

Young People with Special Educational Needs' Experiences of School and the
Transition to Adulthood

Emily Charlotte Forster

Thesis submitted for the Degree of Doctor of Philosophy

University of York

Department of Social Policy and Social Work

February 2012

Abstract

This thesis explores the transitions to adulthood of young people with Special Educational Needs (SEN). It focuses on the experiences of young people with a 'hidden disability' such as Autism or ADHD who attend or attended a mainstream school. The number of young people who are diagnosed with these conditions has increased dramatically. Between 2005 and 2010 the number of school children in England alone diagnosed with an autistic spectrum disorder has increased by 61% to 56000 (DfE, 2011,a). In recent years there has been an increasing focus on including pupils with SEN in mainstream schools. In England, the Special Educational Needs and Dis-ability Act (2002) and the Equalities Act (2010) have strengthened young people's right to inclusion. This research sought to investigate the impact these social changes have had on young people's lives.

Longitudinal qualitative methods were used to develop an understanding of young people's experiences and the interaction between social policy and individual biography. This involved two life history interviews with a sample of young people and their parents which took place nine months apart. This yielded over fifty interviews. These interviews explored young people's experiences of school, their aspirations and plans for the future and the support they had received. Two age cohorts of young people were involved in the research. The first were in school years 10 and 11 at the time of the first interview and the second were aged 18 -20. This made it possible to capture a wider range of experiences of transition. Drawing on all of the data collected for each young person, 14 'case histories' were developed (Thomson, 2007). A thematic analysis was carried out across all of the interviews in the study.

After finishing compulsory education the young people in the study followed mainstream pathways of education and employment. Any additional support they received came from these services rather than specialist provision. Family and friends were also a major source of support. Young people's school experiences influenced their aspirations for the future and their sense of themselves as learners. However, this was not the only factor; for example, some young people who had a

negative experience of school were able to draw on achievements in other areas of their lives to achieve success in further education and employment.

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Declaration

I declare that the work presented in this thesis is entirely my own and has not been submitted for examination at this or any other institution for another award.

Introduction

This research aims to explore young people with Special Educational Needs' (SEN) experiences of school and leaving school. It has a particular focus on the experiences of young people with a 'hidden disability' who attend a mainstream school. My initial interest in this area arose from personal experience. I have dyspraxia and when I was at school I was considered to have special needs. Throughout my education I attended mainstream schools. I became aware that for some young people with SEN, there were few options and little support available to them once they had left school.

In later years when I was studying for my undergraduate degree I learned about the debate around the inclusion of pupils with SEN in mainstream schools. It struck me at the time that there appeared to be little consideration of the experiences of these pupils and if they felt they were included. I also learnt about the social model of disability (Oliver, 1983). Many academics working in this tradition have undertaken research into SEN and given voice to those who have experienced special education. Their work has been a major inspiration to this research. My aim in carrying out this research was to find out about young people with SEN and their experiences of school and leaving school. I was interested primarily in their perspectives and views, although this later grew to include the experiences of parents as well. I admit that I am primarily on the young people's 'side'. However, I suggest that social research of this nature can never be completely value free as research is a 'political act' (Barton, 2005). Much of the research carried out in this area has been criticised as 'ripping off' disabled people and contributing to their oppression (Oliver, 1992).

Around 18% of pupils in England are considered to have some form of Special Educational Needs. This includes children with physical disabilities, learning difficulties and behavioural problems as well as, those who are behind their peers but whose needs are less well defined (House of Commons, 2006). As the categorization of pupils as having SEN only applies to schools this means that, for many young people with SEN, their entitlement to support ends when they leave school. Further Education colleges provide support to students with Learning

Difficulties and Disabilities and employers are obliged to make reasonable adjustments for disabled people. This makes it difficult for young people to negotiate the support they need on leaving school. This is a complex and changing policy area and is discussed in greater detail in the Policy Review chapter.

A recent study carried out for the Department for Education and Skills (Dewson et al 2005) which included young people with the full range of SEN and followed them from their final year of compulsory schooling until they were aged 19-20. This found that while those young people with the most severe difficulties tended to be well supported, for the majority of young people, the support provided tended to be patchier and relied more on their ability to navigate their way through the mainstream education system and labour market. However the type of support to help young people to do this is not always available. As such my own study will focus on young people who attend mainstream school and will include young people with and without statements.

The research questions that this thesis will answer are:

- What are the young people's short term and long term aspirations for the future? - In terms of education, employment, home life, family and relationships.
- What are the young people and parent's experiences of services, in particular those involved in transition planning and how well do these services work together? - Does having a statement of Special Educational Needs make a difference to how well young people are supported by services when preparing to leave school?

The research will set these questions in the wider context of the young people's school experiences.

What follows is an overview of the thesis.

The Construction of Special Educational Needs

This chapter locates the concept of Special Educational Needs in its historical context. It outlines how some children came to be classified as having Special Educational Needs and the way that these children were perceived has changed over time. It also explores why the proportion of children diagnosed with 'hidden disabilities' has increased significantly in recent years. Finally it provides definitions of the key concepts which will be used for the purposes of this study.

Literature Review

This chapter reviews the literature relating to the first research question on young people's aspirations and how this is influenced by school experiences. It provides a brief overview of the literature on youth transitions, with a more detailed look at some recent research which has adopted a biographical approach. It then explores some current issues in the area of SEN, including the debate around inclusion. Finally, I discuss existing research on the transition to adulthood for young people with SEN.

Policy Review

This chapter focuses on the literature relating to the second research question on how well young people are supported by services. It reviews the policies relating to education, employment and training for young people, with a specific focus on policies relating to young people with SEN. Policy in this area is undergoing rapid change and the proposals in the SEN (DfE, 2011,a) and Education Green Papers (DfE, 2010) are also discussed, as well as the proposed changes to the careers guidance system. It is argued that there is a tension between an increasing focus on league tables and the marketization of education and the policy of inclusion.

Methodology

This chapter outlines and reviews the methodologies of previous studies in this area. It argues that in light of the research questions, a longitudinal qualitative approach would be best suited to the research. This made it possible to find out about the young peoples' lived experiences and capture change over time. The research was conducted in a mainstream state secondary school located in a rural area in the north of England. Two biographical interviews were carried out with each of the young people and their parents. These took place between 9 -12 months apart. Due to time constraints on the study I was not able to follow the participants for as long as I would have wished. However, to counteract this, two age cohorts of young people were recruited. The first cohort was in school years 10 and 11 at the time of the first interview and the second, aged 18-21. This enabled me to capture a wider range of experiences of transition. A narrative analysis was carried out for all of the interviews, then, after all of the field work had been completed a "case history" (Thomson, 2007) was constructed for each young person. These drew together the data from both of the young person's interviews with the data from both of the interviews with their parents.

Young People's Experiences of School

This chapter explores the young people's experiences of school. The key themes that emerged from the young people's interviews were : the central role of 'learning support' and the extent to which the learning support the young people received had acted as a form of support or surveillance, the importance of the social side of school to the young people and the degree to which they felt they were included. It includes two "case histories" in which these key themes are explored in more detail.

Aspirations for the Future

This chapter discusses the young people's aspirations for the future and traces what the older members of the sample have done since leaving school. It also looks at the advice and guidance they have received when making their future plans. It draws upon the concepts of "biographical fields" (Holland et al 2006) and "learning careers"

(Bloomer and Hodkinson, 2000, 2002). These two theories helped to explain why the young people invested in the areas of their lives that they did and how their sense of self changed over time. It also includes two case histories. The young people in this research had very similar aspirations in terms of education and employment to other young people their age. However, they often faced barriers to achieving these aspirations that other young people without SEN would not.

Parents

This chapter looks at the experiences and perspectives of the parents. It discusses when parents first suspected that their child had SEN and their experience of their child's diagnosis. It explores their views on their child's school and the extent to which they were involved in their future plans. Several parents said that their child had achieved more than they had ever expected of them and overcome many of their earlier difficulties. This chapter also includes two "case histories".

Discussion

This chapter explores the transition pathways followed by the young people in this research, including the routes they took in terms of education and employment and the support they received. It relates their experiences back to previous research involving young people in general and those with SEN. It then goes on to evaluate how the original research questions have been answered. It also looks at the economic and social background against which the research took place, which was a declining job market and public sector cuts. The experiences of the young people in the research have much in common with those of young people in general, as they were going through the process of exploring their identity and their future options. However, they often faced significant barriers to achieving these goals. The research was carried out in a rural area and this is also considered as a factor which affected the options open to the young people who took part in this research.

Conclusion

This chapter evaluates the strengths and weaknesses of the research. It argues that a key strength of the research is its use of longitudinal qualitative methods. This made it possible to see the young people's transitions within the wider context of their lives and capture change over time. The study also had a very low attrition rate with 13 out of 14 young people and their parents agreeing to take part in a second interview. It explores the implications of the research findings for policy and practice in the context of the proposed changes to the education system. It concludes by outlining the significance of the thesis.

The Construction of Special Educational Needs

This chapter locates our present day concept of Special Educational Needs in its historical context. It discusses why some pupils came to be classed as having SEN and how this has changed over time. Finally, it considers the situation of pupils with 'hidden disabilities' and why they account for such a large proportion of the population of those who are considered to have SEN.

The Emergence of Special Education

Forms of 'special' education have been in existence for many years, with the first schools for blind and deaf pupils founded in 1791 and 1776 respectively. Special education began on a mass scale after the introduction of compulsory education in 1870. The 1870 Education Act did not make any provision for pupils with disabilities or learning difficulties. However, once pupils arrived in the classroom the extent of disability and poor health amongst children from poor families came to light.

“Some children failed to thrive in the elementary schools. Sometimes it was for obvious reasons: they were blind or deaf or dumb or had some visible physical disability. An alarming number were diagnosed as epileptic. Others, in a language that was filtering into Britain from France, were thought to have low IQs to be, in the phrase used at the time, ‘feeble-minded’.” (Cunningham,2006,p189)

The conditions of the new board schools were not adequate to meet the needs of their pupils. Class sizes were high, upwards of 50 pupils to a class, with pupils in the lower classes often being taught by a young pupil-teacher. This necessitated a teaching style which focused on the whole class with strict discipline and little opportunity for individual attention (Read, 2007). Many pupils never made enough progress to move up to higher classes. One school Medical Officer in the 1890's claimed that in almost every London school, there were around 70 pupils in each

Standard 1 class , of whom around 25 were 'almost entirely ignorant' (Cole, 1989). The question of whether disabled pupils should be educated in regular classes remained unclear, in 1872 the newly formed London School Board excluded blind deaf and 'mentally defective' children on the grounds that they were 'permanently disabled' (Hendrick, 2003). While in some areas limited attempts were made to include disabled pupils in regular classes, more and more pupils began to be educated in separate special schools (Cunningham, 2007, Cole, 1989).

In 1889 The Egerton Report, which was the result of a Royal Commission, brought some clarity to the situation. It argued that the education of disabled children was essential on economic grounds to prevent them becoming a burden to the state. The report recommended that blind children received basic elementary education up to the age of 12, this could take place in regular schools and then technical education until they were 16. Deaf children should be educated separately (usually in institutions) from ages 7 -16. Finally it looked at the education of 'feeble – minded', 'idiot' and 'imbecile' children, arguing that they were educable, that school authorities should be responsible for them and they should be taught by properly trained teachers. In 1893 these recommendations were enacted into the Elementary Education (Blind and Deaf Children) Act. This gave local authorities the duty to provide suitable education for blind and deaf children either in one of their own schools or an institution. This Act ensured that all blind and deaf children were at least entitled to an elementary education. Physically disabled children and those with epilepsy who were not included in the act had to rely on education provided by charitable organizations until the 1918 Education Act made it compulsory for education authorities to provide an education for them.

As well as bringing to light the extent of poverty and ill health amongst children. The introduction of compulsory education also provided professionals with unprecedented opportunities to produce scientific studies of the pupils. The 1890s saw the growth of the Child Study Movement, which aimed to apply the methods of modern science to the study of child development. This was inspired by an interest in human evolution (Darwin himself published influential studies of his own children) and the new discipline of experimental psychology and grew out of a concern for the

extent of childhood disability revealed by the introduction of mass education and social Darwinistic concerns about 'racial degeneration' (Hendrick, 2003). Between 1889 and 1906, the British Medical Association and Charity Organisation Society conducted five large scale enquiries on children's 'Development and Brain Condition' involving London school children. During this period child psychology emerged as a discipline and became increasingly influential, with the first 'educational psychologist' appointed by the London School Board in 1913. (Cole 1989).

The group of disabled children who aroused most concern during this period, for eugenic reasons, were those who were considered to be 'mentally defective'. As discussed above the introduction of compulsory education brought lots of young people into education including those with what we would now call learning difficulties. Asylums were set up for these children. However, as eugenicists were concerned about their life long untreatable condition these asylums were intended to house their 'inmates' for life (Borsay, 2011).

IQ tests began to be used to classify pupils, and by 1913 all local authorities had to appoint a medical officer to decide on a child's medical 'condition' and provide appropriate educational 'treatment' (1913 Mental Deficiency Act). Disabled young people were classified into separate special schools based on their impairments and the growth of intelligence testing led to an increasing focus on segregating pupils according to perceived ability. The introduction of educational psychologists also saw the introduction of provisions for children who were considered to be 'maladjusted' (Cole, 1989).

The categorisation and segregation of pupils reached its height with the 1944 Education Act. This introduced the 11 plus exam which segregated pupils at the age of 11 into three different types of schools; Grammar schools for those who were considered to be the most able, technical schools for those who were considered to have a technical aptitude and secondary modern schools for the majority of pupils. In reality very few technical schools were set up, meaning that around 70% of children went to secondary modern schools. The 1944 Act also expanded the classification and segregation of disabled pupils, introducing 11 categories of

impairments for which local authorities must make provision. These were: the blind and partially sighted, the deaf and hard of hearing, the delicate, epileptic, maladjusted, those with speech deficits, the physically handicapped and educationally subnormal. The largest of these categories was educationally subnormal. This category was also the most difficult to define. Some children were considered to be 'ineducable' and therefore were not allowed to attend school.

There was some provision in the act for disabled children to be educated in mainstream schools and additional facilities were made available for this. Disabled children in mainstream schools were entitled to have "a favourable position in the classroom" special equipment aids and furniture and extra attention from the teacher (Clarke, 1951, pp127-8 in Borsay, 2011). Dyson and Hick(2005) argue that a significant proportion of children who would now be considered to have SEN were educated in mainstream schools in 'remedial' classes. However, according to Tomlinson (1982) provision for pupils with special needs failed to develop in mainstream schools. This happened because:

"..suggestions that children in need of special education could remain in ordinary schools immediately conflicted with two educational interests: the goal of removing the children so that normal schools could function efficiently would be frustrated, and the expanding profession of 'special' education would lose clients" (Tomlinson, 1982, pp50-51).

The 1960s saw the growth of comprehensive schools where pupils of all abilities were educated together. Many teachers at secondary modern schools started entering their pupils into exams and these pupils were increasingly successful. This led to increasing questioning of the wisdom of segregating pupils on the basis of perceived ability and of biological determinism in academic ability (Tomlinson, 2010). Research conducted by Edgerton (1967) in the USA highlighted the fact that many young people who were considered to be "mildly mentally retarded" when they were at school were able to integrate successfully into the community as adults. In 1970 the President's Committee on Mental Retardation came up with the term 'six hour retarded child' to describe this phenomenon. It noted that the prevalence rate

of 'mild mental retardation' fell significantly in early adulthood as people who had been considered to have these difficulties in school coped successfully once they had left school.

In 1970 the responsibility for children who had previously been considered to be 'ineducable' passed from the National Health Service to Local Education Authorities. 1978 saw the publication of the Warnock report, which introduced the term "Special Educational Needs". This replaced the old medicalised concept of 'special educational treatment'. Instead pupils were considered to have SEN if they had a "learning disability which calls for special educational provision". Thus SEN was still seen as largely a within child phenomenon, although Warnock did acknowledge that:

"Schools differ, often widely, in outlook, expertise, resources, accommodation, organisation and physical and social surroundings all of which help to determine the degree to which the individual is educationally handicapped" (Warnock, 1978, p 37).

Warnock has stated that her aim was to emphasise that children with SEN were "not a race apart" (Warnock, 2003) and the intention was to replace medicalised categories of disability with a "continuum of need". However, Warnock's original contention that 'Special Educational Needs' were relative and influenced by the social circumstances did not translate in to practice. New ways of classifying children emerged based on bands of 'learning difficulty' (Swain et al 2003). Another major significance of the Warnock report was its recommendation that, as far as possible, children with SEN should be 'integrated' into mainstream schools. However, rather than pushing for full integration, the report argued that this was not practical for all pupils and recommended that special schools should continue to have a role. The recommendations of the Warnock report were passed as the Education Act 1981.

The passing of this act led to a national decrease in the proportion of pupils attending a special school with the numbers falling overall between 1982 and 2001 (Norwich, 2002). However, significant changes to the education system took place in the 1990s which made it more difficult for pupils with SEN to be included in mainstream schools. Over 30 Education Acts were passed between 1980 and 2000,

compared to only three in the preceding 20 year period (Tomlinson, 2010). The 1988 Education Reform Act introduced the 'National Curriculum'. This was influenced by the views of employers and the skills they wanted from their future employees. It also brought in league tables which ranked schools according to the achievements of their pupils in exams. During this period education became increasingly influenced by market forces (Furlong and Cartmel, 2007).

The increasing marketization of education continued through the 1990s and did not stop with the election of the New Labour government. The emphasis on league tables and parental choice of school remained. However, at the same time there was an increased focus on including pupils with SEN in mainstream schools. Most notably, this included the passing of the Special Educational Needs and Disability Act 2002 which expanded the Disability Discrimination Act 1995 to cover education. This drive towards inclusion was driven by a number of factors. Firstly, disability campaigners had pushed for the right to be included in mainstream schools. There was also a desire to promote equality and social justice (CISE, 2004). There was also a drive to improve overall levels of educational achievement to make the workforce more suited to the new 'knowledge economy', as well as concerns that young people with SEN were at increased risk of social exclusion (SEU, 1999). New Labour education policies saw investment in education as a way of developing human capital and aimed to improve the educational achievements of all children, this included those with SEN.

However, despite the rapid reforms of mainstream education that took place during the 1990s and 2000s, there was little change to the SEN system, other than the increased emphasis on including pupils with SEN within mainstream schools. Unfortunately this coincided with a mainstream education system that was not well suited to inclusion. In addition to this, the range of needs that young people with SEN are considered to have has changed considerably.

Emerging Disabilities

The diagnoses that children with SEN have been given has changed significantly over time. It is clear that throughout history the largest categories of SEN have always been the least well defined and therefore the most contentious. Pupils from economically and socially deprived backgrounds and those from ethnic minorities have always been over represented among pupils considered to have SEN (Tomlinson, 2005, Dyson, 2003). In the 1970s around 10% of school children were classified as being educationally sub normal (Ellis, Tod and Graham- Matheson, 2008). In recent years the number of pupils diagnosed with conditions such as Autism, ADHD, Dyspraxia and Dyslexia has increased significantly. For example, between 2005 and 2010 the number of school children in England alone diagnosed with an autistic spectrum disorder has increased by 61% to 56000 (DfE, 2011,a). However, despite some fluctuations, the overall proportion of pupils with SEN has remained at around 1 in 5 as estimated by the Warnock report (Ofsted, 2010, Warnock, 1978).

Dewson et al (2005) used the term 'contested impairments' to describe these kinds of difficulties. The reason why these impairments are contested is that due to their lack of 'visibility' they are diagnosed primarily in terms of observed behaviour for example dyslexia is identified on the basis of a child having difficulty learning to read and spell. This has often led to the difficulties being wrongly attributed to other factors such as a poor home environment (Riddick 2010). Firth (1992) argues that looking at behaviour alone is not an adequate way to define disorders such as dyslexia and autism, as behaviour is influenced by a range of factors such as life experiences or motivation and to provide a clear definition of these difficulties we need to find out more about the underlying causes.

Moving from a diagnosis based on observed behaviour to one based on the underlying cognitive differences has two main advantages. First of all two children can display very similar behaviour for different reasons. For example young children who have suffered from severe neglect often have many characteristics in common with children with autism such as problems with social interaction, impaired language, narrow and circumscribed interests and repetitive rocking (Firth, 1992).

This led many early authorities on autism such as Bettelheim (1971) to wrongly conclude that autism was caused by parents who displayed a lack of warmth towards their children. However, for children who have suffered early neglect, the autistic behaviour diminishes after several years in a supportive home which is not the case for children with autism (Rutter et al, 1999).

The reasons why there has been a growth in the diagnosis of these conditions remains controversial. Possible theories that have been put forward for this include; children being damaged by vaccines, and environmental factors such as pollution from pesticides but there is little evidence that this is the case (Firth, 2008). However, Lorna Wing has suggested that the rise in rates of autism is due to there being more knowledge about the condition resulting in more people being diagnosed. She suggests that for many people who were previously diagnosed as being 'mentally retarded', autism would have been a more appropriate diagnosis. This is borne out by a study carried out in California which found that the increase in diagnosis of autism directly corresponds to the decrease in diagnosis of mental retardation (Croen, et al 2002). Firth (2008) suggests that social difficulties are more apparent because the demands on social competence are higher today than they were in the past. This may have led to more people being diagnosed with Asperger syndrome whose social difficulties would have been excused in the past. This argument can also apply to dyslexia as literacy skills are also of increased importance due to the expansion of education and the importance of exams.

In his cross-cultural study of autism Grinkler (2009) argues that the supposed 'epidemic' is actually a reflection of the social changes that have led to people with autism being more integrated into society. He contends that autism is a more hopeful and less stigmatising diagnosis than these children would have received in the past. There are more ways of helping people with autism than there were in the past. Parent led advocacy organisations have played a key role in promoting increased awareness of and support for people with the condition.

In the past all children with developmental disorders were seen as a homogenous group and there were very low expectations of them. It is likely that many pupils who are now diagnosed with specific learning difficulties or autistic spectrum conditions would have previously been classed as being educationally subnormal or having moderate learning difficulties. As the proportion of pupils diagnosed with these emerging conditions grows, the proportion of pupils classed as having moderate learning difficulties has decreased. However, the proportion of pupils classed as having 'Emotional and Behavioural Difficulties' continues to rise and these pupils continue to be excluded from mainstream education.

The social model of disability, makes a distinction between impairment and disability. Impairment is the functional limitation or loss that a person may have and disability is the consequence of society not taking into account the needs of people with impairments. According to this model it is possible to have an impairment but not be disabled. The social model is also useful in understanding why the impairments that people with SEN have been diagnosed with have changed over time. What is considered to be an impairment changes with the social context. However, not all disabled people regard themselves as having an impairment. For example, some sections of the Deaf community regard themselves as being a linguistic minority. In recent years some people with autism and other neurological disorders have argued that rather than being disabled they just have a different way of thinking. This concept is called 'neurodiversity'. They argue that their differences should be accepted by 'neurotypical' people (Harmon, 2004). Not everyone with autism agrees with this. Kamran Nazeer(2007) has argued that whilst there may be something distinctive and valuable about the way that people with autism think, some intervention is necessary to help them interact with the world. This debate encapsulates the tension within special education between valuing and accepting all students for the way they are and encouraging them to minimise their differences to help them fit in with wider society.

As we have seen in this chapter the term 'Special Educational Needs' has meant different things to different people and there are a wide range of reasons why children may be considered to have SEN. However, for the purposes of this research 'young people with SEN' refers to children who are considered by their school to have Special Educational Needs. We have seen how the focus has shifted from segregation to 'integration' which focus on teaching children with SEN within the same setting to inclusion which is about belonging.

Conclusions

'Special Education' evolved as schools were not able to meet the needs of all of their students. Pupils from socially disadvantaged backgrounds and ethnic minorities have always been over represented amongst those with SEN. When compulsory education was introduced this brought to light the extent of disability amongst the working classes and attempts were made to identify these students and remove them from the mainstream. Expectations of these pupils were low, particularly for those who have intellectual impairments. The Warnock report and 1981 Education Act introduced the modern concept of 'Special Educational Needs' and made it possible for more children to attend mainstream schools. The recent drive to include pupils with SEN in mainstream schools has been driven as much by normalisation and the desire to turn these pupils into productive citizens, as it has by the desire to promote equality for all pupils. Despite this, the focus on inclusion has made pupils with SEN the responsibility of the whole school. The diagnostic labels pupils with SEN have been given has changed over time but those with 'contested impairments' have always made up the largest proportion of those with SEN. At first all of these pupils were lumped together and given labels such as 'educationally subnormal' or 'moderate learning difficulties'. However, in recent years there has been more understanding of the diversity of reasons why they did not fit into the mainstream system. Many of the hidden or emerging disabilities concern pupils who would have formally been labelled subnormal but now there is more recognition that whilst these children have difficulties in some areas they also have strengths and by

developing these strengths and helping to compensate for their weaknesses these children could be successful learners.

The next chapter reviews the literature on youth transitions with a particular focus on studies with a biographical perspective. It then looks in more detail at the concept of SEN and the issue of inclusion and discusses existing research that has been carried out into the transitions of young people with SEN.

Literature Review

The first part of this chapter will provide a brief overview of the literature on youth transitions, looking in more detail at some recent major transitions studies which have adopted a biographical approach. It then considers the importance of place in shaping young people's transitions to adulthood. The second part looks in more detail at the concept of SEN and the issue of inclusion, before reviewing the findings of some transition studies involving young people with SEN. The chapter concludes by discussing the specific issues faced by young people with SEN as they grow up as well as what they have in common with other young people their age.

Youth Transitions

Studies of youth transitions have traditionally focused on three main dimensions or 'careers'. The school to work career, the family career - which encompasses the move from the family of origin towards forming a family of their own - and the housing career in which young people move away from the parental home (Coles, 2000).

However, in recent years, young people's transitions to adulthood have become increasingly complicated, as the school to work transition has undergone major changes (France, 2007). After the decline in the manufacturing industry, the main focus of the economy turned to the service sector. With this came rising unemployment and a new focus on creating 'flexibility' in the labour market, with more part time and short term work. These changes hit young people particularly hard, with steep growth in youth unemployment in the 1980's. This rose from only 2-3 % in 1960 to over 21% in the early 1980's (Coles, 1995). In response to this young people now spend longer in education or training. This means that many young people experience an extended transition, being dependent or semi-dependent on their families for a longer period of time than would have been the case several decades ago. Furlong and Cartmel (2007) argue that young people today face risks

that would have been unknown to their parents' generation, such as the restructuring of the labour market, increasing demand for educated workers and social policies which mean that young people are dependent on their families for a much longer period of time. In particular, young people tend to remain in the family home for a longer period, with some moving back after the completion of university or college courses. With the school to work transition taking longer for many young people, there has been increasing recognition of the role played by other 'markers of status' on young people's transitions. For example, leaving home, being in a relationship and being an active consumer can all help young people forge an adult identity. Young people will remain dependent in some areas while being independent in others (France, 2007).

Some commentators have argued that these social changes have contributed to the rise in mental health problems amongst young people in recent years. The Nuffield Foundation's (Collishaw et al, 2004) study of the mental well-being of 3 generations of 15 year olds found that emotional problems rose by 70 % between 1974 and 1999, while behavioral problems doubled. The report's authors suggest that increasing expectations of academic achievement, with decreasing opportunities for those who are not academically able may contribute to this. There is also the fact that it is becoming more difficult to enter the job market and this has an impact on how young people perceive themselves. These aggravating factors are more likely to apply to young people with Special Educational Needs who are less likely than their peers to achieve academic qualifications.

These changes in young people's transitions are often seen in the light of Beck's (1992) theory that we now live in a Risk Society (Wyn and Dwyer, 2001; Henderson et al, 2006; Furlong and Cartmel, 2007). Beck argues that in late modern society, people are set free from the certainties and ways of living of the industrial age, opening up many new opportunities. However, the stripping away of all the old certainties about class, gender, occupation, family and the belief in science, also creates new hazards and risks.

These risks are increasingly individualised as the shared concept of social class is eroded by increasing standards of living and dependence on education, with its connections with selection and the promise of upward mobility. However, for many people, increasing levels of education only serve to protect them from downward mobility rather than make them better off. The higher rates of young people with qualifications means there is more competition between equals for the same jobs creating the need for people to market themselves. As people are removed from their traditional class commitments they only have themselves to refer to in planning their individual labour market biographies. Beck argues that as a result of this, social problems such as unemployment are more likely to be put down to individual deficits.

Beck describes the impact of individualisation in terms of being a shift from 'normal' biographies to 'choice' biographies. 'Normal' biographies describe a life which follows a conventional linear life pattern defined by shared expectation. As the future is relatively certain those leading a normal biography do not need to question what to do next or who to be. However, for those leading a choice biography everything is much less certain. While much more is possible it is down to the individual to make it happen and there is much less security. All aspects of transition move alongside each other and change is reversible. Choice biographies are not gender specific and can be pursued by anyone.

Studies from many countries have shown that young people are acting in more individualistic ways, particularly in relation to career choices (Wyn and Dwyer, 1999). In many ways their transitions are different to, and more flexible than, those of their parents' generation. For example, it is much more common to combine several activities, such as work and study, at once and to defer some activities and take them up again later in life (France, 2007). Young people of today have a strong belief in the importance of choice, and see having a choice as being critical to their independence. They also see their own choices as being a major factor in shaping their future careers and identities (Wyn and Dwyer, 1999; Ball et al 2000).

Whilst significant changes in young people's life chances have taken place since the 1980s, Furlong and Cartmel (2007) believe that these life chances are still shaped by social structures such as class and gender. Patterns of social reproduction are still shaped by educational achievement. More young people participate in further education and pursue a greater range of courses and there is an increasing emphasis on choice and achievement which can be linked to the process of individualisation. Whilst this has weakened collective responses to education, the relationship between academic achievement and social class remains strong. Beck sees risk as being unequally distributed throughout society, with those who are already disadvantaged bearing a higher share of the risk than those who are privileged. In the context of young people's transitions the risk is unemployment and social exclusion.

Thomson (2007) argues that in light of this it is appropriate to look at youth transitions from a biographical perspective. This perspective takes a holistic approach to transitions; rather than looking at a specific area of their life such as school to work or housing careers, the biographical approach sees these as integrated parts of young people's lives. The emphasis is on understanding young people's subjective experience and which areas of their lives they invest the most in. It is strongly influenced by the 'biographical turn' in social research, and in western societies more generally. Whereas, once, only the life stories of important or high ranking people would be told or written about, now the life stories of ordinary people are being increasingly told and this is reflected in social research. The biographical model of transition is also informed by late modern theory in particular the ideas of Ulrich Beck and Anthony Giddens.

In his 1991 theory of the reflexive self, Giddens sees the self as a reflexive project in which people construct an internal narrative of self, which integrates their life experiences and personal beliefs. As we create and recreate our internal stories we shape our understanding of our pasts and who it is possible for us to be. This is a continuous process as every day decisions such as what to wear and what to eat have to be chosen from a range of life-style choices. The reflexive project of self is a construct of modernity.

“Transitions in individuals’ lives have always demanded psychic reorganisation, something which was often ritualised in traditional cultures in the shapes of *rites de passage*. But in such cultures where things stayed more or less the same from generation to generation on the level of collectivity. In the settings of modernity by contrast, the altered self has to be explained and constructed as part of a reflexive process of connecting personal and social change”(Giddens, 1991, p 33).

In line with this a biographical approach to youth transitions looks at young people’s identity and aspirations across a range of domains such as education, work, home, relationships, family etc. These areas of young people’s lives are seen as sites in which they can establish competence and gain recognition for this competence (Henderson et al 2006). Whereas in the past, competence was seen as being based on economic independence and coming as a package, developing competence and an adult identity is now seen as being a piecemeal affair. If a young person is seen as being competent in one area of their life they will invest in this area in developing an adult identity. If someone struggles to gain competence in one area of their life they will invest more in other areas of their life to try to gain recognition. For example, young people who struggle academically may seek competence and recognition from work or relationships instead (Thompson et al 2004).

Transition studies

Two major transition studies which have adopted a biographical approach to youth transitions are *Inventing Adulthoods* (Henderson et al, 2006) and *Disconnected youth?* (MacDonald and Marsh, 2005). Both studies used repeat biographical interviews where young people were asked to reflect upon their past experiences and talk about all areas of their lives. The researchers then produced ‘case histories’ (Henderson et al, 2006) or ‘life-grids’ (MacDonald and Marsh 2005) for each participant to bring together all the data on their lives. This broad approach allows

us to look at how what happens in one area of their lives affects other areas of their lives.

Whilst traditionally transition studies have fallen into two camps, emphasising either the role of structural constraint or individual choice in shaping future outcomes for young people (Dee, 2004), the biographical approach looks at how structure and agency interact with a focus on how individuals negotiate structural inequalities they may face. By doing this it manages to capture the often chaotic nature of young people's lives.

Inventing Adulthoods (2006) is a major study which followed 100 young people for a period of 10 years from their mid-teens to early adulthood. The research took place in 5 different parts of the UK; a deprived estate, a rural area, a 'leafy suburb', an inner-city neighbourhood and Northern Ireland. As a result of this, the study included young people from a variety of different backgrounds. The *Disconnected Youth* study took place in one of the poorest neighbourhoods in Britain and looked at how young people negotiate their transitions to adulthood in a disadvantaged neighbourhood. It relates young people's experiences to theories about the underclass and social exclusion.

