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The Biographies of Young People with Motor Impairment

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ABSTRACT

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There is a lot of research investigating the effect of impairment on disabled young people but most of this research is from an adult perspective; health and education professionals, parents and disabled adults reflecting back on their childhood. Researchers have generally ignored disabled young people's views and opinions, and as a result their voices have often not been heard. This study investigated the life stories of nine young people with motor impairment, three girls and six boys, by writing and analysing their biographies. Each took part in a series of auto/biographical interviews in which they were asked to talk about their lives. These interviews were transcribed and transformed into written biographies. The final biographies were analysed and four themes emerged: family, friends, school and living with impairment. Although these themes were evident in all nine biographies, each young person provided an individual and different point of view. This study supports the premise that a disabled young person is unique, and as such, it is inappropriate to homogenise and categorise them according to their medical and/or educational label. In addition, the collaboration that can be developed between the researcher and the disabled young person, through the use of auto/biographical methodology, is one way of actively acknowledging the participation rights of disabled young people.

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NOTE ABOUT TERMINOLOGY

I refer to the participants in this research as young people rather than children. This is to emphasise that they are people and to avoid any misunderstanding that the terms 'child' and 'children' may bring.

I also use the term 'disabled young people' rather than 'young people with disabilities'. According to the Social Model of Disability the term 'disabled young people' indicates that a young person with an impairment is disabled by society due to prejudicial attitudes and unequal access to the environment and services (Morris 1998a). On the other hand, the phrase 'young people with disabilities' uses the term disabilities to mean impairment and as a result defines a young person by his/her impairment. This term does not acknowledge the role that society plays in disabling young people.

I do not use diagnostic labels when describing any disabled young person. This is to avoid homogenising these young people and defining them by their impairment. As the title of the thesis suggests I will refer to the young people as people first and then acknowledge that they have impairment. It should be noted that the presence of impairment does not necessarily lead to disability.

There will be occasions within the thesis when it will be noted that I did not comply with these principles. This is because I have used a direct quote from another author, an illustrative quote from the participants involved in the research or I am specifically identifying a parent-child relationship.

Unless you had grown up beside a person from the beginning, had breathed the same air, there was too much about that life you would never be able to explain.

(Miller 2001, p. 22)

CHAPTER 1 INTRODUCTION

When I was about seven years old, the exact age escapes me, I was able to fly! Even now, when I close my eyes and think back to that time, I can still feel the sensation of flying. I was indescribably happy and felt completely free and unrestrained and I had the biggest smile I could possibly have had on my face. I was only able to fly inside the house. I cannot remember taking off or landing, but I do remember swishing through the rooms, in and out of the doors, going up and down, round and round. In fact I can only remember it happening once. And, as no one else was in the house when it did happen, I am the only witness to my one truly unrestrained and sensational moment.

As real as the feelings were (and still are), rationally I know that it was not possible for me to have flown. The sensations that I felt when I did fly have been tempered with the realism that has developed as I grew older and became more removed from a world of fantasy. Yet, the sensation that I did fly, although faded, is still with me, over three decades later. Why this sensation has remained in my memory, when so many others have not even registered, I do not know. There must be some reason; yet it will probably remain a mystery as the event moves further and further into the past.

There is no doubt a logical explanation as to why I felt I could fly. It may have been a dream or a fantasy triggered by seeing or reading Peter Pan. However, strangely enough, it is not the thought of whether I actually flew or not that I think about. Instead, I want to know why I felt so indescribably happy, free and unrestrained. That is the feeling that has stuck with me, even through all the other life events, both happy and sad that have post-dated it. What of significance happened in my life when I was about seven years old that has left its mark on me?

This vague memory of the circumstances surrounding this event has led me to question the insight that can be gained by asking adults to reflect back on their childhood. Their views of childhood would be tempered by the passing of time and quantity and quality of their experiences. It strikes me that if we are to understand young people and enter their worlds, then we need to study them when they are young, not as adults reflecting back. One way of doing this is to ask young people to talk about their life and to work collaboratively on writing their biography.

