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**UNIVERSITY OF SUSSEX**

*‘Hopefully if I like get the right support at college, I’ll be able to like find my way and all that if you know what I mean?’ Experiences of transition from special school to mainstream college for young people with autism.*

---

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THESIS FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY (EDUCATION)

November 2015

## DECLARATION

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree.

Signature:.....

Date.....

**This thesis is dedicated with love to my family:  
Anthony, Emily, Luke and the memory of Hannah**

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## Abstract

This thesis investigates the transition of young people with autism moving from a small, protected and personalised special school environment to a large, busy mainstream college of further education in England. Whilst potentially unsettling for any young person, this transition can be particularly challenging for young people with autism given a desire for predictability and difficulty in adapting to change. This longitudinal research focused on the experience of transition from the point of view of the young people and their parents, and it contributes to the somewhat limited research on post-16 transitions for young people with autism and learning difficulties.

Six young people were at the heart of my research but their parents, teachers, lecturers and careers advisers were also interviewed. A key aim of the research was to develop methods to engage and support the young people in an interview process, without influencing their responses too much or restricting their contributions. With this in mind, 'interrupted interviews' were developed that involved both the use of collage and card sort applications on a tablet, and walking interviews around the college environment. These methods helped to personalise the interview process, to hear the individual student voices and to facilitate communication about the concerns and experiences of the participants.

The research findings demonstrate that young people with autism have aspirations, interests and concerns as they progress towards adulthood; that they both seek and enjoy social interaction and that young people *and parents* need support during and after transition. The tensions between independence and vulnerability are explored as well as the notion of *inter*dependence. While some of the young people in this research made reasonably smooth transitions to college, there were difficulties and challenges, and these lay almost entirely within the area of social interaction. In order for young people with autism and learning difficulties to progress both academically and socially, there needs to be a greater understanding of autism within the whole college community and proper attention given to personalising the transition process to ensure that these young learners can realise their capabilities.

## Chapter One: Introduction and context

This qualitative research study investigates the lived experiences of young people with autism as they make the transition from special school to further education in England. My focus on this group stems from a lifelong professional interest and practitioner experience in education and a personal investment in special educational needs and, more specifically, autism. This chapter introduces the area of research and explains the rationale for a more detailed examination of transition. I will go on to explain my personal and professional interest and motivation; examine the current legislative context where there has been much recent change and conclude by explaining why I have taken this particular approach. My research aims are introduced at the end of this chapter but my research questions are identified and explored in Chapter Two in relation to my theoretical approach.

### 1.1 Rationale

I was surprised to learn that fewer than one in four young people with autism continued their education beyond school (Ambitious About Autism, 2011) and this linked, in particular, to a lack of adequate provision in the further education sector. This report, entitled 'Finished at School', went on to identify the implications of this gap in provision for outcomes for adults with autism,

The most critical factor in improving the transition to adulthood for young people with autism [is] addressing the desperate lack of effective education pathways for 16–25 year olds on the autism spectrum (Ambitious About Autism, 2011, p7)

While, in England, there seems to have been a recent policy focus on transition and the progression to adulthood, the reality appears to have been little investigated or understood. I wanted to explore in detail how young people with autism experienced the transition process. I particularly wanted to include young people with additional learning difficulties rather than just the more articulate and able participants in the research as there still seems to be a relative lack of research on the lived experiences of people with learning difficulties from their perspectives (Stalker, 2012). Previous research on transition to college for young people with autism has tended to focus on the more able end of the spectrum, particularly those with Asperger's syndrome (Breakey, 2006; Chown and Beavan; 2012; Mitchell and Beresford, 2014). I also wanted to examine the move from special school to mainstream college, as this was potentially the biggest leap in terms of setting, size, social mix and academic opportunity. Placement in a special school could be construed as a child not being

deemed able to 'cope' in a mainstream setting or, indeed, that mainstream would not be able to 'cope' with them. Yet, at 16, they were deemed ready for mainstream college, or perhaps college was ready for them. Was it because they were now 16 and could be re-integrated into a mainstream world? Was it that their 'difficulties' had ameliorated during school and they could now be accommodated by mainstream education? Was it that their peer groups were now more adult and accommodating of difference? I had all these questions about this particular point of transition and my intellectual curiosity was aroused.

## **1.2 Professional and personal interest and motivation**

As a teacher in post-16 education in England for over 15 years and with management responsibility for student support, I was aware of some students having additional needs but had little training or experience myself which I felt able to draw on and therefore felt professionally vulnerable and, at times, inadequate. In my more recent role as a teacher educator I have been responsible for equipping new secondary teachers with the skills and knowledge they will need throughout their careers to work with all children regardless of difference. In a nine month postgraduate teacher training course, I am all too aware of how little time is spent on addressing the learning needs of children with Special Educational Needs and Disabilities (SEND) and the concurrent debates about whether good teaching is good teaching for all versus special teaching for special children (Lewis and Norwich, 2005; Thomas and Loxley, 2007; EADSNE, 2010; Lawson et al., 2013). Debates about inclusive and special education have been much rehearsed in the literature where the former seems to have been so hard to achieve in mainstream schools and yet the latter can cause segregation and social exclusion (Alderson and Goodey, 1999; Macbeath et al., 2005; Wittemeyer et al., 2011) so I attend to these debates more fully in Chapter Three. In working with university colleagues to prepare a research bid about young adults with autism in the community, I also became aware of gaps in the literature relating to young people with autism and their experiences beyond school.

As the parent of a child with autism and severe learning difficulties, I am immersed in constantly trying to understand the world from an autistic perspective: trying to manage the challenges and difficulties that arise and constantly thinking up new and better ways to communicate and interact. It is perhaps as challenging for us to make sense of the world of autism as it is for people with autism to make sense of the social world and demands the very best of our empathetic skills. After twelve years of this immersion, I now have some understanding of how to work with young people with

autism but I am still making sense of, and still learning every day, about what I perceive to be a complex condition. Supporting my son to access social and educational worlds requires a great deal of thought, reflection, understanding, patience, empathy and trial and error and I am still not always able to predict his responses to different environments. What I have learned is that autism is a complex condition and that there is still much learning to be done if we are going to be able to support children and adults effectively in education and in society, where they can fully realise their potential and experience a good quality of life. My hope is that I can transfer some of this phonetic knowledge, and some of this empathy, to my research to contribute to understandings of autism as other researcher-parents have done (Ryan and Runswick-Cole, 2008; Kittay, 2009; Rogers, 2011).

### 1.3 What is autism?

There are many ways in which we can define and interpret autism and a fuller exploration of this is given in Chapter Three but here I will briefly outline summaries of autism diagnoses. The National Autistic Society (NAS) summarises autism as,

A lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them (NAS, 2014)

Autism is also defined as part of a spectrum condition that is characterised by a triad of impairments across communication, social interaction and imagination often accompanied by repetitive behaviours and sensory needs (Wing, 1996). Given that it is a spectrum and can occur in isolation or with co-presenting conditions, the range of abilities is vast and its manifestations varied so that no two people with autism are alike or 'when you have met one person with autism, you have met one person with autism' (Shore, n.d.). Those on the Asperger's Syndrome (AS) end of the spectrum often show typical language development and may have outstanding cognitive abilities but be 'socially awkward' and others with more severe autism may have profound and multiple learning difficulties and little or no speech. What they have in common is the 'absence or impairment of social interaction, communication and development of imagination' (Wing, 1996, p25). This is sometimes referred to as the 'triad of impairments' and for a clinical diagnosis, there have to be impairments identified in all three areas.

Autism is often accompanied by additional impairments and it seems difficult to ascertain exact numbers of those who have been diagnosed with autism and learning difficulties of some sort. O'Brien and Pearson (2004) examined a range of studies and

estimated that there are anything between 25 -75% of people diagnosed with autism who also have learning difficulties. There is also a huge variation from mild or specific learning difficulty through to severe or profound learning difficulty and also whether the autism or the learning difficulty is perceived as the primary diagnosis. Equally, there are many people who have autism but no other intellectual impairment.

Knowing that the transition to adulthood can be problematic for many young people, I was also aware that it posed particular difficulties for those with autism. As Kanner, one of the autism pioneers so aptly identified, an 'anxiously obsessive desire for the maintenance of sameness' and a 'dread of change' (Kanner, 1943, p245) were likely characteristics of autism, and therefore it was easy to see why transition could be an even more challenging time for this particular group. Later research in to restricted executive function (Ozonoff, 1997) and weak central coherence (Frith, 1989) theory have also supported these ideas and are further explored in Chapter Three. I focused in on the educational transition between the two settings (special to mainstream) as I felt that this was a significant change in the lives of these young people albeit contextualised within the wider transition to adulthood.

#### 1.4 Legislation

Since the raising of the participation age (*Education and Skills Act*, 2008), all young people leaving school in England, from 2013, have been required to stay in some form of education, employment or training until they were 17 and, from 2015, until they are 18. There is therefore some political pressure for post-16 education to be accessible to all learners, including those with special educational needs. Also relevant to this research has been the development of disability legislation including the Autism Act (2009) and the Equality Act (2010), as well as the more recent Children and Families Act (2014). The Autism Act focuses on provision for adults with autism to enable them to live fulfilling and rewarding lives and put an onus on the government to produce a nationwide autism strategy. This includes a focus on supporting adults with autism to find employment, to access the support they need and to participate in their local communities and is therefore relevant to the transition to adulthood for young people in this research. The Disability Discrimination Act (1995) has now been replaced by the Equality Act, (2010) but its purpose is the same, to make it unlawful to discriminate against disabled people across all service provisions and for public and private providers to 'make reasonable adjustment' to ensure accessibility of all goods and services. All this provided a legislative backdrop to the introduction of the Children and

Families Act of 2014 that attempted to draw together different aspects of some of these statutes and others to improve services and protection for vulnerable children and families. The key changes affecting the provision of services for SEND were: the introduction of Education, Health and Care (EHC) plans to replace statements up to the age of 25; the introduction of personal budgets for families so that they could plan and source the care package required and in schools, a new single category of SEND (for those without statements) instead of School Action and School Action Plus (Department for Education et al., 2014). EHC plans potentially offer a more secure route into further education for young disabled people as the plan remains in place even if they go to a mainstream college at 16 (DfE and DoH, 2014). Statements typically ceased at 16 where the young person moved to mainstream provision but remained in place if they stayed in a specialist setting (DfES, 2001). The changes in legislation meant that the participants in this research would be making their transitions in a time of policy change that could have beneficial or detrimental effects on their experience.

Since the turn of the 21st century, government policy in the United Kingdom (UK) has increasingly turned its attention towards improving outcomes for disabled people in adult life including increasing the number of young people with learning difficulties in employment (DoH, 2011). Employment rates for adults with autism were already very low, with a report suggesting that 85% of adults with autism in the UK were unemployed (Knapp et al., 2007). Other policies included improving the life chances of disabled people (DWP et al., 2005); improving support and raising aspirations for disabled children and young people (DfE, 2011); improving health, housing and employment opportunities for disabled people (DoH, 2009) and promoting choice and control for disabled adults over their care and support (DoH, 2007; *Health and Social Care Act*, 2012; *Care Act*, 2014). However, there have been changes of government during this time and a period of economic austerity that has had an impact on the support and services available to disabled people. The Welfare Reform Act (2012) brought in changes to the way in which disabled people received financial support including moving from the Disabled Living Allowance (DLA) to the Personal Independence Payment (PiP) system. While ostensibly implying greater independence for disabled people the reality of assessments carried out has been challenging and has reduced the numbers of people eligible by attempting to re-classify disability (Roulstone, 2015). Alongside these changes, there has also been the noteworthy abolition of the Independent Living Fund (ILF) that helped to give some choice and control to disabled people by having personal payments made directly to them. These

budgets are now being subsumed by local authorities' generalised care budgets that have been substantially reduced. Local authorities themselves have been subject to substantial funding cuts that seem to have affected the most deprived communities disproportionately and also the poorest within those communities,

Local authorities in England lost 27 per cent of their spending power between 2010/11 and 2015/16 in real terms. Some services, such as planning and 'supporting people' (discretionary social care with a preventative or enabling focus) have seen cumulative cuts to the order of 45 per cent. (Hastings et al., 2015, p3)

This economic context looms behind all the proposed policy changes and suggests that their implementation may be problematic. With local authorities needing to reduce spending wherever possible in order to balance their budgets, the implications for continued choice and control for disabled people over their own lives looks threatened.

The process of transition planning seems well enshrined in English law (Department for Education et al., 2014) and the new SEND Code of Practice (DfE and DoH, 2014) so that there are clear steps to be followed with transition. This includes initiating transition planning from the age of 14 in school as part of the annual review, including parents in the transition meetings, involving Careers Advisers to offer guidance and information and ensuring that person-centred planning is at the heart of transition planning. Whether these procedures were followed in practice, and how the processes were experienced by the young people was then a focus of my research. In Chapter Three I examine the literature and research that has explored post-16 transition experiences, inclusion and special school debates and the wider implications of autism and the social world.

### **1.5 Transition policy and practice in England**

There is, seemingly, a plethora of initiatives, organisations and charities available to support transition for young disabled adults including the National Transition Support Programme, SKILL, Transition Information Network, Mencap and Scope and some organisations that focus on autism in particular including Prospects, Ambitious About Autism, Autism Education Trust and the National Autistic Society. The National Health Service, Social Care and local authorities also have strategies for special educational needs; some have specific autism strategies and transition planning arrangements as well as the responsibility for young people in their care. So why is this experience still so problematic? According to Ofsted (2011) there appears to be very little local, post-16 educational provision for learners with higher levels of learning difficulties which



concur with the findings of the 'Finished at School' report (Ambitious About Autism, 2011). Other research found that although there are transition protocols and processes clearly in place, in practice the outcomes were very variable and that clearer guidance was needed about all the options available to young people with learning disabilities to ensure 'meaningful outcomes' (Kaehne and Beyer, 2009).

Attention has been drawn towards putting the individual at the heart of transition planning and indeed planning for their care services through the SEND Code of Practice (DfE and DoH, 2014) and there has been more focus on trying to seek the opinions of those with learning difficulties or disabilities. Person-centred planning (PCP) is not particularly new but seems to have gained currency more recently in its properly defined format in the new code of practice. This possibly reflects previous dissatisfaction with the way in which the interests of disabled people were not always taken into account despite apparent policy intentions (Mansell and Beadle-Brown, 2004). The process is now directed towards the person's aspirations and capabilities rather than their difficulties or deficits; the whole family and wider social networks should be more involved and transition planning should identify the services required for the young person to achieve their goals (Sanderson, 2000; DfE and DoH, 2014). While perhaps of noble intent, the reality seems a little mismatched and often does not live up to expectations (Mansell and Beadle-Brown, 2004). There seems to be an assumption in the policy that as long as you seek the opinion of the young person then good outcomes will follow yet Small et al. (2013) argued that there was little evidence of a clear link between PCP and positive transition outcomes. This was mainly because the transition planning process had to recognise the young person's social worlds, recognise their interdependent relationships and involve institutions closer to the young person's daily experience (the college, the workplace, the community), 'PCP is transposing an individualist ideal to a group of people whose needs might best be pursued via privileging interdependence' (Small et al., 2013, p286).

A recent DfE funded programme (2013-2015), with Ambitious About Autism, worked with four general FE colleges in different parts of England to ensure support for young people with autism making the transition to college. The evaluation of the programme concluded that more staff awareness and training was needed about autism and about person-centred planning; that colleges should ensure that their course provision meets the needs of learners with autism; that college representatives should attend annual review meetings from year 9 onwards and that young people with autism may need

more support from their schools or parents to access the available opportunities in FE (Cullen and Cullen, 2015).

Concurrent to statutory and policy changes there have been many different initiatives that have aimed to improve the transition to adult life for young disabled people and many of these have been very ambitious and also well-intentioned. However, with changes of government, economic retrenchment and legislative changes, the extent to which these ambitions have been realised has been somewhat curtailed, limited and even abandoned. Prior to the coalition government of 2010, for example, in 2006, the Learning and Skills Council published its 'Learning for Living and Work' strategy claiming that it would make 'England, by 2015, an international exemplar in providing high- quality education and training for post-16 learners with the most complex learning difficulties and/or disabilities' (LSC, 2006, p3). And yet, since then we have seen some colleges completely cut their provision for adults with learning difficulties (Davies, 2014) and indeed the LSC was disbanded. There was a 24% cut to adult skills budgets in the FE sector for 2015/16 (SFA, 2015) and further cuts likely in the next budget statement. The 'Progression through Partnership' strategy (DfES et al., 2007) expressed the government's commitment to improving outcomes for those with learning difficulties and disabilities through the contribution of FE colleges 'to the goal of people living fulfilling lives as local citizens and in particular achieve the goal of paid employment' (DfES et al., 2007, p8). Changes to benefits, a lack of job opportunities for disabled people, changes of government and restricted economic growth have all dented the ambitions of these proposals (Roulstone, 2015).

## 1.6 Research Aims

Given the backdrop of a shifting policy landscape, an austere economic context and significant changes to the processes and procedures of transition, my research has sought to enquire of the young people (and their parents) what the experience of transition was actually like and whether it was addressing their needs and fulfilling their aspirations. My research aims were essentially twofold:

1. To interrogate the experience of transition from the point of view of young people with autism in order to learn from their experiences to inform professionals and participants in the transition process.

And accordingly,

2. To develop appropriate methods in order to engage young people with autism and ensure that their voices were heard in the research.

In order to explain how I arrived at my theoretical position, the next chapter will offer a critique of disability theory, summarise my own position drawing on different theoretical influences and conclude with unpacking the research questions in the light of the theoretical approach adopted. This is followed in Chapter Three by a review of existing literature problematising autism, social and educational inclusion and transition. Chapter Four explains how my theoretical position influenced the research methodology and explores the methods devised and the approach taken to working with young people with autism. Chapters Five to Eight present the data analysis and Chapter Nine brings the discussion together and refers back to the aims and research questions. Finally, I conclude with my contribution to knowledge, limitations of this research and ways forward for future research in this area.

### 1.7 A word on terminology

At times this thesis has been very difficult to write in terms of grappling with appropriate language and terminology with which to describe participants in the research and the condition of autism. Identity is a politically charged area of debate that is not the focus of this thesis, and is therefore not explored in this writing, but nonetheless account has to be taken of the ways in which we call identity into being through the language that we use. Equally, the fear of misappropriating language or using incorrect or out of date terminology should not stifle investigations into matters of real importance and concern such as disability (Foreman, 2005). In relation to people with autism, I have chosen to use the 'person first' approach that favours 'person with autism' as opposed to 'autistic person'. Some people with autism prefer this appellation where others including Blackburn, (2013) say that their autism is inseparable from their personhood or that they are indifferent to terminology. There is no terminology agreed by all; indeed with disability, I have used the term 'disabled person' in accordance with the social model approach where people are perceived to be primarily disabled by society. While most labels are unsatisfactory in some way, I have used the term 'learning difficulties' instead of 'learning disabilities' or 'intellectual disabilities' as it reflects the current language used in schools and statements of special educational need. Finally, I use the term 'autistic spectrum condition' (ASC) and 'autism' interchangeably as opposed to autistic spectrum disorder 'as it is less stigmatising, and it reflects that these individuals have not only disabilities which require a medical diagnosis, but also areas of cognitive strength' (Baron-Cohen et al., 2009, p500).

## Chapter Two: Disability Theory

This chapter explores the key debates in disability theory and leads to a discussion of my own position in relation to this and how theory might help to illuminate my research approach and findings. My research is, above, all designed to generate knowledge that has policy and practice implications for the support of young people with autism in transition. As G. Thomas (2007) suggests, I wanted to use theory as a tool so long as it remained relevant and explicatory to my research topic. However, this chapter will examine the development of various theoretical approaches in relation to disability and evaluate their relevance to my research. The social model and medical models are examined partly in relation to each other but developments and critiques of the social model are also seen as very relevant here. I will also explore the capability approach, critical disability studies and critical realism in order to explain my theoretical position in relation to this research on understanding young people with autism and learning difficulties.

### 2.1 The medical model of disability

There are two key models that have influenced thinking about disability in the UK over the last century: the medical model and the social model. While the medical model lacks a clear grounding in terms of academic research output or as a theory, it came into sharp relief in the 1970s and 1980s with the emergence of the social model in direct contrast to it. Before the 1970s, academic interest in disability was very limited but there was a sense in which the medical model was the prevailing, dominant ideology certainly in evidence in the medical and psychological literature prior to the arrival of some key disability activists and a mobilisation towards collective action.

This medical or 'personal tragedy theory of disability' (Oliver, 1990) identifies disability as intrinsic to the individual and is something that needs to be treated or improved as it may cause them, or other people, difficulties in life. Oliver's (1990) work on the social model questioned why disability had to be medicalised and individualised and his answer, crudely, was one that lay within the constructs of Western capitalist societies in that essentially all citizens are expected to be economically productive (Oliver, 1990). The thrust of the medical model was to change the person rather than their environment, their situation or the people around them and focuses on their 'deficits' or what they are unable to do rather than their abilities. The medical profession then had the role of identifying the disability, understanding it and treating it to minimise its effects and helping to 'normalise' the person as much as possible.

The history of disability studies and research into disability then is a very recent one and until the arrival of the social model, disability was seen as a problem located within individuals that required medical attention and intervention. The limited research that was carried out tended to focus on cure or rehabilitation. Disability movements criticised the medical model for viewing impairments as the determinants of disability as opposed to identifying the disabling effects of society.

## 2.2 The social model of disability

A group of disabled activists in the UK set up a 'Union of the Physically Impaired Against Segregation' (UPIAS) in 1974 that criticised organisations that failed to address the disabling barriers encountered by disabled people. They defined disability as how society restricted their activities and marginalised them,

The disadvantage of restriction of activity caused by a contemporary social organisation which takes no or little account of people who have [impairments] and thus excludes them from the mainstream of social activities (UPIAS, 1976, p14)

UPIAS argued that severely disabled people were completely marginalised and consigned to institutions without any financial or social independence and that financial hardship was a common theme as there were no specific disability welfare payments. One of their key political thrusts was for disabled people to have more choice and control over their lives. UPIAS also made the distinction, for the first time between impairment (as biological and intrinsic to the body) and disability (as socially constructed). This form of social and economic oppression led to Oliver, a disabled activist and researcher, establishing his ideas about a social model of disability in his work of the 1980s and 1990s.

Internationally, there seemed to be a growing interest in disability issues around this time with the United Nations introducing the Declaration of the Rights of Disabled Persons in 1975 that articulated the rights of disabled people,

3. Disabled persons whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible. (UN, 1975)

The social model was not an attempt to discredit or undermine medical interventions where they were useful and appropriate but it was felt that there was an 'over-

medicalising' of disability and a pressure towards conformity and normalisation. It was a deliberate attempt to shift the focus away from the individual and their possible impairments on to the disabling barriers of society. Oliver (1983) first attempted to articulate and define the idea of a social model of disability in contrast, and opposition to, the medical model. The repositioning of disability as something socially constructed and therefore potentially changeable deflected responsibility away from the individual and back onto society and demanded that action was taken. 'It is not individual limitations, of whatever kind, which are the cause of the problem, but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account' (Oliver, 1996, p32). This was ground breaking in that it turned attitudes upside down and forced people to look outwards at the social world rather than inwards on individuals and their 'plight'. Oliver (1983) argued for collective action against the forces of oppression and for disabled people to unite and not dwell on individual differences and lived experiences.

The social model as conceived by Oliver (1983) was largely a materialist approach in that the emphasis was on joining together to unite against economic oppression and through collective action, and drawing on common experiences, to seek political change. He argued that economic conditions and the capitalist society marginalised disabled people and relegated them to people who were utterly dependent and who could have no choice or control over their own lives. Not surprisingly then, there was an emphasis on independent living but also on autonomy and the right to have choices about your own life as a disabled person. For example, having the right to choose your personal carers rather than having them chosen for you which ultimately led to the bringing in of direct payments and personal budgets.

In particular, there was a focus on removing barriers both social and environmental in order to include disabled people more fully in social activities. Putting in ramps instead of stairs, enlarging fonts or making braille information available were seen as essential adaptations and would minimise or eliminate disability. The social model identified disability as a social construct, that society 'dis' ables people with impairments and that it is incumbent on society to make changes, to remove barriers and to make adjustments; it is not solely the responsibility of the isolated individual (Barnes et al., 1999). The social model was not intended to be a social theory (Oliver, 1996) but more of a political intervention and has been defended as such (Oliver, 1996; Thomas, C., 2007; Barnes, 2012) in the face of more recent critiques of it.

### 2.2.1 Critiques of the social model: impairment

There have been disputes, arguments and bitter rows at times over the last two decades about the continued relevance and application of the social model in the current neo-liberal, economic context and many criticisms and counter claims have been made (Thomas, C. 1999; Shakespeare and Watson, 2002; Barnes and Mercer, 2010; Watson, 2012;). The controversy over the different theoretical approaches taken by researchers has led to some very public attacks that I believe are divisive and disempowering. Oliver's attack on Shakespeare when reviewing his book, *Disability Rights and Wrongs*, exemplified this when he not only attacked the ideas but also appeared to undermine Shakespeare's 'authority' as a disabled person to write on such matters, 'only a relatively affluent person with a minor impairment who is never going to be at the sharp end of personal support services could write such well-intentioned but meaningless platitudes' (Oliver, 2007, p232). These disputes serve to demonstrate how ideologically charged, how politically sensitive and how hierarchically produced theories of disability and disability research still are. There are implications for my own researcher identity as a mother of a disabled child, but not directly disabled myself.

Shakespeare criticised the social model for not taking sufficient account of impairment and argued that there is an ontological reality to impairment that gets lost in the social model tradition (Shakespeare, 2014). The social model also informed the research agenda and spawned much research on interpretations of disability but much less research on individual experiences of impairment as there was concern that this would be likely to revert to or reinforce a medical approach (Barnes and Mercer, 2010). The way in which research has been focused on 'disablism' has led to individual accounts or personal experiences being ignored in case they take us back to an individual or personal tragedy model of disability (Barnes, 2012).

Shakespeare however, suggested that impairment and disability overlap and are not as distinct as we may have previously conceived. He gives the example of a multiple sclerosis (MS) sufferer experiencing depression, some of which may be directly due to the impairment of MS bringing pain and physical symptoms with it, some may be due to social barriers which impact on her life and some could be due to depression being a commonly associated symptom of MS. 'It seems likely that the different factors would be inextricably linked, compounding each other in a complex dialectic' (Shakespeare, 2014, p24). His argument is that it is not straightforward to separate impairment and disability and that it would be artificial to do so, rather, there is more of a continuum

between impairment and disability. By 'bringing the body back in', Williams (1999) argued that it is possible to study individual experiences of impairment without returning to the medical model. Shakespeare went further and argued 'that any qualitative research with disabled people will inevitably reveal the difficulty of distinguishing impairment and disability' (Shakespeare, 2014, p25).

Some feminist disabled researchers (Morris, 1991; Crow, 1996; C. Thomas, C. 2007) also took issue with the lack of focus on impairment. Not least because the social model emerged from a predominantly male, predominantly physically impaired group of disabled activists, the disabled feminists felt that the psycho-emotional effects of disability needed to be made visible and given more acknowledgement. Thomas argued that these masculinist, anti-experiential perspectives dominated much of the debate with a focus on removing barriers to 'doing' rather than thinking about the disabling, psycho-emotional states of 'being' (Thomas, C.1999) and how these might be addressed. She also talked about 'impairment effects', a term she employed to 'acknowledge that impairments do have direct and restricting impacts on people's lives' (Thomas, C. 1999, p42).

The feminist researchers argued that impairment related experiences had to be included in research and debate and that barrier removal did not solve everything because of the complexity and severity of particular conditions. However, these writers did still acknowledge the importance of the social model even though they sought for it to be 'renewed' (Crow, 1996). While C. Thomas was an advocate and supporter of the materialist approach to disability, she also theorised the term disablism as a 'form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being' (Thomas, C. 2007, p73).

However, there are those who defend the 'strong' social model including Barnes (2012) who claimed a continued relevance for the original model and argued that if you say that the division between impairment and disability is false then you are also saying that the distinction between the biological is false and this would only take us back to a 'change the person rather than changing the world' approach (Barnes 2012, p22). Barnes also criticised the post-modern and post-structuralist accounts that focus more on cultural representations of disability and discourse analysis and take our attention away from the impact of economic forces on the lives of disabled people. He argued that the move away from the social model seeks to diminish disability studies and will



ensure that disabled people continue to be some of the poorest in society. He also rejected other theoretical approaches including, postmodernist, poststructuralist, critical realist and social relational, because they

focus instead on abstract theorising that has little or no relevance beyond the sterile confines of the university lecture theatres and seminar rooms [and] will almost certainly usher in the demise of disability studies as a credible and meaningful academic discipline (Barnes, 2012, p24)

The main reason for such controversies and clashes within disability studies, certainly in Britain, seems to originate from the fact that the social model emerged from disability activists and was therefore primarily political and based on a Marxist materialist approach; whereas, the later attempts to propose critiques or alternative ideas to the social model have tended to emerge from the academy and are attacked for distracting from the political, activist agenda (Vehmas, 2012). Of importance to my research was both the need to identify social oppression and acknowledge the lived experience of impairment and its impact on daily lives. For those with autism and learning difficulties and their families, impairment effects were a very real part of their experience.

### **2.2.2 Critiques of the social model: Barrier removal**

There is a sense in which the social model leads us to believe that if we could but remove all barriers in society then we would somehow eradicate disability, in fact, Finkelstein wrote that 'once social barriers to the reintegration of people with physical impairments are removed, the disability itself is eliminated' (Finkelstein, 1980, p33). These ideas are still held firmly by Oliver and Barnes, among others, in particular who advocate the continued relevance of the social model in the current economic climate (Oliver, 2013; Barnes, 2015). However, regardless of the fact that it would take years to fully adapt the world to take account of all impairments, it becomes clear that as the most obvious and most unnecessary barriers are removed, it leaves the more complicated and stubborn ones firmly in place (Shakespeare, 2014). If we consider instead, for example, how we would adapt society to accommodate all children and people with autism then we would find it harder to achieve, less obvious to see and it would entail some conflicting demands. To some extent this is where priorities about barrier removal get shaped and where we start to see a hierarchy of impairments emerging, which I will explore later in this chapter.

Shakespeare argued that removing barriers also leaves us with a difficulty in the natural world. On one hand we can criticise man-made towns and cities but it is harder

to justify the social barriers argument in the countryside. Wheelchair users, for example, are disabled by rocky cliffs and inaccessible beaches; visually impaired people still may not see the beauty of nature or the edge of the cliff; people with learning difficulties may not be able to make sense of the transience of snow but we cannot blame nature for constructing these barriers (Shakespeare, 2014).

Challenges emerge when trying to adapt everything to suit all disabled people in that there can be complete conflicts of interest (Shakespeare, 2014): blind people may find that cuts in the kerb interfere with their ability to negotiate the edge of the pavement; the tactile paving for visual impairment can be uncomfortable for wheelchair users; lighting in schools can be too bright for some children with autism or too dim for those with visual impairments. Moreover, even people with the same impairment, such as autism, may require different accommodation because everyone experiences their own impairment differently. Even if all these adjustments could be made, they would not eradicate autism or learning difficulties or the pain associated with chronic illness, so we have to think carefully about balancing barrier removal with disability, the acceptance of difference and neurodiversity. The next section considers the relevance and potential of barrier removal specifically in relation to autism and learning difficulties.

### **2.2.3 The social model, autism and people with learning difficulties**

There are many critiques of the social model and one of the key arguments relevant to this research is that it could encompass a broader spectrum of disability than was perhaps in mind at its inception. Given that the social model grew out of the disability rights movement with the attendant frustration, anger and impetus to collective action the formation of the Union of the Physically Impaired Against Society (UPIAS), it is perhaps unsurprising that the application of the social model to people with autism and learning difficulties does not always seem as pertinent or prevalent as its application to those with physical impairments (Chappell, 1998). Chappell goes on to argue that people with learning difficulties are 'neglected by the social model of disability which ought to promise them so much in terms of its analysis of their experiences and its strategies for change' and that learning difficulties are 'almost entirely ignored'. Although Chappell's work was published in 1998, Stalker argues that there does not seem to be much more recent evidence with which to theorise the position of people with learning difficulties (Stalker, 2012).

For people with learning difficulties, and the range is huge, there have been fewer

opportunities for them to have a voice, quite literally in one sense, but there has also been less research into the experiences of those who do not have good communication skills especially language. People with learning difficulties may not even perceive themselves as disabled but prefer to focus on their abilities (Watson, 2002). There is also a broad spectrum of learning abilities with some separating out of people who are relatively more able and who might distance themselves from the more severely impaired. Shakespeare and Watson argue that the 'strong' social model downplays the lived experience of disabled people in shaping our understanding of disability and oppression, whereas much of the work on learning difficulties is based around life histories. Disability theory thus needs to recognise the significance of all personal experiences, limitations and differences in order to develop our understandings (Shakespeare and Watson, 2002). It is perhaps unsurprising that we have fewer representations of those with learning difficulties both in the academy where a high degree of literacy and intellectual capacity are deemed essential but also in social science research as their views may be more difficult to identify without a more imaginative approach to the process of qualitative research (Nind, 2008). We have many examples of disabled academics in terms of bodily impairment (Barnes, Crow, Oliver, Shakespeare, Thomas, C.) but what if the intellect is impaired? Where does that leave academic representations of disabled lives? And where does it leave the disability research agenda?

Without a return to medieval times or the abolition of capitalism in the western world, it is hard to see how literacy and numeracy are not going to be important attributes necessary for economic and social development (Shakespeare, 2014). The social model does not necessarily work for people with autism and/or learning difficulties, as the focus on barrier removal would not address the very real issues of their social and/or intellectual difficulties. Some people with learning difficulties are going to have little prospect of employment if they cannot perform even basic work tasks or are unable to read, write or speak (Vehmas, 2012). If we consider the case of autism there are also likely to be difficulties in conceptualising what barrier removal might even look like for people with social impairments (Singer, 1999). On one level, people with autism may find the social world overwhelming due to a possible hypersensitivity to sound for example. While reasonable alternative accommodation might be made, such as the provision of quiet rooms or separate shopping facilities, this then moves away from an inclusive society, 'this begins to look less like barrier-free provision, and more like the specialised and perhaps even segregated provision of solutions for special needs' (Shakespeare, 2014, p41). And, it may be in the case of autism that specialist

provision is required both in educational and workplace settings (Shakespeare, 2014; Lewis and Norwich, 2005).

These critiques of the social model and approaches to barrier removal arguably highlight a divisive and unhelpful position where a 'hierarchy of impairments' seems to emerge, where the removal of obvious, and often physical barriers, takes precedence over the more complex and nuanced adjustments that would need to be made for autism and for learning difficulties. The symbol of a wheelchair has become synonymous with disability (toilets for disabled people, car parking spaces) encouraging people to think of physical and visible impairment as the only kind of disability. Docherty et al (2010) perceived a hierarchy of impairments within the Disabled People's Movement, in which people with learning difficulties and those with mental stress are at the bottom of the list and therefore become more marginalised from services and support,

If you look at disability, there's like a chart of different kinds of disability. At the top you've got physical impairment and sensory impairment, we [learning disabled people] come with mental health right at the bottom, so we're like the doormat of disability. The higher you come in disability the better services you get. The lower you come, the more you're ignored. (Docherty et al. 2010, p438)

There is some evidence in employment statistics to support this hierarchy in terms of who is more likely to be employed among the disabled population. About 45% of those with physical impairments are likely to be in employment in contrast to only 21% of those with learning difficulties and only 18% for those with mental health issues (Smith and Twomey, 2002) and only 15% for those with autism (Knapp et al., 2007).

Having explored the medical and social models of disability in relation to autism and learning difficulties, I realised that they did not adequately illuminate the experiences of young people with autism; there was relatively little written about the social model and learning difficulties for example and the needs of this group seemed to have been somewhat overlooked.

### 2.3 The Capability Approach

The capability approach conceived by Amartya Sen in the 1980s and later developed with Nussbaum (Nussbaum and Sen, 1993) seemed to have some relevance to understanding the disability debate in my particular context. It is attractive to this research as it focuses on potential, on what is possible, on what all human beings are capable of achieving, what they can do and be, and what resources might be needed

in order for an individual's true capability to be realised. It grew out of welfare economics and attempted to offer an alternative indicator of prosperity measured not by Gross Domestic Product (GDP) but by examining well-being and quality of life as key indicators. The capability approach is defined by Sen as, 'a particular approach to well-being and advantage in terms of a person's ability to do valuable acts or reach valuable states of being' (Sen, 1993, p30). He identifies capability as the potential freedom a person has to make choices about living the life they want in order to achieve well-being. 'Functionings' are then a set of 'beings and doings' that people choose to value such as being educated, being healthy, walking, reading, being socially integrated and having some control over one's environment. Quality of life is 'assessed in terms of the capability to achieve valuable functionings' (Sen, 1993, p31).

Although Sen did not directly apply capability approach to disability, others have developed it in that way including Mitra (2006). She argued that disability can be thus be understood as the result of a combination of different factors rather than solely the result of oppressive practices and she lists three factors which can affect the nature of disability:

- (a) personal characteristics (e.g. age, impairment)
- (b) basket of available goods (assets, income)
- (c) environment (social, economic, political, cultural) (Mitra, 2006, p237)

Personal characteristics including the intrinsic nature of impairment, for example being in constant pain, can limit a person's ability to leave the house or go to work so that their capabilities are limited thus rendering them disabled. A person can also be disabled by barriers within society; for example, someone with facial disfigurement may encounter negative attitudes and therefore be disabled in their interpersonal relations. In economic terms, a person may find their resources limited as they cannot work and therefore experience restrictions in their capabilities. The capability approach then takes a more holistic view of disability and society and the role that both play in restricting or enabling individuals.

Terzi (2005) applied Sen's capability approach to disability and special educational needs and argued that this approach helps to overcome the duality and tension presented by the medical and social models of disability. It allows for an acceptance of disability and difference as fundamental and part of all society and thus considers disability as relational in a similar way to Mitra (2006): that is in relation to individual impairments as well as social structures and arrangements. By applying capability theory to special educational needs, Terzi argued that impairments are then seen as a

disability only in relation to certain contexts not as a label which pervades every ability or interaction (or 'functioning') of that person and renders them 'abnormal'. Thus a visually impaired person is only disabled in certain 'functionings', such as when braille or adaptive technology is not supplied; their intellectual reasoning, for example, is not impaired and they are therefore not disabled in all aspects of their life. In this way, disability is seen in as relational both to the context within which the person is operating and to the specific impairment, as the impairment is not absolute (Terzi, 2005). It is clear from this argument that the additional provision made by society becomes a matter of social justice in order to equalise the individual's capability to achieve well-being.

The capability approach sits well with relational alternatives to the social model in that it acknowledges both social and individual features depend on environmental factors such as entitlement to free education but also the level of support required relates to the individual characteristics of that person (Vehmas, 2012; Shakespeare, 2014). The capabilities approach is also able to acknowledge the continuum from 'so-called normal people and people with impairments' (Nussbaum, 2006, p190) and recognises dependency as part of the human condition about which we can all claim collective experience. Terzi's application of the capability approach to special educational needs also allows its relevance to be seen in relation to learning difficulties. Hedge and Mackenzie (2012) work through Nussbaum's model in relation to the inclusion of two children with behavioural difficulties in mainstream schools and they question whether the dignity of the child is best served by that environment. If the child cannot convert the resources of mainstream education into realised capabilities then we have to think again about inclusion and whose needs it is serving, and the capability approach helps us to articulate this experience.

The capability approach is not without its critics and Norwich argued that it does not go far enough in clarifying educational capabilities and functionings and how these might be identified; it is too subjective in this regard. He considers what would be classed as 'adequate functioning' in relation to the curriculum and that educational functionings and capabilities are far more complex to determine than those considered valuable for well-being. He also argues that capability theory is limited in its application to special and inclusive education as it does not address the theory of parental choice versus public policy in relation to special or mainstream educational placements (Norwich, 2014). Others have criticised the theory for being too focused on individual needs and over-emphasising individual agency and detracting from the need for collective action,

advocated by the social model, in social and environmental structures (Riddell, 2009).

Despite these criticisms of capability theory, it does remain influential in my thinking about how we best meet the needs of young people with autism and learning difficulties as its focus on human flourishing and positive opportunities is an important perspective to retain and return to throughout research with people with disabilities. It also has, as a premise, that human diversity and difference are central to our society and to our understanding of social justice.

## 2.4 Critical (or Cultural) Disability Studies

There is not sufficient space here to explore all disability theories to the same depth and my focus is largely on those theories that have most influenced my approach to research and my interpretation of research findings. However, it is worth referring to Critical Disability Studies as it has had a significant influence in theoretical approaches to disability. Those engaged with critical disability studies (Corker, 1999; Goodley, 2001; Shildrick, 2012) approach disability from a poststructuralist perspective and their focus is on discourse, language and social construction of disability. They argue that the 'problem' of disability exists because of an obsession with 'normalcy' in our society and that the role of disability studies is to deconstruct, critically examine and contest meanings in which the dualisms of people with and without impairments construct power relationships (Corker, 1999). Critical disability studies focuses more on the cultural and linguistic dimensions of the construction of disability than on the economic and capitalist arguments put forward by the social model. In the case of learning difficulties, it is argued that it is the predominance of the literacy and numeracy focused culture of the Western world that brings attention to these deficits rendering people with learning difficulties of less value to the knowledge economy and therefore more materially deprived and marginalised (Oliver, 1990). Other researchers argue that learning difficulties present differently in some cultural settings and therefore impairment is not viewed in the same way and that people with learning difficulties are still seen as able to fulfil certain roles (Goodley, 2001; Molloy and Vasil, 2002).

Commentators on critical disability studies such as C. Thomas (2007) argued that it would be nonsense to suggest that learning difficulties are entirely socially constructed and that it is important to acknowledge these differences rather than erase them or minimise them. Indeed by burying the experience of impairment and the realities of pain and struggle, the need for additional support and resources could be overlooked

as well as the lived experience of disabled people. Within disability studies there are criticisms of these post-structural and postmodern accounts as they become too remote from effecting change for disabled people, for example if strong social constructionism is taken to mean that 'a social phenomenon such as some specific form of disability exists only as an idea or belief, then it is clearly false' (Bhaskar and Danermark, 2006, p284). Similarly, C. Thomas argued that while we should not give the medical profession exclusive rights over impairment and decisions about disability, we should also not engage with the 'poststructuralist vanishing act involved in treating real bodily variations from the average as entirely linguistically or culturally constructed difference' (Thomas, C. 2012, p14).

## 2.5 Critical Realism

Critical realism as theorised across many works by Bhaskar (1975, 1993, 1998) is a complex and expansive theory and is referred to here in its capacity to illuminate some of the issues in the disability debate; I do not seek to offer an exhaustive exploration of all Bhaskar's work. Bhaskar does identify a crucial distinction between ontology and epistemology and claims that other theories both positivist and interpretivist conflate the two resulting in 'epistemic fallacy' (Bhaskar, 1975). He suggests that there is an independent reality that exists outside of our consciousness and is never fully knowable however, our epistemological understanding of that reality, albeit partial, is wide ranging and encapsulates not only the biological, social, psychological and personal nuances but also acknowledges that independent existence. 'Critical realism indicates that the relation between the real world and the concepts we form of it is the focus of the research process.' (Danermark et al., 2002, p15).

Worth considering here is Bhaskar's idea of stratified reality consisting of three primary layers: the real, the actual and the empirical (Bhaskar, 1975). The 'real' refers to the underlying mechanisms or structures that are responsible for what we can observe – the real cannot be seen but we can speculate on it. It is not something that we have any direct knowledge of. Our own ability to understand what is real is limited by ourselves. For example, using the concept of gravity Bhaskar illustrates that nobody has ever seen it but if we take any object and drop it in a vacuum then that object will fall at a constant rate so it is not directly observable but inferred from the observation. Below the real, is a level that Bhaskar calls the actual which refers to events, people, objects, caused by the mechanisms in the real, so we can observe what things do, like the observable rate of the fall of gravity, we can observe the event caused by gravity.



Similarly, no-one has ever seen human nature but there are debates about what it is and we talk about it as if it is real but we can only observe individual behaviour not 'human nature'. The third layer is the empirical layer that refers to experience, at the sensed or witnessed level, and this is the position of the individual, the scientist or social scientist, the person observing events in the actual level and then making speculations about the real (Bhaskar, 1975; Danermark et al., 2002). The empirical refers to the position of the observer and how they interpret the world. In relation to this research we can refer to transition on the level of the real but we come to know about it through the mechanisms and observable practices around transition as well as the individual experiences, or empirical level of reality.

The concept of 'absence' is central to critical realism and is of particular relevance to transition in the notion of 'becoming and begoing' (Bhaskar, 1993; Alderson, 2013). 'Everything is partly defined by what it is not' (Alderson, 2013, p65), so that childhood is defined by not being adulthood and 'becoming' has to involve its opposite, 'begoing', in recognising an absence and passing away. Bhaskar's argument is that we need to have absences and voids to enable movement, if the world was too tightly packed change would not happen and in order to develop new ideas we need to be able to let go of old ones. Alderson (2013) gives the example of a child learning to read as she becomes a more competent, independent reader she therefore 'begoes' being such a dependent non-reader and listener to stories others read for her. Change thus requires movement and loss. Linked to 'becoming and begoing' is the idea of *emergence*, that knowledge does not simply progress or improve but new understandings emerge. As one idea changes so does another and in relation to childhood, children and parents change in relation to each other in a 'dialectic of intergenerational emergence. As children change so do parents' (Alderson, 2013, p67). These ideas of interdependence and emergence resonate in relation to the young people in my research who were at a key point in their adolescence. By 'begoing' the protected environment of special school and 'becoming' a student in the more independent environment of college, they were enacting a physical representation of their transition to adulthood.

### 2.5.1 Critical Realism and disability

While Bhaskar sets out his critical realist theory across several texts (Bhaskar 1975; 1998a; 1998b; 1993; 2011) he also helpfully uses disability as an illustrative example of how we can apply critical realism to disability studies (Bhaskar and Danermark, 2006). Bhaskar and Danermark claim critical realism to be 'maximally inclusive' in that it can allow for the insights of other theoretical positions without privilege or exclusion, as well

as being the 'ontologically least restrictive' allowing the complex nature of phenomena to be empirically determined case by case (Bhaskar and Danermark, 2006, p280). By using the example of a young woman with dysphagia, they were able to illustrate how there were biological realities to the condition that necessitated medical intervention and yet, there were also social and psychological effects caused by the impairment that had a profound effect on the young woman's mental health and social life. Their central argument in relation to critical realism and understanding disability is that all examples must be considered using this multi-level approach and,

The relative importance and specific role of these components varies from disability to disability, and often from case to case, and is always an empirical question. It follows from this that we cannot, or should not, always give the same form of treatment or social response to each disability (Bhaskar and Danermark 2006, p292)

Shakespeare (2014) continued this idea of understanding disability in a 'maximally inclusive' way. Having been heavily involved in disability theory for many years and not least supporting the social model of disability for some time, Shakespeare latterly developed a critical realist approach to disability which he argued allowed for a broader understanding and conceptual approach to disability issues. He contended that critical realism allowed a focus on both structural barriers and individual agency and this could encompass the different dimensions of the disability experience (Shakespeare, 2014). A key issue for Shakespeare was, as he perceived it, a marginalising of the experience of impairment in the social model; in the critical realist approach, he saw that both individual and structural differences could be examined. Critical realism acknowledges the ontological reality of impairment and suggests that disability is always an interaction between individual and social factors, and people are disabled both by their bodies and by society (Shakespeare, 2014). He also argued that some people are more disabled by their impairments than others and, also, some are more able to deal with their impairments than others, in other words, individual agency does play a part in a complex and nuanced understanding of what it means to be 'disabled'. He takes this further by suggesting that even with the ending of all unfair discrimination against disabled people, not all their difficulties would be solved, 'but even with the removal of barriers and the provision of support, impairment will remain problematic for many disabled people' (Shakespeare, 2014, p85).

## **2.6 Theoretical perspectives of autism**

Different theoretical approaches to disability have been considered but here the analysis draws down to focus on how we theorise autism from a sociological viewpoint.

By way of summarising some of the approaches above and interpreting autism differently, I examine one article that illustrates this multiplicity of readings of autism and learning difficulties: 'Reading Rosie' (Goodley and Runswick-Cole, 2012). While the perspective of the authors is a poststructuralist one, they do offer four different readings of the same child who has autism and learning difficulties. They suggest that by only taking one perspective we ignore other aspects of the child and that the ways in which these 'readings' intersect allows for further understanding of the complexity of disability. The first reading focuses on a medical model where the biological deficit of Rosie's condition is emphasised with attendant negative language borrowed frequently from psychology. In fact, they conclude that readings taken from the medical model suggest that autism is 'almost universally recognised as a medical condition that is real and biologically based' (Goodley and Runswick-Cole, 2012, p56). They deliberately invoke a negative and judgemental medical reading of Rosie's autism and difficulties. From the social model perspective they show how disabling barriers and attitudes within the local community and beyond have affected the way in which Rosie can interact in a social world. With the pursuit of barrier removal, Rosie would have a much better life and would be more included in her local community. The third reading takes a Nordic relational model approach, and the focus here is on Rosie's interactions with family and her life at home that are very positive. When Rosie goes beyond home and family into a bigger environment, she experiences judgemental attitudes because she is not like her peers and that normative judgements are being made. With this model Rosie would be more empowered to lead a more 'normal' life with appropriate support so the agenda is one of normalisation. Finally, the socio-cultural reading of Rosie puts her at the centre of the story, as she is encouraged to take pictures of her life that offer an insight into her preferences and interests. This reading captures more of Rosie's interests and hobbies for example in taking photographs and this diverts attention away from her disability and onto her as a person.

These readings carry different emphasises both on Rosie as a person and Rosie as a disabled person. Goodley and Runswick-Cole (2012) caution against singular readings as they potentially ignore other interpretations and ignore the complexity of personhood. They reject the medical model as pathologising but feel 'unnerved' by the socio-cultural reading as it renders the disability invisible. In taking the critical realist perspective, I believe that we can take account of these different perspectives as it does allow for a more nuanced, complex but inclusive reading of the child that acknowledges difference, impairment and capability. To focus exclusively on one reading would deny other aspects of the child so while the socio-cultural reading of

Rosie is positive and accords with my person-first approach to research, it does not accommodate all aspects of her life, some of which are challenging and difficult.