What is distinctive about these two studies is their holistic approach to understanding young people's lives. What is also apparent is the importance of place as an influence when growing up. During the course of the *Inventing Adulthoods* study:

"It became clear that differences in orientation towards physical and geographical mobility were linked to social mobility. Differences in local attitudes and conditions were the most immediately obvious factors. Strong affinities to local community and its norms, for example, could limit what was possible for young people, contrasting sharply with the options and choices open to those with a more global/cosmopolitan outlook." (Henderson et al, 2006: 101).

This study has a particular focus on rural areas. Furlong and Cartmel (2000) found that rural labour markets operate differently to urban ones and young people enter employment via different routes. They stress the importance of personal contacts and reputation in allowing young people to access the labour market and argue that without these there is a risk of becoming marginalised. They highlight the role of seasonal and part time work as a stepping stone to employment. In addition to this young people in rural areas face significant problems relating to transport; poor public transport links make car dependency a major issue (Storey and Brennan, 2000). As a result of this mobility is structured by social class with 50% of 17-18 year olds from owner-occupied household having passed their driving test compared to only 16% of those who lived in rented accommodation. Little research has been carried out about how young people with SEN negotiate these challenges.

Special Educational Needs

According to Beveridge (1999):

“Special educational need arises from a complex interaction of personal and environmental factors and may be viewed as a mismatch between the emotional, social and learning demands that are made of a pupil and the resources the pupil has to meet these demands” (p, 39).

She argues that in most cases, special educational need is identified in the context of school when pupils do not make the level of progress expected of them, although a smaller proportion of pupils will be diagnosed as having SEN as a result of having impairment. According to the official definition a child is considered to have Special Educational Needs if “they have a learning difficulty which calls for special educational provision to be made for them” (DfES, 2001). Pupils are considered to have a learning difficulty if “they have significantly greater difficulty in learning than the majority of children the same age” or if they have “a disability which prevents or hinders them from making use of educational facilities of a kind generally provided

for children of the same age in schools within the area of the local education authority” (DfES 2001).

The Warnock report estimated that around 20% of pupils would have Special Educational Needs at some point during their school career. This is borne out by the current statistics which show that in 2008 17.2% of all school children had Special Educational Needs but no statement and 2.8% of all school children having a statement of Special Educational Needs (ONS, 2008). Some commentators such as Ainscow and Muncey (1989) have argued that 20% has become a target, with teachers expecting 20% of pupils to have problems and labeling the bottom pupils accordingly. However, at second glance the picture appears to be more complicated than this, as there is a lot of variation in the number of pupils considered to have Special Educational Needs between schools.

Although the Warnock report was meant to signal an end to classifying young people according to type of impairment, the Department of Schools Children and Families still records information about pupils’ main type of needs according to the following categories devised by OFSTED:

- Specific Learning Difficulty
- Moderate Learning Difficulty
- Profound and Multiple Learning Difficulty
- Behavioral, Emotional and Social Difficulty
- Speech, Language and Communication Need
- Hearing Impairment
- Visual Impairment
- Multisensory Impairment
- Physical Difficulty
- Autistic Spectrum Disorder (including Asperger’s Syndrome)

Although these categories are intended to be used for planning and policy development only and it is recognized that some children will fall under more than one of these categories of need, they still demonstrate that the medical model still has a hold on special education policy.

75% of all pupils with Special Educational Needs have either moderate learning difficulties, behavior, emotional or social difficulties, speech and language difficulties or specific learning difficulties as their main 'type of need'. The largest categories of need are Moderate Learning Difficulties which account for 26.2% of all pupils with SEN, and Behavior, Emotional and Social Difficulties which account for 22.7%; these categories have proved the most contentious as it is not always clear-cut who will be considered to have these types of needs.

For example, boys are much more likely to be identified as having SEN than girls. Skabrevik (2002) contends that this is the result of an interaction between genetic or biological differences between the sexes and a pedagogy that does not meet the needs of boys. However, Daniels et al (2009) argue that boys are over-represented amongst pupils recognized as having SEN. They receive higher levels and more expensive forms of support than girls, but this support is not necessarily appropriate to their needs. For example, boys who display problem behavior are often referred for reading support as it is more readily available. Benjamin's (2002) observational study suggests that differential levels of SEN between boys and girls could be partly due to the fact that girls are better at eliciting support from other pupils than boys and are therefore less likely to come to the attention of staff.

Given the problematic nature of the process of identifying Special Educational Needs, it is likely that there will be many young people with similar needs to the young people in this study but who have not been identified as needing support.

Labeling

Another controversy related to the identification of SEN is whether young people should be given specific diagnostic labels. Many people feel that by labeling a child

as having a disability, they will become unfairly stigmatized. This is particularly the case with more contested impairments such as ADHD. There is also the concern that medical diagnosis will encourage people to focus too much on a child's impairment at the expense of their other characteristics and even that if a child is diagnosed with, for example, autism, they may become more autistic (Jackson, 2002).

While there is some stigma attached to being diagnosed with certain impairments and having Special Educational Needs, there are also benefits to diagnosis. The child gets recognition of their difficulties and can receive appropriate support. The school can target support at pupils with similar impairments. Portwood (1999) argues that diagnosis should not be seen as labeling a child but providing a signpost to help understand their difficulties. However, it could be argued that receiving recognition and support for being disabled is too reliant on having a diagnosis. This is particularly the case with 'hidden disabilities' which are often not diagnosed for many years; for example, the average age of diagnosis for children with Asperger's Syndrome is 7. This means that many children have to wait a long time to receive help.

It is worth bearing in mind that diagnosis does not have to be a negative experience for pupils. Riddick's (2010) study of children with dyslexia found that for most children diagnosis came as a relief. The pupils reported that they had been struggling in school for a long time before being diagnosed with dyslexia and some had been bullied as a result of this. Many were relieved to find that other children had similar difficulties to them and that help is available. Whether or not young people with SEN have been given a specific diagnostic label, they are often given, other, much more stigmatizing 'labels' in the form of name-calling.

Inclusion

Perhaps the most contentious debate in the education of young people with SEN is whether they should be educated in mainstream or special schools. The historical circumstances in which specialist schools were set up have been discussed in the first chapter of this thesis. Many disabled people felt that being educated in a special

school exacerbated their unequal position in society as they felt their capabilities were underestimated. This meant they had fewer opportunities to acquire qualifications, which made it more difficult to get a good job (Hyde, 2000). They also argued that the schools were medically dominated and focused too much on their pupils' impairments; for example, pupils were often taken out of lessons for physiotherapy (Harris, 1992). In addition to this, having to attend different schools to the majority of young people in their neighborhoods reinforces their social exclusion, especially if the schools in question are residential ones.

An inclusive approach to education is seen as a way to counter all these problems. Ballard (1997) argues that inclusive education involves all students in the school community without discrimination on grounds of class, gender, ethnicity, sexuality or disability. In order for this to happen the school must make adaptations to meet the needs of its students. The key principals of inclusion are outlined in the Salamanca Statement (UNESCO, 1994). This was drawn up by representatives of 97 countries, including Britain, and 24 international organizations at the World Conference on Special Needs Education in 1994. It proclaims:

- Every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning.
- Every child has unique characteristics, interests, abilities and learning needs.
- Education systems should be designed and educational programs implemented to take into account the wide diversity of these characteristics and needs.
- Those with Special Educational Needs must have access to regular schools which should accommodate them within a child-centered pedagogy capable of meeting these needs.
- Regular schools with this inclusive orientation are the most effective measures of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and

improve the efficiency and ultimately the cost-effectiveness of the entire education system (UNESCO, 1994; paragraph 2).

The critics of inclusion argue that however nice an idea it may be in theory it does not work in practice and one school cannot meet the needs of all children. For example MacBeath et al (2006) argue that many young people with SEN are effectively excluded within a mainstream setting. They cite examples of teachers and classroom assistants emptying tracheotomy tubes and changing nappies, and argue that there are better facilities to meet these children's needs in a special school.

In 2005 Mary Warnock, the architect of the current SEN system, spoke out, claiming that inclusion is no longer working and the system should be overhauled. She argues that while the needs of some young people such as those with dyslexia or physical disabilities can be met in a mainstream setting, those of young people with autism or behaviour problems were "hard if not impossible to meet in this way" (Warnock, 2005, p 13). She contends that instead, small special schools should be set up for these young people.

However, there are those who argue that rather than inclusion not working, it has never been fully implemented. According to Wedell (2005) factors such as the national curriculum and the rigid grouping of pupils into same-age classes can cause problems for pupils regardless of whether they have SEN. One of the key criticisms is that inclusion is incompatible with the standards agenda because of the pressure it puts on schools for pupils to achieve the expected levels for their age. Skirtic (1995) argues that the very structure of schools themselves means that some pupils will be excluded, as in industrial societies schools are run as 'professional bureaucracies' where within the bureaucratic structure of the school, teachers are allowed a great deal of personal discretion. Teachers operate within a range of cultural norms and have a standardisation of skills. This means that pupils whose needs fall outside the teachers' skill sets are likely to be excluded and marginalised.

However, the inclusion debate tends to focus too much on the practicalities of education. What are often missing are the perspectives of the pupils themselves. Do they actually feel included? In their qualitative study which included disabled pupils from both mainstream and special schools, Watson and Davies (2001) found that disabled young people are labelled as different and defined by their impairment regardless of what type of school they attended. In both types of school disabled young people were put under pressure to act 'normally' and confirm to 'normal' ways of walking, talking etc. They found that children with mild to moderate learning disabilities who attended special school actually had more autonomy than their mainstream counterparts who were permanently supervised by their Special Needs Assistants.

In their action research project which looked at the impact of inclusion on the well-being of young people with learning difficulties, Byers et al (2008) asked pupils to make suggestions about how their school experiences could be improved. The pupils said they were just as concerned about their experiences outside lessons as in them. While young people had support in lessons they often felt vulnerable during breaks. It was important to them to have somewhere to go at break-times where they felt safe. They also said that a lot of information in school was not accessible to them as it relied too much on the written word. The young people wanted to be better informed and more involved in decisions about transition planning or moving to a new school.

In her ethnographic study of pupils with SEN in a successful girls' comprehensive school, Benjamin (2002), found that they occupied a difficult position. "They had to find a way to negotiate the school's overt promises that 'girls can do anything' alongside their own failure in norm referenced examinations" (p 282). She showed that the pupils resisted being labelled as 'special needs students'. They developed various strategies to deal with this. Some girls positioned themselves as badly behaved and in opposition to the rules of the school, although Benjamin contends this is a difficult position for a girl with SEN to maintain as her behaviour is interpreted as further evidence of her neediness. Other girls took up the position of 'lazy girls' and are therefore able to blame their difficulties on lack of effort rather

than lack of ability. Others emphasised their vulnerability in order to secure help from staff or other students. French and Swain (2004) point out that there is little consensus among disabled people about whether they prefer mainstream or special schools. There is a great deal of variability between schools and both types of schools have the potential to either positively or negatively influence the identity of disabled young people.

Despite the emphasis on increasing inclusion, at the same time as more pupils with physical disabilities are being included in mainstream schools, pupils with emotional, social and behavioural disabilities and young people with autism are being excluded in increasing numbers. Pupils with SEN make up 80% of all exclusions from primary schools and 60% of all exclusions from secondary schools (House of Commons, 2006). This has led Ainscow (1999) to argue that inclusion features students who would previously have been educated at special school entering mainstream school by the front door, while those with less socially acceptable disabilities are leaving by the back door.

At the same time as schools are being encouraged to become more inclusive, league tables and the marketisation of education have put pressures on schools that make it more difficult to adopt inclusive policies. There is increasing pressure for pupils to meet achievement targets. For example, as Benjamin (2002) points out, the National Curriculum levels which were once described as being typical or average for a particular age group have now become the 'expected' level for that age group. This turns pupils who would have been previously considered to be below average into failing students and a cause for concern.

As the number of pupils who obtain 5 A*- C grades at GCSE is used as the measure of a school's success, this makes pupils who are unlikely to achieve these grades less desirable students. This is a factor which could discourage schools from adopting wider inclusion policies. In addition to this, the amount of lesson time spent preparing pupils for exams would make it difficult for pupils who were not able enough to take the exams to be included in the same classes as the rest of their peers. In an attempt to counter the negative impact league tables have had on

schools with high numbers of pupils with SEN, or other disadvantaged pupils such as those in receipt of free schools meals; 'value added' league tables were introduced. However, compensating schools for having large numbers of certain pupils reinforces negative stereotypes that these students are always going to be low achievers.

While a lot of progress has been made towards making education more inclusive, many pupils with SEN still feel marginalised in mainstream settings. It is clear that there is a lot more to inclusion than being able to attend a mainstream school and more wide reaching changes need to take place to the whole education system so it takes into account the needs of all children. In this context it seems likely that young people with SEN are likely to face additional challenges to other young people during the transition to adulthood.

Transition Studies for Young People with SEN

The biggest study carried out to date on the post-16 transitions of young people with Special Educational Needs was carried out by the Institute for Employment Studies for the Department for Education and Skills (Aston et al, 2005). It involved 1,874 school leavers from both mainstream and special schools and with all types of special need, including young people with and without statements of Special Educational Needs. The research took place in three waves, tracking the young people at age 15/16, 17/18 and 19/20.

The study identified two main groups of young people and the transition pathways they took. The first group includes young people who the researchers describe as having 'largely uncontested impairments' such as sensory and physical disabilities. These young people are likely to have a statement of Special Educational Needs and have either attended a special school or specialist provision in a mainstream school. For this group there are clear transition pathways and multi-agency support, although many of these young people will experience extended transitions. The main issues for these young people are whether the pathways they are on provide them with opportunities for genuine progression and whether the support they receive will still be available to them into adulthood.

The second group of young people are described by the study's authors as having 'contested impairments', a category which includes behavioural, emotional and social development needs, less severe learning difficulties and children who are low educational attainers. These young people have generally attended mainstream school and received a relatively low level of statutory support, and they are less likely to have a statement of Special Educational Needs. These young people are more likely to leave education earlier and seek to enter the lower tiers of the labour market. The main issue that faces this group of young people is how far they are included within the mainstream education system and labour market. The study also identified a third group of young people who are somewhere in between these two groups; in this case the main issue is the appropriateness of the transition pathway that they are on and the level of support they are receiving.

Much of the existing research focuses on young people who would be considered to fall under Aston et al's first group of young people, those with complex needs who receive a relatively high level of support. Some of the key issues highlighted by the research that faces this group involve the transition from children's services to adult services. This transition often takes place when young people have reached a certain chronological age and are considered to be too old for a particular service, rather than when they reach a stage in their development when they no longer require the type of support provided by children's services. Similarly transition support services tend to be provided for young people within a specific age group, rather than people who are ready to make a particularly important life transition (Beresford, 2004). In addition to this, transition from children's services to adult services may result in a reduction of services such as therapies and medical care, even though their needs may not have reduced (Fiorentino et al, 1998; Aston et al 2005).

Research carried out in the East of England (East Together, 2006), indicates that whilst young people with learning difficulties and disabilities are disproportionately likely to be not in education, employment, or training (or NEET), young people with statements of Special Educational Needs, who are entitled to statutory support when preparing to leave school, are considerably more likely to move on to further education, employment or training than those on School Action Plus and are more

likely to do so than those on School Action. Young people with behaviour, emotional and social problems were particularly at risk of falling outside the reach of support. It also suggested that as young people with SEN are more likely to remain in education until age 19 and NEET statistics are only collected for 16-18 year olds, that the number of young people with Special Educational Needs who are NEET may be underestimated. This echoes the concerns expressed by the Social Exclusion Unit in 1999 which looked at the long term problems which are often experienced by young people who are NEET such as long-term unemployment, teenage motherhood and being involved in crime. It also outlined the groups of young people who it considered to be most at risk of becoming NEET, this included young people with Special Educational Needs, in particular those who have learning disabilities and those who are considered to have emotional or behavioural difficulties.

The Aston et al (2005) study mentioned earlier provides a detailed picture about the kinds of activities young people with SEN move on to after the age of 16. It found that while 60% of young people with statements continued in education at 18, only 36% of young people without statements did so. The difference is even more marked when comparing those who attended mainstream and special schools, 76% of special school pupils remained in education at 18 but only 38% of those who had attended mainstream schools did so. As many of these young people remained in their familiar special school or specialist FE provision, this was strongly correlated with experiencing an extended transition.

On the other hand, young people who attended mainstream school were more likely to be in paid employment (33% compared to 9%) or work based training (7% compared to 2%) than those who went to special school. This represents a much earlier than average entry to the labour market which is associated with low skilled and low paid employment and increased vulnerability to unemployment (Furlong et al, 2003). This pattern also holds when comparing those without statements to those with them. However, young people who were not statemented were more likely to be unemployed than those with statements (18% compared to 9%) and those who went to mainstream school were more likely to be unemployed than those who went to special school (16% compared to 8%). Those classified as having behaviour,

emotional or social development needs, were particularly at risk of being unemployed. 28% of the whole sample was in work, 46 % was in education and 19% was NEET.

When the young people were re-interviewed at age 19, 20% of all young people in survey were in employment or training, 24% were in education and 27% were NEET. Young people who had had statements of SEN when they were at school were more likely to still be in education than those who had not. However, they were also more likely than young people who had not had statements to be NEET. For young people with SEN, extended transitions do not necessarily lead to positive employment outcomes.

Of those young people in the study who were in education at 20, 55% studied at a college of further education, 19% were at university and 13% at a specialist college for students with disabilities. This means that they are studying at a lower level on average than the rest of the population. According to the Youth Cohort Survey (2006) 63% of those aged 18/19 in full time education were studying towards a degree. Of those engaged in employment 88% held a permanent position. However, there is evidence to suggest that young people with SEN are 'churning' or moving from activity to activity without any clear outcome.

Whilst there are relatively high levels of support available to help young people with SEN make the transition into further education, the support available to help young people make the transition to employment is erratic (Hendey and Pascal, 2001). The Disability Discrimination Act 1995/2005 enshrines disabled people's rights to equal opportunity in employment in law. Thornton and Lunt (1995) have pointed out that the onus is on the individual disabled worker to bring the complaint against their employer rather than addressing wider structural inequalities in the labour market. As the law regarding employment refers to 'disabled people' rather than those with SEN, not everyone who has special needs at school will be protected from discrimination in employment as an adult.

The period after leaving school or full time education appears to be a particularly difficult time for young people with SEN. For many young people, particularly those

with learning difficulties, there is a lack of suitable opportunities for education and training (Beresford 2004; Morris, 2002). Many young people miss the social opportunities provided by school and the literature suggests that as most young people's social opportunities expand as they enter adult life, the opposite is often the case for disabled young people with their lives becoming more narrowly confined to home and family life (Hurst and Baldwin, 1994). This is particularly the case for those who are not able to work, as within adult services there are not any facilities that provide comparable opportunities for education, training and spending time with peers (Beresford, 2004).

While the majority of transition research has looked at outcomes, there are also some studies which look at the decision making process. Dee's 2004 study looked at the experiences of disabled young people and their families when deciding what to do next after leaving school. While many of the decisions they had to make were very similar to those of other young people of their age, such as what course to study at college and the implications of this for their long term career prospects, there were situations for some young people where they had no real choice at all. In common with non-disabled people there were tensions between their aspirations and the hopes and the pressures of social assumptions and structures. As all the young people in the study had statements of Special Educational Needs, their future plans were subject to much more external scrutiny than those of most people their age.

However, Dee points that some people have more power than others in the decision making process. Parents' views were more likely to be listened to than those of their children, and some young people were allowed more say in their future than others. Young people with learning difficulties were accorded much less of a say than young people with other types of impairments.

During the transition process there is also a lack of information made available to young people and their parents on future opportunities and the kinds of services and support that will be made available to them in the future (Heslop et al 2002; Morris, 2002). There is also a mismatch between what young people and parents

wanted to be included in transition reviews and what was actually included. In particular a lack of attention is paid to issues such as friendship and involvement in social and leisure activities which are particularly important to young people (Heslop et al, 2002).

Studies which have looked at young people's experience of the transition planning process have highlighted that young people and to a lesser extent their parents do not feel that they have been fully involved in the transition planning process despite this being a statutory requirement (Heslop et al 2002, Ward et al 2003, Dee, 2004).

Conclusions

Significant social changes have taken place in recent years which mean that young people's transitions to adulthood are different now to what they were for previous generations. Recent studies have highlighted the often chaotic nature of young people's pathways to adulthood and their struggles to achieve a coherent adult identity. However, despite all the changes that have taken place, people's life chances are still heavily shaped by structural factors such as class, gender, ethnicity and disability, although perhaps in a less predictable way than in the past (Furlong and Cartmel, 2007). Young people today are more likely to experience 'extended transitions' as the increasing importance of education means that entry to the labour market is delayed, and with this, the means to form independent households. As transitions become more complex parents' roles in helping young people make decisions about their future and the resources they can provide to help their children during this time are critical (Ball et al, 2001).

All of this remains true for young people with SEN. However, for them some of these issues have become more pronounced. For example the increasing importance of education and the need for educational qualifications to get a job has disproportionately disadvantaged young people with SEN. The fact that many jobs which did not previously require qualifications now do so means that many young people with SEN who cannot achieve these qualifications are now considered unemployable (Tomlinson, 1995). Conversely, the current importance of education

now means that increasing efforts are being made to ensure that disabled young people and young people with SEN now have the opportunity to access further and higher education.

Policy Review

The previous chapter outlined the recent social changes that have had an impact on young people's lives. Young people are now more likely to experience an 'extended transition' to adulthood with a prolonged period of dependence on their parents. Education plays a much more significant role in young people's transitions to adulthood than it has at any point in the past. While this increased focus on educational qualifications has disadvantaged young people with SEN it has also led to the expansion of opportunities for them to participate in further and higher education. This chapter will explore in more detail the relevant policies relating to education, employment and training and the advice available to young people in this area. These policies have undergone radical cuts over the period of this research due to the change in government and public sector cuts.

Education, Education, Education?

Furlong and Cartmel (2007) argue that the changes that have taken place in young people's educational experiences over recent years exemplify Beck and Giddens' theories about late modernity. Collective responses to education have weakened which means that young people have to negotiate school and college as individuals. Young people spend much longer being educated than they have at any time in the past and there is increasing demand for young people to have qualifications.

The increased importance of qualifications means that young people clamour to get them. However, for many young people, particularly those from a middle class background, these higher levels of qualifications serve only to prevent downward social mobility rather than promoting upward social mobility (Walkerline, Lucey and Melody, 2001). Many professions which did not require degrees in the past such as teaching and nursing now do so. The increased importance of qualifications means there are increased 'risks' for those who are unable to achieve these qualifications, particularly as there has been a decline in career opportunities for school leavers with few qualifications since the 1980s (Furlong and Cartmel, 2007).

The fact that young people stay in education for longer means that they enter full time employment later and form families later.

This increased period of time spent in education has both advantages and disadvantages for young people with SEN. Many young people with SEN have very negative experiences of education and want to leave as soon as possible. If they do so they will have very limited job opportunities as a result of qualification inflation, which means that many people have to stay on in education when they prefer not to. However, for some young people with SEN widening participation in further and higher education has been positive as the fact that further and higher education is no longer for a tiny elite has meant that education providers have had to become more inclusive and take their needs into account. This has opened up the possibility of studying a wide range of subjects and pursuing an interesting career to young people with SEN.

In this context of the importance of education, concerns have been expressed about young people who are perceived to be failing educationally. A number of policy initiatives have been launched to improve the educational achievements of young people with SEN and prevent them from becoming socially excluded.

Equalities Legislation

In recent years successive sets of equality legislation have strengthened the rights of disabled people and young people with SEN. The Disability Discrimination Act (DDA) was passed in 1995. This came much later than other equality legislation. The Sex Discrimination Act was passed in 1975 and the Race Relations Act was passed in 1976. The DDA defines disability as:

“a physical or mental impairment which has a substantial and long term effect on the person’s ability to carry out normal day-to day activities”

It defines discrimination as treating someone unfairly compared to someone who is not disabled, because of their impairment. The Act puts a duty on organisations to make ‘reasonable adjustments’ to allow disabled people to access their goods and services. It also requires organisations to act in anticipatory ways rather than

responding to a situation as they arise. For example, providing printed information in alternative formats in anticipation of someone with a visual impairment requiring it. The Act originally covered access to employment and access to goods and services. It did not yet cover education.

This was rectified in 2001 with the passing of the Special Educational Needs and Disability Act (SENDA). This extended the DDA to apply to schools colleges and universities. The same definitions of disability and discrimination are applied and educational institutions have to meet the same requirements for reasonable adjustments and anticipatory duties. There are also requirements to make adaptations to the physical environment. Further and Higher Education providers have to provide auxiliary aids and services. However, this duty does not apply to schools; it was considered to be covered already by SEN legislation, although in this area only people with statements have a legally enforceable right to these services. Reasonable adjustments might be needed in learning, teaching and assessment, the admissions process, the physical environment or work placements. Educational institutions can still refuse admission to a disabled student on certain grounds. Colleges and universities can still refuse admission of a disabled student on academic grounds but admissions tutors need to be clear about the criteria they use to select students. Secondly, a disabled student may be refused entry if they would be unable to complete a part of the course that is considered a basic requirement and for which reasonable adjustments cannot be made. This is often related to meeting the requirements of professional qualifications such as medical degrees. Thirdly, a decision could be made that the adjustments a student may need to complete the course would be 'material' and 'substantial' meaning they would be too costly to put into place.

The DDA was amended in 2005. This expanded the definition of disability so that more impairments were explicitly covered. This introduced the Disability Equality Duty. Institutions must publish a Disability Equality Scheme demonstrating how policies and provision have had an impact on disabled people. Disabled people must be consulted when drawing up the scheme.

All the legislation above was amended once more with the introduction of the Equality Act 2010. The act brings together and simplifies previous equality legislation. It covers nine protected characteristics which cannot be used as a reason to treat people unfairly and so it not only applies to disability but also incorporates legislation on race, sex and age. The Equality Act introduces protection from discrimination by association. This makes it illegal to treat someone less favourably if, for example, they have a family member who is disabled. An organisation is no longer able to justify not making reasonable adjustments for a disabled person. The Equality Act 2010 makes it more difficult for education providers to justify treating someone less favourably on grounds of disability. They now have to prove that their conduct “was a proportionate means of achieving a legitimate aim”. The requirement to provide auxiliary aids and services was going to be extended to schools. However, the government is now considering its position on this requirement, so it may not be enforced. If the requirement was put into place it would ensure that all disabled children in schools would have the legal right to the support they need. Currently this is only enforceable for children with a statement of SEN who can go to a tribunal. Children on School Action and School Action Plus cannot do this. However, there is a discrepancy between the legal definition of disability and the legal definition of SEN which means that even if this provision was enforced not all children would be covered. For example, people are only covered by disability legislation if their impairments are “substantial and long-term” but people with only short-term needs can be considered to have SEN.

School SEN Policies

The guidelines for identifying who has Special Educational Needs are laid out in the Code of Practice (DfES, 2001,a). This outlines how to assess a child who is suspected of having special needs and gives three stages of support that a child may receive. The first level is ‘School Action’. At this stage the school should provide the child with support that is in addition to and different from the school’s usual curriculum. For example, the child could receive extra help from an adult, have some special

equipment or be taught something in a different way. If the child is still not making good progress they are moved on to School Action Plus and outside support, such as speech therapy, can be brought in. Young people on School Action and School Action Plus should have an Individual Education Plan. This plan should outline the teaching strategies and special provisions the child will receive and set short term targets for their progress. The plan should be reviewed twice each year and parents should be consulted as part of the process.

If a child is likely to need considerable additional support or resources then they should be referred for a statutory assessment to see if they are eligible for a Statement of Special Educational Needs. Not everyone who is assessed will be given a statement, as they are awarded to only a small proportion of young people with SEN. The statement sets out in detail the child's needs, both educational and non-educational, and the provisions that will be made to meet those needs as well as the school they will attend. Crucially, the statement is a legal document and the local authority is obliged to provide everything listed in it. This is not the case with School Action and School Action Plus.

In recent years there has been concern that the SEN system is failing to meet the needs of some children. In 2006 the House of Commons Select Committee on Children, Schools and Families reported that:

“the SEN system is demonstrably no longer fit for purpose and there is a need for the Government to develop a new system that puts the needs of the child at the centre of provision”

In response to this, the Labour government asked Brian Lamb to conduct an inquiry on how parents' confidence in the SEN system can be improved and a report from Ofsted reviewing the SEN system. Lamb (2009) argued that there needed to be change in four key areas:

- There needs to be a stronger focus on the desired outcomes for children and young people. Expectations for children with SEN are currently too low. Too often the weakest teachers are given the responsibility for teaching children

with SEN. Children with SEN should have access to highly skilled teachers. Every school should have at least one teacher with advanced skills in each of the following areas: learning difficulties, dyslexia, speech and language difficulties, autistic spectrum disorders and emotional and behaviour difficulties. Children who fall behind should receive appropriate early intervention.

- There needs to be a stronger voice for parents. Lamb (2009) proposes the development of a 'core offer' which sets out how disabled children and their families will be informed and involved. Local authorities and schools should make information on current services freely available and a national advice line should be set up to provide impartial advice to parents.
- There needs to be a greater focus of children's needs. Since the SEN framework was established there has been increasing delegation of responsibilities and funding from local authorities to schools. Lamb argues that this has led to a lack of strategic focus on the needs of children with SEN resulting in an uneven provision throughout schools. Schools need to know where to go for advice on how best to support children with SEN. Parent's confidence in the SEN assessment process needs to be improved. Lamb found that professionals who were responsible for assessing children's needs did not always follow best practice and that often the wording on statements was too vague to be properly enforced. He argued that the government should consider making the assessment process more independent.
- The system needs to be more accountable and provide better services. There is currently too much variation in the quality of provision. Ofsted inspections should focus more on the quality of provision for children with SEN. Parents of disabled children need to be informed of their rights under the Disability Discrimination Act and schools and local authorities need to do more to comply with the act.

The Ofsted review (2010) evaluated how well the current system met the needs of children with SEN. This review found that the proportion of children with a

statement of SEN has decreased slightly since 2003 from 3% to 2.7%. At the same time the number of children at School Action and School Action Plus has increased slightly from 14% in 2003 to 18.2% in 2010. Around half of the children identified at School Action would not need to be identified as having SEN if the school had focused on improving outcomes for all children and giving individual children personal targets for improvement. Ofsted argue that too often children who have fallen behind are considered to have SEN. This is unsurprising given the woolly definition of SEN which conflates SEN with low attainment. As argued in chapter two this is unlikely to be a new phenomenon.

The review also found that having a statement was not in itself a guarantee that the child's current needs were being met. The inquiry recommended that the system should focus on improving the quality of assessment and ensuring that where extra support is provided it is effective. Improved teaching and pastoral support should be provided to children early on to prevent the children from being considered to have SEN later on. The system should ensure that children are not identified as having SEN when what they really need is better teaching. Accountability for those who are providing services should be measured by the outcomes of the children who receive these services. The legislation should be simplified so that the system is clearer for everyone involved. There needs to be strategic development of specialist provision and services so that they are available to all schools including maintained schools, academies, private schools and colleges.

There are clear areas of agreement between the Lamb and Ofsted inquiries. However, there has been a change of government since these reports were commissioned which means that not all of these recommendations will be implemented.

Careers Advice and Guidance

The provision of careers advice and guidance for young people has undergone significant changes during the period of this research. At the start of this research

advice and guidance for young people aged 13–19 (or 13-25 for disabled young people) was provided by Connexions, which was introduced in 2000 (DfEE, 2001). It combined elements of youth services with careers advice. It was a mainstream service open to all young people but also had targeted support for young people who are considered to be more vulnerable, including young people with SEN.

All young people with a Statement of Special Educational Needs should have a transition plan drawn up for them when they are age 14. The plan is drawn up in the annual review of statement that takes place when they are in year 9. The young person, their parents and a range of professionals are invited to contribute. The young person's Connexions advisor must attend as they are the lead professional for implementing the plan. Social Services should also be involved if the young person has specific disabilities. A relevant teacher must attend and health professionals involved in the child's care should provide advice towards the review and attend where possible.

The transition plan should look at the young person's hopes and aspirations for the future and how they can be achieved. It should ask if the young person has any specific health or welfare needs that will require support from health or social services, either now or in the future. If this is the case it should ask whether the young person's parents will experience new care needs which mean they are likely to require practical help. The transition plan should also look at how the young person in question can continue to play a role in their community. It should build on the conclusions reached and targets set at previous annual review meetings and the plan should be updated each year until the young person leaves school (Contact a family, 2009).

If pupils with a statement stay on at school after 16 then the provisions outlined in their statement continue. However, if they go to college, the responsibility for providing support falls to the college's disability service. Under the Learning and Skills Act 2000, the LSC must 'have regard to' the further educational needs of students who have learning difficulties and/or disabilities, this mainly entails making sure that there are sufficient further education opportunities for such students.

However, it may extend to funding places in a specialist college if a student's needs cannot be met by his or her local college.

Young people with SEN but without a statement are not entitled to a transition plan, although some schools do arrange one. However, the Connexions service has an obligation to provide support to all young people who have difficulty transferring to further education or training and this includes those with SEN. In their final year of school Connexions should produce an outline of the young person's education and training needs and the provision required to meet those needs. This report will be passed on to the young person's new education or training provider. However, this plan is not as comprehensive as a transition plan, focussing only on education and training needs rather than any wider aspect of their lives.