I am particularly interested in hearing the life stories of disabled young people due to my background as an occupational therapist. My professional interests led me to read the autobiographies of disabled people and, in so doing, I became aware that most narratives were written by adults reflecting on their childhoods. These reflections were influenced by the intervening years of becoming an adult. Autobiographies such as "*My Left Foot*" by Christy Brown (1954) and "*From Where I Sit: Making My Way with Cerebral Palsy*" by Shelley Nixon (1999) provide moving accounts of childhood with an impairment but do so from an adult perspective. Although these autobiographies provide detail about the authors' childhoods, I began to question how much these childhood reflections have been changed, particularly in view of the difficulty I have in remembering details from my early childhood. I became interested in knowing what disabled young people thought about their lives while they were still young. This became important as I realised how little I knew about the many disabled young people I had worked with, apart from what was related to the therapy I was offering. I became interested in their views, in knowing what they thought about their lives and how they felt about their impairment. Most importantly, I wanted to hear the disabled young people talk about their present experiences of their lives rather than hear the reflections of a disabled adult.

The aim of my research was to investigate the life stories of a small number of young people with a motor impairment by writing and analysing their biographies. The focus of these biographies was to identify what was important for each young person by encouraging them to lead each interview. The premise of this research is that each disabled young person is unique, and cannot be labelled, homogenised and categorised according to their medical and educational diagnosis.

Structure of the Thesis

Chapter 2 presents a review of the literature, providing the background to the later discussion of the biographies of the disabled young people. This chapter begins with a broad introduction to the complex nature of development, particularly focusing on the newer theories of the *Ecology of Human Development* and the *New Sociology of Childhood.* This is followed by an explanation of motor impairment and the impact this may have on development. A disabled young person's development is also affected by other factors, such as the negative attitude of the general public and the barriers erected by society. The effects of these external influences are explored by discussing two dominant disability models, the Medical Model and the Social Model. This leads into an overview of the international and national legislation and initiatives that specifically affect disabled young people. The final sections of the literature review focus on three specific issues that have a direct impact on a disabled young person's development, these being family, friendships and education. This chapter ends with a summary and an explanation of the research focus.

A rationale for the auto/biographical approach used in this study is provided in Chapter 3. The use of auto/biographical methodology with young people is discussed as this approach is more usually used with adults. The data collection procedure is described, providing detail of the selection procedure and the conduct of the interviews. The procedure for the analysis of the data is explained, followed by a discussion of the ethical issues in using auto/biographical methodology with disabled young people. The chapter ends with a reflection on how the research was evaluated.

The findings and discussion are combined in Chapter 4. Initially a brief description of the nine young people participating in this research is provided. The discussion then focuses on four major themes. Firstly, the views the young people had of their families are considered. This includes some background information about the parents' marital status and ability to financially support their disabled child. Within this the issues of stress, sibling relationships and the role of the extended family are also discussed. The second theme concerns friendships and focuses on the relationships the young people had with other disabled and non-disabled people. The theme of education follows, in which the young peoples' opinions on inclusive and segregated education are discussed. The last theme concerns their view of having an impairment and the impact this has had on their lives.

The final chapter reflects on the methodology and method before providing suggestions for further research and an overall conclusion.

Appendices 1 to 10 have examples of the documents that were used in this research. The biography of each young person involved in the study is found in Appendices 11 to 19.

CHAPTER 2 LITERATURE REVIEW

Introduction

This chapter provides an overview of the life experiences of disabled young people. Initially it covers the complexity of development using the New Sociology of Childhood (NSC) as a framework. This is followed by an overview of the two broad ways of viewing disabled young people, the Medical Model of Disability and the Social Model of Disability. International and national legislation that affect disabled young people are then discussed, before attention turns to three environmental contexts that influence development: the family, social and educational contexts. This chapter ends with a summary of the literature review and a rationale for the research.

Understanding Development

Development is a complex process that has stimulated a diverse array of theories proffering various explanations for the chronological and developmental changes that occur throughout life. In the past many theories were put forward which separated development into several stages. These theories viewed development as moving through a series of stages in which one area was mastered before moving to the next level. A person's behaviour and skills were considered to be qualitatively different at each stage and progressively became more complex as growth occurred. Generally these theories dealt with distinct areas of development such as the motor, psychosocial and cognitive spheres. Two well know stage theorists were Piaget and Erikson (Hinojosa *et al.* 1996, Case-Smith 2001). Stage theorists consider the process of socialisation and development as the way in which young people become adults (Shakespeare and Watson 1998). They see childhood as a period in which young people sequentially learn skills to become fully functioning adults.