## 2.7 My own theoretical position

My research was strongly influenced by the original social model of disability as it turned the idea of disability on its head, away from the 'problem' resting with individuals and prompted a call to collective action and emancipatory change. However, in the case of autism and learning difficulties, I found it less persuasive particularly in relation to barrier removal as it focuses almost exclusively on structures while minimising or undervaluing the role of individual agency. I do not believe that barrier removal could exclusively solve the problem of disability or minimise the impairments sufficiently. However, it does require us to think carefully about social barriers for people with autism and to what extent, social arrangements could be adjusted. Young people with autism present very variably in terms of their abilities, their learning and their communication and the social model did not seem to have articulated many of the very varied and complex experiences of those with cognitive impairments. It would be dismissive to define autism as a social construct and would absolve us of any responsibility to really try to comprehend the nature of the condition in all its complexity, and therefore render it impossible to make reasonable adjustments. Capability theory brings another useful perspective to understanding disability in its acceptance of diversity and attempts to equalise opportunity through appropriate allocation of resources. However, the difficulty with identifying valuable functionings in education and the subjectivity of so doing makes it difficult to comprehend how it could be applied in practice and how it could effect real change.

I have moved towards a critical realist approach where impairment and difference can be accommodated and where echoes of the capability approach and the social model have space to co-exist, critical realism is defined as a 'maximally inclusive' philosophy and this also seems to fit with my approach to research and the people with whom I am researching. It also acknowledges the complexity of phenomena and individuals and affords space for individual difference and analysis on an individual case basis. This was particularly important for autism where no two people were alike. I was also drawn to the capacity of critical realism to include a multi-layered understanding of disability and impairment where intellectual impairment could be acknowledged as having an ontological reality and yet, our responses to it in society could also be challenged. Notions of emergence, interdependence and becoming and becomings also fitted well

with the phenomenon of transition and how the participants in my research were likely to be experiencing many kinds of changes in their relation to their education, social lives, mental states and to parents and teachers.

These theoretical influences led to the design of my methodology as a person-centred approach where new methods were designed in order to take in the views of the young people and to centre my focus on their experiences, their capabilities and their aspirations. This has echoes of the socio-cultural reading of 'Rosie' above as well as chiming with capability theory but my research was also intended to focus on the lived experiences of young people who were going through a transition process in their lives at a particular time. In order to listen effectively to the young people, I had to be prepared to take into account their impairments, to hear their difficulties as well as their achievements. Alongside this, I wanted to make space and give voice to the views of the parents and professionals involved in the process, as their versions of reality were nonetheless valid and were evolving in relation to the young people.

## 2.8 Research Questions

My research questions were intended to be as open-ended as possible as I did not want to prejudge my findings or assume certain influences on young people during their transitions. I wanted to be prepared to find that transition may pose fewer challenges than I perhaps gleaned from literature searches and I wanted to allow space for the responses of the young people to determine the agenda. Equally I was addressing a gap in knowledge about transition as well as about the way in which we theorise disability in relation to learning difficulties and autism. The multi-layered version of reality posited by critical realism acknowledges the level of the real, in this case the phenomenon of transition; the actual, the observable processes and structures of transition and finally the empirical or lived experiences of young people moving from special school to college. The research questions attempt to reflect these levels of reality as well as acknowledge the individual differences among the young people in the study which critical realism as a 'maximally inclusive' approach allows me to do (Bhaskar and Danermark, 2006).

### **1. What are the aspirations, interests, capabilities and concerns of young people with autism as they leave school?**

At the heart of my first research question is an attempt to centre the research firmly on the young people's perceptions of their lives through their interests, aspirations and concerns at this key moment in their lives on the cusp of leaving school. In response to

capability theory, I wanted to focus on potential rather than the deficit and learn about aspirations and hopes for the future as this has implications for the resources these young people might need in order to fulfil their capabilities at college. Equally, I did not want to ignore the concerns that the participants had in relation to transition and wanted to acknowledge the difficulties that they might perceive. Critical realism allowed me to take account of the whole person and discuss both impairment and disability as well as aspirations and capabilities. Listening to young people and allowing space and time for them to communicate (Clark and Moss, 2011) was important to me as the literature suggested that there was a lack of research directly with disabled people (Preece, 2002; Nind, 2008) and so, implicit for me in this research question, was developing an effective way to listen to young people in the methods that I employed. It was clear that I could not theorise disability adequately without qualitative research that attended to the subjectivities and lived experiences of people with learning difficulties including people with autism.

## **2. How well prepared are young people with autism for transition from special school to mainstream college?**

With the second research question I wanted to consider what preparation for transition consisted of, in its broadest possible sense. While the processes and structures of transition might be in place as observable phenomena, in the realm of the 'actual', such as visits to colleges or transition planning reviews, this question takes the perspective of the young people to examine their experience of this preparation. I wanted to know to what extent individual capabilities and needs were taken into account; how personal adjustments to the process were made; how prior experiences of school might shape the attitudes of young people going to college; how social and academic abilities were matched to curriculum offers and how social interaction difficulties were adjusted for. Perspectives from schools, colleges and careers advisers were also important but more important were how young people and their parents experienced transition.

## **3. How do young people with autism and their parents experience this transition?**

My third question focused on the lived experience, at the empirical level, of the young people as they went through the transition both from their perspectives but also from those of their parents. I wanted to understand what transition felt like for them and whether they could reflect on their experiences and how they might have been different, again I did not want to impose my perceptions on how that experience might be and kept it deliberately open. The concept of 'emergence' from Bhaskar's work

underpins this question with both the young people and the parents undergoing changes in their circumstances and their relations with each other (Bhaskar, 1993). The notions of 'becoming and begoing' could be explored through this research question and how intergenerational dependencies were changing. How was this emergence being enacted by the young people? How was it facilitated or undermined by the transition to college? How did parents and young people adapt to these changes?

My research aim was specifically about how the research data might be used in order to improve conditions for young people with autism and learning difficulties in transition. It was important to me that research should try to make a difference to experience and critical realism implies an emancipatory responsibility on the researcher. I wanted the data to feed back to those involved in making the transition from special school to college (young people and their parents) as part of their empowerment, but also to the professionals around them both before and after transition.

Chapter Three reviews the existing literature on autism and explores the category more fully than in the introduction, it also covers debates about inclusive education and transition. Chapter Four explains how my theoretical position influenced the research methodology and explores the methods devised and the approach taken to working with young people with autism. Chapters Five, Six, Seven and Eight present the data analysis and Chapter Nine brings the discussion together and talks back to the research questions. Finally, I conclude with my contribution to knowledge, limitations of this research and ways forward for future research in this area.

## Chapter Three: Literature Review

Disability theory has been addressed in Chapter Two and covers a range of sociological perspectives that can be applied to disability. This chapter investigates the available literature pertinent to my study of transition for young people with autism and my theoretical approach leads me to problematise autism beyond the rather crude definition offered in the introduction to question how autism affects learning and how it might affect social understanding. In my own theoretical framework I have constructed a critical realism based approach that also takes account of the social model and capability approach. In this section, I examine the ways in which autism affects both learning and social worlds and how reasonable adjustments might be made to include people with autism. I argue that only by taking a critical realist-based account of the whole child or person with autism and learning difficulties and their varying presentations can we start to make sense of the condition and begin to consider how to effect inclusive environments. By reflecting on concepts of risk and resilience in relation to disabled children and young people, the ways in which the social environment can be adapted can be explored. Given the nature of autism as a spectrum condition, it is difficult to categorise it as a homogenous condition. The group within autism that my research specifically encompasses is those with autism and additional learning difficulties, as those with a 'higher-functioning' or Asperger's Syndrome presentation are less likely to be at special school and therefore not in my sample.

### 3.1 Problematising autism

In taking a critical realist approach, it is important to my research that autism is examined as a condition that presents variously in biological, psychological and social ways in different people identified within 'a necessarily laminated system' (Bhaskar and Danermark 2006, p292). In this way, critical realism allows us to consider individual impairment as well as social barriers and attitudes towards disability, and here I will explore more fully the different ways in which autism has been viewed and how this might affect our understanding and research about it.

#### 3.1.1 Medical and psychological perspectives on autism

In Chapter One I briefly summarised autism as a spectrum condition characterised by a triad of impairments, and indeed this is reflected in the fifth revision of the Diagnostic and Statistical Manual (American Psychiatric Association, 2013) used to diagnose children and adults with the condition although it is still labelled as a 'disorder'. The following criteria, in brief, have to be met for a diagnosis of autism:



- A. Persistent deficits in social communication and social interaction
- B. Restricted, repetitive patterns of behavior, interests, or activities
- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)
- D. Symptoms together limit and impair everyday functioning.

(American Psychiatric Association, 2013)

ASC is also understood to be a lifelong developmental disorder that affects how a person makes sense of the world, how they process information and how they relate to other people (NAS, 2011). Different disciplines approach autism in different ways. For example, medicine works from a biological imperative to identify, improve or cure the condition; psychology from cognitive theories of mind, and sociology from socially situated perspectives. Within the different disciplines there are contested theories and here, moving on from the sociological interpretations offered by disability theory detailed in Chapter Two, I consider medical and psychological perspectives in order that a rounded understanding of autism can be examined.

Medically, autism is seen to have a variety of physiological markers but there are no blood tests or specific genes identified for autism as yet even though over 100 genes have been associated with the condition, (NAS, n.d.). The Medical Research Council (MRC, 2001) refers to autism as a 'neurodevelopmental disorder' and of the 'overwhelming evidence for a biological basis and a strong genetic component' (p21). There is also evidence from brain scans that the shape and structure of the brain is different in autistic and non-autistic children (Baron-Cohen, 2004; ASA, 2015). These investigations of the potential causes of autism have given rise to a proliferation in neurological studies; research on interventions both medical and therapeutic and indeed, searches for a cure, although the latter is contentious and has been recently widely rejected (for example, Happé, Ronald and Plomin, 2006). Co-morbid conditions have also been identified as commonly occurring in people with autism, such as up to one third of people with autism having epilepsy, up to 83% experiencing insomnia (Jeste, 2011) and are more likely than children without autism to experience gastro-intestinal symptoms (McElhanon et al., 2014).

The medical research gives us cause to consider an ontological reality to the impairments experienced by people with autism: that there are genetic markers and neurological differences in the structure of the brain that affect, to different degrees, a person's ability to interact with and make sense of the world. These difficulties can cause anxiety, frustration, self-harming, speech and language delay, developmental delay and learning difficulties (Frith, 1989). There are no single tried and tested

medical treatments that work for all cases of autism, and certainly no 'cure', and the most commonly cited early interventions are behaviourist ones such as Applied Behavioural Analysis (ABA), focused speech therapy or specialist education (Baron-Cohen, 2004).

There is much psychological research into autism that typically constructs it in negative terms such as a 'devastating developmental disorder' (Happé, 1999, p216) or a 'devastating neurological abnormality' (Frith, 2003, p1) but there is dispute about the fundamental challenges of autism. Different, and contested, theories have been posited by cognitive psychologists including theory of mind, weak central coherence and executive dysfunction, as perhaps the three most prevalent and worthy of mention in relation to understanding autism.

Theory of mind suggests that people with autism are unable to understand other people's mental states or that they are unable to empathise with others and understand different perspectives (Frith and Frith, 2005). The Sally-Ann tests carried out by Baron-Cohen et al. (1985) found that individuals with ASC were unable to imagine a scenario in which the participants had different knowledge to themselves. This contributes to an explanation of why people with autism may have difficulty in social interaction such as understanding the subtle emotional or physical cues that people reveal in social situations.

Weak central coherence theory has also been explored as a way of showing how people with autism often have 'an inherent preference for processing local elements over the global whole' (Pellicano 2011, p237). This leads to a difficulty with seeing the bigger picture and leads to Frith's conceptualisation of the 'weak central coherence' theory (Frith, 1989; Happé, 1995). In Frith's experiments, children with autism tended to focus on isolated details, for example finding hidden figures within a larger, more meaningful picture and were equally able to recall jumbled sentences as well as coherent ones. This helps to explain why there might be difficulties with a phenomenon such as transition across educational settings where a young person with autism might only be able to focus on fragmented parts of this process rather than seeing it as a coherent whole.

Executive function is associated with planning, cognitive flexibility and working memory; the way in which we regulate and control our cognitive processes. A deficit in executive functioning (or executive dysfunction) has been linked to autism (among other conditions) as a way of explaining certain behaviours. In particular, difficulties

with planning, with transitions and with the exhibition of stereotyped and repetitive behaviours (Ozonoff, 1997; Ozonoff and Jensen, 1999).

Despite these competing psychological accounts, there is dispute about their relative primacy in relation to autism and whether they are found in all people with autism and to the same extent. There is no agreement about a single deficit model of autism and instead psychologists have embraced a 'multiple-deficit' explanation and urged others to 'give up on a single explanation of autism' (Happé et al. 2006, p1218). This concurs with the complex picture emerging of what constitutes autism across the psychological, neurological, biological and social domains.

### **3.2 How does autism affect learning?**

Autism has a huge impact on learning in both positive and negative ways. Special interests (sometimes called obsessions), a tremendous capacity for memory and often profound attention to detail are all key strengths that many people with autism possess and yet these are sometimes identified as difficulties or deficits (Frith, 2008). For example, an intense focus on details, or 'hyper-systemising' (Baron-Cohen et al., 2009), can lead to superior abilities in mathematics and computer science. Some people with autism seem to have an excellent rote memory and can recall intricate details of past events, as well as being able to remember complex numerical or alphabetical sequences or geographical routes and layouts (Boucher et al., 2012). Special interests or 'obsessions' are often focused on the way things work rather than the way people interact and this can lead people with autism to develop extreme competence with technical workings of machinery or computers for example (Baron-Cohen and Wheelwright, 1999). So there are many ways in which autism impacts upon learning that are not wholly negative, and some of these capabilities can be harnessed in helping children to learn, for example using a special interest to teach across curriculum subjects (Frith, 2008). However, in order to fully understand autism and to make appropriate adaptations in education, it is important to consider the potential difficulties in accessing learning.

#### **3.2.1 Conceptual difficulties**

Impairment in 'imagination', can manifest itself as a difficulty with creating imagined worlds or imaginative play in children but it also refers to a lack of flexibility of thought and limited ability to foresee the consequences of one's actions (Wing, 2007). People with autism are likely to struggle to adapt their learning and transfer it from one context to another which can pose difficulties in their learning at school (Plimley and Bowen,

2006) and the executive dysfunction theory could partly help to explain this (Ozonoff, 1997).

Similarly, skills learned in one context do not necessarily transfer to another but have to be re-learned in that new context (Vermeulen, 2001; Plimley and Bowen, 2007). This links back to the weak central coherence theory from psychology which suggests a fragmented learning style (Frith, 1989). The ways in which people with autism construct their understanding of the world can be complex and time-consuming as a result of this conceptual difficulty. Grandin (2006), an animal welfare scientist with autism, talks about chairs as an example: if she came across something which might be a chair, she had to compare it in her mind to other versions of chairs and if it did not match then she had to create a new mental model of it and file it accordingly (Grandin, 2006). This is a very time-consuming way of processing information about new objects and concepts and requires much mental energy and space which can impact on the individual's ability to then keep up with other learners (Jordan, 2011).

### **3.2.2 Communication difficulties**

Communication abilities can vary from the very sophisticated and sometimes advanced language of the person with Asperger's Syndrome through to someone with no expressive language and attendant learning difficulties. One common feature seems to be that there is a tendency to take language literally, or at face value, indicating a difficulty with understanding figurative speech or idiomatic language (Attwood, 2007). For example, Blackburn (2013), an adult speaker with autism, talks about being asked to 'go and wash her hands in the toilet', a task which she carried out quite literally as a child (Blackburn, 2013). Facial expressions and body language can also be hard to interpret, as well as everyday social situations, where behavioural or social expectations are not inherently 'known' in the same way that they might be for non-autistic people (Jordan and Jones, 1999). Being literal about their understanding can mean that people with autism follow instructions very specifically, but equally may struggle with making inferences from non-literal language (Jordan and Jones, 1999) which can cause particular problems with literacy.

### **3.2.3 Social interaction difficulties**

It is likely that most young people with autism will struggle to interpret the social world (and social interaction is considered more fully in 3.4) and their learning is likely to be affected by their difficulty in engaging in group and peer learning both formally in the

classroom and informally at social times (Chown and Beavan, 2012). Learning in social contexts, learning through discussion and group work are all key features of secondary education and yet these will pose particular difficulties for children with autism and they may need to be taught explicitly how to work in a group or how to learn from their peers (Jordan and Jones, 1999). They do not always identify as being part of a group and may need to be addressed personally to understand that an instruction applies to them and they may not understand principles of turn-taking and therefore become disruptive or interrupt when others are talking (Plimley and Bowen, 2007).

### **3.2.4 Sensory difficulties**

There are many sensory difficulties associated with autism and these can occur in varying degrees in different children but they tend towards sound sensitivities, a propensity to sensory overload and an inability to screen out certain stimuli over others (NAS, n.d.). These sensitivities can make it very difficult for children with autism to concentrate in the classroom where there are likely to be a range of visual, auditory and olfactory disturbances from which to select the most important (Jordan and Jones, 1999). Equally, hot or cold temperatures, textures of floors, chairs or pens, flickering lights or noisy projectors can all cause distraction and sometimes discomfort.

Taking into account the potential difficulties that learners with autism may have, the question of appropriate educational settings now needs to be addressed in relation to the most appropriate and maximally inclusive setting. This necessitates a discussion of the philosophical and practical issues of both inclusive and special education for children with autism and learning difficulties.

## **3.3 Appropriate learning environments?**

Disability theory relates to perspectives on special and inclusive education, in that advocates of the social model conceive of special education as oppressive and marginalising: 'the special education system has functioned to exclude disabled people not just from the education process but from mainstream social life' (Oliver, 1996, p78). In the context of schools, the social model critique implies the need for such strategies as: adapting the physical environment, differentiating the teaching and removing barriers to learning to ensure that every child can access the curriculum. By contrast, those who concur with an individual or medicalised approach would be more likely to seek to perpetuate the current segregated system of education where those with special educational needs are educated separately in accordance with their

impairments (Farrell, 2006). However, I would contend that both models have limitations: the medical model tends to overlook the role of the school in supporting all children, promoting social inclusion and making appropriate adaptation and curriculum provision, whereas the social model risks minimising the individual's needs to the point of not acknowledging them and therefore could compromise the educational provision made (Norwich, 1993; Terzi, 2005). Critical realism and capability theory allow me to take a modified view of inclusive education (discussed below) in order to assess whether it is in the best interests of the child; are they able to maximise the resources in the setting in which they are placed?

### 3.3.1 Adapting the learning environment

It is the responsibility of all educational settings to make reasonable adjustments ('Equality Act,' 2010) to take account of the difficulties that learners with autism may encounter including both environmental and pedagogical changes. Although there is no single intervention which is proven to be effective for all learners with autism (Happé et al., 2006; Jordan, 2011), account needs to be taken of specific impairments so that teaching and learning can be adapted accordingly. Jordan argues that education has to 'take on the therapeutic role of compensating for the effects of ASD' (Jordan, 2011, p364) as well as ensuring that all pupils have access to the breadth of the curriculum. Children and people with autism tend to respond well to rules and routines (Wing, 2007; Humphrey and Lewis, 2008). The predictability and safety of school structures and the use of visual timetables can support their learning very effectively (DfE and NAS, 2012), 'set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Trying to keep everything the same reduces some of the terrible fear' (Jolliffe, Lansdown and Robinson, 1992).

Teaching or learning support assistants are often deployed to support learners with additional needs in mainstream schools and colleges and while the extra adult support can be beneficial (Cremin et al., 2005), it can also have a negative impact on the student by effectively isolating them from their peers, diminishing the amount of contact students have directly with teachers and undermining their academic performance (Symes and Humphrey, 2011). The extent to which students are 'attached' to their teaching assistants on a daily basis can become problematic as identified by a recent review of children with special educational needs in mainstream classrooms,

There were concerns with regard to children getting too attached to the TA and not getting sufficient teacher attention. The danger of creating over-reliance and

dependency on particular TAs was described as 'velcroing' (Galton and Macbeath, 2015)

People with autism are often overwhelmed by the sensory onslaught of the world as they find it difficult to separate out and 'turn down' different sounds or images and this can cause them to become distracted by such things as a flickering light or the noise of a radiator (Ambitious About Autism, 2011). However, buildings are not often built with autism in mind so learners may have to cope with less than satisfactory learning environments. Although there can be strategies adopted such as: physical adjustments to lighting and windows, the creation of quiet spaces, clear signage and the organisation of classroom space, these are unlikely to eradicate all difficulties that learners with autism might encounter and therefore some intervention to support the young person to manage their sensory overload can be beneficial (Breakey, 2006).

Similarly, adjustments can be made to the learning and teaching strategies to include more visual learning to address communication needs; giving clear instructions; explicit teaching of meaning in language; accessing the curriculum through special interests; explicit teaching of group work expectations and giving support with managing change and managing time are all helpful to learners with autism, and arguably to all learners). The learners in my research are leavers from special school who are going on to mainstream colleges, so here I will consider the arguments for inclusive and special education as well as evidence of both in practice.

### **3.3.2 Inclusive education**

From a human rights perspective, the concept of inclusion and the right of access to education for all children and disabled people is enshrined in laws ('Education Act,' 1981; DfES, 2001), stating that the special educational needs of all children will 'normally' be met in mainstream schools. Similarly, access is endorsed in international conventions (UN, 1991; UNICEF, 2006), stating that 'all persons with disabilities can access inclusive, quality and free education on an equal basis with others in the communities in which they live' (UN, 2006). The value of inclusive education is argued by the Salamanca Statement in that mainstream schools with an inclusive ethos are 'the most effective means of combating discriminatory attitudes, building an inclusive society and achieving education for all' (UNESCO, 1994), the implication being that without inclusive education, inclusive societies and communities are much harder to develop.

There is, however, a history of inclusive education in this country, largely since the

Warnock Report (DES, 1978) and the subsequent Education Act (1981), which stated that the education of children with special educational needs should, wherever possible, be carried out in 'ordinary' schools thus advocating the right of all children to be included in mainstream provision and to be enabled to participate in the curriculum. From the 1980s until the early 2000s, there were significant closures of special schools as the trend moved towards inclusive education and more children with special needs were included in mainstream provision (DfE, 2012). Yet in the UK, we still have a divided and segregated system in which there has been a recent growth in the number of special schools (DfE, 2012).

Others including Lewis and Norwich (2005) and Oliver and Barnes (2010) argued that an inclusive society must cover the education system and that resources should be properly allocated to mainstream schools to enable them to remove the barriers to learning more effectively than has been the case. Lewis and Norwich (2005) argue that teaching strategies considered to be effective for children with special educational needs also work with many other children and they identified strategies on a continuum from low to high intensity rather than different approaches for different needs. Special schools are also now geographically dispersed, due to closures in the 1990s, so those attending are likely to be physically located at some distance from their local communities for their education and thus even more socially excluded. Some large international surveys did suggest that segregated schooling could lead to more difficulties with social interaction and community inclusion as an adult (Hegarty, 1993; Kitchin, 2000).

Tomlinson argues that while special education is 'permeated by an ideology of benevolent humanitarianism' it was also a 'social categorisation of weaker social groups' (Tomlinson, 1982, p5). She also suggests that special schools are a way of treating children unequally and yet, are assumed to be 'doing good' to the children. In a society and education system that values academic achievement as a route to success, to be 'categorised out of 'normal' education represents the ultimate in non-achievement in terms of ordinary educational goals' (Tomlinson, 1982, p6). Considering that Tomlinson was writing this in 1982 soon after the Warnock Report (1978) was published, her critique makes powerful reading and forces us to consider whether the educational landscape has changed very much since then.

G. Thomas and Loxley (2007) argue strongly for the reorganising of special and mainstream schools in order to effect true inclusion. They state that the proliferation of



special schools (at least until the 1980s) led to a perception of specialised knowledge that only special school teachers had and that mainstream teachers now think that they are not skilled enough to teach 'special children',

The legacy that 100 years of special education has given to teachers is the idea that this [teacher attributes] isn't enough; that you need all sorts of special procedures and qualifications to help you understand them and all sorts of special techniques before you can make any sort of a job of helping them.(p27)

They argue that inclusion is about much more than the integration of children with special needs into mainstream schools and that all children with all their differences and individualities should be 'valued equally, treated with respect and provided with real opportunities at school' (ibid, p124). They define inclusion as being 'about comprehensive education, equality and collective belonging' (ibid, p124) and that inclusive education should diminish differences rather than exacerbate or exaggerate them. This is a broader understanding of inclusion that offers a framework within which all learners can be catered for, not least those with varying manifestations of autism and learning difficulties.

Developing inclusive practice in schools depends on working towards an understanding or a definition yet definitions of inclusive education are contested and elusive, with no consensus within countries let alone globally. Ainscow and Miles (2008) define inclusion as a set of principles which, they argue, should constantly energise and guide schools towards inclusion:

- (a) inclusion is concerned with all children and young people in schools;
- (b) it is focused on presence, participation and achievement;
- (c) inclusion and exclusion are linked together, such that inclusion involves the active combating of exclusion; and
- (d) inclusion is seen as a never-ending process (Ainscow and Miles, 2008, p20)

This ongoing sense of *working towards a state of inclusion* rather than implementing various policies or strategies in order to achieve full inclusion resonates strongly with the conceptualisation of inclusive education that informs my own professional practice as an educator, as well as the theoretical framing of this thesis. Ensuring that all students are included, that they all participate, that they all achieve and that their contributions are valued are pivotal to my understanding and interpretation of inclusive education.

A case study of a school in Stockport is put forward by Morewood et al. (2011) where the challenge of including pupils with ASC in mainstream provision is acknowledged

but, the paper argues, children can thrive in the right setting with the right inclusive ethos. A 'saturation' model is outlined whereby the whole school is involved in continuing professional development in the understanding and awareness of autistic spectrum conditions. A positive learning ethos, flexible provision, use of visual communication, peer education and awareness and direct support and intervention are all given as prerequisites for inclusion in this school to be truly effective. In particular, flexible and personalised provision – including dual placement at special school where necessary – is seen as key to ensuring that individual needs are met on a daily basis rather than sticking to one plan over the whole school career. They also stress the commitment required by all staff at all levels: 'this commitment, if it is to be sustainable and truly 'inclusive', must saturate all areas of school life and practice, and work in conjunction with more traditional models of support' (Morewood et al., 2011, p67).

Alderson and Goodey (1999) questioned educational policies and practice in relation to children on the autistic spectrum in their study of pupils in specialist and inclusive primary schools. Their findings suggested that educating children with autism in specialist settings needed to be challenged as it could not only disadvantage them socially but even exacerbate some of their repetitive and withdrawn behaviours, 'autistic tendencies of isolation and self-absorption are more noticeable in the segregating education system itself, which appears to project and enforce these characteristics on to the pupils we observed' (Alderson and Goodey 1999, p260). Their study of an autism unit seemed to exemplify particularly unacceptable teaching practice and did not resonate with some of the good practice identified by Ofsted (2010). The poor practice observed in the unit was then contrasted with a primary school exhibiting seemingly exemplary inclusion practice. In terms of pedagogy, there are some teaching strategies, which have been adopted by autism specialist schools that seem to work for many children on the spectrum. These include: highly structured, brief teaching sessions (according to the TEACCH<sup>1</sup> method); applied behavioural analysis (ABA); a 'total communication environment', including augmentative and alternative communication (AAC); intensive interaction and social stories (Farrell, 2006)

Holt, Lea and Bowlby (2012) researched specialist autism units within mainstream schools and talked about them as 'normalising spaces' where children could choose to go and learn about social skills and appropriate behaviour. Their findings were mixed in

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<sup>1</sup> The TEACCH method was developed by the University of North Carolina and stands for the Treatment and Education of Autistic and Communication-Handicapped Children.

that they saw them as containers for the ‘abnormally behaving’ and that children were sometimes ‘sent’ to the unit if their behaviour became too challenging. However, they also found the units helpful as places where children with ASC could be more relaxed, could benefit from specialist staff to help them and could learn about social interaction. The units themselves were also seen as having powerful potential to transform the social norms of the school,

Despite some critiques of special units (Holt, 2004), they can act as sites of specialist knowledge and safety for young people on the AS [sic], and as a launching pad to reproduce more inclusionary social and communicative norms. (Holt et al. 2012, p2203)

Inclusive education then is still under construction in mainstream schools, where approaches to best practice have been identified (Lewis and Norwich, 2005; Humphrey and Lewis, 2008; Guldberg, 2010) and yet, still appear to be problematic in practice (Dyson, 2002; Ravet, 2011; Chown and Beavan, 2012; Lawson et al., 2013).

Underlying the examples of good practice are principles of sharing a common philosophy about inclusion, using peer group approaches to learning and respecting all learners and their differences within the learning community (Nind and Wearmouth, 2006; Morewood et al., 2011). Notions of belonging to a school community, accessing equal opportunities and being valued all inform the understanding of inclusive education used in this thesis.

### 3.3.3 Special education

While educational inclusion may philosophically be seen as the ultimate answer to the end of segregation and oppressive practices and the only way forward for a rights-based approach to disability, it is not necessarily universally conceived as the right answer for every child. Hedge and Mackenzie for example, examine the usefulness of capability theory for understanding the educational experiences of two children with different impairments and conclude that, ‘Universal inclusion will not represent a good ethical choice if it fails to afford justice and dignity to, and respect for, each and every child’ (Hedge and Mackenzie, 2012, p340). Similarly, it would be foolish to place a child in an educational setting that was not conducive to their positive sense of well-being if it were just for the philosophical point of human rights and they use the American phrase of ‘least restrictive environment’ to qualify this claim,

With inclusion aimed at justice and equality, educating pupils in the ‘least restrictive environment’ looks like a good target if it means choosing the place of learning and care that would be most conducive to a pupil’s cognitive, social and

emotional development, well-being and dignity. (Hedge and Mackenzie, 2012, p340)

Farrell's book, 'Celebrating the Special School' takes the approach that schools should primarily be about education and not just about inclusion, 'the danger is that inclusion will come to be seen as more central to the work of schools than education' (Farrell 2006, p2). Equally children with a particular type of special need might be better in an inclusive setting and others with a different impairment in a specialist setting. He also promotes increased collaboration between special and mainstream schools but urges us to question inclusion as it could be at the expense of an appropriate educational setting, which concurs with Hedge and Mackenzie's argument.

This concern was echoed by Mittler (2000) who wrote, in contradiction to Thomas, G. and Loxley's (2007) view, that while teachers approved of inclusion, they did not necessarily feel equipped or trained with the necessary skills to enable children with more complex needs to access the curriculum. Others argued that not enough resource was diverted to mainstream schools in order to properly address the demands of inclusion, that teachers were not sufficiently trained and that inclusion was not working for everyone (Macbeath et al., 2005). It is also pertinent to remember that these same teachers have not been brought up in an inclusive education system or indeed particularly inclusive society so it is not surprising that they cannot readily conceive what full inclusion should 'look like'.

It is also obviously pertinent to consider the views of other stakeholders in inclusive and special education, parents and children in particular. Rogers consulted parents on their experiences of having their children with SEND included in mainstream schools and decided that 'inclusive policies and directives are in direct conflict with how some parents experience this education process. No parent that I interviewed had a positive experience of mainstream education' (Rogers, 2007, p66). She concluded her article with suggesting that the discourse should not be about inclusion or exclusion but about the best education for all children and that school placement played a part in this. However, further attention needs to be given to social inclusion and developing community education sites if mainstream schools are to change (Rogers, 2007; Thomas, G. 2013). Poet et al. (2011) consulted both parents and children with complex needs about their experiences of being in residential special schools. Parents praised the schools and valued the ways in which their children were supported to develop their independent skills and access a broad range of opportunities outside school.

Wing (2007) was positive in her response to the Warnock pamphlet on special educational needs (Warnock and Norwich, 2005) agreeing that 'special schools are needed and will continue to be needed for many, though not all, children with autistic spectrum disorders' (Warnock and Norwich, 2005, p32). Both Wing, Warnock and others including Moore (2004) and Farrell (2006) argue that children on the autistic spectrum face particular challenges in mainstream schools due to their need for routine, predictability and low sensory stimulation, much of which is often at odds with the busy and vibrant atmosphere of a typical mainstream secondary school environment. Wing goes further and implies that the placement of a child with classic autism in such a mainstream environment could be very frightening and disorientating, 'it is reasonable to ask why one should put a vulnerable child through the ordeal of mainstream schooling, making their anxiety and social isolation much worse, because of the theories of idealists who have no knowledge of or empathy for children with autism' (Wing 2007, p28). This dilemma in respect to segregation is not yet resolved and while philosophically there is some agreement about the rights argument for all children to access mainstream education, in practice, mainstream education is not yet fully inclusive and able to accommodate all pupils. The biggest barrier to inclusion seems to be a lack of understanding from staff (Jordan, 2011) although, I would add, the wider student community might be implicated too.

Charlotte Moore, a parent of two children with severe autism, considers that a 'blanket policy in favour of inclusion in mainstream schools is harmful. At best it is misguided, at worst it is an immoral and ineffectual cost-cutting exercise' (Moore 2007, p34). She argues that while mainstream may suit some children with autism, autism is essentially a social interaction impairment that is not ameliorated by access to the curriculum through mainstream provision. Indeed the environment of a mainstream school with busy corridors, bright lights, colourful displays and lots of noise could be diametrically opposed to the needs and well-being of a child with autism. This also supports the idea of diversity among children with autism and endorses the ontological reality of the differences in their conditions. Moore (2007) also suggests that the likelihood of being bullied is also very high for a child with autism who may be often on their own, who might exhibit 'different' behaviours and who might not think of telling an adult because they did not understand what was happening to them. Adapting the learning environment to suit learners with autism is not a straightforward task and may directly challenge the needs of non-autistic learners (Moore, 2007). Similarly, Jordan (2008) suggested that 'forced integration' was a retrograde step and only set back our expectations and experiences of inclusive education. She argued that pupils with

autism could be educated in mainstream schools if the work was sufficiently differentiated, if there was an understanding of ASC and if teachers and schools were prepared to be flexible. She suggested that even those with severe and complex difficulties could be educated alongside their peers although they would need specialist support and a safe 'haven' to escape to. Jordan acknowledges a continuing role for special schools as centres of excellence and innovation in that they could support inclusion, as opposed to the current system, where special schools tend to pick up those who fail in mainstream. In a sense they are servicing mainstream education and perpetuating a segregated system (Jordan, 2008).

### 3.3.4 How included are young people with autism in FE?

Many young people leaving special school do now progress on to further education courses (Breakey, 2006; Chown and Beavan, 2012) and yet their experience can still be very segregated and separate from the mainstream life of the college (Mitchell, 1999). If we are to seriously embrace social inclusion, there is much work to be done in colleges to help prepare this group of learners for their adult life to ensure that they are enabled to fully participate 'with knowledgeable support there can be an improved prognosis for persons with autism, however, such support is considered to be rarity in further education at present' (Chown and Beavan, 2012, p477). Breakey (2006, p21) cautions that those with more complex needs, who are being increasingly placed within FE colleges, may be 'effectively segregated within what is seen as an inclusive environment'. She, more specifically argues that reasonable adjustments have to be made for those on the autism spectrum, in terms of careful preparation for transition to college, in order to redress the balance between them and their non-autistic peers, 'many autistic students fail to access FE because of the lack of such provision,' (ibid, p19).

McConkey and Smyth (2001) talked to over thirty parents and students with severe learning difficulties about their experience of post-school transition. Most of the students went on to FE colleges and reflected very positively on their experience citing factors such as making friends, using computers, visiting the city and having new teachers as the things that they liked most about college. Almost all the young people (91%) had aspirations of having a job when they left college although their parents were not so optimistic. Parents' reflections on schooling were largely positive generally because of the informal curriculum that encouraged independence and any dissatisfaction usually related to their children not being pushed enough academically. While some parents believed that mainstream education would have been better for

social interaction most felt special schools suited their child's needs better. The research reported that parents rarely mentioned qualifications, and yet school performance is always graded on this. Parents were undecided on whether mainstream or special school was the best way of promoting inclusion and society's acceptance of their children. It just seemed to be an either/or decision regarding a mainstream, but not really inclusive school, or special school environment (McConkey and Smyth, 2001).

### 3.3.5 Which learning environment is most appropriate?

My research addresses the divide between special and mainstream education, as the young people in the study are leavers from special schools going on to mainstream colleges. It becomes apparent that current mainstream education provision is not yet fully meeting the needs of learners with autism, and while inclusion as philosophical ideal may be hard to argue with, if this is not enacted in school, it can make children with autism feel even more excluded and isolated than if they were in a specialist, segregated setting. According to Humphrey and Lewis's analysis of the experiences of children with autism in four mainstream secondary schools, 'the gap between 'inclusion rhetoric' and 'classroom reality' was very wide in some schools' (Humphrey and Lewis, 2008, p138).

We now have a system where 'inclusion' is still emphasised in policy but with an acknowledgement that some children with more severe learning difficulties, albeit defined by slightly arbitrary thresholds, might need specialist educational provision and indeed the new legislation aims to 'remove the bias towards inclusion' (DfE, 2011, p5). Mary Warnock now describes her original (DES, 1978) proposals on inclusion as 'a disastrous legacy', stating that it was a mistake to have supposed that all children could be educated 'under the same roof' and that disabled children had suffered as a result of this, she has more recently called for special school provision to be maintained (Warnock and Norwich, 2005). It also may be the case that inclusion needs more time and more resources in order to be effectively realised. Ainscow and Miles (2008) argued that inclusion is an ongoing process and that the state of perfect inclusion is never reached, as a school should always be adapting and changing according to the diversity of its students.

However, there are others who argue for a more moderate approach to inclusion, or a 'needs-based' approach where a 'mixed economy' of schools is preserved until more progress is made with inclusion in mainstream schools (Low, 2007). Ravet (2011)

identified these contradictory positions on inclusion and autism distinguishing between the rights-based and the needs-based perspectives; the former argues for an end to all educational segregation in order to become a fully inclusive society and the latter advocating special schooling for some groups, arguing that there is a lack of clear evidence to support mainstreaming for all pupils. Ravet's way through this dichotomy was to suggest an 'integrative' perspective where all mainstream teachers are trained in autism-specific pedagogies (which is distinct from a 'special' or 'common to all' pedagogy) and that all mainstream schools need to adapt to become autism-friendly. This would seem to concur with G. Thomas and Loxley's argument (2007), suggesting that teachers need to feel empowered to teach all children, while Ravet acknowledges the need for additional autism-specific training. She also adopts a more integrative approach away from 'inclusive versus exclusive' debates. This can embrace the complexity of determining appropriate educational perspectives, 'rather than privileging the voices that suit us best, our challenge is to listen, engage and negotiate multiple meanings to find a form of inclusion that can both meet learner needs and maximise inclusion' (Ravet 2011, p680).

It seems clear that current mainstream provision for children with autism and learning difficulties, despite limited examples of good practice, is not yet appropriately inclusive and therefore learners are not able to convert the resources of mainstream education into positive capabilities (Terzi, 2005; Hedge and Mackenzie, 2012). Exploring the participants' experiences of special school and mainstream college in this research are therefore going to be valuable in the light of these debates.

### **3.4 How does autism affect social interaction?**

Impairment of social communication and social interaction are two of the three key elements in the autism triad required for diagnosis (Wing, 1996). It is likely then that young people with autism may encounter difficulties in forming and sustaining friendships, interacting with others in social settings and understanding social conventions (NAS, 2013). Many people with autism have now written and spoken about their experiences of social interaction and about the difficulties they have come across and have perhaps given us a new language with which to understand autism (Hacking, 2009). Their thoughts on social interaction are particularly relevant to my research in privileging autistic viewpoints and offer suggestions about how people with



autism may experience the social world and, not surprisingly, they argue from the different perspectives of their own versions of autism.

Grandin (2012) wrote specifically about some of the unique talents and achievements of people with autism, despite or even because of their specific learning differences. In terms of social interaction, some people with autism can appear to be withdrawn, aloof or 'in their own worlds', often avoiding eye contact and this would certainly fit with a commonly held perception of autism, categorised as 'classic autism' by Wing (1996) and Kanner (1943). However, people with autism can also be very sociable, sometimes 'over-sociable' or socially awkward and lacking a social understanding (Jordan and Jones, 1999).

Blackburn (2013), for example, is adamant that you cannot be autistic if you are at all interested in the social as this does not fit with her own experience of autism. On the other hand, Higashida, a young man with severe autism and no speech (but had the capacity to point to letters on a grid) claimed that people with autism do not want to be left on their own rather that it is people without autism who find it too difficult to deal with them and therefore leave them alone, 'I can't believe that anyone born human wants to be left all on their own, not really...the truth is we'd love to be with other people' (Higashida and Mitchell, 2013, p47). Others, like Grandin suggest that there is interest in, and reaction to, the social, 'to say that an autistic child has absolutely no response to people is a misconception' (Grandin and Scariano, 2005, p11). But Grandin also writes that her communications with people were problematic and often came across as abrupt and rude. Similarly, Williams has recounted that she often reacted badly in social situations trying to befriend someone by repeatedly swearing at them, as she did not know how to form friendships. She talked about not knowing how to make friends with children and wanting to participate but 'never in the right ways' (Williams, 1992, p28). Jackson explains from his perspective as a young man with autism how he finds social interaction confusing and how it is hard to tell how other people are reacting,

I am always being told off for standing too close to people or for following them around all the time but it is difficult to know when it is right to follow someone around and carry on talking and when the conversation has ended and I am to leave them alone. I will never be able to tell if someone is bored unless they tell me, and even then I have to admit that I sometimes carry on talking if it is about my favourite topic. It is easy know things in theory but not so easy to carry them out. (Jackson 2002, p164)

What becomes clear from these accounts is that people with autism struggled with friendships as they were growing up and were aware of their difficulties in interacting with others from quite an early age. Despite being aware of their differences they did not know how to participate effectively in the social world but this did not mean that they did not want social interaction.

### 3.4.1 Difficulties with social interaction

To what extent people with autism are motivated by social interaction is an interesting point and as yet not widely researched. Chevallier et al. (2012) explored a 'social motivation theory' of autism that brought together different areas of research across biology, neuroscience and psychology and suggested that autism was an 'extreme case of diminished social motivation' (p231). They argued that interest in the social and the maintenance of friendships was not sought out by children with ASC and that they had impaired attention to social stimuli evidenced in their findings but also supported by biology and neuroscience. In other words, social motivation theory is predicated on the idea that children with ASC lack the intrinsic desire to interact with others. Deckers et al. (2014) tried to examine whether there was an inherent *desire* for social interaction among children with ASC. They reported fewer friendships and lower friendship quality among children with autism than in the general population although a fraction was able to maintain friendships. In their experiments, which included self-reporting questionnaires and an 'approach-avoidance' screen-based task, they found a lower desire for social interaction on the questionnaire but a higher tendency to approach social stimuli on the computer-based task (Deckers et al., 2014). While these psychological studies seek to quantify responses to stimuli in a controlled environment, they do not always access the more nuanced understandings of how desire for social interaction might be made manifest.

Research indicates that people with autism find it hard to interpret body language, facial expression and mood so they have to learn about all these potential meanings in an explicit way as they just do not possess that innate social knowledge (Plimley and Bowen, 2007); they have to work out social cues by thinking them through cognitively (Jordan, 2011). This leads us to a dilemma about social skills, and whether people with autism need some form of social skills 'training' or whether the responsibility for adapting to different social needs rests solely with education and the social world. Schools create opportunities to learn from peers, participate in a social world and thereby develop understanding but are these opportunities accessible for children with autism? Jordan (2011) concludes that if children can interact happily with their peers

then all three areas of deficit are improved and believes that both cognitive and social aspects of learning should be covered in school curricula.

Small et al. (2013) found that most of the young people with intellectual disabilities (some of whom had autism) in their research had limited social networks, that they seldom accessed leisure activities and those at special school made it more difficult to socialise locally. Many, however, expressed a desire to socialise with friends after school hours, 'in this study, it is evident that young people with intellectual disabilities have limited social networks, limited involvement in mainstream activities and limited interaction with nondisabled peers' (Small et al., 2013, p297). The significance of friendships was not given much attention during transition planning (Ward et al. 2003; Small et al., 2013).

Many people with autism have been able to articulate their differences from non-autistic people in the realm of social understanding. Jackson (2002), for example, explains that he does not 'get' the unwritten rules of social codes and conventions and yet, it is not straightforward for people with autism to acquire these social skills. Just exposing children with autism to social situations in the hope they will develop social skills is unlikely to be productive as they simply do not assimilate learning in that way (Jordan and Jones, 1999). There are specific challenges then for young people with autism in that they have been diagnosed with a social communication disorder which potentially puts them at odds with a predominantly social world (Breakey, 2006).

#### **3.4.2 Bullying and social vulnerability**

Bullying can be an issue for children and young people with autism, firstly because they may not realise that they are being bullied as people are not likely to clearly state that they are bullying you; secondly because their impaired social skills can make them more vulnerable (McLaughlin et al., 2010; Fisher et al., 2013) and thirdly as they may not think it necessary to let anyone know given the potential lack of theory of mind (Moore, 2004). Fisher et al (2013) reported that young people with autism and an additional learning difficulty experienced higher rates of victimisation. They also reported that the lack of friends and likely dependence on parents were contributory factors, 'We found that the presence of an intellectual disability, the absence of friends, and more independence were all related to increased social vulnerability for individuals with disabilities' (Fisher et al., 2013). Similarly, social skills difficulties were also more likely to lead to peer victimisation or rejection and to increased instances of bullying (McLaughlin et al., 2012). However, much of the research in this area locates the

problem or the deficit or difficulty within the child rather than considering the broader social factors at play (McLaughlin et al., 2012).

### 3.4.3 Online social interaction

The explosion in online social networking among teenagers and young people has included those with autism and there are some early investigations into the role that social media might have in facilitating friendships among this group. In particular, the opportunities it affords in terms of easing pressure on social interactions, allowing some control over communication and giving time for reflection (Mazurek, 2013). It also allows the participant to communicate from a place in which they feel comfortable rather than in a potentially noisy or crowded social space (Byrne, 2013). Byrne's question was whether online social networking translated into improved communication skills or a wider social network in real life and in this, the results were inconclusive. In Byrne's report for Scottish Autism there were difficulties encountered with cyber-bullying (not always as the victims), being blocked suddenly by 'friends', some cases of obsessive internet use and also people with ASC being prone to various forms of deception on line. Mazurek's study claims to be the first research to explore social media use among adults with ASC and found that individuals with ASC did use social networking 'primarily for social engagement and connection' (Mazurek, 2013, p1711) as well as for gaming and shared interests. Almost 80% reported using social networking sites and the average number of online friends reported was 210, both statistics broadly mirroring the general population fairly closely. Some participants reported on the fact that they liked social media because they could connect with others without needing small talk, found it to be a comfortable way of communicating or could maintain a level of detachment. However, there did not seem to be a correlation between the number of online friends and an increased off line friendship network so there may be limits to the social skills benefits of online social networking (Mazurek, 2013).

Seale's (2014) concept of positive risk-taking in relation to adolescents with special needs and their use of technologies is useful here in that it considers balancing risk with opportunity. This is particularly pertinent in relation to the potential opportunities of social media and technology to transform the lives of people with learning difficulties and yet, Seale argues, this potential can be somewhat limited by the over-mediation and control sometimes exerted by supporters and caregivers. Therefore, using a positive risk-taking framework and a shared approach to understanding risk, the beneficial opportunities presented by social media and technology might be more

effectively realised (Seale, 2014).

### 3.5 How do we adapt the social environment?

Children with autism and learning difficulties are likely to be among those who are the most challenged in terms of making friends and understanding social norms and yet can be doubly disadvantaged by being placed in special schools. Being segregated in this way, they are further removed from the very communities in which they need to play a part, if they are to succeed in 'mainstream' adult life. This can have negative effects on their lives as it does not prepare them for life beyond school, reinforces attitudes that disabled people are different and separates children from their peer groups (Kitchin, 2000). Indeed Kitchin went further to say that if we build separate spaces for disabled people then we do not have to accommodate or adapt spaces for them in mainstream life. When these young people do emerge into adulthood and into mainstream spaces, how do we adapt the social environment to address the social needs of young people with autism and learning difficulties?

The explicit teaching of social skills is advocated by some professionals as a way to improve social interactions: to identify and address the 'deficit'. However, one counter argument is that people with autism do not necessarily learn in that way (Williams, 1992; Jordan and Jones, 1999; Jackson, 2002) and cannot adapt their learning to new social situations. A meta-analysis of a range of social skills interventions has concluded that these are minimally effective for children with ASC (Bellini et al., 2007). From another perspective, some people with autism argue against social skills training in that it presupposes social norms and that these are culturally constructed and therefore negotiable and flexible, not fixed (Breakey, 2006; Milton et al., 2012).

Concepts of risk and resilience have been seen as a potentially useful framework in which to understand and make adjustment to the social experiences of young people with learning difficulties (Dyson et al., 2002; Seale et al., 2013). Resilience can be defined as 'a class of phenomena characterised by good outcomes in spite of serious threats to adaptation or development' (Masten, 2001, p228). Knowing that the experience of transition, even in the smallest of activities on a daily basis (Jordan and Jones, 1999; Plimley and Bowen, 2006; Hume, 2008), can pose challenges for children with autism, the bigger transition of moving from one educational environment to another in the midst of adolescence becomes a 'serious threat to adaptation or development' (Masten, 2001, p228).

Difficulties with social interaction appear to identify young people with autism and learning difficulties as a more vulnerable group, than their contemporaries, to dealing with adversity in their lives (Morrison and Cosden, 1997; Mather and Ofiesh, 2005; Evans and Plumridge, 2007). The identification of negative peer relations or limited social networks has been identified repeatedly as a risk factor by many researchers in the resilience field (Morrison and Cosden, 1997; Mather and Ofiesh, 2005; Luthar, 2006; Evans and Plumridge, 2007). Mather and Ofiesh see this as a real risk factor for people with learning difficulties as 'students who lack the ability to create and maintain relationships tend to lose the support network needed to resolve life's challenges and crises' (Mather and Ofiesh, 2005, p244). Researchers also reported that young people with learning disabilities were an 'ability-stigmatised group' (Mather and Ofiesh, 2005, p240) and argue that failures at school and constant comparisons with peers lead to low self-esteem, 'clearly, negative teacher and peer feedback contribute to feelings of low self-worth' (Mather and Ofiesh, 2005, p243). Similarly, Luthar (2006) summarised, in his synthesis of research across five decades, that two key protective factors kept recurring: cognitive functioning and positive relationships, both of which have implications for young people with autism and learning difficulties. It is argued though that the challenges presented by cognitive impairment can be tempered by individual characteristics, 'the presence of a learning disability is, in itself, a risk factor; however, there are wide variations in the emotional and social adaptation of individuals with learning disabilities' (Morrison and Cosden, 1997, p45).