The *Valuing People* white paper (2001), which outlined the government's plans for young people with learning disabilities, recommended the use of Person Centred Planning in transition reviews. Person Centred Planning is often used with people with a learning disability as a way of giving them a meaningful say of what they want from their lives both now and in the future. The young person is put at the centre of the planning process which is carried out in a way that is accessible to them. Most person centred plans followed a list of key questions:

- Who are the most important people in their lives? These people will be involved in drawing up the person centred plan and then putting it into action.
- What are the person's gifts? This will help people to think appropriate education, training and career options for the young person to pursue.
- What is important to the person now and in the future?
- What are the supports the person may need to make things happen to get the future they want?
- What do we need to do?

This last stage is called action planning and involves identifying people who will be responsible for helping the young person to implement the plan and outlining how the plan can be put into practice (Smull and Sanderson, 2005).

The idea of introducing person centred transition reviews is to make sure that the young person is more involved in the transition planning process. This is an important development as many studies have highlighted the fact that this is often not the case. In her 2004 study of decision making in the transition planning process Dee found the meetings often focused on procedural formalities rather than giving young people and their families the opportunity to discuss their concerns or explore opportunities. Perhaps as a result of this parents were much more likely to express dissatisfaction with the transition review than professionals.

Young people with autism and their families who gave evidence to the House of Commons Working Group (2009) said that young people often did not understand the concept of transition plans and that 'transitions' of any kind are particularly difficult for young people with autism to deal with as they find change hard. They also pointed out that there were many other transitions in people's lives that they were likely to need support with after they have left school such as leaving the parental home, getting married and becoming a parent.

Studies which have looked at young people's experience of the transition planning process have highlighted that young people and to a lesser extent their parents do not feel that they have been fully involved in the transition planning process despite this being a statutory requirement. During the transition process there is also a lack of information made available to young people and their parents on future opportunities and the kinds of services and support that will be made available to them in the future (Heslop et al 2002; Morris, 2002). There was also a mismatch between what young people and parents wanted to be included in transition reviews and what was actually included. In particular a lack of attention is paid to issues such as friendship and involvement in social and leisure activities which are particularly important to young people (Heslop et al, 2002).

At the time of writing Connexions has been largely disbanded and there is uncertainty about the future of its remaining services (Hooley and Watts, 2011). Many local authorities have made big reductions in service provision and staff numbers. In some areas the Connexions brand has disappeared altogether. There is currently huge variation in the types of services provided across the country. This is due to the lack of guidance from the government on the future of service provision in this area. The government is to set up a new all age careers service in 2012 this will be called the National Careers Service. However, with the exception of its telephone and web based services, it is likely to serve adults in the main as most of its funding comes from the Department of Business, Innovation and Skills rather than the Department of Education. The responsibility for securing the provision of careers advice has fallen to schools that have received no extra funding for this and are experiencing an overall cut in budget. Schools have also lost the support of Aim Higher, which provided advice and guidance for young people considering university and funded university summer schools for school aged young people. Schools' responsibility to provide careers education has been removed.

Inclusion

As discussed in the previous chapter, in recent years there have been moves towards including more and more young people with Special Educational Needs in mainstream schools. However, this has had only a limited degree of success and while more pupils with physical impairments have entered mainstream school, many other pupils with SEN (in particular those with autism) have been excluded. It is important here to look at the government's policy of inclusion for pupils with SEN in the context of the rest of education policy.

According to *Inclusive Schooling*, a guide produced by the DfES on how to implement the Special Educational Needs and Disability Act 2001:

“Schools supported by local education authorities and others should actively seek to remove the barriers to learning and participation that can hinder or exclude pupils with Special Educational Needs.”

(DfES, 2001b, paragraph 7)

While the need to remove barriers to learning and participation is key to the ethos of inclusion, it is important to note that the official government definition of inclusion refers only to pupils who are considered to have Special Educational Needs whereas most other definitions of inclusion stress the need to remove the barriers to learning of all pupils. The fact that the government's policy on inclusion is only for pupils with SEN means that children have to be labelled as having SEN before steps can be taken to include them. In many cases if efforts had been made to include the child from when they first started having difficulties this would prevent their problems becoming severe enough for them to be considered to have SEN at all. For example until relatively recently children could not be diagnosed with dyslexia until they were seven because the diagnostic criteria was a discrepancy between the child's reading age and their chronological age. This meant that children were not diagnosed until they had failed to learn to read by which point many children feel like failures in the classroom setting (Riddick, 2010). As discussed in previous chapters classification of young people as having SEN is still strongly based on the medical model of disability which sees the child as being pathological and fails to recognise the social structures which cause discrimination and exclude the young people (Armstrong 2005). In the current education system pupils with SEN have first to be excluded and labelled as pathological before they can be recognised as having SEN and be included again.

Another problem with the fact that inclusion only applies to pupils with SEN is that it is at odds with many of the government's other education policies. For example, the policy of market competition between schools, fuelled by league tables, enabled some more successful schools to choose their pupils and they select those pupils who were likely to do well in exams and enhance the school's league table position. This meant that those children with SEN or those from disadvantaged backgrounds are more likely to end up in less desirable schools (Tomlinson, 2005). The increasing focus on exams and testing makes it hard for pupils who are not capable of doing the exams to be included in a mainstream school (Aspis, 2004).

SEN Green Paper

The system described above is going through a process of radical review. In 2011, the coalition government published the green paper, Support and Aspiration: A new approach to Special Educational Needs and disability (DfE, 2011, a). The green paper proposes abolishing the existing three levels of support for children with SEN (School Action, School Action Plus and statements). School Action and School Action Plus are to be replaced with a single school based category of support which covers all children who require support over and above what is usually provided by the school. Reducing these two categories down to one category is intended to tackle a perceived 'over identification' of some types of special needs. Concerns have been expressed that there is not enough funding available to implement all of the proposed changes and that as a result of this fewer children will be eligible for support (Skill, 2011). Statements of Special Educational Need are to be replaced with a single "Education, Health and Care Plan". The aim of this is to reduce the number of assessments young people with SEN have to go through as it will cover all of the support they need across education, health and social care from birth to 25. This is intended to enable early identification and support before children start school and continuity of support once they leave. It is intended to replace the statutory learning difficulty assessment for further education and skills training. As well as detailing the child's needs and support, the proposed Education, Health and Care Plan will also outline the "learning and life outcomes" hoped for the children and young people. The reviews will focus on their progress towards these life outcomes in education, employment, health and independent life. This is a much more holistic approach than the statement. This plan is expected to be in place by 2014.

The proposals are intended to give parents much more of a say in the support their child receives and to make the system less adversarial. Parents will have the right to express a preference for any state funded school and if parents and local authorities disagree they will go to mediation first. The government are also considering involving the voluntary and community sector in the new assessment process to remove what some parents consider to be a conflict of interest where the local authorities who are responsible for providing the support to children and young

people with SEN are also responsible for assessing what their needs are. There is also the possibility for families to have more control over the services that their children receive through receiving direct payments. Trained key workers will be available to help families arrange the support their child needs. There are also proposals to reduce the time period for the statutory assessment process from 26 weeks to 20 weeks. This will be welcomed by parents as concerns have been expressed about the waiting time for statements. Unlike statements the proposed assessments will also be transferrable across local authorities. This will eliminate the need for a new assessment when moving to a new area.

The green paper also proposes to “remove the bias towards inclusion and propose to strengthen parental choice by improving the range and diversity of schools from which parents can choose” (DfE, p5). It also proposes to halt the closure of special schools. Parents will have the opportunity to run any special school that is proposed for closure as a free school or to set up a special free school in their area. However, whilst the green paper acknowledges that some parents’ choices are limited by the fact their local mainstream school does not have appropriate provision for their child it does not outline any plans to address this. It is questionable whether there ever was a bias towards inclusion as for many children with more severe impairments, who need support with their medical and physical needs during the school day, a special school is still the only realistic opportunity available to them (Booth, Bush and Scott, 2011).

The green paper received a mixed reaction. Its’ proposals to create a single assessment of needs and to improve the training of staff working with young people with SEN were generally welcomed (House of Commons, 2011). Several commentators emphasised the importance of adequate funding to ensure all of these proposals can be put into place in the face of local authority redundancies and budget cuts (Ritchie, 2011; Lightman, 2011).

As the proposed new assessment will cover young people up to the age of 25 it will incorporate what is now the transition plan, as well as assessments for FE and employment. However, despite applying well into adulthood the green paper has

nothing to say about young people's participation and choices, only referring to parental choice. It is not clear how the plan will adapt to meet people's changing needs. Provision of support in further and higher education is currently much more centred on the needs of the young person receiving it than support is in schools (Skill 2011).

New Education Policies

In November 2010 the Government published the education white paper *The Importance of Teaching*. This outlined a wide range of changes to be made to the education system. This includes reforms to teacher training, requiring new graduates to have at least a 2:2 degree and to shift the focus of teacher training to make it more schools based and establishing a network of training schools. It proposes to reduce the amount of bureaucracy schools have to deal with. It also outlines measures to strengthen discipline in schools with increased powers for teachers to discipline pupils and more powers for head teachers to exclude pupils. A new approach to exclusion which gives schools on going responsibilities for the education of children they exclude is being trialled. As children with SEN are much more likely to be excluded from school they will be disproportionately affected by these proposals. The white paper also proposes changes to the National Curriculum to make it focus more on traditional academic subjects and offer fewer vocational options up to the age of 16. A review of the National Curriculum is underway, due to be completed in 2013. Alison Wolfe (2012), has carried out a review into vocational qualifications. This recommends that many vocational courses that currently count on the league tables as equivalent to GCSE should no longer do so.

A new performance measure was introduced in 2011 to encourage schools to focus more on traditional subjects. The English Baccalaureate (EBacc) ranks schools by the proportion of the pupils achieving 5 A*- C in five subjects specified by the government: English, Maths, two sciences, Geography or History and a Modern or Ancient Language. It is not a qualification, just a measure used by league tables to show which schools offer more traditional academic qualifications. However, the government does intend to issue certificates to recognise success in the EBacc (Gillie,

2011). The introduction of the English Baccalaureate was controversial, not least because it has been introduced retrospectively with the results published for pupils who took their exams before the measure was even announced. In 2010 only 15% of children nationally achieved the new benchmark compared to the old benchmark of 5 A*-C which was achieved by 75.4% of pupils that year. It is not compulsory to study the EBacc but the government is keen for all young people to have the chance to study the subjects it comprises up until age 16. The House of Commons Education Select Committee has expressed concerns that the introduction of the EBacc could encourage schools to focus more on those students who are most likely to achieve it, diverting attention away from the most disadvantaged students including those with SEN (House of Commons, 2011).

This focus on giving schools increasing levels of autonomy weakens the capacity of local authorities to provide strategic guidance to schools, with many schools being out of local authority control all together. Local authorities play a key role in the provision of services to children with SEN. For example they employ educational psychologists responsible for assessing and diagnosing children, are responsible for the provision of statements of SEN and provide authority wide provision for children with low incidence needs such as deaf children. The Lamb inquiry (2009) recommended strengthening the role of local authorities in developing and commissioning services for children with SEN, and Ofsted proposed making local provisions available to all schools including those outside of local authority control. Philip Parkin (2011), Secretary General of the Teachers' Union, Voice, has expressed concerns that the proliferation of academies will reduce the capacity of local authorities to provide centralised services such as support for children with SEN.

Further Education

Statements of SEN are only applicable for as long as a young person remains at school. The term 'Special Educational Needs' does not apply in Further Education; instead colleges have to make 'reasonable adjustments' for people with 'disabilities and learning difficulties' under the Disability Discrimination Act 2005. Until March 2010 funding for further education in England was funded by the Learning and Skills

Council. As a result of the change of the leaving age for compulsory education or training this has been replaced by two new organisations. The Young People's Learning Agency is responsible for students up to the age of 19 and the Skills Funding Agency is responsible for students over 19. The Young People's Learning Agency gives colleges money to provide learning support services for disabled students as part of their general funding. They also have the responsibility of funding a place for a student at a specialist college if it is felt that their needs cannot be met in a mainstream college.

Further education qualifications are offered at a range of different levels so courses are available for people of all abilities (see appendix for table of National Qualifications Framework). However, research carried out by the NUS (Grehan, 2010) has highlighted the fact that disabled students are disproportionately represented on the lowest level courses at entry level and level one. The number of disabled students who progress on to level two courses falls off dramatically which suggests that these students are either repeating level one courses or leaving education early putting them at risk of becoming NEET.

The government's further education reform programme, proposes merging the Additional Learning Support and Learning Support Funds. Disability Alliance (2011) has expressed concern that merging these funding streams will result in inconsistency in provision as the Additional Learning Support Fund exists to ensure FE providers meet their statutory obligations to make reasonable adjustments for disabled students and the Learning Support Fund is discretionary.

Higher Education

In recent years there has been considerable expansion of higher education. In the academic year 1995-1996, there were approximately 1.5 million students in higher education in the UK; by the academic year 2009/2010 there were almost 2.5 million (HESA, 2008; HESA, 2011). This has brought many students into the system who previously may not have considered university, including disabled students and those who were considered to have SEN when they were at school. Consideration of

disabled students in higher education is a relatively recent phenomenon. The first research study of disabled students in the UK was published in 1974 (National Innovations Centre, 1974). In the same year the National Bureau for Handicapped Students, later, Skill: National Bureau for Students with Disabilities, was established. However, it was not until 1993 that any specific funding was made available to support disabled students. This came in the form of Disabled Student's Allowance. This is a grant to help students meet the extra costs incurred through their study as a result of disability. It can be used to pay for any specialist equipment they might need, such as computer software, extra travel costs incurred as a result of disability, and the costs of someone to support the student such as a note taker. The money is not paid directly to buy the equipment but instead goes to the university's disability service so they can pay for the support provided. This approach focuses on helping the students adapt themselves to meet the needs of their course rather than focusing on making higher education institutions themselves more inclusive.

Higher Education Institutions have been slower to move towards inclusion than schools. However, significant moves have taken place in recent years. Since 2001, when the Disability Discrimination Act was amended to include educational institutions, universities have had to make "reasonable adjustments" for disabled students. This act also puts anticipatory difficulties on educational institutions to plan in advance what they need to do to make the course accessible to disabled students.

While disabled people are more likely to be studying at university than ever before they are seriously underrepresented in professional courses such as medicine, nursing, law, teaching and social work and more likely to be studying arts subjects (Riddell, 2010). This will have consequences for their future employability.

NEET

The acronym 'NEET' stands for young people who are not in education, employment or training. It came into widespread use after the publication of the Bridging the Gap report by the Social Exclusion Unit (1999). This report expressed concern that

these young people were at risk of social exclusion in later life. It identified young people with SEN as a group who were particularly at risk of becoming NEET. Young people identified as NEET are a heterogeneous group as it encompasses young parents, those with caring responsibilities and those who are unable to work due to health problems.

The previous government set up the Connexions service to tackle the number of young people who are NEET. This is undergoing radical changes as described earlier in the chapter. The proportion of young people aged 16-24 who are classified as NEET has increased since the start of the economic crisis. In the second quarter of 2011, 16.2 % of young people aged 16-24 were NEET. This compares to 13.1% of young people in the last quarter of 2007 (DfE, 2011b). However, the proportion of young people aged 16-18 who were NEET actually decreased in this period, with 9.8% of this age group being NEET in the second quarter of 2011 compared to 11.9% during the same period of 2009. This is due to an increase in participation in further education rather than an increase of those in employment. Young people age 18/19 are most likely to be NEET (DfE, 2011b) suggesting that many young people complete further education but are unable to move into employment.

Employment

Aston et al's 2005 study into the post 16 transitions of 1,847 school leavers found that half of them were in employment at age 19/20. The majority, two-thirds, were in jobs without training. However, 27% of those surveyed were NEET. This is much higher than the proportion of young people in general who are NEET.

Many young people who had SEN at school are covered under the disability provision of the Equality Act 2010. This means that they are entitled to protection from discrimination and 'reasonable adjustments' in the work place and when seeking work. They may also be entitled to support under the Access to Work scheme. This funds extra employment related costs incurred by disabled people, including fares to work for those who are unable to access public transport, specialist

aids and equipment, support workers and adaptations to the work place. However, Aston et al (2005) found the school leavers with SEN had a very low level of awareness of disability discrimination legislation and their rights under it so may be unlikely to claim their rights under it.

One of the proposals of the SEN green paper is to link up assessments for support at college or university to access to work assessments, streamlining the process. If these proposals go through, this will simplify the process considerably. Riddell and Weedon (2011) found that disabled students are less likely to declare a disability during the transition to employment as they fear discrimination at work.

Conclusions

There is a contradiction between the policies in 'special' education and in education generally. Until recently the focus was on including, as far as possible, pupils with Special Educational Needs in mainstream school, although this was not extended to all pupils. This is set against the background of a mainstream education system which is increasingly marketised and focused on league tables and exam results. This makes it more difficult for some young people with SEN to be included in mainstream schools.

When it comes to transition there is a much clearer pathway of support for young people with statements. The support available for young people without statements was patchy to begin with and much of it is now being eroded due to budget cuts.

The entire SEN system, covering early years to age 25 is currently under review. The proposed new system contains many positive elements such as a single assessment process for all areas in which a young person requires support. However, there are concerns that budget cuts combined with the government's intentions to reduce the proportion of children who are considered to have SEN will lead to a reduction in the number of children actually receiving support.

Methodology

The research aimed to gain an understanding of the transition to adulthood of young people with SEN who attended rural mainstream schools. It sought to explore both their aspirations and the factors which, from their own perspective, helped to achieve them. It also examined how well the services designed to support young people, met their needs.

The first section of this chapter outlines the research questions and discusses appropriate methods of addressing them, drawing on previous studies. The second section describes the process of data collection including the original research design and reflections on how the study eventually changed direction and the third focuses on analysis. The final section reflects on the benefits and limitations of the research design, the validity of the conclusions and the ethical issues which need to be taken into account.

Nature of the Research

As discussed in the previous chapter, many factors have an impact on young people's transitions to adulthood. The research methods used need to be able to take these into account as well as being particularly suited to finding out about the experiences of disabled young people. As the focus of the research is on young people's experiences and perspectives a qualitative approach would be most suitable. It would also be helpful for the research to have a longitudinal element as the transition to adulthood takes place over a period of time and this would allow us to see how the young people's lives develop. Finally the research methods used have to be inclusive of the disabled young people the research seeks to find out about, including those who have social and communication disorders.

First of all to find out about how young people's lives develop over time it would be helpful to use longitudinal qualitative methods. One recent study which pioneered these methods in studying youth transitions is *Inventing Adulthoods* (Henderson et al 2006). This involved 100 young people from five different research sites: a rural area, a deprived area, a leafy suburb, the inner city and Northern Ireland. They were

followed over a ten-year period between 1996 and 2006 using a series of biographical interviews. These aimed to explore developments in their lives across different fields which the researchers saw as sites within which young people can begin to develop an adult identity. These fields were: education, work, leisure and consumption, and the domestic (the latter encompassing family, relationships and care). The young people were also asked to keep memory books and make 'life lines' (Henderson et al, 2006) outlining their hopes for the future in terms of home/housing, education, work, relationships, travel and values at three particular points in their lives (i.e. in three years time, at 25 and at 35). In following the young people in this way the researchers were able to track how their plans developed or changed over time and identify 'critical moments' (Thompson et al 2002) in their biographies. In the interviews the young people were also asked to reflect on their past experiences and this allowed the researchers to see how memory is used to construct and reconstruct their identity.

These ideas are based on Giddens' (1991) notion of the reflexive self, as discussed in the previous chapter. Giddens explores how people construct internal narratives which integrate their life experiences and personal beliefs, and how as we create and recreate these narratives we shape our understanding of our past and who it is possible for us to be. This is a continuous process as everyday decisions such as what to wear and what to eat have to be chosen from a range of lifestyle choices. In covering such a wide range of areas within young people's lives, the study gives us a picture of how various aspects of their lives interact. It also explores which aspects of their lives they invest the most in. It argues that young people invest most in fields where they can develop a sense of competence and gain recognition for this competence. The study also aimed to explore how young people's opportunities are shaped by class, gender and ethnicity as well as the localities where they live.

The main strengths of this methodology lie in the longitudinal element which gives a much wider picture of change over time. This is particularly important in documenting the experiences of young people as so much in their lives can change in such a short period of time. By locating the individual biography in the wider context of the community it allows us to see "the interplay of agency, structure,

resources, resourcefulness, contingency and social policy” (Henderson et al, 2006, p41) in shaping an individuals’ life. The process of analysis had both longitudinal and ‘cross-sectional’ dimensions. After each round of interviews a thematic analysis was carried out across all the interview transcripts to identify cross cutting issues. Data was also analysed longitudinally using ‘case histories’ which detailed the changes in an individual’s circumstances over time and how their narrative developed.

Although some visual methods are used in the form of ‘memory books’ and ‘life lines’ the main method of data collection in *Inventing Adulthoods* is the biographical interview. This may not be suitable for all young people with learning disabilities who often have difficulties articulating their views (Booth and Booth, 1996). Liamputtong (2007) argues that more innovative methods are needed to find out about the experiences of vulnerable groups; she highlights participant observation and photographic methods as ways of doing research which have been used successfully with young people with learning disabilities. Visual methods are increasingly being used as a means of allowing people who have difficulties with speech to have their opinions heard. For example, the interactive environments project in Tower Hamlets has pioneered using specialist video technology to help young people with severe learning difficulties to communicate (Gaines, 2008). Watson et al (2000) and Benjamin (2002) have both used participant observation to find out about the school experiences of disabled young people.

The *Life as a disabled child* project (Watson et al, 2000) used a mixture of participant observation and interviews and involved over 300 children in 14 schools across England and Scotland, including both mainstream and special schools. The researchers took on the role of non-teaching adults in order to spend time with pupils in a variety of settings. From this they continued to work with 165 children with more in depth methods such as individual, paired or group interviews, or the production of written and visual accounts. The types of research technique used were, in part, guided by the preferences of the children themselves. For example, some young people invited the researcher to come to their homes or take part in out of school activities, while others opted to take part in school hours only.

Benjamin's (2002) study was carried out in the inner city school where she worked as a learning support teacher. A group of nine year-11 girls and nine year-7 girls took part in the research, many of whom Benjamin already knew through her teaching role. They had expectations that when she accompanied them to lessons she would be there to help them with their work. As a result of this, instead of acting as an observer she continued to support the students in her usual way, whilst documenting what took place in the classroom. In addition to this the girls took part in group interviews in which they were invited to discuss their experiences of school and asked to role play 'successful' and 'unsuccessful' students and describe them and their school in as much detail as possible. They were also given a disposable camera to take some pictures of their school lives and the photos were used in the next session to make a captioned display. She also held a feedback session for the year-11 group at the end of their exams where they were invited to discuss what they felt about what was said in the interviews and were given the opportunity to re-record part of them if they had changed their mind. The girls then noted some of the key phrases which had come up in the interviews. These phrases were put onto flash cards and the girls sorted them into themes. Some of the pupils then interviewed the year-7 pupils using a topic guide based on the themes they themselves had developed.

Both studies offered participants different levels of involvement depending on what they felt comfortable with. Participant observation was used as a base from which young people could become more involved with the study. These methods are a sensitive and appropriate way of finding out about the experiences of young people with SEN, by combining participant observation with biographically focused interviews we can also achieve a much fuller picture than would be possible if just one of these methods were used.

Previous Studies

Another major study in the area is *Post 16 transitions a longitudinal study of young people with Special Educational Needs* (Aston et al, 2005). This was the first national

transition study to be carried out in England and included students from both mainstream and special schools with a wide range of special needs. It used a mix of quantitative survey methods and qualitative case studies. It aimed to find out about the experiences, achievements and attitudes of young people with SEN leaving compulsory education, and their activities after they left, as well as identify the strengths and weaknesses of the services charged with supporting them. It looked at many aspects of the young people's lives, including hobbies and social life as well as education and employment. Unlike most studies about pupils with SEN it included young people with and without statements, highlighting the different transition pathways of these two groups, as discussed in the previous chapter. The study took place in three waves, the first was when the young people were in school year 11 (age 15-16), the second wave took place when they were aged 17-18 and at the final wave they were 19- 20.

Most studies carried out prior to this have been relatively small scale, often focussing on particular groups of young people such as those with learning difficulties (Heslop et al, 2002) or those who attended a special school (Mitchell, 1998). Many of the studies focus on the transition from children's services to adult services and look at how services such as health, social care and education work together (or not, as the case may be) (Beresford, 2004). However, some studies have also explored young people's experiences and expectations of growing up (Hirst and Baldwin, 1994) and have examined what adulthood means for young people who are unlikely to achieve some of the traditional markers of adulthood such as, having a job or living independently (Mitchell, 1998).

With the notable exception of Aston et al (2005), most previous studies have focussed on young people with a statement of special needs, in particular those who are in receipt of a range of services and have aimed to look at how well these services work together. However, little attention has been paid to young people without statements who may not be entitled to such support. This is an issue of particular concern as there is little consistency in the awarding of statements with some local authorities providing many more than other authorities thus making

provision of support something of a 'postcode lottery' (House of Commons Education Select Committee, 2006).

This research aims to explore the post-16 experiences of young people with SEN, including both those with and without statements. As a result of this, the research will focus on pupils who attend mainstream schools. This focus will also provide the opportunity to look at how well mainstream services, such as Connexions (or alternative youth support service), cater for young people with SEN. At the same time it will investigate young people with SEN's experiences of transition as well as their aspirations for the future.

Research Questions

The research had two main aims. Firstly, it sought to investigate the experiences of school and leaving school from the perspective of young people who are considered to have Special Educational Needs. Secondly it aimed to explore what the young people's needs are during this transition period and discover how well young people feel they have been supported by services. As the research took place in a rural area it aimed to identify specific issues which might be particularly pertinent to young people living in rural communities and services and supports relevant to the needs of those living in such communities.

More specifically the following research questions were derived from these aims:

- What are the young people's short term and long term aspirations for the future? - In terms of education, employment, home life, family and relationships.
- What are the young people and parent's experiences of services, in particular those involved in transition planning and how well do these services work together?
- Does having a statement of Special Educational Needs make a difference to how well young people are supported by services when preparing to leave school?

The research will explore these questions in the wider context of the young people's school experiences.

To answer these questions, repeat biographical interviews with young people as well as interviews with parents and professionals were conducted.

Original Study Design

The original study plan was to carry out a period of participant observation in the two schools that I planned to recruit the sample from and to carry out three interviews with each young person in total. If I had achieved this, it would mean that I had followed the young people in the sample for a period of two years. Although I did do participant observation in two schools, in one case over the period of two school term, in the other case three school terms, in the end it was not possible to recruit a sample from these schools. This forced a radical rethink of the research design. Fortunately I was able to find another suitable school that was happy to take part in the research and have managed to recruit a sample from there. However, there was not enough time left of my PhD registration to repeat a similar period of participant observation so straight away I recruited a sample to interview. Again, due to time constraints I decided to do two interviews rather than three. In spite of the changes I have had to make to the research design, I have tried to stay as true as possible to the original plan. After carrying out the first round of interviews I decided to supplement the interviews with an online survey. I decided to do this as now I only had one school in the sample and I wanted to get a wider range of responses.

Study Design

These research questions placed a number of demands on the research design. To understand transitions from young people's perspective requires a detailed knowledge of individual views and experiences. To achieve this, a qualitative approach is necessary. To understand the complex multifaceted nature of young people's lives previous studies have argued that an holistic and/or biographical and longitudinal approach might be (as used by Henderson et al (2006) and MacDonald and Marsh (2005)) would be appropriate.

At the same time the research aims to find out about service provision for young people with SEN. Due to this study's focus on a particular geographical area where there will only be a small number of professionals, an in-depth qualitative approach would still be appropriate, but this could be more structured. Because of this it was decided to interview the relevant professionals in each area using a series of semi-structured interviews. These would explore what forms of provision was available, who was entitled to it, how it was delivered and what impact the professionals felt it had on the young people.

As the transition to adulthood is not a single event but takes place over a period of many years, a longitudinal study is arguably the best way to capture this process. In the case of young people with SEN, formal preparation for leaving school begins at age 14 when they have a transition review, although many young people start to think about what they want to do in the future long before then. Many young people with SEN experience 'extended transitions' with a prolonged period of dependence on their parents (Aston et al, 2005). Ideally, a study would begin before the end of compulsory education to find out about the preparations the young people are making for their future and follow them to age 18/19 by which time most will have finished at least the next stage of their post-compulsory further education. However, for this to be accomplished would require a fieldwork period of at least 4 years, longer than would be possible over the doctorate registration period. It was not possible to do this within the time constraints of the study so my original solution was to recruit two cohorts of young people and follow them over a period of 18 months. The first group would have been aged 15/16 at the beginning of the study and been followed through their final year of school until just after they left. The second cohort would have been aged 17/18 at the beginning of the study and they would have been asked about their activities since leaving school and followed over a period of 18 months. This would have enabled me to find out what the young people who went on to further education did after they finished their course. This is important as previous research suggests that many young people with SEN have difficult transitions into the labour market or post-18 education as they are left with nothing appropriate to do after they finish further education (Aston et al 2005). The

compromise I made was to recruit a group of young people who were in year-11 at the time of the first interview and follow them up in the autumn term after finishing post compulsory education. I also recruited a group of young people who were in the school sixth form across both years 12 and 13. This enabled some follow up of those who had finished courses but not to the extent of the original design. This also does not include young people who left school at 16 or who went to study at a different FE college.

Another advantage of the longitudinal nature of the study was that as the initial analysis and data collection took place alongside each other, the developing findings could shape the direction of the research design. As the interviews were deliberately designed to be flexible it was easy to modify the topic guide to include themes that had been found to be of importance in the previous round of interviews. This allowed me to explore themes that I had not pre-defined as crucial or paramount at the start of the research.

Pilot Study

For the researcher's Masters Degree dissertation a small, pilot study was conducted at a different school to those taking part in this research. This study also involved year-11 students. The plan was to carry out one interview with the young people and one with their parents shortly after they had left school and to use photographs taken by the young people as an icebreaker at the beginning of the interview. I had handed in a disposable camera to the school for each young person who had agreed to take part in the study with written instructions to take photos of their last week of school and return the camera to me in the stamped addressed envelope provided. I would then get the photographs developed and bring them to the interview.

However, this did not work out as planned. Out of the five young people who had agreed to take part only one returned the camera, and I was only able to arrange interviews with two young people, both of whom said they were not sure what to do with the camera. I realised that I had caused confusion amongst the participants about what was expected of them, but I did not have an opportunity to explain the

research to the young people in person as the planning process was too rushed and it was almost the end of the school term by the time access had been negotiated.

This was something I hoped to rectify in the main study. In order to be able to find out more about the young people's school experiences and build up a rapport with them before the interviews I decided to undertake a period of participant observation in schools. I had hoped that this would also give me the opportunity to explain the research in person to the participants, but as I explained earlier it did not work out this way as I did the participant observation in a different school to the interviews

Despite this, the interviews went well and my decision to interview parents, as well as the young people themselves proved fruitful as parents were able to provide information about things such as what support their child received that the young people themselves were not sure about. The topic guides I used worked well and I have used the same set of questions for the first round of interviews (see appendix 1). Although this study was on a small scale; two young people, two parents and two teachers (the school SENCO and deputy head teacher) were interviewed, it was a useful preparation for the main study.

Data Collection

The research took place in a mainstream state secondary for pupils aged 13-18, with around 1000 pupils. The local authority in which it is based has a 3 school system where pupils attend a First School until the age of 9, a Middle School from aged 9-13 and a High School from aged 13-16. This means that pupils experience two transitions between schools. It serves a small market town and a wide surrounding rural area. It has similar number of pupils in receipt of free school meals and those with Special Educational Needs to national proportions. Due to the rural location of the school the 6th form has developed a large range of courses. As well as offering A-levels it is possible for students to study vocational qualifications such as childcare to levels 2 and 3. There is also a vocational training route run in partnership with an FE college and local businesses.

Definitions

As discussed in the previous chapter the concept of Special Educational Needs is contentious and it is more appropriate to see it as an administrative category than as describing a coherent social group. For the purposes of this research the definition used will be people who are considered by the school to have Special Educational Needs. All pupils in years 10 and 11 who were on the school special needs register were invited to take part in the research.

This definition has its limitations as someone who is considered to have SEN in one school may not be in another. For example in one of the schools where I carried out the participant observation only one pupil out of 150 in his year is diagnosed with dyslexia, whereas in another out of a much smaller year group there are several. It is likely that the difference in rates of diagnosis reflect the policies of the individual schools. Pupils with problems that go unrecognised are likely to face similar issues to those who are recognised as having SEN. However, there is no reliable way of identifying these young people and therefore they are not included in this study.

Sample

Although I was recruiting from a relatively small population, I still hoped to achieve a relatively diverse sample, both in terms of class and gender and types of special need. I recruited my sample by sending letters out to all the young people in year 11 (aged 15-16) and the students in the school 6th form (aged 16-18) who were on the school special needs register this included both young people with and without statements of Special Educational Needs. As I was not allowed to know the pupils' details prior to them expressing interest in taking part in the study I had to give the letters asking them to take part in the research along with an information sheet explain what the research was about to the school SENCO and get her to send the letters out on my behalf. I included a reply slip and a stamped addressed envelope for them to get back to me. The letters went out to the parents of 30 young people. At first I did not get any response and then I send out a second letter as a reminder. This time I got 8 responses all of whom were in school years 10 or 11. As I wanted to

include people who were in the older age range in the study I decided to recruit more participants by snowball sampling. In snowball sampling the researcher makes contact with a small group of potential participants and uses them to make contact with other people they know whose experiences may be relevant to the research topic (Bryman, 2004). I asked my existing participants if they knew anyone who fitted the research criteria deciding to expand the age range of possible participants up to 21 to ensure I got some slightly older young people.

