASD before and after their transition from primary to secondary school	28 children with ASD (mean age = 11.29 years) transitioning from primary to secondary school, their parents and teachers.	Quantitative: data collection through administration of a range of standardised self, parent- and teacher-report measures before and after transition (e.g. WISC IV, SDQ, Vineland)	Quantitative analysis of standardised measures

McLaughlin and Rafferty (2014)	Exploration and deconstruction of qualitative literature purporting to give a voice to young people with Asperger syndrome (AS), followed by depiction of thematic analysis of conversations with young people with AS	Six young people with Asperger syndrome (5 males, 1 female) in Year 10-13 of a mainstream secondary school	Semi-structured interviews	Thematic analysis
Mitchell and Beresford (2014)	Exploration of the process of transfer from school to a FE college from the perspective of the experiences of young people with HFA/Asperger syndrome	18 young people with HFA/Asperger syndrome aged 15-25	Semi-structured interviews	Thematic analysis
Moxon and Gates (2001)	Review of recent relevant research regarding the continuing needs of children with ASD as they move into adulthood, with illustrations from casework and personal observations of a 'service user'	Research review drawing on clinical experience with one male 'service user' (aged 23)	N/A	N/A

Perfitt (2013)	Investigation of the impact of transition upon pupils with speech, language and communication needs from the perspective of the pupils themselves	15 young people with ASC aged 11-14 (14 males, 1 female) transitioning from one special school to another, following its closure	Pictorial Measure of School Stress and Wellbeing	Not clear from the paper
Shepherd (2015)	Examination of the methodological approaches used in an investigation of the lived experiences of young people with autism as they transitioned into FE colleges	Six young people with ASC from three different special schools transitioning into five different colleges of further education.	Semi-structured interviews incorporating card sorts, photos, Talking Mats and walking interviews.	Not clear from the paper
Tobias (2009)	Exploration of attitudes of students with ASD and their parents towards additional support received at mainstream secondary school	7 Year 9 pupils and 3 Year 11 pupils with diagnoses of ASD attending a mainstream secondary school linked to a support centre, and 5 parents	Three separate focus groups	Interpretative Phenomenological Analysis
Williams and Hanke (2007)	Gaining pupil perspectives on the most important features of mainstream school provision	15 pupils with ASD aged between 6 yrs 9 months and 14 yrs 11 months	Personal Construct Psychology ('Drawing the Ideal School')	Coding and thematic analysis of the data

## Appendix C: Participant information sheet

**Researcher's name: Jane Park**

### **INFORMATION ABOUT THE RESEARCH**

**What is it for?** This study aims to find out about the experiences of young people on the autism spectrum aged 18-25 years old at key transition points. I am conducting the study as part of my doctoral training course in child, community and educational psychology at the Tavistock and Portman NHS Trust.

**What do I have to do?** Before deciding if you would like to take part, it is important that you understand the research and what it will involve. Please read this information sheet carefully before deciding whether or not to take part.

I am very interested to hear about your experiences of transitions. I am asking you, as a participant, to set aside around an hour and a half of your time, and to be interviewed by me for around one hour. There are no right or wrong answers to the questions I would ask.

The interviews would take place at a time and place which is mutually convenient. The interviews will be recorded on an audio Dictaphone and transcribed for the purposes of analysis. The recording and this signed Participant Consent Form will not be formally submitted with the finished project, though research staff may request to see and/or hear either item. All personal information provided by yourself will remain confidential and no information that identifies you will be made publicly available; however, absolute confidentiality cannot be guaranteed as research staff will see the finished project and the transcripts. You may choose to use a pseudonym if you prefer.

While no physical or emotional risks to you are expected as a result of this research, it is possible that discussing this topic may stir up unexpected feelings. The following measures will be in place to minimise any concerns about potential risk to participants:

- Interviews would take place in a quiet, safe room in your school/college where members of staff may also be in the building.
- You would be treated with honesty, sensitivity and throughout the process.
- It may be that some questions raise distressing feelings in some participants. I would be available to discuss these issues with you after the interviews.

You would be free to refuse any questions and may withdraw at any point up until the data has been anonymised and analysis has begun, since after this point withdrawing data will become more difficult and may affect the quality of the study. You would own the copyright to the recordings made and may request access to them or ask that they are returned to you. You are welcome to ask for more details about this research at any time.

## Appendix D: Participant consent form

TAVISTOCK & PORTMAN NHS FOUNDATION TRUST

**Title of research project:** Young people on the autism spectrum in transition: a psychosocial investigation into the experiences of young people with high-functioning Autism Spectrum Conditions as they enter post-18 education and training.