While young people with autism can be constructed as vulnerable and at-risk in social environments due to their inherent difficulties, equally they can be constructed as powerful and able to develop resilience in the face of difficult situations (Goodley, 2005). Goodley referred to resilience in relation to self-advocacy and argued that it is contextualised and relational rather than located within the individual with learning difficulties, 'resilience is not an individual attribute but a product of the contexts in which it can emerge' (Goodley, 2005, p334). He also saw resilience as optimistic (similarly to Masten, 2001, who called it 'ordinary magic') and acknowledged the capacity of people (with learning difficulties) to resist oppression. Again, a critical realist approach is helpful here to consider both individual agency and structural factors influencing social inclusion and developing resilient strategies.

The research carried out by Evans and Plumridge (2007) is particularly relevant here because of its focus on inclusion and the importance of social networks to disabled children and their families. They refer to protective factors in relation to child resilience

in particular and highlight: attributes of the children themselves, characteristics of their families and their opportunities to engage in social life (Evans and Plumridge, 2007). They examined the different programmes in terms of their inclusive practices, integration and building family networks. All the programmes did seem to build protective factors in relation to resilience 'increasing their confidence, enabling them to develop social and independence skills and social networks with their peers.' (Evans and Plumridge, 2007, p235). Parents particularly valued the provision of integrated activities as they had little opportunity to meet up outside school 'disabled children often had to travel a considerable distance from home to attend a special school...and therefore had little opportunity to meet other children living in their locality' (Evans and Plumridge, 2007, p236). They concluded that more needed to be done to address and remove the disabling barriers at the wider community level of these projects in order to improve and sustain effective social inclusion for these children and their families.

This draws attention to the additional provision that may need to be made for young people with autism in transition in order to address their social interaction needs. If the focus on social inclusion is addressed through integrated activities and inclusive provision, these experiences can be turned into protective factors that would build resilience as these children grow up and make transitions towards their adult lives. A risk and resilience approach to reframe transition experiences, for example, was advocated by Dyson et al. by focusing 'attention away from the neediness of young people and the adversities with which they are surrounded, towards whatever it is both in themselves and in their environments which might allow them to overcome adversity' (Dyson et al., 2002, p14).

The literature on resilience offers an interesting insight into how we might view the experiences of young people with autism and learning difficulties going through transition. Their risk factors are potentially higher in their social interaction challenges, their cognitive impairments and their need for predictability and stability and these ideas around resilience could be helpful in supporting young people and their families in transition planning. However, the resilience approach is not wholly unproblematic, particularly for people with autism, as it does tend to assume that learning can be transferred from one context to another; that learning in social contexts is straightforward and that social networks can be readily developed (Plimley and Bowen, 2007). Adapting the resilience approach for young people with autism would clearly be necessary and would require imaginative and creative development to fully address the needs of this group. It is interesting to note that the research literature on autism and

resilience there is very little about young people with autism themselves (Hill et al., 2007), the focus is more on the resilience of families, or parents, or siblings.

### 3.6 Problematising transition

Transition can be defined in many ways so it is useful to clarify the boundaries within which I am defining transition in this research. While transition to adulthood in its wider sense can be identified through changing roles (child to adult, student to employee etcetera), Arnett's (1997) exploration of the meaning of the concept of transition for young people, revealed that most identified increased responsibility for oneself, making independent decisions and progressing towards financial independence as key factors they would associate with transition. McGinty and Fish (1992) talked about transition as both a phase and a process, both of which still resonate today,

- It is a phase or period of time between the teens and twenties, which is broken up educationally and administratively. During the phase there are changes of responsibility from child to adult services, from school to further and higher education and from childhood dependence to adult responsibility.
- It is a process by which the individual grows through adolescence to adulthood and achieves the balanced state of dependence and independence that a particular community expects of its adult members. (McGinty and Fish, 1992, p6)

Although writing over 20 years ago, the same structural changes apply in the movements of young people between adult and social care and from school to college and are still relevant today. Indeed they also defined some major transition issues that are only just beginning to be addressed in current legislation. They identified the importance of education, health and social care working together, of harnessing the contribution of parents, of acknowledging achievement outside academic subjects and ensuring that young people with learning difficulties and their families are put at the heart of transition planning.

My research focuses very specifically on one part of the bigger transition phase, that of the educational transition from school to college, moving from one very small, very specialist setting to a very big, very generalised institution. For disabled young people there could be additional barriers to making a successful transition as evidenced in the longitudinal study carried out by Polat (2001), Dewson et al., (2004) and Aston et al., (2005). As Morris summarised, 'transition to adulthood for young disabled people is both the same and different as it is for non-disabled young people' (Morris, 1991, p.24).



In special schools, both the curriculum and the learning are personalised to match the individual needs and abilities of the learner whereas colleges make accredited courses available to students according to different academic levels and groupings but have less capacity to adapt to individual learning needs (Chown and Beavan, 2012). The process of transition is much more complex for young people with autism and learning difficulties as the 'balanced state of dependence and independence' (McGinty and Fish, 1992, p6) is much more nuanced, person-specific and developmentally defined.

Aston et al.'s (2005) research into post-16 transitions for young people with special educational needs was a large longitudinal study of over 1000 young people in the years immediately after compulsory schooling. They concluded that there were four sets of factors important in determining outcomes of the transition process for young people with special educational needs leaving school and going to college: 'young people's capacities and characteristics; the purposefulness of familial support; the nature and effectiveness of local support systems and the range of local opportunities available to young people such as college courses, employment and training options' (Aston, 2005, xiii). This leads us to consider not only the external structures of educational and professional settings but also the individual agency and capability of the young person.

There was less literature that related specifically to young people with autism in transition and specifically in transition from special school to mainstream settings. Given that children and young people with ASC often find transition difficult even in everyday classroom transitions from one activity to another (Sterling-Turner and Jordan, 2007; Hume, 2008), it is not surprising that a major transition in educational setting and a move towards adulthood can cause great anxiety for them. Young people with autism can become very stressed and anxious moving from a structured school environment with which they are very familiar to a less structured, new, and in the case of colleges, much larger setting.

Dyson's (2002) case studies offered some insight into the transition experience of young people leaving special school and he concluded that the notion of transition is too short-sighted and focuses only on the immediate 'leaving school' part of the transition and yet, the young people in his research went on to experience many transitions from school to college, to work, to training schemes, to unemployment and beyond. Both Dyson (2002) and Mitchell (1999) argued that these fractured transitions

require more attention and support from professionals to limit the ‘turbulence’ experienced by young people (Dyson et al., 2002).

### 3.6.1 The importance of person-centred planning (PCP)

The process of transition planning attracts some attention in the literature as it typically cuts across education, health and social care (Mitchell, 1999; Ward et al., 2003; Beresford and Cavet, 2009; Small et al., 2013) and the importance of these services working together seems key (Ward et al., 2003; Dewson et al., 2004). Various messages for professionals were distilled from this research including improved multi-agency working, improving the format of meetings to ensure that all can participate as well as supporting parents during a period of stress and uncertainty for them too.

Small et al., (2013) investigated the person-centred transition planning processes in place for young people with intellectual disabilities and concluded that they were not working effectively and were failing to shape service provision. By using Bronfenbrenner's (1979) ecological model as an alternative approach to transition planning, they argued that it allowed them to put the young person at the centre and identify their social and educational networks as well as acknowledging the interactions between the young person and their different environments or ‘systems’. For example, the family and the school were found to be right at the heart of the young person’s ecological systems, as their ‘mesosystem’ but as they were leaving school, these relationships would shift and the young person would be thrown back on their own vulnerable ‘microsystem’. Small et al., argued that the disruption in moving from school to college is huge in that, apart from family, school is the only real social network that young people at special school have at this age that the transition process has to take account of this and ensure that the ‘exosystems’, like work and leisure, are more connected to the central experience of the young person. Plimley and Bowen also argued for early planning for transition, a multi-agency approach and more support for learners with autism in making decisions about college options as they ‘will have the combination of fewer social links, be more emotionally immature and less experienced in ‘knowing the ropes’ to help them decide’ (Plimley and Bowen, 2006, p56).

Ward et al., (2003) talked to parents of young people with learning disabilities about their expectations of transition planning and found a stark mismatch between what parents wanted to find out about including: leisure and social opportunities, housing and benefits information; transfer to adult social services and transport to post-school provision, and the typical topics discussed including: FE options, independent living

skills, relationships, employment opportunities and self-advocacy (Ward et al., 2003, p134). While two-thirds of the parents in the study did feel involved in the transition planning process at its inception in school, they felt that this engagement dropped off as the process continued into college.

Hendricks and Wehman reviewed the research into transition for young people with autism into college, work and adult life in the United States and concluded that person-centred planning had been 'greatly overlooked' (Hendricks and Wehman, 2009, p83). Young people with autism also needed to be prepared for all aspects of adult life and their transition goals should address communication skills and social skills in the community, at home and at work. In the UK, while the discourse of PCP is in common currency, the true enactment of it in transition planning seemed less evident and PCP as policy prescription did not necessarily lead to improved transition outcomes (Mansell and Beadle-Brown, 2004).

Personalising the transition planning process seemed to recur as an issue in the research literature in that young people and parents were not necessarily being listened to and their needs in transition were not taken in to account. Research with young people with 'high functioning' autism or Asperger's syndrome who were just leaving or had just left school carried out by Mitchell and Beresford (2014) identified that young people with ASC needed support in their decision-making. They also needed access to administrative and emotional support as well as college visits and taster days; they particularly wanted practitioners to have an understanding of ASC as a condition. The young people also expressed their concerns about the social demands of college and yet none reported having received any social skills support from a practitioner (Mitchell and Beresford, 2014).

Time and the ability to manage time have also been found to be problematic for young people with autism who often respond positively to timetables and proscribed activities. Orsmond and Kuo (2011) investigated how adolescents with autism managed their own time, as there is very little previous research on this. They concluded that they spent most of their time alone or with their parents and less time engaged in social activities than typically developing adolescents. It varied according to their autism and any co-morbidities such as learning difficulties which meant that those with more severe learning difficulties spent more time alone and with their parents (Orsmond and Kuo, 2011). Interestingly one of the students in Howlin's study was given a timetable

without any free lessons but given something to do in each of the free periods – even if it was a walk around the grounds (Howlin, 1997).

### 3.6.2 Adapting the college environment

Mitchell's research in 1999 investigated the experience of young people with learning difficulties leaving special school. She found that although these young people were moving from special school into a more adult mainstream environment at college, the ways in which their courses were organised and structured meant that they were still segregated within college, 'the young people frequently remain a 'special' group, socialising within a very specific and segregated populations similarly labelled 'special educational needs' (Mitchell 1999, p757). Opportunities for social inclusion and social interaction were therefore missed during link courses but also on arrival at college.

Breakey (2006) identified transition as a period during which reasonable adjustments can be made by a college to adapt to the specific needs of the learner with autism. She suggested various factors be put in place for the transition to college including: time in the early weeks for the learner to adjust to their new environment, an identified transition support person, a specified time period for transition so that it could be reviewed, flexible arrangements for changes to be made and regular communication with parents or carers. Additionally, there appears to be a certain antipathy for learners with autism towards the introduction of anything new, 'the consequence is that almost all new situations are likely to give rise to a negative response at first, and that the child or young person will need time to adjust to new situations before they can be expected to learn in them.' (Jordan, 2011, p370).

Adapting the learning environment to suit learners with autism is not straightforward and may directly challenge the needs of learners without autism, or indeed other learners with autism who have different needs (Moore, 2007) and this can be a complex, nuanced and intractable task that we do not yet fully understand. It could be for this reason that learners with autism encounter challenges in mainstream schools and why 'inclusive' education is not yet working as effectively for them as it might, those with higher functioning autism often meet academic expectations but not necessarily social ones and yet their difficulties in this area are not explicitly addressed (Humphrey and Lewis, 2008).

Even at college, Howlin reported that there were problems of teasing and bullying for students with autism, as they were being put in compromising situations and their

peers set out to exploit them. For example, one student was nominated for President of the Union because his speeches were outrageous and caused everyone to laugh; another, who was desperate for a girlfriend, was encouraged to follow girls into the toilets (Howlin, 1997).

### 3.6.3 Enabling progression

Elson (2011) carried out a case study on a large secondary special school to examine what the choices were for pupils leaving special school. Most of the pupils went on to mainstream college courses or SEN college courses but overall the range of courses available to them was very limited and tended to assume SEN pupils were a homogenous group; colleges tended to duplicate or repeat what had been already studied at school and progression to the next level was problematic because of the young person's learning difficulties. Elson concluded that the range of provision was often limited for those with more significant learning difficulties and for those with ASC and that there were huge inconsistencies in the range and quality of FE provision. Dyson et al., (2002) make the distinction between transition and progression arguing that while transition planning meetings bring together parents, professionals and young people to construct a formal plan, 'this is, no doubt, a worthwhile activity, but it fatally confuses transition and progression' (Dyson et al., 2002, p10). The transition process is therefore not sustained but just focuses on the immediate movement from school to college, training or work and does not look ahead to the bigger future. They argued that the young people in their research may have made smooth transitions but this did not lead to more advanced *progression*.

Carroll and Dockrell (2010) examined the social, academic and employment outcomes for a group of leavers from a residential special school with specific language impairments (SLI). While young people with SLI do not typically have cognitive impairments, their attainment profiles tend to be lower than their peers where their language difficulties continue into adolescence. These leavers attended both specialist college and mainstream college settings and half of them reported finding the work either 'fairly easy' or 'very easy'. 'One common experience for some of the participants was to repeat the same level of course in the first year out of school and then progress a level in the second year' (Carroll and Dockrell, 2010, p137). Interestingly, Howlin's study from 1997 found that young people with autism did not necessarily find courses that met their academic needs and conceptual understanding, 'all too frequently, students with autism who manage to find a place in college either become bored at the low level of teaching or frustrated by their lack of ability to cope with the more abstract

components of the course' (Howlin, 1997, p169). She found that the people in her study needed lots of preparation for going on to college and while some students might have excelled in some areas (e.g. practical mechanics) they might have found other areas more challenging (e.g. the writing of essays) and the curriculum needed to be adapted for them to be able to succeed.

In 2009, Cullen et al. investigated the role of the Connexions service in supporting young people in transition, their focus was specifically on those with speech and language impairments but they evaluated the work of the Connexions service and its potential. They found that personal advisers (or careers advisers) had very little training in SEND, so their ability and understanding in working with young people with special needs was limited. While Connexions had been intended to improve the transition support for vulnerable young people, in practice, the service delivery was very variable and some careers advisers only had limited knowledge of their client group and the range of opportunities beyond school for this group. It is perhaps not surprising then that young people were not always offered or placed on the most appropriate courses (Cullen et al., 2009).

#### 3.6.4 Acknowledging interdependence

A recurrent theme in the literature relates to the differing states of independence, adolescence, adulthood and dependency experienced by young people with autism and/or learning difficulties. Howlin's (1997) seminal longitudinal study of adult outcomes for people with autism highlighted these interdependent states that mark a contrast to non-autistic peers. Leaving the relatively supported world of school and going on to college was often daunting and stressful for the participants in Howlin's research when for most young people, it would be a time of growth towards independence,

For most students the social environment and the removal of parental restraints will actively foster personal development and greater maturity. For someone with autism these factors may significantly interfere with their ability to make progress. For them the transition will require much greater help and support (Howlin, 1997, p174).

Tensions between parental protection, student independence and vulnerability are also illustrated by Howlin. A student who had mild learning difficulties was going to do a course in the learning support unit at college because his parents felt that he would not cope initially with the social communication required at college. The admissions tutor however, was impressed by his knowledge at the interview and thought that the

parents were being overprotective by seeking to put him on a lower level course so they put him on a higher level. As his parents predicted, by the end of the first term, the student's anxiety levels were so high in having to deal with the unstructured world of college that he had to leave. Another vignette, about a female student who had been at special school shows how the pressure of hastening independence can cause real anxiety for the young person (Howlin, 1997, p176). The parents requested transport to college but the college said that she was capable of walking there, as she had no physical difficulties so they would not provide transport. The girl became so stressed about walking to college on her own that she started getting up earlier and earlier until she hardly went to bed at all and the parents had to keep her at home.

Many parents of children with autism will admit to being 'over-protective' but feel that they have little choice in the matter. Their concerns are not just for the possible physical danger to their children but the emotional trauma, and the widespread effects of this, which can result from inappropriate demands of the failure to meet the needs of a young adult with autism. Clearly, parents and children do need to move apart as time goes on, but few students with autism will have acquired the social competence of the level of independence required to survive when they first enter college. To expect them to be able to cope without support from their families is to deprive them of a vital back-up system, as well as college staff losing a valuable source of information. (Howlin et al., 2004, p177)

It is argued that we are perhaps making demands of people with autism that are potentially beyond their scope, 'students are given the rights and responsibilities of adults, which place increased social pressures on the student with ASD, both to take responsibility for their own studies and to cope with fellow students, who may be less controlled than at school' (Plimley and Bowen, 2006, p17). The move to a more adult environment is therefore likely to take more time and adjustment for those with social interaction difficulties and it is coupled with a time where they are deemed to be of adult status so that parents can no longer anticipate the same rights to information that they previously had about their child.

Dee (2006) also identified the importance of parent/carer involvement at transition but argued that it could be a very emotional time for them. Parents found it harder to articulate their aspirations for their children than to talk about their fears about independence and moving on to adulthood. (Dee, 2006) The reliance on parents at this crucial stage of progression into further education and adulthood, meant that parents would need to be supported in the transition with relevant information, timescales and opportunities made clear to them. To not involve parents and young people in this decision-making process about the future was both thoughtless and ultimately constituted a denial of human rights (Dee et al., 2006). According to Dewson et al.

(2004) and, later in the same longitudinal research, Aston et al. (2005), parents had continued to act as a major point of support for the young people at this stage of their lives and yet they were not always fully included or consulted in the transition process. In a very recent study of transition to college for young people with high-functioning autism and Asperger's syndrome, parents also emerged for this group, as the most significant, yet undervalued, source of support who often felt under-informed about preparing their child for college (Mitchell and Beresford, 2014).

Some researchers have acknowledged the tensions in over-emphasising the notion of independence as a key signifier of progression towards adulthood (Kittay, 2009) in that some children and adults will remain dependent all their lives (Watson, 2014). This is not to say that they would be utterly dependent for everything but it would be unrealistic to suppose that they could become totally independent and that states are constantly shifting and are in flux throughout disabled lives (Vorhaus, 2007). However, this interdependent relationship between carers and disabled people is not unreciprocated or without reward for the carer, as Kittay reminds us when she talks of mothering her profoundly disabled child,

It is perhaps self-delusional to say that I am as dependent on her as she is on me, but perhaps not. Others could take care of her and even love her – in fact I must think that she will continue to thrive with or without me. But without her, I would wither. (Kittay, 2000)

Similarly, Ryan and Runswick-Cole (2008) examined the ways in which mothers had been positioned within disability studies but also in relation to their own children. They reported that they were marginalised in different ways in particular as mothers who advocate the medical model through seeking diagnosis and support from services and potentially as oppressors of their own children in seeking to restrict their independence.

Small et al.'s research also identified the centrality of the family to the young people with intellectual disabilities in their research in the absence of broader social networks, 'their [young people with intellectual disabilities] reliance on carers reveals that interdependence is at the heart of their engagement with the world' (Small et al., 2013, p297).

### **3.7 The need for further research**

This chapter has summarised the available literature on autism, inclusive education, transition and resilience by way of identifying the background, context and current research in this area but it is clear that there is still a need for further research. Chown



and Beavan's review of the literature (2012) and research on students with autism in FE found little relating to learners with autism. Even so, their focus is more on Asperger's Syndrome and those capable of achieving academically, and how to deal with the difficulties they face in social settings, rather than the ASC learners with additional learning difficulties. They identify the need to look at the prevalence of autism in FE and barriers to access for learners with ASC.

Beresford and Cavet (2009), investigating the transition to adult services for people with disabilities identified that involving a young person in transition planning meaningfully was dependent on the level of impairment and learning difficulties but went on to say that, the direct involvement of young people with significant learning and behavioural needs in a research project would present challenges. 'Any such work will have to be innovative in finding ways to meaningfully include these young people' (Beresford and Cavet 2009, x).

The Autism Education Trust report also identified a need to consult with all young people with autism whatever their level of communication about their hopes for adult life as well as collecting systematic data on the long term outcomes for students (Wittemeyer et al., 2011). Sloper et al., (2011) also saw a need to follow young people in transition over time noting that 'research following young people over transition, including more in-depth research with young people, could help further define good practice' (Sloper et al. 2011, x).

Hughes et al., (2013) carried out a literature review on secondary school transition for children with special educational needs and concluded that there was limited literature in this area but that children were more likely to have difficulties with social adjustment, be more prone to bullying and have lower levels of social support than typically developing children. They also suggest that children with specific learning difficulties are likely to be more susceptible to low academic self-esteem alongside their typically developing peers. Overall, there is a dearth of literature relating to transition for children with special educational needs and they recommend more longitudinal studies, a focus on risk and resilience and a comparison of subjective experiences and objective outcomes, all of which are pertinent to this research. 'We can then seek to identify what factors promote resilience at transition for particular groups of children with a view to developing interventions enhancing these protective factors for all children at risk of poor adjustment at transition' (Hughes et al., 2013, p33).

My research questions, already embedded within my theoretical framework also work towards addressing some of these gaps in the literature by a focus on consulting with young people with autism and developing appropriate methods; by considering the aspirations and capabilities of young people with autism and learning difficulties – not just focusing on the more able end of the spectrum and by focusing on transition itself and what might be needed to best support transition.

This literature review has interrogated the definitions and interpretations of autism and suggested that critical realism allows us to take a holistic and ‘maximally inclusive’ approach which can take account of biological, psychological and sociological levels of experience (Bhaskar and Danermark, 2006). The current educational contexts and theories relating to special and inclusive education have also been explored to explain the school settings from which young people with autism have emerged and to what extent they have been prepared for transition to college and, indeed, adult life beyond. The analysis of risk and protective factors at stake for these young people is explored and how a resilience framework might seek to address some vulnerabilities without absolving us of a social responsibility to adapt social and learning environments, to embrace difference and to seek to empathise.

## Chapter Four: Methodology

### 4.1 How did my theoretical framework influence my methodology?

As discussed in my theoretical framework, I was unable to determine that one theory of disability fits neatly on to my research approach but rather a set of influences from the theory take me towards a position of critical realism. Shakespeare's work on disability theory and critical realism identifies the importance of impairment in disabled people's lives and that this cannot be marginalised or underestimated. There is a reality to impairment that the social model does not quite address; for some disabled people, all barriers could be removed and yet their impairments and contingent difficulties remain and I think that this particularly applies to autism and to learning difficulties. I also believe that the 'strong' social model can lead to hierarchies even within disability and, while this is not helpful, it also undermines the thrust of collective action that is at its very core.

The aim of this research was to examine the lived experiences of young people with autism in transition, and they were my focus from the very beginning and influenced all that I read and developed from that point. My theoretical position grew out of that preoccupation and from a, perhaps over-ambitious, desire to conduct research that could make a difference to the lives of these young people. Emancipatory and participatory research were very appealing and seemed to dovetail with some of the ideas of critical realism which allowed for 'maximum inclusion' (Bhaskar and Danermark, 2006) of theoretical approaches. I was also influenced by capability theory (Nussbaum and Sen, 1993) and the more positive framing of ability and 'functionings' and this led me to my first research question on ability and aspiration. Critical realism distinguishes between ontology as real existence and epistemology as thought and imagining and Bhaskar argues that researchers sometimes reduce and lose a sense of reality in their thoughts and perceptions, an issue he termed the 'epistemic fallacy' (Bhaskar, 1998a). It became impossible to write the stories of the young people in this research without reference to the ontological reality of their impairments and in particular, their difficulties with social interaction and understanding. This is where critical realism allowed for the social construction of the concept of disability alongside the acknowledgement of an external reality of impairment.

I have argued in chapter two that I do not believe autism and learning difficulties to be socially constructed although some researchers (Goodley, 2001; Molloy and Vasil,

2002) argue that it has become more visible in post-industrial societies that are driven by economic forces and attach a high value to literacy and numeracy. If you think about autism on a continuum, it is possible that those at the more able end of that spectrum, without any attendant learning difficulties, could be constructed as quirky or odd rather than accepted for their difference. It is interesting that increased diagnoses seem to be happening at this end of the spectrum and they may have been identified as 'eccentric' in previous generations. And yet, it is hard to perceive those with more severe learning difficulties as wholly conceptualised and identified by their contexts albeit with wide ranging attitudes within different communities. Accordingly, my ontological assumptions have emerged from a view of reality, which is not static, objective and fixed, but rather subjective, negotiated and constructed (Cohen et al., 2011). My perceptions of the issues around transition for this group derived from my reading, my personal experience, my professional expertise and my observations of people with autism. The positivist approach in this instance may yield some hard data about the quantifiable nature of transition (the measurement of outcomes, key interventions, 'success' criteria and so on) but would not offer the rich, 'coloured-in' case studies, which I have tried to produce, in order to illuminate these experiences. Given the demand, arising from the literature and from advocacy groups, for more attention to be paid to the wishes of young people and the move towards person-centred planning (DfE and DoH, 2014), it was appropriate to focus this research on the individual, caregivers and the professionals around them.

In keeping with my theoretical influences, I have approached the research with the young people at the centre of it and tried to customise my research methods in order to give them space and voice in the research. Qualitative methods have been most apposite here as much previous research on disabled children and adults has come from a more quantitative position where people have been measured, counted, performance assessed and treated as objects of research (Walmsley, 2001; Small et al., 2013). The views of people with autism or severe learning difficulties have not always been sought due to the challenges and difficulties of working with those who have communication impairments (Booth and Booth, 1996; Nind, 2008; Nind and Vinha, 2013). While, not underestimating the difficulties of working with these young people as respondents in the study, or, I hope, underestimating their ability to participate, I did think it incumbent on me to try to devise suitable 'adapted interviews' where I could seek their views, or at least their preferences, on their futures beyond school. I was therefore using, 'a disability interpretive lens focus on disability as a dimension of human difference and not as a defect' (Creswell, 2013, p34).

Methodologically, this entailed the development of appropriate research instruments as well as getting to know the young people. Along with the young people in this research I also saw the need to include parents whose caring role for their children inevitably illuminated some aspects of their children's experiences (Kittay, 2009) where the young people were not able to do so. Parents are also sometimes overlooked both in research and in the transition planning process.

The research adopts a qualitative approach that is most appropriate to this project as it allows the exploration of complexity and diversity of the lives of the young people involved, their aspirations and experiences around transitioning, and their specific difficulties and capabilities. As Denzin and Lincoln explained,

Qualitative research is a situated activity that locates the observer in the world...qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (Denzin and Lincoln, 2005, p3)

Given the extent of diversity within the autism spectrum and the mantra in common parlance, 'when you have met one person with autism, you have met one person with autism' alongside differences between young people in their school settings, home life, communication, personal development and social interaction - it would be problematic to try to quantify these complex and heterogeneous experiences in some way, 'rather, what is needed is a deeper understanding of the nature and outcomes of individual educational events and situations' (Ainscow, 1998, p13). My concern was primarily for the young person and how they 'understand the subjective world of human experience' (Cohen et al., 2011, p36) and make sense of their social worlds in transition. My aim was to allow the exploration of complexity and diversity of the young people involved, their aspirations and experiences around transitioning, and their specific difficulties and capabilities. In doing so, I moved away from the positivist paradigms more frequently associated with psychological research into autism and was concerned instead with, 'the socially constructed nature of reality, the intimate relationship between the researcher and what is studied and the situational constraints that shape inquiry' (Denzin and Lincoln, 2005, p8). I wanted to explore that subjective reality and try to understand how the experience was constructed through interaction with a social world in which some would have limited understanding and comprehension.

## 4.2 Researcher Identity

My identity as a researcher is shaped by my social and cultural background, my education and my professional experience and therefore I bring many influences to the shape of the project, the research design and these would inevitably influence the conduct, nature and content of the interviews I carry out. There is then a need for 'the researcher to be self-conscious about their position in the research from the outset...' (Dunne, Pryor and Yates, 2005, p22). I am aware that my professional background as a teacher and teacher educator positions me as someone who has insider knowledge of what it is like to work in schools and colleges, to manage timetables, resources and students and to make strategic decisions. I therefore think that I was sympathetic to the stresses in school and college settings at times including understanding the time pressures involved but I also think that teachers trusted me a little more in doing research in an environment with which I was familiar and cognisant of those stresses.

I am also a parent of a child with autism and severe learning difficulties who attends a (different) special school so I have had years of daily experience in communicating with a child who is constantly challenged by the demands of the social world. The experience of living with autism on a daily basis and the different kind of 'knowing' that that brings (Kittay, 2009; Alderson, 2013) to the research has been helpful in working with both the young people and their parents. This 'practical wisdom' or *phronesis* (Thomas, G. and Loxley, 2007) adds another lens through which to interpret and encounter transition experiences. To an extent, this lends credibility in the eyes of parents who may have had to deal with many professionals who did not necessarily know much about autism. Equally I could be perceived as a mother with a vested interest in the future outcomes for her child or with my own personal agenda. All these identities came into play and I knew that there would be challenges and conflicts: in carrying out a scoping interview I realised how some comments from a teacher I was interviewing would 'hit me in the gut' as a mother but as a researcher I had to be able to hear them. Delamont (1992) suggests that familiarity can act as a barrier when carrying out research, her argument being that the less we know, the more we pick up on. I would challenge this in relation to my research project as I believe that an understanding of the context within which teachers are operating and an understanding of the challenges and concerns facing parents can be helpful to make the interviewer empathetic and sensitive to demands on time and on recognizing the value of the research: the 'insider-outsider researcher' (Humphrey, 2007). However, the position that I did not occupy in any sense was that of a young person with autism and learning

difficulties so I had to be very sensitive to that and listen extra carefully to the voices of the young people without being distracted by my parent and teacher identities.

Nind (2014) dissects the range of approaches to participatory or inclusive research and uses 'inclusive research' as the umbrella term under which we locate participatory, emancipatory research. True participatory research would involve the respondents, being involved in at least some, if not all, of the decision making processes about the research questions, the research design, the methods of data collection, the analysis of the data and writing it up. Of relevance to this research though is the idea that, 'only the excluded need inclusive research' (Walmsley, 2004, cited in Nind, 2014, p13) but Nind argues that others will also benefit. Certainly this approach sat well with my thoughts on inclusive education and the way in which I wanted to seek to understand the transition experiences of young people with autism. However, being a new and tentative researcher with my own agenda of knowing what I wanted to find out about and also knowing that it would be me who emerged with a doctorate, I did not follow a truly inclusive research pathway. Instead, I sought to get to know the participants in my research and their families and to walk alongside them for a short part of their journey to adulthood but I did not consult them on the data collection process although I did ask their views on the methods I used.

In researching the social I had to be constantly aware of my relation to the social phenomena on which I was reporting as well as the ways in which I was creating new meanings and interpretations of those phenomena in my research. Both the researcher and respondent have multiple identities behind their personae, the 'active' interview subjects (Gubrium and Holstein, 2002) bring many influences to bear in the research process and these interactions, discussions and dialogic enquiries help to construct new versions of reality. This approach also located me within the research and allowed me to examine and critically reflect on my interrelationships and influences (Dunne et al., 2005).

### 4.3 Research Design

The research design emerged from my person-centred approach, from disability theories, from a critical realist perspective and also from methodological research with children and young people with learning difficulties and disabilities. I decided on a longitudinal approach to data collection in order to follow the young people through a period of transition and to discover their lived experiences along the way. A

longitudinal approach was most apposite as it allowed me to develop understandings of the transition process as lived by the participants. As Holland and colleagues write:

qualitative longitudinal methods can offer fresh perspectives into established arenas of social enquiry, drawing attention to the psychological and biographical processes ('lived through experience') through which social outcomes are generated and mediated.

(Holland et al., 2006, p2).

A longitudinal approach thus enabled me to gather data on the perspectives of the participants as they left special school to embark on their college careers and, crucially, allowed for a prolonged engagement with young people who may not have engaged with the research so effectively within a short time frame. Qualitative Longitudinal Research (QLR) is defined by Farrall (2006, p2) as embodying 'a range of mainly in-depth interview-based studies which involve returning to interviewees to measure and explore changes which occur over time and the processes associated with these changes'. However, the specific time frames, number of data collection points, variety of methods or contexts are not defined in the literature, rather the nature of the research should indicate appropriate parameters (Farrall, 2006). The focus of my research was the case of transition, and so the period of time in which the case was bounded (Stake, 1995) was partly driven by the school terms and the period when transition to college would actually happen. Consequently, I focused on a 10 month duration from June 2013 through to March 2014, during which the young people left school and embarked on their first year at college. This allowed me to focus the research on a specific, bounded period of significant change in the participants' lives, whilst recognising, of course, that the lived reality of transition is more fluid and complex, and would not begin and end at precise points coinciding with my fieldwork.

While I wanted the young people to be at the centre of the research, I was also interested to understand the perspective of their parents, teachers and other professionals and how that might differ from that of the learners themselves. Initial observation of the classes helped me to understand the ways in which the teacher and young people were communicating in class as well as bring me closer to the participants' environment and experience. I kept field notes from the observations in order to inform my methodological design but also kept a reflective journal throughout the research to capture my thoughts and question my position and influences.



In terms of sampling, I wanted to get a mixture of students from different backgrounds and with differing degrees of severity of autism and learning difficulties and yet, with a small group, I knew that it could not be representative of a wider population. In order to achieve some breadth in my sample, I did contact schools in three different local authorities but I kept the numbers of participants small in order to retain depth for each case study. I had contact with some schools through my work in teacher education and was able to approach some with whom I was already familiar. By working with cohort groups of special school leavers, I was then able to send information home via the school to those identified with autism in order to engage their interest in the study. Ultimately I had to work with those who came forward and I did get an interesting mix of students across the three schools. Unsurprisingly, I had more boys than girls (5:1) in my sample as it is thought that autism is four times more prevalent in boys than in girls (Ehlers and Gillberg, 1993).

#### 4.3.1 The Case Study Approach

As the research was driven by a desire to research the individual lived experience of a clearly identified, yet poorly understood phenomenon – transition from special school to mainstream further education - a case study approach seemed the most pertinent. Case study approaches work towards a holistic understanding of the subject of study and allow for the study of real people in real situations. Yin's (2003) definition of the case study method as 'an empirical enquiry that investigates a contemporary phenomenon within its real-life context' (p13) allows for multiple sources of evidence to be used and sits well with the understandings of transition that I aimed to research. Given the need to engage and work with young people with autism in a very individual and flexible way, and the absence of any clear interventions or strategies that have been identified as effective for every person with autism, it seemed that a detailed case study design were most appropriate in researching autism and education in order that I could pay attention to individuals and their unique circumstances.

The research followed a case study approach to allow for detail and depth while also opening up the possibility of drawing comparisons and highlighting differences (Yin, 2003), drawing attention to salient factors within the transition process. Case studies are intended to address a specific issue and would therefore be identified as 'instrumental' in Stake's (1995) terms of case study intent. Case studies are increasingly used in education research to illustrate specific learning points despite the criticisms of limited reliability and validity sometimes ascribed to them (Wilson, 2012).

In any case study design, the specificity means that questions of replicability and generalisability need to be treated with caution, and this was true of my research too: the case of transition that I would examine was specific to the young people in the study, and their educational experiences. Nonetheless, by using multiple sources of data and establishing a chain of evidence (Yin, 2003), the case study approach allowed me to interpret, infer and identify possible issues and ways forward for the transition process as encountered in these schools and colleges. In this way, the experiences of the young people in the study illuminate the case, illustrating commonalities as well as differences within the varieties of their experiences. That is not to say their experiences are representative of all young people with autism who make similar transitions, but the depth of attention to participants' experiences that comes with a case study approach has wider value for understanding transition from special school to mainstream further education for young people with autism.

The collective case study of transition was centred on the experiences of six young people with autism, charting progress, aspiration, experience and capability as well as challenges. The sample size was necessarily limited to allow for depth of study and richness of data. I interviewed young people with autism, their parents or carers and key teachers and professionals in their lives, as well as carrying out observations of the young people in class both at school and then at college and by looking at documentary evidence such as their 'moving on' plans. Through this kaleidoscopic approach to the case of transition I was able to build a very detailed, almost microscopic case examining these experiences in their 'completeness' (Thomas, G. 2011, p23).

#### **4.3.2 The development of 'Interrupted Interviews'**

While semi-structured interviews were an extremely valuable instrument in gaining the views of the non-disabled participants in the research, they were not the most obvious choice for sitting down and talking to people who may not make eye contact, may not have much language and may be discombobulated by new people intruding on their private spaces. The premise in much of the literature is about the ability of participants to express themselves clearly, thoughtfully and openly (Weiss, 1994; Gubrium and Holstein, 2002; Kvale and Brinkmann, 2009), and that the 'respondent is someone who can provide detailed descriptions of his or her thoughts, feelings and activities if the interviewer asks and listens carefully enough' (Gubrium and Holstein, 2002, p8). These premises do not apply in the context of research with people with autism. As Nind (2008) concluded after conducting a review of methodological challenges with

people with learning disabilities, 'the history of qualitative research with people with learning/communication difficulties is relatively short' (Nind, 2008, p4) and therefore further exploration and experimentation in using appropriate methods is timely. This is also an ethical imperative as Booth and Booth earlier argued, 'too often the potential problems of interviewing inarticulate subjects are seen in terms of their deficits rather than the limitations of our methods' (Booth and Booth, 1996, p67). One of the ethical and methodological challenges for my research was about how to 'interview' young people who may require a more scaffolded or supported methodological approach without influencing their responses too much, 'putting words in their mouths', (Brewster, 2004, p166) or somehow diminishing the value of their responses. In this way, (and see also section 4.6), ethical considerations were critical to the research process, where every aspect – including (but not only) the methodological decisions discussed here – was designed to centre young people's perspectives and experiences in the case of transition.

The design of relevant 'interrupted interview' methods for the young people with autism began with classroom observation. I had researched various methods prior to knowing who my respondents would be but it gave me a good background to then get to know them and devise research instruments according to the specific considerations of work with each individual. From the observations of the classes in action and from talking to teachers and looking at formats used by the young people in their transition documents, I was able to create a suitable interview schedule using the idea of an interview but incorporating activities based on tablet applications. In preparation I consulted the literature on a variety of research methods already tested out either with very young children or with those with learning or communication difficulties. The way in which Clark and Moss (2011) approached observation in pre-verbal children was particularly helpful in terms of paying attention to body language, noises, facial expression and movement to build up an impression of a young child in a learning environment. Similarly, their use of 'tours' of school and mapping was helpful later on in my work when thinking about the young people's perspectives of their college environment and the things that were important to them. This idea of assembling data in a 'mosaic approach' helped me to build up a holistic understanding of the transition process.

Augmentative and alternative communication (AAC) methods are commonly used to support the communication of people with learning difficulties including visual timetables, social stories, Makaton, cue cards and talking mats. Cue cards, for

example, have been used to provide a structure to elicit views from children or adults with communication difficulties and have been found to be particularly useful in working with autistic participants (Lewis, Newton and Vials, 2008). Similarly, talking mats help to realise thoughts by using images of key concepts, ideas or objects and can facilitate conversation and provide a focus for the research participant (Murphy and Cameron, 2008). Ward *et al.* (2003) had used 'pictorial workbooks' in order to maximize participation of young people with learning difficulties who had been at special school. It was an interactive book that used visuals to explain the concept of transition as well as questions about the research and stickers to help answer some of the questions. Small *et al.* (2013) used 'Talking Mats', a pictorial approach to interviewing young people with intellectual disabilities as a way of mapping their transition experiences.

Potential methodological approaches were explored in relation to literature on ASC and on research methods. Booth and Booth (1996) explored the 'excluded voice thesis' in relation to people with learning disabilities and identified four particular challenges when carrying out narrative research which proved to be useful markers for considering interview research in this project: 'inarticulateness' which relates to limited language skills as well as anxiety in social situations; 'unresponsiveness' as respondents might find it difficult to answer open-ended questions; 'concrete frame of reference' which might be characterised by difficulty in generalising from experience and thinking in abstract terms and similarly difficulty with imagining the future, and 'problems with time' making it difficult to order past events (Booth and Booth 1996, p56-57).

Preece (2002) identified very limited research with children and young people with learning difficulties and proposed that consultation with young people with autism had not considered the specific impairments associated with ASCs. He concluded that aloofness, social anxiety, poor memory and the limited and idiosyncratic use of language all impacted on the ability of those with autism to participate in the consultation process and, for this study, all these areas had to be taken into account. While there is little known about which research methods might afford the best opportunities for the participation of young people with autism (Harrington and Foster, 2013), it is incumbent on researchers to consider the individual, common and exceptional needs (Lewis and Norwich, 2005) of the participants and design, and adapt methods accordingly. With this in mind, 'interrupted interviews' that involved both the use of collages and card sorts on the tablet were developed for the early interviews, and walking interviews around the college environment were planned for the later data collection point.

All the methods used within the interviews had another purpose in helping to readjust the power relationship between the researcher and participant (Lewis and Porter, 2004) by sharing the process more with the participants themselves. Handing over the tablet to order the card sorts, to arrange the collage and to take photos all contributed to this changing relationship to the point where, in the walking interview, the participant was literally leading the researcher around unfamiliar territory.

#### 4.3.3 Collages and card sorts

My participants all had autism and all had varying degrees of learning difficulty which had necessitated statements of special educational need and they or their families had opted for a special school placement. They were all more articulate than I had perhaps anticipated so I did not need to use AAC or Makaton but could instead focus on the idea of an interview but with adaptations. Given a predilection for technology among some people with autism and with some teenagers, I adapted some tablet applications to create activities to break up the intensity of the interview. The first was a collage application, as I wanted to start with getting to know the young person and the kinds of things they enjoyed in school and outside. This involved some pre-loaded pictures of school type subjects that they could enlarge or shrink and move to the top or bottom to indicate their preferences. They could also add their own choices through words or images if there were other activities that they wanted to mention. The card sorts were a line of cards preloaded with things that they might be looking forward to about going to college and another card sort about things that they might be worried about. They had to put these in order of their preferences or concerns. The other reason for this was to hand over the tablet and to give them time and space to think about their choices, to discuss them if they wanted to and to ease the power differential a little. Copies of their collages were sent to them after the first interviews as I had taken a photo of them to put in the middle but this was removed to retain anonymity in the writing up process.

For the second interview that took place at college, I wanted to begin with looking back at the collages and card sorts from the first interviews, partly as a reminder of our previous conversation as they were a helpful material record of that exchange and partly to encourage the participants to think back to how they were feeling when they left school. As a prompt and to aid recall these pictures and cards were very helpful in scaffolding thought processes and also helped to remind the participants who I was and what I was doing in coming to see them again.

#### 4.3.4 Walking interviews

I aimed to interview the participants at home first and then at college for the second round of data collection although this did not work out for everybody in practice. I wanted to know about the participants' experiences of starting at college and I wanted to get a sense of the bigger picture of their environment and how they fitted in to it. Invoking a critical realist approach to my methodology, I wanted to talk about transition and inclusion but I did not want to lose sight of the real, or the referent (Bhaskar, 1993) and visiting the young people in the reality of their college environment and trying to see it through their eyes led me to think about walking and talking. Again, I worked on the idea of the interview needing a clearer purpose and requiring scaffolding of some sort. Burgess highlighted the intentional nature of research with a definition of an interview that can be said to be 'a conversation with a purpose' (Burgess, 1993) and I felt that I had to make the purpose more explicit to my participants. The idea of a walking interview was appealing both in terms of the intentional nature of the interview: that showing me around college and taking some key photos, but also in the valuable insight it could offer in terms of the young person's palpable experience of college and physical inclusion.

I thought carefully about the second round of interviews and broke it down into two parts, the first being interviews at home with parent and child and, knowing the young people better and hoping that they felt a little more relaxed with me, I decided to use a walking interview format (Clark and Emmel, 2010) at college with the consent of both parties. This would again serve the purpose of shifting the emphasis away from interrogation and eye contact and towards a more casual encounter but also, I hoped would alter the power balance (Butler and Derrett, 2014). I wanted partly to see college through the students' eyes and to see where their walk would take me and to give this more of a purpose, I asked them to take photos, again using the tablet, of places that they visited at college, they liked or they did not like. Each student carried out this task differently but as I was unfamiliar with the colleges, I was literally following their route and they were showing me their new environment. This also contributed, in an embodied sense, to my understanding of how inclusive the environment at college was for them and how they navigated it. The work of Holt et al., (2012) identified specialist units in mainstream schools as sites of inclusion and exclusion within schools; in my research I hoped to understand the social construction of space within college and whether this contributed to a sense of inclusion.

#### 4.4 Data collection

I worked with three different special schools in three different local authorities in the first instance and contacted them to explain my research and whether they could send out information leaflets (Appendix A) and consent forms (Appendix B) to year 11 pupils with autism and their parents. I approached schools with whom I already had a working relationship and they were very positive in their responses. The schools sent the information out but the next step in finding people who were willing to take part was more problematic. I did put return envelopes in with the information but it was hard for me to get the schools to follow up on responses. Once I was in touch with some families, I could move the research forward and arranged observation of classes in June 2013, the final few weeks of school for most of the young people. I designed the topic guides (Appendix C) and interview questions (Appendix D) for young people, parents and teachers and then began by interviewing the teachers at school and the careers advisers involved in the transition planning and in writing the Moving On Plan (Appendix E). From there, I arranged interviews with the young people, two were interviewed at school but the others were all at home as it was, by then, the beginning of the summer holidays. I also interviewed their parents or carers.

My plan was then to track the students through to whichever colleges they move on to and to seek consent from those colleges. Five further education colleges, again across the same three local authorities, were the destinations of the participants so I followed them there. I had some email contact over the summer (always copying in parents and young people for safeguarding reasons) but did not interview the participants again until the Spring Term of 2014 to allow them time to settle in without research interference. At this point, I also interviewed their parents again and their college tutors.

| <b>Timing</b>                                      | <b>Research Activity</b>   | <b>Data collected</b>   |
|--|--|---|
| <b>TIME ONE</b><br>April/May<br>2013               | Contacting potential participants through special schools; information leaflets and consent forms sent out; emails and letters | Identified teachers, families and careers advisers  |
| June/July<br>2013                                  | Interviews; collages and card sorts; observations  | 6 interviews with young people (all completed a collage and 2 card sorts each)<br>5 interviews with parents of the young people (5 parents also did 2 card sorts each)<br>3 interviews with teachers at the three schools attended by the young people<br>3 classroom observations – one at each school |
| Late August<br>2013                                | Emails to ask about how the summer holidays had been   | 18 email responses from parents and young people  |
| September<br>2013                                  | Interview not previously captured  | 1 interview with parent (card sorts not completed)  |
| <b>TIME TWO</b><br>1 <sup>st</sup> October<br>2013 | Emails to reflect on first term at college   | 9 emails with parents and young people<br>1 classroom observation of young person at college  |
| January/<br>February<br>2014                       | Arrangements for Time 2 interviews and college visits  | 20 emails with parents, young people and college tutors   |
| March/April<br>2014                                | Interviews; observations; walking interviews   | 4 interviews with parents<br>4 interviews with young people at home<br>3 walking interviews with young people at college<br>3 classroom observations at three colleges<br>5 interviews with college tutors at four different colleges   |
| April 2014   | Telephone interview  | 1 interview with parent previously unavailable  |
| June 2014  | Walking interview  | 1 walking interview with young person not captured earlier  |
| May-Sept<br>2014                                   | Emails continued with some participants  | 24 emails with parents and young people   |

**Figure 1: Data Collection Summary**



As soon as I had completed each interview during the first round of interviews, I collated the documentary evidence in terms of Moving On Plans, (Appendix E) collages (Appendix F), card sorts (Appendix G) and my own field notes (sample in Appendix H). This enabled me to build my initial case studies and develop a sense of each emerging story. The first interviews were carried out either at school or at home depending on individual circumstances and what the family was comfortable with. Some of the young people had a parent present during the interview but most were given space to answer questions directly rather than a parent intervening. The use of collages and card sorts helped to scaffold the interview and the use of visually mediated methods helped to support the communication of the young people with ASC (Preece, 2002). In preparation for the Time 2 interviews, I built the interview schedules around the data from the first interviews (Appendix D2) around the Time 1 responses for parents and young people and prepared ideas for the walking interviews.

#### 4.5 Data analysis

While transcription is inevitably laborious and time-consuming (Bird, 2005), it served a very useful purpose as the first stage of my data analysis as it made me climb inside my data and walk around in it and listen again to the way in which points were made but it also prompted me to make notes in my research journal as I was transcribing (Appendix J). I went from a list of many codes and ideas through to a shorter list (Appendix K) but at this stage I did not seek to refine it any further until I had completed the second and final round of data collection as I did not want to create too much of a framework at this point (Silverman, 1993). These codes and early themes were mainly used to inform the interview schedule and methodological design for the second round of interviews.

Once I had transcribed all the interviews I used Nvivo to undertake my coding analysis and a thematic approach to the data analysis seemed most appropriate to both the longitudinal case studies and my theoretical approach of critical realism. Braun and Clarke (2006) argue that thematic analysis can be used in different ways for different theoretical approaches,

It can also be a 'contextualist' method, sitting between the two poles of essentialism and constructionism, and characterised by theories such as critical realism (e.g., Willig, 1999), which acknowledge the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of 'reality'. Therefore, thematic analysis can be a method, which works both

to reflect reality, and to unpick or unravel the surface of 'reality' (Braun and Clarke, 2006, p9).

However, they also suggest that you must choose between inductive and deductive analysis but I felt that I had to do both in order to ensure that emerging ideas were not overlooked in my quest to address certain themes and indeed this does seem to fit with the dialectical reasoning within critical realism (Bhaskar, 1998; Alderson, 2013). Ultimately it was my judgement that decided which themes emerged out of a range of potentially disparate codes, and inevitably not all data could be used in this thesis. The process described by Braun and Clarke was ultimately helpful in finding a way through the iterative and reflexive combing through data to identify initial codes through to more substantial linking of codes to make themes.

Using Nvivo allowed me to play with codes by using multiple codes for the same piece of data and regrouping the codes in different ways, it also allowed me to search for specific quotations that I remembered and was a repository for all my data including the collages, card sorts and learning difficulty assessments.

#### **4.6 Ethical considerations**

Ethical considerations for any research should consider the interests of those who are respondents in the research to preserve their anonymity; to ensure their free agreement to the study; to allow the possibility of them withdrawing from the research and to ensure that their views, opinions and knowledge are not exploited or misrepresented to further the individual ends of the researcher (ESRC, 2012). My approach to ethical considerations with children and young people has been influenced by my own role as a parent of a disabled and non-disabled child and my experiences of being asked to participate in research. Ethical considerations and respect for the participants, the young people in particular, informed every stage of the research process, not least in the desire to centre the research on their voices, to design methods that would be supportive of their participation and enjoyable insofar as possible, and to ensure that they were happy to continue with the process at every stage.