Participant Observation

In the spring and summer term of 2008 I did participant observation in three schools. This was intended to be the first phase of the research and involve the young people who I would later interview. Although I was not able to use the participant observation in the way that I planned, it still provided some useful background data and context to the research. However, as the focus of the research is on leaving school and the transition to adulthood and the young people who took part in the participant observation were not followed up on leaving school this data is not discussed in the analysis chapters.

I started off by work shadowing teaching assistants to find out how learning support was provided in each of the schools. This is to be important as each of the three schools had completely different ways of providing this. In one school some pupils have full time support workers with them in all lessons. In another, some pupils were taken out of two lessons a week to work intensively with an assistant and catch up on their work. Because of the different roles being played by the assistants, the participant observation took different form in each of the schools. This also depended on relationships with staff and students at the school. It was always my aim to participate in, and contribute to, naturally occurring interactions. Once I became familiar with the schools and got to know some of the individual students, I then asked a selection of students if I could shadow them for a day or part of a day. Most of the students who were happy to do this received a lot of support at school and were used to being followed around by adults. This concurs with the findings of

Watson et al (1999) that disabled children are subject to a lot of adult surveillance in both mainstream and special schools.

Interviews with professionals

I conducted semi structured interviews with professionals in both the schools where the participant observation took place the school from which the interview sample was recruited. Ten professionals were interviewed in total. This included the school SENCO, the Connexions Personal Advisor, and whichever member of staff was in charge of work experience. The aim of these interviews was to begin to assemble a more complete picture of the range of support available to young people with SEN and how the services have been adapted to meet the needs of those living in rural areas. This was done without any specific reference to any particular student. The interviews were carried out at an early stage in the research process and were intended to provide context to the young people and parents experiences. The interviews included questions on:

- Their role within the school;
- Options available within the local area, for young people in general and for young people with SEN in particular;
- What support they provide for young people with SEN
- Any specific patterns of support developed because of the rural catchment area of the school?

Interviews with Parents

The interviews with parents had two aims. The first was to triangulate data provided by the young people as the pilot interviews indicated that parents were more likely to remember certain details such as whether the young person had had a transition review. The second was to find out more about the young person's background and family attitudes to education. As far as possible a narrative interview was carried out.

At the start of the interview the researcher explained that the purpose of the interview was to find out about their child's experiences of school the help they had received and their plans for the future. This generally went well and the parents (mostly mothers) talked at great length about their child. However, I did have a list of areas that I needed to cover in each interview to allow for a degree of standardisation and where necessary I would prompt the interviewee to ensure all of the topics below were covered.

- SEN history of young person;
- Young person's perceived strengths and weaknesses;
- Attitudes to school and education;
- Expectations and aspirations of adult life for their child;
- Their views on the support they and their child had received

Interviews with Young People

The interviews with young people were designed to give as detailed a picture as possible of the young people's experiences, not just about leaving school but about wider aspirations for the future and what shapes them. To reduce the impact of recruiting participants through the school and avoid stereotyping young people with SEN, repeat biographical interviews were carried out (Henderson et al 2006). This meant the participants' experiences of school and their aspirations for the future can be put in the wider and dynamic context of their lives.

In order to get a picture of change over time, two rounds of interviews were carried out. The first of these took place in March and April 2010 when most of the participants were in year 11. The second took place during the autumn of the following year to find out what they had been doing since reaching minimum school leaving age. The original plan was to do three interviews with the first taking place in the autumn term of year 11, so although the number of interviews have been reduced, the students are still followed from compulsory schooling to their next step,

which was the main aim of the study. Carrying out two interviews had a number of benefits. Firstly, it minimised the risk of “retrospective re-construction” – young people reinventing their stories of the past to fit in with present – something which has been recognised as a problem in previous studies of youth transitions (Henderson et al 2006). For example, if someone wanted to study a particular course at college and did not get good enough exam results and had to do another course instead they may pretend that was what they wanted to do all along.

All the interviews took place in the participant’s homes although they were offered the option of having them at a local youth centre if they preferred. Two hours were allocated for each interview, to ensure the interviews were not rushed, although most were expected to take less time than that. All interviews were recorded, with the participant’s consent using a digital recorder. Participants were also given a gift voucher in appreciation of their time.

One of the biggest challenges in doing in-depth interviews is building a rapport with the participants, and it was anticipated that participants in this research may be nervous, apprehensive or reluctant to discuss things fully and openly for a variety of reasons. Being considered to have SEN can be stigmatizing and it was always possible that people might be reluctant to talk about such issues with anyone seen as being connected to the school or education. Doing multiple interviews also provided the opportunity for potentially sensitive questions to be posed in later interviews after the respondent had learned that the interviews were not threatening and a relationship of trust has been built up. Another difficulty that had to be thought through was that young people with learning difficulties may have difficulty in articulating their views (Booth and Booth, 1996). Although this was not the case for all the people who took part in the research spending time in schools and getting to know the young people before interview them gave me the chance to make sure that the interviews were done in a way that was appropriate to each participant's level of understanding.

In addition to this, I decided that a good way to break down barriers at the start of the first interview would be to talk about photographs the participants had taken of

things they considered to be important to them (Kenwright, 2008). It was also thought to be a good way of finding out about the experiences of those participants who are less articulate. Aldridge (2007) argues that the use of photographs in research emphasises the capabilities rather than the deficiencies of participants with learning difficulties and is a good way of including their views in research.

Shortly before the interviews took place the researcher met with the participants to brief them about the forthcoming interviews to find out if they are still happy to take part. The researcher gave all the participants a disposable camera and asked them to take photographs of things they felt were important to them or might help indicate to the researcher something about their interests, activities, hobbies or relationships. The researcher provided the participants with a stamped addressed envelope and asked them to return the disposable cameras in the envelope provided and made sure that everyone was clear about what they needed to do.

The researcher then got two copies of the photographs developed. Before the start of the interview the participants were given the chance to go through the photographs and discard any that they were not happy with. The researcher and the participant then sat down and talked about the photographs, with the participant being asked why they had chosen to take photographs of those particular things and what was particularly significant about them. One of the sets of photographs was kept as part of the data, if the participants gave permission, and the other one was given back to the participant to keep.

After talking about the photographs the interview moved on to talking about their experiences of school, starting from as early as they could remember right up to the present day. Because the aim of the interviews was to examine a developing vision of aspirations the interview went on to discuss their young person's plans for the future and the guidance they had had for preparing to leave school or taking part in post-compulsory education. The researcher aimed to keep this as informal and conversational as possible.

One of the major challenges in longitudinal studies is retaining the sample throughout all the stages of the research (Holland et al 2004). The researcher made

sure they had more than one set of contact details for each young person so that in the event of someone moving house or changing their mobile phone number, it would still be possible to contact the participants. If participants did not reply to requests for an interview a reminder was sent out. To try to maintain people's interest in the study, after each round of interviews, summaries of the findings so far were sent out and participants were invited to comment on these.

The second interview took place in the late autumn/early winter of 2010. By which point the participants were likely to have settled in to their next activity (in terms of education, employment or training) after leaving school or into the school sixth form if they have decided to stay on. In this interview the participants were asked about what they had been doing since their last interview and if and how their future plans had changed at all. An important part of both interviews was trying to get the participants to look forward and imagine their lives in the future, thinking about what they would like to be doing in 5 years, 10 years and 20 years time. This was something many of the young people in the study found difficult. A possible reason for this is that many of the participants had very limited options for the future and there are few prominent role models for disabled young people to help them imagine themselves as adults.

The table below shows the participants who took part in the research.

Name	Age at first interview	Type of SEN	Parent interview
'Josh'	Age 15 year 11	Dyslexia, ADHD (is also considered to have conduct disorder and oppositional defiance disorder but both he and his mother dispute this)	Mum
'Adam'	Age 15 year 11	Dyspraxia, Asperger's syndrome, Non Verbal Learning Disability	Mum
'Maisie'	Age 15 year 11	Dyslexia, Dyspraxia, Hypermobility Syndrome	Mum
'Liam'	Age 14 year 10	Dyslexia, ADHD, learning difficulties	Both Parents interviewed
'William'	Age 14 year 11	Dyspraxia, Asperger's syndrome (mental health problems)	Mum
'Ben'	Age 14 year 10	Dyspraxia	Mum
'Richard'	Age 15 year 11	Dyslexia	Mum
'Callum'	Age 15 year 10	Health problems, learning difficulties	Both parents interviewed
'Dylan' (older brother of Josh)	Age 20	Autism, Dyspraxia	Mum
'Simon'	Age 20	Autism , Epilepsy	Both parents interviewed
'India'	Age 18	Dyslexia	Mum
'Sophie'	Age 19	Dyspraxia, Hypermobility Syndrome	Mum
'Fraser'	Age 18	Dyslexia	Mum
'George'	Age 20	Autism	Mum

Table 1: Research Participants

Analysis

Thompson (2007) argues that to get the best out of longitudinal qualitative data it should be analysed both longitudinally and cross-sectionally. This way, it is possible

to pick up on trends across all cases as well as being able to follow the progress of individuals over time. Therefore as in the “Inventing Adulthoods” study there were two strands to the analysis.

Soon after each interview, a narrative analysis was conducted which looked at narrative style, subject positions taken and the pace of the narration, as well as the researcher’s reflections on the interview and their hopes and fears for each participant. All interviews were then fully transcribed and loaded on to *Atlas ti*. This software package was used as it can be used to analyse visual data such as the life lines as well as text. A thematic analysis was carried out across all the interviews in that particular wave. Young people, parents and professional interviews were analysed separately.

After the first round of interviews, a case study was constructed for each young person. This included information from both the young person’s interview and the parent’s interview. Bringing the data together in this way helped identify what gaps there were in the information about that young person as well as interesting issues to explore further in the next interview. However, the information in the case studies came from two different sources and the young people and their parents often offered contrasting accounts of the same situation. It is important not to privilege one account over the other, particularly in cases where the young people have communication difficulties and have not said as much as the parent who was interviewed. As a result of this the case studies state which interview the information came from and if there was a difference in point of view between the young person and their parents. After the second round of interviews, all of the case studies were re-written to take into account the changes in the young people’s lives and the new information required.

As part of the analysis I also looked for ‘critical moments’ (Thompson et al, 2002) in their lives. In doing this I had to consider who decided if something was a critical moment or not. For example, one of my participants did not appear to connect the death of his Dad, his depression and the difficult time he was having at school but his Mum felt that this was the cause of the problems.

Ethical Considerations

Holland (2003) argues that in longitudinal qualitative research projects, ethical issues can become magnified as the researcher spends more time with the participants and gets to know more about their lives. In addition to this, the cohort who took part in the research present their own set of ethical challenges, both due to their age and the fact that they are considered to have SEN. It is therefore clear that in a project such as this, ethical considerations are particularly important. The research was carried out to the standards of the Economic and Social Research Council's Research Ethics Framework (2005) and has approval from the university's ethics committee. However, Liamputtong (2007) argues that ethics should be an inbuilt part of the research project rather than just a bolt on and should be considered an on-going set of issues rather than a series of barriers to be confronted only at the outset of a study.

As the participants were recruited through the school it was particularly important to ensure that they were fully aware that they were free to decide whether or not to take part in the study. I explained the purpose of the research to the young people in person making it clear that the research is my personal project and not being done by the school and that taking part is optional. I also provided information leaflets about the research for the young people to take away. The wording of these leaflets was carefully considered in order to make them as clear as possible without being patronising. This was challenging as the young people varied widely in terms of ability. I did many drafts of the leaflets and consulted with my supervisor and some young people who had SEN when they were at school about the content and presentation. However, as with all longitudinal research, consent should be seen as an ongoing process throughout the duration of the research rather than a one off event (Holland et al 2004). Therefore, before each interview, participants were asked if they were still willing to be part of the research and if they were happy for the data they provided to be used in the research. The consent forms were designed to be as

clear as possible using large print fonts and simple language, but the researcher also read the forms out to the young people before the interview started to ensure they were fully informed.

As I was doing research with young people, child protection concerns also had to be taken into account. Before I had any contact with the young people I had a criminal record bureau check. I also familiarised myself with the procedures of the various schools about what to do if a child made a disclosure of a danger of serious harm or abuse or if there was reason to believe they were at risk. If this happened I would be obliged to notify the relevant authorities. This meant that there was a limit to the confidentiality I could offer to the young people and parents taking part in the research. This was made clear both on the consent forms and when I explained the research to the participants. In bringing this up there is a risk of causing offence as people may think I am insinuating that I think they are likely to abuse their children. To make sure I had phrased this in the most tactful way possible, I contacted Dr Carol-Ann Hooper who has carried out a lot of research in the area of child protection and she sent me the briefing sheets from her latest research project (Hooper, 2008). In line with this I informed young people and their parents that they would have confidentiality unless they told me that a child or young person was not safe, which is the same language used by the government's 'Every Child Matters' agenda. I was aware that, to young people, 'being safe' is likely to be interpreted as being safe from all forms of harm, rather than being safe specifically from child abuse. Although I would not be legally obliged to act if a young person revealed they were being bullied, having promised I would do something if they felt unsafe, it would be wrong to ignore their concerns. I discussed with the school what I should do if a young person revealed that they were being bullied.

Although Special Educational Needs are not the same as disability, there is considerable overlap between the two groups and many of the ethical issues in disability research also apply to young people with SEN. All the young people who took part in the study had an impairment of some kind. Most notably, Oliver (1992) has condemned much research into disability as a 'rip off' which has done little to improve the lives of disabled people or challenge the oppression they face. He

argues that an emancipatory research paradigm should be adopted. Emancipatory research attempts to address the imbalance of power between the (usually powerful) researcher and the (usually powerless) researched. To do this the research:

“must not only faithfully capture the experience of the group being researched but also be available and accessible to them in their struggles to improve the conditions of their existence. This isn’t just about making researchers more accountable but of giving over ultimate control to the research subjects.”(Oliver, 2002, p 11)

The emancipatory research paradigm is openly partisan, arguing that when doing research on issues such as oppression it is not possible to be neutral and it is better for researchers to be open about their motivations for doing the research (Barnes, 1996).

Part of the criticism that has been levied at disability research stems from the fact that historically most research into disability was undertaken by non-disabled people and as a result often viewed their participants as other (Oliver, 2002). Shah (2006) argues that when doing this type of research, disabled researchers have the key advantage of being able to empathise with their participants and that interviewing people who have similar experiences encourages the generation of richer material. However, she points out that there is a fine line between empathy and exploitation and that we need to recognise the differences as well as the similarities between the researcher and the researched. Shah also discusses how her shared background with her research participants encouraged them to ask her questions about her own life such as, had she encountered similar barriers to them when she was growing up and what had she done to overcome them. I had a similar experience when carrying out my own research as some of my research participants asked me about my experience of university and what support was available to disabled students.

It is clear from the description of my methods above that I have not handed control of the research over to the participants. However, I have taken some steps to reduce the balance of power between researcher and researched. I attempted to put the experiences of the participants at the heart of the research, allowing them, at least in part, to control the themes being explored and questions addressed.

Emancipatory research should also be of use to those who participate in it or be used to improve policies for them. This research is being done primarily for the researcher's PhD. Although the school has requested a copy of the findings and the researcher will attempt to have them published, there is no guarantee any recommendations which seem to flow from the research undertaken will be acted on. However, this is true of much academic research.

One of the issues raised by the ethics committee was the appropriateness of the term "Special Educational Needs" and whether it is appropriate to label young people as such by virtue of their very inclusion in the research. I realise that when applying labels such as SEN to young people there is a risk of stereotyping and I have outlined the problems with this term in the previous chapter. However, Special Educational Needs is a widely used term and describes the young people's status in law. Pupils who are considered by schools and education authorities to have Special Educational Needs are already labelled and this research does not intend to add to this. To use another term instead would potentially be more stigmatizing. SEN is also a term that is familiar to young people and they are aware that it applies to them.

Reflections on the research process

I had originally hoped to recruit slightly larger sample than I managed to achieve as I aimed to recruit 15-20 young people. I was aware that being considered to have SEN was a potentially sensitive topic for some people and that taking part in a longitudinal study is a bigger commitment for the participants than a one off interview. However, a much higher proportion of the young people agreed to take part in the second round of interviews than I anticipated. Thirteen out of the fourteen young people and their parents agreed to take part in a second interview. As the research was opt-in, it is likely that those who agreed to take part were more interested in the research.

Another possible reason for this is that my own experiences meant that I was able to emphasise more with the participants. Everyone who took part in the research knew that I had dyspraxia and had been considered to have SEN when I was at school. This allowed for an element of reciprocity as some of the participants asked me questions about my own experiences of school and university. For some of the older participants whom I recruited through 'snowball sampling' the knowledge that I had similar experiences to them was a crucial factor in deciding to take part in the research.

However, there was a slightly different dynamic in play in the interviews with the parents. This was particularly evident in the second interview with Sophie's mother. At the time of the interview, Sophie was preparing to move out of the family home in order to start a new job. Sophie's mother was not convinced that her daughter was ready to live independently. However, she was aware that like Sophie, I had dyspraxia and hypermobility syndrome. After talking about her doubts about Sophie leaving home she asked me how old I was when I left home. I told her I was 18 (the same age as Sophie). She said "you probably think I'm being an over-protective mother". I replied that I did not think that at all. I did not want to get drawn in to the difference of opinion between mother and daughter. She then changed track and admitted that because of the difficulties Sophie had when she was younger she had not expected her to leave home and found it hard to get used to the idea. Sophie's mother thought that as I had been in a similar situation to her daughter, rather than agreeing with her, I might see her as "an overprotective mother" who was "making a big fuss". I think this interview would have ended differently had it been carried out by a different interviewer.

Chapter Summary

The research used a mix of participant observation and repeat biographical interviews to investigate the experiences of leaving school and future aspirations of young people considered to have Special Educational Needs. It also used semi structured interviews with parents and professionals to look at the support available to young people with SEN during this period.

The next three chapters present the findings of the research. The analysis draws predominately upon the data from the young people and parents interviews. Both the participant observation and the interviews with professionals were carried out at an early stage of in the data collection process. Their main purpose was familiarisation and to provide context to the research.

In keeping with the way the data was analysed the findings are presented from both a thematic and a longitudinal perspective. The chapters are organised by themes but two longitudinal case histories are integrated into them. The first two chapter focus on the experiences of the young people in the study and the third explores the parent's experiences. I decided to organise the chapters thematically rather than by research question as the issue of support from services is something that is central to all of the chapters. The two chapters on the young people's experiences are organised roughly chronologically starting with the next chapter focusing on the time when they were at school and the next one on future plans, further education and employment.

Young people's experiences of school

The previous chapter outlined the methods that were used in the study. It detailed the rationale for using longitudinal qualitative methods, including interviews with young people and their parents, as well as explaining that the data will be analysed longitudinally, in the form of case histories, and cross-sectionally using thematic analysis.

This chapter will look at the young people's experiences of school. It draws on data from both the young people's and the parent's interviews but the focus is predominantly on the young person's perspectives. The key themes that emerged from across the sample are the extent to which the learning support the children had, acted as a form of support or surveillance, the importance of the social side of school and the degree to which the young people felt included. As well as exploring these themes this chapter contains two detailed case histories Liam and Maisie. These case histories are used to explore in more detail some of the key findings.

I was interested in the support the young people had at school and how they had experienced this support, as well as how far they were included in the life of the school. The type and level of support the young people received varied enormously across the sample. It also varied significantly across the young people's school careers. There were cases of young people who had a great deal of specialist help in their early years of school but in later years were in mainstream education with little extra support. For example, Maisie attended a special unit for pupils with moderate learning difficulties from the age of 7 to 9; by the time of her second interview she was studying a mainstream course on child care in her school 6th form and receiving only two hours of support a week from her teaching assistant (TA). There were also some young people in the study who received little or no extra support when they first started school but later received all of their education outside a mainstream setting. This was the case for Josh who had limited support in first school but as he

fell increasingly behind spent more and more time outside of mainstream school, eventually completing his GCSEs with a one to one teacher.

The young people had experienced a range of types of support throughout their time at school. Many of them had professionals - such as occupational therapists, physiotherapists and speech therapists - come in to school when they were at first or middle schools but this no longer happened at High School. Some of the young people were pulled out of lessons for one to one tuition or small group support in something they had difficulty with, usually literacy.

Everyone in the sample had received at least some additional support from a teaching assistant (TA). This varied from a few hours a week in one of their weaker subjects to having full time TA support. It was the policy of the school where the research was conducted that the young people would have a different TA in different subjects to allow each TA to specialise in particular subjects. This was different to the system that had existed in some of the participants' middle schools and it took a while for some of them to get used to it. The young people's experiences of having a TA were mixed. Maisie valued the support she got from her TA and wished that more was available:

"In Maths and Science even though it's a harder subject it's easier cos Mrs_ is with me and she helps. In everything else I have to go by myself."

Sophie also liked having a TA.

"The lady who helped me when I was at the High School was good. She understood what things I needed help with and explained things to you really well"

However, some of the young people felt that having a TA marked them out as different and felt that having an adult with them prevented them from socialising with other pupils. As Fraser put it:

“It’s annoying cos sometimes in class you want to talk to your friends and that and you can’t cos you have to have this woman sitting next to you making you do work and nobody else has that. It’s not fair.”

Liam also felt that his TA was *“always on my back”* and wished that she would leave him alone. He asked permission to be allowed to go to English without his TA who he did not get along with. However, without her, he struggled to do the work and argued with his teacher, leading to the incident for which he was excluded (see the case history for more details).

India felt that having a TA marked her out for unwanted attention.

“If you have a TA everyone thinks, oh, she’s one of the stupid ones and I didn’t want that. I would rather ask my friends for help”.

The concerns expressed by some of the young people about having a TA echo those found by the *Life as a Disabled Child* study (Watson et al, 2001) which involved children who came from both mainstream and special schools. They argued that in some cases children who attended a special school had more autonomy and opportunities to interact with their peers than their counterparts who attended mainstream school with a TA. As I was aware of this research I asked all of the young people how they felt about having a TA. Not everyone felt that having a TA limited their ability to interact with other young people in the class. For example William said:

“I don’t think that having her there stops me talking to people because there isn’t anyone in that class I would want to talk to anyway”.

Most of William’s school friends were other young people with SEN. The people who felt that having a TA stopped them from interacting with their friends had friends who were not considered to have SEN. Richard was ambivalent about having a TA who sat with him in English.

“I don’t like everyone thinking I’m different to everybody else but the work is so hard that I don’t think I would be able to do it if she wasn’t there”.

Richard’s quote encapsulates the issues around providing learning support. Most young people wanted to have help with the things they found difficult but they wanted to receive it in a way that did not mark them out as different. The quality of the relationship with their TAs also influenced how young people felt about having them.

The Social Side of School

However, not all of the support young people received was academic. The social side of school was equally important to the young people’s experience. Some young people actually found the period in between lessons more stressful than the lessons themselves. Whilst lessons were relatively structured and support was available, should they need support outside of lessons this was not the case. Adam, whose main difficulties are social, enjoyed lessons but found being in noisy spaces such as the playground and the dinner hall distressing. To help students who found break times difficult, pupils with SEN were allowed to use the learning support centre as a social space before school and at break times and lunch times. Here they were able to play board games and computer games. A member of staff was usually on hand if anyone had a problem. Adam identified making use of this space as the main form of support he had at school. Several of the other young people in the sample, including all of those who had an ASD, made use of this facility and valued it as a place where they could socialise without being bullied.

Whilst the young people valued having somewhere to go during break times some did not feel confident outside of the learning support centre and worried that they might be bullied. For example Ben felt that:

*“I like to stay in 01 when its break time because I am with my friends.
If I go outside in the yard people call me names and stuff so it’s better
just to stay in”*

Wedell (2005) argued that most SEN policy and practices seem to be intended to “soften the blow” (p4) rather than actually promoting inclusion. The very fact that the school provided a safe space for young people with SEN to go at break times highlights the fact that in the rest of the school, some of the pupils did not feel safe.

Friendship was central to young people’s experience of school. Having friends helped people feel like they belonged. Some of the young people in the study had friends who also had SEN, particularly those who chose to spend break times and lunch times in the learning support centre. The only situation in interviews where the young people referred to themselves as being disabled was when identifying themselves with friends who were also disabled.

*“I prefer to just be by myself. I got bullied so just stayed inside with
other friends who have disabilities” (Josh)*

*“My best friend is Ben, he’s another disabled boy....at break times we
stay in here (the learning support centre) and play computer games”
(William)*

It was mentioned earlier that young people’s attitudes to and experiences of learning support are influenced by their friends. People whose friends also had learning difficulties viewed it more positively than those whose friends did not have it. This was partly because they resented being made to feel different to their friends. Simon chose not to have any learning support once he went to college as he saw himself as being just like anyone else.

For some of the young people the help they got from their friends with the academic work was important to their success at school. When Josh (who had difficulties with organisation) was at middle school:

“I had a couple of friends who helped they helped me out if I’d forgotten something. They made sure I had my stuff like my PE kit and my planner they helped me because I was with them in every lesson They would read things out for me and stuff so it was like having a one to one teacher but it was a friend at the same time When I went to the high school it was all right different you were muddled up in different classrooms”

As his friends were in different classes he struggled without the support and started getting into trouble.

For India, peer support was critical to her success. India’s best friends at school were all high achieving students. Although she had a teaching assistant at middle school, when she was at high school she sat next to her friends in lessons and they would help her with spelling. When she was revising for her GCSEs she would revise with her friends. However, although India valued the support she got from her friends she often compared herself unfavourably to them which was damaging to her self-esteem. *“There was this one project we had, it was on Macbeth and I spent hours doing it, it was really hard and my friend Sam did it on the bus on the way to school and she got a better mark than me and you just think what’s the point“.* Although she got 6 GCSEs at grades A*-C she felt that she had done really badly.

However, not everyone felt that they could share their difficulties. Richard tried to hide the fact that he was receiving learning support from his friends.

“I used to have to go out and get extra help with spelling and stuff and I would tell my friends I was somewhere else like the dentist or something like that”

Fraser was selective about who he told.

“Some of my friends know that I have dyslexia but I don’t tell everybody because some people can be funny”

All of the above demonstrates how the academic side of school and the social side of school are strongly linked and the importance to the young people of being included

in both areas. The following case history follows Liam who throughout his time at school was excluded in both of these areas.

Case History “Liam”

This case history is based on the two interviews with Liam and two joint interviews with both his parents. The first of these sets of interviews took place in the spring term when Liam was in year 10 and the second took place when Liam was in his final term of school in year 11.

Liam lives with his Mum and Dad in a farm cottage in a very rural area. He has an older half-brother who no longer lives at home. He enjoys living on a farm as he is interested in all aspects of agriculture. Liam has had a very troubled school history having attended 3 different First Schools and two Middle Schools, and has struggled at school from the start. He received a statement of Special Educational Needs when he was 7. At the time he got his statement he had not been diagnosed with anything but he now has a diagnosis of ADHD, learning difficulties, writing difficulties and borderline dyslexia. One of his main problems, according to his Mum, is that when he is anxious and in situations where he can't cope, he loses his temper which leads him into trouble.

Liam's first school move was due to the family moving house but he was only at his new school for a short period of time before his mother removed him, as his teachers sent him to see an educational psychologist without consulting her. When he was in year 2 at his third first school, Liam got his statement of Special Educational Needs because of his behavioural difficulties. It became apparent by the time Liam was 9 that he needed to see a psychiatrist. He started seeing a psychiatrist at the age of 9 and was diagnosed with ADHD aged 10 in the first year at his new school. Throughout this time Liam said he was always in trouble at school and spent a lot of time in the Head Teacher's office.

Later on in Liam's interview he described a time when *"I was a zombie... I never went out I was always in the house sitting in my bed."* His mother later explained that at this time Liam had been prescribed antidepressants which had a bad effect on him. *"so when he was going to school he was like a zombie and he was that tired he couldn't be bothered and while he was like that, it (the school) was fine but the medication that they had put him on was making him unwell. It was giving him aches and pains, sore belly everything else and I went back to my GP and took him off the medication and when he managed to come off the medication they wouldn't have him in school"*. During this period Liam received home tuition but this was only for a couple of hours a week which his mother was not happy about. His mother had requested a second opinion so Liam went to see another psychiatrist at a different hospital, Liam was diagnosed with ADHD and put on medication for this and as a result was allowed back into school. This medication had none of the bad side effects of the antidepressants and helped Liam to cope in school although it he had to change from taking 3 tablets a day to a slow release tablet as in the time between one tablet wearing off and when he was due his next tablet Liam's behaviour would get worse again which resulted in him being sent home.

Liam's mum was increasingly angry at Liam being sent home as both this and the time he was not allowed in school due to his not being on any medication were classed as 'informal' exclusion which are technically illegal. Liam was also not getting all the hours of support outlined in his statement and had to share his support worker with other pupils. When Liam was not allowed to go on the school trip this was the final straw for Liam's parents. They took his school to a disability tribunal, which they won, but after this Liam's parents decided to move him to a different school.

Changing schools turned out to be a positive experience for Liam. At his new middle school he was well supported by his teachers and learning support assistant. During this time his behaviour improved and he started to make friends. He also went on an *"amazing"* school trip to the Lake District where he went abseiling. As Liam was no

longer on the antidepressant medication, which had made him lethargic, he was able to take part in activities which he enjoyed. He particularly liked going to speedway races with his friends. On Saturdays he would go down before the race and help the racers get their bikes ready. He knew how to strip a speedway bike and put it back together but is not sure if he would remember how to do it now.

Although he had made significant progress during his time at middle school his teachers expressed concerns about how well Liam would be able to cope at High School. To prepare him for his transition to high school Liam started to make weekly visits to the high school with a group of other students who had SEN to get him used to his new school. On these visits Liam coped well but when he eventually got there it would be a different story.

Liam struggled at High School from the very beginning. He missed the consistency of rules and teaching that he had had in his old, small middle school. He had many more teachers than he had before, his mother thought that not all of them knew about his difficulties, and several different teaching assistants, not all of whom Liam got on with. At high school Liam had to have his TA sat next to him all the time which he didn't like as he felt that he had someone '*on his back*' all the time. He also felt that having a TA with him all the time highlighted his difficulties to other students. This made him feel uncomfortable. As discussed earlier on in the chapter, Liam was not the only young person in the sample to feel resentment towards his TA. The subject Liam struggled the most which was English partly due to his dyslexia and difficulties with writing and partly because of the way it was taught. Unfortunately Liam did not explain the difficulties he was having in the most tactful way and this got him into even more trouble "*the teacher I got into the most trouble with every lesson wasn't on the same subject it was something different every lesson and I 'd go Miss what's this crap... do something different this lesson, different this lesson - Liam apologise go out*".

Liam struggled especially with writing, in particular when he had to write things by hand. These difficulties affected Liam even in the subjects that he thought he was good at such as technology where although he was good at the practical work he was marked down because of his written work. Due to his difficulties with most academic subjects his teachers felt that rather than doing the same number of the options subjects at GCSE, Liam would be better suited to doing a vocational course. The only one the school offered at an appropriate level was Business Studies. Liam's Mum did not think this was appropriate and the school arranged for Liam to do a BTECH Diploma in Agriculture in conjunction with the local agricultural college. The programme is specially designed for Liam and is flexible so rather than studying for a fixed qualification he works through the coursework and they will decide which award to enter him for later on. As part of the diploma, Liam does one day work experience at a firm that hires out agricultural machinery. This is something that Liam really enjoys as it involves repairing tractors.

After starting high school, once again, Liam was repeatedly sent home and informally excluded. This happened until one day when Liam's mum was called to come and collect him she refused until the teacher who was sending him home called her to explain why he was being excluded from school. She did not call and Liam did not go home. During this period Liam's parents felt under a lot of pressure to agree for Liam to go to the study centre for all his lessons. This is a unit for pupils with SEN and includes a mixture of pupils with learning difficulties and pupils with behaviour problems. Liam did not like the study centre as it had bars on the windows and reminded him of a prison. His parents were even less keen for him to be there as they had heard reports of the behaviour of some of the children there with behaviour problems and did not feel this was a suitable environment for Liam.

All of Liam's problems with school came to a head when he was accused of pushing his English teacher, something which he vehemently denies. He had gone to the lesson without his teaching assistant after falling out with her, and struggled with the work. Since this incident, which occurred in November, he has not been allowed

back into school although he is not formally excluded and has all his lessons in the fire station. According to Liam's parents there is some uncertainty about whether Liam will be able to return to school. They were told by the head teacher that if Liam was allowed back into school even for 5 minutes he would probably do something which would cause him to be expelled. However, the school SENCO has discussed with them the possibility of Liam making a gradual return to school starting with him coming in only one day a week in the next academic year.

Liam gets 10 hours a week with a one to one teacher and 10 hours a week with his learning support assistant. His teacher works for a service called 'Education Other Than At School', which is run by the Local Educational Authority to provide education for pupils who have been excluded from school, pupils whose health problems prevent them from attending school and pupils with SEN whose placements have broken down. Although Liam hated going to school he does not like having all his lessons by himself in the fire station. As he lives in an isolated location with no public transport links he only sees his friends occasionally at the speedway. He feels that now it is just him, the teachers are "*on his back*" even more.