**Researcher's name:** Jane Park

		<b>Please place your initial in the box below if you are in agreement with the statement</b>
<b>1.</b>	The researcher, Jane Park, has briefed me to my satisfaction about the research project for which I have volunteered.	
<b>2.</b>	I understand that I have the right to change my mind about taking part at any point and may withdraw from the research project without giving a reason.	
<b>3.</b>	I confirm that I have read the Participant Information Sheet and understand what is required of me when I consent to participate in this research project.	
<b>4.</b>	I confirm that I have had the opportunity to ask questions about the research project.	
<b>5.</b>	I understand that my rights to anonymity and confidentiality will be respected.	
<b>6.</b>	I understand that the interviews between myself and Jane will be audio recorded.	
<b>7.</b>	I would like to be informed of the outcomes of the research project and would like to be given the opportunity to feedback about my experiences of taking part.	
<b>8.</b>	I consent to take part in the research project.	

**Signature of participant:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Signature of researcher:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Appendix E: Anonymised GEM grids

### 1. Stephen

I am interested in what you associate with experiences of transition. Please express what you associate by using images and/or words. Please put one image/word/phrase in each box. Sometimes a really simple drawing or word can be a good way of portraying your thoughts and feelings.

<p>The next another door just waiting</p>	<p><sup>in life</sup> stage is into a new world to be explored.</p>
<p>Never judge a person by their looks + their needs, we need to find out what they're good at + their minds will produce something unexpected. Never waste a human mind</p>	<p>When people say they can't do anything never say never. Perseverance Give these people extra time, a little boost of confidence + reassurance.</p>

## 2. Ben

I am interested in what you associate with experiences of transition. Please express what you associate by using images and/or words. Please put one image/word/phrase in each box. Sometimes a really simple drawing or word can be a good way of portraying your thoughts and feelings.

Happy and Scared 1	Learning 2
New Experience 3	New Start 4

## 3. Samantha

I am interested in what you associate with experiences of transition. Please express what you associate by using images and/or words. Please put one image/word/phrase in each box. Sometimes a really simple drawing or word can be a good way of portraying your thoughts and feelings.

 1	 2
 3	 4

## 4. Jamie

I am interested in what you associate with experiences of transition. Please express what you associate by using images and/or words. Please put one image/word/phrase in each box. Sometimes a really simple drawing or word can be a good way of portraying your thoughts and feelings.

<p>① Young age 0-6 / • could never • explicit things</p> <ul style="list-style-type: none"> <li>• Never looked people in the eyes</li> <li>• Parents split</li> <li>• Never socialised to a degree</li> <li>• Scared of new people</li> <li>• everything in order</li> </ul>	<p>② Primary School Age: 6-10</p> <ul style="list-style-type: none"> <li>• Start of bullying</li> <li>• Was fascinated (got into trouble, e.g. racist)</li> <li>• formal friends</li> <li>• speech and language class</li> </ul>
<p>③ High School Age: 11-16</p> <ul style="list-style-type: none"> <li>• extreme bullying</li> <li>• severe autism</li> <li>• No friends, lonely</li> <li>• fell in love with music through school and guitar lessons, guitar hero</li> <li>• Panic attack over exams</li> </ul>	<p>④ Now! Age: 17 - Present</p> <ul style="list-style-type: none"> <li>• Confident</li> <li>• Love what I'm doing</li> <li>• Psychology</li> <li>• Secret - M/handg</li> <li>• Burnt Chip Pans</li> <li>• Steve Peters</li> <li>• work environment</li> <li>• questions!</li> </ul>