With these underpinning ethical values, I attempted to manage the research process with the young people in mind so as not to intrude too much on their lives and to try to make the research relevant and interesting for them and for their families. My experience as a teacher has also instilled a sense of duty of care to the professionals

involved in research as they know the young people very well and typically work very hard to ensure that their needs are met on a daily basis, I did not want my research to impinge on their ability to do their jobs effectively. I had to approach schools initially in order to seek their permission to send out details about the research to any potential participants. I applied for, and was given, ethical clearance from the University of Sussex Ethics Review Committee as part of the requirement to go ahead with research of this nature but it inevitably caused me to think carefully about what I wanted to do and what would be the most ethically responsible way of doing it. During this process I was able to focus in on the topic guides for my interviews and prepare information and consent booklets for both the adults and young people in my research. My only concern was that this was a one-off process and that ethical issues could develop during the research process but I was fortunate to have recourse to a supervisor who could advise on this.

#### 4.6.1 Informed and ongoing consent

While, according to Loyd (2015), there have been few examples of researchers obtaining valid consent from individuals with learning and communication difficulties, I had to consider whether the participants would have the mental capacity to consent to the research so I worked with the schools to identify suitable participants, whom the school, and later their parents, judged to have the mental capacity to consent to this research in accordance with the Mental Capacity Act (*Mental Capacity Act, 2005*). Consequently, both the school and the parents were involved in identifying the participants and putting forward those who they believed had the mental capacity to give informed consent.

Cameron and Murphy (2007) did explore this issue in depth when gaining consent from adults with learning difficulties. They concluded that there needs to be an ongoing relationship between the researcher and the participants and that accessible methods of communication should be used. The information sheets written for the young people with autism in the research included my photo, an indication of the timescale of the research and were carefully worded to avoid the need for inference or deduction but rather were written in simple language. It felt as though there was a delicate balance between not excluding those with learning disabilities from research while, at the same time, ensuring that they are not coerced into taking part in something that they do not fully understand. At that point I did not know what the communication abilities of my potential participants would be but separate versions were prepared for the parents and consent forms given to both parties (Alderson, 2004). There was also a balance

between devising an age-appropriate information sheet versus a visual version that could have been patronising when I did not yet know the participants (the actual versions used are in Appendix A1 and A2).

Given that this research was longitudinal, at each stage of the research I asked if the young people were happy to continue, and even during the interviews I built in additional checks to ask if they were willing to participate in the activities I had devised such as card sorts on the tablet that I was exploring with them (Alderson and Morrow, 2011). I also gave them a time out card they could use if they wanted to stop the interview or have a break. With parents I also checked that they were happy to continue when confirming an interview time or following up progress by email; I also checked that they wanted to do the tablet activities as I could sometimes sense some nervousness about the technology. One parent did prefer not to do the tablet activity and another parent withdrew her child (and herself) from the project when things became too difficult at college.

#### 4.6.2 Confidentiality and anonymity

Issues of confidentiality and anonymity were especially important to this research so that young people, parents and professionals could be as open as they wanted to be without their opinions or their educational institutions being identified. With the young people I asked them if they wanted to come up with their own pseudonym as it felt right that they could have some say as to what they were called in print, three of the participants came up with aliases taken from film or television characters. However, I needed to be clear in my information leaflet and consent form that there were limits to confidentiality if I thought that the participant was at risk of harming themselves or others. I also identified my boundaries as a researcher and, in particular for young people with autism, I needed to let them know the timescale of the project, when and how I would be working with them and when it would end and I showed them on a time planner when that would be. I also think that there are limits to the amount of confidentiality and anonymity that can be assured (Boddy et al., 2011) as any of my participants were potentially identifiable especially in a small-scale study such as this one, and in the relatively 'small world' of special educational needs. For example, only one of the young people was female, one had a very rare genetic disorder (globally) and one went on to an agricultural college, all of these markers limited my assurances on watertight anonymity. In disseminating findings I therefore had to ensure that I adequately anonymised people or places in relation to possible audiences, including audiences that might know the young people, families or professionals who took part.

I also had to take account of confidentiality during the course of the research and amongst the participants as parents asked to know what their children had said and teachers wanted to know what parents had said. In each case, I said that I would have to ask permission of the particular participant but that all data was being treated confidentially and anonymously. There were a couple of occasions where the young person gave their consent for their parent to see their card sorting activities on the tablet where they had expressed their main concerns about going on to college and their positive thoughts about it. In both cases, a fruitful discussion between the parent and child took place about their move to college where parents realised that their children had different concerns to them.

#### 4.6.3 Dignity and respect

It was likely that young people with autism who were leaving their familiar special school environment to go to a new college would be stressed and anxious during the time in which I was involving them in my research. I needed to be alert to signs of anxiety in the participants and encouraged them to talk to their teachers and caregivers to alleviate their concerns. I was always aware of the power disparity between my participants and me and therefore tried to address this through the methods that I used as they attempted to hand over some control, especially to the young people in the project. It was also critical to consider my impact on a young person with social and communication difficulties as they might find interaction with a stranger challenging, at least at first. I tried to build up relationships with the participants to the extent that I could with a time-limited project but also had to be respectful of their communication preferences and their need for time and space so that I was not intruding too much.

Responsibility to participants does not stop when the data collection process is complete but continues during the data analysis, the writing up and the dissemination of research findings (Boddy et al., 2011). Whilst transcribing the data I had to listen very attentively to understand the recordings of some of the young people whose diction or inflection made their spoken language more difficult to understand. Given my commitment to privileging the voice of the young people, this meant that ethical decision-making was also central to reporting the analysis and research findings. While it might have been expedient to afford more space to some of the more articulate participants, including non-disabled adults as well as young people with relatively fewer difficulties with communication, a key ethical consideration in research is 'who gets to speak' and whose voices are heard (Maguire, 2005).

This chapter has explained the approach taken to the research influenced by my theoretical approach. The development of appropriate methods to understand ASC viewpoint has also been explained and the sensitive, ethical nature of the work undertaken.

## **Chapter Five: Data Analysis (1) – Introducing the young people and their social worlds**

While the data analysis is presented thematically as explained in Chapter Four, the discussion in Chapter Nine will bring together the themes to address each of the research questions. The four data analysis chapters are divided partly across time with Chapters Five and Six focusing on the young people as they prepared to leave school and Chapters Seven and Eight exploring their reflections on transition and their experiences at college. In this chapter, the young people are introduced through their collages and initial interviews; the importance of social aspects of their lives is identified and their past experiences of education and school are explored.

### **5.1 Introducing the young people**

In keeping with my person-centred approach to this research, the data analysis begins with introducing the young people in order to humanise and ground their experiences using their collages as a way of presenting them. While there is no truly objective way of presenting these young people as demonstrated by the 'Reading Rosie' paper (Goodley and Runswick-Cole, 2012), I have endeavoured to privilege their perspectives on their lives in these representations. Their experiences form the basis of the longitudinal case studies put forward in this research along with the views of their parents, teachers and other professionals. This first chapter examines the aspirations and abilities of the young people in their final year at school and then goes on to explore their social lives and their prior education experiences. This helps to form a broader picture of how prepared they were for moving on to mainstream college. In keeping with my methodological approach and trying to privilege the voices of the young people and their parents, I have used quotations as fully as possible to exemplify their experiences.

The young people in this research all had statements of special educational needs issued at different ages; all had a diagnosis of autism spectrum condition with various manifestations; and all had additional learning difficulties of different degrees. I met them towards the end of their final year at special school (Year 11 for all except one, who was Year 12) and all were going on to different courses at mainstream further education colleges. However, my case descriptions also draw heavily on the data from parents and professionals as I was building a case from the young person's perspective but creating a mosaic of understanding around each case (Clark and Moss, 2011).

### 5.1.1 Jake

Jake lived at home with his mother, stepfather and two younger half-sisters who did not have learning difficulties and talked about the support of his family, especially his mother. His natural father died when Jake was four and a half years old, at the time when his mother was deciding on what school provision would be most appropriate, and Jake had been educated in special school provision since that age. Socially Jake was able to attend clubs and activities outside school including drama, swimming and a church youth club although these had to be arranged and organised by his mother. He had a couple of friends from school who occasionally got together for birthdays at each other's houses but Jake was not able to go out on his own to socialise. Most recently Jake's mother had been very involved in helping Jake to prepare for his GCSE exams by orchestrating structured revision sessions at home and helping to prepare him for college by practising the journey using public transport. Jake's teacher commented on his diligence and commitment to his work,

But he's one of these boys who, everything he does, he does to the best of his ability, you know, he's not 'oh this is boring, I'm not doing this' or whatever...  
(Angie, Jake's teacher, Time 1)

According to his teacher and his Moving On Plan, he was building good relationships with staff and students, was good at following clear instructions and was developing independent travel skills. The plan also identified autism and moderate learning difficulties as affecting his ability to interpret the body language and facial expressions of others; and that he was working on understanding humour and accepting that others may have different opinions to him. His teacher commented on this,

I mean one of Jake's, I mean he's autistic this is no big surprise, but he has very, very specific views on things [...] but he's much more able to see that's their choices or that's how they're living their lives, I don't need to comment on it, I can have my beliefs, they can have theirs (Angie, Jake's teacher, Time 1)

Jake was very responsive when I spoke to him and seemed interested and focused during our 40 minute long interviews and said that he enjoyed the tablet activities.

### Future plans

For the future, Jake wanted to spend his first year at college on the Foundation Level course and then go on to Level 2 BTEC in ICT and then Level 3 the year after culminating in an apprenticeship in the industry. He was very clear about his future path and specific about which part of the industry he would like to work in too,



I like using software...but I want to focus on the hardware side of things as well like building computers, repairing them, upgrading them, that sort of thing  
(Jake, Time 1)

Overall he was very positive about the future, he talked about living away from home with friends, having a girlfriend and that it would be nice to get married one day.

Jake: I'll probably get a flat to start with and move up to a house if I get enough money, yeah  
 JS: Live with friends or...?  
 Jake: Live with friends, yeah  
 JS: And do you think you might get married one day or anything like that?  
 Jake: I possibly could, yes [joyfully]. I don't have a girlfriend at the moment but you never know when I go to college I could get married, yes  
 JS: Meeting new friends, that might...  
 Jake: I'd love to get married when I'm older, that would be really nice  
 (Jake, Time 1)

He left school with C grade GCSEs in Maths, Media, ICT and Science and a D for English. He went on from school to a general college of further education to a Foundation Level course that gave him opportunities to sample a range of vocational activities. After this first year at college he was accepted on to a BTEC Level 2 in ICT about which he was delighted and keen to tell me at our final meeting.

### 5.1.2 Beth

Beth was 17 when I interviewed her as she had stayed on for an extra year at special school to ensure that she was ready to move on to college. Beth had had a troubled school history in mainstream and had been labelled a 'school refuser' by education professionals as she was out of school for three years (from the age of 11 to 14) while an appropriate school setting was agreed between her mother and professionals. Once she got to Beechwood School in Year 10 (when she was 14) she thrived. Her mother had had numerous battles with education and social care professionals and was still in the throes of getting a diagnosis of epilepsy for Beth when last interviewed.

Beth lived with her mother and two siblings, both of whom were on the autistic spectrum with different degrees of learning difficulties. Her parents divorced some years ago so Beth's mother was a lone parent who said she suffered from depression and that her own mother (Beth's grandmother) committed suicide a couple of years ago. Beth's grandmother had been an important source of support for the family and there was a sense now of them being quite isolated.

Beth was very sociable and, on her collage, added 'socialising with friends' as an important factor in her life. She was able to socialise online via Skype and social media but did not meet up with friends independently outside school. She spent a lot of time making very detailed and imaginative animations that she uploaded onto YouTube. Her teacher praised her creative talent as an animator and musician, 'she's an absolutely fantastic animator, the animations that she does are absolutely amazing. She writes and sings her own songs so has an awful lot of talent'. Beth was aware of her autism and had some ideas how it affected her learning,

I also find it hard to like...sometimes when people talk too fast...and I get stressed out because I can't catch it all or something and ...um...and so it's actually really helpful so I am aware about that if you know what I mean...I mean...probably understanding stuff like... um... slow processing or something but ...yeah..I think that's part of my autism, I'm not really sure...um...I know that I have like loads of obsessions (Beth, Time 1)

Her teacher at school talked about her obsessions, her obsessive compulsive disorder and her rigidity of thought, and the Moving On Plan also referred to an 'extremely low processing speed'. This meant that she needed clear and repeated instructions as well as extra time to complete tasks and for this to be continued at college.

### **Future Plans**

Beth was looking forward to going to college and felt that the course in media was just right for her and she felt much more ready to go than she had done the year before so her extra year at school had seemed to be very beneficial. She certainly saw her future as an animator or storyboard artist,

Yes, I want to be an animator and make cartoons or help make cartoons and contribute with them and that and if not, I want to be a storyboard artist which is where you storyboard for the cartoon, if not that then I'd like to draw comics, which is all kind of the same thing.

Longer term she hoped to live abroad possibly in America or Canada ('all the good places I like'), ideally living with friends at first but later on getting married.

Beth left school with A\*s in Art and Photography GCSEs, an A in Media and a B in English, she also got a D for Maths that she was hoping to retake at college. She went on to Ashcroft College to study for a BTEC level 3 in Media and hoped to go on to do some courses in animation and work as an animator later on. Beth did go on to college but was unable to stay on the course; her mother said this was because the college

was not able properly to support her epilepsy. Beth's mother also asked for Beth to be withdrawn from the second data collection phase of the research project.

### 5.1.3 Eric

Eric was 16 and in his last year at special school when he was first interviewed for the research. He had started school at the local mainstream primary and went on to a mainstream secondary school but had struggled in those settings and his mother fought tirelessly to get him into a special school. Once he got to Larkspur special school when he was 12, both Eric and his mother were much happier that it was the right place for him – in fact his mother just grinned when she first mentioned it in the interview. He lived at home with his mother and stepfather and, in January 2014, just after his first term at college, his mother gave birth prematurely to his baby half-sister.

Eric was referred to by his teacher at school as someone with 'a really good sense of humour and is really mature, funny student, really nice lad'. He was sociable and particularly so with girls. Eric was able to go into town with friends or to the cinema if it was all carefully organised by his parents including dropping him off and picking him up but his mother expressed concerns that he was still taken advantage of by some less scrupulous 'friends'. She also talked about him being socially isolated and spending a lot of time in his room and on the computer. He had been to college for a series of taster days and had been guided towards an appropriate entry-level course at his local college.

Eric had a diagnosis of autism accompanied by other co-morbidities including ADHD, dyslexia, and severe asthma and more recently he had been suffering from an eating disorder. He was always interviewed either with his mother or his teaching assistant present as I occasionally struggled to understand his intonation and he also found it hard to talk to strangers, he required constant supervision at college and it was more difficult for him to focus on the questions. His mother explained how he was diagnosed with severe dyslexia but not until he was 14 and after all the other diagnoses he had had, she thought that this one label that he had escaped,

He was 14 years old he was diagnosed with severe dyslexic, 14 years old and I said why has it taken all this time? I cried cos I thought that was the only thing he never had wrong and he struggled and struggled with what he went through for all them years but it's his memory, the woman said to me, cos I read the report, I burst out I said I didn't know this (Carol, Eric's mother, Time 1)

### Future Plans

Eric's ideas about the future were connected with people and jobs that he already knew and so he was thinking about getting a job in a pub run by his stepfather's sister. He had had a really positive work experience placement in a local supermarket, while he was still at school and both his teacher and his mother talked about how he had grown during that experience and their hopes that he might get a job there eventually.

Yeah they're trying to get, when there's a place, he might be getting a job there on a Saturday so hopefully cos he was so well behaved and they absolutely adored him and that so um, we're hoping, fingers crossed that he gets in there and since he went there he's got more, what's the word, he just grew up a little bit, a bit more independence, he just grew up in certain ways

(Carol, Eric's mother, Time 1)

Eric left school having taken GCSEs in Maths, English, Science and Art GCSEs and went on to a Foundation Learning course at Meadowlands College.

#### 5.1.4 David

David had been educated in special schools since he started his education and his mother talked of mainly positive experiences as a result but was rather concerned about the transition to mainstream college. He lived at home with his mother, father and young sister. His parents were very supportive in always seeking out opportunities for him and organising any social life, including taking him to the cinema and transporting him to see friends. David was on the autistic spectrum with moderate learning difficulties but also had a diagnosis of two rare conditions that affected his physical abilities such that it could be difficult for David to write, to hold his head up or stand for long periods, to take up some sports or to walk long distances. His social communication and language skills were 'significantly delayed' according to his Moving On Plan. The Moving On Plan also suggested that David would need support in developing social skills, accessing the community and special arrangements for exams. He was not an independent traveller to school and also had anxiety in relation to using public transport and busy situations.

On David's Moving On Plan his strengths are listed as 'ICT skills. Excellent reading and reading comprehension skills' (p2) and that he had 'a positive approach to learning and he enjoys learning' (p3). David's teacher at school was full of praise for his academic progress but was concerned about his shyness which particularly became apparent on a visit to another college,

David is a very able student, you know, national curriculum level-wise one of the highest in the group but confidence-wise and independent skills-wise when we

were over at Nettledown college...he was very nervous and very shy, very intimidated (Dan, David's teacher, Time 1)

However, he did spend a lot of time at home on his Xbox, according to his mother, and his inclination seemed to be to stay at home. His mother commented on his social interaction as often being minimal and a learned response to social situations. His teacher at school, David also confirmed this and was worried that he may not be saying how he really feels about things preferring to give a short response to questions about transition.

### **Future Plans**

David found it very hard to conceptualise the future so it was difficult to discuss hypothetical questions with him about how he viewed the transition to college and what it might be like, as well as thinking about what he might want to do in the future.

At GCSE level, David got a C in Maths, D for Science, G for English and F for Art as well as entry level certificates in English, Maths, Science and DT and went on to the Explorer course (entry level 3) at Meadowlands College which offered opportunities to sample vocational areas. After a year on this course he was accepted on to a BTEC level 2 course in ICT in which he had always been very interested.

### **5.1.5 Ellis**

Ellis was 16 and attended a small secondary special school and he lived at home with his mother and stepfather and had no other siblings. His mother was very supportive and was in regular contact with his school and had fought to get him a placement at special school for his secondary years as he had struggled in mainstream primary schools where she felt that behaviour relating to his autism had not been particularly well managed. She could see his potential as a carpenter or plumber and did not see that his learning difficulties should hold him back,

Just because you might have a learning difficulty, it doesn't have to stop you from um, doing what you want so hopefully I'd like him to go out on his own and maybe earn enough money to save so he can have some driving lessons and get his own start but I also know friends in that trade [carpentry] and we might be able to have a word with them. (Elaine, Ellis's mother, Time 1)

Ellis was very personable and sociable when he was interviewed and was able to engage with the activities on the tablet and respond fully to interview questions. He often went out on his bike and could go on a bus into town independently although he did not seem to meet up with friends outside school. His school praised his interaction with others as reported in his Moving On Plan, he is described as a 'likeable member of

the school and he is regularly praised for his politeness, kindness, friendliness and respect for others' and 'Ellis has matured during his time at Windmill School and is a fantastic member of the tutor group...he is a mature and dedicated student who often sets a very good example to other students'.

Ellis had a diagnosis of autism and speech and language difficulties and articulated his perception of his autism in his Moving On Plan, 'I have autism, I get angry really quickly, I don't understand some things, I don't get jokes' (p4). While he had displayed oppositional and challenging behaviour in the past according to his mother and his teacher, this had gradually improved with maturity so that he was now able, at times, to remove himself from a potentially difficult situation (Moving On Plan).

Ellis did do a day release course in sport and cooking at Deepvale College during Year 11 and a day a week at some allotments. He said that that he really liked this and he had done really well with it according to his Moving On Plan. He was clearly good with practical subjects and his mother showed me photos of the woodcarving he had done at the allotments. While at school he started a course in woodwork at a local mainstream secondary school but found it difficult to adjust without the same level of support and left after a few weeks.

### **Future Plans**

Ellis talked about going on to do a full-time course in construction after his first year at college and wanted to be a carpenter in the future 'make chairs, make bedding and sell them'(Ellis, Time 1). He was able to travel independently both on the bus and on his bike although if the bus was busy he would sometimes walk and was then late to school. When asked about whether he might leave home one day he was, at first, keen, 'ooooh, yeah, I might move out one day' but then later reconsidered and said that he might 'live here until my 50s. I don't like to be away from my Mum for too long. If I go to my Grandad's, I phone my Mum every day' (Ellis, Time 1)

Ellis took GCSEs in Maths, Science, RE, English and Philosophy and Ethics and from his Moving On Plan, he was predicted to get Es, Fs and Gs. He went on to Deepvale College to do a Foundation Learning course where he studied English, Maths and ICT as well as trying out some vocational courses. His attendance was initially very poor in his lessons (27%) although he was attending college but was often found by his tutor in the coffee bar. He clearly enjoyed the social aspects of college but his tutor thought he was slower to get used to the expectations of attendance on the course.

### 5.1.6 Frankie

Frankie lived at home with his father and his mother had died when he was 14 years old. His father was very supportive and was engaged with the school and active in preparing Frankie for college life. Frankie had been to a mainstream primary school that was a fairly successful experience but his father felt that he needed a more supportive environment in secondary school and so went to Windmill School in Year 7. He was interviewed at home with his father in the background and was happy to participate in the interview activities and they helped him to focus on our discussion.

Frankie did take part in a choir and drama club outside of school and also attended a youth club on a Friday evening. Here he could meet friends, play music, play Xbox and go to the tuckshop. According to his Moving On Plan, Frankie was 'kind, polite and has a good sense of humour. He is persistent and always keeps trying' (Moving On Plan, p2). He was also able to catch the bus on his own and go to the cinema.

Frankie was diagnosed with autism and learning difficulties and had difficulty with fine and gross motor skills that could affect physical activities including handwriting. He also had a limited attention span and was easily distracted according to his Moving On Plan but this was also evident in the interviews as he tended to 'go off at a tangent' in his responses and talk about memorable incidents which had upset or excited him in some way but which were not necessarily pertinent to the discussion.

While still at school, Frankie went to Nettledown College once a week to do an Animal Care course (Level 1 certificate) and this helped him to get used the college environment that he ultimately attended. He did very well on this course and was awarded 'student of the year' during this day release course and this helped to build his confidence with the transition, 'It was wonderful for him to get that award really, it was just fitting and well deserved so um, yeah, that's good' (Eve, Frankie's school teacher, Time 1). He loved animals and therefore particularly liked the animal care course and had his own pet dog at home that he regularly took for walks. Frankie had been bullied at school and on the bus home from college when other students drew on him.

#### **Future Plans**

In talking about the future, Frankie did say that he would perhaps like to be a zookeeper after his course at Nettledown but did not talk about whether he would live away from home or life beyond college. He left school with two Fs for his GCSEs as well as his certificate in Animal Care and started his one year full time Level 1 course

at Nettledown College. In his second year at college he continued there on a horticulture course at the same level.

### 5.1.7 Collages as representations of capabilities and interests

The collage activities were used in the initial interviews with young people (as well as the card sorts) as, inspired by capability theory, I wanted to foreground their interests and capabilities so that I could find out more about what they enjoyed rather than just focusing on their difficulties. The collage task required participants to organise and select both preferences and interests in and out of school to focus on their strengths and capabilities. The images of typical school subjects were pre-loaded and they could be removed, made bigger and smaller according to likes and dislikes, and moved around so that images nearest the top and bigger indicated their main interests with those smaller and lower down being of less appeal. The collages are shown below and offer a snapshot of each of the participants.

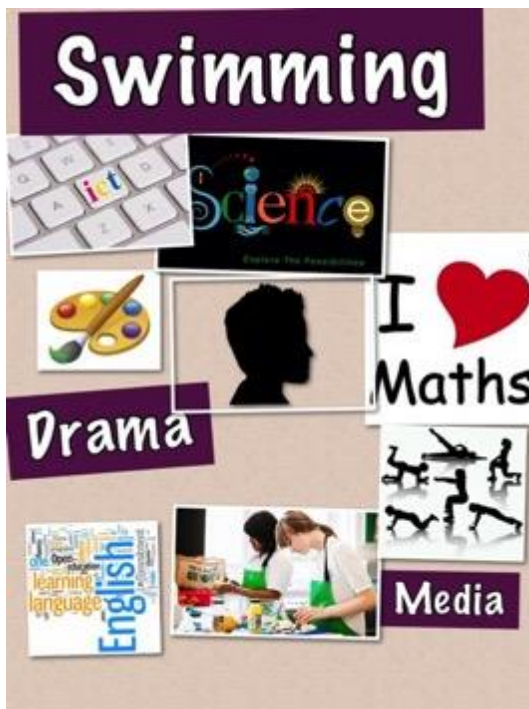


Figure 2 Jake

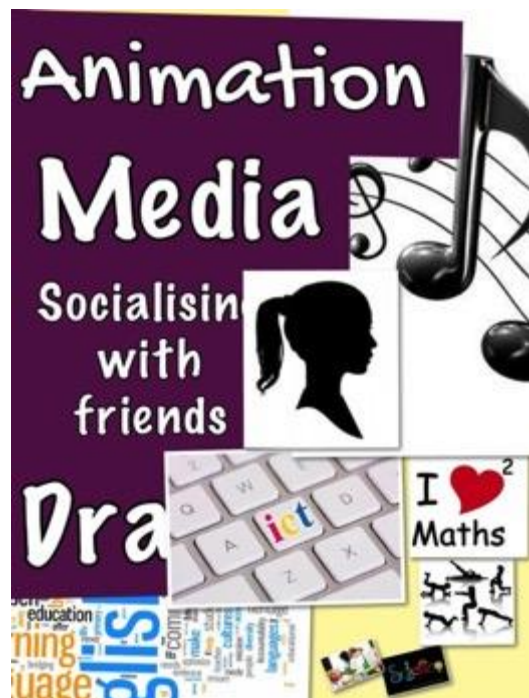


Figure 3 Beth





Figure 4 Eric



Figure 5 David

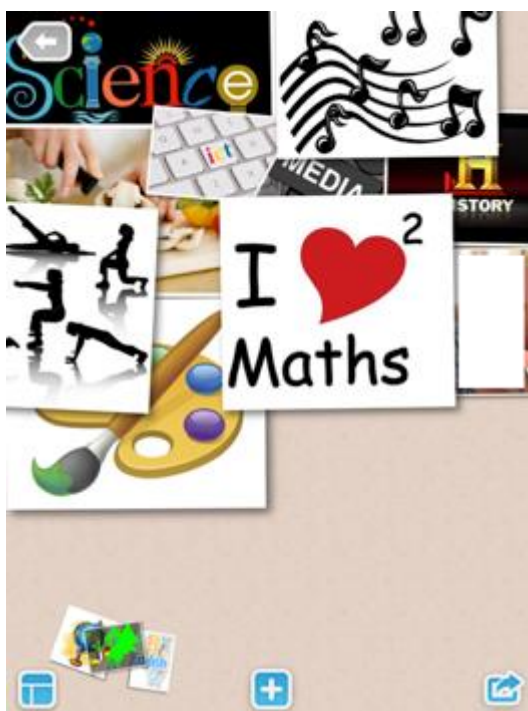


Figure 6 Ellis



Figure 7 Frankie

Both Jake and Beth were keen to add other ideas to their respective collages as they had interests outside school that were not represented in the pre-loaded images. For Beth, it seemed that the animation and media were huge outside interests and, in fact, these were both career interests for her, but socialising with friends was also very significant and she talked about this while she was doing the collage. Jake had added the swimming and drama clubs he attended outside school.

The other participants did not want to add things to the collage although David, prompted by his mother, did include 'Xbox' as he spent a lot of his time playing on it. Eric kept the media image on there but talked more about drama than media at school and had it as one of his top favourites. He seemed unsure about what some of the subjects were and completed the task quite quickly, wanting to hand the tablet back to me as soon as he could. Both Eric and David enjoyed ICT and Maths, with David going on to secure a C grade in his GCSE Maths.

According to his collage activity, Ellis enjoyed Science, ICT, Music, Cooking and Maths at school and said that he 'loved ICT', he did not add other images or words in relation to his interest in carpentry and working with his hands but perhaps did not feel confident to do so. Similarly Frankie could have added an image to do with animals, as his course at the local college had been really successful for him culminating in him being awarded 'student of the year'.

## 5.2 The significance of the social

These introductions to the participants offer an insight into their abilities, interests and concerns just prior to them leaving school as well as their hopes and aspirations for the future. Given that autism is primarily a condition that affects communication and interaction with others, it was perhaps noteworthy that all the young people mentioned their social lives to a greater or lesser extent and parents also commented on the extent to which they were able to socialise independently or with parental support.

Outside the school or college environment it was quite difficult for the young people in the study to sustain friendships and to meet up outside their formal education settings. This was in part due to the logistical difficulties of attending special schools often at some distance from home so friends at school were also have to travel a way to school but also due to the extent of their autism and how it affected their social awareness, understanding and sense of danger. The reasons for their social lives being restricted

were in part due to their autism and social interaction difficulties which meant that they were not yet able to travel independently, but for David and Beth, additional physical impairments also affected their ability to go out. Some young people had more independence than others and were able to meet up with friends on their own but for most the construction of a social life relied almost entirely on the efforts and encouragement of parents.

### 5.2.1 Frankie's emerging social life

Frankie seemed to have a degree of independence and social awareness so that he was able to go out on the bus and meet friends in town. When his teacher rang up at the end of school, she was pleasantly surprised to find that he was out at a friend's house, 'and that wouldn't have happened a while ago and he's getting more independent' (Eve, school teacher, Time 1). Frankie was also able to take part in a youth club and drama club and was also a member of a choir. His clubs were less specifically set up for special needs so it seemed that he was able to access a broader, more inclusive, social experience. He talked about what he did at youth club,

Well you get to do what you like there's like a...you get to sit down and just relax...er..You get to um, you get to have a look, um, like, you get to play on like, stuff like um, a thing called the Xbox connect and there's also the PS3, we go out sometimes, there's a tuck shop... (Frankie, interview, Time 1)

### 5.2.2 David and an inter-dependent social life

David's involvement with clubs was more limited and his mother explained that he did attend a Saturday Club specifically for special needs but that he was reaching its upper age limit and was becoming less interested in going but this was the only social activity he attended. She explained how she tried to create social opportunities for him,

I'm always up for, if there's something there that he can try then just give it a go and keep going, at least you can say you've had a go and we've always tried, I mean he's driven a mini round Goodwood and we do all these things just to try and I just like him to have as many experiences as he can do and not, I don't want to restrict him as a parent and say 'oh you can't do that' you know, I just think go and have a go so if an opportunity arises for employment or anything like that then I'll do everything I can for him to get to that point' (Denise, David's mother, Time 1)

When David talked about the summer holidays, he thought that he would meet up with friends over that period at each other's houses to play on the Xbox,

JS: And do you think you'll see any of your friends over the summer?  
David: Yeah

- JS: Yeah and what might you do - do you meet up and go to their house or do you go out somewhere?  
 David: Yeah, yeah meet up and do stuff  
 JS: Yeah, more Xbox or...  
 David: Yeah (David, Time 1)

When Denise talked about David's friends at school and how they try to organise meetings in the holidays, she explained how it was not straightforward due to David's difficulties but also those of his friend. Denise realised that David might not think of contacting a friend and so was able to suggest that he contact people and arrange to meet up. She was then able to help David to get there so that he could experience a social life albeit a supported one,

I mean there's one boy who lives quite local and um, he's been really good but it's a case of me having to say to David 'right you need to say to him, let's meet, you come round here or you go round there' but he doesn't like anybody coming here - you know his friends in his room and stuff, he doesn't really like that um..So it tends to be more that he goes the other boy's house...but it's very much that I have to push it in the holidays and stuff because otherwise they wouldn't see each other (Denise, David's mother, Time 1)

### 5.2.3 Jake's orchestrated social life

Given Jake's difficulty with spontaneously and independently meeting up with friends outside of school, some compensations were made through attending organised clubs and activities, often organised specifically for children or young people with special needs. Beth, Ellis and Eric did not report on any organised activities outside school but Jake, Frankie and David had all taken part in some activities. Jake attended swimming, drama and youth clubs in his spare time and talked about his swimming club here:

- JS: And what about out of school? [meeting friends]  
 Jake: I've got a few out of school as well so I meet them on Saturdays after my swimming so I do have a few after school, yeah  
 JS: And is that a swimming club or something?  
 Jake: That's a swimming club, yeah, so I meet them at the swimming club and we just do swimming together which is really good (Jake, Time 1)

Alison, Jake's mother talked about having to organise everything if Jake did want to meet up with friends and that this could be difficult,

- JS: You also said that he meets up with some of them outside school. Is that the two who are younger?  
 Alison: Yes, we have to organise everything because they live in Southshore so it's a bit of a headache and we can really only do that in holiday

times because obviously after school there's no time. Weekends are very busy because he does um, a couple of activities on Saturdays...  
(Alison, Jake's mother, Time 1)

Jake and David were reliant on their parents to organise their social lives for them or to support them in maintaining social contacts and this family support is a key factor in developing resilience. However, the interdependent nature of their relationships with parents (Howlin, 1997; Aston et al., 2005), presents other barriers in their progress towards forming peer relationships and learning to cope with new situations alongside their peers (Small et al., 2013).

#### 5.2.4 Romantic relationships

When Beth was asked about her future she talked about it in terms of being sociable and living with friends rather than being on her own and, even longer term, talks about the desire to get married,

Beth: I'd probably like to begin with I'd like to share a flat with friends or something, I wouldn't like to be on my own as I'd feel quite vulnerable and scared and alone whereas...yeah...with friends it would be much more company and fun  
JS: Yeah, it would be fun  
Beth: Yeah hopefully when I'm older I will get married...I hope  
(Beth, Time 1)

Beth was also showing signs of interest in boys although Debbie, her mother, talked about her being like a much younger child in many ways and that this was a very innocent relationship in relation to 'average' 17 year olds,

It was so sort of naive in a lot of ways, she would say my new boyfriend and I were holding hands and that's as far as it goes and I suppose if I look at your average 17 year old they're not just holding hands but Beth in my eyes because she ... behaves like that or thinks like that, she's about equivalent to a 6 or 7 year old in the playground (Debbie, Beth's mother, Time 1)

When asked what she did outside school, Beth talked about using Skype as she enjoyed socialising with friends, here she was discussing her collage,

Beth: I mostly just go on my computer and draw and talk to my friends on Skype [laughs]  
JS: Social things as well  
Beth: Yeah  
JS: Let's add social  
Beth: Yeah, I do really like my friends at school  
(Beth, Time 1)

For the future, Jake was certainly excited by the idea of having a girlfriend and eventually getting married but had not yet had a girlfriend as mentioned in his

introduction. His mother approached the whole subject with some trepidation as she just thought it would be so difficult for him to navigate his way through the complexities of relationships and could see that she would have to put in lots of support to be able to help him to understand. At one point she even says that she hopes she's not alive by that stage so that someone else would have to deal with it just because it would be so demanding. When I asked whether she thought he might have a girlfriend one day, this was her response,

I kind of hope not! [laughs] oh dear, a whole load of barrels of problems that one is, it's even worse than all the other topics isn't it?! [laughs] Well, he's interested in girls definitely. He wants to get married...I've said it's very hard for someone with special needs, very, very hard. He knows someone who is married with special needs actually at his swimming group, there's a pair of people with disabilities, more severe than him, and they have got married um...they're having tons of support....[sighs] I suppose I would just have to take it one stage at a time really, um...I think it would be very hard, very, very hard for him to maintain a relationship because of the egocentricity of autism um... if the relationship broke down, we'd be picking up the pieces and oh... goodness...I don't know...I kind of hope I'm not alive by then ...[laughs]

(Alison, Jake's mother, Time 1)

It was very clear from these individual accounts that social lives were very important to these young people in many different ways. Despite some of the difficulties in meeting up with peers independently and organising social lives, they found ways, typically through social media, to extend their peer group interactions. Parents reported their role in this as they saw the importance of developing social networks for their children.

### 5.3 Experiences of school

The young people and parents in this research had had a variety of school experiences across mainstream and special schools including a specialist ASC unit attached to a mainstream school. Apart from Frankie's father, no parent commented very positively about their child's experiences of mainstream schools supporting findings on parental and children's views of inclusive education that being placed in a mainstream environment is not necessarily the same as experiencing inclusion (Rogers, 2007; Humphrey and Lewis, 2008). Interestingly, social interaction issues pervaded the accounts of life at school, not that the children had not been sociable but that mainstream school environments had not been able to adapt to their developing, and sometimes different, social abilities.



### 5.3.1 The challenge of mainstream provision for Ellis

Ellis and his mother described his placement in primary mainstream as a struggle although he did go to a school with a specialist ASC unit in later primary years. Elaine, Ellis's mother had felt that although Ellis had always been very sociable, the teachers did not understand him and that he was in the 'wrong environment'. She had been contacted about 'incidents' almost every week. Elaine was able to secure a special school place for Ellis's secondary years in a much smaller school and that seemed to have worked well for him as he had got on well with the teachers and had matured while he was there.

Ellis: And 7,8 and 9 was a bit iffy but 9 and 10 started to get a lot better

JS: What do you mean by iffy? What was that like?

Ellis: Like, I used to get in a lot of fights um...couldn't cope...but because the teachers there got to learn and they also had autism themselves [Ellis believed that everyone is on the spectrum somewhere] so...yeah, and when I got to Y10 and11 I got a bit more mature, had no fights, bringing up the younger ones so teaching them what's right and what's wrong and just got a lot better (Ellis, Time 1)

While there were still 'incidents', these had become less frequent 'one thing a month or something' (Elaine, Ellis's mother, Time 1) but the police were called on one occasion when Ellis had been in a fight with another boy. Ellis's mother, Elaine explained how Ellis's sociability had improved over time partly with maturity but especially when he was in the 'right' school environment after having moved to special school,

...Um...I think now he's older and has got a better understanding, when he was younger it was certainly more difficult, him understanding things and stuff, he is very sociable, very polite but when he was younger it was, yeah he couldn't cope well but I think he was in the wrong environment as well so...and I had to learn how to do things differently too (Elaine, Ellis's mother, Time 1)

Ellis had had some continued contact with a local mainstream secondary school that was linked to the special school as arrangements were made for pupils who wanted to pursue a specialist GCSE subject that the special school could not provide. Ellis enjoyed working with his hands and tried to take a woodwork course at the local mainstream secondary school as part of his timetable but, despite the support of a teaching assistant accompanying Ellis, it seemed that the experience was not particularly successful. His mother did not think that he had been very well understood or supported in that environment,

He wanted to do woodwork and I think that was the only lesson he was going to at Marton School for [mainstream secondary] but he ended up leaving even though he'd had someone with him because he kept asking questions. He was

asked to be quiet because it was keeping everyone else behind which was like if you're going to allow them in then you've got to allow them to ask the questions if they're not understanding what you're saying. There was two lads from Windmill School and both of them left. (Elaine, Ellis's mother, Time 1)

This misalignment between special and mainstream schools is highlighted in this quotation from Elaine, and reveals some of the challenges for mainstream schools that have not adapted to meet the needs of all learners. That Ellis was unable to continue with the course because he was asking questions and that he was keeping the others behind illustrates both the pressure on mainstream schools to cover the curriculum quickly but also the disabling environment thus presented to Ellis and he becomes marginalised (Plimley and Bowen, 2006; Oliver and Barnes, 2010). This experience seemed to influence the way in which Elaine viewed Ellis's imminent transition to college and that if it had been a mainstream course in college (as opposed to a more protected foundation learning course) then she would have been more concerned,

If it was just a regular course with regular kids, I'd be really concerned because he wouldn't keep up, he wouldn't be able to keep up what was going on or...or even understand what was going on. (Elaine, Ellis's mother, Time 1)

### 5.3.2 Battling for the right environments for Beth and Eric

Neither Eric nor Beth were able to get a special school placement until they were 13 years old in Years 9 and 10 respectively, they and their parents had struggled with professionals, with the education system, with statements, with diagnoses and yet, once they got to special school, they enjoyed being there and their parents thought they were in the right place. Beth's prior experiences in mainstream settings had not been positive as she had been bullied and had not felt properly understood by her teachers,

No, that's ...er...I was...in middle school and I did actually find mainstream quite hard and I ...they...and my mum like moved schools for me because I kept getting bullied and that and teachers didn't really understand so it was before I was diagnosed and then I went into a middle school which was smaller and I made a few friends there but unfortunately ...um...I kind of like epilepsy kind of started up and I was off school for a while and then it was the end of Year 7 and I really didn't feel like I was able to cope because they wanted me to go to Charlton Rise school but that's a really, really big school and I really didn't feel able to cope.  
(Beth, Time 1)

Beth talked about the amount of time it took to get her into a special school placement once she had a diagnosis of autism and seemed to resent the years that she missed as she loved to learn,



- Beth: But...for some reason...yeah...it took ages and they didn't really help me and I was out of school for three years which was really annoying because I could have been here
- JS: Yeah, were you at home during that time?
- Beth: Yeah it was ...really...it was quite...they kind of just left me and it was a bit...and then they... cos
- JS: Was it quite difficult being at home?
- Beth: Yeah cos I really want to learn that's the thing, I'm always really eager to like learn and then I went to this out of school learning thing but I really didn't cope there and then finally Mum managed to get me here which was really good and I really enjoyed it (Beth, Time 1)

Beth had been particularly stigmatised as she had been labelled, according to her special school teacher, as a 'school refuser' until she had joined them in Year 9. This label had emerged during the time that her mother was trying to secure a special school placement but could not get the local authority to agree. Beth's mother was not prepared to send her daughter to school when she did not feel the setting was appropriate, when, in capability approach discourse, she could not convert the resources available into meaningful experiences (Hedge and Mackenzie, 2012). When they finally did get the news that a special school placement had been secured, Beth's mother, Debbie talked about their joy after such a long fight,

When I told Beth and we danced, leaping up and down cos Beth was really excited so it had been a three year battle but there had been many battles before that one over the other two [children] so it was nothing new  
(Debbie, Beth's mother, Time 1)

For her own part, Beth was really happy when she did get to special school and loved being there as she explained,

It was scary but I ...because I had been out of school for a long time but I really did like enjoy it...I did um...yeah I think I settled in really well and all the teachers are really understanding. I made lots of new friends and yeah, definitely really good. (Beth, Time 1)

Eric had similar difficulties during his time in mainstream settings although he was not officially out of school for long periods like Beth but their stories and 'battles' do echo each other to some extent. Eric's mother, Carol, talked of battling for years with the local authority in order to secure the right placement for her son,

I think he went to Larkspur in Year 9...took me years to get him into a special needs school absolutely years, it turned out that I had to take it to tribunal... because Eric should have been in a special needs school from a very early age and that and I've got all evidence from specialists, and it was Professor Green, she was very good, that was Eric's specialist, her and her team knows Eric and she was shocked and disgusted that he was going to a mainstream school and it took all that time. (Carol, Eric's mother, Time 1)

Carol explained how negative the experiences at mainstream primary and secondary had been describing the schools as 'terrible' and the teachers as being 'horrible to him' and 'very nasty' and she had clearly felt that they were not protecting Eric adequately as he kept getting bullied. Here she gave an example of the teacher not taking her concerns seriously,

He used to get bullied at school, beaten up constantly when I tell you not one, but three boys was kicking him in the head and had got him on the floor and I said to the teacher, he's getting bullied by this particular group and um...'no he hasn't, they're just playing' and I said no he's got cuts and bruises all over him and I took him to the doctor's and that's on record what they did to him and....what happened? I took him again to the teacher again and said Eric has got massive bruises up his leg where he's been kicked and punched, she laughed at me 'children have accidents' (Carol, Eric's mother, Time 1)

The relief that Eric's mother felt when Eric finally got a place at special school echoed that felt by Beth's mother, and it was the first time in 14 years that she had experienced the relief of her son being in safe hands while he was at school,

But when Eric went there [Larkspur], it was the first time ever that I had peace of mind and that was priceless, I knew he was safe and I knew he was looked after (Carol, Eric's mother, Time 1)

She went on to praise the teachers for their commitment and that they got to know Eric and understood how to help him, this was quite a contrast to how she had felt about the mainstream teachers,

So we had a terrible time but when he got into Larkspur, it's the best school ever [smiling] and the teachers are so committed, they just want to do the best for him, they want to do it for Eric not the name, not a number but a person and um, Dan [one of the teachers], he's fantastic, he really liked Eric and you could tell, he wanted the best for him and um, I've got so much respect for them it's unbelievable. (Carol, Eric's mother, Time 1)

Eric's school teacher was able to articulate both the difficulties Eric experienced in managing his own behaviour at school as well as his positive social attributes. Eric had become used to the smaller environment of special school whereas at college he would have many more people and situations to deal with and that this would be a challenge for him but it is interesting to note that the teacher locates Eric's emotional responses firmly as Eric's problem rather than thinking about how he could be more accommodated in his environment,

His challenges are to just kind of control his reactions to certain people and certain staff when he gets wound up about things really and that will be testing at

college because there will be more people that could potentially do that as opposed to his classmates here so but I feel confident that Eric will get on well and find his own little group (Dan, Eric's School Teacher, Time 1)

Beth and Eric had both found special school environments more adapted to their needs and more able to foster their positive well-being (Hedge and Mackenzie, 2012). Their parents too felt pleased and relieved when, after their long battles, they were able to access specialist education where they felt that teachers were more able to understand their children's needs (Mittler, 2000).

### 5.3.3 Leaving the safety of special school for Jake and David

Both Jake and David had been in special education settings throughout their schooling and both they and their parents were positive about their experiences during the interviews. Being in special schools throughout tended to mean that they reported very few battles over statements and school placements. This did not lessen the trepidation about the transition to mainstream college, as it would be the first time that these two young people had mixed in an educational setting with mainstream peers. For David's mother, past experiences of mixing with mainstream students outside school had been problematic so the transition was very worrying,

David's been in special school all the way through so he's never been to a mainstream, um, which is the slightly scary thing with him going to college now is quite daunting as he's never really mixed, as I say, he's academically never really mixed with mainstream children and we've always found it a problem when he gets together with mainstream children, he's found that really hard and the other children have found it really hard to deal with him as well because obviously he says inappropriate things and he's that bit different and it's caused, in the past, quite a few difficulties when we have mixed with mainstream children  
(Denise, David's mother, Time 1)

### 5.3.4 Jake's social experience of school

During his first interview, when asked if he had enjoyed school, Jake had fondly remembered his experience of residential trips at school and highlighted them as something he had really enjoyed.

Jake: Good bits probably the residentials I've done. I've done a few residentials. I did one in Y8 at ...um...Kingswood, Kingswood and that was really, really good so I enjoyed that  
JS: Right, good  
Jake: Yeah, we went on the high swing and all that so it was very good  
(Jake, Time 1)

It was interesting that these were highly social experiences that had resonated for Jake although his mother remembered those trips for Jake being repeatedly kicked by another boy.

There was another episode where another boy in his class spent the whole residential trip kicking him as far as I gather and we didn't hear about it until he came back. And school weren't aware because it had been done quite snidely but they did deal with it. I told them about it and they did sort it all out and it was never a problem again but generally he hasn't had any problems with bullying or anything like that, he seems to me extremely settled, very happy and I think he's become more accepting of other people's opinions.

(Alison, Jake's mother, Time 1)

Jake commented positively about the friends he had made at school and felt that he had '*quite a few friends*', something that his mother witnessed in practice when she went to a careers evening partly expecting Jake to be with her finding out about future plans,

We had a careers evening actually a couple of years ago and he [laughs] he wasn't really interested... he wanted to talk to his friends and in the end he went off and talked to his friends, we were left sat talking to the man from college so, in fact, he seems to relate quite well to the other children in the classes

(Alison, Jake's mother, Time 1)

Jake's Moving On Plan mentioned social difficulties but suggested that they were Jake's 'mistakes', again in a rather medicalised version of his condition, from which he was trying to learn,

Jake has experienced a few difficulties with friendships this year, mainly due to his rigidity of thought. He has been willing to talk about his mistakes and is willing to try hard to learn about them. (Moving On Plan, 26/11/2012)

Interestingly, difficulty with social interaction was seen as making 'mistakes' that are intrinsic to Jake rather than identifying the need to make adjustments and to offer support in social skills in his transition to college. Jake's mother did, however, feel reasonably confident that Jake was going in to a semi-protected environment within the college as she had been up to observe the learning support department and seen the manager of that department in action. This had reassured her that Jake would be well supported on the course that he had chosen,

It's really tailor made um...for people with mild to moderate difficulties who've got special needs, who need more support than the mainstream but not the total support of the ones who are more severe, so yeah, I think it will be OK. I think it will be good for him (Alison, Jake's mother, Time 1)

### 5.3.5 Frankie's positive experience of mainstream

Unlike the other young people, Frankie was unique in that he had been in a mainstream primary school that had been a relatively successful experience for him. The primary school had been supportive but his parents felt that he needed a more specialist setting for secondary school as, after visiting their local mainstream secondary, they, and Frankie, felt that his needs might not have been fully met there,

- JS: So Rivermead [mainstream primary] worked well and you had enough support there and
- Phil: Yeah
- JS: Yeah, but then when it came to secondary school were you already thinking...
- Phil: Well we looked at Millstream but we just thought it was too big a school and we didn't think that the support for kids like Frankie was good enough um
- Frankie: That was true with another friend of ours cos, well I mean, he told me all about that he'd been picked on at Millstream and stuff and told me that the teachers weren't very nice because they wouldn't help him at all or anything like that
- JS: Yeah, that's hard isn't it? So, that didn't seem like the right place?
- Phil: Yeah, I mean it was a very good school but we just figured that, in terms of Frankie, would he be in the teachers' priorities, it wouldn't be at the top so we thought that Windmill School, you know would have...
- (Phil, Frankie's father, Time 1)

With these varied and often negative experiences and expectations of mainstream education, these young people and their families understandably faced the transition into mainstream college with some trepidation and anxiety about how it would be. However, it could also be argued that their self-esteem and academic ability may have been developed more in special school thus preparing them better for adult life than if they had remained in a difficult mainstream environment. The special school experiences had all been positive by contrast to mainstream environments and this demonstrates the lack of inclusive education experienced by these young people and their parents (Rogers, 2007; Humphrey and Lewis, 2008). While the next section focuses explicitly on how the preparation for transition took place from the perspective of the schools, the parents and the young people, this lived reality of special, inclusive or mainstream education inevitably coloured the attitudes of both the young people and their parents. To what extent did being wholly in special school encourage young people to be more dependent or to what extent did it help to build their self-confidence and self-esteem in better preparation for their college lives? Did experiences in mainstream primary or secondary education help to prepare young people for transition to college?

## **Chapter Six: data analysis (2) – Preparing for transition**

This chapter explores the different ways in which the young people were prepared for transition by their schools, parents and colleges and goes on to examine how the young people and their parents experienced that preparation. The chapter concludes with the theme of time and managing time as they faced the three month gap between school and college over the summer holidays.