Liam's exclusion meant that he could not study the options subjects that he had chosen for his GCSEs, this was particularly unfortunate as these were the only subjects Liam liked and felt that he was good at and his woodwork teacher was one of the few members of staff that he had a good relationship with. Liam was still studying for GCSE's in English and Maths, a BTECH in Science and IT and preparation for life. He was also continuing with his agricultural diploma and still attending his work placement one day a week. However, this placement was only guaranteed until the summer and was not certain if he was able to continue as new legislation says that if a young person undertakes work experience at the same place for a period of more than three months then the member of staff that they spend the most time with has to get a police check.

In the future Liam hopes to have a career in agriculture. He currently gets paid to cut the grass on the farm where he lives and in the farmer's garden. He gets paid £14 per week for this. Liam wants to leave school at 16 and get a job straight away. His parents are trying to encourage him to get an apprenticeship but Liam is not so keen. He has considered going to agricultural college but it is too far for him to travel in everyday and while it would be possible to board at the college he does not feel ready to leave home. Liam and his Mum have had a lot of meetings with teachers to discuss his future and the school SENCO is trying to encourage Liam to stay on at sixth form. However, Liam does not want this and his parents feel that this is unrealistic as Liam is not in school at the moment.

At the time of the second interview Liam was just about to start his final term of compulsory education but had still not been allowed back into school. His relationship with his one to one teacher was strained; Liam had recently been excluded from one to one school for three days for swearing at him. This came after Liam's lessons had been moved from the fire station to the local library without Liam being informed in advance. When Liam was dropped off by the school transport taxi outside the fire station he was told that he had been moved to the library and he had to walk about 2 miles to get there. Liam had also fallen behind in English, Maths and Science so he had to stop studying for his agriculture diploma until he caught up. As the diploma was the only thing about school that Liam enjoyed he had become increasingly despondent and his mum said that it was hard to get him up for school, although in the holidays he got up at 7 every morning to work on the farm. Liam's parents were concerned about his mental wellbeing and were trying to get him counselling. His school were also trying to refer him to the educational psychologist to have him assessed for Asperger's syndrome. His parents felt that he probably did have Asperger's syndrome but were not sure whether there was any benefit to Liam being diagnosed at this stage as he was nearly finished school and they were concerned it would harm his job prospects. However, due to cuts in the educational psychology service they were not accepting referrals at the moment. Liam was just looking forward to three months' time when he would finally be finished school.

One of the things that is striking from Liam's case history is the amount of time he spent out of school and the number of exclusions he had. Pupils with SEN are over eight times more likely to be excluded from school than those without SEN (DFE, 2010). Liam was not the only young person in the study to be excluded from school. Josh was excluded from high school twice, once for smoking and once for swearing at a teacher. Both Liam and Josh were struggling to cope with school at the time of their exclusions.

Vulliamy and Webb (2001) argue that exclusion from school is socially constructed as different schools have different criteria for exclusion and someone who is excluded from one school may not be excluded from another and other factors such as problems in the relationship between home and school can also contribute to this. There was a clear difference in how Liam's parents saw his difficulties and how they were interpreted by the school. The disagreement between Liam's parents and the Headmaster over his placement in the study centre was also a contributing factor.

Transitions between schools

As the local authority where the research took place had a system of first, middle and high schools this meant that the young people in the study had to deal with at least two transitions between schools. It has been well documented that the transition between schools can be a particularly difficult time for young people with SEN (Maras and Aveling, 2006). In recognition of this, the high school that the young people attended had a special programme to help young people with SEN cope with the transfer.

This programme had a mixed impact. Adam, who has Asperger's syndrome and dyspraxia, went into a panic at the high school open evening because there was so many people and lots of noise. He did not think he would be able to cope with going there. However, as part of the programme, Adam and a small group of other students visited the high school with their teaching assistants and took part in activities to help them become more familiar with the school and to get to know

their way around. This really benefited Adam, as once he arrived at high school he was already familiar with the place and coped better than he or anyone else expected. Liam and Josh also mentioned attending the same programme with considerably less success. Josh only attended high school for about six weeks (he is unsure of the exact times) before falling down the stairs and breaking both of his feet. He never went back to school full time after this incident.

As well as the transition to middle and high schools, three of the young people in the study transferred schools because of problems they were having at their current school. Liam's experience of this is discussed in the previous case history. Ben was very unhappy in his first primary school as he was bullied. He also remembers being scared of his class teacher and struggling with his work. Due to his unhappiness at school his Mum transferred him to a special unit for children with moderate learning difficulties (MLD) within another mainstream school. However, she feels that she was pushed into it as whenever she went into the school to complain about Ben being bullied:

"...they just said that he'd be better off in the special unit and if he's not happy here you should send him there. They didn't want him at the school so they weren't going to do anything to make it better for him"

Ben was happier in the special unit as he was no longer bullied, but his mum had doubts over the suitability of this placement as Ben does not have MLD he has dyspraxia. The next case history will focus on Maisie who had a very similar experience to Ben of transferring schools due to bullying.

Case History Maisie

This case history is based on two interviews with Maisie and two with her mother. The first interview took place when Maisie was 16 and in year 11 and the second interview took place when she had just started her first term at 6th form.

Maisie is an only child and lives with her Mum and Dad in a terraced house in a village. At the time of the first interview her older cousin was also living with them in

order to be closer to his work. When the first interview took place Maisie was preparing to sit her GCSEs.

During Maisie's first few years at school she had a difficult time. Her mother felt that she was "*shunted to one side*" because of her learning difficulties and said she was not given the support she was supposed to be getting according to her Individual Education Plan. Maisie also experienced severe bullying. In one incident another child jammed her hand in the door. The bullying came to a head when another child stabbed Maisie in the eye with a pencil. Maisie says that no one called her Mum to come and get her and she had to remain in school until the end of the day. When her Mum came for her at the end of the day she took her to hospital.

After this incident Maisie's mother decided to take her out of that school. She said it was not just because of the this incident "*it was lots of things that had happened to her. We'd just had enough*". Maisie was transferred to another school which had a special unit for pupils with moderate learning difficulties (MLD). The unit had only one small class so Maisie got a lot more individual attention. Maisie does not have MLD which is defined as having an IQ between 35 and 50. However, Maisie's parents felt that the staff there had a more understanding and supportive attitude towards their daughter. It was also an all age class so she had the same teacher from when she started attending the unit aged 7 to when she left aged 9. In order for her to get a place in this unit, Maisie's parents had to pay for her to have a private assessment with an educational psychologist, who diagnosed her with dyslexia and dyspraxia. Her parents also paid for her to have extra tuition at an Indirect Dyslexia Learning (IDL) centre. IDL is a programme which uses a multi-sensory teaching style, to help people with dyslexia learn to read and improve writing and spelling. It is taught on a computer and students learn to touch type. Maisie attended the IDL centre from the age of 7 until the age of 16 when her parents decided that after her better than expected GCSE results she had no need for further tuition.

At the unit Maisie started to make progress and she continued to do well at middle school where her Mum felt that she was getting good support. Despite attending a special unit Maisie had never had a statement of Special Educational Needs. Her

Mum made a final attempt to get one for her before she started high school at age 13. Because of her lack of a statement Maisie only got support in Maths and Science. Her Mum did not feel that this was enough. However, despite struggling with some aspect of the academic work Maisie said she liked school and was happy there.

At her first interview Maisie seemed unsure about what she wanted to do in the future. When I first asked her the question she shrugged and only answered when prompted about education, work etc. Maisie was hoping to study child care as she was currently doing the level 2 CACHE course (equivalent to two GCSEs) but was unsure about whether to stay on at school or go on to 6th form college. Several of her friends went to a college in the nearest city and Maisie was considering going there as well. One of her friends who she went to the IDL centre with also attended this college and said that the dyslexia support there was really good. However, she would need to travel there and back every day on the train. Maisie did not anticipate any problems with this as she could travel there and back with her friends, but Maisie's Mum worried she might have problems. The course Maisie wanted to do was also offered at her school 6th form so she was looking into it. Maisie had not had any experience of paid work but was hoping to get a Saturday job in a supermarket. She said that this would have to be stacking the shelves as she is not good enough with money to work on the tills. Maisie has an aunt who lives in New Zealand and she is hoping to go there for an extended stay in the near future and is looking into working when she is out there but is not sure what she will do.

At the time of the second interview Maisie had just finished her first term in 6th form. She had decided to stay on at the 6th form in her school to study for the CACHE childcare course level 3 (which is equivalent to A levels). Maisie had done better than expected in her GCSEs. She passed 11 GCSEs in total but most of these were at grade D. She had got an E in Maths but said she was pleased to have got a grade at all. The subjects she got the best grades in were the ones which were based on continuous assessment rather than exams. She got Cs in childcare, ICT, science and resistant materials. This was despite science being one of the subjects Maisie said she struggled the most with. Part of the reason for this was that Maisie struggled with handwriting and found it easier to do work on the computer, as the IDL programme

that had helped her to read and write was computer based. Although Maisie had had a reader in her exams she did not have someone to write for her and she would have liked this.

While Maisie was enjoying her course and looking forward to her placement in the nursery of a local school, she was finding the written work hard. Her parents had bought her a laptop as a reward for doing well in her exams and she spent most evenings working on her computer to catch up on her coursework. Her learning support assistant still helped her for two hours a week with her written work in her free periods. It was clear that Maisie was putting a lot more effort into the course than would be expected for the average student and was determined to succeed. However, she seemed far from certain she would be able to pass. Although the course was mostly continuous assessment there was one exam, which she was dreading. *“It’s on child psychology. It’s meant to be really hard. Miss says that even good students, people who get As and Bs have failed it”*. It is worth noting that here Maisie identifies herself as not a good student and compares herself unfavourably to the other students on the course who got As and Bs.

Maisie hoped to get a job working with children once her course finished. However, the 6th form had recently had several talks about going to university and having realised that this was a possibility she was also looking into courses relating to childcare at university. This was a possibility she discussed at length asking me, as the interviewer, some questions about my time at university, my course, and the support available to students with dyspraxia. In the first interview, university had not been considered as a possibility as she was not sure she would achieve any GCSEs and she had clearly gained in confidence as a result of her achievements.

Through the course of the study we can see Maisie’s developing sense of herself as a student. Maisie has always tried hard at school as well as having extra lessons at the IDL centre. At the time of the first interview, she is far from certain that this will translate into exam success. Although she had learned to type as a compensatory skill to make up for her difficulties with handwriting, she was not able to use this in her exams. As it transpired, Maisie did better than expected in her exams achieving

good enough grades to progress on to the course of her choice. Although most of her results were below grade C, the official measure of exam success, she was still pleased with them as she had feared she would get an ungraded in Maths and was relieved to get an E. Benjamin (2002) would describe this as the “consolation discourse of success”. This discourse applies only to special needs students and compares their achievements to their past performance rather than normative goals. However, drawing on this discourse did not prevent Maisie from comparing herself unfavourably to a “good student” who got As and Bs.

Diagnosis and Labelling

As discussed in the literature review many commentators have been highly critical of the role diagnosis play in the lives of children with SEN, and argue that it is wrong to ‘label’ children. However, the experiences of the young people themselves suggest a more complicated picture. Whilst none of the children like being marked out as different they felt that this is something that would have happened to them anyway rather than being connected to diagnosis. The majority of the young people viewed their impairments as a fact of life and as such did not object to talking about them. For example Adam said:

“I don’t think there is anything wrong with people saying I have Asperger’s because I do have it. If people know then they can understand why sometimes I have difficulty with things”.

Ben felt that he would be ‘labelled’ whether or not he had a diagnosis:

“I don’t think that it (dyspraxia) is a bad thing to call anyone... you get called much worse things like oh he’s a spaz or you’re thick or stupid”.

Not everyone was aware what their diagnosis was. Callum was not sure what he was diagnosed with just that he had special needs.

The only young person in the study who rejected all diagnostic labels was Simon, who is diagnosed with autism and epilepsy: *“I’m just the same as everyone else”.* Although he is entitled to extra support at college Simon chooses not to take it and

manages well without it. Josh was diagnosed with dyslexia, ADHD and conduct disorder. Whilst he is happy to say he has dyslexia and ADHD neither Josh nor his mother accept that he has conduct disorder. Conduct Disorder is described in the diagnostic and statistical manual of mental disorders as a disorder where people's behaviour challenges the rights of others and social norms and is characterised by behaviour such as fighting, lying, stealing and cruelty to others and in adults it can develop into antisocial personality disorder, which is related to psychopathy. Josh says that his behaviour was only because of the circumstances where he couldn't cope with school and got in with a bad crowd of people and got into fights. He was also being bullied. He points out that since he has been getting help from his one to one teacher he has not been in any trouble at school.

"I don't have that problem anymore, now I have a teacher who explains everything crystal clear so I know what I'm doing now and where I'm supposed to be, so I find it easier and I'm a lot calmer and happier now."

Josh's mother felt that she had to accept this diagnosis in order for him to get a statement of Special Educational Needs so that Josh could get the extra help he needed at school.

India's attitude to her diagnosis of dyslexia changed over time. When she was at school she did not like it, as it meant she was classed as having special needs and she resented the low expectations associated with this. However, when she went to college she was happier to accept learning support from the college dyslexia service, as this was separate from her classes so did not mark her out as different. Her confidence was boosted by having been accepted on to the advanced rather than the intermediate diploma in art and design. By the time of her second interview India was studying for a degree in Graphic Design at art school. India was becoming more accepting of the fact that she had dyslexia and was reassured by the fact that she was managing to keep up with her friends on her course who had done A levels. She had recently watched a TV documentary on dyslexia featuring the actress Kara Tointon. India said that prior to watching this documentary she:

“...didn’t realise that dyslexia affected your organisation and stuff as well as your writing cos I’ve always had difficulty with stuff like that... and you know the help she got in the programme, well I’m going to see if I can get something like that from the uni”

Seeking out help from the university was a big change for India who had previously tried to hide her difficulties.

Exams

Exams and academic qualifications were central to the young people’s experiences of school. When it came to high school, the entire school curriculum was focused on working towards qualifications and this made it difficult for anyone who for whom this was not possible to be included in the life of the school. According to George’s mum:

“right up until high school – ‘till about year 10- most of the time he was in with everybody else but then everyone started doing their GCSEs and George didn’t do GCSEs so he then he was in just a little class, just 5 or 6 of them”

However, the rest of the young people in the sample did work towards a least some GCSEs. Students had to take GCSEs in English and Maths, and had the option of studying either GCSEs or a BTECH in science. Many of the young people in the study had chosen their options at GCSE level to avoid taking exams. Richard felt that whilst he did have a choice of subjects he still did not have the option to study anything he was actually good at.

“I picked them because they’re the best of a bad bunch really. I’m only good at practical things not writing and stuff and you even have to do writing in GCSE PE”

Fraser felt a similar way:

“There’s not really anything at school that I would say I was good at, except PE – so I just had to pick the ones I was least bad at”

As we have seen from the example of Liam in the case history, not everyone was able to complete the options they had chosen. If a student had fallen behind with their work and was no longer able to keep up or needed one to one tuition, the subjects the young people had chosen to study were the first to be dropped so they could focus on the compulsory subjects. Josh had wanted to take business studies at GCSE but as he had all of his lessons with his one to one teacher he was only able to study 5 GCSEs in English Language and Literature, Maths, Double Science and ICT.

Some of the young people felt that exams were not the best way for them to be assessed. India did not feel that the grades she got in her exams reflected her knowledge of the subject:

“...like in history. I knew all about the First World War and that but in the exams I didn’t know how to write it down and you had to give long answers and I didn’t know how to structure them. I got a D which doesn’t really count”.

Not everyone struggled with exams, Adam excelled in his GCSEs achieving 11 passes all at grades A-A* and B. However, prior to taking them he was extremely nervous as it was really important to him to do well. Like all of the other young people in the study, Adam was entitled to special arrangements in his exams to ensure he was not disadvantaged because of his disability and had 25% extra time and the use of a computer.

The young people were aware that, whilst GCSEs and vocational qualifications were meant to be of equal status, the reality was that GCSEs were more highly valued than their vocational equivalents. Sophie expressed the view that:

“I think I only passed the ones where you don’t have to do exams and everyone knows they’re not as good. I got art and ICT and childcare, I didn’t pass English or Maths or anything like that”

Conclusions:

The young people in the study had varying experiences of being included in mainstream school. Some felt they were 'just the same as anyone else' whilst others were marginalised and excluded from activities undertaken by their peers. However, in contrast to recent narratives which have been critical of inclusion which see the child's impairment as an insurmountable barrier to a child's inclusion in mainstream school (Warnock, 2005, Philips, 2005) the young people's experiences show that the main barriers are structural and attitudinal.

Having a TA with them in some or all lessons was a common experience of all of the young people in this study. This is in keeping with Blatchford et al's (2009) findings that individual support for pupils with SEN is generally provided by TAs rather than teachers. There was ambivalence about this among the young people in the study. While some young people valued having extra support there was concern that having a TA marked them out as different and prevented them from interacting with their peers.

For those who were not able to meet all of the demands of the academic curriculum there were limits to how far they could be included, as so much of the school day was taken up with preparing for exams. This meant that as the children moved through school, inclusion became harder to achieve. The young people were very aware of the normative markers of success which is considered to be 5 A*-C at GCSE and that often they did not measure up to them.

The next chapter will explore the young people's aspirations and the advice and support that they had in planning and for the future. It will also discuss the experiences that the older members of the sample have had since leaving school.

Aspirations for the Future

This chapter discusses the young people's aspirations for the future and the advice and guidance they have received when making their future plans. It also outlines the experiences that the older young people in the sample have had since leaving school. It contains two case histories. The first discusses the future plans of Adam, who was in year 11 at the time of the first interview, and the second follows Sophie, who was 19 at the time of the first interview, and her experience of further education and employment. This chapter draws predominantly on data from the young people's interviews with some reference to the parents interviews. However, the parents' experiences are discussed at much greater length in the next chapter. The concepts of 'biographical fields' and 'learning careers' to understand the young people's experiences and the choices they make.

'Biographical fields' is a concept developed by Holland et al,(2006). It is based on a holistic approach to understanding young people's transitions to adulthood and centres on the importance of 'competence' and gaining recognition for this competence to developing an adult identity. Holland et al (2006) argue that young people invest most in the areas of their life, or 'biographical fields' where they are most likely to develop competence and have this recognised. The 'biographical fields', that are available to young people depends on their social situation. Investment in one 'biographical field' is often matched with disinvestment or lack of investment in other areas of their lives.

Bloomer and Hodkinson's (2000, 2002) concept of 'learning careers' is helpful in understanding the young people's evolving sense of themselves as learners. In their longitudinal study of young people's experiences of further education they found that people's approaches to learning change and develop over time and students construct their experiences of learning through their interactions with their college. Although students have a range of dispositions towards learning, these change over time and a student's disposition towards their college course is also influenced by the experiences they bring from outside college as well. What both of these approaches have in common is that they look at how individual agency interacts with

structural constraints. As such, they are helpful ways of understanding people's choices.

Future Plans

The future plans of young people with a statement of Special Educational Needs are subject to more official scrutiny than those of other young people. Young people with SEN are legally entitled to have a transition plan. This is a plan outlining what the young person proposes to do when they leave school and is supposed to ensure that the support they require is put in place. It is drawn up when they are 14 and reviewed annually until they leave school. Young people with SEN who do not have a statement are supposed to have extra support from Connexions, although there is no official process to trigger this. During the course of the research, government funding was withdrawn from Connexions and it is now left up to local authorities to decide what advice and guidance services to provide. In the local authority where the research took place all of the staff who worked for Connexions were being kept in their post and incorporated into another department. However, in some other parts of the country there are no services at all. In the future this may create a 'postcode lottery' of support for young people.

Five of the 14 young people in the study had statements of SEN. Their experiences of the statutory support this conferred were mixed. Josh (whose case study features in the Parents chapter) did not have a transition plan, even though he had a Statement and had received little support in helping him prepare to leave school. Josh's statement was only put into place in year 10 which meant that he missed out on having a transition review, as these are normally held in year 9. By this time he was only attending school part time and as a result missed the mainstream careers advice and guidance his school had organised as part of the 'preparation for life programme'. However, Ben, who was in year 10 at the time of the first interview felt it was too early to make any plans. *"I know that I want to do something with computers but everything depends on your results so I can't say what I am going to do because I don't know what I am going to get and I'm not very good at exams."* Ben achieved good course work grades but had got poor grades in his recent mock

exams and thinking about the future with this uncertainty increased his anxiety. However, his mother found this planning helpful as she thought it was useful to know what all the options for Ben were. It is common for transition reviews to bring out young people's anxieties. The SENCO at Ben's school said that young people often worried about their transition reviews. Research by Dee (2005) found that transition was a time when many disabled young people had to face the possibility that their options for the future may be limited as a result of disability. Ben was concerned that his aspirations may not be possible for him and that is why he found transition planning difficult.

As Liam was currently being educated outside of school, his parents had been to many meetings to discuss the possibility of Liam returning to school. Liam's mother was not sure which of the many meetings she had attended was actually his transition review as: *"I'm in there all the time and we talk about what he's going to do all the time but they want him to stay on or go to college but if he doesn't go to school at the moment how can he do that"*. It is common for parents of young people with SEN to have to attend many different meetings and this can be confusing. Liam was determined to leave school at 16 and get a job and given his previous difficulties with school his parents felt that staying on was not a realistic option. As a result this disagreement between Liam and his family and the school transition planning was not found to be very helpful for Liam.

George's mum found transition planning helpful as the school helped him prepare for what he was going to do next. George had stayed on at school to study for a key skills course in conjunction with the local college. As there was not very many students on the course it had been tailored to their interests and George had achieved a level 1 qualification in IT (level 2 qualifications are GCSE or equivalent). However, she felt that *"the advice they give you is good but at the end of the day there are very little options available for someone like George, especially where we live"*. George was currently working part time on a supported employment scheme for people with learning difficulties.

For the young people in the study who did not have statements of SEN the formal advice and guidance they received was mainly from the mainstream service that was available to all young people. Most of the young people in the study had had careers appointments with a Connexions personal advisor. The school where the research took place had a system in which all the students in year 10 and 11 had a teacher who acted as their personal tutor. They had a session with their tutor each term to discuss their progress and explore options for careers and further education. This was part of an effort by the school to encourage everyone to go on to either further education or training. This system had only been in place for three years at the time of the research so some of the older young people in the study had not experienced it. Josh and Liam did not have a personal tutor as they were outside of mainstream school. However, Adam, (see case history below) who hoped to become the first person in his family to go to university really valued having this support. Many of the young people in the study said that informal guidance from family and friends was important in influencing their decisions. This is something that can be seen throughout this chapter.

Case History: Adam

For Adam the key biographical field is education. This makes him unusual amongst the sample as this was an area where most of the participants struggled. This case history is based on 2 interviews with Adam and 2 interviews with his mother. Adam was aged 15 and in year 11 at the time of the first interview and just about to sit his GCSEs. The second interview took place when Adam was 16 and in his second term of sixth form.

Adam lives with his Mum, Dad and younger brother. When he was at first school he was diagnosed with dyspraxia. He was given support from a physiotherapist and an occupational therapist who each devised a programme for him to work through with his classroom assistant. The aim of these programmes was to help him improve his coordination and practical skills such as holding a pencil, using scissors etc. Adam says *“I hated it at the time but I’m sort of grateful now”*. Adam does not remember

very much about his first school or middle school but says he thinks he was ok and has always enjoyed school.

When he was in year 7 at middle school, Adam was diagnosed with Asperger's Syndrome and Non Verbal Learning Disability. It took 2 years from Adam's first appointment with the doctor to getting a diagnosis. During this time, Adam's Mum felt that the school was very supportive. However, she felt that in retrospect if they had informed her about all of the difficulties Adam was having he may have got a diagnosis earlier. Adam has always been academically very able and the main difficulties he has are social, especially with anxiety.

When Adam came to move up to high school there were concerns about how he would cope. On the open day when families went to look at their new school before moving up, Adam was extremely distressed. He found it hard to deal with the number of people and the noise. Adam's Mum went to see the school's SENCO who arranged for Adam to have some support in preparation for starting High School. Adam was part of a small group of young people who were considered to need help bridging the gap between middle school and high school. He went several times with his teaching assistant at break times and lunch times to familiarise himself with the school. He then took part in activities as part of the group. Adam says that this support: *"really helped because I was a nervous wreck at the thought of moving up there and that really helped and I think because of that I've been pretty confident all the way through."* Adam's mum describes the type of support he currently has:

"...and I must admit that Mrs_ (SENCO)'s support has been really good. He's on school action plus but he's not stated or anything official. He gets help in his exams and spends break times and lunch times in (the learning support classroom) or before school and things. I don't think he's ever actually outside but Mrs _ is always there and he knows he can always go to her if he has any problems. Before he used to come home and say this is terrible and that is terrible but now he will go to Mrs _ more or the teaching assistants and say he's not happy about what's happened but at

least he speaks to them or if there is somebody in the classroom helping somebody else if he's getting agitated or something they will help him even though he's not on their programme."

At the time of the first interview, Adam was hoping to stay on into the school sixth form to study for A levels and then go on to University. He had recently attended a maths day school for gifted and talented pupils at a local university. Adam felt that going on this course was helpful for him in deciding whether or not to study 'A' level maths. One of his friends from school had also attended the day school but in a different subject. Adam had also been invited to attend a longer summer school at another university but he had turned it down as he did not feel confident enough to go away from home by himself.

At the time of the second interview Adam had settled in to the school 6th form having achieved excellent results in his GCSEs which were all at grades A*, A and B. This came as a relief as Adam had worried a great deal about the exams and put pressure on himself to do well. He was now studying A level Religious Education, History, Maths and English Literature. He was also one of the few top pupils in the school to study for the British Baccalaureate, which involved taking extra As levels in Critical thinking and General Studies and Writing an extended project. Adam's extended project was on teaching as he wants to be a teacher. He has been spending time in his old middle school doing classroom observations as research. Adam feels that he is coping well with his large workload. He is enjoying his work and although he is finding Maths much harder than any of the other subjects he finds the extra challenge rewarding. Adam is also mentoring GCSE students in Maths.

Adam is aware that to achieve his ambition to go to university he needs to become more independent. Shortly before the second interview he completed a residential 'taster week' at a university. This was an opportunity he had turned down the year before as he was worried about being away from home. Adam enjoyed the course, which gave him the opportunity to experience university level tutorials in English, Philosophy and Psychology and found that being away from home was not the problem he had anticipated. The week before the residential he went with his mum

to meet the course coordinator to explain the support he needs. Adam has also planned some day trips where he goes on the train by himself. He is keen to learn to cook because *“I can make toast and a pot noodle and that’s about it”*. His Dad who was a cook in the Royal Navy is going to teach him.

Adam will soon be old enough to learn to drive. This is something that he is keen to do but is not sure if he will be able to do it. Many people with dyspraxia have difficulty learning to drive. However, there are no restrictions to them doing so. Adam plans to have some lessons and see how he gets on.

Adam is currently researching universities that he might like to go to and planning open day visits. This is something he is doing mostly by himself with some advice from school as his parents do not feel that they know very much about university having both left school at 16. Adam’s school have informed him of the type of support available to disabled students at university and how to apply for disabled student’s allowance to fund this support. However, as the university summer school and taster session he attended had both provided him with what he needed in terms of support, he doesn’t anticipate any problems.

Adam’s Mum is very proud of everything he has achieved. She feels that if he gets the right support he will do well. She said *“In some ways Adam is very adult but in others he is quite vulnerable”*. The main difficulties Adam now has are with new situations or situations where something unexpected happens. It is clear that he has put a lot of hard work and determination into achieving his goals. The support he currently gets at school works well for him and he has done everything he can to prepare himself for university. In terms of a learning career, Adam has made use of taster courses to explore his interests in different areas to decide what he would like to study at university. However, his disposition to learning has remained the same throughout the period of the research with success in his exams merely confirming his approach.

It is clear that Adam’s positive experiences of school and his sense of himself as a good student have given him a sense of confidence. He draws on resources from this area of his life to help him develop an adult identity, as can be seen by his decisions

to mentor younger students with maths and choose teaching as the subject for his extended project. The main source of advice for his future options has been from his teachers. Adam's aspirations fit in neatly with those of his school which had embraced a lot of initiatives to get more young people into further and higher education. His aspirations to go to university have given him the motivation to be more independent and tackle his anxiety about new situations and leaving home.

However, Adam was unusual among the young people in the sample as he had such a neat fit between his own aspirations and those of the school. In contrast, Liam, whose aspiration to leave school as soon as possible and get a job ran counter to those of the school, the support he got during transition planning was not found to be helpful. His teachers encouraged him to stay on in education despite the fact that he was not allowed to return to mainstream school.

Employment

Five of the 14 young people in the study had experience of paid work. In the majority of cases this was in part time or temporary positions. Josh whose case history features in the parents chapter had just begun working in a holiday camp after dropping out of his 'A' level course. Fraser had worked for a year at a sports centre before starting his university course. Dylan was currently working part time in a supermarket. This was a job he had had since he was 16 and still at school. He had been offered full time hours but was happy working part time. He felt that his employers were understanding of his difficulties with organisation and that generally, *"it's an alright place to work"*. However, this had originally been his Saturday job when he was in sixth form. He had hoped to go to university and eventually have a better job so he was frustrated to still be there. India worked in a clothes shop at weekends and in the school and university holidays. Liam was paid to cut the grass on the farm he lived on and helped out there at weekends.

George was currently working part time in a supported employment scheme for people with learning difficulties. He had started going to the scheme as a work

experience placement when he was in 6th form. George hoped eventually to get a job working in a supermarket but his Mum felt that first he needed to become more confident in dealing with the public. George is happy doing what he is doing and has made friends through the scheme.

There was a sense among the young people in the study, and their parents, that while there were jobs they could do, these were more limited. Ben was looking for a Saturday job but felt that *“a lot of things people do, like working in a café or like MacDonal’d’s I would be crap at”* due to his difficulties with coordination. William’s mother felt that:

“a lot of what people see as being low skilled jobs, being a waiter, working in a call centre would just be impossible for William. You can imagine. He would spill soup on everyone; he won’t talk to people on the phone. But he’s really good at things other people find hard. He knows a lot about computers and like I said he’s writing a novel.”

The next case history follows the experience of Sophie who aspired to work with animals. At the time of the second interview she was about to start work as a veterinary nurse.

Case History: Sophie

Sophie grew up on a farm and has a strong sense of herself as being a *“natural with animals,”* especially horses. This love of animals was central to her biography, inspiring her career choice and giving her a sense of competence that she had struggled to achieve elsewhere. Sophie’s approach to learning has changed significantly throughout her ‘learning career’ from having a difficult start at school to being a confident college student. She was 19 at the time of the first interview and in her third year at college. She lives with her mum, who was also interviewed, and younger sister.

As a baby Sophie was slow to develop speech and motor skills. Her Mum was worried about this and brought up her concerns with her GP and health visitor. However, she felt that they were not taken seriously until Sophie started nursery at three years old and was obviously behind her peers. Sophie was referred to a speech and language therapist. As a result of this her first school were aware of her difficulties before she started school and help was put in place for her from the beginning. When she was five years old she was diagnosed with dyspraxia. At this point she also started seeing an occupational therapist and a physiotherapist. As a result of Sophie's early difficulties her mother had feared that she would never achieve independence.

Sophie says she has never enjoyed school *"I think when I was younger I struggled a lot but I don't really remember... it took me a long time to catch up with reading and writing and stuff"*. She was also bullied because of her difficulties with speech. Sophie's Mum felt that her school did their best for her but, given her circumstances, Sophie was always going to have a difficult time. In middle school Sophie remembers her class teacher being encouraging but she struggled more when she moved up to year 7 and had lots of different teachers, some of whom understood her difficulties better than others.

At high school Sophie had a slightly easier time, as she had made more friends. Sophie has a love of animals and is an accomplished horse woman having ridden from an early age and most of her friends share this interest. As her speech had improved she was no longer bullied. Sophie still found the academic side of school difficult but managed to get four Cs at GCSE which she was pleased with.

Sophie has always wanted to be a vet but realised that she was unlikely to achieve the grades needed and so decided to try and pursue an alternative career as a veterinary nurse. Sophie has done work experience in her local vets during the school holidays and so knew what this involved as a career. She has also taken care of animals all her life so she was sure that this was what she wanted to do. In order to become a veterinary nurse Sophie knew that she would need to go to agricultural college. Sophie sought the advice of her friends when considering her choice of

college course but did not recall seeing a careers advisor or asking the advice of her teachers. Some of her friends went to a local college and because of this she did not look at anywhere else. The college she wanted to go to involved an hour and a half bus trip each way. There was an option to board at the college during the week but Sophie said she did not feel ready to move away from home and was also used to getting up early in the morning as she lived on a farm. There was another college which would have been quicker for her to travel to and offered her course, but Sophie had not considered this option as she did not know anyone who went there. As most of Sophie's friends and family come from farming backgrounds she felt that they would "know best" about the right career choices for her.