## Appendix F: Example annotated interview transcript for 'Stephen'

- 84 I: that makes total sense. And so the first erm kind of association that you have written here is  
85 written 'the next stage in life is another door into a new world waiting to be explored'
- 86 R: that is, basically, what transition means.
- 87 I: can you say a bit more about that?
- 88 R: Ok. I'm actually, that...person who is unsure about what they want to do in life, so this applies to  
89 anybody. Especially teenagers. Um, Think of the next stage in life as a door. You're not sure where it  
90 will lead you but it is a good starting point. Take a little peek at it, see if you like it. If you don't like it  
91 then you try something else. So, that's why I think that entering into a new world of something that  
92 you're not sure about is scary, but if you think about it, if you think of that concept, that it's just, that  
93 like, is, another door going into a new world of your life, the next stage of your life, everybody has to  
94 go through it. Pick something that you're interested in and that you're good at and go for it,  
95 persevere. Don't let people...don't let people say you can't do it.
- 96 I: mmhm
- 97 R: give them a little boost of confidence and reassurance. If they want to do it, just go for it and you  
98 shouldn't judge people by their looks or their needs. Don't waste a human mind. Just because they  
99 may be different doesn't mean that they're no less of a person and their minds tend to be, with  
100 people that need extra time, with people that have learning difficulties, their minds actually tend to  
101 be much more creative and much more detailed than people who don't have extra time. [mmhm] so,  
102 that's my explanation of transition. (end)
- 103 I: so, I'm wondering, when you're describing erm the person who is you know feeling feelings that  
104 it's a bit scary, that they're looking through a door into a new world and you don't know what it's  
105 going to be like, is that kind of your experience, is that how it was for you?
- 106 R: Yes. Yes. If you ever get nervous about something or scared about something, it's Ok, you know.  
107 As long as you have support and love and guidance and advice and reassurance. You can't do it by  
108 yourself. These people can't do it by themselves. They need people to guide them. And, you just  
109 need to just reassure them that everything will be Ok, just give them a little boost of confidence for  
110 transitioning into a new stage of their life. The thing is, when you transition, for example when you  
111 transition from a child into a teenager, think about it, you...there is no..rule book in terms of, you  
112 know, when you're a child you need to follow certain rules. When you're a teenager, you experience  
113 the world differently and the same if you're an adult, you take matters into your own hands when  
114 you turn into an adult. But when let's just start from child to teenager here; their bodies change,  
115 their moods change, and new clothes, new social customs, new friends. It's a whole new scary thing  
116 for them, it's a completely different world to childhood because you count on your parents for help  
117 when you're a child and exactly the same when you're, when when you move from being a teenager  
118 to an adult. You have to start being responsible for your own matters. There will always be people to  
119 support you, but, if you're able and you're capable enough to make your own choices, it's time to  
120 make your own choices.
- 121 I: mm, and I'm thinking about what you were saying about your experiences of being 'caged in' and  
122 not being allowed out and actually, sometimes support, please correct me if I'm wrong, can be too  
123 much. And that you need actually a balance between being supported and protected, and freedom  
124 and the right to...
- 125 R: I think there's a certain humiliation in that. At they were a bit...scared...to let us go outside for  
126 too long because they might, well, it's the same with, this is the same with parents who get a



## Appendix G: Participant-friendly research summary

**Title:** ‘Another door into a new world waiting to be explored’: a psycho-social investigation into the transition experiences of young adults with autism using the Grid Elaboration Method.

**Researcher:** Jane Park, Trainee Educational Psychologist, Tavistock and Portman NHS Trust

**Feedback:** Your feedback is very important to me. I would like to know what you think about the themes which are presented here. There are no right or wrong answers, I am just interested in your views. At the end of this document there is a box for you to write down any thoughts and feelings you may have in response to the themes and information presented here.

**Summary of findings:** I interviewed four young people and asked them about their experiences of transition. I recorded each interview on an audio recorder. I transcribed the interviews by listening back to them many times and typing out exactly what each participant said, and what I said too. I then looked through the transcripts for themes which seemed to be important.

Six themes emerged, which were: 1) Resilience, 2) Growth and Development, 3) Relationships, 4) Mental Wellbeing, 5) Agency and 6) Understanding Difference.



### 1) Resilience

In terms of these findings, 'resilience' means **overcoming fears or challenging experiences**, when we **keep trying** even when things are hard; **never giving up**. Having a **positive attitude** even when things are difficult. Having **access to the right support** at the right time and having **self-belief**.

### 2) Growth and Development

Participants reported enjoying having **new experiences, learning** new academic and life skills and **growing independence**. Developing from being a teenager into an adult. **Looking forward** to the next stage in life. Feeling **ready to move on** and find work, **develop a career**. Making a **positive contribution** to the community, through work and volunteering.

### 3) Relationships

Relationships with college and school staff were important to all four participants. These were mainly seen as **positive, helpful relationships**, which helped these young people overcome any 'scared' or 'anxious' feelings they might have experienced at transition points. Participants spoke of **excitement about meeting new people** and being taught by **understanding staff**. Importance of **friendships**: it helps if you know someone already during the move to college, and it's also good to have **support to make new friends** once you get there.

### 4) Mental Wellbeing

These findings suggests that, to support young people's mental wellbeing when transitioning to college, it is important that they have access to the **right kind of support**. It is also important to get on a **suitable course** in the first place. Having access to **mentoring** or **counselling** is helpful for some. **Feeling understood** is very important to all. Importance of **staff training in autism awareness**, understanding and acceptance at all levels. Availability of **individualised support** to suit each individual's needs.

### 5) Agency

'Agency' means having the **right to choose**, for example choosing and accessing the most suitable college course. It also means developing **independence, confidence, practical and emotional skills** and **self-belief**. One important part of 'agency' that participants talked about was **knowing their own strengths** and **areas of challenge** (things they find more difficult) and **knowing what works for them**. It was also important to be able to **pursue their own interests**.

### 6) Understanding Difference

Participants let me know that they feel college and school staff should be the ones to learn and **make adaptations** to accommodate the needs of '*people who are different*'. They spoke of **fears of being negatively judged**. Many participants had experiences of a **lack of understanding** on the part of the wider public, and sometimes of school and college staff.