### **6.1 Preparing for transition – schools, young people and parents**

From a critical realist perspective, the idea of a stratified reality into different ontological domains: the real, the actual and the empirical (Bhaskar, 1975) is helpful to the analysis of the experiences of transition. This section examines the formal transition processes in place initially from the schools' and careers advisers' perspectives which helps to offer an insight into the 'actual' level of reality but it goes on to examine the 'empirical' level as experienced by the young people with autism and their parents. A consideration of how the young people were feeling about college through the card sorting activity and about the gap in the middle of transition arrangements (the summer holidays), are explored. The two latter sections help to interpret the 'empirical' reality of the participants whilst continuing to acknowledge their impairments as a part of the domain of the 'real' and interrogate the observable or 'actual' mechanisms of transition.

#### **6.1.1. Systems and processes in place for transition**

There are procedures and processes in place as a young person comes up to the age of transition and from the annual review in Year 9, transition planning becomes part of the formal process. The SEND code of practice (2014) addresses transition planning and due to EHC plans being extended up to the age of 25, it talks about 'preparing for adulthood from the earliest years' (DfE and DoH, 2014) where high expectations for employment, education and independent living are encouraged.

All three schools had transition arrangements in place that meant that careers advisers did attend annual reviews from Year 9 and were involved from that point to offer information and guidance on local provision. Schools had links with most local colleges although the degree of connection with them varied considerably; some transition arrangements were very formalised and others were more ad hoc if the school did not have a strong link with a particular college. There was evidence in the interviews that schools and careers advisers were trying to keep up with changes to courses on offer as well as changes of personnel. Careers advisers were working with young people

and teachers to create personalised transition plans, (more recently called Learning Difficulty Assessments or the '139a' but referred to throughout as 'Moving On Plans') although the degree of person-centred planning varied and a limited range of courses on offer.

### 6.1.2 Information, Advice and Guidance (IAG) – Y9 Annual Reviews

The Windmill School viewed the whole of the secondary experience for their pupils as preparation for transition to adulthood more broadly, whether it was moving from one key stage to another or from school to college, all members of staff had some input to that and this connects with the spirit of the new SEND code of practice (2014),

From the minute they get here really, we're nurturing them, helping with transition from KS2 to KS3 and then from KS3 to 4 and the options, already preparing them at GCSEs, what you choose then affects what you can do at college and what you do at college affects whether or not you go to university or whether you want to or whether you want to apply for a job.

(Eve, Ellis and Frankie's teacher, Time 1)

All the participants had had annual reviews in Year 9 that involved a careers adviser and to which parents were invited. This was the point at which the school started to formally discuss the young person's future and their transition beyond school. Careers advisers and teachers sought the views of the young people as well as soliciting parents' views, valuing their contribution and, to a certain extent relying on them to help with transition. Careers advisers had valuable knowledge about the range of courses on offer in the local area and different college admission processes so they were able to offer up-to-date information, advice and guidance which would be really challenging for teachers to keep up with. The careers adviser for Windmill School outlined the areas discussed with young people during their Year 10 and 11 transition interviews and how important it was to seek parental views with students from special school,

Talking to them about school, what they like, what they don't like, what he's done well, what his goal is and at that point in time, yeah, I got together a list of possible courses, talk to his family, read the information, get the prospectus sent to him and that I'll see him again. The other thing I do with Windmill School students which I don't do with mainstream school I usually get the young person's permission to talk to their carer or Mum or Dad cos I want to get their view as to whether or not they feel that's appropriate.

(Emma, Ellis and Frankie's Careers Adviser, Time 1)

Another careers adviser, Abbie, for Beechwood School, talked about how important it was for parents to be involved from Year 9 annual reviews to help them to think about the future for their children beyond school,

...Because I think Y9 parents haven't really thought that far ahead really and I think perhaps it's a bit of shock sometimes and the Y9 parents quite often haven't thought about travel training yet and haven't started doing the travel training and mobility and road safety and stranger danger (Abbie, Jake and Beth's Careers Adviser, Time 1)

Person-centred planning, albeit much referenced in the code of practice (DfE and DoH, 2014), was not referred to by parents, careers advisers or teachers apart from Abbie who did explain the process in her reviews at Beechwood School although it clearly had not worked very well in some other schools. While the process was more time-consuming, it seemed to be really beneficial for the participants, not least in helping parents to think about the future,

Yeah, I think it's got pros and cons to it really,...we do concentrate on the strengths and the positives of the student which is obviously good. erm...and it's supposed to be more centred around the young person, they can be involved in the whole meeting and they get to choose their own music and they can bring biscuits, they don't actually [laughs] but they could...I think Y9 parents haven't really thought that far ahead really and I think perhaps it's a bit of shock sometimes and the Y9 parents quite often haven't thought about travel training yet and haven't started doing the travel training and mobility and road safety and stranger danger so it's a gentle way of moving that forward sometimes as well.  
(Abbie, Jake and Beth's Careers Adviser, Time 1)

There was evidence of some personalised provision in relation to course choices although this was generally related to finding the right course for the student rather than adapting courses or timetables to meet students' needs. Emma talked specifically about Ellis and his interest in construction but going straight onto a mainstream course was not necessarily the most appropriate way forward for him. Ellis was keen on construction or carpentry or plumbing but his careers adviser could see the benefit of him following a foundation learning course first as he had at three years of further education available to him at college,

In some ways you could say should we put Ellis straight on a construction course but I think that would have been a disservice to him, he's got three years of education that he can access, paid education and he's still going to have plenty of time to get those qualifications and I think he's better getting the support that he will get on the Foundation Learning first and I'd be very surprised, if Ellis's not on a construction course after he's done that year  
(Emma, Ellis and Frankie's Careers Adviser, Time 1)

Equally, Jake was not seen as ready for a mainstream course straightaway at college as he needed more support during his first year at college. His Careers Adviser, Abbie, called it a transition year as she could see that he could academically be making more progress than this course afforded,



I think they're able to offer entry level 3 qualifications so it's probably academically not going to progress him a great deal but then the aspergers-y type young people, he'll probably benefit from doing tasters in vocational areas and more work-related learning and having more awareness of the world of work really...basically it will be a transition year really

(Abbie, Jake's Careers Adviser, Time 1)

The careers advisers seemed to have some knowledge of children with special educational needs although this seemed mainly through their differing experiences rather than any formal training. One careers adviser was less sensitive in her understanding of young people with autism,

If you use the wrong...the first thing he said to me was 'it smells in here' you know which actually was really quite rude but obviously that was ... for somebody who's not used to it and even me...it was like 'oh god, do I smell?' [laughs] I came home and said to the kids, do I smell alright today?

(Emma, Careers Adviser, Time 1)

Overall, careers advisers were helpful in that they did have valuable local knowledge of courses and colleges available but they were more focused on academic progression rather than considering the wider needs and capabilities of the young person and their knowledge of their client group was limited in some cases (Cullen et al., 2009).

### 6.1.3 School preparation

School preparation for transition generally took the form of specific visits to colleges ranging from one day, ad hoc visits to one day a week year long courses. This level of exposure to the colleges was helpful on the concrete level of experience, in that young people with autism are likely to benefit from observing the concrete reality of their future education environment and this also resonates with Bhaskar's notion of the 'real' and the 'actual' reality of college. The more truly 'empirical' experiences came from the longer and more realistic experience of pursuing a proper qualification at college for one day a week over a whole year. Frankie had had a good prior experience of his college in this way so he and his father felt that he was very well prepared to move on to the college fulltime,

Phil: I felt Nettledown was a very good choice cos what they've done, they've used small animals to get more information into him, not so much the Trojan horse as the Trojan hamster [laughs] poor lad he has to live with this

JS: OK and do you think school have prepared him well for transition? Do you think he's ready to leave a special environment and go on to...?

Phil: I think that doing it a day a week at different places has been a good way of doing it because when we went to the open day, Frankie knew his way around and was taking me around all the places so I could tell

he felt very much at home and the staff knew him and um, I was very pleased with that. (Phil, Frankie's father, Time 1)

This experience of taking a full part in college life had offered Frankie a truly empirical experience of the reality of college life, what it was like to have lessons, have lunch, work with college lecturers and be a part of the college community and how it is different every day.

Similarly, some students who were leaving Larkspur School, were able to go to their closest linked college, Meadowlands, once a week for a couple of months to do an induction course which the school literally had to buy places on,

Like this year the majority of students were going to go on to Meadowlands so I set up an induction to college life proposal that the tutor over there planned and delivered but we bought in to so every Thursday afternoon for two and a half hours, our students would go over to college for a whole term and do an induction to college life so it was you know, learning about what happens at college, the difference between school and college, getting to know the campus, refectory facilities (Dan, teacher, Larkspur School, Time 1)

Beechwood also had strong links with one college that many of their students would go on to and here they would have regular visits and courses set up to give learners experiences of a range of vocational courses, in a similar way to Larkspur. The Windmill School was able to link up with the local mainstream secondary school in order to enable learners to access to specific GCSE subjects as well as help to prepare the young people for mainstream transition. Eve, the class teacher, spoke about this possibility for more specialist subjects and thought that the scheme worked very well,

To begin with they get all the support they need, they're accompanied there, they're supported in lessons, and gradually over the months and weeks and days when they no longer need as much support then we back off a bit.

(Eve, Ellis's teacher, Time 1)

However, there is a contrast here with the experience reported by Ellis and his mother (in 5.3.1) where teachers in the mainstream school did not seem responsive to Ellis's learning needs and he did not continue with that course. While it is a really good idea in principle, in practice there needed to be more preparation with the mainstream school to manage their expectations of learners from the special school.

Visits were arranged to other colleges, beyond the linked college, albeit in a much less formal way and without so much direct experience of the course or college. As Beth was the only learner going on to Ashcroft College, she did not have the same transition

preparation as other learners going to Highdown that was more traditionally associated with Beechwood. She just sat in on a lesson that was taking place as opposed to having a formal transition course or series of visits,

Angie: Beth is the only person who's going to Ashcroft from here and Mum has actually organised for her to be there for a couple of days because her brother and sister are both there and she knows the SEN department so they've sort of facilitated that.

JS: And has she had a taster of her actual course?

Angie: Yeah, she just sort of went and sat in on a lesson, there's not been a formal transition programme or anything and that's possibly something that we need to look at in the future (Angie, Beth's teacher, Time 1)

Beth had also needed an extra year at special school to prepare for moving on to college partly as she had been out of school for three years and only joined Beechwood in Year 10 and so benefited from staying on. In this way, the school were able to personalise the transition for her to accommodate her needs,

JS: So the extra year here, was that parents and you and Beth all sort of thinking that was the best?

Angie: Yes, she wasn't ready to go into a mainstream environment and actually, touch wood, it's worked because she's now really looking forward to going to Ashcroft and doing a Media level 3 course (Angie, Beth's teacher, Time 1)

However, Angie did seem to be aware of the social connections that Beth would need to make when she got to college. She expressed some concern that Beth would need to find someone early on to whom she could relate amongst the students, as she had been very connected to the school through her friendship groups,

I am worried because if she doesn't have that one person in terms of a student then she needs to have a member of staff that she can feel that link with as I am worried and she is one that I would have liked to have kept a place here open so that if all else fails, and that's something I'd like to look into in the future  
(Angie, Beth's teacher, Time 1)

A major concern was that if college was not successful for these learners then there was no way back to the special school environment even where they had post-16 provision. This was because the statement ceased if they went on to mainstream FE college but, with new legislation in September 2014, (Department for Education et al., 2014) they can now request an assessment for an EHC plan up to the age of 25, however, during the research period, none of the young people and their families had done so.

#### 6.1.4 College preparation

Most of the impetus for transition planning came from the schools as they were supporting these young people on to their next step and although there were visits to colleges, there seemed to be very little evidence of colleges visiting the schools or making connections with the school curricula. The teacher from Larkspur School talked about the local FE college but their intake came from a 30 mile radius which took in many other colleges that might be nearer geographically to young people's homes. As KS4 teacher, he had to work hard to develop and maintain his networks with colleges in order to keep up with all the changes. He was also wanting colleges to make the links back to schools so that colleges could also keep up to date with them,

It's in our interests and in their interests to have a bit of er...more informed transition so we know what they're offering and I do know what they're offering there but I think they now know what we're doing here a bit more but obviously we're changing what we do and they're changing what they do

(Dan, teacher, Larkspur School, Time 1)

However, the Tutor for learners with learning difficulties and disabilities, at Highdown College suggested that she was very much connected to her local special schools (Beechwood was not one of them) through her attendance at review meetings, meetings with parents and more general visits but most of the work in deciding on the appropriate courses was done during the six week induction period at college,

Yes, we start from the beginning and go to the special schools and meet the students, we invite them in for various functions, I go to some of the special schools, I go to their review meetings, their final reviews so I'm there to talk to parents at that point (Avril, Jake's College Tutor, Time 2)

Frankie's father, Phil, thought that the college had been very supportive of Frankie as he had attended the course one day a week during his final year at school and the college had made him 'student of the year' which had helped boost his confidence for attending full time the following year,

Yeah I do, I think that Nettledown is a really good choice because the nice thing as well they do is that this year, he won student of the year for his course which was great because they said he'd made such good progress and that he'd worked so hard, he'd been very punctual, always asking interesting questions and um, they were very, very pleased with him and he got up and won a prize

(Phil, Frankie's father, Time 1)

Interestingly for some students, the first year at college was conceptualised as a 'transition year'. For Jake, and other young people, who were capable academically of going on to further study at Level 2 or 3, this was not considered to be necessarily the

best way forward as they still needed support with social interaction and getting used to mainstream college. Angie, Jake's teacher thought that he would need a 'more secure environment'

Within my class, erm, there's two students who are going to the special needs provision within Highdown because it was felt that that was the best thing for their next step that they'd outgrown here but weren't quite ready to go in to the mainstream part of college, they're going into that slightly more secure environment of, I think they call it 'XX' courses at Highdown so that's what Gary and Jake are doing (Angie, Jake's teacher, Time 1)

There seemed to be many processes set up to help young people prepare for going on to college including attendance at taster courses or, in Frankie's case a weekly one day release course, and these were very helpful at the more concrete level of visiting new sites and meeting potential new teachers. There were gaps in this preparation though in that there did not seem to be much evidence of 'person-centred planning' beyond the rhetoric, Ellis's experience of attending a GCSE class at a local mainstream school had not been successful and by conceptualising the first year at college as a transition year, there is a danger that it becomes a year where little progress is made.

## 6.2 Young people's and parents' experiences of preparation for transition

While the schools and colleges had their processes in place, it was important to get a sense of how the young people and their parents experienced these transition arrangements and how well prepared they felt for college. It became clear that parents were key in plugging any gaps in the transition provision and often assisted with further visits or more preparation on travel training for example. This section looks at the experience of 'being prepared for transition' and what concerns the young people and their parents had about moving to mainstream college. This section focuses on three young people in particular, Beth, David and Ellis who came from three different schools and went on to three different colleges. Beth had stayed on an extra year at her school in order to be better prepared for college; David had followed a fairly well-organised transition course at his local college for a day a week over 6 weeks and Ellis had had slightly more ad hoc arrangements. They all responded differently to the card sorts but in each case, it added to the picture of how they were feeling about moving on to college and what their concerns, and those of their parents, were. The social was clearly important to all three of them as 'new friends' was the top card for each in terms of what they were looking forward to at college.

### 6.2.1 Beth's experience

Beth's teacher, Angie, had talked (above) about Beth needing an extra year at school in order to be better prepared for going on to college. Interestingly, the extra year at school and preparation for transition had been mainly around improving Beth's confidence socially. As she was out of school for some time, this was particularly significant for her and she clearly derived great pleasure from both her learning at school and her recent friendships,

- JS: So how do you think school has helped you to get ready for college, having this extra year at school, how do you think that has helped?
- Beth: Um, just like I don't know...definitely this year I've become more social, I guess because my friends in my class now we have much...even more than in my class before although I had friends, we have much more in common and ...um...and I think I've definitely got more confidence as well as we've like um...as well as just like learning stuff in general as well  
(Beth, Time 1)

She had also met some of her teachers and she liked them as well as going for a visit at the end of the summer term (while she was still at school) as her brother had won an award there. This visit was organised by her mother rather than school as Beth was the only learner going on to Ashcroft College so the links were less formal. She liked what she had seen so far which included some of the teachers she would have and classrooms she would be taught in. However, Beth's mother, Debbie, expressed concern about the transition to college especially as the special school 'protected' environment had been so successful for Beth so the transition to college felt like going out into the big wide world,

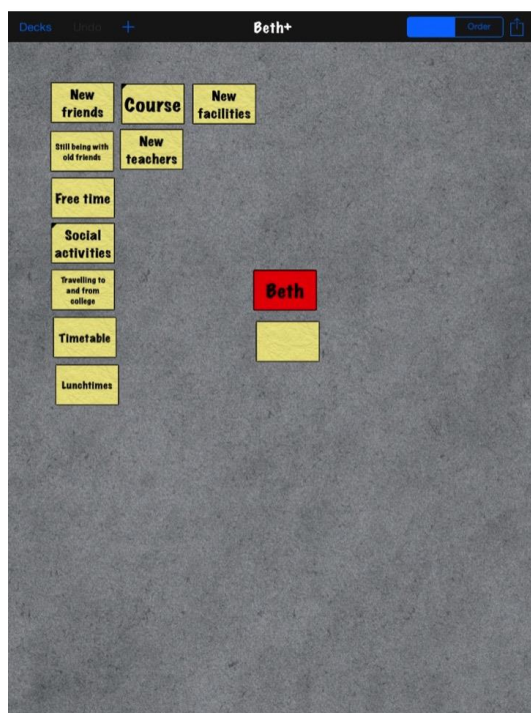
So for Beth, it was just fantastic for once she was going to school happy um...the bonding of friendships seems to have happened in the last year she was in and the majority of them were boys so...but she loved her teacher Mrs Stowe as well, so it was perfect but I think it has worried me that she's sort of gone from this nurtured scenario to the big wide world really (Debbie, Beth's mother, Time 1)

Beth especially enjoyed socialising which was demonstrated initially in her collage (Figure 3) as she chose it as one of her key interests and wanted to add it to the pre-existing images. She appeared to be very socially skilled although autism in girls can present very differently and the ability to imitate social skills can mask the degree of autism (Attwood, 2007). Making friends and being accepted socially were clearly going to be key for Beth and she talked about this during her card sort,

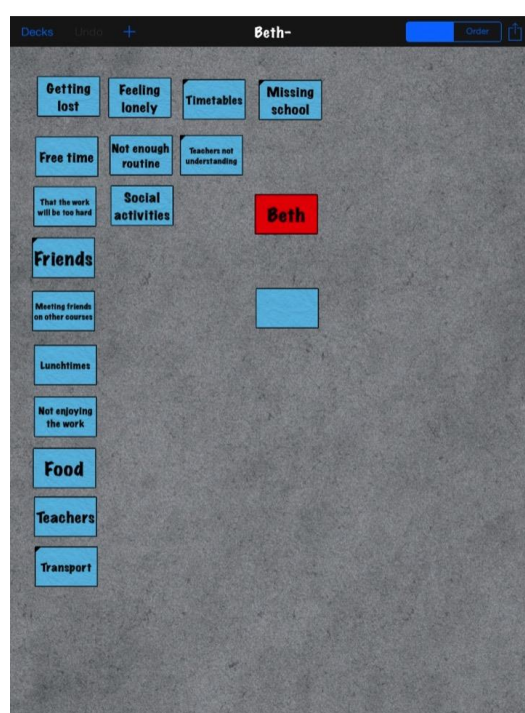
- Beth: It depends cos if I meet new friends then I could like be with them...erm...and this one again, if I had friends, I would enjoy the social activities (Beth, Time 1)

It was striking that new friends topped the list of what she was looking forward to and yet, friends, loneliness, social activities and free time were at the top of her list of worries. While the social side of college appealed to her she also had some concerns about, and some awareness of, how difficult making new friends might be.

a) Looking forward to



b) Worried about



**Figure 8 Beth card sorts: attitudes to college**

Beth was also able to add to the cards available in the sorting activity, as she was concerned about not being able to understand the teachers in case they were talking too fast but also she wanted to be able to tell them what she was feeling,

- JS: So is there anything we've left off there that you are worried about?
- Beth: Erm.....maybe...teachers talking too fast or something or teachers not seeing when I'm worried and me not being able to say to them that I'm upset or something
- JS: Teachers not understanding shall we put? And we can put things like talking too fast?
- Beth: Or that I can't say to them when I'm feeling weird or something
- JS: Can't tell them how you're feeling?
- Beth: Yeah or they can't see that cos sometimes it's hard to say what you're feeling (Beth, Time 1)



Beth was very clear that the right support at college would help her and she was also concerned about having to move classrooms and college being rather busy. Ultimately though, Beth wanted to be able to make friends and ask her peer group for help,

Also the thing I'm a bit worried about is apparently the media class, they have to change classes all the time or something, because...because... I've forgotten why but yeah...cos...sometimes it can be a bit busy and there's no classroom to be in so they're apparently scattered around a bit if you know what I mean but hopefully if I like get the right support at college, I'll be able to like find my way and all that if you know what I mean? (Beth, Time 1)

And yet, as the time to start college approached in August, Beth's was getting nervous as she still did not know who her support worker would be and she, understandably in relation to her autism, wanted to have those details finalised and know who would be working with her. This interim holiday period served to increase her anxiety about starting at college,

I am a bit nervous as I don't know who my support worker will be yet and the person organising that is on holiday. Other than that I am quite nervous but excited at the thought of starting! (Beth, email, August 2013)

### 6.2.2 David's Experience

David found it difficult to imagine the future and so, to some extent, appeared to be less troubled by transition as it was not yet here. He was able to articulate responses to the card sort activity and his mother did help to interpret and re-phrase my questions while not answering for him. David did not find it easy to talk to me especially in this first interview, partly, I am sure, because I was unknown to him. Both his mother and his teacher at school also said that he had difficulty expressing his feelings,

Well you can have conversations, it's very learnt his responses and you'll get 'how are you David' whatever the situation he will always be 'fine' because that's the response he's learnt. Everything's yes and no, it's all very short, it might not even be what he thinks but it's an appropriate answer to the question and that's how he gets through (Denise, David's mother, Time 1)

David is quite monosyllabic in his answers so you kind of ...so you ask him something and he just sort of says 'yeah' or 'no', so you say are you OK, 'yeah', are you looking forward to going to college, 'yeah' as you'll have seen and it doesn't always give you a massive insight into how he's actually feeling (Dan, David's teacher, Time 1)

This is where the card sorts were useful, to help him prompt and structure his responses, as he found it hard to recall some of the contact that he had had with college and also found it hard to imagine the future as it was not here yet. David struggled to conceptualise the imminent transition to college but also life beyond that

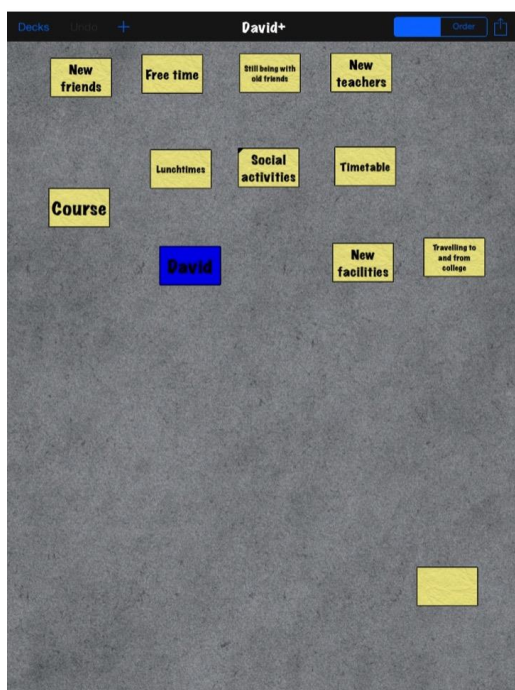


and was perhaps frustrated by my questions in this way. Here he reiterates that he just does not know what the future holds,

- JS: So, what do you think will happen after, thinking even further ahead now which I know is hard but say you do your course next year and that's all good, what do you think you might do after that?
- David: Don't know. Seriously do not know.
- JS: Do you think you might want to stay at college longer then?
- David: Mmm, second year probably?
- JS: What sort of thing would you like to do, do you think?
- David: I honestly do not know
- JS: And what about ...do you see yourself leaving home and sort of living with friends one day or...
- David: Don't know, haven't really thought (David, Time 1)

While doing the card sort activity however, David was able to articulate some ideas about his concerns but the activity itself was intrinsically useful in that it forced him to make choices and to put the cards in order. Given wholly blank cards, it might have been difficult to think about the future and about concerns about college; this card sort helped to structure a response and also created physical referents on the tablet that could be touched and moved.

a) Looking forward to



b) Worried about

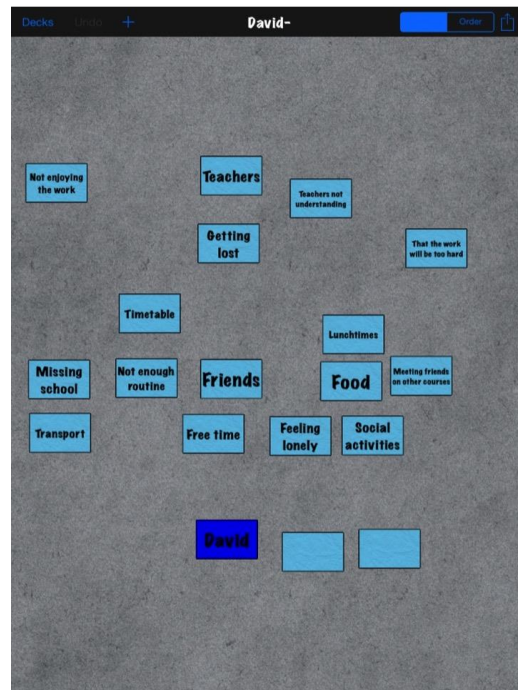


Figure 9 David Card Sorts

Although it was harder for him to discuss and explain his choices and here he relied more on his mother and I to summarise his thoughts,

- JS: And then teachers? Just bit worried about new teachers and what they are going to be like?
- David: Yeah, what if they're going to be like...I don't know....[pause]
- JS: Yeah...and teachers not understanding? Bit worried that you might get lost because it's new buildings and there are quite a few buildings at the college aren't there especially if you've got to change from one lesson to another?
- David: Yeah
- Denise: I think they're done in groups though aren't they? When we visited David, yeah? Do you remember? They were saying that if you were going to go off to do like your carpentry then they will take you in groups with a tutor so that they'll always be guided so you should be fine with that. We shouldn't lose you! [laughs] (David, Time 1)

His card sort also showed that he was looking forward to making new friends at college as well as being with his old friends; he was concerned about not enjoying the work and teachers not understanding him. David did have a sense of the move to college though and had been on regular weekly visits for several weeks that had been organised by his school (Larkspur). He had more of a sense of the concrete changes to do with uniform and who would be going from his school,

- JS: Um and what do you think might be different about going to college than going to school?
- David: Well, you don't have to wear school uniform
- JS: Yeah, good point. So will you prefer that?
- David: Yeah (David, Time 1)

Denise felt that the college preparation for transition for parents was a little confusing as they seemed to have been invited to the generic welcome evening, that emphasised issues like the importance of homework for example. This had added to the stress and confusion of transition,

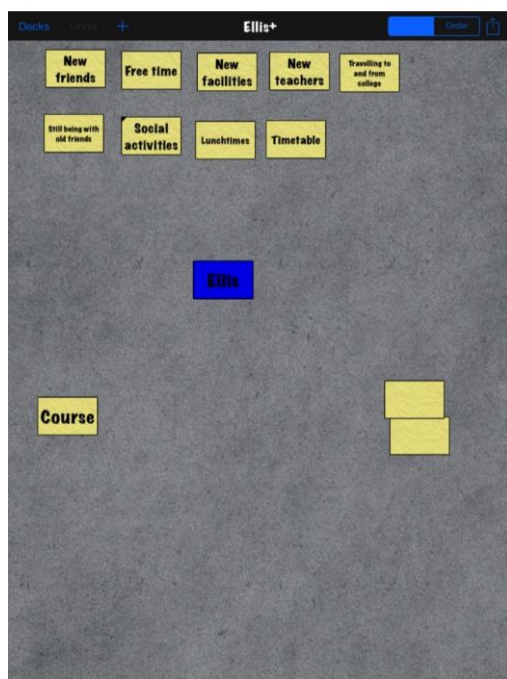
At this stage, I don't really have concerns about that, as I say the homework is the biggy for me because the other night they were saying if they don't do the homework they won't be able to stay on the courses and you know, there's no excuses, you know, there were all these people in the hall [at the welcome evening] and I was thinking have all these people got special needs children, you know, I didn't know quite where I fitted in with everybody else (Denise, Time 1)

### 6.2.3 Ellis's Experience

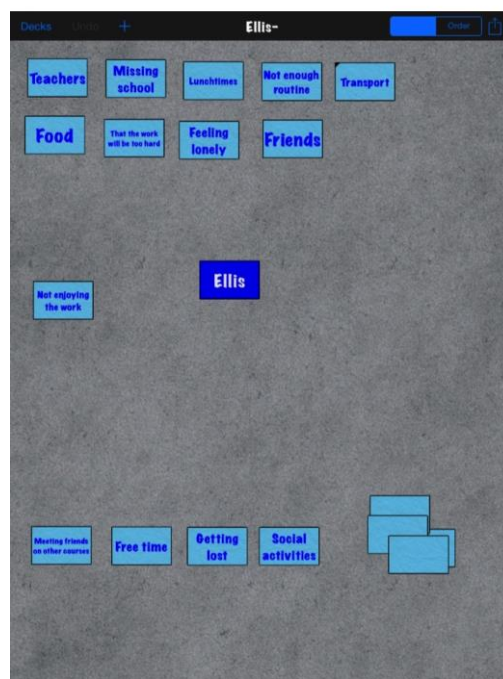
Ellis was going on to a local college within cycling distance, or a bus journey from his house, and was going to take a vocational learning course that would introduce him to

different subjects during the year at foundation level. He had been on visits to the college although there had been some confusion about the different sites. Ellis did the card sort activity remarkably quickly, partly because he understood it straightaway but also because he was in a hurry by then to go out. He arranged his cards in lines of equal importance.

a) Looking forward to



b) Worried about



**Figure 10 Ellis Card Sorts**

Clearly he was looking forward to free time and making new friends. We discussed a couple of concerns including his apprehension about the teachers but also about food during the conversation afterwards,

- JS: So things you're worried about...teachers, is that because you don't know them yet and how will they be and will they understand and everything?
- Ellis: Yeah
- JS: Missing school a bit. Lunchtimes - is that...do you mix with the whole college at lunchtimes?
- Ellis: Everyone uses the same cafe, yeah.
- JS: Not enough routine?
- Ellis: Yep, getting used to that new routine.
- JS: Transport, might be alright but if you move that might be more tricky mightn't it? Food - is that....do you normally take packed lunches and things to school? And will you carry on with that or go to the cafe?
- Ellis: There might be things there that I will not probably eat and then I would end up going hungry cos I wouldn't eat it
- Elaine: We'll probably carry on with the packed lunches. I know what he's eating then (Ellis, Time 1)

Ellis's mother, Elaine, had had some confusion with communication from the college prior to Ellis starting there (similarly to David's mother), and had had to contact the college to make sense of arrangements. A letter had gone out to some people and not others but had contained some incorrect information,

I've been in only once with them and the only other contact I had, they phoned up and said have you received a letter and it was like no, some people have received it and some people haven't but all the information on it is wrong and it's actually happening today so it was something which comes from somewhere else, it doesn't actually come from the college, but um, anyway, I sorted it out with them and he went down and had the pizza and stuff, you know, he's been two or three times, once with me, once with the school and this third time (Elaine, Ellis's mother, Time 1)

Ellis's mother also talked about the limitations of visiting Deepvale College but going to a smaller site which was 3 miles away from the main college which was not much use to Ellis who needed to see where he would be in September. The literal inclinations of autism and desire for the concrete (Wing, 1996) should surely guide the transition process more effectively?

Elaine: I think as well because on a Thursday, they used to go to Deepvale College but at Parker's Field

JS: Ah right so it's a different site, yeah

Elaine: Yeah a different site and they're being told they're going to college, but they'll be going to another college but because they go to this one... they shouldn't expect any differences, do you know what I mean - that they are both the same college, do you know what I mean?

(Elaine, Time 1)

Ellis, however, felt he had met some of the teachers and seen some of the classrooms he would have in September, he did have some really clear ideas about what the school could have done to help prepare him better for transition,

They could have done like a situation like erm...like role playing like what would happen when you go to college so they could have said to you - well I know that you don't have to wear uniform, you can wear what you want to school and you can call them by their first names erm...you don't have to call them missus or sir, erm, but they could have showed us what it would have been like before we went for a visit, so they could have showed us, oh you'll go into a room with some other people that you don't know, erm you'll be introduced and they'll introduce you with what you'll be doing, what floor you'll be on, where the lunch hall is...(Ellis, Time 1)

Elaine, Ellis's mother, would have been concerned if Ellis was going straight into the mainstream of college but as the course was set up for people with additional needs and she had been in to find out more about it, she felt reassured,

If it was just a regular course with regular kids, I'd be really concerned because he wouldn't keep up, he wouldn't be able to keep up what was going on or...or even understand what was going on, as it is designed for special needs kids and stuff and we, as mums, have got to go in and find out more about it and stuff and that's made me feel a bit better about it and the fact that they, if they need a scribe or something they can still have that there and um, you know he can have his own social worker there, not a social worker but his own confidante there, and stuff, they do supply quite a bit so....but I think until he goes and does it and gets the first day out of the way, it will creep up on him. (Elaine, Time 1)

These experiences reveal the different states of readiness in which the young people found themselves prior to transition: Beth had had an extra year at school which had helped but her mother was putting in the extra support to arrange college visits; David was struggling to imagine his future after school although he had attended weekly sessions at college and Ellis had had visits to a different college site but had suggestions of how they could improve transition. There was a sense in which the first year at college was being viewed as a transition year for these young people (Carroll and Dockrell, 2010).

#### 6.2.4 The importance of parental support

Where personalised transition was necessary, the key people who really seemed to adapt the transition experience were parents. Formal transition processes left gaps, especially where the colleges chosen by the young people were not the usual link colleges for the school. This is where parents of the young people in my study stepped in and added extra visits and extra preparation. As Angie explained above, Beth's mother had organised some separate taster days for Beth although she did suggest that the school would step in if the parents were not able to,

Actually all of them, they've got very supportive parents who have actually taken them for visits and things like that but had parents not been able or willing to do that then we would've done that (Angie, Beth's teacher, Time 1)

Angie also talked about Jake's mother being very supportive in terms of helping him to revise for his GCSEs but also in practising his new journey to college but it also implies that young people without such supportive parents would struggle more with independent travel and visits to their new colleges,

It would be interesting to see how he does because mum is very, very supportive in a positive way so he has been doing revision all year and he does the train on his own so he goes from H station to C station so he has to change at another station and then walk to the college so yeah, Mum is very good in that way, she's very organised and will give him those experiences

(Angie, Jake's teacher, Time 1)

The experiences of 'being prepared for transition' are inevitably variable and from the cases presented, they each seem to hold some anxiety about their respective moves to college that might be expected of any young person in this position. The card sorts helped to prompt their concerns but also drew attention to the fact that they seemed to be looking forward to many aspects of moving on to college. Some concerns could be relatively easily addressed such as identifying a key worker for Beth earlier on; clearer expectations set out for David and his family and as Ellis suggested, role playing the transition to help deepen understanding of it.

### 6.3 Managing time

Time recurred as an issue throughout the time 1 and time 2 interviews both in terms of dealing with unstructured time over the long summer period and in adapting to a part-time timetable at college. Here the summer holidays are addressed as a time during which there was little or no contact with school or college, a real time of 'limbo' for the young people and their families. There is also a rising concern expressed at the kind of timetable the students would have when they started at college and how this would work for them. On the whole, parents were more concerned than their children about the gaps in time but they were acutely aware of their own role in trying to help their children to participate in meaningful activity (Orsmond and Kuo, 2011).

#### 6.3.1 Summer holidays: 'it's going to be quite a big gap to fill'

After all this preparation to move on to college, young people and their families were then faced with a three month break from education which caused anxieties and difficulties around how to fill this unstructured time. They neither 'belonged' to school or college at this time. While the long summer holidays can be hard to fill for many young people, the challenge is compounded for young people with autism as they are likely to find it even more difficult to get temporary or part time work, initiate contact with friends, go out independently or have even have a concept of time. They were also in transition from school where they had had shorter summer holiday breaks, had had more opportunity to attend holiday clubs and were secure in knowing that they were returning to school in September. Young people with ASC can struggle to understand the concept of time and therefore planning ahead (Orsmond and Kuo, 2011) can be very difficult to do as already evidenced in David's case. There was no real preparation for the period of limbo between finishing at school and starting at college, it was just lots of preparation prior to leaving school (and prior to the exam period) and then nothing until September. Certainly that is how Jake's mother, Alison perceived it,



- Alison: And there isn't really any sort of link as in they don't give you...you know if you're going to start a course usually they give you preparatory reading or something
- JS: So it is a bit of a void in between?
- Alison: Yes it is a void, we've got to sort of make it up
- JS: And there's nothing happening to keep in touch with school over the summer?
- Alison: No, nothing at all (Alison, Time 1)

Jake did not seem concerned about the long summer holidays and felt that he was happy pottering at home, doing jobs and seeing friends, that he had enough going on over the summer for him not be anxious about it,

- JS: OK what are you going to do...it's quite a long summer break...
- Jake: Well I've got the prom on the 1st of July and then...probably...I'll be doing a bit of jobs ...seeing my friends and I'll be going to France for just over two weeks on my holiday
- JS: Oh that will be nice. So are you quite happy when you're at home?
- Jake: I'm happy
- JS: ...quite good at just doing things on your own and being at home?
- Jake: [laughs] I can do things on my own. I'm quite relaxed when I'm at home. I just do my own thing generally, yeah, just do my own thing. Sometimes go on the trampoline, sometimes go on my laptop, sometimes watch television, just do a mix of things really (Jake, Time 1)

In fact, it seemed that the long holidays were more of a concern for parents than the young people themselves, partly as parents felt responsible for organising any activities and that without their intervention, they were worried that their children would stay in their bedrooms. Parents also had a clearer concept of time and knew that it would be hard for their children to organise themselves so the parents had to do it for them. Denise was very concerned about how to fill the time for David and that he would be on his Xbox in his room for much of it but it was hard to find ways to entertain him,

It is a long time and I do feel at the moment that I'm left with nothing and how am I going to fill this time because he will just sit there, he will play on Xbox for 10 weeks so I need to be able to do something and people say, 'get him to come off the Xbox' and it's like 'to do what?' what do I do with him? He's happy and contented doing that but I just need to find other things that he will do erm....you know so it's going to be quite a big gap to fill... (Denise, David's mother, Time 1)

David was far less concerned about having time off, and struggled to imagine the future as reported in 5.3.2, although could perhaps see that the summer holidays were particularly long,

- JS: And what do you think about the summer holidays David, do you like having free time or do you prefer to be at school or college when you've got more things going on in the day

- David: Hm, it depends, if I have like one or two weeks it's really good because you don't get bored of like seeing everyone else and you get time off as well
- JS: And do you think you'll see any of your friends over the summer?
- David: Yeah
- JS: Yeah and what might you do - do you meet up and go to their house or do you go out somewhere?
- David: Yeah, yeah meet up and do stuff
- JS: Yeah, more Xbox or...
- David: Yeah (David, Time 1)

In fact, Meadowlands College was the only college that had been able to put on some days during the summer holidays to provide a bit of continuity and contact during that time. This was helpful for David and his mother to know a bit more about what to expect in September,

We've got I think 5 taster days that we're doing in the middle of August at the college erm and they're just getting to know the students so he gets to do that which is quite good so we've put down for that (Denise, David's mother, Time 1)

The summer holidays were of more concern to parents than young people partly due to the nature of autism and not being particularly able to conceptualise time but also because they relied on their parents to arrange social and leisure activities for them where they were unable to do so. The gap of three months did seem to be an 'interruption' to the whole transition process and put everything on hold during that time.

### 6.3.2 Timetables: when is full time not full time?

For some parents, the reality of starting at college meant that their children were no longer in 'full time' education because college courses are structured around a number of learning hours rather than a full timetable every day of the week. For example, to retain child benefit for a young person once they are over 16, they must be in 'full-time education' which is classified by government as at least 12 hours a week. Most colleges operate full time courses at around 16 hours or three and a half days a week. For parents, 'full-time' courses at college had connotations of full-time schooling or even full-time work hours. Jake's mother, Alison talked about how to manage Jake's free time during the week and how challenging it might be especially to help him to secure some part-time work,

- Alison: Yes, it's classified as full time but in reality it's three and a half days
- JS: And how will that be, him not being at....him having that day and a half? Are you around at home? Is that something you can help him manage?
- Alison: We're hoping that he'll be able to do something on that other day. We've got various ideas but it's quite um, I mean one thing is to try the supermarket because he did some work experience and it's something



that is quite good about school, they've organised work experience and he did a week at the supermarket and they liked him very much, they gave him a very good report and said if anything came up he'd be considered... which is nice but obviously we realise that it's not easy trying to get a job if you're special needs as they have to invest so much time in the person... (Alison, Time 1)

Jake was more relaxed about having time off in the week and could not foresee the difficulties that his mother was concerned about so he thought he would get a job in his spare time although he does agree that it would be hard to find a job,

- Jake: I get a half day and I get a day off on Wednesday so it's only three and a half days a week  
 JS: And is that good or bad?  
 Jake: Well it's good because it means there's less time at college but errmm...it should be good  
 JS: And what will you do at home on your day off do you think?  
 Jake: Errm...I'll probably just find a job cos ...well I'm gonna hopefully get a job in the summer and then I'll be able to just do that (Jake, Time 1)

Interestingly, parents worried that this lack of structured time could lead to greater anxiety for their children and this concern was expressed not only by Alison but also by David's and Eric's mothers,

I think a degree of anxiety comes into play if there's nothing happening and he doesn't know what's happening when um, so yes I think we need to get something sorted out (Alison, Time 1)

Denise was trying to work out how much contact time David would actually have and that the college had had to cut a lot of courses (this also happened to Jake whose course changed),

It seems to be three and a half days a week um...but then we got a letter saying the government had cut funding to the teachers and tutors and stuff and a lot of the courses, the teaching time is now going to be reduced so whether it's going to still be three and a half days, I don't know [laughs] (Denise, Time 1)

The idea of a full time course being only three days was a shock to Phil, especially as a single working parent, it presented some issues for him. Fortunately he was part-time and his employer was reasonably flexible but it still had an impact,

- Phil: Yes, they said it's full time and then I said, great, five days a week and they said, yep, that's three days a week, eergh, that's not full time that's part time.  
 JS: Yes, when you get to college that's how they quantify it isn't it?  
 Phil: That's how they count things, yeah, 5 equals 3  
 JS: So how's that going to work?  
 Phil: I don't know yet cos I work three days a week so obviously it would make sense for my work and so forth to coincide so that we can sort

of like um, do other things or so forth the rest of the time (Phil, Time 1)

Phil shared the anxiety Denise expressed in terms of engaging his son in meaningful activities during his time off,

- JS: Yeah. And how are you going to cope with those two days a week when he's not at college, what do you think he might do during that time?
- Phil: [pained] I don't know. I'd like him to do something apart from sitting on the sofa looking at the computer and so we're going to have to think about that.
- JS: Would you prefer it to be full time?
- Phil: Um...yeah I think I would, yeah, it would be easier, even 4 days would be a lot easier, um...and I would and I would prefer there to be something structured for him to do in the other two days other than pick himself up because I think it's been sold to me as sort of like directed learning whatever on the other two days and yeah, right (Phil, Time 1)

Preparation for transition then has been explored from the perspectives of the school and also the young people and their parents. While it was clear that systems and procedures were in place and transition planning was a key part of the schools' agenda, there were discrepancies in how preparation took place and what the concerns of the young people were. Preparation for transition to college seemed to rely on formal links with certain colleges but if the young person fell outside that planned route then transition arrangements were more ad hoc, less satisfactory and relied more on parental organisation. This preparation did not really include how to manage the summer holidays or indeed how to manage a part time timetable once at college. The concerns of the young people, in particular relating to their autism, were not necessarily taken into account by the school preparation for transition. Beth's and Ellis's needs were not specifically addressed, for example, Beth's need to know who her support worker would be or Ellis needing to see the actual college site where he would be taught and not the satellite site. Similarly, parents were not well informed by the colleges and received inaccurate information, or no information or were included in a generic welcome meeting that raised anxieties rather than contained them.

The next chapter begins by reflecting on how the young people and their parents managed the summer holidays and the part-time nature of college and goes on to explore the experiences of the young people at college, how they progressed academically and socially.

## Chapter Seven: Data Analysis (3) – starting at college

This chapter begins with a reflection on how the young people and their parents managed the long summer holidays and the new part-time timetables of college. It then moves on to examine the academic and social transition experiences of the young people as they progressed into their colleges of further education. In particular it explores the tensions between academic and social progress; the inherent challenges presented by the social world for young people with autism; the extent to which their lives are managed by others and returns to the theme of social interaction touched on in 5.2.

### 7.1 Managing time

At the end of the last chapter, the young people were leaving college and their parents were already concerned about the length of the summer holidays, here the data analysis reflects on how they experienced the summer holidays, how they managed that time and how they adapted to part time timetables once at college.

#### 7.1.1 Managing the summer holidays

Towards the end of the summer holidays just prior to starting college, I emailed the young people and their parents with the same set of questions about how they managed the summer holiday period:

- 1) I wanted to know how the summer holidays have been going for you and what kinds of things you've been doing.
- 2) Have you been into college, or had any communication with college over the summer? Do you know what date you are starting at College?
- 3) How are you feeling about starting at college?

David replied succinctly:

- 1) It's been alright and i met with my friends [sic]
- 2) Been to the summer school and start date might be the 9th September
- 3) I'm alright (David, email 23/8/2013)

However, it is interesting to consider what is left out of David's response when contrasted to his mother's email. She gave a more detailed account and said that he had only met up once with his friends and that he had spent a lot of time on his own:

He didn't do anything socially really, didn't want to get involved in anything, didn't want to go anywhere and that's what he's always like but through the summer holidays it's very difficult [...] you know, he sat on his own, which obviously isn't doing very much good for him so yeah, it was, he did spend a long time on his own and despite me saying do you want to do this, do you want to do that, go to the cinema, suggesting things and offering to take him to places, he did spend

quite a long time on his own (Denise, David's mother, email, 23/8/2013)

More significantly, Denise had become very concerned during the summer holidays about David's mental health and that long periods alone in his room were not helpful,

I would definitely say that David has been quite withdrawn over the summer break and he has not wanted to take part in any activities. Although he says he has seen his friends over the holiday, the reality is that he has seen one friend and that was only because he travelled to college and school with us for the summer school and to collect results. I am looking forward to him starting college so he has some social contact. To be honest I am a little worried that he might also be a bit depressed, I know this is common in people on the spectrum.

(Denise, email, during summer holidays)

At the time of the first interview, Frankie had already been at home for a month and had been spending quite a lot of time on his computer. Frankie, unlike David, was able to go to the cinema on his own occasionally, so he did get out more but his father was concerned about the amount of time, he was at home on his own,

Phil: He finished a month ago so he's been sitting around not doing a great deal haven't you?

Frankie: No, just been on my computer all the time

Phil: Cos I've been working and he's had nobody to hang out with so he's been a bit bored

JS: [to Frankie] Is that quite difficult having the holidays from school that it's quite a long time this year isn't it? Or do you like just going on the computer, are you happy doing that?

Frankie: Well sometimes, it's a bit of both really, I prefer to go out and do something (Phil, Frankie's father, Time 1)

Frankie's father also reflected on this in the Time 2 interview when I asked how the summer holidays had been and again he comments on the length of time as well as Frankie's time spent at home not doing very much,

For three months, it just went on and on and on and so that was bonkers and the other thing was I didn't appreciate the fact that he would be out of school after he did his exams so that was a surprise to me so he was actually sitting on the sofa for quite a long time doing bugger all (Phil, Frankie's father, Time 2)

These difficulties with managing time resonate with the research carried out by Orsmond and Kuo (2011), who identified that adolescents with autism spent more time using computers and watching television than their peers without autism. They also spent more time alone at home, typically with their mothers, or paid care-givers than socialising with their peers.

### 7.1.2 Managing part-time timetables

Frankie talked about how he managed his free time during the week and thought that he might prefer to be at college when he did not have anything to do at home sometimes,

- JS: So what do you do in the day if you're not going to college?  
 Frankie: I either go out or stay in and play games or chat with friends on Facebook  
 JS: And that's OK is it? Is it alright on those two days?  
 Frankie: Yeah, sometimes but sometimes I don't have anything to do  
 JS: Would you rather be at college every day?  
 Frankie: Maybe (Frankie, Time 2)

But the attitude from the college tutor was very different that with the kind of students they have on their course (a mixture of students with learning difficulties and students who had behavioural issues or who were low attainers) that they just wouldn't come in, but she did not seem to be thinking of students like Frankie at this point,

- JS: Do you think they would benefit from 5 days a week?  
 Fiona: They wouldn't do it, the problems we have getting them in 3 days a week  
 JS: Is the attendance not great then overall?  
 Fiona: No, not always, a few phone calls home  
 JS: Even though there are buses laid on aren't there?  
 Fiona: Yeah, oh it's honest and they're like we couldn't be bothered to get up - they're very honest  
 JS: So it's quite a long day is it when they come?  
 Fiona: Yeah, they just don't see education as important, they just don't, mind you, neither do the Level 3s so I think it's students...but I don't think they'd come in for five days, I don't think they'd cope with it  
 JS: And what do you think they do on their days off?  
 Fiona: I know what they do, they all sit around and they play computer games and they don't do anything (Fiona, Time 2)

The tutor was very sure that students would not attend a full time course and yet was very aware of how they might be spending their time when not at college. This does not chime with Frankie's response that maybe he would rather be at college full time.

David was not especially concerned about having time off during the week although he was not clear about how he filled the time,

- JS: So what do you do on your days off?  
 David: Erm...mostly sit at home or whatever, pretty much prepare for the next day  
 JS: Yeah, and do you mind that? Would you rather be in college every day or not?  
 David: No, I'd prefer to be ...obviously not too many days off but...

JS: Yeah so do you think it's the right balance at the moment, that you've got enough time at college and enough time off?