The difficulty with stage theories is that they simplify the complex interactions involved in development by neglecting the contribution of extrinsic and social factors and underestimating the contributions that people themselves make to their own development (Barrett 1998). In addition, they also tend to be misleading and oppressive because they misjudge, control and denigrate young people by reinforcing stereotypes (Alderson 2000). Hence, it is not uncommon to judge young people according to preconceived physical, developmental and social criteria and blame their inappropriate behaviour on the stage they are going through (e.g. 'the terrible twos' or 'because they are teenagers') with no reference to the multiple other factors that may be influential.

Bronfenbrenner's *Ecology of Human Development Theory* (Bronfenbrenner 1979, Bronfenbrenner and Morris 1998) is an example of the move in psychology away from the supposition that young people develop in definable and observable stages (Mayall 1996, Llewellyn and Hogan 2000, Davis and Watson 2002). This theory, which according to Barrett (1998) is the most cited and influential in developmental science, purports that a person's ability to learn is not primarily dependent on his or her developmental stage but is more likely to be a result of exposure to opportunities to learn and the ability to acquire relevant experiences. This approach to understanding development recognises what Earls and Carlson (2001) term 'social ecology'; the interactive relationships and arrangements of the family, neighbourhood and community contexts in which people live.

According to the *Ecology of Human Development Theory* the most important aspect of development is a person's previous acquisition of relevant learning and communication strategies, along with the motivation to learn and develop (Barrett 1998). Development is influenced by how people perceive and interact with their environment. People contribute to their development by actively choosing the parts of their environment with which they will engage. Their choice though, is often restricted by a lack of opportunity, resources, encouragement and cultural attitudes. Choice can also be restricted by the presence of physical, sensory, emotional and/or cognitive impairments. In addition, exposure to a wide variety of domains such as language and music and cultural experiences provides a richer opportunity for some people to complement their motivation, interest, attitudes, values, self-esteem and expectations. This can contribute to a person's feelings of competence and success (Rogoff 1990).

This shift in the focus of development theory and the realisation of young people's rights and agency, has lead to the development of the New Sociology of Childhood (NSC) which sees the concept of childhood as a social construction (Prout and James 1997, Lavalette and Cunningham 2002). Young people are recognised as having their own perspectives of their lives and the capacity to develop complex and multiple identities (Davis *et al.* 2000, Connors and Stalker 2003). Although there is acknowledgement that young people are biologically immature compared with adults, what is important in this approach is how this immaturity is framed by society's discourses reflecting particular views of childhood. These discourses on childhood vary between and within cultures and change and evolve over time (Mayall 1996, Montgomery 2003, Stainton Rogers 2003, Woodhead 2003).

The NSC recognises that young people develop their own discourse about their childhood and as a result considers listening to them and hearing what they have to say as fundamental to understanding them (Lavalette and Cunningham 2002). This approach is about understanding what Vygotsky terms the 'historical child', the social construction and reconstruction of childhood (Woodhead 2003). This means that young people are not isolated from society, they are affected by society and they also influence society (Lavalette and Cunningham 2002). The essential themes of the NSC are that young people are a specified social group who are able to create their own discourses about their childhoods.

As childhood is considered to be a social construction, each young person is a local construction rather than a global entity. As Lavalette and Cunningham (2002) suggest, childhood is intrinsically connected with wider societal elements. Young people are not homogeneous and cannot be understood in terms of universal judgements. Each young person is a product of his or her own context. As a result the social construction of childhood cannot be understood without looking at the totality of social relations within society and how these affect the perceptions of, and attitudes to, young people, and their responses to these perceptions and attitudes. An example of these perceptions and attitudes is provided by Alderson (2000) who suggests that adults who feel young people can be involved in decision making tend to trust them to think independently and respect their understanding of the world and their point of view.

The focus of the NSC is on seeking to understand the experiences and feelings of young people themselves (Shakespeare and Watson 1998). Young people are regarded as a social group whose experiences are structured by wider policies and practices and whose everyday behaviour is policed and directed by adults. Shakespeare and Watson (1998, p. 19) propose that this,

> raises questions of power, and focuses attention on the way that social structures and adult behaviours cause problems for children. It highlights the effect of different environments on children's lives. Finally, and perhaps most importantly, it encourages us to take children's own views and feelings about their lives far more seriously than either academic or professional 'experts' have done previously.