The course she had originally wanted to do required five GCSE at A*- C, as, Sophie had narrowly missed these grades she enrolled on a 1 year Vet Care Assistant Level 2 course. (Level 2 courses are considered to be equivalent to GCSEs whereas level 3 courses are considered to be equivalent to 'A' level). This involved a considerable amount of hands on work with animals which she loved. Sophie had a work experience placement and the college had its own animal management centre. *"It's brilliant, they've got donkeys, wallabies, emus and you learn how to look after them and what to feed them"*. The college had some initial queries about her ability to perform injections due to the fact that she has dyspraxia, *"and I had to prove to them that I had done it before on work experience and on the farm and that or they wouldn't have let me do it"*. After overcoming this hurdle Sophie did well on the course. She then progressed on to the Vet Nursing Level 3 course that she had originally wanted to do. Her experience of working with a wide range of animals at the college had led her to choose a general rather than the equine specialist qualification she had originally considered. At the time of the first interview she was in the second year of this course.

Sophie felt it was important to learn to drive because as she lived in a very rural area it would give her much more independence. Having a driving licence would also be a real asset when looking for a job as a vet nurse. However, Sophie was unsure about whether or not she could legally learn to drive. When she was younger Sophie had suffered from seizures and had been told that people with epilepsy were not allowed

to drive. However, a friend from college who also had epilepsy was learning to drive and had sent a letter from her doctor when applying for her driving licence. Sophie had begun to investigate whether she would be considered eligible to learn to drive.

As a result of the problems Sophie has with her joints, she suffers from severe tiredness to the point where she almost collapses. This had caused her occasionally to have to take days off from college to recover, especially in the winter months when her joint problems are worse. At the time of the first interview Sophie was stressed about catching up with all of the work she had missed in time to complete her diploma, especially as she felt that she took longer to do the written work compared to other people on her course. Sophie was aware she could have learning support at college because she has dyspraxia but was reluctant to ask for any support because of her early experience when they had questioned her suitability for the course.

At the time of the second interview Sophie had successfully completed her college course and was qualified as a vet nurse. It had taken her a few months to find a job after graduating as none of the vet practices in her area were hiring but she had recently got a job in a practice near her old college. This job provided living accommodation so for the first time Sophie was going to live away from home. This made her one of the few people in the study to make the transition to living independently. Her boyfriend, who she had met at college, lived and worked on a farm that was not far away from where she was going to be living so she felt that this was an ideal situation. Sophie had found out that she was allowed to learn to drive as long as she reapplied for her driving licence every three years with a letter from her doctor stating that she had not had a seizure. She had not yet started to have driving lessons as when she was unemployed she could not afford to pay for them.

Sophie's sense of herself as being "*a natural with animals*" in particular her love of horses was central to her biography. It helped her to make friends after a difficult early start at school. The sense of confidence she drew from her years of working with animals was what helped her to persist with her veterinary nursing course despite all the difficulties she faced. Sophie lacked confidence with the academic

side of her course but because of her practical experience in caring for animals she felt that she would be a good vet nurse.

Sophie's early experiences of education were poor and she lacked confidence in her academic abilities. However, once starting college she was able to draw on her knowledge and experience of animal care. She found that as what she was learning was related to what she already knew it was much easier to understand.

"The reason I had to do the extra year was because I didn't get science at GCSE. So I was worried about that bit of the course cos there's a lot of science. But it's all related to animals so I knew a lot of it already, and I actually knew stuff that some of the other people didn't know. The only thing I found hard about my course was all the writing you have to do."

Science had been a subject Sophie had struggled with at school but as she had support from a TA in science lessons her new found success changed how she saw herself as a learner. She was confident that she would be "a good vet nurse". In this sense her college experience enabled Sophie to construct a new positive learning identity for herself. However, the fact that the college had questioned her ability to perform some of the requirements of the course because she had dyspraxia had prevented Sophie from learning in other areas. Although Sophie continued to struggle with writing she decided not to seek help with this from the college's learning support department because of this past experience. Despite this she managed to successfully complete her course.

Maisie and Richard had a similar experience to Sophie when they went on to further education in that their confidence in their academic ability was low but they felt they had good knowledge about the vocational aspect of their course.

Further Education

All of the young people in the study, with the exception of Liam, continued into further education or intended to do so. The majority of the young people stayed on to their school 6th form. This is possibly due to the school's rural location as the two nearest colleges were 40 minutes away by train or an hour and a half journey by bus.

One was in a different local authority which meant that students could only secure funding for their travel if the course they wanted to study was not available in the local authority where they lived. Choosing to stay local limited the young people's educational options, because due to its size, the school sixth form only offered a small number of courses. For those who did not achieve the five A*-C GCSEs required for A level or equivalent courses, options were limited even further.

This was the case for Simon, who had originally planned to study child care as his parents were foster carers and he enjoyed working with children. However, when he went to enrol on the course he realised he was going to be the only boy so decided to take business studies instead. Despite not having an interest in that area, it was the only other course offered by his sixth form that he had the requisite grades for. Simon often worried that the other pupils at his school would laugh at him and feared this would happen if he took "*a girls' course*". This gendered notion of what course was appropriate was expressed by other boys in the study. Support from his family was key to Simon finding a more appropriate course. After doing business studies for a year and not really enjoying it, Simon decided that he wanted to study music. He plays the guitar and the piano and wanted a practical rather than a theoretical course. Simon had passed his GNVQ in Business Studies which meant that more options were available to him as he met the entrance requirements for level 3 courses. As Simon's mother was a teacher she was well informed about the educational opportunities in the local area. She found a suitable course that was a mixture of performance and production and applied for a travel grant so that Simon could go to college and back on the train. Simon's older sister, who was now at university had also studied at this college. In this instance the knowledge and support of his family were crucial. Although the college provided specialist support for students with Autism, Simon chose not to engage with this service as he considered himself to be "*the same as anyone else*" and did not want to be made to feel different. This sense of being "*the same as anyone else*" was important to Simon as when he was at school some of the other pupils made fun of him. Simon does not like going out in his home town as he worried that he might meet someone he knows from school as he finds it difficult to work out whether people who come

up and speak to him are being friendly or not. However, he feels confident going out in the town where his college is and where his girlfriend lives. At college he has made friends on his course who share his interest in music.

Some of the young people who had struggled with exams and written work welcomed the opportunity to study a more practical vocational subject. For example, Ben hoped to do a vocational course in IT because *“the only lesson that I’m really good in is IT.”* India chose to study for a Diploma in Art as she felt that Art was the only subject she was good at *“and I went from being the one that struggled to being one of the best in the class”*. The subjects chosen by India and Ben were longstanding interests which they spent significant amounts of time on outside of school. As a result of this, they had many positive experiences (from outside of school) to bring to their courses.

Richard’s first choice would have been a joiner’s apprenticeship but as he had not managed to secure one by the time he left school, he decided to stay on to do a BTEC in Engineering. As he had not initially intended to stay on at school he had not given any consideration to the courses on offer. *“I basically went up to the school and said what can I do and it was Mr- said “you could do engineering” so that’s what I did”*. This worked out much better than he had expected. *“Originally I didn’t want to stay on at school but this is much better than normal school because you get to design things and make things: you still have to do a bit of writing though”*. All of the young people in the study who studied for a vocational course found that once they had an opportunity to focus on what they were good at, they were more successful than they had anticipated.

Dylan, who was one of the first young people with a statement to stay on to his school sixth form, had a difficult experience of further education. Dylan originally started studying for A levels in RE, History, Biology and Business Studies. He found Biology too difficult and dropped it after the first term. His mum felt that as Dylan was one of the first people in the 6th form with his level of difficulty, the school were not sure what support he needed. Dylan successfully completed his remaining 3 AS Levels but the school decided not to offer the full A Level in RE as not enough people

wanted to continue with it. As this was Dylan's best subject and he had hoped to study philosophy at university, this was a major setback. This only left Dylan with two subjects at A level which the head of sixth form said was not enough. He advised Dylan to choose a different set of A levels and start sixth form all over again. Dylan did this and achieved another 3 AS levels. However, these were his second choice subjects and his grades were not as good as for the previous set of AS Levels. When all of Dylan's friends went off to university and he was still struggling with his A levels, Dylan became very depressed. He dropped out of 6th form. At this point he said *"I was fed up with it all really"*. After dropping out of school Dylan started to receive treatment for depression and his support worker encouraged him to apply for an access to university course at a FE College. After a year of working part time in a supermarket he started an access course in social sciences. Although Dylan enjoyed this course and was successful, he was not sure if he did want to go to university. Bloomer and Hodkinson (2000) noted that people's learning careers are often influenced by factors that are outside their control. There are many instances of this in Dylan's case. The first barrier he faced was not getting appropriate learning support at the start of sixth form. The second was his RE course being discontinued. From this point on Dylan began to lose his confidence. Had he been able to continue with his RE course it is likely that he would have progressed to university with the rest of his friends. At the time of the second interview, Dylan had successfully completed his access course. However, he was now uncertain whether he would ever achieve his original aspiration to go to university. *"Well I could go now because I did well on my course but I'm not sure if it would be worth the hassle"*. He continues to work part time in the supermarket.

Once they entered further education the young people were able to choose whether or not they engaged with learning support, whereas, whilst they were at school this was not the case. Whether or not students accessed this support depended on how they saw themselves as learners. As we have seen, Simon chose not to access learning support because he did not consider himself to be different from anyone else and valued the fact that now he was at college he was treated the same as his peers. Sophie also chose not to have learning support at college as she did not want

to draw attention to the fact that she was disabled. This was based on the fact that previously her ability to perform certain aspects of the course had been questioned as a result of this. However, Adam did not feel that receiving learning support compromised his identity as a good student. When discussing the support available at university he said *“from talking to the woman at the summer school there are a lot of disabled people who go to university so I don’t think it would be a problem”*. The knowledge that support was there if he needed it gave him confidence. Most of the young people(everyone except for Simon and Sophie) were used to having some form of learning support and so did not question whether or not to continue receiving it.

Higher Education

Two of the young people in the study had entered Higher Education. India was studying for a degree in Graphic Design at Art School and Fraser was studying for an HND in Sports Development at university. This section explores their routes into higher education in more detail and looks at factors that helped or hindered them.

India did not feel that she had done well enough at school to stay on to the school sixth form. *“I wasn’t clever enough to do A levels and none of the other courses like childcare and that were things that I wanted to do”*. She decided to go to college to study for a National Diploma in Art and Design. This is a two year course that is equivalent to A levels which gives students a good grounding in all aspects of Art and Design. In contrast to school, India enjoyed college and felt for the first time that she was good at something. She enjoyed all aspects of her course, in particular the module on fashion drawing. She grew in confidence as she progressed through the course and although, before going to college, had never thought she was capable of going to university, she was encouraged by her tutors to apply. India also enjoyed the social aspects of college and the increased independence it gave her.

At the time of the first interview, India had been offered a place at University starting in September. She was surprised at how many Universities would consider her

application without A levels but *“because it’s Art it goes on your portfolio...so I worked really hard on my portfolio and I had to go to interviews and I was really nervous but I got offered a place at all of the places I applied to so that was really good”*. India applied for Disabled Students Allowance in order to access support at university. However, she needed a recent psychologist’s report as proof that she had dyslexia. She had to pay for this report herself. Her Mum had agreed to pay for this so she could get the help she needed but India found filling out all of the required forms stressful.

At the time of the second interview India had just finished her first term at university. She had achieved a distinction in her National Diploma. There were people on her course who had done A levels followed by an art foundation course which is a more traditional way of preparing for entry to an art degree. India had some initial worries that she would be at a disadvantage compared to them. However, she had got her first assignments back with good results. There was not a huge amount of written work on her course but extra support was available from the University’s dyslexia service. India also had a mentor: a post graduate-student who met with her once a week to help her organise her work. Fraser’s experience of higher education was less positive. He is a keen sportsman and hopes to become an outdoor activities instructor. He had started to study for A levels and found the course too difficult. His mother encouraged him to stay on until the end of the year and see how he did and said that if he didn’t like it then he could look for a job. Fraser persisted and achieved 3 AS levels with a C in PE as his best grade. After this he decided not to stay on at school. On results day, Fraser’s PE teacher who had initially doubted his ability to complete the course came up to him and congratulated him. This act meant a great deal to Fraser who felt that *“I could say that I left school having achieved something. I proved to them I could do it”*. As well as studying for his AS levels, Fraser had completed a community sports leader award. This led to Fraser getting a job at the local sports centre. In consequence, Fraser decided not to stay on and complete his A levels, instead choosing to work full time at the sports centre.

Whilst working at the sports centre, Fraser applied for courses that would train him to be an outdoor activities instructor. By the time of the second interview, Fraser had started an HND course in Sports Development at University. However, the course was not what he had hoped it would be. There was a lot more writing and theory

involved than he had expected and Fraser struggled with this side of the work so much so that he was considering leaving university. Fraser was aware that he could have some support from the university's dyslexia service but did not think it would help as he was too overwhelmed. Instead, he emailed his project to his mum who tried to help him but did not know anything about the topic. Fraser had started to look in to other ways of qualifying as an outdoor activities instructor, including work based training in case he did not pass his first year.

These two contrasting experiences highlight the importance of having the advice and support to choose an appropriate university course. India had sought the advice of her tutors at college who were knowledgeable about the different courses available and what they involved. The learning support department at her college advised India about the support available and how to apply for it. This was critical as India explains:

“Applying for it was really confusing. If at college... they hadn't helped me and said, like you're definitely entitled to this I wouldn't have bothered. Especially because my Mum had to pay for a report form a psychologist. It cost like £150. And that was to say that I am dyslexic. I had to have that even though I already knew so it was a bit of a rip off.”

The year India applied for university there were major problems with the application process for Disabled Students Allowance which meant that many students experienced severe delays in getting the equipment and support they needed, and, in many cases this was not in place in time for them starting university. In some cases students had to quit their courses (BBC News, 2010). Getting this put in place early and being informed about the process meant that India was able to avoid these difficulties. In India's case, her successful transition to higher education was facilitated by her positive experience of further education and the increased confidence this gave her as well as the support she received from her college with her application.

Fraser was much less well informed about applying for university and many of his problems stemmed from the fact that the course was not what he had expected it to be. He had hoped for a practical course and it was much more academically oriented. Fraser did not know anyone who worked as an outdoor activities instructor who he could talk about training and routes into this career. As Fraser left school after his AS levels, he missed out on the advice and guidance that he would have had in preparing for university had he stayed on an extra year. Fraser wishes that he had found out more about the vocational training as, in retrospect, it is something he feels that he would be better suited to. He admits that lack of planning was a problem *“I don’t really plan things through. I get an idea and I just do it and it doesn’t always work out”*.

Conclusions

The young people in the study had similar aspirations in terms of education and employment to other young people their age. However, they were not always sure if what they wanted was achievable and often faced barriers to realising their goals. This was demonstrated by the difficulties Dylan had in his school sixth form as they were unsure how to support him, due to the fact that he was one of their first disabled students. Having the right advice and guidance was critical to helping the young people make informed decisions about their future. They felt that they needed to be informed, not just about education and employment opportunities that were available but the support that would be available to them. At the moment, services providing this kind of advice to young people are being cut back (BBC News, 2011).

The young people’s attitude to learning and their sense of themselves as learners changed as they progressed through education. Whilst in some cases, previous negative experiences continued to have an adverse effect, moving into further education and a course of their choice gave some of the young people who had previously struggled an opportunity to focus on something they were good at. The previous experiences of learning that students brought to further and higher education courses did not just come from their time at school but from other

'informal learning' they had taken part in through their hobbies and interests. All of the young people in the study had something they felt they were good at and had gained some success in but for most of them this was something outside of school.

Parents' experiences

"You have to fight for your child"

This chapter will discuss the parents' experiences of having a child with SEN. The main section of the chapter uses data from the interviews with parents but the case histories draw upon data from both the young people and the parent's interviews. In most cases the parent interviewed was the child's mother. However, in three cases joint interviews were carried out with both their mum and dad (see table in methodology chapter for more information). I sought to find out from the parents much more information about the young people's earlier years and in keeping with a life history approach the chapter is structured in a roughly chronological order. The chapter will also discuss how the parents' perspectives are similar or different to that of the young people.

Early Indicators

One of the first things I asked all of the parents was when they first suspected that their child might have Special Educational Needs. Many of the parents were aware that their child had problems with their development before they started school and had worried about how they would cope. For example, Callum had health problems from birth. He spent the first three months in hospital with a tracheostomy tube. He was behind in terms of development when compared with other children his age and because of this, his parents knew that he was likely to need extra support when he started school. Simon's parents were concerned when he did not did not learn to talk.

"He got to about two and he still wasn't talking. He has an older brother and sister so we knew that he should have been able to by then"

Simon was referred to a speech therapist and when he had not learned to talk in sentences by the age of 4, he was diagnosed with autism. Because of this he attended a first school which had a special unit for pupils with moderate learning difficulties. Simon's mum and dad were not the only parents in the study whose concerns were first raised by comparing their child's development to their older children. Conversely, other parents said that while their child was, in retrospect, a late developer they had not been aware of this at the time as they had no other children to compare them to. This was the case with George's mother who first became concerned about George following the birth of his younger sister.

"I started to worry about him when he was about two... when his sister was born. Because even when she was a tiny baby she would look at you but George never had, he was just in his own little world."

She reported her concerns to both the health visitor and the family GP. However, she felt that no one really took her concerns seriously until George started nursery.

"When he was with other children the same age it was really obvious that he couldn't do the same things ... he wouldn't play with the other children or anything like that... that's when they sent him to be assessed"

Sophie's mother also felt that her early concerns were not taken seriously until Sophie started school and that she was just dismissed as a "neurotic mother".

"Then...when she started school she couldn't dress herself or talk properly and that, so they said it was because I was an over protective mother and I never let her do anything for herself so you can't win"

However, other parents reported that their child's difficulties only began to emerge when they started school. India's mum first had concerns when she started learning to read.

“They started sending reading books home and were meant to get her to read them but she couldn’t do it she would just guess the story you know, with the picture on the page...and she used to cry because she didn’t want to go to school”

According to the parents’ accounts, all of the young people in the sample had started to have significant difficulties by year 1 (age 5-6) of primary school. However, some young people had longer to wait before they started to receive additional support, and longer still to wait for a diagnosis of their difficulties. This time between expressing concerns about their child and having support put into place was a frustrating time for parents. Some of them felt it took too long for professionals to take their concerns seriously. For example, Ben’s Mum said:

“The first time I went in they just said “oh he’ll be fine you know. He’ll catch up.” But they never gave him any help to catch up and he just kept falling further and further behind and he hated school. When it got to the point when they said I think he does need some help he was really miserable.”

Assessment and Diagnosis:

It was clear that the parents had weighed up the consequences of diagnosis for their child. As we have seen above some parents actively pursued a diagnosis for their child as they had concerns about their development. In doing this they hoped to find out why their child was struggling and what could be done to help them. Cole (2004) argues that parents of disabled children are often blamed for their child’s difficulties, especially when their child has conditions such as autism and ADHD where the source of their difficulties is not immediately obvious. This was something that some of the parents who took part in this study had experienced.

“Before Sophie was diagnosed people would say why can’t she do this when everyone else can? As if I was a bad mother. Like when she was at nursery and she could hardly speak and she still wasn’t properly potty trained they said she should be able to do these

things at her age. And when the psychologist said that she had special needs they were much nicer about it."

Whilst for some the diagnosis helped to reduce the stigma, this was not the case for everyone. Both Josh and Liam were considered to have 'Emotional and Behavioural Difficulties' and their parents felt that they were blamed for their child's behaviour.

Parents reacted in different way to receiving the diagnosis. As Adam was not diagnosed with Asperger's Syndrome until he was 11, his parents saw the diagnosis as confirmation of what they already knew. At the suggestion of the educational psychologist Adam's mum had kept a diary of the difficulties Adam was having so there was enough evidence to base the assessment on. Ben's mother was unsure how to react to the diagnosis.

*"To be honest with you when they said he had dyspraxia I had never heard of it, so I didn't really know what to think...
Except, you know, are they going to give him some help now?
But then I did some reading about it and I thought, you know,
that does sound like Ben."*

Some parents weighed up the implications of pursuing a diagnosis for their child. For example Liam's mother was considering asking for him to be referred for an assessment for Asperger's syndrome.

"I think if he was diagnosed he would get more help and he might be able to get some counselling because at the moment he's really unhappy. But then again he's only got a few more months left of school and he wants to get a job and you don't know if it might count against him".

The diverse reactions of the parents to their child receiving a diagnosis are in contrast to the bereavement model which has traditionally been used to understand this issue (Freeman- Copley and Bodenstiener, 1987). This suggests that on finding out that their child is disabled, parents go through

the process of grieving for the healthy child that they expected to have. As the majority of young people in this study were not diagnosed until they started school or nursery their parents had already accepted them and parents saw diagnosis as being a way of getting their child the help they needed. Runswick Cole's (2009) research also found that parents have a diverse range of responses to their child's diagnosis and suggests that parents with 'hidden disabilities' such as autism, ADHD and dyspraxia, have more varied responses, as diagnosis tends to come later.

Parents were more likely to accept a diagnosis if they think it is an accurate description of their child's difficulties. This is in keeping with the findings of Riddell's (2007) study on dyslexia. As we shall see in more detail in the case history; neither Josh nor his mother felt that the diagnosis of oppositional defiance disorder was an accurate reflection of his difficulties. However, his mother felt that she had to accept this diagnosis in order to get him the support that he needed in school.

Some commentators (Connor, 1997) would see parents who seek a diagnosis for their child as being responsible for pathologizing their child or using the diagnosis as an excuse for their child's inadequacies or bad behaviour. However, this does not take into account the wider social pressures that cause parents to seek a diagnosis for their child. Although in some cases the parents were given a say in whether a particular diagnosis was appropriate for their child, none of them were able to choose if their child was considered to have SEN. This decision was made by the school. In light of this, many parents felt that their child was informally labelled as 'less able' or 'badly behaved'. The majority of young people in the study were classified as having SEN before receiving any medical diagnosis.

For all the parents the deciding factor in deciding whether or not to accept a diagnosis for their child was the fact that it would lead to their child getting the support that they needed. This is unsurprising given the way that the education system works. Children have to be classed as have SEN

in order to get provision put in place to include them in the school. A medical diagnosis is often necessary for them to get other forms of support they may need, such as speech therapy. In this sense the parent's attitude to diagnosis can be seen as pragmatic. Parents' reactions to diagnosis have been used as a test of which model of disability they subscribe to but it is more complicated than that. The social model of disability recognises that people have impairments but it argues that it is social factors which cause them to be disabled. The parents in this study were motivated to accept a medical diagnosis for their child as they believed it was necessary for them to get the support they needed to remove the social barriers they face. Parents were more likely to weigh up the options and be concerned about the potential impact of labelling. This can be seen in Liam's Mother's concerns about the impact of him being diagnosed with Asperger's. Their child's diagnosis (in several cases they had more than one) was a significant event in many of the parent's life stories. As we have seen in the first findings chapter, young people tended to accept their diagnosis as a fact of life and few recalled being diagnosed.

The following case history follows the experience of William. What is significant about this case history is the extent to which his mother, who is a teacher, was able to act as an advocate for her son.

Case History: William

William was 14 at the time of the first interviews. William's mother was also interviewed. Both William's parents were teachers. His Dad taught maths and his Mum was an SEN teacher. William was the first born child and he has a younger brother. His mum reported noticing that there was "*something not quite right*" with William at an early age. William was a floppy baby and when he learned to walk, he walked on his tip toes. However, it was not until William started school that he had any major problems.

“When he was in reception class he struggled a lot and his teacher kept saying that he was not able to access the curriculum I didn’t think that was right, it’s not that he’s not capable but she was a very inexperienced teacher”

As an experienced teacher herself William’s mother was in a good position to refute his class teacher’s views that he was not able to cope in a mainstream classroom and have her opinion taken seriously. When William was in year 1, help began to be put in place and he started to make good progress. When he was 7, William was referred to his local child and adolescent mental health service for assessment. He was diagnosed with Asperger’s syndrome and dyspraxia. At this point:

“...we had to decide whether or not to accept the diagnosis and we decided that if William did have a diagnosis it would be easier for him to get the help that he needs”

As a result of this diagnosis William was given a statement of SEN and started to receive more individual support at school.

When William was 12, his family moved to a new area as his Dad wanted to set up a new business. Whilst he and his brother enjoyed living in their new home in the country, it took William a while to adjust to his new school as he had started in year 8 which is the last year at middle school. He was also very behind in Maths. To help him catch up, his Dad sat with him every night and helped him with the maths he had missed. On his school prize day before going up to the high school William won the prize for being the most improved pupil in Maths.

Less than a year after moving to their new home, William’s Dad was diagnosed with cancer and died just 4 months later. The whole family were devastated by his loss but William was affected particularly badly. He started to self-harm and would howl loudly for hours. His mum was extremely concerned about him. He was referred to the local child and adolescent mental health service but did not receive an appointment for over a year by which time he had improved. In his interviews, William spoke about the death of his Dad and about how he had been depressed but

did not seem to connect the two he said *“I don’t really know why I felt so sad but it’s a bit better now”*. As people with autism have difficulty understanding emotions they often find it hard to work out why they feel the way they do, which can make difficult emotions hard to deal with (Nazeer, 2007). It is possible that this was the case with William.

Because of everything William had been through following the death of his Dad, his Mum felt that her main priority for William was for him to be happy.

“I know he’s capable of getting qualifications but he can go and do that at any point in his life. It’s more important for him to be settled at school and have friends and just be happy “

By the time of the second interview William was a lot more settled at school. He had made friends, most of whom also had SEN, and spent break times and lunch times playing computer games in the learning support classroom.

William said he was not really sure what he was going to do in the future but he would be interested in working with computers or being a writer. He was writing a fantasy novel set in medieval times. His mother felt that William could achieve anything that he wanted to but was concerned that he occasionally had doubts about whether he would be able to do any job. William expressed these doubts in his first interview:

“I’ll probably only be able to get a not very good job. Like working in Tesco or being a bin man.”

William was considering going to university but said it depended on his exam results. Apart from IT he is not sure what he wants to study in 6th form as he is not finding most of the other GCSE subjects he is studying for as interesting as he thought he would. William is clearly academically able but prefers to pursue his own interests than follow the curriculum for his GCSEs. He says that although he is writing a book he has no interest in reading books written by other people. William’s mum has just started to research the options and support that will be available to him once he leaves school as unlike school support she feels that this is an area she does not

know much about. She clearly feels that that organising support for William as an adult is her responsibility, although she stresses that it is up to him to decide what he wants to do.

Compared to most of the other parents in the sample, William's mum has a strikingly empowered approach to getting support for her son. She attributes this to her knowledge of the system gained from being a special needs teacher. In her interviews, William's mother came across as being quite timid and not as naturally assertive as some of the parents in the study. Since the death of her husband she has been without a support network as she knows few people in the area where she lives. Yet she was more successful in getting her views taken into account than Liam's mother who came across as much more assertive but felt that because of her efforts to advocate on behalf of her son she was seen as *"a problem mother"*.

Whilst William's mum felt that being a teacher meant that she was in a good position to help her son, Simon's Mum who was also a SEN teacher was not so sure that this had been beneficial.

"I think sometimes because I was able to give him a lot of help they didn't realise how bad he was"

Simon had attended the primary school that his mother worked in and was in the class she taught for children with moderate learning difficulties. Despite being diagnosed with autism he did not receive a statement of SEN.

Other parents felt less empowered to lobby for their children. Richard's mother had struggled when she was at school and lacked confidence when talking to Richard's teachers as a result of this.

Expertise:

As we have seen above, the extent to which the parents in the study felt that they were able to advocate for their child varied. However, most of the parents felt that they had grown in ability to advocate for their child over time. For example, George's mother said:

“ I know a lot more now than I did when George was first diagnosed, because you have to know how to work the system, people don’t just say your child’s autistic here’s all the help, you have to fight for it. Then once you leave school all the support disappears.”

The ‘expertise’ acquired by parents of children with SEN is being increasingly recognised. As part of the changes that have taken place in the last 20 years and the shift to the marketization of education, there has been an increasing focus on seeing parents as partners in their children’s education (Riddick, 2010). However, research by Hodge and Runswick-Cole (2008) has found that some professionals have a deficit model of parents and expect them to comply with their views and as a result of this some parents are wary of questioning professionals as they do not want to be seen as unreasonable or demanding.

Some parents in the study were members of support groups for parents of disabled children. Following Ben’s diagnosis with dyspraxia, his mother helped to found a local support group for parents of children with the condition.

“When Ben was diagnosed there was nothing out there and nobody seemed to know very much about dyspraxia. I mean I didn’t know very much but I know a lot more now from being in the group”.

Founding this group was clearly an empowering experience.

“We would have a lot of professionals come to the group to talk to the parents and after a while of running the group they started to see me as somebody who knows something.”

Some academics have suggested that members of support groups for parents of children with SEN are predominately middle class (Tomlinson, 2011). However, Ben’s mother and all of the other parents who were members of a support group were working class. This chimes with Riddick’s (2010) study on dyslexia which found that parents of all social class backgrounds were members of support groups and

organisations. Membership of a support group allowed parents to share expertise and learn from other parents in a similar situation to them. A good example of this is when Liam's mother was trying to organise some counselling for him.

"I had tried to go through the educational psychologist but they weren't taking any more referrals and there was going to be a long waiting list and he's going to be leaving school soon. One of the Mums at our support group, she used to be a teacher in a special school and she knows so much. She says that we would be quicker going through CAMHS or social services, so he's been referred to CAMHS and we are waiting for the appointment to come through."

Some of the parents and young people attended social activities such as swimming and day trips organised by support groups. The parents who were members of a support group appeared to be more knowledgeable about the system and their child's legal entitlements than those who were not. They also were also more likely to use the sort of language used by professionals. The strongest example of a parent as an expert is Josh and Dylan's mother, whose experience is discussed in more detail in the next case history.

Relationship with their child's school:

As discussed in the first findings chapter, three parents felt the need to move their child to another school because they felt that child was unhappy and their needs were not being met. Maisie's mother felt that because her daughter was quiet and well behaved in lessons that her difficulties, particularly with maths, were ignored.

As all of the participants in this study lived in a rural area, this affected the range of schools that were available to them. This meant that while they had a choice of first or middle schools, the high school was the only one in the area. The local special school catered for pupils with severe and profound multiple learning difficulties which meant that for most of the parents in the study it was not an option. George's mother had considered sending him to the local special school.

“When he first got his statement, when he was about 7, he had the option of going to the (local special school), and we went for a look around. And they did have much better facilities and things like that, but he would have been one of the most able ones there and we thought that might hold him back. But when all the other kids started doing their GCSEs and George was left out, I did think then would he be better off in special school, but (the school SENCO) has been ever so good, so I don’t know really”.

Some parents were very clear that if a special school place was available for their child they would have opted for it. For example Liam’s mother expressed the view: *“I don’t think that children with learning difficulties can be included in mainstream schools”.*

As well as affecting school choice, some parents felt that living in a rural area affected the specialist help available to their child.

Other family members with SEN:

I asked the parents if anyone else in the family had SEN or had experienced similar problems to their child. This is because there is some evidence that dyslexia, dyspraxia and autistic spectrum conditions have a hereditary element (Muter and Likierman, 2008). William’s mother said:

“I think both me and my husband have some of the traits that William has, like not making eye contact, but neither of us ever had enough difficulties for anyone to think it was a problem”

Some of the parents said that they themselves had had similar difficulties to their child but that when they were at school it had not been thought of in that way. For example Adam’s mum said:

“Well I think I probably have dyspraxia too but when I was at school it was called being thick”

“...my husband probably has dyslexia. He is still terrible at writing and spelling and I have to do all his paperwork.. But they didn't know what it was when he was at school so he has never been diagnosed or anything like that but all of the problems Fraser has he has too”

I asked these parents if they felt that the education their child was getting was better than the support they had received.

“I don't think I learned very much at school, it's all just a blur really. But definitely, Adam's getting a better education than I had”

Sophie's mother's comments suggest that as some parents of children with SEN also have similar difficulties this can create barriers to them getting the support their child needs.

“I'm not very good with reading and writing myself so it was quite hard to get Sophie all of the help she needs because there was a lot of paperwork and forms to fill in. When they tried to get her a statement, I never understood all the stuff they put in the reports and in the end she didn't get it”.

The next case history concerns the experiences of Josh whose two brothers both also have SEN. Josh's older brother Dylan also took part in the study.

Case History: Josh

Josh was 15 and in year 11 at school when he was first interviewed.

From an early age Josh had always been hyperactive and was sent for various assessments but his mum was told that his problems with attention could be due to

the fact that both his older and younger brothers had problems. He was late learning to talk and had speech therapy. Although he had had struggled at school from the beginning his Mum felt that the school were slow at putting any help in place.

"...he couldn't sit down to concentrate on anything for any length of time and he was really struggling with his literacy. We kept seeing the school and saying Joshua is really not making any progress: this was at (first school). We are doing all this work with him and he still isn't making any progress. We are reading with him every night but he doesn't know the words at all or the flashcards you do with them when they are small he never got them right at all. They said, 'well you know we can't do anything until he's two years behind'."

Josh's mum felt that due to this delay in getting support he never really caught up with reading. When Josh was diagnosed with dyslexia at around age 8 his parents requested a statement but this was turned down and he went through first school with only a small amount of extra help with reading. As he continued to struggle he was given easier and easier work. It was around this time that Josh's mother joined a support group for parents of disabled children. She became increasingly involved in this group, eventually taking over the running of it and became a member of the local parent carer and professional forum.

When Josh started at middle school his new teacher realised that apart from his problems with literacy, he was actually quite bright and he began to make progress. He had friends who helped him with his organisation, and would write his home work for him in his planner. In year 8 his parents made a renewed attempt to get him a statement before he started high school but after not hearing anything back discovered that the local authority had lost the paperwork. When Josh started high school the process started all over again, as Josh had to be at his new school for a set period of time before they could apply for a statement to prove that they were not able to meet his needs without one.