David: Yeah (David, Time 2)

David's timetable was part-time but got even smaller as he had passed GCSE Maths so he had three more hours of free time when he would have been taking numeracy. It seemed as though the more David progressed academically, the more free time he was given by design or default, and yet, free time was the aspect of college he was likely to find the most difficult. Additionally, because he finished coursework on his vocational options, he only had to go in on Mondays and Tuesdays for three weeks just prior to half term,

Denise: Originally they had him down for Maths and he started doing that and then when they realised he got a grade C they said 'oh he doesn't have to do it' ... so at the moment he's doing the English and the ICT on a Monday afternoon and doing this whole day on a Tuesday and these are finished so he doesn't go in any more [pointing to the rest of the week]

JS: Why have they finished?

Denise: At the moment he's not doing very much time at all at the college, apparently he finished the coursework and that's it so until the other side of half term now he's not going in any more

JS: So he does all day Tuesday and Monday afternoon and that's it

Denise: And that's it. So it's still a bit of a struggle. (Denise, Time 2)

Jake and Eric had talked of trying to get a part-time job on their one day off during the week but this had not come to fruition. Lack of structured time in the week was problematic for Frankie and David to an extent, although it was of less concern to them than their parents. While being in their bedrooms on the computer might be an issue for young people more broadly, there are additional factors for the young people in my research as they had less access to a peer group (Jackson, 2002; Mather and Ofiesh, 2005; Small et al., 2013) and possibly less ability to plan ahead for social times (Ozonoff, 1997; Jordan and Jones, 1999).

## 7.2 Academic Progress

This section focuses on two case studies in particular that give contrasting examples of academic progress, highlighting that this part of the transition is not as straightforward as it might seem. Typically young people leaving school and going on to college apply for courses and qualifications at a level suited to their predicted or actual grades and are interviewed for their suitability to those courses. For young people with learning difficulties leaving special school, a careers adviser will explain the range of courses available locally, discuss their future plans with them and write a 'Moving On Plan' but

academic *progression* was not necessarily seen as the most important element in this process by the parents or the teachers in this research.

### 7.2.1 Jake and the academic compromise

Jake, who had done well at GCSE level and was technically qualified to go on to at least a level 2 course at college, chose, following advice from his parents, careers adviser and teachers, to go on to a foundation level qualification. The rationale for this was that he would get more support, as the course was taught within the special needs department of the college, than he would if he went straight in to the 'mainstream' of college. Interestingly, Jake did find the work easier but he did not mind that too much as he felt that he had a good English teacher (a subject he had struggled with previously) and this experience of the level of work being easier, resonates with Carroll and Dockrell's (2010) findings for young people with speech and language impairments,

- JS: And how are you finding all the work this year? Are you finding it easy, is it easier than school? Is it about the same? Is it more difficult?
- Jake: Well I would say it's easier because it's lower quality but...because last year I was doing GCSEs, this year it's like entry level...but I am doing functional skills 2 in English which is equivalent to a C but I would say it's slightly easier...it's gonna be harder when I do my next course because that's more mainstream but I think I should cope well because I know lots of people
- JS: And you don't get bored in any of your lessons because you think it's too easy?
- Jake: Well no, it's always good to make the most of the course because the course is actually helpful to me at college (Jake, Time 2)

Alison, Jake's mother was very aware of the fact that Jake would be working at a level lower than he was used to but felt that in order to make the transition to the mainstream, then it was a necessary choice and yet she had put hours of work into supporting Jake through his GCSEs and really making sure that he achieved the best that he could,

Yes, I mean Avril [college tutor] was quite frank at the beginning really, she said you know, really he's at a higher level than all of the others and we occasionally do get somebody like this who needs that time, that support, because really we felt that going straight to mainstream from special would have been too much [...] I think he'll probably be a bit bored by some of the options um...but...I think it's a sort of necessary process really. (Alison, Time 1)

Jake's college tutor, thought that he was very able and that he could have coped academically with a higher level course but the support would not have been as

comprehensive and he still needed support with social interaction in the bigger environment of college.

- Avril: He's probably the highest ability student I have ever had, I've had equivalents to him but yeah, he is the top of my range really
- JS: Because technically could he have gone into the mainstream of college at level 2 or something
- Avril: He probably could if he'd applied for it but this department is just that little bit more protective, it's a bit of a step from a small school which he came from into the big wide world, it's about his socialisation, that's still a little bit problematic, he's not always entirely um, appropriate with his peer group and how he phrases things so but yeah, this has been a good year for him, he's done really well and worked really hard, he does, you know, a class full of Jakes and my life would be a joy! [laughs]  
(Avril, Time 2)

The support that Jake received during his first year at college was effectively a 'transition year' and did seem to help him to prepare to go on to a BTEC course alongside 'mainstream' students the following year. When we met, during his second term at college, to do the walking interview (Appendix L), one of the first things he told me was about his progression onto a BTEC level 2 course for the following academic year and how he had been accepted after his interview,

- JS: And how's it all going...are you enjoying it?
- Jake: Yeah, I had my interview yesterday for my new course
- JS: Oh, is it ICT?
- Jake: ICT BTEC level 2, yes. They said that I'd be the perfect candidate for it [smiling]
- JS: Oh, well done (Jake, Time 2, walking interview)

He wanted to take a picture of the room in which he had had the interview for the course as it had been a really positive experience and while the photo was taken into the sunlight coming through the door, it seemed like an appropriate metaphor for how he felt about continuing his studies the following year,



**Figure 11 Jake's interview room**



Although Jake had found the work at college easier than at school, he did appear to be settled at college and was happy to show me all the parts of college that he visited. The time he had spent in the learning support part of college did seem to help him to prepare for the wider environment beyond.

### 7.2.2 Beth and the support compromise

Beth had also done well in her GCSEs and had achieved some excellent grades including A\*s for Art and Photography, A for Media and a B for English. She also had a D for Maths. Beth's mother was keen to support and fight for her ambition to take up a BTEC level 3 course in Media as she was academically capable and therefore should be entitled to proceed at that level. She was not, however, oblivious to the potential difficulties that could come with this transition given Beth's mainstream school history.

They didn't actually want her to do level 3, they were trying to dissuade her and saying do level 2 cos then you'll get more support and der dee der, and I just thought well, no, cos academically, and they really were pushing her to do level 2 and she said to me that when she was shown around. The kids that were doing the level 2, she would already have done that work and I just thought, cos she said she'd really like to do level 3 and I think you need to do level 3 Beth but they were really, they were really trying to push level 2 for her and...We kind of fought that one and I said no, she wants to do level 3 and now I'm sort of thinking, if you start, I'm going to start quoting laws, I'm going to dig out, you know, disability laws and stuff and...um....and as I reminded them, academically she'd got the grades, the only one is Maths I think she's gonna have to resit. (Debbie, Time 1)

Having spent an extra year at school, Beth was feeling confident and positive about the decision that she had made 'definitely feel that it's right, I get a good feeling about it if you know what I mean?' In the previous year she had been more interested in performing arts but was concerned about cliques. This course felt right and that she could go on to pursue her interest in animation afterwards. Despite this conviction about making the right course choice, Beth was very aware of the support that she would need and she certainly had anxieties about going on to college and how the support would work. Unfortunately, it would seem that she did not have enough support or understanding at college and she left during her first term. Her mother withdrew Beth from the study before the follow-up but wrote explaining that her withdrawal from college was due to the college not understanding Beth's needs in relation to her epilepsy.

One could argue that Jake opted for a slower transition into college by choosing to follow a lower level course than that of which he was capable and, as a result, was

making progress socially in acclimatising to the college environment. Certainly when compared to Beth's case, it would seem that Jake made a good decision and yet, why should young people with autism need to compromise academically because of the difficulties with their social environments? If Beth had had more appropriate support whether for her epilepsy or her social interaction needs, her story could have ended on a more positive note (Breakey, 2006). Similarly, Jake could have progressed academically had the social support been in place on mainstream courses (Plimley and Bowen, 2006) and not confined to the learning support department (Kitchin, 2000).

### 7.3 Social Interaction

One of the most striking findings of this research is the overwhelming interest in social interaction that these young people articulated and exhibited. Despite the difficulties and challenges that they sometimes faced when negotiating the social world, all of the young people in this study wanted to have friends and connect with people on a daily basis and for all of them it was in their top three cards in the card sorting activities when thinking about what they were looking forward to about going to college. While they had expectations of having friends, a social life, potentially having girlfriends or boyfriends and getting married one day, their lived experience and that of their parents was not so straightforward and it was clear that their experience of the social world could be fraught with misunderstandings. Friendships, peer groups, bullying and socialising were all themes which recurred throughout the data across the case studies and seemed to play a huge underpinning role in the relative success of the transition process and the ongoing engagement of young people in further education.

These experiences affected their wider lives both positively and negatively; they had an impact on academic progress and course choices; they influenced family relationships and also their overall wellbeing. Some of the young people or their parents gave examples of bullying, very restricted social lives, but others did take part in clubs and activities outside of school and were able to socialise more independently. This section focuses on social experiences and examines friendship, bullying, social lives, use of social media and the developing social confidence seen in some of the young people. The section ends with a discussion of how profoundly these social experiences had implications for successful transitions to college and to adult life.

### 7.3.2 Eric and getting it right with girls

JS: So what do you do in your spare time then when you've got free time at college?

Eric: Ah, just sit with the girls and Georgia

JS: In the cafe?

Eric: No, just sit in the college and speak to them or wind up Kim

(Eric, Time 2 interview)

We don't really have that many behavioural difficulties with him but then I do hear in other lessons that he will kick off and they'll get inappropriate language or abuse hurled particularly towards females calling them 'slags' and things like that without an awareness of upsetting other people's feelings or quite how severe it is to call someone a 'slag' just because you happen to be in a bad mood.

(Cathy, Eric's College Tutor, Time 2)

Although Eric's interest in girls might be seen as age appropriate, there were issues raised in relation to the way in which he behaved towards girls both at college and also online. These concerns were borne out by his tutors (Cathy and Maddy) at College and it was clear that they were keeping an eye on his relationships with girls as some of the girls were very vulnerable themselves and Eric's behaviour was bordering on stalking,

Maddy: [in hushed tones] He's kind of found girls....

Cathy: He's vulnerable, he is vulnerable because we were very worried about some of the ...one in particular, Foundation girls contact with our students who are actually not EBSD or whatever it is but are actually autistic or with learning difficulties, I think there is a real vulnerability there

Maddy: The majority of the Foundation girls are actually really sweet and really good and he didn't stalk them but nearly ...so we were saying to the girls, right you need to tell him really nicely that we're just friends, that's inappropriate so they were really, really good but as Cathy said, there's kind of one that we're watching but there's no reason to think that there's anything but yeah, he's lovely at the moment because he's getting hugs from all of them, these quite pretty Foundation girls so it's kind of ...a whole new aspect of coming to college

(Cathy, Eric's College Tutor, Time 2)

Some of Eric's social difficulties were about being able to tolerate other people and regulate his own responses. There were several occasions where Eric referred to situations that he found annoying, or that the people who were in those situations annoyed him, one example of this was two girls who chatted a lot ('annoying Sandra and annoying Rachel' as he referred to them) which he found difficult to tolerate to the point he wanted to 'mute' one of them,

Eric: Sandra, she talks, talks, talks...it's like when you want to talk someone, you don't want to turn around and tell them to be quiet or have some control so you can mute them

JS: So it's tricky?

Eric: If you could mute people I would invent a mute for people so I can mute Sandra (Eric, Time 2 interview)

Eric was formally excluded from college at the beginning of his second term in January because he had hit back at a student who hit him over something that Eric had said. This coincided with Eric's mother being in hospital with pre-eclampsia and the premature delivery of her baby so Eric was excluded from college for several weeks instead of days as his mother could not get to the meeting at college any earlier. Sally, Eric's Learning Support Assistant tried to help him to make sense of what happened,

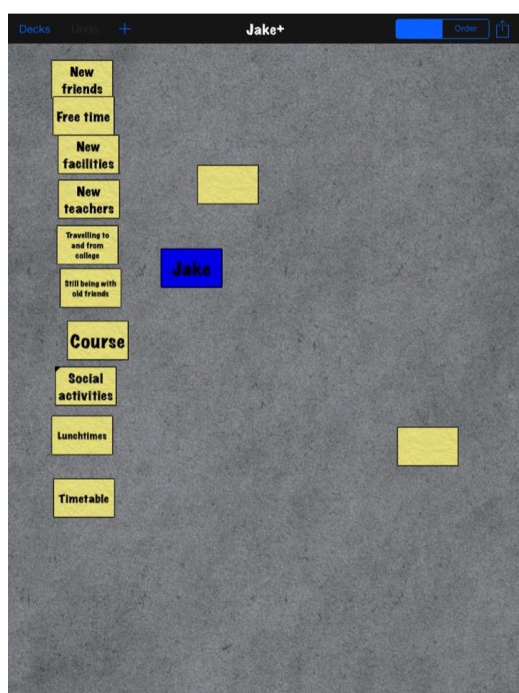
JS: So what happens if there are people you don't like then? Sounds like Sally's saying you're a lot better at not getting so cross

- Eric: Someone did punch me in the face once and I punched him back um, he got suspended and he came back early and I got suspended for weeks and weeks for no reason
- Sally: You both got suspended but the point is when you get suspended because there is a no tolerance of
- Eric: But he hit me first (Eric, Time 2)

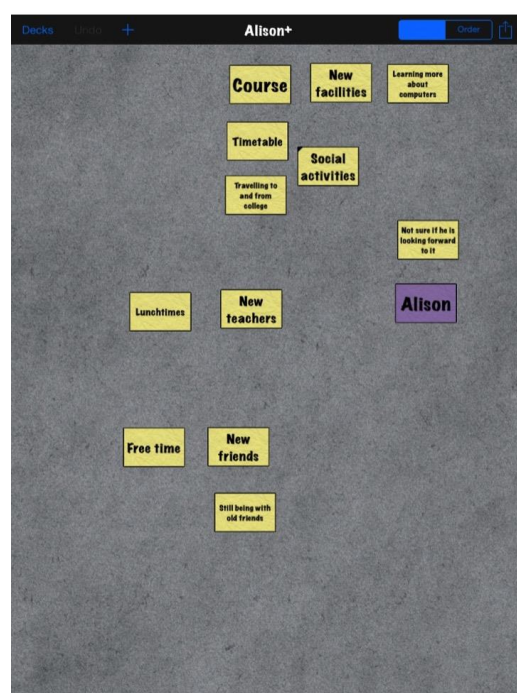
Interestingly, all the young people had established positive relationships with adults, particularly with their parents but also with teachers or teaching assistants at their special schools. Eric was particularly able to get on with adults, perhaps more so than his peers, as he did not really talk about friendships during his interviews with me but he did acknowledge the bond he had with Sally, his Learning Support Assistant (LSA). Sally was present during my interviews at college with Eric to help facilitate the discussion, to support Eric as he had to be supervised at all times and to help me make sense of things he was saying sometimes.

### 7.3.3 Jake and friendships

a) Jake looking forward to



b) Alison thinks Jake is looking forward to



**Figure 12 Jake and his mother's card sorts: looking forward to going to college**

Jake talked about the teachers being generally good at college which was one of his concerns on his card sort although he did express concern about his social interactions. Once at college, Jake did have a few difficulties partly because he went

into a wider social world where the other students were perhaps less aware or less understanding of his social difficulties. One of the first things he commented on when I asked him about how college was going and how it had been with new friends was this break up and he is disarmingly honest about the reasons why they might have got back together,

Uuuuummmmm, I've had a few problems, a few break ups but it seems to be, at the moment going well with friendship side of things, um, I met one of my old friends from school, he's in Year 10 at school but I met him last week so I still get to see some of my old friends but it's nice that I'm starting to make new friends which is good, I've been doing that since the autumn term but I've had one break up but then we've sort of got back together cos my friend kind of has a, well his dad's got a brain tumour and he's going to go for an operation in the summer and he said he might not make it so I think he kind of wants to be friends with me not because I'm a nice personality but because he wants someone to comfort him in that part of time (Jake, Time 2)

This incident had upset Jake although he was able to make some sense of why it had happened but it had not felt very good to have broken up as friends for a while. I asked him if he knew why they had broken up as friends,

At the time he had a girlfriend, and it's kind of my fault because of what I mis- um, what I basically said and what I shouldn't have said, I was talking about his girlfriend and I shouldn't have really been talking about his girlfriend um, and mis-pronounced her name, and he got up and said ' ooh do you want a punch or something?' and the TA at the time was like ' now do you want to have 5 minutes outside?' but yeah, we were kind of weren't friends for a while, like about a few days and now, for a few weeks we weren't proper friends and then we became friends so he forgave me for that which was [exhales relief] (Jake, Time 2)

Both Jake and Eric needed some support with understanding social situations with their peers; Eric had been excluded as a result of possibly mutual misunderstanding; Jake had experienced an unsettling time following his break up with a friend. While social skills interventions per se have not been proved to be very effective (Bellini et al., 2007), some ongoing work with peer groups and developing resilience could have been helpful (Morrison and Cosden, 1997; Mather and Ofiesh, 2005; Evans and Plumridge, 2007).

#### 7.3.4 Bullying

One of the difficulties for a young person with autism is that they may not realise that they are being bullied because nobody actually announces that they are going to bully you so it is not necessarily obvious (Jackson, 2002; Moore, 2007). The other difficulty is that they might not think of letting an adult know which could, in part, be due to 'mind-blindness' or a lack of theory of mind (Baron-Cohen, 1985). In this research,

Jake, Beth, Eric and Frankie had all experienced bullying to some degree and their parents did know about it. However, it is inevitably unclear whether there were any other bullying incidents not mentioned, or whether the other two young people had experienced any bullying but not reported it. Some of the bullying incidents are touched on here.

In the Time 2 interview with Jake's mother Alison, she was surprised that Jake had not mentioned an incident that she had considered to be worse than the falling out with friends, which was when another student had hit him. Certainly, Alison had not known about the incident with Jake until later in the Christmas holidays,

In the Christmas holidays he said that James had hit him and um, never mentioned it before...and I tried to get information out of Jake which was very hard to come by. He wasn't very willing to talk about it and um, the gist of it is that I got in touch with College afterwards because I really wasn't sure whether it was a playful punch or whether it was something more, I mean Jake said it was because he was talking too much about computers. Apparently it wasn't in the lesson, it was outside a lesson, otherwise obviously I would have hoped staff would have dealt with it but the staff knew nothing about it because it was outside a lesson. (Alison, Jake's mother, Time 2)

While there had not seemed to be any incidents while at school, Frankie did talk about a bullying incident at college where he had been forced to smoke by another boy and threatened with a whip. He was clearly upset and scared by what had happened,

Frankie: Sometimes yeah, cos we've had someone called Ellie who is very nice, cos like, well this happened a while ago this year, some horrible person like forced me to smoke  
 JS: Really?  
 Frankie: Yeah cos he said 'oh if you don't smoke I'm going to whip you with this whip'  
 Dad: Was it a real cigarette Frankie?  
 Frankie: Yeah it was a real cigarette  
 Dad: Not an e-cigarette?  
 Frankie: No, it wasn't an e-cigarette it was like a real one  
 JS: And this was another student was it?  
 Frankie: Yeah and I had to tell my Dad straightaway cos like I was very scared of what happened (Frankie, Time 2)

During the college tutor's interview however, it became apparent that there had been at least one other bullying incident although this was not mentioned by Frankie or his father. Ellie, Frankie's tutor, highlighted the challenges for both young people in this instance as they were both on the autistic spectrum:

They took a board rubber covered in black and just started, they just blacked Frankie up you know, just completely blacked him and that's one I caught myself,



I heard all this shouting, I came out ready to be cross with the person shouting and found it was Frankie being attacked and I was able to stop it in midstream and deal with it straightaway you know, but the boy doing it, he's got his own problems and I think a lot of the time when these things happen it's because, you know, it's not a problem in the college as such it's just again dealing with people with all these differences you know. (Ellie, Frankie's college tutor, Time 2)

Jake and Frankie had clearly struggled to make sense of the social situation in which they found themselves and also delayed or did not tell other about these incidents. This connects with Baron-Cohen's argument (1985) about lack of theory of mind in autism and these experiences concur with those recounted by Moore (2004, 2007).

### 7.3.5 Use of social media

Social media had played a role in the social lives of most of the young people and had enabled them to keep in touch with friends virtually when it was sometimes difficult to meet up in person. Eric and David tended to play Xbox and other games online with other people, and Beth, David and Jake used it more to keep in touch with people via Facebook and Skype. Jake in particular was a very keen use of Skype, Facebook and Twitter and was very motivated by the idea of being able to contact his friends,

- Jake: Yes, yep, I've managed to keep ...both of them are on Skype so I talk to them both on Skype, one of them who's actually at school still actually got Skype about two weeks ago surprisingly enough... but...yeah...it's kind of nice to still keep in touch with people through Skype so I still do some of that
- JS: And do you use any other things like Facebook or twitter?
- Jake: I use Facebook and I use Twitter um...I use Steam which is this thing where you can play games and chat to people at the same time but...I use...well I use emails occasionally (Jake, Time 1)

David also frequently used Skype in his bedroom to play games with friends via the internet and this was more sociable than just playing Xbox on his own and was mentioned in his second interview when he seemed to have become more socially confident,

- JS: I was also talking to your mother about using, you don't use Facebook or twitter
- David: Not that much no
- JS: But you might Skype friends or
- David: Yeah I use Skype all the time in my room
- JS: Right and is that when you're playing games and stuff or
- David: Yeah like I can't talk to them through the games and stuff so I just turn Skype on and use that
- JS: So is that every day nearly or most days?
- David: Like every other day probably (David, interview Time 2)



At the time of his second interview, Frankie was still keeping in touch with friends from school and beginning to be in touch with friends from college in the same way. His father interrupted to emphasise the amount of time he was spending on social media,

- JS: Oh good and do you still keep in touch [with friends from school]?
- Frankie: Yeah, cos we're on Facebook
- JS: So do you go on Facebook quite a bit?
- Frankie: Yeah, I just go there just to check
- Phil: Like all the time [in the background]
- Frankie: No I do that to check if people, like if I've got any like messages or if people like or if I'm chatting with someone or that sort of thing
- JS: So that's a good way for you to keep in touch with old friends from school but also friends from college? Are they on there as well?
- Frankie: Some yeah.... (Frankie, interview, Time 2)

For some young people then, like Beth, Jake and Frankie, access to Facebook and Skype had been particularly positive in enabling them to maintain friendships when they were not at school and really opened up another channel of social communication for them reflecting the findings of Mazurek's research (2013). For Eric, however, it had presented some real challenges. The 'abuse and nasty language' (Carol, Time 1) Eric used on Facebook was not appropriate and not typical for him in his offline life. It had caused real problems for girls online because Eric didn't understand the social conventions of using social media and Carol, Eric's mother had concluded that Facebook was really dangerous for people like Eric as it made them vulnerable online.

Facebook is the worst thing ever invented, it's very bad, people don't know how dangerous that is, it is terrible, and I think if you've got something wrong with you, you really shouldn't go on it because you're so vulnerable and you might say things in anger that really wouldn't come out of your mouth at any other time (Carol, Eric's mother, Time 1)

It became clear that Eric had struggled with understanding the boundaries of online communications with girls via Facebook to the extent that his mother had to ban him for life,

- Carol: That's another worrying thing he's very obsessive and he's been banned from Facebook over it, it's disgusting, it really is revolting so for his own safety and his own protection, we have banned him from Facebook and if he does go on Facebook ever again he will be banned completely from the internet
- JS: Right and is that from being in touch with people he shouldn't be or...?
- Carol: Well I think it's what he's saying on there more than anything and he's very obsessive with girls. He really wants a girlfriend and it can get very serious what he says on there sort of thing, what he'd like to do with

them so erm, it is disgusting so he's banned for life and I said if he wants to go on there he can find his own house [laughs] cos we're not having that and we're protecting you from yourself from doing that aren't we Eric. (Carol, Eric's mother, Time 1)

Evidently, there had been difficulties and risks around social media use for Eric bordering on obsession with particular girls and they had become victims of his 'disgusting' comments. This concurs with Byrne's (2013) report that people with autism are not always the victims online but can become perpetrators of abuse by not fully understanding the social contexts in which they find themselves. Jake, however, seemed to be well informed about its potential hazards and had been supported by his parents in this; he was cautious about making friends online, keeping information private and not updating his status constantly,

Oh yes, there was this one person on Google Plus that decided to say 'ooh would you like to chat' and I pressed yes and this person was like 'hey babe, would you like...' and I just instantly removed them cos I thought it was my friend but then I thought 'no, no, it's not my friend at all!' I've had quite a lot of people on Facebook that have actually added me and I don't know them at all [...] so I just declined the friend request. I always make sure that, as Dad says, I do not upload information about my holiday saying I am at France right now um... but... what I would do is just upload pictures but not upload like a status until I get back because if you're in another country then people just think, 'oo, let's go and steal some money' [laughs]. But yeah, Dad actually warned me about not doing that and I didn't do it but I am generally sensible. I try to make sure that I don't put every single thing I'm doing on Facebook like I'm going to the toilet right now [laughs] or I'm stripping off right now to go in to the shower or something like that, I'm not that sad (Jake, Time 2)

The different ways that the young people were using social media highlights both the range of opportunities it offers for different kinds of friendship formation but also the very real challenges for young people with ASC who may need support to understand the different social contexts, conventions and expectations (Byrne, 2013). There is both a huge potential as well as danger in the use of online social media and, in this instance, Eric's mother had taken control to exclude him from social media use (Seale, 2014). Despite the difficulties experienced by Eric and his parents in managing online friendships, there was certainly an interest in, and potential for, exploring social media to develop supportive peer groups. Jake commented on how his father had guided his online interactions and this shared risk-taking approach could be helpful other young people with autism (Seale, 2014).

### 7.3.6 Social confidence and maturity

Over the time that I got to know these young people there was a definite sense of progression and development in terms of their social confidence and maturity. It was

more noticeable for some than for others but David was perhaps the one who seemed to have developed the most. There were real changes for David socially since he went on to college, when presented with his collage from the first interview, he talked about what had changed for him when Xbox was one of the biggest items on the collage, he had recently been able to be more sociable at home spending more time in the living room with the family rather than in his bedroom,

JS: What do you think has changed?

David: Well I don't go and get the Xbox - it's in here now [in the living room] so that wouldn't be on my list um, (David, interview Time 2)

Denise confirmed this new, more sociable version of David,

My main measure is that he seems happy, he does seem to have changed slightly which is good, um, he's a little bit more sociable, he'll come into the room now in the evenings and watch a bit of television with us which, you know, he wouldn't have done by choice before so that's an improvement and generally he seems quite happy (Denise, David's mother, Time 2)

However, being sociable started causing some difficulties for Ellis at college in a different way, as it became clear that he enjoyed the social aspects of college life more than attending lessons. This was causing concerns for his tutor although I was not able to talk to Ellis directly at this time,

He should be in college over 4 days, 2 whole days and two half days, he does three vocational days and one professional skills day and those are his core modules for accreditation so um...his attendance I think is running at something like 27% because we're now putting zero in the classroom when we were working...before we were working so intently with him and his mum and we were putting him as authorised because we were working on a plan with him but now he's throwing it back in our face, we're actually being brutal...it's really poor and so we're going to be inviting Elaine in with Ellis so that we can address it because he doesn't like it when we have joined up thinking

(Esther, Ellis's College Tutor, Time 2)

She went on to explain how he was making full use of the social spaces of college and seemed to have excuses for not getting engaged with enterprise projects at college,

I think he likes being here, I think he likes being here but he's so used to not doing anything that he feels he doesn't have to so he's coming in and he's adopting the persona of a man at leisure and sitting down and having a cappuccino on the first floor balcony and sitting there as if he's reading the Times, he's actually making the most of the environment as he wants to use it, um but he's making up excuses not to do things, he is very frustrating (Esther, Time 2)

Contrary to some of the research literature on a lack of social motivation in autism (Chevallier et al., 2012; Deckers et al., 2014), there was clear evidence among the

young people in this study that social lives were important to them despite their difficulties in forming friendships. While they struggled in some social environments (and some like Jake and Beth were aware of their struggles), like other people with autism have explained (Williams, 1992; Jackson, 2002; Higashida and Mitchell, 2013), they wanted to connect with others but may not always do so in ways that we might anticipate.

## Chapter Eight: Data analysis (4): Independence and vulnerability

Transition is an ongoing process for children as they progress towards adulthood and although this research focuses on one section of that transition between educational settings over a one year period. This section looks at how the students and their parents were supported at college and covers the issues around communication, the level of support and the bigger picture of preparation for adult life. The first year at college tended to be a transition year where the young people acclimatised to their new environments with the protection and support of a special needs department, but as they started to make plans for the following year, it was clear that moving on to a mainstream course within the college would also be a huge transition. This was summed up by Jake's mother in an email during his second term at college, 'but the real challenge for students making the transition from special schools across to FE is when they hit the mainstream, not the Special Needs department'. This was perhaps an indication that ongoing research is necessary at different transition stages.

### 8.1 Support at college

As I have shown the young people in the research had different academic and social abilities and required different levels of support once they arrived at college. Here I select three cases to illustrate the varying levels of support experienced by Eric, David and Jake, with reference to Beth, and to what extent this impacted on their experience at college.

#### 8.1.1 Eric and need for constant supervision

Eric's mother Carol felt that Eric was developmentally so far behind his peers that it felt like sending a much younger child to college with all the anxiety that that would bring,

Everybody's on a different course but because he's so behind, he's very socially and mentally behind in his age and that so it's going to be very, very hard, it's like sending a 12 year old to college, you know, Eric is very immature..

(Carol, Eric's mother, Time 1)

Consequently, at college, Eric was assigned one-to-one support at all times and this meant that he had to be accompanied in all lessons but across breaks and lunchtimes too so that he was not able to go to shared areas such as the canteen or playing fields without supervision. Eric's walking interview (Appendix M) was very significant in that he took photos of classrooms all in one corridor of one building located on a large college campus. This extract reveals a part of that experience and our conversation with his Sally, his LSA, with us,



- JS: Yeah. Do you want a picture of the room that makes you too hot?
- Eric: [shakes head]
- JS: No, OK he's shaking his head at that one. OK where we going
- Eric: That's it
- JS: That's it, so you never go anywhere else?
- Eric: No

- Sally: You do sometimes
- Eric: No I don't
- Sally: Well I've sat on the grass out there with you
- JS: Ah, out on the grass
- Eric: [takes photo of grass through window] and that's it

- JS: Is that it? You don't go to the canteen?
- Sally: You've been to the canteen [and then to me] and I think also sometimes the difficulty is, although Eric obviously thinks I'm great, it's not always nice to have one to one is it? So as long as Eric is in a good mood, I'm quite happy for him to go over with his friends without me following him.
- (Eric, walking interview, Time 2)



He did seem very attached to Sally, his Learning Support Assistant (LSA) and expressed some anxiety about not having her with every day at college (as the role was shared) but was also worried about the following year.

- Eric: I asked Christine [Sally's boss] if you could be with me five times a day, I

- mean 5 days a week
- JS: So do you have any lessons where you haven't got Sally? Was English one of them?
- Sally: Yeah you don't have me on a Monday or a Friday do you?
- Eric: Yeah because two days ago it was sports
- JS: So what's that like when Sally's not there is that OK?
- Eric: It's boring
- Sally: You have another LSA don't you?
- Eric: But it's not that fun - you're fun because I can wind you up (Eric, Time 2)

Eric needed full on one-to-one support even to go to the canteen at lunchtimes and his mother also reported that he wanted to go to the supermarket but recognised that he needed support. She wanted him to learn to be more independent but was not sure how college planned to do this,

Eric will have to stay in that room unless someone takes him to the canteen, he won't be able to go out because he's not capable of leaving the building by himself without cos that what' we're trying to learn him how to do to be safe ...I don't know how I feel about that yet and I think if he really wants to go [to the supermarket at lunchtime], someone should walk him over there a few times to make sure he knows where he's at, how safe he is, things like that and give him the time to come back you know, obviously he's got a mobile and they can phone him up but he needs to learn about his independence but I don't know how that's working there (Carol, Eric's mother, Time 1)

There was a contradiction for Eric in that while he required constant supervision at college at all times, he was also deemed ready to travel independently and this irony did not go unnoticed by his mother,

I said that's two different things, so you're telling me that Eric is not mature enough, you know, he's not mature enough and all this and that, let alone he's mature enough to walk across a dangerous road, walk a mile to the train station, it must be 15 minutes from my house to the train station, get on the train, get off the train, with all strangers then walk through an alley and to college all by himself but you're telling me he's not mature enough to go to the next level [academic level of course], can you see where I'm coming from?  
(Carol, Eric's mother, Time 1)

Eric's experience of college was somewhat limited by having an LSA with him at all times and reminded me of the 'velcro' LSA from the Galton and Macbeath (2015) report ; he had all his lessons within one corridor of the learning support unit and was unable to explore any other areas by himself. This would also limit his interactions with peers and his progress towards independence (Symes and Humphrey, 2011).

### 8.1.2 David and relative freedom

Support for David was more relaxed although he was at the same college as Eric and he said that he preferred this new environment,

- JS: So do you think you prefer it here to school or about the same?  
 David: Yeah, I prefer it here  
 JS: Yeah it's nice, especially when it's sunny  
 David: The main thing is there's a cafe down there and you don't have to do as many hours (David, walking interview, Time 2)

David had needed a little more support at the beginning of term as, although he had had the five transition days over the summer the actual enrolment day was very stressful for him as it was such a chaotic day. It was also a unique day in the college calendar and was unlike any timetabled, more structured day. It consisted of queuing up, getting photos taken, filling in forms and generally fulfilling the administrative requirements of enrolment at college. It was hard for David to wait around for long periods of time (not least because of his physical difficulties and the pain that that caused) and he really struggled to fill in forms so the whole day was not really appropriate for him or others like him and was the first formal introduction to college.

The only thing that David struggled with and I know a couple of the others struggled with was the enrolment day, it was manic, there were just people everywhere and he just had to go off on his own and sit in various classrooms and have talks, there were forms to fill in and he really struggled with having to do that on his own and with all these people around um, and it was so busy and so hot and of course he didn't really know where he was going and he came home quite flustered after that... yeah and he doesn't really know how to sign his name even so it's quite difficult for him to sit down and do a form like that, it's not something he's ever done before but I never saw the form so I don't know what he wrote on it! [laughs] (Denise, Time 2)

In contrast to Eric though, David did have more freedom and was able to explore the whole campus. During his walking interview (Appendix N), we walked out to his carpentry lesson which was at some distance from the main learning support block. The only difficulty for David was a physical one as it was sometimes painful to walk long distances,

- JS: It is a long way to carpentry isn't it? [laughs] Maybe we wouldn't have done this if it was raining!  
 David: Yeah, I think there's always pretty much people in there... like always people in the workshop and stuff but we can get to peep through the door  
 JS: Yeah and we can always take a picture outside or something  
 David: Oh there's no one inside  
 JS: Brilliant, can we get a picture alright of that?  
 David: [takes pic of carpentry workshop] got it





- JS: Well done, thank you. So do you feel quite comfortable in all the different bits of college? Are there some bits you don't like or...?
- David: Well, walking here....during my break time
- JS: Because of the distance...I bet you've had some rainy days to do that haven't you?
- David: Yeah  
(David, walking interview, Time 2)

Although David had a personal tutor, he did not have access to one-to-one LSA support but did not think that he needed it. He seemed to be able to enjoy some freedom and this was having a positive impact on his experience at college and his growth towards independence.

### 8.1.3 Jake and the safety net of support

Despite the fact he could have gone on to another course, Alison had felt that Jake needed the safety net of the special needs department in order to support his transition year at college and to make sure that he felt comfortable there,

- Alison: We felt that we needed to play cautiously really, um..so ...and I don't regret...well, I don't know.....no, I don't think I do regret it actually because I feel the safety nets were there if he needed them, he hasn't needed the safety nets actually, he's been fine
- JS: But you couldn't have known that in advance?
- Alison: No, we couldn't have known that after years and years of being in special school but no, he's actually risen to the challenge quite well I think, of getting there, getting home again, coping with...you know...people...yeah I think he's coped really well with it on the whole  
(Alison, Jake's mother, Time 2)

Even with this level of support, it had still felt like a difficult start to the term at college when there were several timetable changes and the support was not as straightforward as Alison had hoped.

Also no less than 3 timetable changes since the start of term, with the result that, since the English has been moved, Jake has effectively 'lost' TA support in one of his 2 English Lessons-for purely logistical reasons! AARGH! I am on the verge of starting a complaints procedure, as the person who is meant to be dealing with this has so far ignored all my emails-AARGH again!  
(Alison, email from beginning of year 2 at college)

Once they went onto mainstream courses at Highdown College, there did not seem to be any formal connections between the special needs department where Jake had been and the learning support unit in the mainstream of college. Jake's mother was concerned about this and surprised that the two areas were not more connected,

Alison: They may be involved in a bit of liaison ...um... and I think Paula said well, they have had one or two who've moved into the mainstream that come back to do some work, you know, come back if they want a bit of reassurance, they're always welcome to come back but there's no official involvement

JS: They don't get additional support once they're in the mainstream

Alison: Not from the special needs department, yes they can have additional support, yes...um...from the ....what's it called - I think it's just called learning support, um... (Alison, Jake's mother, Time 2)

#### 8.1.4 Beth and support needs not met

Beth progressed straight in to the mainstream of college by taking up a Level 3 course in media and although both Beth and her mother were concerned about the transition, their experience (with Beth's siblings) had been that there would be support in place. In the early days of college, Beth did find it difficult to get to know people and to understand how to get along socially. Her email from October of the first term at college revealed her anxieties:

To be honest I found the first few days really hard as I didn't know anyone and it's a big change. It's mostly the social and friends side of things which I'm finding really hard. I keep trying to talk to people but everyone's always in groups and I often feel that they're leaving me out and then I get really worried that I've said something wrong. I feel a bit sad that there's no one like at Beechwood in my class but I've met a few people on other courses who are really nice so I guess I'm just a bit unlucky with who's in my class. (Beth, email, 10/10/2013)

She did comment, however, on the support that she was getting from tutors and this did seem positive,

My main tutors are really nice and funny and they say I'm doing well with my work which is good. And I have a support worker who's really nice which is also good. (Beth, email, 10/10/2013)

However, it was Debbie, Beth's mother, who sent a text initially in the second term of college to say that Beth was struggling at college and later, in the summer term, said that things had not worked out at college because 'they couldn't maintain the epileptic level of needs'. This was a sad end to Beth's transition story and also meant that she did not want to continue with the research. The problem of attrition is highlighted by

Caton and Kagan (2006) when they tried to track school leavers with mild intellectual disabilities, and they experienced a surprisingly high level of attrition among their participants early on in the transition from school. Of concern was the young age at which these adolescents started to lose contact with support agencies and for Beth, it is not known whether she is currently engaged in any further education or training.

## 8.2 Support for parents

Parents were not making the transition to college themselves but, as I have shown, they were very involved in supporting their children where gaps in provision emerged and they would continue to be needed to do so while their children were at college (Aston et al., 2005; Dee et al., 2006). Communication is a big issue for people with autism in that they may not remember certain things, they may not think it important to share information with others and they may lack theory of mind (Baron-Cohen, Leslie and Frith, 1985; Pellicano 2011) which would lead to them not realising that it might be helpful to pass on information. Most special schools operate a communication system with parents known as the 'home-school book' or online versions of that idea so that a teacher or teaching assistant can pass on information about what has happened that day of significance, this might refer to behavioural issues, progress in curriculum or social terms, or other pertinent incidents during the school day. The parents in this study were used to receiving this daily communication about their child and felt reassured by that regular contact and they were struggling with the lack of information from college as it undermined their ability to be able to support their children (Mitchell and Beresford, 2014). Jake's mother was concerned in the summer term, prior to Jake starting at college that this could be an issue,

I think the weird thing is, it's going to be me getting used to me having an interface because I've always had home school books all the way through and got used to writing in my questions and so on in there [...] but I don't even know when the first day of term is yet actually but I'm presuming that she's [the tutor] going to tell me and that it will become clear (Alison, Jake's mother, Time 1)

When Alison was interviewed again during Jake's second term at college she clearly felt that her fears had been realised. She explained that the complete lack of communication had been disappointing and confusing and she had not known which bit of information to believe,

I'm afraid there's a complete lack of information... it seems you have to burrow and delve to find out everything...um...and um...yeah...I'm disappointed really in that I have to say, I'm also a bit disappointed in the Head of Department because I...I've been trying to find out um...[sighs]... what is going to happen about Jake's

English next year because I've been told all sorts of different things and none of them completely match up (Alison, Time 2)

Alison's frustration was clear to the extent that she hardly knew what course he was on, 'maybe he's doing a skydiving course, or something [laughs] I haven't the faintest idea'. This became more serious when Jake told her that he had been hit by another student and she had not heard anything about it from the college, she tried to find out more but there was no response from the person she believed to be his course tutor,

She's described as his course tutor whatever that means, um...and she had been very helpful earlier, then she went through a phase of about 6 weeks where she wouldn't reply to anything, I kept emailing her about things and getting absolutely nothing back and on one occasion I had to email the Head of Department because I didn't get a reply from his tutor so then I thought at Christmas well, who do I contact? So...yeah...it was a bit upsetting really because I'd always thought he was very happy there and then we suddenly got 'oh yeah, mummy' ... (Alison, Jake's mother, Time 2)

There had been a lot of support for the transition from special school to college, but there seemed to be virtually no information or advice on the move on from the foundation course to a mainstream BTEC course in ICT within the college. As an active and involved parent, Jake's mother sought out this information for herself and felt frustrated that she was not encouraged to ask questions prior to Jake's applying for the course,

It's worse than I thought actually. I did think that the special needs department would be much more ingratiated within the whole college than it is, it appears to operate as an independent unit almost, um...as far as I can gather, I may be wrong but I'm afraid from the parents' point of view that's what it feels like - all the information gathering about the courses he's going to do next year, we've had to do under our own steam, there's been very little support or help with trying to find out about courses and even the support, well...I actually would like to know now before he applies. (Alison, Jake's mother, Time 2)

The initial period at college was worrying for Denise as there was no feedback at all from the college and David had typically been very non-communicative with his family, his mother reported that he always said 'OK' or 'fine' to most questions that he was asked. She was troubled by the fact that she would not necessarily know if he was struggling or being bullied or who his peer group at college was – in comparison to special school where they had all had learning difficulties of some sort.

I think that initial period was quite worrying because you are thinking you know, I didn't really know what the other students were like, were they mainstream? Did they have special needs too? Or how is settling? Is he being bullied? And all these questions and no feedback from the college so that's been a bit difficult but I do feel I would probably know, I'm sure I would know and I think that he's

changing and he's stepping forward a bit and things are getting better I think is a good indicator that it's going quite well so yeah, yeah  
(Denise, David's mother, Time 2)

Despite the lack of communication and the contrast with the home-school links at his special school, Denise felt that she would know if David was not happy but she just did not know any detail of what happens at college,

Well after the experience of school where you are kept in the loop and you're very much informed and you have a much more closer relationship with the staff and you know you can speak to people. To go into somewhere that you just don't know and to have no communication like that it feels, um, it feels a bit scary, cos I don't know what's going on and whether he should be doing something or and I just feel a bit out of touch with what's going on with him really.  
(Denise, David's mother, Time 2)

David could not always remember to tell his mother about changes or give her information about what was happening; consequently on one occasion, they got up and ready for college when it was an in-service training day but David had not remembered until they were ready to leave the house. Even when letters did come home there seemed to be little notice of events. Denise, however, could see that at the age of 17 perhaps it was appropriate for David to take more responsibility and yet, he still needed to be prompted to wear the right clothing for the weather.

I'll get like a letter today saying he's going on a trip tomorrow, there's no preparation time or anything like that and it's all very quick and I feel very out of the loop in what's going on with him. But I suppose you know, he's coming up for 17 and, you know, I suppose he has to take responsibility. I mean sometimes things go wrong because he forgets or he doesn't take the right things or whatever, you know, we're still at a stage where he can't pack his own bag in the morning in fact, we don't pack a bag in the morning now, he's just decided he doesn't want to so he just goes off as he's standing up and I have to catch him if it's raining and say David you need a coat. (Denise, David's mother, Time 2)

It was not necessarily easy to let David not take a bag, especially given the nature of autism and learning difficulties, and knowing that, left unprompted, David would not take a coat even if it was cold or raining. David's mother was very aware of her own bias in relation to her son and felt that she could therefore not be the best judge of what he could or could not do. She was also conscious of his age and that it was becoming appropriate for him to become more independent as she had been at that age and so there was really a sense of her really trying to stand back,

And there comes a point where you have to do that and it's healthy to have that and to give him his independence because I don't think that I can make a judgement or make an unbiased judgement as to whether he can or can't do things and I think I have to let him try so that's sort of how I feel about it and, as I

say, I wouldn't be best pleased at 17 if they were reporting back to my mum and dad so...yeah as much as it's awkward I don't feel that there's any problem so yeah (Denise, David's mother, Time 2)

Carol, Eric's mother, had similar concerns to those voiced by Denise and Alison, that they had not communicated to Eric about his course for the following year as he had been hoping to progress on to the next level. The college, however, believed that he still needed a higher level of support than was available on that course – a similar double-bind that Jake experienced in not being able to progress straight on to the right academic level as there was not enough support available. Carol was worried that Eric was going to be very disappointed and that college had left it so late in the year to tell him.

He wants to go on Foundation 2, he's so happy cos he said oh I've done all my exams, I think I done really well and when I go back, I'm going to the Foundation level 2 but when I phoned them up and said I ain't heard nothing from you, to say Eric is moving up so is Eric moving up? No, he's not capable, he's not ready to do that so my concern is one, that that's going to really upset him and they're gonna tell him just before, they'll tell him next week, you know what's next week don't you? It's the last week isn't it? So they going to tell him next week that they're going to tell him that he's not going to Foundation 2 that he's got another year there and it'll devastate him (Carol, Eric's mother, Time 2)

The parents reported a lack of communication from college in all respects and while, as David's mother said, the young people were getting older and learning to take more responsibility, it seemed as though more communication between college and parents could have helped to support smooth transitions. We know that young people with learning difficulties are more dependent on their parents at this age than their peers (Howlin, 1997; Aston et al., 2005; Dee et al., 2006; Mitchell and Beresford, 2014) and it would therefore make sense to engage parents in dialogue to facilitate and even hasten progress towards adulthood and greater independence (Plimley and Bowen, 2006).

### 8.3 Ongoing support towards adulthood

Transition from school to college is only one stage of the bigger progression towards adulthood and the young people at these colleges were negotiating progress on to their next stage at college on more mainstream courses but what of their broader futures? All of them had some ideas about their futures and their adult lives although some found it harder than others to imagine. How did colleges support the ongoing needs of these students and help to prepare them for adult life?

### 8.3.1 Frankie and the challenge of academic progression

Frankie's college tutor, Fiona, was very concerned about his future and when thinking about his next stage at college was thinking of the much bigger picture of his adult life and how the next stage would help to inform that. She questioned the role of education and the purpose of staying on at college and for what it might prepare Frankie. When I asked Fiona if she thought that Frankie would progress on to a level two course, she was adamant in her response,

No, no way, that will never happen...you know...and this is the sad thing for people with his disability, what do they do? And I don't know, I would love to be a multi-millionaire because then I would set up companies whose express aim was to employ disabled people and not expect to make money out of them but provide them for useful...where they could...what they need is to be able to do something where they felt they could contribute and they could earn a little bit of money (Fiona, Frankie's college tutor, Time 2)

While I was interviewing Fiona, another of Frankie's tutors (Naomi) joined the discussion, and had some different ideas to Fiona about his future. In contrast, she felt very strongly that he would be able to hold down an appropriate job and seemed more positive about his abilities and potential. Fiona's concern though was palpable and seemed way beyond the remit of her immediate role at college, but she was able to articulate some of the concerns for all these students, and their parents, as they approach adulthood.

I have sat with parents and cried you know because they've come in and we've talked and I've ended up in tears with them ....what is the answer for these young people, what are they going to end up doing? Where are the jobs for them? Where is the life for them? Where is the net which will hold them? I just think if we were going to invest in anything, that's where I would invest the money, I would make places where they could live forever, work forever, die, you know, their whole life is guaranteed, they'd have a routine, a structure, a place where they could feel useful, contribute, have a social life, be supported forever, you know we have these young people being born all the time and yet we're not providing for them as a nation, you know, it is a national problem  
(Fiona, Frankie's college tutor, Time 2)

### 8.3.2 Eric, David, Jake and the value of work experience

Eric's mother, Carol, had high hopes for him by the time he left college and hoped that his time there would help him towards independence as she seemed very aware of how he could be almost overprotected at home,

I'm hoping he will be independent by the time he leaves, that he'll have a bit of a life, that he have a life cos at the moment I don't think it's much of a life what he's

got, it's not like when we was younger, load of mates around, and he's very mollycoddled at home and suffocated and he is, you can't deny it, cos he ain't safe but I'd like him to have friends (Carol, Eric's mother, Time 1)

Carol felt that college should be addressing what she called 'anti-social behaviour' where too many teenagers were spending too much time in their bedrooms and not socialising which was even more significant for those with autism who had difficulty maintaining friendships,

You see what I'm talking about and I said to college, I said I'm having a lot of trouble at home, I said I think he, I think there's a big thing about people growing up and having independence and things and I think they should address that in the college about getting out of their bedrooms because Eric is not the only person because all his friends are in their own bedrooms and that is not normal behaviour. I said that is anti-social behaviour, I said I think you should be addressing that problem[...] They get very into theirself.

(Carol, Eric's mother, Time 2)

When Eric was still at school he had gone to a supermarket on work experience in Year 11 and it was striking how successful this placement had been when his teacher, Ben, talked about it as 'probably our most surprising and most successful work experience placement', as Eric took to it so well and seemed to have learned so much.

He absolutely loved it there. Asked the manager for a job there, really wants to get a job there so he's on the kind of waiting list for any possible job opportunities that come up there and he was just in his element, he just sort of was really good with customer service, he was confident with showing people where things were, he was polite, he was kind of - you know he was very surprising cos he's not always, wasn't always like that in school but he obviously could see the clear difference between being at school and the work [...], he had a brilliant, brilliant experience there and just wants to go and work there and you wouldn't have seen that side of Eric unless he'd done a work experience placement.