Young People with Motor Impairment

Disabled young people develop their own discourse about their childhood, which is, in part, influenced by their impairment and their interactions with their social environments. This research focuses on young people who have a motor impairment as a result of neurological brain damage, either before, during or soon after birth. This is a common cause of motor impairment (Lepage *et al.* 1998, Brown 1999). The non-reversible brain damage results in a disorder of muscle control that usually leads to difficulty with moving and positioning the body for life.

The distribution and severity of motor impairment will be different for each young person, with the variation dependent upon the location and extent of the brain damage (World Health Organisation 1993, Lepage *et al.* 1998). Young people may have floppy, stiff and tight and/or fluctuating muscle tone, which may affect all their body or be more obvious in specific parts of the body (e.g. the legs being more affected than the arms). This motor impairment may mean that the young person will require a wheelchair, walking frame or sticks for mobility and may have some difficulty doing certain activities of daily living independently.

In addition, young people who have a motor impairment as a result of brain damage may have a wide range of other developmental difficulties (World Health Organisation 1993, Finnie 1997, Levitt 1997). These other developmental difficulties may result in more complex impairments as they may impact on a young person's educational and social independence. Some young people will have perceptual difficulties, which may affect their ability to read or write, while others will have a cognitive deficit affecting their education potential. Speech and language difficulties are common and may affect a young person's ability to communicate and interact with others.

All these impairments may contribute to the young person having social and emotional difficulties. As each young person with a motor impairment grows and develops in a unique environment the impact of their impairment on their development is intrinsically intertwined with the opportunities with which they are presented. Furthermore, although the brain damage is non-progressive, the effect of that brain damage on each young person's development may change constantly as they grow older (The UK Federation for Conductive Education 1998).

Although the focus of this research is on young people with a motor impairment, the literature review will apply to disabled young people in general. This is because even though the premise of this research is that each young person is unique and that homogenisation is inappropriate, there are some general issues that affect disabled young people. As Read and Clements (2001) suggest, all disabled young people share some common experiences, even though they are unique and have diverse backgrounds and characteristics.

Society's Attitude Towards Disabled Young People

Disability is a complex concept (Coles and Zsargo 1998). Preece (1996) proposes that as a concept disability cannot be reduced to a singular notion because it covers a diversity of variables. This diversity and complexity, however, is not recognised by the two dominant models used to describe disability, the Medical Model and the Social Model. Nevertheless, these two models have such a profound impact on the lives of disabled young people that an overview of each is essential.

Medical Model of Disability

The Medical Model of Disability underpins the dominant view of disability in Western society. Within this model, disability is perceived to be an illness and is considered to be something that can be cured, remediated or rehabilitated. This view of disability reinforces stereotypes and the concept of achieving 'normality', something that is unlikely for many disabled young people.

The Medical Model sees the disabled young people as the problem suggesting that impairment automatically leads to a disability that requires medical intervention to correct or resolve (Rieser 1995, Morris 1997, Llewellyn and Hogan 2000). A disabled young person is to be made as 'normal' as possible so that they can fit into the non-disabled view of the world (Llewellyn 2000). The difference between 'normal' and 'abnormal' are key concepts in this model (Imrie 1997). Impairment and disability are seen as 'abnormal'. Where a disabled young person cannot be made to fit into the world, they are segregated as they require special services and are cared for in such a way that they are considered to be dependent. Medical intervention generally focuses on the impairment rather than the young person. Disabled young people are not considered as individuals but are labelled and categorised according to their diagnosis and condition (Imrie 1997). This approach to disability is paternalistic and exercises control over disabled young people rather than giving them control of their own lives.

Within the Medical Model the tragic view of disability is promoted (Llewellyn and Hogan 2000, Swain and French 2000). This view suggests that disabled young people cannot lead fulfilled lives and denies their real life experiences. This is in spite of accounts of disabled people that demonstrate that, far from being a catastrophe, being impaired can have benefits and provide different, but equally rewarding, views of life compared with non-disabled people (Swain and French 2000). Those who subscribe to the tragic view of disability value disabled young people who show courage, independence and determination at overcoming their impairments, seeing it as a matter of individual effort (Llewellyn and Hogan 2000). This again emphasises that disability is something to be overcome rather than accepting disability as one of the many diverse aspects of life.