**Feedback:** Your feedback is very important to me. Please write/type/draw any thoughts or feelings you may have about the themes above. There are no right or wrong answers, I am just interested in your views. You can email me on [jpark@taviport.nhs.uk](mailto:jpark@taviport.nhs.uk) 😊

**Next steps:** I will be talking about these findings to colleagues in the Educational Psychology (EP) Service who may be working in further education colleges in the future. I will also share these findings with my colleagues on the EP training course. I also plan to speak with staff at [REDACTED] FE College. I will be handing in my finished write-up in a few weeks' time.

**I would like to take this opportunity to thank all my participants for their time and interest and to acknowledge the contribution that they have made to this area of research. I hope that my participants feel valued and that their contribution will make a difference.**

Appendix H: Letter from the Trust Research Ethics Committee  
formally granting ethical approval

The Tavistock and Portman   
NHS Foundation Trust

Quality Assurance & Enhancement  
Directorate of Education & Training  
Tavistock Centre  
120 Belsize Lane  
London  
NW3 5BA

Tel: +44(0)20 938 2699

Email: [AcademicQuality@Tavi-Port.nhs.uk](mailto:AcademicQuality@Tavi-Port.nhs.uk)

<http://tavistockandportman.uk/research-and-innovation/doing-research>

Jane Park



07th May 2015

**Re: Research Ethics Application**

***Title: "Young people with high-functioning Autism Spectrum Conditions in transition: a psychosocial investigation into the experiences of young people on the autism spectrum as they enter post-18 education and training"***

Dear Jane,

I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely

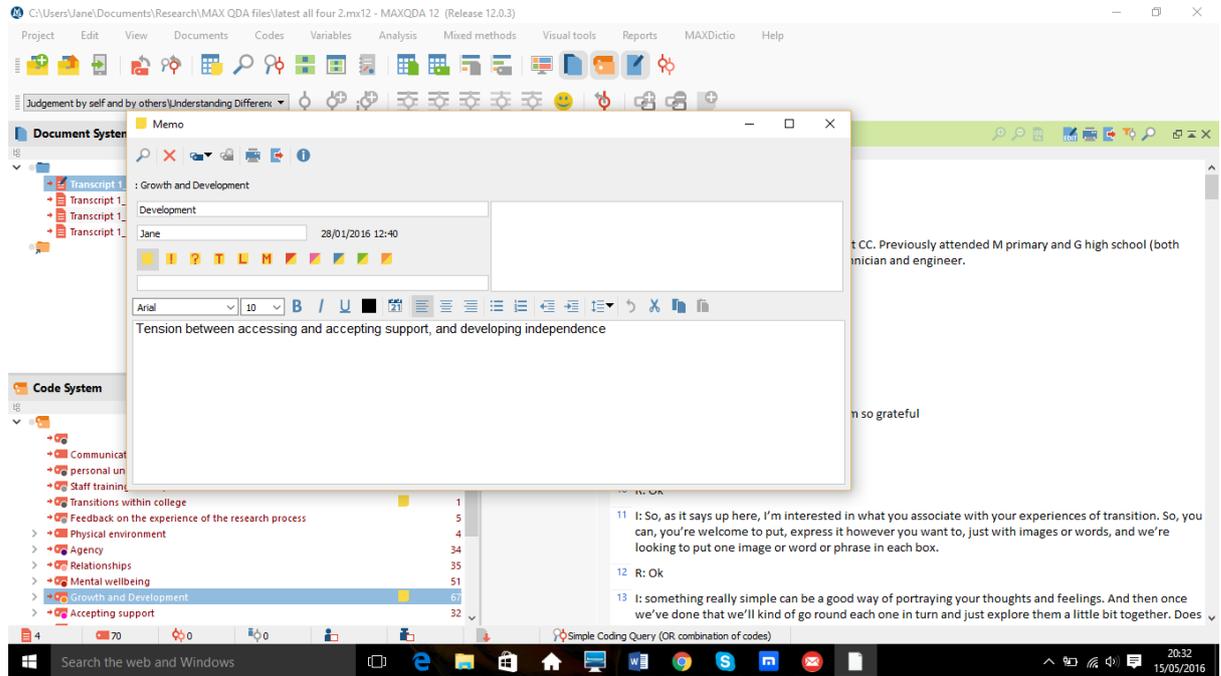
A handwritten signature in dark ink, appearing to read "Louis Taussig".

Louis Taussig

Secretary to the Trust Research Ethics Committee

Cc Brian Davis

## Appendix I: Screenshot from MAXQDA to demonstrate use of memos and colour coding in data analysis





## Appendix J: Coded segments and related themes/subthemes

Refer to attached CD-ROM for access to the themes/subthemes and the related coded segments (MS Excel format).