(Dan, Eric's school teacher, Time 1)

Given this amazing success, it was surprising that the possibility for work experience at college seemed so much more limited, and was in fact not on offer at Meadowlands for first years. Eric's mother was still hopeful that he might be employed by the supermarket when a vacancy arose,

cos he was so well behaved and they absolutely adored him and that so um, we're hoping, fingers crossed that he gets in there and since he went there he's got more, what's the word, he just grew up a little bit, a bit more independence, he just grew up in certain ways (Carol, Eric's mother, Time 1)

Both Jake's mother and David's mother echoed this concern about work experience. Here, Jake's mother was frustrated that some work experience had been suggested by college but nothing came of it and she was having to chase it up,



Cos the other thing that happened, I don't know if Jake told you is that she said that Jake was going to be doing some work experience at a computer company and eyes lit up and thought marvellous and nothing has come of it, nothing has come of it at all. [...] She mooted it in about October and Jake came home and said 'oh I'm going to be doing this computer...' and we said 'wonderful' and I emailed her and said where is this wonderful...? I've not heard any more about that which is again very disappointing, especially to raise his hopes and then nothing happening (Alison, Jake's mother, Time 2)

And yet, while David's college tutor could definitely see him holding a job down one day and could see the value of work experience, she knew that it was logistically difficult for the college to organise it. This was disappointing for students like David who would have benefited,

They don't tend to get work experience which is a shame because I think there is an element there that we could do that with them and I think it would be very beneficial for them um, it's not really been set up because I think the logistics of it will be quite a big thing and someone will have to take it over to do it but yeah, work placements, I know some vocational areas set up their own placements  
(Della, David's college tutor, Time 2)

Schools had been able to provide work experience opportunities that had been very successful for these young people and they all reported positive experiences, it is therefore disappointing that this success was not built on at college.

#### 8.4 Travel training

'Travel training' seemed to impact on most of the young people's lives as the local authorities were trying to move away from providing taxis to children with special educational needs once they got to college. It involved a series of practise trips on buses or trains with the travel trainer who would then confirm that they were ready to travel independently. However, it was not necessarily happening at the right time or at the right pace for these young people and Eric, David and Jake had different stories to tell. Both Eric and David were being pushed beyond their capabilities too quickly and Jake became an independent traveller through the relentless efforts of his parents rather than school or college. Tensions, and indeed contradictions, between how independent the young people were and how vulnerable they were thought to be was brought into sharp focus in this context.

#### 8.4.1 Eric and 'no choice in the matter'

Carol, Eric's mother did seem clear about the need for Eric to develop independence and was positive about the idea of travel training. Her main concern was that it should be done at Eric's pace, not at the pace required for college to meet their targets,

Yeah but I want to make sure first because I'm not happy because when I explained my concerns she said well, there's no choice in the matter really, um, the county council's not going to provide travel care for all pupils, we're just getting everybody, everybody needs to do it so I said to them, well I know that, but that is not my concern and the second thing is, I'm pleased Eric is doing his travel training, I said he needs his independence but I don't want it rushed, he's only had a few sessions and they think he can go by himself now  
(Carol, Eric's mother, Time 2)

She also experienced a lack of danger awareness with Eric when he was with the family. He was oblivious to cars because he did not look but also wore earphones with his music on very loudly so he was distracted from the dangers,

Cos I said it's funny that he can do it with you but when he's out with me and my husband we're still pulling him back from the road and we always tell him to keep looking and, he doesn't have the earphones on when we're around, but when he's walking and that he has his earphones on (Carol, Eric's mother, Time 2)

The travel trainer at college seemed to believe that Eric was capable of being travel trained and was making progress with travelling independently and blamed Carol for holding him back. Carol felt that she knew him better than anyone and she was responsible for keeping him safe so saw the travel trainer's challenge as very threatening to her but also cavalier in his approach to Eric's safety. She was not happy that he was being 'passed' as able to travel independently when he was still so vulnerable but it seemed to her that she was not being listened to,

He [the college travel trainer] was very aggressive to me, the man, he shouted at me. He said parents like you don't want their children to grow up and have independence don't you want him to have a girlfriend and have a job, don't you want him to have a normal life? I said, do you want my son in a coffin? I said his death will be on your shoulders, I said I'm his mother, it's my responsibility is to keep him safe [...] that man knows more about Eric than I do and all he's seen of Eric is half an hour through the day but he knows more about Eric than I do ...I think it is very disrespectful and I'm not having it and Eric is passing and I'm still not happy about that and I said to him, I am not happy, well he's passing, he will have to make his own way to college. When I spoke to someone about it and said I'm not happy about this, Eric is still very vulnerable and that, he is very vulnerable. (Carol, Eric's mother, Time 2)

The final email from Eric's mother about travel training vindicated her point of view and demonstrated that the college had listened to her concerns and taken up her suggestion of following Eric at a distance to see how he got on,

Paul from travel training agreed with me that Eric is not safe to travel by himself does not look when he crosses the road. Paul followed him without Eric knowing and told Eric yesterday he has not passed (Eric's mother, email, 25/6/2014)

#### 8.4.2 David and taking account of physical difficulties

David was not concerned about travel to and from college during his initial interview as he was still going to be travelling by taxi each day and transport was right at the bottom of his concerns on the card sort. His Moving On Plan was clear about his need for transport both because of the anxiety associated with his autism but also because of his physical difficulties,

David is not an independent traveller and will require transport to take him to and from college. David has some anxiety linked to using public transport and with busy situations. Physically David does tire and he cannot walk long distances.  
(David's Moving On Plan, January 2013)

By the time I interviewed David during his second term at college, he was undergoing travel training. He was accompanied by a mentor who stayed on the bus with him initially but would gradually withdraw. David was buying his own ticket and knew which stop to get off at but was finding the physical demands of walking home from the bus stop at the end of the day quite tiring, 'mmmm well I've run out of energy by the time I get home' (David, Time 2). David was, however, optimistic about his ability to catch the bus on a regular basis but because of his physical symptoms this was actually leading him to choose subjects according to when they take place during the college day. The travel training was potentially restricting his curriculum choices,

- JS: So do you think that at some point you'll be able to get to college and home from college on your own on the bus?
- David: Um,, yeah...probably...yeah
- JS: What about if you had a morning start?
- David: That's what I was...cos next term I was thinking of changing tutor group so we had all afternoon lessons so I don't have to get up in the morning
- JS: And then do you think it would be more manageable to get the bus?
- David: Yeah
- JS: Yeah, yeah so what subjects are you doing after half term then?
- David: Music and sport I think...it depends if they're in the afternoon or not
- JS: So you don't mind so much what you do?
- David: No it's just when
- JS: Right - that matters more to you than what?
- David: Yeah (David, Time 2)

When I visited David a few weeks later to do his walking interview (Appendix N) around college, he had moved on again with the travel training but it seemed as though some compromise had been reached over the provision of taxis on some mornings,

- David: Yeah I get a bus in Monday and back and then I get a taxi in Tuesday and I get a bus back and I get a taxi on Thursday and I get a bus back  
 JS: Right, OK and how's the bus training going, is that...?  
 David: Yeah, it's good  
 JS: And is your timetable OK now cos you were trying to change things around weren't you cos you had quite a few early starts before?  
 David: Yeah.  
 JS: So how many early starts have you got now?  
 David: Um...I have two but they're both with taxis so that makes that work...  
 (David, time 2, walking interview)

David's mother, Denise, wanted him to be able to travel independently as she thought it would open up new opportunities for him but she was very clear that she wanted David to gradually develop his independence 'I would like him to be an independent traveller say a term in'. However, she did feel under pressure from the college to hurry the process and she wanted to be sure that he learned gradually and safely,

They're [the College] quite pressured to, you know financially, to get this travel training done and I quite like the idea of it but it is hard because I don't feel that he knows what he's doing um, and I don't feel happy for him to go entirely on his own to somewhere like that um, but it's a stepping stone. It's something in the right direction but yes, I wouldn't be too happy if they just said right that's it, he's got to go on his own because I just think that would just dangerous for him really so um, yeah but hopefully we'll get there (Denise, David's mother, Time 2)

She was later concerned about the physical demands made on him by walking to and from the bus stop and could anticipate his anxiety about having to try and get the bus first thing in the morning which was a particular struggle given his additional physical difficulties,

Cos it was sort of a 10, 15 minute walk at least from the nearest bus stop that we have here and up until he started travel training he hadn't been walking that distance because obviously he has trouble with his joints and that, um, but now he is walking from the bus stop, I've had to pick him up, I think twice, since he's been doing it, um...but he finds it in the morning really hard, I mean it's a struggle to get him ready for half past eight which is when his taxi turns up  
 (Denise, David's mother, Time 2)

She has had to trust the travel trainer to be confident in her son's ability but did not believe that he had watched him and deemed him safe to cross roads. David did become more independent and was travelling home on his own by the second year of

college but did continue to get a transport to college when he had early starts due to his physical needs.

#### 8.4.3 Jake and parental travel training

Jake was facing a journey to college that involved getting a lift to the nearest station from his house, changing trains and platforms half way and then walking from the station to the college. His parents had foreseen the complications of this journey and realised that he would probably not get enough practice through school and college to be able to do the journey safely by September, and yet would be pushed to do so, so they decided to do that work with him. Jake did refer to going on school outings on public transport but this had been very much as a class group and was not independent travel as such. He was very clear about the journey in his mind, had practised it 'quite a few times' and that it was his parents who had helped him the most with that process so when I asked him how he was going to get to college he was very clear about his route,

Well, because I live in A\_, my parents are going to have to drive me up to the train station in B\_ then I'm going to go and take a ticket to D\_ but then I'm gonna go to C\_ then change from C\_ to D\_ and then I'm just going to walk all the way to college from D\_ station (Jake, Time 1 interview)

When interviewed at college during his second term, Jake talked about his experiences with travelling to college and how it had mostly been successful but the difficult days had certainly made an impression on him. He was clear that his parents had done the work on preparing him for independent travel and perhaps the school could have done more,

I think they prepared me well, basically school didn't really prepare me in terms of transport, I actually had, well they did do some trips with me like as a group in the class, but in terms of independent travel they didn't really, they should have helped me more with independent travel and said we had to get a carer from Crossroads and my parents to help me with that so they should have helped me with that. (Jake, Time 2 interview)

Jake had coped with some difficult journeys as he went on to describe and although they shook him up and he remembered the details very clearly, he did do the right things like phoning home and he was OK. Changes to routine can be particularly unsettling though for young people with autism so being dropped at a different platform can be very confusing.

And that at one time, I think it was two weeks ago, I was stuck waiting for a train for 45 minutes [laughs] so it wasn't exactly brilliant, standing there waiting 45

minutes because there was signalling problems at Gatwick airport and flooding or something. Well the thing is, unfortunately, the train that usually picks me up dropped me off at a different platform so I was just like normally walking, just walking there and suddenly the train just left and I was just like legging it and the train just went and um, so I missed the 08.30 to H\_ and then the next one was 8.45 so I thought this isn't going to be too bad then it came up on the noticeboard saying it's going to be late, delayed by 10 minutes then it said 20 minutes etc so I was stuck waiting there for ages and ages and it was so annoying cos unfortunately on that day I was about half an hour late for the lesson but um, I was kind of anxious because I was just annoyed that I'd kind of, one because the train had gone to a different platform and because I'd missed the train and two, it was just because I didn't want to be late for college (Jake, Time 2)

Alison was clear that they had had to practise the public transport lots of times for Jake to be able to be safe and to understand what he needed to do. She talked about it taking a long time and still being worried about what could happen to him on a journey as he was still vulnerable, even though he travelled independently,

We had previously worked on going up there quite a few times - he has a Crossroads person and he did it with him. My brother did it with him. We took every opportunity we could to make that journey so that wasn't the 3rd time he did it - it was the twelfth or something time that he did it. um...so but I knew he was ready and eventually we got to the point where I could literally just drop him at H, he could buy his ticket, make the journey, meet up with them in the college and come back all by himself but I'm just dreading the day when he gets accosted by somebody and...you know...fortunately [laughs] nothing's happened so far but...you know...you always worry don't you when he's out on his own because he's not out on his own very much at all. (Alison, Jake's mother, Time 1)

Jake's travel training experience shows how he was able to learn about his journey to college, was able to memorise the route very accurately and was able to practise it prior to starting at college. However, the flooding episode that he recounted, and the story his mother told of him getting the wrong bus, shows how unpredictable events can make him anxious (Jolliffe et al., 1992). This resonates with executive dysfunction theory and autism in being able to plan and adapt to change (Ozonoff and Jensen, 1999).

These examples of travel training demonstrate clearly some of the issues for young people with autism as they try to negotiate a path towards greater autonomy, for their parents as they try to keep them safe and for the colleges as they try to encourage independence. The resilience literature reveals that the young people in my research are more at risk than their peers due to cognitive difficulties and diminished social networks (Morrison and Cosden, 1997; Mather and Ofiesh, 2005; Luthar, 2006). The narrow focus on travel training did not allow for the wider development of protective

factors and resilience across social contexts, nor for a broader engagement with structural barriers; the training was a more behaviourist, individual approach.

## Chapter Nine: Discussion

The aim of this thesis is to deepen understanding of the transition experience for young people with autism and learning difficulties who were leaving special schools to continue their studies at colleges of further education. Sen's (1993) capability theory of social justice and equality inspired my original approach to this research as it guided me towards an investigation of the potential of young people with autism rather than concentrating solely on their difficulties (Sen, 1993). However, it later became problematic when I found that I could not write the story of transition without acknowledging and understanding the impairments and impairment effects experienced by these young people in their everyday lives. A critical realist approach allowed me to embrace a wider theoretical perspective that encompassed impairment whilst not losing sight of individual capability and potential, or of the disabling barriers encountered in society. I was able to examine the multi-layered realities of their experiences in the context of autism, inclusion and transition. Critical realism also allowed me to refer to experiences at different ontological levels: at the biological level where autism can be identified as a neurological difference; at the psychological level where a diagnosis of autism can help to identify the right educational support and assist with adaptation of the environment; and at the sociological level where the difficulties of learning and social worlds can be explored (Bhaskar and Danermark, 2006). People with autism and learning difficulties are highly vulnerable to social exclusion and, in order to understand their experience, a deeper knowledge of this intractable condition is required in order that we might conceive and make reasonable adjustments.

At the heart of the thesis was a desire to understand not only the experience of transition from the point of view of the young people with autism, but also to consider perspectives from their care-givers and the professionals involved in their lives. The methods devised (in Chapter Four) to support the interviews go some way towards ensuring that the voices of those with autism and additional learning difficulties can be heard. However, it was also important to consider the caregivers' and professionals' accounts, as they were able to offer perspectives on the interrelations and interactions between themselves, young people with autism and the wider world. This discussion will examine the key findings in relation to the research questions and consider ways forward in supporting young people with autism in transition. As a researcher, I also reflect on the challenges and difficulties I experienced whilst conducting my research



during which, at times, I struggled to understand my participants' worlds just as they struggled to understand mine.

### **9.1 What are the aspirations, interests, abilities and concerns of young people with autism as they leave school?**

Despite the categorisation of autism as a social communication and social interaction disorder (Wing, 1996), the young people in this research clearly had an interest in, and a motivation for, the social world. They clearly liked the idea of friendships, took part in peer activities where it was possible to do so, and yet they also experienced difficulties with social interaction. Outside school, some young people had social interests and hobbies that were, to a greater or lesser extent, facilitated by their parents and which demonstrated their continued interdependent relationship with their care-givers (Small et al., 2013; Mitchell and Beresford, 2014). They also had aspirations to live independently, to be employed and to form long-lasting relationships, not unlike their non-autistic peers (Dewson et al., 2004; Aston et al., 2005).

#### **9.1.1 Interest in the social**

It was clear that these young people did desire social interaction, as was made explicit in conversation with them and also in reports from parents and teachers. For this reason, it would be hard to concur with social motivation theories such as those made by Chevallier et al (2012) where autism is viewed as 'an extreme case of diminished social motivation' (p.231). Similarly, this would challenge Deckers and colleagues' research (2014) claiming that children with autism had a lower desire for social interaction than their typically developing peers, although it is not possible to say how the young people who took part in my research compare to their non-autistic peers in this respect. At an empirical level they were clearly interested in social interaction, wanted to have friends and to belong to a social world. These socially motivated aspirations have also been reported by other people with autism (Williams, 1992; Jackson, 2002; Grandin and Scariano, 2005; Higashida and Mitchell, 2013).

There is evidence in the literature, as well as in my research, that young people with autism enjoy screen-based technology, and engaging with the opportunities to develop social skills and widen social networks afforded by social media (Mineo et al., 2009; Mazurek, 2013). Indeed the young people in this research were more independent and active on social media with regard to having a social life than it was possible for them to be in their 'offline' lives. One of the real benefits of social media for the young people in the study seemed to be that they could conduct a social life more

independently from their parents. Use of online social media for people with autism is not however without the difficulties and risks that any new social situation can bring, and for some young people, like Eric, for example, there were difficulties in making sense of the implicit social codes surrounding online communications. In being exposed to the negative risks of social media, Eric's mother reported wanting to both protect him and other people, and therefore tried to ban him from using Facebook for life. A more shared approach to understanding online risk-taking (Seale, 2014) in this context might be a useful way in which to support both Eric and his mother so that they could both explore possible ways forward with social media. Byrne (2013) acknowledged that the internet could be both 'a place of opportunity and possibility but also a place of disappointment and tribulations' (p.5). Nevertheless, online worlds were of great importance to the participants and social media, in particular, offers a new and exciting arena (as well as a challenging one), in which they can be engage with the social world.

### 9.1.2 Friendships and difficulties

It was perhaps less surprising that the social lives experienced by the participants were, at times, confusing and difficult. Employment of the card sort method gave evidence of their desire to make new friends at college as something that they were really looking forward to, but they also cited making new friends as one of their top three areas of concern and, given their potential difficulties with social understanding, this is perhaps to be expected (Williams, 1992; Jordan and Jones, 1999; Jackson, 2002). There was no doubt about their interest in the social world despite sometimes having difficulties and concerns about how best to interact with other people and how to make and sustain friendships. In line with findings from Aston and colleagues (2005), young people who had attended special school or had communication difficulties were less likely to go out independently to meet friends in the evenings or at weekends. From a critical realist perspective this acknowledges difficulties with autism and social interaction but also has implications for the social barriers that they encountered. All the parents of children who had attended mainstream schools reported that their children had been bullied at some point and that, in some cases, this was a large part of the decision to seek a special school placement. This reflects the conclusions from the literature that children and young people with special needs are more vulnerable to bullying and that poor social skills as well as cognitive impairments increase that vulnerability (Morrison and Cosden, 1997; Newman, 2004; McLaughlin et al., 2010; Fisher et al., 2013) .

### 9.1.3 Capabilities

By foregrounding the capabilities rather than the deficits of the participants, my research was able to focus on how their specific needs, abilities and concerns regarding transition might be met and not solely how their impairments might be addressed (Terzi, 2005). It became clear that the aspirations and capabilities of the participants were not surprising from a group of teenagers: they preferred some subjects to others, some enjoyed hobbies outside school, they had friends and most used social media and played computer games. Yet the challenges that they faced, in moving from a protected special environment to a larger mainstream one, were significantly different from their peers (Burchardt, 2004; Caton and Kagan, 2007). All the young people in the research had mild to moderate learning difficulties along with autism which affected their progress in learning, and yet all studied for GCSEs and some had attained very good grades. All had clear abilities, albeit not always located in national curriculum subjects, that sometimes indicated a 'spiky profile' or highlighted 'islets of ability' (Shah and Frith, 1983). For example, some were operating at GCSE grade C level in certain subjects but were really struggling with others, notably English. In this way, young people are differently abled and are not impaired in all aspects of their lives. David, for example, was not impaired in his ability to do mathematics although there were barriers to him being able to continue with it. He also had physical impairments that restricted his ability to take up some sports. Additional provision at school often needed to be made in order to recognise the abilities of these young people and equalise their capability and opportunity to succeed (Terzi, 2005).

### 9.1.4 Aspirations and the future

The variety of aspirations for the future expressed by the participants reflected some of those reported in the literature including aspiring to employment, accessing more leisure activities and going to college (McConkey and Smyth, 2001; Small et al., 2013). However, for David in particular, at the time of the first interview, it was clearly hard for him to imagine his future at college, let alone beyond that, even though he had been for taster days and had been 'prepared' for transition by his school. This could relate to 'theory of mind' explanations for autism where scenarios not yet experienced, cannot be imagined (Frith, 1989; Frith and Happe, 1994). Again, consistent with a critical realist approach is the need and desire for a concrete understanding for young people with autism in order to make sense of the world. Indeed the psychological literature on autism refers to difficulties with planning and executive function as noted in Chapter

Three (Ozonoff and Jensen, 1999) and at critical moments such as transition, it was clear that more support and more explicit framing of transition was needed.

Given the interests, capabilities, aspirations and concerns of the young people in this research as identified by research methods employed such as collages and card sorts, it would seem appropriate to centre the transition planning around these individual differences and personal characteristics in order to plan effectively for a positive transition (Ward et al., 2003; Mitchell and Beresford, 2014).

## **9.2 How well prepared are young people with autism for transition from special school to mainstream college?**

There was evidence of much preparation for transition in the annual reviews from Year Nine, including the involvement of careers advisers (Cullen et al., 2009) and visits to appropriate colleges. One of the research participants, Frankie, was even able to study at his preferred college every week for a year prior to transition and both he and his father reported how beneficial this had been. However, the focus for others tended to be on the mechanics of transition (or of reality at the actual, observable level), such as visiting buildings and meeting teachers, some of which would be relevant on arrival at college. Academically, the students were generally prepared well in that they typically sat for some GCSE subjects as well as other accredited certificates, and the work had clearly been differentiated for them and their learning styles, in line with other studies on academic outcomes (Farrell, 2006; Jordan, 2008; Carroll and Dockrell, 2010). The range of courses available at college and their content was explained by careers advisers although there was sometimes a limited choice available (Elson, 2011) and some careers advisers, by their own admission, had little experience or training in working with young people with autism (Cullen et al., 2009). However, overall the preparation for transition was not holistic, it did not centre the needs of the young person adequately and therefore did not address all their concerns. Reliance on completing Moving On plans on time, ticking all the relevant boxes on that plan and ensuring that each student had applied for a course, seemed more important than considering whether they were ready and able to make the transition, and indeed what their individual needs might be. The compromises made by Jake, academically, and Beth, socially, are evidence of this.

It also became clear that preparation for transition did not include the period of the summer holidays which was completely ignored by careers advisers and most teachers. The concept of transition was thus fragmented and split into two discrete

time periods and locations: leading up to transition at school in the summer term and starting at college in the autumn term. The time in between these two periods was not acknowledged (Mitchell, 1999; Dyson et al., 2002), the only exception to this being the one college that hosted some introductory sessions in the summer holidays. Unlike their peers, young people with autism in my research had fewer opportunities to participate socially or get summer jobs, and this time was also worrying for parents who felt that the burden of orchestrating meaningful activities rested with them. Several of the young people seemed to have spent a lot of time in their bedrooms on the computer. This is consistent with research carried out by Orsmond and Kuo (2011) that identified adolescents with autism spending more time alone and with their parents than their typically developing peers. The participants were often not prepared for the nature of study at college where they were expected to become more independent learners; where more responsibility would be devolved to them, and that they would need to develop strategies for coping with gaps in their timetables, as evidenced in other studies on supporting learners with autism (Howlin et al., 2004; Breakey, 2006; Plimley and Bowen, 2007). Preparation for transition then was narrow in its focus; it did not prepare students (or their parents) for the summer holidays, or for the nature of part-time study, neither did it equip them with requisite time management skills or prepare them socially for moving on to a more mixed and diverse learning environment where their needs might be less well understood or less readily accommodated.

### 9.2.1 Past experiences of school

The experience of special school was overwhelmingly positive from all participants' perspectives, young people and parents alike, as the level of support and understanding was generally felt to meet their needs. This, in itself, implies that they felt included and that they were able to study alongside their peers so although they occupied a segregated space in education (Tomlinson, 1982), it could be argued that they felt very much included in their special school community. In the literature (Mitchell, 1999; Polat et al., 2001; Parsons et al., 2009), parents and young people generally reported more positive experiences of special school and of transition planning than those in mainstream settings and the responses of my participants resonated with this. The experiences of mainstream education however, had been largely, but not universally, negative and this certainly echoed Moore's (2007) argument that the environment of mainstream schools was diametrically opposed to the needs of those with autism (Moore, 2007). Two participants, Beth and Eric had experienced bullying and both had been kept off school by their parents as a result of this. In Eric's case this had happened on specific and limited occasions, but for Beth, it

meant being out of school for three years while her mother fought for a special school placement. This inability to convert the resources of mainstream education into realised capabilities, emphasises the point made by Hedge and Mackenzie (2012) that we need to think again about the mechanisms of inclusion. Indeed Farrell (2006) argued that there was a danger that the philosophy of inclusion could be privileged over the work of schools to educate children.

Clearly the experience of mainstream education had not been helpful in preparing these young people for transition and yet, the two participants who had always been in special school, were perhaps more protected from the realities of the mainstream experience. There was evidence that children with autism were not being sufficiently well supported in mainstream schools, which led to some parents seeking specialist settings where they felt that teachers better understood their children's needs. Other research has supported this finding (McConkey and Smyth, 2001; Rogers, 2007). There is still a huge amount of work to be done in converting mainstream schools into inclusive schools that can accommodate the needs of all learners and this theme has been revisited in the literature many times (McConkey and Smyth, 2001; Rogers, 2007; Thomas, G. and Loxley, 2007; Humphrey and Lewis, 2008; Ravet, 2011). For the young people in this study, mainstream schools had not yet delivered the kind of inclusive education necessary for their academic and social development and a deeper, more nuanced understanding of autism and learning difficulties (Moore, 2007) - acknowledging and valuing difference, with a focus on communities of learning (Thomas, G. 2013) - would help to evolve appropriate learning environments for all learners.

The existence of transition plans and college visits did not necessarily mean that the young people in the research (or their parents) felt well prepared for transition or knew what to expect. Links with colleges usually depended on the school's local arrangements and so for pupils who lived further away, or who wanted to go to a different college, there were additional barriers. One school worked very hard with a local college to set up a one day a week link course which was helpful to those planning to go to that college but less useful for those venturing elsewhere as there would typically be difficulties in translating that learning to other contexts, according to weak central coherence theory (Happé and Frith, 2006). There were mixed experiences here as Ellis, for example, had some college visits but these were to an entirely different campus than the one he would be attending when he started there. The need for concrete experiences of the new college environment are really important

for young people with autism (Wing, 1996). For example, to meet the staff who will be teaching them, to visit the classrooms they will be taught in, to eat in the cafés where they will have lunch and to experience the whole campus to which they will be exposed (Breakey, 2006). One of the participants, Jake, met some staff and visited some classrooms at his new college but they were not the same ones he would be going to in September. Beth's mother had to make most of the arrangements herself as the school did not have strong links with the college that Beth had chosen. Transition planning responsibilities fell almost entirely on schools as the colleges did not have outreach visits to schools to meet the young people and see them in their familiar environments, and lack of resources seemed to be an issue for colleges in this respect (Breakey, 2006; DfE, 2015). Considering how well prepared children with autism need to be for even the smallest transitions (Ozonoff and Jensen, 1999; Sterling-Turner and Jordan, 2007; Hume, 2008), it would seem appropriate that colleges should be more proactive in going into special schools to make sense of their students' prior experiences and to learn from seeing them in a setting in which they felt comfortable.

### 9.2.2 Parental preparation for transition

Although this question focused specifically on how well prepared the young people were for transition, it emerged in my research that, in many respects, their parents were perhaps less well prepared for this process. There was an over-reliance by schools on parents to fill any gaps in preparation that, for the participants in this study, seemed manageable, but for less able, educated or resilient parents then it would seem likely that their children would lose out. Some of these parents undertook various activities to support the transition of their children including: practising travel to and from college, supporting GCSE revision at home, organising additional visits to college, making contact with college tutors, chasing up school teachers and orchestrating wider social lives. These parents seemed to 'plug the gaps' in transition arrangements (Dewson et al., 2004; Aston et al., 2005; Plimley and Bowen, 2006) to ensure that all went smoothly, and yet, as other researcher have identified, parents were frequently overlooked in the transition planning process (Ward et al., 2003; Dewson et al., 2004; Dee, 2006). Equally, the responsibility to support their children over the summer holidays (three months for most students) fell exclusively to parents and there was little or no access to school or college during this period.

### 9.2.3 Person-centred planning

Schools were able to invoke 'person-centred planning' as part of the annual review



process and careers advisers did take part in discussions about the young people's futures (Cullen et al., 2009). Schools were also able to personalise provision in the sense that Beth stayed an extra year at school to better prepare her for college; Ellis was able to attend a course at mainstream school as this was not available in his special school and Frankie was able to join his chosen college for a diploma in animal care. However, there was no differentiation in their provision and thus they were treated like any other year 11 pupils sitting GCSEs, being given study leave when school finished after exams were over, which did not seem appropriate to some parents given their children's difficulties with time management (Howlin et al., 2004; Orsmond and Kuo, 2011).

The college that offered five taster days over the summer had realised that some time spent in college without other students there would be helpful to this group, and yet the registration day at the beginning of term was busy, chaotic and confusing for David who found form-filling, standing and waiting very difficult to do. Similarly the limited range of courses at foundation level assumes that all learners would benefit from the 'package' on offer as opposed to tailoring courses to suit their abilities both socially and academically. This disjunct between the rhetoric around person-centred planning, what it translates to in practice and the provision made for young people at college has been identified by other researchers (Mansell and Beadle-Brown, 2004; Small et al., 2013).

### **9.3 How do young people with autism and their parents experience this transition?**

#### **9.3.1 Social and academic compromise**

Some of the young people in this research had to make compromises in order to succeed either socially or academically and sometimes a trade-off occurred between the two. Jake studied at a lower level than he had done at school and found the work very easy, echoing those in Howlin's (1997) study who were bored (Howlin, 1997). Beth continued to the next level for which she was qualified, but struggled with the social understanding for which she was not prepared (Humphrey and Lewis, 2008; Chown and Beavan, 2012) together with a lack of support for her medical needs. David was denied the opportunity to continue studying Maths at college as he had achieved a grade C for GCSE. This also impacted on his timetable as he had free lessons where Maths would have been, causing him, potentially, more difficulties in organising his free or social time. Other non-disabled students are encouraged to continue studying the subjects that they enjoy or achieve in, but for David this meant that he had to stop



doing a subject that he liked.

### 9.3.2 Social difficulties

Most of the difficulties that the young people in my research encountered at college were related to social interactions in their different college environments. Jake's most upsetting times in starting at college were related to falling out with his friends by inadvertently upsetting them, although he did not tell his tutors about this; Eric was excluded from college because he mis-read an argument with another student and ended up becoming involved in a fight; Beth said that she did not feel that she was properly part of her class on her new course; Frankie was picked on and bullied by some other students and Ellis misconstrued the social environment of college, staying in the coffee bar instead of going to lessons. These experiences are not surprising if we consider how others with autism have articulated their difficulties with friendships and the social world (Williams, 1992; Jackson, 2002; Grandin and Scariano, 2005; Blackburn, 2013; Higashida and Mitchell, 2013). There seems to be a real need not only for an understanding of social transition for young people with autism and what it means to make new friends and adapt to the social demands of a broader range of learners (Plimley and Bowen, 2006), but also for the colleges to really understand what support these young people need. My research shows that college provision seems to be very patchy in this regard with some staff having a much better understanding than others largely through their own experiences as opposed to the provision of formal training. The young people generally did not struggle with their work and they understood how they were being assessed but they often misunderstood social situations in an unfamiliar environment (Chown and Beavan, 2012).

### 9.3.3 Transition for parents

My findings show that parents struggled with their child's transition not least because they generally felt unsupported and cut off particularly when their children started at college. At special school they had had daily contact with staff who knew their children very well; at college, they received very little communication and did not always know who they should contact or who was responsible for their child's welfare. Both in the areas of transition planning and college communication, there needs to be more effective support for parental transition and an acknowledgement that these young people may be in a more negotiated state of inter-dependence with their parents than other students (Vorhaus, 2007). While all parents may experience separation as their children grow up and go through adolescence, for parents of children with autism the

feelings may be more acute as they have always done so much in order for their children to be successful and their children are more dependent on them than other young people of the same age (Mitchell and Beresford, 2014). These young people with autism and learning difficulties continued to need parental assistance and it seems likely that they will continue to need parental support beyond college (Morrison and Cosden, 1997). Yet parents were often undervalued and under-informed in the transition process (Mitchell and Beresford, 2014) even though strong family support networks are identified as a fundamental protective factor for vulnerable young people (Mather and Ofiesh, 2005; Luthar, 2006; Evans and Plumridge, 2007). In line with other studies of families of disabled children, the parents in this research (predominantly mothers) had experienced various battles in order for their voices to be heard and to be taken seriously; they had enabled their children to be educated in the 'least restrictive' environments and they had become the back-stop between school and college when all else falls away. This marginalisation, notably of mothers as the most frequent caregivers, has been evidenced in the literature in different contexts (Kittay, 2001; Ryan and Runswick-Cole, 2008; Rogers, 2011) and in my research it is found in relation to the transition from school to college and beyond.

#### 9.3.4 Independence and vulnerability

The case study of transport detailed in Chapter Eight is metonymic of the tensions between independence and vulnerability for the young people in the research and the constantly emergent nature of the interrelationships between parents and children on the journey towards adulthood. These tensions are also representative of the tensions between institutional constraints and individual needs. Young people with autism can learn the routine of getting on a bus on a particular route on particular days but they may not be so good at dealing with uncertainty and change (for example, cancellations, or route changes or different drivers and passengers), as they have difficulty in generalising their learning to different contexts and in executive function (Ozonoff and Jensen, 1999). Equally, we have already seen how these young people lack peer groups and friends and one of the key vulnerabilities on public transport is travelling alone. In the case of Eric, his mother felt that he was being pushed through travel training and yet was not safe to cross roads and travel alone. As children, these young people have been to special schools, often getting taxis every day, and have been separated from their peers by geographical distance as well as by their disability: they have been segregated so they do not have the same access to a peer group as their non-autistic peers (Evans and Plumridge, 2007). Typically young non-disabled people are able to work out how to catch the bus together and deal with any difficulties

together, whereas the young people with autism in this study are trained with an adult after which, they are usually on literally their own.

On one level, encouragement towards independence is helpful and necessary for all young people, including those with autism and learning difficulties, and they should be encouraged to make choices to travel independently if they feel ready and capable of doing so (NAS, 2007). Dependency is part of the human condition (Nussbaum, 2006) and it would be unrealistic to expect these young people to become independent merely by virtue of their age or their attendance at college (Howlin et al., 2004). Similarly, parents should be allowed a voice in how the transition towards independence is managed, and a shared approach to risk-taking (Seale et al., 2013) with college professionals could work well for all parties concerned. This movement away from 'neediness' towards recognising risk and resilience in young people and their environments (Dyson, 2002) would seem to be a positive way of addressing the tensions between independence and vulnerability.

### 9.3.5 Inclusion

Moving on to college presented different challenges for different students depending on the way that the college managed their foundation learning programmes and their other learning support which, also affected the extent to which young people could properly be said to be 'included' in college. For example, Eric was on a foundation learning course geographically contained within one section of college, and was supervised one-to-one at all times. He rarely ventured further than that particular corridor and so he was still segregated within the institution (Mitchell, 1999; Kitchin, 1998, 2000). When we did our walking interview at college, he was only able to take pictures of that corridor and, significantly, out of the window to the canteen. He was being protected as a vulnerable student but was also unable to take a fuller part in college life or meet a broader range of his peer group. Kitchin (1998) argues that disability is spatially as well as socially constructed and this was evident in Eric's experience. By contrast, David, at the same college, was able to access various parts of the campus without additional support. Beth was perfectly academically able to take on a mainstream level three course but, as a consequence, had much less support than the other participants. While she may have had more opportunity to take a full part in college life, she evidently lacked the support to be able to do so (Chown and Beavan, 2012) and had withdrawn from college and from my study by the second phase of research interviews. Frankie accessed the whole rural campus without an additional adult but he had experienced bullying at college. It would seem unfair that these young people

should have to compromise either on their academic or social progress and their chances of full inclusion and while they were learning to adapt to their new educational environments, there did not seem to be much evidence of these same learning environments adapting to accommodate them (Kitchin, 1998; Mitchell, 1999).

#### 9.4 Addressing the research aims (1)

1. *To interrogate the experience of transition from the point of view of young people with autism in order to learn from their experiences to inform professionals and participants in the transition process.*

This research aimed to identify how young people's experiences of transition might be used to inform the transition process. It represents a part of the wider context of transition towards adulthood, towards greater independence and towards fulfilling capabilities. While the experiences were very varied, there still seems to be much that can be done in order to improve the experience for all parties and to ensure that young people with autism are given the greatest chance to progress and flourish in the college environment. The findings from the experiences of these young people reveal their desire for social lives, their social vulnerability and their aspirations and capabilities as well as the potential to develop a thriving interdependence. My holistic theoretical approach has allowed me not only to consider their strengths, capabilities and difficulties at the ontological level of real impairments but also epistemologically at the level of experience. The young people in this study were also found to be disabled by their college environments in addition to their autism (Bhaskar and Danermark, 2006; Shakespeare, 2014)

##### 9.4.1 An holistic approach to transition

A critical realist approach ensures that we take account of difference by looking at the whole person and not just particular aspects of their lives. Too often, in my research, it seemed that the transition process was fragmented by time and space, focusing on courses or colleges without connecting back to consider the needs of the young person at the centre. By talking to young people and trying to gather a holistic picture of their lives, interests, capabilities, aspirations and concerns, this research has been person-centred all the way through. The individual needs of the young people in the research group were very variable, even in a sample of six, and in order to support their transition, attention needs to be paid to these individual differences in order that reasonable adjustments can be put in place. In particular, the students' social communication needs did not seem to be taken into account in the transition process but instead the focus was on the range of courses available and visits to the college

itself rather than the emotional and social experience of transition. Capitalising on the interest in, and capacity for, online social media presents opportunities for developing the social worlds of young people with autism and this could be built upon during the transition process. While the mechanics of transition planning were in place via annual reviews, careers advisers, course information and Moving On plans, these tended to focus on outcomes and 'ticking boxes' rather than holistic experiences of the participants themselves.

The lack of continuity over the summer period left 'a big gap to fill' for the young people and their parents and Bhaskar's notion of 'absence' is interesting in this respect as he talked of movement from one idea or one state to another as requiring an absencing of the space previously occupied (Bhaskar, 1993). This absence allowed for movement and change and yet, in the case of the participants in my research, the long period of absence over the summer holidays was more like a void where progression towards college, towards the next phase, was hard to determine. Similarly the ideas of 'becoming' and 'begoining' (Alderson, 2013), while helpful in the bigger picture of transition to adulthood and changing relationships with parents, were somewhat stuck during this period as the young people needed a more concrete frame of reference at this time.

#### 9.4.2 An appreciation of interdependency

Unless we foster an appreciation of interdependency and acknowledge that we are all dependent to some extent during the different stages of our lives then we are failing to make sense of transition to adulthood for the young people in this research. Yet these young people are hampered in this progress by their autism and by their learning difficulties, leading them to experience reduced social networks, increased vulnerability and greater dependence on their parents (Howlin et al., 2004; Dee, 2006; Carroll and Dockrell, 2010). In order to support their path to successful transition and for them to be able to maximise their independence and exercise some choice and control over their lives then we need to consider how to improve the transition process. In particular, there is a discontinuity in preparing young people for such factors as the social transition to college, the less structured timetables and the expectation of taking more responsibility for their own learning ( Breakey, 2006; Plimley and Bowen, 2007). Not only do young people with autism have difficulties associated with social interaction but they are also often deprived of a peer group due to these social difficulties which affords them reduced social protection, and therefore more vulnerability to bullying (Morrison and Cosden, 1997; Newman and Blackburn, 2002; Fisher et al., 2013).

Even in their social lives, some of the young people in this study were dependent on their parents for organising and orchestrating social activities as they were often unable to travel independently, unable to organise meetings, unable to make or sustain friendships or unable, as in David's case, even to think of making a social arrangement (Dewson et al., 2004; Aston et al., 2005). One of the two key recurring protective factors in the resilience literature is about having positive peer relations (Luthar, 2006; Evans and Plumridge, 2007) and parents described trying to support this. Parents said they have to be advocates on behalf of their children and the notion of 'disabled families' needs to be taken into account so that parents can be supported to manage their children's transition to college and beyond (Rogers, 2011). Interdependence does not need to be seen as a failure to achieve independence or as a lesser state, but as a changing, dynamic process in which the individual's needs and rights are taken into account in order to promote independence, where this is possible, and mutual support, where it is not (Watson et al., 2004).

This interdependent relationship can thus be beneficial to both parties and this would be no less valid for the young people and their parents in my research. Developing creative notions of interdependence away from immediate family support and into peer relationships at college could foster mutually beneficial progress. For example, we have only to think of David and his ability in mathematics, yet he was not allowed to continue with his study of this at college. If he were encouraged to coach other students, he might develop more peer relationships, and equally, his fellow students would benefit from his mathematical ability by the process of peer learning. If we think of Beth and her difficulties in settling socially at college, she could have been supported to organise a lunchtime workshop on animation, enthusing others about her interest which would have undoubtedly helped her to integrate socially at college. And even where there is no apparent or obvious potential for the exchange of goods or services, there are pleasures to be derived from learning with, and mutually supporting others, as exemplified by Kittay, 'For my daughter dependence of the most profound sort will be part of her normal existence. But profound dependence does not preclude a certain form of mutual dependence' (Kittay, 2002, p273).

#### **9.4.3 An understanding of inclusion**

We cannot properly realise inclusion or inclusive education without paying due consideration to both of the above: a holistic approach to transition and an acknowledgement of interdependent relationships. Unless we make sense of autism

and additional learning difficulties and work hard to understand how the attendant social barriers might present themselves, then we cannot properly support these young people in our colleges, in our schools or indeed in our communities. Making sense of inclusive education is clearly still in its infancy if we are to consider the past experiences of these young people in mainstream education. Making adjustments for disabled people is an ongoing, challenging and creative process but the way in which we can make adjustments and remove barriers for those with autism and learning difficulties is not yet properly understood let alone realised. While we can facilitate with the development of social skills, assist with travel training, provide taster courses and tours of buildings, we have not yet been able to change the educational environments to accommodate all learners. For example, we still segregate learners in special schools (Thomas, G. and Loxley, 2007) and also in corridors within college (Mitchell, 1999).

Given that the experiences of the young people in this study have often been problematic in relation to social interaction, it seems only appropriate that we should look to the social world to make changes. Milton's (2012) notion of the 'double-empathy problem' (p884) is a useful reference here as he argued that it is illogical to talk of an individual having a 'social' deficit of some sort. Rather, that social interaction between people with autism and those without is problematic because neither fully understands the other. They both have problems in terms of empathising with each other which Milton terms a 'double empathy problem'. It would make sense then to consider educating each about the other: students in college would benefit from learning about how people with autism might interact and vice versa.

## 9.5 Addressing the research aims (2)

2. *To develop appropriate methods in order to engage young people with autism and ensure that their voices were heard in the research*

The methods described in Chapter Four were used to support the interviews with young people in order to enhance the ability to be able to articulate their experiences. The research methods employed, including collages, card sorts and walking interviews, to some extent enabled participants to express preferences for certain subjects or to order cards in a sequence to demonstrate their primary hopes and concerns about transition. I do think that these methods were helpful albeit not without limitations which are explored in the final chapter. The collages and cards sort methods were devised in order to support the interview process and to try to capture snapshots of

what was important to the participants at the beginning of the research. These visual aids were also helpful reference points when I returned later to interview the participants at college.

One of the dangers of scaffolding the interviews and using collages and card sorts with pre-determined choices is that the results can sometimes be too prescriptive, as Brewster explains, in relation to interviewing people with learning difficulties with little or no speech,

A characteristic many of these methods share is a reliance on pre-selected vocabulary; but how do you identify the specific vocabulary without 'putting words into their mouths? (Brewster, 2004, p.166)

For example, Jake was able to add some choices to his collage but did not add any extra cards to the card sorting exercise, and this may have limited his range of considerations regarding the transition to college. It could be argued that these methods could have been used more effectively if more participation had been sought from the respondents earlier on in the research process. They would all have been more likely to contribute to ideas concerning likes and dislikes at school and anxieties about college that could have helped to inform the design of the collages and card sorts to assist with other participants (Nind et al., 2004). And, despite my intentions, I recruited a fairly articulate group of young people with autism and learning difficulties, as their families were the ones who gave their consent; more still needs to be done to hear from those with more severe and profound learning difficulties and also from their families and carers.



## Chapter 10 – Conclusion

This chapter draws the research and the research journey to a close by reflecting on the whole project, assessing contributions to knowledge, limitations, recommendations and suggestions for future research.

### 10.1 Reflection

At the outset I knew that I wanted to research directly with young people with autism. My teaching background and years of experience in post-16 education, my personal interest in autism and my professional role in teacher education and research all came together to inform my investigations into transition. My intellectual curiosity about what autism really is, whether inclusive education really works and how young people with autism cope with their educational environments fuelled the research questions and led me towards my theoretical position and research design. The challenge and the difficulty was in drawing boundaries around the research and my original plans would have produced more data than I could have assimilated. I decided on an approach that allowed for researching in depth and across time but was therefore limited in breadth and scope. I chose to focus on a small number of young people across two data collection points in order to gather detailed longitudinal data from them and from those around them.

I have endeavoured to conduct research has been ethical, empathic and respectful to the young people and their families not least because I followed the clearance process at the university but was also informed by ESRC guidelines. I have been fortunate that my participants have been so willing to engage with the research and share their experiences. The young people with their ambitions, their creativity and their capacity to adapt to a complex world have been inspirational to me and they taught me so much about their lives. Their parents too, mostly mothers but also Frankie's father, have revealed their tenacity, their commitment and their dedication to ensuring that their children's lives are as fulfilled as they can be.

### 10.2 Limitations of the research and the research design

Time, perhaps inevitably, was a factor in carrying out longitudinal research within the constraints of a full-time doctorate and I learned early on how difficult it was to carry out longitudinal research. In particular, I had to work quickly in order to get started with the data collection in my first year. This meant that I had less time to observe and get to know the participants better before interviewing them. With a longer lead-in I could

have spent more time observing them in classes and observing preparation for transition, whereas I had to rely more on teachers' versions of this than seeing it for myself with the students. More observation time would also have allowed me to personalise the research methods further according to the different interests and abilities of the young people. For example, the collage task could have been adapted to give more space to their outside interests; the language of the card sorts could have been adapted to better match their comprehension skills. Pre-loading the collages with typical subjects studied at school provided a starting point for some young people and they were able to add to that collage; for others, it limited their choices and they were not able to add any more interests to it.

By not including young people with autism, at least in the design of my research methods, this project cannot really be called participatory or emancipatory and yet, this is still an approach that I believe to be valuable that I would want to strive towards. As a result I had to rely on methods that I devised based on my own experience and understanding of autism; the methods would probably have been richer, more imaginative and more fit for purpose had I had the confidence to test out and plan methods in a participatory process.

### **10.3 Contributions to knowledge**

This study focused very specifically on young people with autism and learning difficulties leaving special school, as I wanted to ensure that their voices were heard. Much of the research, albeit limited, with children and young people with autism has focused on the more able, more communicative Asperger's children and I wanted to ensure that I worked with a more diverse range of students. While there have been some studies that examine progression from special school (Beresford, 2004; Aston et al., 2005; Carroll and Dockrell, 2010) they have not focused on this specific group nor specifically looked at transition onto mainstream college. There are three main areas in which I believe that I have made a contribution: substantively, methodologically and theoretically.

#### **10.3.1. Contribution to knowledge about transition**

In Chapter Nine, I was able to draw out three strands from the research that come together to inform our understanding of the transition process for young people with autism: a holistic approach to transition, an appreciation of interdependence and a deeper understanding of inclusion. By starting with a focus on their personal characteristics: their interests, their aspirations and capabilities as well as their

concerns, it is possible to build person-centred planning around them. Social progress emerged as just as important as academic progress and the preparation for transition needs to acknowledge that. In order to understand the young people we need to deepen our understanding of autism and learning difficulties and what it really means on the biological, the psychological and the sociological level so that we can make reasonable adjustments in education and in society. I do not believe that we have yet fully understood how to include people with autism and how to remove barriers in learning and social environments.

By appreciating that dependence on others for some needs might always be necessary, but that independence in other ways can and should be encouraged and developed, the complex interdependent, interrelationships reported by the young people and their parents can flourish. While it is different for each individual with autism, the emergent relations with parents is a morphing and dynamic one. By involving parents more in the transition phase, professionals can work in partnership to support young people with shared understanding, shared goals and shared risk-taking. This in turn, could lead to improved peer relations and a new interdependent relationship with them and ultimately less reliance on adults or, as Beth put it, 'but if I make friends then hopefully I'll be able to ask them if I need help or something'.

While it remains clear that mainstream schools are not yet being experienced as truly inclusive, it remains a fundamental human right to be included in your local, community school. It is only through a whole school or college community committing to inclusion that environments can change, as exemplified by Morewood et al., (2011) in the school in Stockport. We need to consider the educational environment and how young people with autism interact in that environment both spatially and socially. Most of their difficulties lie in the social domain and we therefore need to support them through better preparation for social transition, and through fostering peer group relationships. This can only be effected if colleges embrace inclusion, but equally, or perhaps more importantly; we need to teach others about autism. In the words of Higashida, 'For us, you see, having autism is normal—so we can't know for sure what your 'normal' is even like' (Higashida and Mitchell, 2013). I would argue that we struggle to understand what the autistic 'normal' is like and as Milton (2012) and Higashida above suggest, we are caught in a double-empathy problem. While teachers and lecturers would benefit from a deeper understanding of autism, college students (whose numbers far outweigh those of lecturers) would also benefit from learning about diversity within the college community. By showing others how these relationships can be rewarding for all

involved we can start to make real progress on inclusion. Young people are still segregated at college and most seem to face a transition year before they really join the mainstream of college, almost as if they are being prepared to 'fit' the wider college environment rather than that environment making adaptations for them.

The research therefore highlights three critical strands in the transition process for young people with autism moving from special school to mainstream further education in England: a holistic transition, an appreciation of interdependence and a deeper understanding of inclusion and autism. Attention to any one of these in isolation is unlikely to improve the transition process as the research showed that these three strands were inextricably connected and they have to be considered together. The research reported here focused on a specific case, that of understandings of transition for young people with autism making the transition from special school to college in England. But the learning from this specific case has wider resonances for other children and young people who experience trouble with transition whether from primary to secondary, from childhood to adulthood or from college to work (Arnett, 2001). Indeed, in considering the relevance of the research across contexts, it is important to recognise that the participants in my study were not only young people *with autism*, but are *young people*, grappling with positive and challenging aspects of transition such as making friends, managing bullies, becoming more independent, and working out their career aspirations and options. Equally, whilst the nature of educational provision, and the surrounding policy and legislation, is specific to the English context, it is not unique. The insights that the research offers into problems with transition and the challenges of educational and social inclusion raise implications that transcend national boundaries.