The Medical Model is a major factor contributing to the stereotyped views that have developed around disability. Further, it underpins many of the medical interventions that disabled people are subjected to and in so doing contributes to maintaining and reproducing inequalities and injustices (Morris 1997, Read 1998). The stereotyped images and narrow understanding of disability resulting from the Medical Model can have a profoundly negative affect on the self-identify of disabled young people (Dowling and Dolan 2001).

The stigma that is attached to being considered disabled reinforces feelings of low-worth (Harper 1999, Watson 2002). As Watson (2002) points out, in the British social order, there is little status to being described as disabled. In fact the discourses of disability inherent in the Medical Model create categories, which are viewed either from a charitable perspective or with disdain and curiosity. For example, the term 'special', used to describe disabled young people in the education system, emphasises the relative powerlessness of this group and creates categories in which young people labelled as 'special' can be placed into segregated education (Adams *et al.* 2000). These labels and categories are used to distinguish between those that have an impairment and those that do not have an impairment, seeing these two as essentially different (Connors and Stalker 2003).

Social Model of Disability

Not surprisingly, disabled people generally object to being referred to as abnormal and different (Llewellyn and Hogan 2000). The Medical Model does not match the experiences of many disabled people and is not considered to be a useful way to explain disability (Dowling and Dolan 2001). Many disabled people feel that although impairment and chronic illness do cause difficulty, these are not the cause of the disability. In reality, what is felt to cause disability is society's pre-conceived and stereotyped attitudes towards disabled people. These attitudes are reinforced by the media and present probably the biggest barrier to disabled young people fully participating in their communities.

Rieser (1992) and Selway and Ashman (1998) argue that disability stereotypes are based on superstitions, myths and out-dated beliefs. They are rooted in deep-seated anxieties that people have about impairment and include disabled young people being considered pitiable, helpless and dependent, achieving against the odds, a burden to society, non-sexual, and incapable of fully participating in everyday life. Stories, films and charities perpetuate stereotypes in such a way that the public considers disabled young people as pathetic, useless and dependent (Shakespeare and Watson 1998).

A major problem for disabled young people is that they live in a society that views impairment as problematic (Murphy 1995, Shakespeare and Watson 1998). Technology has been developed to prevent disabled young people being born and those that are born with, or who acquire, an impairment are subjected to a range of medical, surgical and social interventions attempting to eliminate or reduce the impairment. This creates negative images and attributes to them a status of low worth.

In the Social Model, the term 'impairment' refers to functional physical, sensory, emotional or cognitive limitations, whilst the term 'disability' explains the social, economic and political experiences associated with an impairment (Morris 1997, Read 1998, Llewellyn and Hogan 2000, Shakespeare and Watson 2002, Connors and Stalker 2003). The Social Model proposes that the major cause of disability is society's non-acceptance of diversity and hence society's negative attitudes (Rieser 1995). Disability is considered to be a social construction that is imposed on people with impairments (Llewellyn and Hogan 2000). The experiences of disabled young people are of social restrictions in the world around them. Hence, an individual's experience of disability is created through interacting with physical and social environments that are designed for non-disabled living (Preece 1996, Leicester and Lovell 1997).

Whereas the Medical Model attributes disabled young people's problems mainly to their impairment, the Social Model suggests that the problems are a result of the barriers and negative attitudes of society (Alderson 2001). The Social Model is less concerned with bodily limitations resulting from impairment than with the physical, emotional, psychological and social affects resulting from prejudices, discriminations, barriers and exclusions inherent in society (Barnes 1999). Oliver (1995) suggests that the Social Model definition of 'disability' refers to the disadvantage caused by a social organisation, which takes no account of people who have impairments and as a result excludes them from mainstream social interactions. Disability is seen as a political problem caused by attitudes of society and by physical and social barriers (Coles and Zsargo 1998).

Fundamental to the Social Model is the suggestion that it is more appropriate to pursue a policy of social change than one of medical cure and rehabilitation because it is society that needs to change not disabled young people (Shakespeare and Watson 2002). Some of the limitations of the Social Model, however, are similar to the Medical Model in so far as both homogenise disabled young people, but in different ways. The Social Model proposes that all disabled young people are disabled by societal barriers and does not recognise the effect of specific and varied impairments (Davis *et al.*

2000, MacKay 2002). Corker and Shakespeare (2002) argue that because disability is a complex and multi-dimensional concept the Social Model is an inadequate tool as it excludes important dimensions of disabled young people's lives. The recognition of impairments and the affect they may have is not to move away from the premise that the most restrictive and difficult features of the lives of disabled young people and their families are socially and politically constructed rather than a consequence of impairment. However it is to acknowledge that impairment is part of that young person.