However, after the first couple of weeks at high school Josh began to struggle. His two friends who had helped him with his work were in a different class to him. Josh

started to have more asthma attacks and complained of feeling unwell. When his mother insisted that he went to school he started to deliberately misbehave in lessons he struggled with in order to be sent out. After only 8 weeks at his new school, Josh was involved in an accident. He fell down the stairs and broke both of his feet.

Following his accident Josh was only allowed to attend school for 2 hours a day as his teachers felt that he needed one to one support and there was not enough cover available for him to have it full time. As a result of this Josh had to have a statement. During his assessment for his statement he was diagnosed with oppositional defiance disorder. His statement was awarded on the grounds that he had emotional and behaviour difficulties rather than on grounds of his learning difficulties. His Mum reluctantly accepted this as *“it was the only way he could get one”*. She added:

“...if you look at Josh’s statement it makes quite horrendous reading he sounds like the devil incarnate”

The result of this statement was that Josh was only attending school for two hours a day with his one to one teacher. This meant that he had to drop many of the options subjects he had chosen to study for his GCSEs and educated separately from all of the other pupils.

“yeah they didn’t know how I’d react if I was in mainstream school. I prefer to just be by myself, I got bullied so just stayed inside with other friends who have disabilities”.

There was a positive side to this experience in that Josh got along really well with his one to one teacher and felt that he really understood how he learns. He was able to get through a lot of work in each session.

Josh planned to stay on to the school 6th form in order to study for A levels in Business Studies and Accounting, as in the future he hoped to set up his own business. The school SENCO had arranged for Josh to be able to have a reduced timetable so he could still have his one to one support. At the time of the first interview he had recently attended a taster session for A level Business Studies

which he had enjoyed and in spite of being the only person in the class not to have studied it at GCSE, answered most of the questions in the class discussion.

However, Josh's mum was concerned that this was not a realistic option for Josh as she felt that Josh was unlikely to have a career as an accountant. She was concerned that Josh did not have a realistic idea about the world of work.

Something which was not helped by the fact that Josh had missed his two weeks of work experience organised through the school due to his asthma and had not been able to take part in the programme of careers advice the other pupils in his year were studying as he did not attend any mainstream lessons. Josh's older brother Dylan had been one of the first pupils with a statement of SEN to stay on at the school 6th form and had not had a good experience.

At the time of the second interview, Josh had done well enough in his GCSEs to be able to stay on to study for A levels, which his mother felt that the school had not expected him to do. Josh had started his A level course but it had not worked out as he had hoped. His Accountancy course was only available as a night class at the local community centre and as a result of this; his one to one teacher was not allowed to attend without enrolling on the course. This meant that Josh was only studying for one AS level at school, but was still expected to attend full time, even though he only had 4 hours of lessons a week. Josh was discouraged by this. During the winter Josh missed a lot of school due to asthma. He was asked to leave due to his poor attendance.

After leaving school Josh went to the job centre to start looking for jobs but was told that as he was only 16 he was too young for the service and was referred instead to Connexions. Josh went there once a week for 3 months whilst he searched for a job. As no one at Connexions was aware of Josh's learning difficulties, all of the information they gave him on job hunting was in a written format and he struggled to read it all. At the time of the second interview, Josh had just started a new job working in a holiday camp. Despite his mother's concerns expressed in the first interview that the support Josh needs is not available in the work place he appeared to be coping well in his new job without any adjustments at all. As part of his job, Josh received 3 weeks of training in the classroom.

“The training we do for work is very similar to what we did at school but it’s OK because they don’t know about the problems that I had at school and no one calls you a chav or winds you up”

Although his new job mainly involved cleaning caravans and pays the minimum wage Josh is optimistic about his future prospects having talked to other people who started off in his role and progressed to higher level jobs at the holiday park. Josh said in his second interview that eventually he hoped to leave home but reflected that he was likely to be the only one of his brothers to do so.

Throughout both of her interviews, Josh’s mum emphasised that she had had to fight for the support that Josh received and that had he received the help he needed when he was younger he would not struggle as much now.

Like Liam, Josh’s behavioural problems tended to occur in situations when he was struggling with his work; particularly written work or in social situations where he was anxious.

It is worth comparing the experiences of Josh’s mother to those of William’s mother in the other case history. Although Josh’s mother had acquired considerable expertise through her support group and being an advocate for her own children, she was not as successful in securing the support for her children as parents who possessed more traditional ‘expertise’ by way of being professionals.

Differences in perspective between young people and parents

Parents tended to put much more emphasis on their child’s difficulties than they themselves did. Many parents also described their child as being ‘vulnerable’, a description none of the young people applied to themselves. The most extreme difference of opinion in this area was between Simon and his parents. Simon was diagnosed with autism and epilepsy. He did not consider himself to be disabled and emphasized throughout his interviews that he was “just the same as everybody else” and that he did not need any support. However, his parents felt that he had continuing difficulties. According to his mother:

“He gets upset if there are any changes to his routine; he always phones his girlfriend at 9.00 and if he can’t get through at 9.00 exactly he gets upset- he doesn’t have any flexibility. He won’t speak to anyone else on the phone”.

His father added:

“he still gets anxious in social situations. He doesn’t like going out in case someone speaks to him. He can’t work out if they are friendly or if, you know, they are going to make fun of him. I think most of the time they are being friendly but he doesn’t realise that”.

In spite of their differing views on Simon’s needs, Simon’s parents respected his opinions and accepted his decision not to receive learning support at college. *“For him to be able to say, ‘I’m not disabled’ and to be able to fit in with everyone else, that just shows how far he has come”.* In her PhD study of students with dyspraxia, Kirkby (2010), herself a mother of a grown up child with dyspraxia, argues that young people with neurological conditions tend to underestimate the difficulties they have and to get a full picture, it is important to ask the parents. However, this could also bear a different explanation. Earlier on in this chapter it was suggested that young people are more likely to accept their impairments as a fact of life. The difficulties the young people had were not particularly important to them. Martin (2008) suggests that young people with Asperger’s syndrome often exceed the expectations their parents had for them but due to the early difficulties they had, parents continue to worry about their child. This chimes with the experience of Sophie’s mother. *“When she was growing up, because she couldn’t speak, I never really imagined that she would ever leave home. So I’m not just being an over protective mother. I never thought she would be able to achieve as much as she has”.*

Leaving School

It is well documented in previous research that the period running up to the time when their child is due to leave school can be an anxious time for parents of children with SEN (Aston et al 2005, Dee, 2001). All of the parents in this research expressed concerns about what the future would hold for their child. Callum’s mother spoke of

the fact that she preferred not to think of the future. *“To be honest with you we haven’t made any plans for Callum. Hopefully he will be able to stay on at school a bit longer but we just take it one day at a time”*. For many of the parents this has been a concern for a long time. According to Simon’s father *“It was the first thing I thought when he was diagnosed, what’s going to happen to him when he grows up.”* Maisie’s mother said *“obviously, you do worry what’s going to happen to her when she leaves school. That was the big worry all along.”* Underlying this anxiety was an awareness of the fact that compared to other young people their child had few real options.

“I am really worried about what Ben is going to do when he leaves school and whether he will be able to get any kind of job. He wants to do computers but you need a lot of qualifications for that. I think Ben knows and that’s why he doesn’t really want to think about it.”

Parent’s involvement in decision making

The degree to which parents were involved in helping their child make decisions about the future varied significantly. However, all of the parents were a major influence on their child’s plans. As we have seen in the previous chapters, young people’s plans were subject to change and therefore decision making was often a messy process. Perhaps unsurprisingly, the parents who had the highest degree of involvement in this process were those who felt that their child was not likely to become fully independent. George’s mother made all of the decisions about what he was going to do on his behalf as she felt that this is something he would find difficult to do himself, but she received a lot of guidance on this from the school SENCO.

“George is not very good with the idea of things changing you know and if you asked him what he wanted, he would be like, ‘why can’t I stay at school?’ and there didn’t seem to be very many options for him. What I wanted was for him to gradually get used to the idea that, you know, things were going to change. He started going to (the supported

employment scheme) when he was in sixth form just one day a week to see if he liked it and he did so he kept going”.

George’s mother saw herself as her son’s long term carer and therefore responsible for securing his long term future. *“I think that long term, he’s going to stay here with me. I don’t think he’s every going to be able to live by himself”.*

Simon’s parents were also very much involved in helping him choose his college courses. They were originally keen for him to study for a childcare qualification as his father explained:

“We do respite care and Simon is really good with the kids who come and stay with us. They have autism and have similar problems to what Simon had when he was younger so he can relate to them. If he did the childcare qualification it would have been something he was good at that would have led to a job”

It is not clear from his interviews whether Simon was ever keen on the idea of studying childcare. However, as we have seen in the previous chapter Simon decided to enrol on a Business Studies course instead, without consulting his parents. He says that he changed his mind on the day he went to enrol on the course after finding out he would be the only boy. This was not something that his parents thought was an important consideration. It is possible that Simon was trying to assert himself when he disagreed with his parents. After completing this course he went on to study a music technology course that his mother had found for him.

Most of the parents were less directly involved in decision making for their child’s future. Their children were more able to assert their views on what they wanted to do and were likely to achieve more independence. Here, parents saw themselves as responsible for supporting their child to achieve their aspirations. This is best encapsulated by this quote from Maisie’s mother:

“She’s at the stage now where you can’t really do that much to help her. I mean you can talk to the school to make sure she is getting the help

she needs so she can do what she wants to do, but you can't do anything for her."

For some parents this involved supporting their child even if they were not completely convinced of their choices. As we have seen, Josh's mother supported him in his aim to study for A levels in Business Studies and Accountancy even though she was not sure if this was a realistic goal for him.

Richard had hoped to secure an apprenticeship for when he left school, something both of his parents had helped him with. However, when by September, he had not been able to get one, his mother made him go back to school. *"I don't think he was particularly keen go, but I told him he had to"*.

The parents of the young people who either went on to or were considering higher education had little involvement in helping their son or daughter choose their course or institution. They said the reason for this was that this was something that their child knew more about than they did. For example, India's mother said:

"I don't really know anything about graphic design. What she does at college goes over my head really".

This was echoed by Adam's mother:

"I'll probably go with him to look round the universities but like I said, I left school at 16 so I don't know about all the different courses like he does".

However, the young people felt that their parents had supported them a lot with the application process. Fraser's mother filled out his student loan application and accommodation forms for him as he had difficulty filling in forms. India's mother arranged her disabled students allowance for her. She paid for India to have a private dyslexia assessment as she needed one which had been carried out since she was 16 to prove her eligibility for support at university. However, when Fraser started to struggle with his HND course his mother felt that there was very little that she could do to help him.

Although all of the parents were involved to a significant degree in their children's plans for the future it is not clear to what extent this differed from young people without Special Educational Needs. Other research into young people's transitions has highlighted the fact that parents play an important role and are a key influence during this period for the majority of young people (Ball, et al 2000).

Conclusions

Although all the parents had suspected their child had difficulties before they had started school, finding out the cause of these difficulties and getting support put into place for their child was a slow process. Although parents expressed some concerns about the potential negative effects of 'labelling' their child they felt a medical diagnosis was necessary for their child to get the help they needed. Diagnosis was often an important point in the parent's narratives, which it rarely was in the young people's. Most parents knew little when their child was first diagnosed but had over the years developed considerable expertise about how to negotiate the support that their child needed. For some parents this was gained through involvement in a support group. The extent to which parents involved themselves in their child's future plans reflected the degree of independence they felt their child was likely to achieve. George's mother made all of the key decision for him. However, he was unusual in this amongst the sample. In most cases the young people were able to gain more independence and were able to assert their opinions. Most of the parents saw their role as providing support to their child to make sure they achieved their aspirations. All of the young people in the study felt that their parents were a key influence and source of support.

Discussion

This qualitative study has documented the experiences of 14 young people with Special Educational Needs as they move into adulthood. The purpose in undertaking this research was to find out about their experiences of school and future aspirations. I wanted to find out how well they were supported by the services in transition planning and if having a statement made a difference in the support they received.

At the time of writing (August, 2013) the policy context is in a state of flux and issues that are relevant to this research are constantly in the media. However, there comes a point where gathering information for a thesis has to stop in order to write it up and the discussion and conclusions at the close of this thesis were finalised in August 2013.

This chapter discusses the different transition pathways followed by the young people in this study. It sets them in the context of transitions followed by young people in general and other young people with special educational needs. It then goes on to discuss how the research has answered the original research questions It also looks at the social and economic background that the research took place against. Finally it explores the ways in which the experiences of the young people with SEN who took part in this study are the same as, or different to, those of other young people.

School Experiences

The young people's school experiences suggest that there are still significant barriers to their inclusion both academically and socially. The forms of learning support they received often separated them from other pupils within a mainstream environment. This ranged from having a few hours of support a week in class with a teaching assistant to having all lessons with a one to one teacher. There was a degree of ambivalence about this situation; while many found that having this support was a positive experience it also marked them out as different and reduced their

opportunities for interacting with other pupils. Sadly, some young people said that they did not want more opportunities to socialise with other young people in their year group as they preferred to stay with other pupils who had special needs because they worried about being bullied. When they reached further education the young people had the choice whether or not to receive learning support. Simon and Sophie chose not to do so as they did not want to be seen to be different. However the majority of the young people in the study chose to continue to have learning support and accepted it as normal.

The social side of school was clearly important to the young people in this study and some of them found it more difficult to cope with than the academic side. The school where this research was carried out allowed pupils to use the learning support classroom as a social space before school and at break times. Those who made use of this facility valued it. Several young people had reported experiencing bullying. For both Ben and Maisie this was so severe that their parents moved them to a different school.

The young people's experiences of diagnosis and labelling suggest a more complicated picture than much of the literature suggests. Whilst none of the young people liked being made to feel different, they felt this would have happened to them anyway due to the difficulties they had at school. Parents took a more pragmatic approach to the diagnosis than the young people. They saw it as necessary for their child to get the support they needed. This led some parents to accept diagnoses for their child that they were not sure about or in the case of Joshua's diagnosis of conduct disorder, strongly disagreed with.

From year 10 onwards working towards exams dominated the young people's time at school. For George, who was not entered for any GCSEs, this meant he was able to take part in very few mainstream classes. All of the other young people in the study did work towards at least some GCSEs; the majority of them had chosen vocational subjects or options which did not have exams as they felt that they would do better at them and be able to choose what they want to study. All the young people with the exception of Adam reported finding English and Maths difficult and welcomed

the opportunity to study a wider range of subjects. There is increasing pressure on schools to focus on traditional subjects and the government have reduced the number of vocational courses that can count as equivalent to GCSE in the league tables (Wolf, 2011).

Unlike previous studies all of the young people in this research attended mainstream schools. This is likely to have had a significant influence on the pathways they followed after the age of 16. Research by Casey, Davis, Kalambouka et al (2006) comparing the aspirations of young people age 15-16 with moderate learning difficulties and emotional and behavioural difficulties attending mainstream and special schools. It matched young people with similar needs to examine the effect of attending a mainstream or special school. This found that while young people in special school were more likely to aspire to continue with education post 16 they aspired to lower level courses than young people with similar needs in mainstream schools. The effect a school had on young people's aspirations was greater for special schools, with young people in special schools having similar aspirations despite differences in parental occupation. In mainstream school parental occupation had a stronger influence on young people's aspirations.

Transition Pathways:

As discussed in the literature review, young people are experiencing extended transitions – taking longer to achieve traditional markers of adulthood such as ; marriage, parenthood, and establishing an independent home, than was the case for previous generations (France, 2007). It was argued that education plays a significant role in that with young people from all social class backgrounds spending longer periods of time in education than at any time in the past (Furlong and Cartmel, 2007). In this context other markers of adult status have become more important (Henderson et al, 2006). Taking this into account, it is important to remember that the oldest participant in the study was 21, so this research only provides a snapshot of the transition process. However, bearing this in mind it is worth exploring the transition pathways followed by the young people in this study to identify any trends.

To put the experiences of the young people in this study into context we will draw upon data from the Youth Cohort Study and Longitudinal Study of Young People in England (DfE, 2011, b). These are two longitudinal studies that have been combined to create a larger data set with a sample size of 13,300. This shows that the most common main activity for young people at age 19 was education, accounting for 45% of young people, 37% of young people of this age are in employment, 4% are in government supported training and 14% are NEET. When the same young people were interviewed at age 16, 76% of them were in education, 12% were in employment, 7% were NEET and 5% in government supported training. 56% of those who were in education at 16 had continued on at 19 and 30% had moved into employment, 10% were now NEET and 3% were in training. Of those who gave employment as their main activity at 16, 69% were still in employment at 19 and 18% were NEET. The survey shows that of the 7% of young people who were NEET at 16, 49% of them were still NEET at 19. The percentage of young people who were NEET peaked at age 18 at 15%. This is possibly due to many people finishing further education at this age. By the age of 20 84% of the young people in the sample had achieved a level 2 qualification (see appendix 1 for qualification levels) and 60% were qualified to level 3, 40% of the sample were in higher education and a further 2% had applied to study at this level.

From this data it is possible to identify several main transition pathways. The first is for those who are heading towards higher education. The second is for young people to stay in further education until 17 or 18 and then enter employment (although some members of this group did end up NEET). A third smaller group entered work at 16. This group was likely to continue in work, with some experiencing periods of NEET but was unlikely to enter education (only 7% of those surveyed had moved from employment to education). Finally, there was a less secure pathway where young people experienced either prolonged or multiple periods of being NEET. It was relatively common for young people to experience a spell of being NEET 35% of young people in the study had done so. For the majority this took place between two activities, for example in between finishing education and starting work. However,

there was a smaller group who experienced more than one spell of being NEET. 8% experienced two spells of being NEET and 3% of young people were NEET for 3 or more periods. 11% of young people in the study were NEET for 12-23 months and 3% were NEET for longer than 24 months. Unsurprisingly young people who had been NEET for extended periods were less likely to have achieved qualifications than those who had never been out of education, employment or training. None of those who were NEET for more than 24 months had achieved 5 A*-C at GCSE including English and Maths this compares to 79% of young people who had never been NEET. While most of the young people who took part in this research are not yet 19 we can see that they represented in all of the first three pathways described above with some heading towards university some further education and some going out to work age 16. While Josh was NEET between dropping out of 6th form and starting work no one has yet been long term NEET. However, the majority were still in full time education at the time of the final interview the peak age for becoming NEET according to the Youth Cohort Study and the Longitudinal Study of Young People in England was 19. By this point many young people have finished education.

The most detailed study that focuses specifically on the transitions of young people with special educational needs was carried out by Alan Dyson and the Institute for Employment Studies (Aston et al 2004). As discussed in the literature review , it includes young people with the full spectrum of SEN. This found a wide range of experiences and trajectories taken by the participants. It identified two main transition pathways taken by the young people in the study. The first applies to those who are more obviously disabled such as those with sensory or physical impairments. These young people generally had a statement and attended a special school or had specialist provision in a mainstream school. They have received support from different agencies relating to their impairment. For this group there is a clear pathway of support. The main issues are wherever they will make genuine progression and whether their high levels of support will continue to be available into adulthood.

The second pathway relates to those whose needs are less obvious or well defined for example, those with social and emotional needs or less severe learning difficulties. This group were less likely to have a statement and more likely to have attended mainstream school. They have generally received a low level of statutory support and are more likely to have left education and entered the lower end of the labour market. Any support received by this group was likely to have come from mainstream systems, why the researchers suggested was not able to meet these young people's needs. There was also a third group of young people who fell between these two groups. These young people had special needs relating to learning difficulties, and or communication and interaction difficulties. These difficulties were often attributed to what the report's authors describe as 'contested impairments'. Some people in this group had statements and had had multi agency support and others had not. The transition pathways taken by this group are less well known and understood.

I chose to focus on young people with 'hidden disabilities' as they were likely to fall into the category of need that was less likely to trigger the support that they need. This means that most of my participants are likely to fall into the second and third categories. When we look in more detail at the pathways taken by the participants we can see that they do fit predominately into those categories. The only person who I felt fit into the first group or more traditional 'care' transition pathway was George. George had a statement when he was at school and his Mum had the option of sending him to special school. He was in sheltered employment for people with learning difficulties and seemed unlikely to be able to live independently.

The majority of my participants fit into the second pathway in that they have come from a mainstream school and the support they received came mostly from mainstream systems. This group included: Josh, Adam, Liam, Richard, Simon, Maisie, India, Sophie and Fraser. Some were well supported by the mainstream or had developed effective coping strategies. The person for whom this had worked best for was arguably Adam who, since this research was completed has achieved excellent A

level grades and gone on to study Maths at university. Like India, who was also at university studying art, he had a real aptitude for the subject he was studying a put in a lot of hard work to achieve success. Both only required a small amount of additional support whilst at Sixth Form College and university and their needs were easy to accommodate within the existing system.

Maisie and Sophie also managed to achieve success within the mainstream system; however they did so with considerable difficulty. They both struggled at school and had low confidence in their academic ability but had a more positive experience of vocational courses in sixth form. Much of the support Sophie had received came from informal systems, such as her family and friends as she was wary of drawing attention to her disability due to past negative experiences. Sophie had frequent absences from college due to illness her friends supported her by getting her notes and helping her catch up with the work she had missed. Maisie's parents had paid privately for her to have extra support with reading and writing at a dyslexia centre. Maisie herself chose vocational and course work based options at GCSE and in sixth form as it took her much longer to complete any written work. Both girls developed strategies to adapt themselves to school and college. However, they had continuing difficulties. Maisie still struggles with even basic maths and the health problems that Sophie experienced during school and college continue and still affect her now she is in work.

Josh and Liam had struggled to find a place within the mainstream, both dropped out of education aged 16 having attained few qualifications. At the time of their final interviews Liam was about to leave school without a job to go to and Josh had obtained seasonal employment on a caravan site after months of being NEET. Dyson et al (2004) expressed concern about these young people making an early entry to the bottom tier of labour market and the likelihood that this would lead to them being trapped in low skilled employment. The research found that young people who were considered to have emotional and behaviour difficulties were most likely to leave school at 16 for employment Both Josh and Liam were considered by their

school to have emotional and behaviour difficulties. Raising the age until which young people must participate in education or training to 18 is intended to improve the opportunities for young people and prevent them from being constrained to low paid jobs. However, as Josh and Liam's experiences show, for some young people remaining in school until the current leaving age of 16 is challenging in its self. Both boys had a statement and so were entitled to additional support in the form of a transition plan but this did not translate into good outcomes. Josh did not have a transition plan as he got his statement too late and Liam did not engage with his as he did not have a good relationship with school and did not want to go to college. Young people who are considered to have emotional and behaviour difficulties are more likely to become NEET (Middlesbrough Children and Young People's Team 2013). It is likely that when continuing in education or training to age 18 comes into force young people with emotional and behaviour difficulties will be more likely to 'drop out.' In the USA where it is expected that young people will remain in 'High School' until they are age 18 or 19 and achieve a high school diploma (Tomlinson, 2013) students considered to have an 'Emotional and or Behavioural Disability' are at increased risk of dropping out of high school (Ackerman 2006).

It is harder to place Ben, Callum and William into one of the three pathways as they had not yet left school when they had their final interview. However, as all three intended to go on to further education most likely a vocational course, they are also most likely to follow the second pathway of fitting into the mainstream. Ben had a statement so was likely to have more support.

Looking at the experiences of the young people who took part in this research, it appears that achieving success within mainstream systems of education and employment depended on how well the young people themselves were able to negotiate these systems, relying on informal support from family and friends. The support available to the young people was limited, especially for those who are not in education. A further barrier was that young people were not always willing to access the support they might be entitled to, as Sophie and Fraser's experiences

show. Their families were a strong influence to all the young people. It is worth considering this point in relation to the research carried out by Casey, Davis, Kalambouka et al (2006) which found that parental influence was stronger for young people with SEN who attended mainstream schools than it was for young people with similar needs who attended a special school. As discussed the chapter on parents, some parents are in a better position to help their children than others.

However, it is important to remember that transitions are not fixed or finished. Any research project can only follow someone for a certain period of time and the participants lives could change significantly after this. As discussed in the literature review, it is increasingly common for young people to experience non- linear transitions, for example moving between work and education, or moving back into the parental home after a period of living independently (see for example Wyn and Dwyer, 2001, Henderson et al, 2006, and Furlong and Cartmel, 2007). After I had completed all of the fieldwork for this research I had a chance meeting with Fraser in a supermarket. I asked him how he was and what he was doing now and he told me that he had quit university and was working as an instructor in an outdoor activities centre. He expressed relief that he was working in a job that he enjoyed rather than struggling with his degree course. I was not surprised that he had chosen this path as I had the impression during his second interview that he was likely to drop out of his degree. The fact that he had been able to secure a job in the field he was hoping for without a degree, highlights the fact that higher education was not the best option for Fraser who had always felt that any educational success he achieved was precarious. However, it shows that it is unwise to see people as being part of any fixed transition pathway.

Dylan, would best illustrate the third group of young people who fall between the 'care' and 'mainstream' pathways. He was diagnosed with autism and had a statement when he was at school and continued to receive support from mental health services as an adult as a result of depression. However, he had always attended a mainstream school right up until sixth form and had secured employment

in a supermarket although he only felt able to work part time. Both Dylan and his mother felt that he would have benefited from more support particularly in sixth form. He was one of the first pupils with autism to attend the mainstream schools he went to and his mother thought that because of this it they were not sure how to meet his needs especially as he was a high achieving student. The incidence of young people with diagnosed with autism is increasing with recent prevalence studies estimating that it affects 1% of the population (Baron Cohen et al 2009). Over half of pupils diagnosed with autism are educated in mainstream schools with 47 % being taught in mainstream classes and a further 11% in specialist provision within mainstream schools (DCSF, 2009). It is likely that young people in Dylan's situation who are in mainstream but needing more support are becoming more common.

There is a particular gap in support for adults with autism who as we have seen from the examples of Dylan and George do not fit neatly into the existing support services for learning difficulty and mental health. Research by the National Autistic Society found that at least 1 in every 3 adults with autism experience severe mental health problems due to lack of support and understanding (Rosenblatt, 2008, p3). Moves have been made to put more support in place to meet the specific needs of adults with autism but this is in the early stages. The Autism Act which was passed in 2009. It gave the Government a duty to produce a strategy for meeting the needs of adults with autism. It states that local authorities and the NHS have a statutory duty to provide autism training for all staff. However, this only applies to people with autism, there are no plans to put additional support in place for adults with other conditions such as ADHD who may have un-met needs.

The proposed Education, Health and Care Plans (EHCPs) which are set to replace statements of SEN will provide for young people's needs up to the age of 25. This should hopefully lead to an increased focus on the needs of adults with SEN. By February 2013 around 440 children and young people had received an EHCP as part of the trial 'pathfinder project 17% of them were aged 16-25 (DfE and DH, 2013). However, the government intends that a smaller proportion of young people will

have an EHCP than currently have a statement (Department for Education, 2011, B). This may mean that even fewer people with a 'hidden disability' are eligible for them than currently have a statement, so may not improve support in adulthood for this group.

Transition to what?

No matter how good the educational and social support young people with special educational needs receive, the extent to which they are included in adult life depends on other factors such as the state of the labour market or the level of care they are likely to receive.

Tomlinson's (2012) international study of how school leavers with 'learning difficulties' are treated in the labour market looked at the opportunities for education and employment for this group of young people in England, USA, Malta, Germany and Finland. In all of the countries studied, young people with SEN appear to be concentrated in lower status vocational courses and thus more likely to enter the lower tier of the labour market than the 'knowledge economy'. Finland, has the best educational outcomes for young people with SEN. Around a quarter of young people are considered to have SEN at some point during their schooling and they receive extra help from highly qualified teachers (special education teachers in Finland are required to undertake six years study and have a Master's degree) with the aim of minimising low attainment. Finland has topped the Programme for International Student Assessment (PISA) tests, which compare the educational achievements of 15 year old pupils, in reading maths and science in different countries four times, in 2001, 2003, 2006 and 2009. Sabel and colleagues (2010) point out that it is the bottom 20 % of those who took the test that out performed those in other countries, bringing Finland to the top of the table. This shows that educational failure is not inevitable for young people with SEN. However, even Finland has increasing youth unemployment following the global recession which

began in 2008. Tomlinson quotes statistics from the United Nations Office of Statistics that 20.5 per cent of young people age 15-24 in Finland are unemployed and argues that youth unemployment is a concern for government. However, Tomlinson does not make it clear if young people with SEN are more likely to be unemployed than other young people.

The example of Finland highlights that while good educational support for young people with SEN can improve their educational outcomes, the opportunities available to young people in the labour market are also important. Shalberg (2012) argues that Finland's success in achieving high educational outcomes for all young people should be seen in light of the fact that Finland is a highly equal society. In contrast, the fact that England has highly unequal educational outcomes for young people is a reflection of wider inequalities in society.

As discussed earlier the Youth Cohort Study and Longitudinal Study of Young People in England data shows that young people with low qualifications are more likely to become NEET. All of the young people in this study were aware of how hard it was to get a job if you did not have good qualifications. For example, Ben said: *"Everybody knows that you need really good qualifications to get a job so if you fail your exams it will be really hard"* Current strategies to reduce youth unemployment tend to focus on the deficits of the young people themselves, with the emphasis on improving qualifications and work related skills. However, while these strategies may be successful in helping some individuals secure employment, they do not increase the total number of jobs available. Many young people are currently doing jobs that they are 'overqualified' for. A study carried out by the Higher Education Careers Service Unit of 244,680 people who graduated in 2011 found that 61,395 were in non-graduate occupations (Redman et al 2012). Increasing levels of qualifications in the workforce does not in itself promote economic growth, Ha-Joon Chang (2011) argues that "the link between higher education and national productivity is tenuous and distorts the rest of the economy" (2011, p 188).

Not everyone will be able to achieve the increasingly high levels of qualifications deemed necessary or obtain paid employment. Some people, like George in this study will need continued support well into adulthood. The government does not appear to have a coherent strategy for this group. The new benefit Employment and Support Allowance, which is being phased in to replace Incapacity Benefit from 2008, is designed to reduce the number of people who are eligible (Newman, 2011). At the same time programmes to support disabled people in work such as Access to Work, which funds adaptations and support to help disabled people in employment, has significantly reduced the range of equipment it will fund. This has shifted the responsibility to employers to provide disabled staff with adaptations such as voice activation software (Ability Magazine, 2010). These moves reduce opportunities for those who may be able to work but would need some support, whilst at the same time restricting their access to welfare benefits.

Research Questions:

- What are their long term and short term aspirations for the future? – In terms of education, employment, home life, family life and relationships.

The young people who took part in this research had similar aspirations in all of these respects to other people their age. Some had definite careers in mind such as Richard who aspired to be a joiner or Sophie who successfully qualified as a veterinary nurse. However, most were still deciding what they wanted to do. They went through a similar process of exploring their identity and deciding who they want to be as other young people their age. This was why I drew on the theories of biographical fields (Holland et al 2006) and learning careers (Bloomer and Hodkinson, 2000) which come from the main stream literature on youth transitions, to understand this process. The main difference was that they often had more barriers to achieving these aspirations than other young people and they were often unsure about whether their goals were achievable. For example, Adam and Sophie wanted to learn to drive but were not sure if this would be possible for them as they have dyspraxia. Securing paid work was an important aspiration for all of the young people

in the study. Some had already achieved this but those who had not, were concerned about finding work in the future. Everyone in the study, with the exception of Liam, either went on into further education or aspired to do so. Most chose to study vocational courses. Some parents commented that their children had exceeded the expectations that they had for them, as due to the difficulties they had when they were younger they did not imagine them making as much progress as they had.

Dee's (2001) research into young people with SEN's experiences of leaving school found that young people with learning difficulties were given very little say in the decision making process with the views of parents and professionals being given greater weight. This was not the case for the young people in this research all of whom had a voice and exercised agency over their future. However, they often recognised that their options were limited. For example when Richard was unable to find a job after leaving school he realised that he had little option but to return to school.

- What are the young people and parent's experiences of services, in particular those involved in transition planning and how well do these services work together? - Does having a statement of Special Educational Needs make a difference to how well young people are supported by services when preparing to leave school?

The main requirement for support the young people and parents said they needed during transition planning was advice about their options and to signpost them towards the support they needed to put their plans into action. This worked well in linear transitions. For example India and Adam were given good advice about applying to university and how to access support for disabled students by their school and college. However, Fraser who applied to university from employment was unsure how to access support. This situation is exacerbated by the fact that the criteria and process of accessing support was different at school, college and university and in employment. This makes it more difficult for young people to organise the support they need.

Josh and Liam who were not included in mainstream lessons missed out on all of the careers advice and planning that other young people in their school took part in. Josh managed to miss out entirely on the formal transition planning service for young people with SEN and Liam had a very poor experience of it. Transition planning tended to focus heavily on education. The young people felt that they were strongly encouraged to continue even if this was not what they wanted. It was this pressure to go on to further education that caused Liam and his parents to disengage with the transition planning process. Preparation for employment did not feature as highly in the process as some young people and parents would have wished. George was the only young person to have a work placement organised as part of his transition plan and this was with a supported employment scheme. The professionals involved in transition planning were teachers and occasionally, an educational psychologist. Representatives from social services are sometimes involved in transition planning but none of the young people in this research had a social worker.