### 10.3.2 Methodological contribution

The research began with an ethical concern: to make visible the perspectives of young people with autism within the case study of transition. As a consequence, one of my key explorations in this research was how to support interviews with young people with autism in order to 'turn up the volume' on more marginalised voices (Clough and Barton, 1998, p.129). While participants' levels of engagement with and understandings of the research were varied, the use of innovative and participatory methods and the tailoring of methods to individual participants, clearly allowed more opportunity for the voices of the young people to be heard. This approach was evidently effective; participants did not experience the 'inarticulateness' to which Booth and Booth (1996) refer, and the methodological approach could also accommodate participants' styles of social interaction idiosyncrasies in their language (Preece, 2002).

The collage activity and the card sort methods required some participant reflection and so they also allowed for silences during the interview as well as thinking time or 'use of pause' (Lewis 2001). The ensuing discussion was then framed around the visual choices made, with a focus on the tablet rather than one-to-one eye contact. In taking into account the individual needs of the participants, designing empathic methods to enhance their contributions and thinking through how to scaffold their communication abilities, I was better able to understand their lived experiences of transition.

By sending copies of the collages to the participants after the interviews and reminding them of the card sort activities at their second interviews (after a six month gap), I was able to support any difficulties with memory (Preece, 2002) by offering concrete visual representations of our earlier conversations. These activities had also opened up a third space for dialogue in prompting conversations between parents and children about transition where the card sorts had highlighted their different concerns, echoing Abbott's (2012) research with young men with Duchenne Muscular Dystrophy and the different views of parents and children. Another major preoccupation of this research was an intention to seek, respect and represent the views of the participants with autism by foregrounding their abilities and interests primarily as young people. Oliver's (1992) call to researchers to enact more relevant and transformative research with, not on, disabled participants was an ever-present consideration. To that end, the first activity in the interviews with young people was a collage that attempted to create a picture (quite literally) of who they were and what they were interested in. This ensured that I had an insight into their abilities and aspirations from the outset and it informed my subsequent work with them.

Another key consideration was managing the power relationship between the interviewer and the interviewee (Lewis and Porter, 2004; Nind, 2008). Giving the tablet to the participants to create collages or sort cards was one way in which there was a sense of control being passed over but this was especially evident with the walking interviews. Walking interviews (Jones et al., 2008; Clark and Emmel, 2010; Kusenbach, 2012) were helpful in this context as they gave the interview a more obvious purpose while also physically demonstrating how spatially included the young people were at college.

In working longitudinally, I was able to develop relationships with the families over a 15 month period and an appreciation of differently appropriated time during this phase as well as an understanding of gaps and 'absences' (Bhaskar, 1993). Overall I believe that in combining the range of methods and perspectives in a mosaic approach to data

collection and analysis, I was able to attend to the complex story of transition by weaving together the multi-layered voices and perspectives. By foregrounding but also combining the scaffolded voices of the young people with other perspectives, I generated uniquely complex, temporally and spatially situated data that afforded a nuanced understanding of a multi-dimensional phenomenon. I was only able to arrive at this substantive understanding by employing this methodological design.

### 10.3.3 Contribution to theoretical debate

By using a critical realist approach to the research I was able to include ideas from both capability theory and social model of disability in the framework. This allowed me to consider all aspects of the young people's lives and I found that some of Bhaskar's concepts were particularly relevant in this research. By referring to the different levels of reality, I was able to make sense of the observable transition process and realise that it was separate to the lived experience or empirical nature of the reality for the young people. The ideas of 'becoming' and 'begoining' and emergence helped to interpret the process of transition from one place to another but also the journey towards adulthood and the changing nature of relationships between parents and children. While the notion of absence seemed pertinent to the gaps in transition, the spaces where support was absent, or the long holidays that formed a key part of the transition process, I did find it slightly problematic in addressing the summer holiday 'absence'. While Bhaskar contends that absences allow for movement and change, this particular 'absence' seemed to be more of a void where little movement or development was able to happen (Bhaskar, 1993; Alderson, 2013). In the absence of school or college, or even a sense of the transition process continuing, it seemed that it was hard for the young people in my study to have a sense of themselves as emergent college students.

By linking together ideas from capability theory, the social model of disability and critical realism, I was able to draw on aspects of theories that were most pertinent to my research. This allowed me to consider both disability and the social construction of attitudes and barriers but also to hear the personal experiences of impairment and the individual capabilities of young people whose experiences of autism, learning difficulties and education were all very different. Ideas from the social model link to the 'double-empathy' problem outlined by Milton (2012) while ideas from critical realism keep sight of the real experiences of young people with autism in the social world. A way of viewing the overlapping aspects of the theories and how my approach emerged under the inclusive umbrella of critical realism is offered in Appendix P.

## 10.4 Recommendations

In drawing together some emerging recommendations from this thesis, it is clear that there are some very specific suggestions that relate to the focus of the case study: the experience of transition from special school to mainstream further education for young people with autism in England. But there are also wider implications for children, young people, teachers and those involved in transition planning that are applicable beyond the local context.

### 10.4.1 Involving young people in their own transition planning

Given that young people with autism had similar aspirations to their peers and clearly had ideas about their own futures, this research suggests, and concurs with Burchardt (2004) that their views and aspirations should be central to the transition planning process. Individuals will vary in their needs and interests as well as their capabilities and impairments, so person-centred approaches are needed, to ensure that transition planning is suitably flexible and varied to accommodate all young people.

Communicating with young people about what *they* want and what *they* think would be helpful would seem to be a necessary step in developing good practice in transition planning. As part of this person-centred understanding in relation to autism, it could be useful for college staff and college students to visit special schools prior to the summer holidays as a means of promoting awareness and understanding. This could also be extended beyond autism to other students being educated in non-mainstream provision whose transition needs require a deeper understanding. While, in England, some of the policy rhetoric around person-centred planning exists, it has not necessarily been fully enacted to ensure positive outcomes (Mansell and Beadle-Brown, 2004; Mitchell and Beresford, 2014).

### 10.4.2 Time management

Managing unstructured time in the day - during the 'down-time' of the long summer holiday periods and subsequently within part-time timetables at college - caused anxiety for the young people in this study and has been recognised as problematic more widely for people with autism (Orsmond and Kuo, 2011). The 'down-time' of the summer holidays could instead be an opportunity to offer some connections between leaving school and starting at college through short courses at college or organised social activities with current students from college (buddies or mentors perhaps). Once at college, the research indicated that part-time timetables needed to be explained and individual programmes drawn up to encompass ways to manage time and also to

protect young people from risk of bullying during unstructured time. Where budgets allow, a timetable with more contact time is likely to be beneficial; just 16 hours of contact time did not seem to be adequate for these young people, who needed more structured time to be able to learn and make progress.

#### 10.4.3 Parental involvement

It was clear that the presence or absence of family or peer support networks was crucial to transition planning and understanding, in line with other research (Plimley and Bowen, 2006; Small et al., 2013). While much activity in college was focused on young people's *independence*, the research highlighted the need to recognise their *interdependence*. Parents need to continue to be involved in provision for their child's educational needs even when they have progressed to college so that they can work in partnership with college staff to maximise the potential for their son or daughter and manage risk where appropriate. In the English context, part of the Moving On plan could create a profile of interdependence to ensure that all young people are supported and encouraged towards appropriate independence insofar as it is possible.

#### 10.4.4 Fostering peer relationships

One way in which to help prepare young people with autism and learning difficulties for adulthood might be to implement social skills 'training' and to make explicit the codes and conventions of the non-autistic world. However, there are many and various examples of such approaches in evidence across schools and colleges but their efficacy is by no means proven or are 'minimally effective' (Bellini et al., 2007). The young people in my research did not report on any such programmes at school or college and it could be far more productive to engage in dialogue with other college students and with staff to promote an inclusive, accepting and positive learning environment. Opportunities for young people with autism to engage with their non-autistic peers seemed to have been largely overlooked at college, and again this accords with other research in the field (Mitchell, 1999; Breakey, 2006). This finding has fundamental implications for understandings of educational inclusion and for inclusion in our wider society, and is of critical concern for young people at the cusp of entry into adult worlds. A holistic understanding of inclusive practice could offer significant potential benefits for all those engaged in college life, built on dialogue between disabled and non-disabled students and staff to promote an inclusive, accepting and positive learning environment, whilst addressing the specific risks of bullying and exclusion faced by young people in my study.



### 10.5 Further research

- Further longitudinal research into the ongoing transitions to adulthood with this same group of young people (or another similar cohort) would be really interesting to see how their lives continue to unfold and to track their aspirations and interests over time. As Jake's mother said to me, when Jake was applying to go on to a mainstream course for his second year at college, 'in a way that's going to be the real transition isn't it? That's going to be the first time he's ever been in mainstream.' So it would be good to capture more longitudinal data from this group and a wider cohort as the Howlin (1997) study is now nearly 20 years old and the policy changes that extend education provision to 25 are now in place.
- While there is much written about resilience, and some literature about resilience and disability, much of this research seems to concern the families of disabled children (Hill et al., 2007) or reports on resilience strategies for disabled children and young people (Mather and Ofiesh, 2005; Hegarty et al., 2007) rather than researching directly with the disabled children themselves. Given that having cognitive impairments is a recurring risk factor, further work with children with learning difficulties and resilience would be very informative.
- An interesting area that emerges from my research and is worthy of further investigation is the social motivation exhibited by young people in the research. Exploring the possibilities of social media for young people with autism and learning difficulties would link up the debates about social interaction, positive risk-taking and the possibilities of online networking.
- Further research into possible interventions in post-16 environments with disabled students and their non-disabled peers to foster an inclusive learning community. Working in a participatory way with the students to design the project would be very exciting.

### Coda

I would like the final word of this thesis to go to one of the young people in the study. Jake emailed me out of the blue, just a few weeks ago, to tell me how he was getting on at college. He is in his second year of the Level 3 BTEC in ICT, has managed (with

the help of an imaginative support worker) to secure a work experience placement for one day each week and is now looking towards his future as he prepares to leave college at the end of the academic year:

Hi Jackie

jus wandering how everything is going?[sic]

I am at College it's my final year and I managed to pass my GCSE English at grade C and I got a D\* [starred distinction] in my IT.

everything seems to be going well so far done a couple of assignments and going to the ISLE of Wight in a couple of weeks time for five days.

I also have a new phone now which the lumia 535 and it's great!

Everything at college is not too bad now I hope in July 2016 I will be able to start a level 3 IT apprenticeship for one year then to become a fully qualified Junior IT Technician.

I had a good review at *[the work experience company]* lots of positive comments and there is going to be a meeting in May 2016 about my future there so hopefully that will go well.

Hope everything is going well from your end.

Jake

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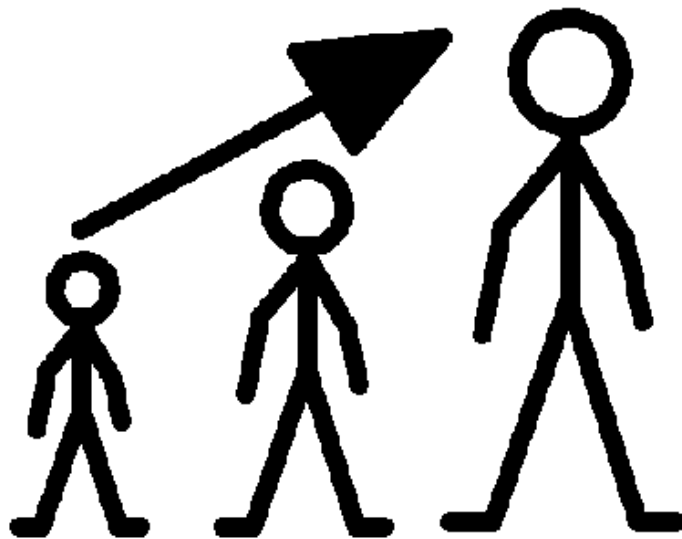
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## Appendices

### Appendix A1 – information sheet for young people

**What happens when young people with autism leave special school and go to college?**



**A research project**

**Who am I?**

I work at the University of Sussex near Brighton and am currently studying for my PhD (Doctor of Philosophy) in Education. This means that I am trying to find out more about what happens when young people with autism, like you, leave special school and go to college. I also have a child with autism.

**A study of young people with autism leaving special school to go on to a college of Further Education**

I would like to invite you to take part in my research project but before you decide I would like to explain why the research is being done and what it would mean if you agreed to take part in it. Please let me know if you have any questions about it.

**Aim of the Research Project**

The aim of this research project is to find out how the move from special school to college works out for you and your family. The questions that I ask you will help me to write a long essay to hand in.

**Why have I been invited?**

Your school and parents or carers have said that I can come and talk to you because you are leaving school this year. Several families have been asked if they would like to be involved from this school as well as two other schools in Sussex.

**Do I have to take part?**

No, you don't have to take part if you don't want to. If you are interested then I can go through this information sheet with you and then will ask you to sign a consent form if you are happy to take part or you can say to me that you are happy to take part and I will record you on my tape recorder. You are allowed to change your mind at any time during the project without giving a reason. This would not affect anything about your move to college.

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

If you agree to take part in this study, I will ask to see a copy of your transition plan either from you, your parents or from the school. I will also come in to see some of your classes in school. Also in the summer term, I would like to talk to you about how you feel about leaving school and going to college. I can interview at school or at home - whatever you are most comfortable with. I will also talk to some of your teachers and your parents or carers.

After you have been at your new college for a term, I would like to come and interview you again in January or February 2014. I will come and see some of your classes at college and talk to you again to see what you think of college. I will also be talking to your parents or carers and some of your teachers or lecturers. Over the summer and during your first term I will be in email or phone contact with you and your parents or carers.

### **What will happen if I don't want to carry on with the study?**

If you decide that you don't want to take part in the project any more, you can just tell me or your parents or carers and you don't have to explain why. I will ask you, at that point, whether I can use any of the information that we have talked about or whether you would like me to get rid of it.

### **Will my taking part be kept confidential?**

When I am writing about the project, I will change your name and the names of other people so that you can say things to me without worrying what other people might think. I will record and write down things that you but no-one will know that it was you who said it. I will keep all the information safely on a computer with a secret password and lock up any information on paper in my filing cabinet. I will also be asking if I can keep all the information for up to ten years as in case I am able to come and talk to you again when you are older.

I will also ask you if I can take photos of you or film you to help collect information for this project but it will not be shown to anyone else except my supervisors at the university. You can say no if you do not want your picture taken and I will still want to include you in the project.

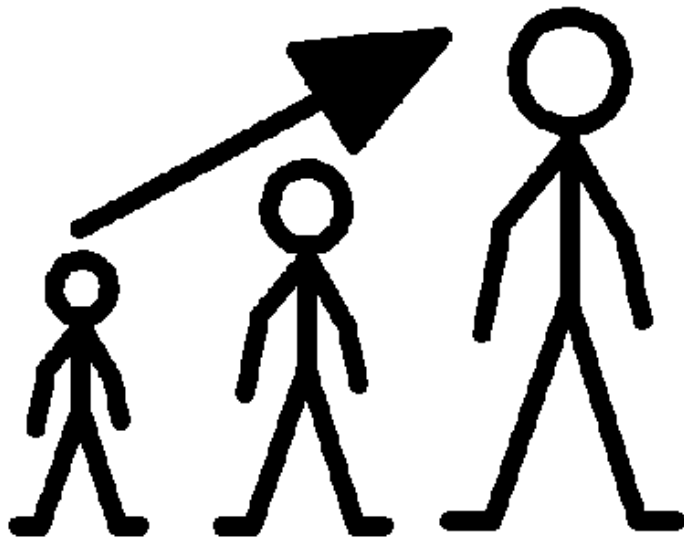
Everything you say is secret unless you tell me something which worries me - that you might be being hurt by someone or that you might hurt someone else - then I would have to tell someone but I would talk to you about this.

### **What will happen to the information from this project?**

I will write my long essay but I will also write a special report for you so that you know what I found out during my project.

Appendix A2 – information sheet for parents

**What happens when young people with autism leave special school and go to college?**



**A research project**

## **Who am I?**



I work at the University of Sussex and am currently studying for my PhD (Doctor of Philosophy) in Education. I have been a teacher for many years and trained secondary teachers and now am researching into what happens when young people with autism leave special school and go on to college. I am also the parent of a child with autism.

## **A study of young people with autism leaving special school to go on to a college of Further Education**

I would like to invite you to take part in the research study but before you decide I would like to explain why the research is being done and what it would involve for you and your child. Please let me know if you have any questions about the research or your involvement in it.

## **Purpose of the Study**

The purpose of this study is to examine how the process of transition from special school to further education is experienced by young people with autism and their families as they go through it. This research study forms the basis of my PhD.

## **Why have I been invited?**

You have been identified by the school as a parent or carer of a child with autism who is in their final year at the school and is planning to go on to study in Further Education. Several families have been asked if they would like to be involved from this school as well as two other schools in different locations across Sussex.

## **Do I have to take part?**

Taking part in the research is entirely up to you. If you are willing to take part I will ask you to sign a consent form to confirm that I have explained the research, and answered your questions, and that you have agreed to be part of the study. You are free to withdraw that

consent at any time during the project without giving a reason. Your decision about whether or not to take part in the study will not affect your child's transition or school or FE in any way.

### **What will happen if I take part?**

If you agree to take part in this study, and consent for me to ask your child to participate, I will ask to see a copy of your child's transition plan either from you or from the school. I will also go in to observe the class that your child is in for half a day during the summer term. Later in the summer term, I would like to interview you and your child – this can be done together at home, or I could interview your child at school – whatever you prefer.

In the Autumn Term 2013, I will ask if I can observe one of your child's classes at College and follow that up with an interview with you and your child (in the setting of your choice) to find out how the transition has been and how they are settling in to College. I will also interview relevant lecturers.

I will repeat this process during the Spring and Summer Terms but will be in email or phone contact with you (whichever is preferable) in between these times. The observations and interviews will finish in the Summer Term next year, 2014.

With your permission, I would also like to keep in touch after the end of the study, because I hope that in future I might secure funding to come back and interview your family again, after a longer period of time.

### **What will happen if I don't want to carry on with the study?**

You or your child can change your mind about taking part at any time. Doing the first part of the study does not mean you have to carry on. I will ask you each time I get in touch whether you are happy to continue with the study. If you decide to change your mind about participating in the study at any other time, you can email me to let me know. You do not need to give a reason. If you decide to withdraw from the study I will ask you, at that point, whether I can use any of the information your family has provided or whether you would like it to be destroyed – that's also up to you.

### **Will my taking part be kept confidential?**

All participants in the research study will be anonymous in any reports that emerge from it - so real names of young people, parents, schools and colleges will all be changed. I may quote directly from interviews with any of the participants but I will ensure that the quotes do not identify the participant.

With permission, interviews will be recorded for detailed analysis. All data stored securely by me in locked filing cabinets and protected computer files. I will also be asking your permission to keep your data for up to ten years as in case I am able to secure funding to follow the young people's progress to adulthood for longer but your data will not be shared with anyone other than my supervisors.

I will ask for consent to take photos and video of you and your child as part of the data collection process but this will not be shown publicly, it will just be seen by me and my supervisors. If you do not want any filming or photos taken then that is fine and does not mean that I won't want to include you in the project.

Everything you say is confidential unless you, or your child tells me something that indicates that you or someone else is at risk of being hurt. If possible, I would discuss this with you before telling anyone else.

### **What will happen to the results of the study?**

After each stage of the research, I will send you a summary of the findings to tell you about what the study has learned.

The results of this study will be written up to produce a final thesis for submission to the University of Sussex for the award of PhD in Education. There may also be journal articles published from this thesis but care will be taken to ensure that no one can be identified in reporting from the study.

*This research has been funded by the Economic and Social Research Council*



## Appendix B1- Consent Form for young people with autism

### A research project about young people with autism leaving special school to go college

Thank you for thinking about taking part in this research project. If you have any questions please ask me before you decide whether to take part. You will be given a copy of this form to keep and look at any time.

|   | Yes                      | No                       |
|---|--------------------------|--------------------------|
| I have read and understood the information sheet dated March 2013 for this research project.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I have been able to think about the project, ask questions and have understood the answers  | <input type="checkbox"/> | <input type="checkbox"/> |
| I know I don't have to take part.   | <input type="checkbox"/> | <input type="checkbox"/> |
| I know I can decide that I do not want to carry on being involved in the project, and I can say no at any time without giving a reason. My care or legal rights will not be affected. | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that information collected during this project might be looked at by individuals at the University of Sussex who are supervising this project.                           | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that if I withdraw from the project the data collected up to that point would be destroyed unless I say it can be used.  | <input type="checkbox"/> | <input type="checkbox"/> |

I give permission for the researcher to keep in touch with me after the end of the study

☐ ☐

I agree to photos or video being taken of me for this project by the researcher

☐ ☐

I agree to the interview being audio recorded so that my comments can be typed up and used as research information

☐ ☐

I agree that the information can be safely stored for up to 10 years

☐ ☐

I agree to take part in the study.

☐ ☐

Participant: \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Researcher: \_\_\_\_\_

Signed \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix B2 – Consent Form for parents or carers

### A research project about young people with autism leaving special school to go college

Thank you for considering taking part in this research. If you have any questions please ask me before you decide whether to take part. You will be given a copy of this consent form for keep and refer to at any time.

|  | Yes                      | No                       |
|--|--------------------------|--------------------------|
| I confirm that I have read and understood the information sheet dated March 2013 for the above research study.   | <input type="checkbox"/> | <input type="checkbox"/> |
| I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily   | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that my participation in the project is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected.   | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that the data collected may be looked at by individuals at the University of Sussex who are supervising this project. I give permission for these individuals to look at my child's transition plan and interview data. | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that if I withdraw from the project the data collected up to that point would be destroyed unless I give permission for it to be used.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree to photos or video material to be taken of my child for data collection purposes only  | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree to the interview being audio recorded so that my comments can be typed up and used as research data  | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree to photos or video material to be taken of me for use in this study.   | <input type="checkbox"/> | <input type="checkbox"/> |
| I give permission for the researcher to keep in touch with me after the end of the study   | <input type="checkbox"/> | <input type="checkbox"/> |

I agree that the data can be safely stored for up to 10 years

☐☐

I agree to take part in the study

☐☐

I agree to my child taking part in the study

☐☐

Participant: \_\_\_\_\_

—

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

—

Researcher: \_\_\_\_\_

Signed \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix C1 – topic guide for interviews with young people

### Transitions of young people with autism from special school to further education

Topic Guide for interviews with **Young People** – these will take the form of ‘adapted interviews’ appropriate to the communication needs of the young people.

#### **Interview 1** (last term at special school, May/June 2013)

##### About school:

Education history and how long at this particular school  
 Favourite subjects and any exams being taken  
 What has been learned at school  
 Friendships, social life at school and home  
 Family background  
 Relationships with members of staff  
 School preparation for adult life  
 Discuss transition plan  
 Who has helped the most to prepare for transition (i.e. that I could then interview – key professional?)

##### About college:

Which college and what kind of course  
 Contact and involvement with college so far  
 Apprehensions and expectations  
 College as preparation for adult life

##### About the future:

Hopes and aspirations in relation to possible employment, independent living and social/community life  
 Peers and their plans  
 Key sources of information, advice and support.

#### **Interview 2** (beginning of second term at college, January 2014)

*(Some topics will be adapted in response to first interview.)*

Settling in to college - examples of what went well; what didn't go so well  
 Timetable – how much unstructured time; how is that dealt with  
 Social life – mixing with other students or additional needs group  
 Who has helped the most at college  
 Would anything else help to settle in to college? Work, social, travel, other.  
 Changes to aspirations for the future  
 Future plans for college and beyond  
 Sources of information, advice and support

## Appendix C2 - Topic Guide for interviews with Parents

### **Interview 1** (last term at special school, May/June 2013)

#### Background:

Education history and how long at this particular school  
 Diagnosis and learning needs  
 Family background and support networks  
 Favourite subjects and any exams being taken  
 What has been learned at school  
 Friendships, social life at school and home  
 Relationships with members of staff  
 School preparation for college/adult life  
 Discuss transition plan and the process of planning  
 Who has helped most to prepare for transition (i.e. that I could then interview)

#### About college:

Which college and what kind of course  
 Choices/opportunities made available  
 Contact/involvement with college so far (parents and young person)  
 Concerns, apprehensions and hopes  
 College and role in preparation for adult life

#### About the future:

Hopes, concerns and aspirations in relation to possible employment, independent living and social/community life.  
 Most useful sources of information, advice and support.

### **Interview 2** (beginning of second term at college, January 2014)

*(Some topics will be adapted in response to first interview.)*

Settling in to college – what is going well, what has been difficult, were there any surprises?  
 Examples of what went well; what didn't go so well.  
 Timetable – how much unstructured time; how is that dealt with  
 Social life – mixing with other students or additional needs group  
 Who has helped the most at college – key link person  
 Would anything else help to settle in to college? Work, social, other.  
 Changes to aspirations, interests or concerns for the future  
 Future plans for college and beyond  
 Most useful sources of information, advice and support  
 Progress on course – what is going well and what is difficult?

### Appendix C3 – topic guide for interviews with teachers

## Transitions of young people with autism from special school to further education

Topic Guide for interviews with **teachers in special school**

**Interview 1** (last term at special school, May/June 2013)

### Background:

Teaching background and length of time at school/college  
 Relationship with young person – length of time  
 Role in relation to transition and preparation for college/leaving school  
 Transition plan and its appropriateness  
 Knowledge of range of opportunities available for this young person  
 Progress of young person at school, curriculum strengths  
 Social skills and non-curriculum strengths  
 Ability to be flexible and adapt to change  
 Key factors in successful transition for this young person  
 Aspirations, concerns for this young person in transition  
 Which college and what kind of course  
 Links between school and college  
 Transfer of relevant information to college – relevant tutors  
 Hopes for the young person's future  
 Hopes, concerns and aspirations in relation to possible employment, independent living and social/community life.

## Appendix D1 – Student interview schedule

### Student interview schedule (Time 1)

**Name:**

**School**

1. How long have you been at this school?
2. Do you like it here?
3. Do you get on with the teachers? How have they helped you in relation to your work and study but also in other ways?
4. Have you got friends at the school or out of school?
5. What subjects have you studied at school? Do you think you have done well in your exams?
6. What are your favourite subjects? Which ones do you think you are best at?

***\*\*Activity on tablet: abilities, strengths and interests (piccollage)***

**College**

1. Which college are you going to?
2. What course are you going to do? What kinds of things will you study? Is it a full time course? Will you have lessons everyday?
3. Have you been to college for a visit? Did you go to the classrooms you will be using? Did you meet the teachers? Do you know your way around? Do you feel ready for college?
4. How has school helped to get you ready for college?
5. Has anyone else helped you to prepare for college? (at home, connexions, other)



6. Do you feel ready to go to college now?
7. Will you have any contact from school or college over the summer holidays?
8. What date do you start at college?

**\*\*Activity on tablet: sorting exercise – concerns about college, looking forward to**

### **Transition/future**

1. When I come and visit you again in January or February – how do you think you will have settled in to college?
2. How long do you think you will stay at college?  
  
What kind of job would you like to do?
3. Where would you like to live in the future and who with?
4. Will you need to do any other courses?
- 5.

### **Follow up:**

|                              |  |  |
|------------------------------|--|--|
| <b>Email addresses</b>       |  |  |
| <b>Summer holidays</b>       |  |  |
| <b>Ideas for diary</b>       |  |  |
| <b>Send collage and list</b> |  |  |

## Appendix D2 – example of Time 2 interview questions

Example of customised second round of interview questions: David 23/1/2014

### A. Looking back

1. (at your card sorts): You were looking forward to new friends, free time, still being with old friends and new teachers – have those been the best things about starting college or were there some other things which were really good? You were a bit concerned about not enjoying the work
2. What about your collage – would you say that Maths, Xbox, media and ICT are still the most important interests? Has anything changed?
3. Looking back do you think your school prepared you well for going on to college? Could they have done anything else which would have helped?
4. How were the summer holidays? What did you do? Did it feel like a long time or was it OK? Was it good to go in to college for a few days? Did you meet up with any friends?
5. Were you pleased with your results from school?

### B. Induction and starting at College

1. Can you remember what your first day was like at college?
2. Did you gradually build up to all your lessons with a smaller timetable or did you have a full timetable straight away?
3. Could college have done anything more to help you to settle in?
4. How is your daily journey to college? Have you had any difficulties with that?

### C. College life – course, timetable, social

#### Course

1. How is the course going? Do you enjoy it? Is it hard work or do you find it easy? Is it easier or harder than working for your GCSEs?
2. What different subjects do you have? Which ones do you enjoy the best? How many teachers do you have and do you have to move around college a lot?
3. Do you think all the teachers understand your abilities and things you find difficult? What do they do to help you to learn?
4. Has the course changed your mind about what you want to do in the future? Do you know what you will go on to next?

#### Time/Structure

1. What is your timetable like?

2. Do you have free time between lessons? What do you do then?
3. Do you have breaks and lunch in the college cafes or canteens?
4. Do you get to move around to lots of different lessons across college or are you taught mainly in a few classrooms in one block?
5. What do you do on your day off/afternoon off? What would you like to do?

#### Friendships/social life

1. Are you still in touch with anyone from school?
2. What do you think friendship means?
3. Have you made any new friends? Do you meet up outside of college? DO you use facebook or twitter or any other social media to keep in touch with friends
4. Do you do any activities or clubs at college or out of college?

#### D. Future

1. How is college different to school? Do you miss school? What are the biggest changes for you?
2. What do you think you will do next – in terms of next year and the next course? Or job?
3. Did you get any work experience at school and will you get any at college? Do you know what you would like to do for a job?

## Appendix E – Example of blank Moving On Plan



### Learning Difficulty Assessment (Otherwise known as Moving On Action Plan) Prepared by Connexions on behalf of the Local Authority

This Learning Difficulty Assessment has been written for

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Number \_\_\_\_\_

Mobile Number \_\_\_\_\_

Parents names: \_\_\_\_\_

Local Authority: \_\_\_\_\_

Currently attending: \_\_\_\_\_

School contact: \_\_\_\_\_

Aims for the future and type of provision interested in (FE/WBL/  
Full-time/Part-time)

Applying for Level .....

Young person's preferences and reasons

Parent/Carer's preferences and reasons

**PART A: PRESENT INFORMATION****1. Background Situation:**

| Situation  | Details |
|--|---------|
| Exams Taken (incl likely grades)                               |         |
| CAT Scores   |         |
| Learning Style/Preferences                                     |         |
| Attendance and Participation (including social interaction)    |         |
| If left school then a brief summary of activities since school |         |
| Strengths  |         |
| Interests  |         |
| Family Situation (if appropriate)                              |         |
| IF/Link Programmes   |         |
| Work Placements  |         |
| Health Issues (and prognosis if appropriate)                   |         |
| Other  |         |

**2. LDD Status – select as appropriate**

| Statement | School Action Plus | School Action |
|-----------|--------------------|---------------|
|-----------|--------------------|---------------|

**3. Looked After Child -****4. Presenting Needs**

|   |   |   |  |
|---|---|---|--|
| Sensory Impairment                          | ✓ | Communication Difficulties                  |  |
| Moderate Learning Difficulties              |   | Autism / Aspergers                          |  |
| Severe Learning Difficulties                |   | Physical Difficulties                       |  |
| Mental Health Difficulties                  |   | Specific Learning Difficulties              |  |
| Behavioural, Emotional, Social Difficulties |   | Profound and Multiple Learning Difficulties |  |
| Other:                                      |   |   |  |

Further Details of Presenting Needs and Current Position including strategies that have been successful up to now:

**5. Assessments Completed**

✓

| Assessment                                   | Date of Assessment | Copy Attached |
|--|--------------------|---------------|
| APIR (Connexions Assessment)                 |                    |               |
| Statement of Educational Need                |                    |               |
| Action Plan/Interview Summary                |                    |               |
| CAF  |                    |               |
| Medical                                      |                    |               |
| Pathway Plan                                 |                    |               |
| Care Plan                                    |                    |               |
| Speech/Language/Sensory                      |                    |               |
| Annual Reviews                               |                    |               |
| Transition Plan                              |                    |               |
| Educational Psychologist                     |                    |               |
| Physiotherapy/OT                             |                    |               |
| Mobility                                     |                    |               |
| ASSET (YOS Assessment)                       |                    |               |
| Dyslexia                                     |                    |               |
| Individual Education Plan/Provision Mapping  |                    |               |
| Personal Education Plan (LAC)                |                    |               |
| School Report                                |                    |               |
| College Reports                              |                    |               |
| Exam boards approval for access arrangements |                    |               |
| Other  |                    |               |

**Specific relevant details of assessments**

**6. Ability to travel independently**

**7. Any long term medication or health needs to be noted**

**8.**

| Other agencies currently involved | Yes/No | Named Worker | Contact Details |
|-----------------------------------|--------|--------------|-----------------|
| Educational Psychologist          |        |              |                 |
| Behaviour Support (via school)    |        |              |                 |
| Speech and language therapy       |        |              |                 |
| EWO                               |        |              |                 |
| Youth Offending Service           |        |              |                 |
| Social Care                       |        |              |                 |
| Learning Mentor                   |        |              |                 |
| Sensory Impairment Service        |        |              |                 |
| Physiotherapy/OT                  |        |              |                 |
| Mental Health Service             |        |              |                 |
| LAC/14+ Social Worker             |        |              |                 |
| Other (please specify):           |        |              |                 |

**Part B RECOMMENDATIONS FOR TRANSITION & PROGRESSION**

**9. Additional Needs/Specialist Support recommended** (this is developmental and may change as the young person starts and progresses through the provision)

**(PLEASE READ IN CONJUNCTION WITH PART A, WHICH DETAILS PRESENT SUPPORT BEING RECEIVED.)**

a) Tuition (in class activities)

b) Accreditation support including examination concessions

c) Skills (eg literacy, numeracy, organisational skills required in order to access the curriculum)

d) Vocational/Practical

e) Independence Training

f) Personal Care Support

g) Therapy and/or counselling

h) Equipment

i) Personal and Social

j) Finance/Housing

k) Extra Curricular

l) Health Care

m) Other

#### 10. Review Arrangements

.....will be contacted to check that he/she has settled at college and offered information, advice and guidance to enable her/him to consider future options

This Learning Difficulty Assessment has been discussed with the young person who has agreed to copies of this and other assessments and reports going to relevant Providers.

#### Signed

Young Person/Parent/Carer

Date

Connexions Personal Adviser

Date

#### Sent to

Provider

Date

Local Authority

Date



## Appendix F – original collage

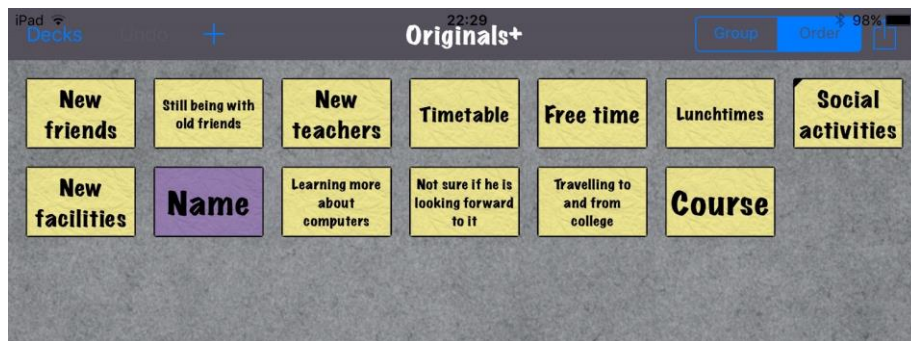
These were the original images used on the collage and participants were asked to move them around, make them bigger if they liked them and smaller if not, putting their favourites towards the top of the screen.



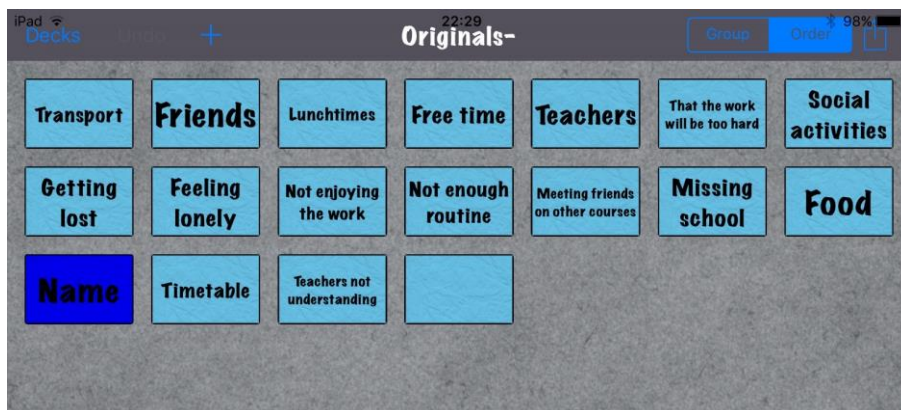
## Appendix G – card sorts

Original card sorts given to participants to rearrange/add to or delete about what they were looking forward to about going to college and what they were worried about

a) Looking forward to



b) Worried about





## Appendix H – example of field notes from visit to Meadowlands College

12/11/13 - Fieldnotes [redacted] college.

[redacted] Retail lesson. [redacted] (Teacher [redacted])

7 students - a couple away? 4<sup>th</sup> week of retail. ([redacted])

[redacted] wants this one & creative media?  
one girl.

[redacted] sitting next to [redacted] but working with [redacted].

working in pairs - [redacted] with [redacted].

hitting down as many shops as they can in 2 mins.

[redacted] go for 3 shops.

Taking full part in lesson & offering answers.

Hamleys only one in London.

Other boys saying [redacted] talks about computers in  
retail lesson & during lunchtime.

Making shopping bags out of paper.

(don't know what lesson obj was & thought it was  
all a bit vague etc).

Spoke to Peter a bit when they were making  
bags out of paper. He seems to have settled really  
well & if anything was more relaxed & chatty  
than when I saw him at school - he coped  
really well with a boy sitting next to him (who  
was from [redacted] mainstream school) & managed  
to keep him in check or not be put off by him -  
almost gave as good as he got. He talked about  
going on to BTEC Level 2 next yr & is choosing  
retail & creative media as his options for  
the rest of this year (as well as perf arts as an  
additional one). I asked him about his time  
off - his day & a half & what he did & he  
said that he did chores in the morning (&  
tomorrow he has to hoover the car) & then  
had lunch & might skype his friends  
in the afternoon. He keeps in touch with  
friends from school & although has

## Appendix J1 – Transcribing Frankie, sample notes from journal

approaching literature"

See Kvale (1996) p204 for ad hoc  
meaning generation in data analysis

Thurs 19th Sept 2013

Just transcribing [redacted]. Thinking  
about friendship again + the nature of  
friendship + keeping up with them on  
FB etc.

Another theme connected to capability  
theory seems to be where [redacted] for  
example were rewarding [redacted] - student  
of the year on that course + really going  
with what he can achieve.

Concerns about life beyond college.

Fri 20th Sept

[redacted] transcription - thinking  
about glimpses of bullying scenarios  
which [redacted] hunts add at through  
his descriptions eg being written on  
on the bus, snowball in mouth +  
yelling at lunchtime.

Also worries about college -  
some things generic about college  
+ some specific things which I  
would never have included in  
the card sort like worrying about  
putting up dead animals to give to birds  
of prey



## Appendix J2 – Transcribing David and Denise, sample notes from journal

Try to gather timetables and work out what the contact time is for each of my students. Just transcribing [redacted] & [redacted] interviews and in January [redacted] was only at college on Mon pm & all day Tues as his courses had finished until after half term.


Wed 7<sup>th</sup> May

Transcribing [redacted] interview.

Thinking about [redacted] going on the NCS camp thing & then wanting to wear a suit to the graduation ceremony - [redacted] was really impressed that he went on the camp although she had reservations

about it but that it's good to let him have a go. But also with the suit - he has real issues with clothes & throws tantrums over certain clothes etc so really good he was able to wear a suit.

⊛ Makes me think of the tension b/w indep & vulnerability [redacted] again - parents being able to let go & this is where colleges could really help to facilitate that rather than going 'cold turkey' & just saying these adults now but support that transition to independence. More comm<sup>n</sup> with parents especially at first.

⊛ Could travel training be a metaphor for the whole transition experience? All about making YP more independent but need appropriate support to do that. Might be able to cope with predictable journeys but how to cope with uncertainty - how to teach flexibility & coping with change? 

Need timely comm<sup>n</sup> from college too - not a letter the day before a trip with no preparation time.

## Appendix K – data analysis

### From codes to themes in the data analysis process

Some of the early codes from the first round of interviews were:

- Course choices, range of options
- Mainstream vs protected
- Pressure of y11
- Funding – affecting course availability
- Courses at college not full time
- Communication with school/college
- Different expectations of young person, parent, professional
- Loss
- Change
- Young people and social communication/interaction - challenges
- Travel and distance from school
- Friendships
- Timetables
- Future hopes/plans
- Parental strife/influence
- Abilities

But by the end of the first round had become slightly more coherent themes but not yet fixed:

1. Life beyond college: imagining a future or not, aspirations for the future
2. 'Full time' courses are not full time: unstructured time, summer holidays
3. Transport: independent travelling vs taxis, fears and concerns,
4. Parental influences and attitudes: well organised, clued up parents
5. Levels of understanding: about own condition, future options, communication and cognitive abilities
6. Autism Plus: learning difficulties, epilepsy, physical difficulties, no two people with autism the same
7. Socialising: having friends, what is a friend, real vs virtual contact
8. Battles, fights, struggles: education, statements, school choice
9. Family situation: loss, bereavement, siblings, parents
10. Communication: with professionals, with school/college, btn parents and children and btn children and peers
11. Capabilities: in and out of school, achievements, talents, creativity
12. Informed choices?: availability of courses, YP understanding, advice given, level of course

13. States of mind: Happiness? Depression, anxiety, coping strategies

14. Role as researcher: identity as parent of ASC child – help or hindrance?

It was not until the final combing, coding and organising the data to tell a story, which had to take in the temporal aspect of the research, that the themes were more streamlined into the list below. This could only be carried out after looking at the data and the cases as a whole.

- Aspirations, abilities, future plans
- Experience of school
- Preparation for transition
- Time and managing time
- Academic progress
- Social interaction
- Supporting ongoing transition

## Appendix L – extract from Jake's walking interview

**Extract from Jake's walking Interview at college**  
**Thursday 6<sup>th</sup> March 2014 (met Jake in College canteen)**

Jake: so that's good

JS: so that's what you want to go and do next year

Jake: Yeah, in September

JS: Good. And what's happening with English now, do you think you're going to do....

Jake: I'm going to do functional skills this year and then I'm going to do the GCSE next year

JS: Great. That's really good....good ...so that's all sorted then is it?

Jake: aha

JS: [getting to LRC and whispering] and is it quiet in here, do we have to be quiet?

Jake: quiet, reasonably quiet it's like a study area for students who want to catch up with any course work or anything, that kind of thing then they do that

JS: it's a nice area

Jake: lots and lots of computers

JS: yeah

Jake: and downstairs is where you can borrow books

JS: good

Jake: I'll just take a picture.... [takes picture of upstairs area in LRC P3]





P3) Upstairs in LRC

JS: so do you come in here if you have gaps in between lessons?

Jake: If I have gaps in between lessons, I sometimes come in here

JS: yeah, yeah

Jake: so yeah, take a picture there. Do you want to go downstairs and take a picture?

JS: I don't mind, do you mostly go upstairs or downstairs

Jake: I go downstairs but I sometimes go upstairs, downstairs is where you can read the books down there.....[walking downstairs] ...so you've got the ICT, public services, you've got all sorts of books there

JS: right, that's really good isn't it?

Jake: I'll take a picture there...right that's taken [takes picture of downstairs in LRC P4]



P4) Downstairs in LRC

JS: good....so...where...shall we go to where you had PSD this morning for example? Or...?

Jake: that's my classroom..[laughs]...do you want to ...we could take a picture of my classroom..

JS: Would that be OK?

***(and a later section of the interview where he showed me the classroom where he had his interview for a higher level course for the following year)***

JS: and did you hear anything from...was it the care home?

Jake: oh no...do you know what happened with that? I called up yesterday and they said that apparently the person that interviewed me was ill, sick so it's been even more delayed now [get to floor 6] and this is where I was yesterday

JS: that's where you were, OK

Jake: that's where most of the level 1 students do their course

JS: shall we just take a picture of the outside like that? [people in the room] - it's a bit bright with the sun but never mind [takes photo outside the room with sun streaming in P11]



P11) ICT room where Jake had his interview for BTEC level 2 next year

Jake: and er that's it really, that's the place I was in but unless you want to take pictures of the other classrooms?

JS: no that's fine. So is everything good? You seem really happy here

Jake: yeah and one of my friends is going to be coming here, he stayed on to the KS5 bit and he's moving straight on here to a media course but I'll still see him at breaks and he lives in Hassocks so he'll be on the same train as me so I'll be able to see him on the train

JS: so do you meet anyone else in the mornings on the train - does anyone else make the same journey?

Jake: no

JS; so where are we now...is this the tower block?

Jake: tower block yes, so that's it really

JS: so can you take me back to the main reception.....[ends]

### Appendix M – extract from Eric's walking interview

#### Extract from Eric - walking interview at College

(with LSA, Thursday 19<sup>th</sup> June 2014 at 9.30am)

JS: so, you just open it up to take photos [passing the tablet to Eric, he took photo of LSA straightaway]...so where are we going to go? Where do you have some of your lessons? You might want to take a picture of some of those but we have to be careful to not get too many people in because they might object

ERIC: I think they're good looking girls, come on

JS: well you can show me who they are but we won't take pictures of them OK? Are you still having fun at college?

ERIC: Yeah

ERIC: this is one of the rooms...[takes photo]



E1 – general classroom

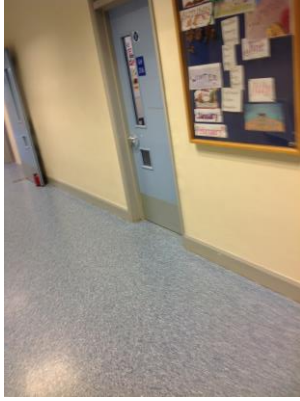
JS: OK what do you have in there? What lesson

Eric: Oh, can't remember, something with A---, he looks like something from Scooby-Doo

JS: I remember you had all sorts of names for people before didn't you?

LSA: yeah, hobbit, dwarf, all kinds I've been called

ERIC: This is another room that I go in – 206 [takes another photo]



E2 – Floristry classroom

JS: 206 and what do you have in there

ERIC: Miss, what do we have in there? Oh yeah floristry

LSA: yeah ongoing project work, I'm only with Eric when he does those lessons but he's got English things here

ERIC: 208 is after cooking, we do portfolios [takes photo]



E3 – portfolio  
classroom

JS: right, yeah. Ok where else do you go?

ERIC: I used to go in that one

LSA: remember you can say if you don't like it cos I know you don't like that room do you, because it makes you too hot doesn't it?

ERIC: yeah. I love the break room



E4 – Break room

JS: Yeah. Do you want a picture of the room that makes you too hot?

ERIC: [shakes head]

JS: No, OK he's shaking his head at that one. OK where we going

ERIC: that's it

JS: that's it, so you never go anywhere else?

ERIC: no

LSA: you do sometimes

ERIC: no I don't

LSA: well I've sat on the grass out there with you

JS: ah, out on the grass

ERIC: [takes photo of grass through window] and that's it



E5 – Grass outside Learning Support corridor

JS: is that it? You don't go to the canteen?

## Appendix N – extract from David's walking interview

### Extract from walking Interview with David at college 27/2/2014

David: all morning, yeah, that's that then there's like an option or something so it could either be sport, enterprise or

JS: are you still doing the sport one?

David: no we haven't had sport yet, no. So we've done work skills which was in there so I don't do that any more now we're on enterprise which is in...202 I think

JS: OK shall we go and have a look at that?

David: is that door open? [pushes open door – takes picture M3 of Enterprise classroom]



M3) The Enterprise Room

JS: this looks like a good room. So what do you do in here?

David: this is enterprise which is like arts and crafts and stuff, making it and selling it and stuff like that

JS: Ah OK so have you made anything here [artefacts on display] what sort of things...?

David: yeah, don't know if it's in here but those houses at the back we made [bird houses]

JS: and do they sell them, what, in college or...?

David: yeah, like a fair or whatever

***(Extract 2: discussing the canteen)***

David: Yeah, then that's Tuesday done then I have Thursday which has carpentry which is all the way over there

JS: do you mind going over there

David: Yeah Ok ,we'll go over. It's in a workshop which will most likely have people in it

JS: It would just be useful to see ...you know...how far...cos obviously it's a huge college isn't it? Lots of buildings. So do you have most of your teaching in this block then?

David: yeah, carpentry's the only thing that's not in this block

JS: OK so it would be useful to have a look at that...and is carpentry ...is that because it's got specialist facilities?

David: Yeah, it's like a workshop type thing with all these saws and all that stuff

JS: and so then...is this the cafe you come to sometimes?

David: yeah

JS: so we could go in there maybe?

David: shall we go in there first then? Take a picture of something? I dunno...there's lots of people around

JS: yeah, so do you get your lunch here most days when you're here then? [entering noisy cafe]

David: Yeah...

JS: Well let's come in a bit and maybe take one over here [trying to avoid taking pictures of people as David was concerned about that] take one maybe just down there [as there was a space with no people] at least it will remind me of the place....[David takes pic M4 of an area of the cafe discreetly]



M4) The main Cafe

JS: so everyone from all over college can come to this cafe then?

David: Yeah, it's not normally this busy...cos like everyone's in and you actually have to come in on a Thursday if you're on explorer so you're going to go in there

JS: so are there a lot of people doing the same courses in there then?

David: er...think so..yeah...like every single course in the college goes there

***(Extract 3: going across campus to carpentry)***

JS: so what do you do on your days off?

David: erm...mostly sit at home or whatever, pretty much prepare for the next day

JS: Yeah, and do you mind that? Would you rather be in college every day or not?

David: no, I'd prefer to be ...obviously not too many days off but...

JS: yeah so do you think it's the right balance at the moment, that you've got enough time at college and enough time off?

David: Yeah

JS: it is a long way to carpentry isn't it? [laughs] Maybe we wouldn't have done this if it was raining!

That looks like all the things that went wrong in carpentry [pointing to skip]

David: yeah, I think there's always pretty much people in there... like always people in the workshop and stuff but we can get to peep through the door

JS: yeah and we can always take a picture outside or something



David: Oh there's no one inside

JS: brilliant, can we get a picture alright of that?

David: [takes pic M5 of carpentry workshop] got it



M5) The Carpentry Workshop

JS: well done, thank you. So do you feel quite comfortable in all the different bits of college? Are there some bits you don't like or...?

David: well, walking here....during my break time

JS: because of the distance...I bet you've had some rainy days to do that haven't you?

David: Yeah

JS: does it get flooded around here at all when it was really bad?

David: down there, yeah, it was all flooded

JS: yeah. [walking back towards main buildings]

## Appendix P – My theoretical framework