Thomas (1999) contends that the definition of disability must include what she coins 'impairment effects'. She describes these as the restrictions of activity that a person may encounter from living with impairment. Connors and Stalker (2003) provide an example of this by stating that a person with an amputated forearm will be unable to hold a utensil in that hand. Unlike the Medical Model, Thomas does not equate the 'impairment effect' with being disabled. She sees it as a relevant aspect of disabled young people's lives and identities because an impairment will affect their function in some way (Davis and Watson 2002). In this way, she suggests that impairment cannot be ignored as it is part of the person and at least in part contributes to the interaction between the person and the environment.

The Social Model also does not acknowledge that disabled people have agency and can influence their own lives (Read 1998). Although the Medical Model denies agency by giving professionals the power and recognising them as the experts, the Social Model denies agency by proposing that the only cause of disability is societal barriers. This is contrary to the daily experiences of many disabled people who lead fulfilling lives even without the removal of societal barriers (Swain and French 2000).

Finally, contrary to the views of some disability activists (Oliver 1996), there has been a change of focus amongst some disability writers. While recognising that the removal of societal barriers is important, some are now more accepting of interventions that aim to improve the function of disabled people or to functionally compensate for impairments (Thomas 1998, Read and Clements 2001, Davis and Watson 2002, Shakespeare and Watson 2002, Thomas and Corker 2002). These interventions originally came under considerable criticism from proponents of the Social Model because it was believed that they were heavily underpinned by the Medical Model (Oliver 1990, 1995). It was felt that these interventions were oppressive, reinforced professional expertise, focused on the problems within the young person with no regard for context and aimed for 'normality'.

Proponents of these interventions state that they are aiming to develop more functional skills to enable disabled young people to have control over their bodies and enhance their chances of being involved in activities that matter to them and achieve a sense of well-being (Hurr 1995, Thelen and Smith 1998, Ketelaar *et al.* 2001). Afterall, as Shakespeare and Watson (2002) ask, what is so wrong with maximising functioning and seeking to reduce the impact of impairment? Although the obsession with cure may be misguided and some interventions can cause psycho-emotional as well as physical harm it would be wrong to discount the possible benefits of impairment avoidance and reduction. Appropriate action on impairment can co-exist with the removal of disabling environments and practices.

These models of disability and the actions that extend from each viewpoint influence the development of disabled young people, who are subjected to a variety of medical, educational and therapeutic interventions and who interact in a society that appears to be mainly geared for non-disabled people. They have both influenced international and national legislation and initiatives that focus on disabled young people and this is discussed in the following section.

International and National Legislation and Initiatives Affecting Disabled Young People

International and national legislation has a profound affect on the opportunities and rights of disabled young people. Up until the 1980s most legislation in England promoted the separation of disabled young people from their families and their placement into segregated institutions. From the 1980s there has been a closure of institutions and a move towards inclusion within their own community (Connors and Stalker 2003). It has been recognised that young people, including disabled young people, need a stimulating social environment, which helps them to develop self-respect and social competence (de Winter *et al.* 1999). It is through this recognition that laws have been introduced in England aimed at providing disabled young people with the same opportunities as non-disabled young people.

The many changes to this legislation are in line with the international move toward promoting the rights of all young people, including disabled young people (Mayall 2001). Although there have been many positive changes over the last three decades, much of the legislation in England continues to operate within the Medical Model of Disability (Kenworthy and Whittaker 2000). Hence legislation focuses on ‘fixing’ disabled young people rather than reducing societal barriers (Shakespeare and Watson 2002).

International Initiatives

The United Nations has been instrumental in promoting policies that aim to remove discrimination and respect human rights. Of particular importance for disabled young people are the *United Nations Convention on the Rights of Children* (United Nations 1989) and the *Salamanca Statement on Principles, Policy and Practice in Special Needs Education* (United Nations Education Scientific and Cultural Organisation 1994).

The specific rights of young people were officially recognised in the *United Nations Convention on the Rights of the Child* (United Nations 1989). This *Convention* was the outcome of a movement that started to recognise that young people had rights which were separate from the rights of parents and families and other adults involved in their care. The *Convention* aims to protect and promote the rights and welfare of young people (Flekkøy and Kaufman 1997).