Five out of the fourteen young people in this study had a statement. They were Dylan, Josh, Liam, George and Ben. In comparison to the young people without statements who took part in the study these young people did have a higher need for continuing support when they left school. The young people with a statement of SEN had significantly more input from professionals than those without a statement. All of them had a transition plan, except for Josh who was not statemented until after the point in the process where one would normally be drawn up. However, their experiences of this were mixed. Parents were more likely to say they found transition planning helpful. Arguable having a transition plan worked out best for George as it arranged him the placement in the supported employment scheme where he still works. He was the only person in the study who was following the more traditional transition pathway for young people with SEN which involved support from specialist services. The other young people with statements required support to include them in mainstream further education and employment. Ben found the process of transition planning stressful as thinking about the future made him anxious. He hoped to study IT at college and get a job working with computers

but struggled with written work and feared he would not get the exam results he needed. Despite having a transition plan Dylan felt that he did not have enough support when he was studying for A levels at his school sixth form. Liam felt his desire to leave school at 16 and get a job was not taken seriously. In this case there was a difference between Liam and the professionals' idea of what constituted a 'good' outcome. Although young people are meant to have a say in transition planning the system is intended to promote what professionals consider to be a good outcomes such as continuing in education which might not always be what young people want.

Those without a statement had the same system of advice and support that all other young people preparing to leave school would have. The young people who were in year 10 and 11 at the time of the first interview had been part of a tutoring programme at their school. Each student in year 10 and 11 was allocated a teacher to be their personal tutor and they met up each term to discuss their progress and future options. The SEN code of practice (DfES, 2001) states that the Connexions Service has a responsibility towards pupils with SEN, but without a statement, who might require support with their transition. They should provide a needs and provision assessment for these young people. However, the young people in this study had had little contact with Connexions. Most reported having a meeting with a Connexions advisor but this was the standard careers appointment that all young people have. No one had the needs and provision assessment outlined in the code of practice. However, not everyone felt that they needed this extra support.

It is hard to tell if having a statement in itself led to a better outcome for young people. The process of transition planning is not particularly young person friendly. As a result of this none of the young people who had a transition plan felt they had been involved in the process. Some of the pilot projects for the new Education Health and Care Plans which will replace statements have involved young people in the process. For example, in Darlington, a 'young leaders group' made up of disabled young people age 14- 25 have been consulted on the service being set up in their

area and in Cornwall consultation events have been held for young people with learning disabilities (DfE and DH, 2013). The new reviews will also be person centred which should involve young people much more in the process. However, it is still too early to tell as the evaluation of the pilot projects has not been completed.

The Social Context of the Research:

Saldana (2003) argues that it is important for longitudinal qualitative research to be located in 'historical time'. By this, he means that researchers should be aware of the impact of change over time and alert to social trends which may influence the lives of the participants. The research took place at a difficult time for young people and many of the policies that have supported the young people in this research have been scrapped or had their funding seriously cut. Aim Higher, the organisation that encouraged widening participation in Higher Education which funded the summer schools that Adam attended has closed down. Educational Maintenance Allowance, which helped students from lower income families towards the costs of further education, has been abolished. Connexions which provided advice and guidance to young people and specific responsibilities towards 'vulnerable' young people including those with SEN, has largely been abolished. In some areas, elements of this service still remain but this is at the discretion of local authorities.

These cuts have taken place at a time of high unemployment for young people. At the time of writing, 1.02 million young people aged 16-25 are out of work (BBC News, 2011). This includes young people from all educational backgrounds. Young people with higher academic qualifications are more likely to be in employment than those who lack them, although they may be in jobs that they are 'overqualified' for. This has further disadvantaged young people with low qualifications as they are competing against people with more qualifications than them for the same job. However, whilst the economic crisis has exacerbated the situation, this is not a new phenomenon. In an article on the political economy of special education needs, Sally Tomlinson (1995) argued that up until the collapse of the youth labour market in the 1970s the majority of young people with learning difficulties found work on leaving

school. Now more people are competing for the same jobs, which means that higher qualifications are expected of them. It was structural changes to the economy and not a decline in the skills of young people which led to the decline in this type of work. However, vocational qualifications and training schemes were seen as the solution to this problem.

This is part of a wider trend towards 'credentialism', where academic qualifications have become increasingly important to getting a job. Many professions, such as nursing, now require a degree for entry when they did not in the past (Redman et al, 2012). Jobs which traditionally did not require any qualifications at all now do. This has resulted in there being very limited options for those who lack qualifications.

How comparable are young people's experiences

In many ways the experiences of transition of the young people in this study are very similar to those of young people in general. Previous research has highlighted the non-linear and often messy nature of young people's transitions (see for example, Ball 2000, Henderson et al 2006). At this stage in their life young people are exploring their identity and trying out different possibilities and it is common for events to proceed in unpredictable ways. This was equally true for the young people in the study. It is best illustrated by the learning career of Simon, who went to register for a childcare course in his school sixth form and decided to enrol instead on a Business Studies course when he realised that he would be the only boy studying childcare. He later went on to an FE college to study music production.

The main difference between the experiences of the young people in this study and the findings of more general transition studies is that young people with Special Educational Needs tend to have more limited options and may face greater barriers in achieving their aspirations. For example, some young people expressed concerns that they might be limited in the type of work they were able to do or that they might not be able to achieve any qualifications. The extent to which this was the case

varied considerably depending on the young people's characteristics and circumstances.

In the 'Inventing Adulthoods' study, the participants were encouraged to reflect on possible future selves by constructing 'life lines' discussing what will be going on in different areas of their lives in 5, 10, 25 and 25 years' time (Holland et al 2006). I tried to build this into the methodology for this research but it was not a success. Many of the young people were reluctant to think more than two years into the future and 'life lines' are intended to explore much longer term plans. As a result this research has not explored imagined futures as much as other longitudinal qualitative studies.

There is an assumption that parents of young people with SEN have much more influence over the transition process than parents would in other circumstances. However, Hodkinson et al (1996) and Ball et al (2000) have both argued that the level of involvement of families and their influence on young people's plans is much more significant than researchers have previously given credit for and there are very few situations where the family's role is not significant. For young people with SEN and their parents it is likely only to be a difference of degree. The level of involvement of the parents in this study varied significantly. George's mother, in conjunction with the school SENCO, planned what he would do when he left school and he went along with this decision. The options available to George were very limited and his mother felt there was little choice for him other than the sheltered employment scheme which he was involved with. India's mother was much less involved in her decisions as she felt that she did not know enough about art courses to be any use to her. However, she provided her with support in other ways. There were huge differences in India and George's situations and the level of independence they were likely to gain. George's mother saw herself as her son's life long carer and felt that he was unlikely to leave home. Sophie's mother was aware that her daughter was capable of making her own decisions but admitted she found it hard not to be involved.

“When she was younger I didn’t think she would be able to leave home, or not so soon anyways, so now she’s going it is hard to get used to”.

The research was carried out in a rural area. A relatively small proportion of the population live in rural communities so the experiences of the participants will not be typical of the experiences of young people in general. However, the experiences of young people in rural areas are not as well documented as those who live in urban communities. I am not aware of any research on the experiences of young people with SEN in a rural area so this will be an addition to the literature. Growing up in a rural area has clearly shaped the opportunities the young people had and influenced their aspirations. Liam and Sophie, who both grew up on farms, aspired to careers related to agriculture. As the participants in this study lived a long travelling distance away from the nearest FE College this was an influence on their decisions on the kind of course they wanted to study. There was a more limited range of career opportunities locally and not everyone felt ready to move away from the area or would be able to drive to travel to more opportunities. Many parents felt that living in a rural area made it more difficult for their child to access specialist services as they lived too far away. It is possible that had some of these young people lived in an area with more facilities they may not have gone to mainstream school. The town and its surrounding area where the research took place, was served by a special school for pupils with severe and profound and multiple learning difficulties and all other pupils went to the local secondary school.

Conclusions:

The majority of young people in this research were following mainstream transition pathways with only one following a ‘care’ pathway more traditionally associated with young people with SEN. Everyone else attempted to fit into mainstream education and employment with limited support. This fits in with what previous research has found about young people with less obvious impairments (Aston et al 2004). The young people who this worked out well for were those who were well suited to the course that they had chosen and well behaved. They needed relatively few

adaptations to include them in the mainstream. There were limited options for those who did not want to continue with education after 16. Those with emotional or behaviour difficulties or social difficulties had difficulty fitting in with the mainstream. Due to their behaviour problems they often had a high level of support at school. However, there was a lack of support for this group post 16 as they did not fit in with existing adult services for people with learning difficulties or mental health problems.

This research took place during a recession, a time of poor prospects for young people but where those with the fewest qualifications were particularly disadvantaged. This had an impact on the young people who took part in this study. The participants went through a similar process of exploring their identity and future possibilities as other young people their age but were aware of more limitations on them. In common with other young people, parents were a crucial support and influence.

This chapter has discussed the transition pathways followed by the young people in the research and related this back to the findings of previous research. It has outlined how the original research questions had been answered. It has located the research in historical context (Saldana, 2003) and outlined the policy changes that have taken place during the course of the research. Finally it explored how representative the participants of the study are as young people in general.

The next chapter will evaluate the strengths and weaknesses of the research, including the methodology used and the sample. It will discuss the implications the findings of this research have for policy and practice.

Conclusions

This chapter will discuss the strengths and weakness of the research, evaluating the methodology used and the sample. It will outline the policy recommendations suggested by the findings of this research. Finally it will explore the implications of this for the proposed changes to the SEN system.

Benefits of a life history approach:

A key strength of the research is that it adopted a life history approach. This made it possible to see young people's transitions within the wider context of their lives, taking into account their past experiences and other issues that are going on at the time. This wider focus avoids seeing the young people in the study solely in terms of disability which is something I was keen to avoid in this research. Dee (2005) argues that adopting a life history approach to understanding young people's transitions to adulthood is particularly beneficial to understanding the experiences of young people with SEN.

“ Not only do they address many of the dilemmas faced by professionals working in special education by proposing a much broader notion of career which is thus more inclusive, but these ideas also provide a much clearer rationale for careers education and guidance in the school environment. They also help us see that the so-called unrealistic ideas of many young people with learning difficulties and/ or disabilities are part of a natural process of exploration which may take longer for some than for others, as young people come to terms with their own strengths needs and interests (Dee 2005, p223).”

A life history approach was also helpful in understanding why a form of support was seen positively by one person and negatively by another. For example I did not realise that Liam and Josh had the same one to one teacher until the second interview

because they presented such different accounts of him I did not connect them as being the same person. Josh described moving from being in mainstream lessons to having a one to one teacher as follows: *"...now I have a teacher who explains everything crystal clear so I know what I'm doing now and where I'm supposed to be so I find it easier and I'm a lot calmer and happier now."* Whereas Liam said; *"It's worse now (than it was when he was in mainstream lessons) because I'm by myself now with the teacher and he's always on my back"*. Liam and Josh's differing experiences are understandable when you look at them in the context of their previous educational experiences. As Josh did not have a statement until he was in year 10 he had not had a lot of individual support up until this point and welcomed being taught in a way he could understand. Liam had had a teaching assistant with him in most lessons throughout his whole time at school and had always resented this. While Josh was still in school for his one to one lessons and could see his friends at break times, Liam was out of school completely and as he lived on a farm in an isolated location had few opportunities for seeing his friends out of school.

This research also used Holland et al's (2006) idea of "biographical fields" (p13) to understand why young people invested in the areas of their life that they did. This stems from the idea that young people invest the most in the areas of their life where they can gain a sense of competence and have this competence recognised by others. Investment in one "biographical field" tends to be matched by less investment in other areas. The different biographical fields that are available depend on the young person's social situation and the likelihood of gaining recognition. The young people in this study had a more restricted range of biographical fields available to them and many felt that they had reduced opportunities compared to other young people in education and employment. As a result of this, it was harder to establish a sense of competence. For the majority of the young people this sense of competence came from an area outside of school. Another key theory used in the research was Bloomer and Hodkinson's (2000) concept of learning careers. This also made use of the life history element as it explores how peoples dispositions to learning change over time as their situations change.

As the research is longitudinal it is able to capture change over time rather than just capturing a snapshot. In this research I was able to follow the young people over a period of 9 months to a year at a critical time in their lives. This included transitions into employment, and into college or university. For some of the young people the plans they had at the first interview had not worked out and they had to try something else. Josh had intended to stay on at his school 6th form, despite his difficult early experiences at that school. However, this did not work out as he had hoped and he dropped out and was for a time, NEET and not old enough for unemployment services. At the time of the second interview he had just started work in a holiday camp. Richard also had to reassess his options during the course of the research. He had originally intended to leave school at 16 and get a job. At his first interview he said:

“At the moment I’m trying to get an apprenticeship. I want to be a joiner but anything like that really I’d be happy to do. I don’t want to stay on at school. I’m a practical person not a book person.”

However, Richard was unsuccessful in getting a job so he did go back to school.

“I really didn’t want to come back (to school) but I couldn’t get anything not even stacking shelves in Morrisons and Mum said you’re not doing nothing, just sitting around the house. But it’s not that bad. I like my course. So originally I didn’t want to stay on at school but this is much better than normal school because you get to design things and make things. You still have to do a bit of writing though.”

We can see how Richard’s disposition to learning changed throughout the study. When he was at school he had an instrumental attitude to work *“I just do enough work so that I don’t get into trouble with the teachers”*. However, in his second interview once he started sixth form he described his project work with enthusiasm. *“We just started this module of welding so we spend a lot of time in the workshop at the moment. We’ve just done engineering drawing and I did CAD which is when you draw something on the computer”*. Richard’s antipathy to written work remained, but this was a less significant part of his course.

For those young people whose plans had worked out, there was a considerable growth in their confidence between the first and second interviews. For example at the first interview India was worried about how she would be able to cope at university.

“I am a bit worried because there will be a lot of the people on the course who have A levels and they’ll know a lot more than me. Because it’s not just art, there’s a lot of other coursework so it might be obvious that I’m not as clever as them. I still don’t know yet if I’m going to be able to get help like I do at college because I have to have a report that says I have dyslexia and I don’t have one.”

However, these fears turned out to be unfounded. By the time of her second interview India was progressing well on her course.

“I think on the practical side I was actually better prepared than other people because not everyone has done technical drawing and stuff so I didn’t need to worry about not knowing enough.”

Another benefit of having repeat interviews is there is an opportunity to develop more of a relationship with the participants. In many cases I obtained richer data at the second interview. There was time to reflect on how the interview could have been improved and I listen to the first interview recordings again before the second interview. By doing this I came to understand the nuances of the young person’s communication better. For example, although my first interview with Adam went well, I felt that there were certain issues that could have been explored in more detail. When I got home I listened to the recording of the interview again and realised that I could have phrased some of the questions better. Before the second interview I considered carefully how the questions could be rephrased. At the second interview I felt that I had developed a rapport with Adam and he gave much fuller answers. Adam said afterwards that he was much more relaxed about the second interview than he was about the first as he knew what to expect and the sort of questions I was going to ask.

Another key element of longitudinal qualitative research is that it analyses how the passing of time interacts with the data and how the research is located historically (Saldana, 2003). The last chapter discussed in more detail the significant economic changes that have occurred over the period of the study and the impact this has had on the young people's employment prospects and access to services. These changes, in varying ways, have had an impact on the participant's biographies.

Limitations of the study:

Most longitudinal qualitative research follows the participants for a much longer period of time than was possible in this study. Saldana (2003) argues that there is no consensus as to how long a study needs to be to be longitudinal. However, he suggests that in educational settings, studies need to take place over a minimum of 9 months to capture change over time. In this study the participants were followed for between 9 and 11 months, making it a short study in longitudinal terms but probably the maximum that could be achieved in a doctoral study. Studies into transitions to adulthood tend to take place over much longer time periods, for example the *Inventing Adulthood* research followed the young people over a period of 10 years (Henderson et al, 2006). In an attempt to remedy this, two age cohorts of young people were included, a younger group aged between 14 and 16 and an older group aged 18- 21 . This made it possible to include a broader mix of experiences of transition.

The Sample:

Fourteen young people and either one of both parents agreed to be interviewed for this study, of these, thirteen sets of young people and parents agreed to take part in a second interview. This was a much higher proportion than I had expected as this kind of study usually has much higher attrition rates. This generated 52 interviews in

total (not counting those with professionals) and provided rich data to draw upon in the case histories. Possible reasons for this low attrition rate are the fact that the participants had to opt in to the research so those who agreed to take part were more committed to the research. All of the participants were aware that I had dyspraxia and had similar experiences to them.

Including both young people and parents' perspectives gave a more detailed picture of the young people's transition to adulthood. The views of young people with a learning or communication disability, which some of the participants had, are underrepresented in research. Parents are not only a major influence on their children's decisions but the school leaving period can also be an anxious time for them too. Parents also tended to provide more information than the young people about the early years at school and the support their child received. Young people and their parents emphasised different issues in their interviews, this provided a picture of the similarities and differences in their priorities. The data from the parents and young people was given equal weight. Any difference in opinion between young people and parents was seen as a difference of perspective rather than one being right and one being wrong.

Generalising from a case:

As this research is qualitative in nature and based around a small number of case histories, all of whom attended the same school, it cannot make claims to be representative of the population. Stake (2009) argues that while you cannot generalise from a case study in the traditional sense, case studies as a way of presenting information are more in harmony with the readers' experience and therefore "a natural basis for generalisation". Readers will decide for themselves what generalisations they can draw from a case study depending on the similarity between the case and their own area of interest. In line with this, it is important to give the reader as much information about the case as possible so that they can judge for themselves how relevant it is. I feel that I have done this as I have carried

out repeat in depth interviews with young people, their parents and their school so the data is triangulated. As longitudinal qualitative methods have been used by other studies into young people's transitions to adulthood it makes it easier to compare the findings of this research to those of other studies.

Implications for policy and practice:

Earlier in this study I outlined the legislative and policy context to the research and underlined that this was an area that is undergoing significant changes. I will now return to this to draw together the practical implications of the research. In doing so I would like to focus particularly on support in schools, careers advice and guidance, further and higher education and employment.

- There needs to be more focus within schools on social inclusion of young people with SEN.

The young people in this study had, to varying degrees; received forms of 'special education' separated them within the mainstream, such as having a TA or being in a special unit. While many of them valued the support that they received, it often meant that they had fewer opportunities for interacting with their peers. Many of the young people had experienced social isolation and bullying. Several also reported missing out on activities such as school trips or clubs. There needs to be more emphasis on supporting young people's inclusion in the social side of school. As many young people with SEN spend a significant amount of their time at school with a teaching assistant, teaching assistants should receive training on supporting social inclusion.

Inclusion in mainstream schools is a difficult balance to achieve. A placement in a mainstream school can represent the best and worst of possible worlds. In the best case scenario a child would have the same educational and social opportunities as other children without special needs whilst still receiving any specialist support that they might need. Some of the young people in the study, most notably Adam, did feel that they had achieved this. A worst case scenario would see a child missing out on the opportunities enjoyed by other children in their mainstream school but not

receiving the specialist support they need. We have seen that some of the young people had been in this situation. Liam's mother expressed the view that she felt her son would have been better off in a special school. The majority of young people in this study felt they were somewhere in between these two positions. The parents in this study had differing views on inclusion but what they had in common was that they wanted their child to be in a place where they felt they belonged and were accepted. It would perhaps be more helpful to think of inclusion in its broadest sense, in promoting full participation rather than focusing on the type of school placement, which policy makers have tended to do.

- Pupils need to be able to study a curriculum that is suited to their needs and abilities. This means, they should have the opportunity to study academic and vocational subjects.

As pupils move through school, the demands of the curriculum make it more difficult for young people with SEN to be included in mainstream lessons. This is particularly significant towards the end of secondary school when the curriculum becomes more focused towards exams. Having a broad curriculum where students are able to choose from a range of academic and vocational subjects at GCSE, with a range of different methods of assessment, helps promote inclusion. However, education policy is currently moving in the opposite direction with an increased emphasis on pupils passing GCSEs in traditional academic subjects and moves to reduce the number of vocational options offered at GCSE level. League tables now measure the number of pupils achieving 5 A*-C grades in English, maths, science, a foreign or ancient language and either history or geography. At the same time, the Wolfe review of vocational qualifications (Wolfe, 2011) recommends that some vocational qualifications should not be counted by school league tables. This is intended to discourage schools from offering vocational qualifications at GCSE level. However, for many of the young people in this study, vocational equivalents to GCSE provided a stepping stone to further education. These were all pupils who had difficulty with writing and struggled with exams but were otherwise academically able. All forms of assessment also measure things which are outside of the aims of the course and with exams this is the ability to write under timed conditions (Race, 2005). This also

suggests that if there was more diversity in terms of assessment in traditional GCSEs it would be a fairer reflection of these students' abilities.

- When planning the proposed changes to the careers service the government should take into account the specific needs of young people with SEN.

Connexions has now been largely disbanded. It was formerly responsible for providing careers advice and guidance to young people and had specific responsibilities towards young people with SEN who did not have a statement. However, Connexions did not work for the young people in this study in the way it is intended to, according to the SEN code of practice. Most of them had had a careers interview but none of them had had any further support. Not all of them felt that they did need extra support. In these cases, either the mainstream system of support at their school had worked well for them, or they had got all of the advice they needed from family and friends.

The responsibility of securing careers advice has now fallen to schools but they have received no extra funding to help them fulfil this responsibility. An all age careers service is due to be set up in 2012. However, with the exception of its telephone and web based services, it is likely to mainly serve adults. Some of the young people in this research missed either some or all, of the careers advice and guidance organised by their school as they were withdrawn from mainstream lessons. If the only way that young people can access careers advice is through their school, there is a risk that young people who are either outside of school or who have a poor relationship with their school will miss out on careers advice altogether. These are likely to be the people who are most in need of advice and most at risk of becoming NEET. As schools now have the responsibility for careers advice it perhaps would be appropriate for them also to have particular responsibilities to ensure that students with SEN are given appropriate careers advice. If the mainstream system works well not everyone will need additional advice. However, concerns have been expressed that schools are not knowledgeable enough about the full range of careers to support young people in general. Staff at mainstream schools are unlikely to be

particularly well informed on the full range of specialist options for young people with SEN. There should be staff at the proposed all age careers service with specialist knowledge of Special Educational Needs who can be called in to schools to advise in these circumstances.

- Young people should be actively involved in constructing their “Education, Health and Care Plans” as proposed in the SEN Green Paper.

Some young people found the process of transition planning intimidating and as a result they were not involved in the process. As the proposed “Education, Health and Care Plans” will cover all support young people receive up until the age of 25, it is vital they are fully included in the process. To ensure this happens the equivalent to the transition review should be conducted in a person centred way (person centred transition reviews are discussed in more detail in the policy review chapter). It is concerning that the current proposals say nothing about young people’s choices, despite aiming to cover people well into adulthood. This could be a step backwards from the current system where support in further and higher education and employment is centred around the needs and wants of the young person (Skill 2011).

- The system for accessing support should be streamlined across education, employment and health to reduce the number of assessments young people have to go through and make it easier to arrange.

All of the young people in the research had been through numerous assessments to prove their eligibility for support in these different areas. Once they reached adulthood there were different eligibility criteria for adult services. Within education there are separate criteria and process for getting support at school, college and university. Even though India had already been diagnosed with dyslexia at school and had a needs assessment from college she still had to pay for a separate one for university. One of the proposals in the SEN Green Paper (DfE, 2011, a) is the introduction of an “Education, Health and Care Plan” which covers health, social care, education and support into employment. However, this is intended as an equivalent to the statement and only a minority of young people with SEN will be

considered to need one. The experiences of some of the young people in this research suggest that there are a lot of people who may not need a full plan but who could benefit from a transferrable assessment in some of these areas.

- There should be a programme of support available to help young people with Special Educational Need access employment.

Gaining paid employment was an important aspiration for all of the young people in this research. However, not everyone was sure that they would be able to achieve this. George had been working on a supported employment scheme for people with learning difficulties since leaving school and several other participants expressed concerns that they would be unable to find a job when they left school. There was not a lot of support available to help them prepare for employment apart from the two weeks work experience that all young people took part in. However, several participants in this research missed out on this. Sophie, with the help of her family, managed to organise work experience for herself at a vets practice and this proved critical to her eventual success. The numbers of young people with learning difficulties entering employment has decreased significantly since the 1980s (Hornby and Kidd, 2001). This is possibly due to the increased importance of qualifications discussed in the previous chapter. Given the importance of gaining employment to the young people and the difficulties they are likely to face achieving it, it is surprising that more support is not available in this area.

Significance of the Thesis

The significance of this research is that it focuses on the experiences of students with hidden disabilities, who make up an increasing proportion of pupils with Special Educational Needs. It follows both their experiences of attending a mainstream school and for the older members of the sample, their experiences since leaving school. Repeat biographical interviews with 14 young people and their parents were carried out. Using a life history perspective provided a detailed picture of the young people's transitions and helped understand their decisions by looking at them in the wider context of their lives. The diversity of these stories and the fact that the

experiences of young people with autism and social and communication difficulties are included is a key strength of the research. On one level this research has highlighted how much young people with SEN have in common with their peers. At the same time it has shown that while they have similar aspirations to other young people they often face more barriers to achieving them. In compliment to the young people's experiences, this research has also sought to understand the parents' perspectives. In looking at these together we are able to see both what they have in common and how they differ.

Appendix 1

Consent Forms and Information Leaflets

Leaving School Research Project

Information for Parents and Guardians

I am inviting you and your child to take part in a research project about young people with Special Educational Needs who are about to leave school. Please read this leaflet and let me know whether or not you would like to take part.

Who is doing the research?

The research is being done by Emily Forster, a PhD research student at the University of York. It is funded by the Economic and Social Research Council.

What is the study about?

The study is about young people with Special Educational Needs' experiences of school and how they decide what they want to do when they leave school. It looks at what options are open to them and what advice and support they receive, as well as their long term aspirations. I want to find out about the experiences and opinions of young people and their parents.

Why have I been invited to take part?

I am contacting you through your child's school as they are in year 11.

What's involved?

I would like to come and interview your child three times in the next 18 months to follow their progress on leaving school. As well as talking to you once.

Interviews with Parents

I would like to arrange a time and place to meet to talk about your child's plans, what information you received and how much you were involved in the decision. The interviews will last about an hour and will be tape recorded if you are happy with this.

Interviews with young people

I would like to talk to you child about the same issues, but hope to do three interviews over a period of 18 months following their progress after the age of 16. Before the first interview your child will be given a disposable camera to take photographs of things they think are important to their lives. The photographs will be used as an icebreaker to the interview and they can keep them afterwards.

How will the information I give be used?

The study is being carried out as part of the researcher's PhD degree. It is hoped that the findings will also be published in academic journals. No names will be mentioned in any reports or publications about the research. After the research is completed I will send you a summary of the findings and a copy will also be sent to the school.

Will you tell anyone else what I say?

All information you provide will be treated with the strictest confidence, unless you tell me that a child is not safe. No one from the school or any other organisation will be told what you have said. If I used any quotes from what people have told me no names will be mentioned. All records will be kept in accordance with the Data Protection Act 1998. However, you are free to tell other people what you have said in the interview if you want to.

What do I have to do next?

If you want to take part in the research please fill in the response slip enclosed and I will contact you and tell you more about the project and give you the chance to ask questions about it. If you are happy to take part we can then arrange a time for interview.

Contact Details

If you have any questions about the research please contact Emily Forster at the Social Policy Department, University of York on 01904 321264 or email ecf103@york.ac.uk

Thank you for your time

Leaving School Research Project

Would you like to help?

My name is Emily Forster and I am a PhD research student at the University of York. I would like to talk to young people who were considered by their school to have Special Educational Needs about their experiences now they have left. I am writing to ask if you would like to help.

Why me?

I am looking for young people who will leave school this year, who can tell me about what they want to do in the future and what they think about the advice and support they got to make this decision.

What do you want to find out about?

I would like to find out about:

- Your experiences of school
- What you have done since leaving
- Your plans for the future
- What help and advice you have had to help you decide what to do next

What is involved?

If you agree to take part in the study, I would like to talk to you about your experiences of school, what you decided to do once you left and your plans for the future. I would like to arrange a time to come and visit you in the next few weeks with two more follow up visits over the next 18 months. I would like to tape record the interview but if you prefer I can take notes

Will you tell anyone what I say?

Everything we discuss is private, and you can choose what you want to talk about. This means I will not tell your parents or teachers what you say without your permission, although you can tell people if you want to.

I will not use your name in any of the reports I write about the research.

Do you want to take part?

I hope you will want to take part but this is up to you.

If you want to take part please fill out the consent form and return it in the envelope provided. Remember to get your parents' signature as well.

Topic Guide for young people

Welcome:

Talk about photographs, why did they choose these particular things

Experiences of school

What subjects studied/ qualifications taken and grades expected,

Friendships at school,

Activities involved in (e.g. sport)

Relationships with teachers,

Likes and dislikes about school,

What they are good at and what they find difficult,

Have they been in any trouble

Any bullying

Home life and family

Where is home/ who lives there

Relationship with family

What support do they get from family/ what responsibilities do they have

Work

What experience have they had of work

How did they get the job

How job fits in with school and leisure

Looking forward

What do they plan on doing immediately after leaving school

How did they decide on this /what advice did they receive

Who was most influential in helping you making decision

Local options; what are their friends doing

Expectations of Adult Life

Home. Where do they expect to live, who with

Work

Family and relationships

Education

Do you feel like an adult? In what circumstances

When do you expect to feel grown up? What milestones

Topic Guide Parents

Introduction

Explain purpose of the research and confidentiality

Child's circumstances

SEN history of young person

Child's interests, strengths and weaknesses

Parents' educational background and attitudes to education

Education of child's brothers and sisters if relevant

Expectations of adult life for their child

What do they hope will happen? What do they fear

Prompt: housing, education, training, employment, relationships

How involved were they with their child's decision on what to do after leaving school

Support for Transition

What advice and support have they and their child received from professionals to prepare them for leaving school

Does their child have a transition plan

What do they think of the support they received

Is there any advice and support you wish was available but you didn't get

What other sources of support has their child had

Examples

<p>Entry</p>	<ul style="list-style-type: none"> ▪ Entry level certificates ▪ Skills for Life at Entry level 	<p>Entry level VQs:</p> <ul style="list-style-type: none"> ▪ Entry level awards, certificates and diplomas ▪ Foundation Learning Tier pathways ▪ Functional Skills at Entry level 	
<p>1</p>	<ul style="list-style-type: none"> ▪ GCSEs graded D-G ▪ NVQs at level 1 ▪ Key Skills level 1 ▪ Skills for Life ▪ Foundation Diploma 	<p>Level 1 VQs:</p> <ul style="list-style-type: none"> ▪ BTEC awards, certificates and diplomas at level 1 ▪ Functional Skills level 1 ▪ OCR Nationals ▪ Foundation Learning Tier pathways 	
<p>2</p>	<ul style="list-style-type: none"> ▪ GCSEs graded A*-C ▪ NVQs at level 2 ▪ Level 2 VQs ▪ Key Skills level 2 ▪ Skills for Life ▪ Higher Diploma 	<p>Level 2 VQs:</p> <ul style="list-style-type: none"> ▪ BTEC awards, certificates and diplomas at level 2 ▪ Functional Skills level 2 	
<p>3</p>	<ul style="list-style-type: none"> ▪ AS/A levels ▪ Advanced Extension Awards ▪ International Baccalaureate ▪ Key Skills level 3 ▪ NVQs at level 3 ▪ Cambridge International Awards ▪ Advanced and Progression Diploma 	<p>Level 3 VQs:</p> <ul style="list-style-type: none"> ▪ BTEC awards, certificates and diplomas at level 3 ▪ BTEC Nationals ▪ OCR Nationals 	<p>Framework for Higher Education (Maintained by the Quality Assurance Agency)</p> <p>Examples</p>
<p>4</p>	<ul style="list-style-type: none"> ▪ NVQs at level 4 ▪ Key Skills level 4 ▪ Certificates of higher education 	<p>Level 4 VQs:</p> <ul style="list-style-type: none"> ▪ BTEC Professional Diplomas, Certificates and Awards 	<ul style="list-style-type: none"> ▪ Certificates of higher education
<p>5</p>	<ul style="list-style-type: none"> ▪ Higher national diplomas 	<p>Level 5 VQs:</p> <ul style="list-style-type: none"> ▪ HNCs and 	<ul style="list-style-type: none"> ▪ Diplomas of higher education and further

<http://www.ofqual.gov.uk/qualifications-assessments/89-articles/250-explaining-the-national-qualifications-framework> (Accessed on 21,02,2012)

Glossary

CAMHS – Child and Adolescent Mental Health Service

DCSF- Department for Children Schools and Families

DFE- Department for Education

DfES- Department for Education and Skills

DSA- Disabled Student's Allowance, funding to provide equipment and support for disabled students at university

DSM- Diagnostic and Statistical Manual of Mental Disorders- handbook which outlines diagnostic criteria for mental disorders

EBacc- English Baccalaureate-

EBD- Emotional and Behavioural Difficulties

EHCP- Education health and care plans, will replace statements and outline the provision made for a disabled child or young person from birth to 25

FE- Further Education

HE- Higher Education

LSA- Learning Support Assistant

MLD- Moderate Learning Difficulties

NEET- young people who are not in education, employment or training

PMLD- Profound and Multiple Learning Difficulties

SLD- Severe Learning Difficulties

Statement- A statement of Special Educational Needs outlines the support that a child needs and conveys on them a legal entitlement to support

TA- Teaching Assistant

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