The 54 Articles in the *Convention* can be grouped under four different types of rights: provision or survival rights, prevention or development rights, protection rights and participation rights (Flekkøy and Kaufman 1997, Burr and Montgomery 2003). Of these, participation rights are the most controversial as they acknowledge that young people are active social players and have the right to hold and express opinions and assume responsibility, thereby raising the issue of their competence (Lansdown 1994, Alderson 1995, Lansdown 2001).

Even though the *Convention* clearly states that it is applied to all young people, there is specific mention of disabled young people (Morris 1998a). There appears to be a recognition that disabled young people aspire to equality of opportunity and a quality of life comparable to that enjoyed by non-disabled young people (Read and Clements 2001). The *Convention* specifies that disabled young people should be helped as much as possible to be independent (Sebba and Sachdev 1997) through special care, education and training (Flekkøy and Kaufman 1997).

Although the focus on disabled young people in the *Convention* is written with the best intentions, there is a paternalistic tendency based on the Medical Model of Disability (Freeman 1995, Flekkøy and Kaufman 1997, Freeman 2000). The *Convention* suggests that the problem is with the disabled young people and systems have to be in place for their care and rehabilitation. There is no mention of governments working towards the removal of societal barriers.

The *Salamanca Statement and Framework for Action on Special Needs Education* (United Nations Education Scientific and Cultural Organisation 1994) calls for inclusion to be the norm in the education of all disabled young people in the recognition that segregation of any kind is morally wrong (Florian 1998, Vaughan 2002). It proposes that inclusive schools are "the most effective means 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" (United Nations Education Scientific and Cultural Organisation 1994, p. ix). The *Statement* considers education to be an underpinning of societal values and is important in nurturing a society that is inclusive (McConkey 1998). McConkey (1998) warns, however, that the *Statement* offers a moral attitude towards inclusion rather than one based on solid evidence supporting the effectiveness of inclusive education.

National Legislation and Initiatives

The *Children Act (England and Wales)* (1989) is based on the belief that the welfare of young people is considered to be paramount, that they are generally best looked after within their family and that they should be involved in decisions that affect their lives (Alderson 1995, Statham and Read 1998, Read and Clements 2001, Burr and Montgomery 2003). This *Act* was the response of the English and Welsh government to the international focus on young people as depicted by the *United Nations Convention on the Rights of the Child* (United Nations 1989), and national legal proceedings, such as the Gillick Ruling (Alderson 1995, Morris 1998a). The Gillick Ruling gave young people under the age of 16 years the legal right to give consent to medical treatment without consultation with their parents, if they have sufficient understanding (Alderson 1995).

In spite of the suggestions that the *Children Act* (1989) promotes young people's rights, the *Act* itself does not use this term (Alderson 1995). The *Act* is in fact criticised because it tends to focus more on the responsibilities of parents or caregivers, than on the rights of young people (Alderson 1995, Mayall 2001). This goes against the principle of listening to them and involving them in decisions that affect their lives.

The *Children Act* (1989) considers disabled young people under the label of 'children in need'. Connors and Stalker (2003) state that the

Act embodies several key principles in relation to disabled young people including inclusion, interagency collaboration, participation and promotion of their welfare. However, the language in the *Act* is that of the Medical Model of Disability, and does not require Local Authorities to remove disabling barriers. Instead it charges Local Authorities with providing services for disabled young people to minimise the effect of their impairments and give them opportunities to lead lives that are 'as normal as possible' (Children Act (England and Wales) 1989, Schedule 2 Paragraph 6, Sebba and Sachdev 1997). It is evident that the *Act* focuses on correcting the young person rather than removing disabling barriers (Morris 1998a). In addition, the focus on assessment, care plans and reviews, although well-intentioned, tends to lead to disabled young people being referred to services that are segregated from the local community, their families and peer groups. Morris (1998a) states that it is rare for local authorities to find out what is important to a disabled young person and to provide services to meet these needs. Instead they tend to slot the young person into existing segregated services, as this is easier and more convenient.

The *Disability Discrimination Act* (1995) was a major piece of legislation aimed at ending discrimination towards disabled people in all sectors of society (Sebba and Sachdev 1997, Read and Clements 2001). The *Act* states that disabled people must have equal opportunities compared with non-disabled people in terms of access to, and involvement in, education, employment, services and the community in general. With regard to education, mainstream schools and colleges are required to implement measures that do not discriminate against the admission and education of disabled people.

Following on from the *Disability Discrimination Act* (1995), there have been changes within the Department of Health which attempt to implement ways of meeting the needs of these young people. *Quality Protects* (Department of Health 1998) was a three-year initiative aimed at reorganising children's services in England to make them more efficient and offer greater protection and better quality care (Connors and Stalker 2003). With regard to disabled young people, they were to be provided with the same opportunities as non-disabled young people, in relation to health, education and social care. Read and Clements (2001) state that the *Quality Protects* (Department of Health 1998) initiative moved towards providing better quality information to disabled young people and their families so that they were informed of, and consequently would use, the range of services available to facilitate them living as ordinary a life as possible.

A further initiative from the Department of Health was the implementation of the *Framework for Assessing Children in Need* (Department of Health *et al.* 2000). In relation to disabled young people, this Framework attempted to move away from the Medical Model of Disability and to instigate good practice of listening to the needs of the young person and family (Read and Clements 2001). The outcome of an assessment following this framework would be a report that considered the young person's developmental needs, the abilities and resources of the parents, and the wider family and environmental support and influences. There is an attempt here to consider the wider social factors that affect each young person rather than just seeing him or her as the problem. The framework encourages the formulation of individual intervention plans rather than slotting the young person and family into a range of already existing services.

Within education legislation, the Warnock Report (Department of Education and Science 1978) was the first official move towards inclusion. This Report was the outcome of the Committee charged with investigating the educational needs of disabled young people, or as the report referred to them 'handicapped children and young people'. The Committee attempted to promote a move away from the categorising of disabled young people that resulted from the selection of pupils by ability (and hence, by disability) sanctioned in the *Education Act* (1944) and the *Education (Handicapped Children) Act* (1970) (Johnstone 1995, Alderson and Goodey 1998, Adams *et al.* 2000). The Report sought to be person-centred, by focusing on the needs of disabled young people and move away from the previous categories used to segregate pupils. As a result the Committee introduced the term 'special educational needs' (Johnstone 1995, Adams *et al.* 2000).

Although this alternative means of thinking about disabled young people's educational needs did not rule out the possibility of mainstream education, it did not specifically push the inclusion argument forward. The focus was still on how to change the disabled young person to fit into the system rather than building the education system to meet the needs of each pupil (Clough 1998, Adams *et al.* 2000). In addition, Corbett (1996), suggests that the term 'special educational needs' has come to be used as another label, further highlighting the powerlessness of disabled young people.

The importance of the Warnock Report was that it provided the basis for the *Education Act* (1981), which entitled disabled young people to have a statutory assessment to determine the difficulties they might have in learning compared to their peer group. The outcome of this assessment would be a formal Statement of Special Educational Needs (Alderson and Goodey 1998, Wolfendale 1999, Kenworthy and Whittaker 2000). This process gave parents the right to be involved and to appeal if they did not agree with the decision of the Local Education Authority.

Although the *Education Act* (1981) encouraged Local Education Authorities to place a disabled young person into a local mainstream school (Sebba and Sachdev 1997), the conditions for doing this meant that many could still legitimately be segregated. The conditions for admission to a mainstream school were that the disabled young person's special educational needs could be met in the ordinary school, the presence of the young person did not affect the learning of other pupils and that mainstream education was compatible with the efficient use of resources. Kenworthy and Whittaker (2000) demonstrated that these conditions provided Local Education Authorities with loopholes which allowed them to preserve the special education, and hence segregated, sector. Indeed, earlier research by Sebba and Sachdev (1997) had shown that this enabled Local Education Authorities to refuse parents' request for mainstream school placements even with the threat of a right of appeal. The other main outcome of the *Education Act* (1981) was that it required schools to formally identify a Special Educational Needs Co-ordinator (SENCO) who would be responsible for the day to day operation of the school's special educational needs policy and co-ordinate the provision for all young people with special educational needs.

The *Code of Practice on Identification and Assessment of Special Educational Needs* (Department for Education and Employment

1994) clarified the responsibilities of school and Local Education Authorities in meeting the specific needs of pupils within their budget (Corbett and Norwich 1997, Sebba and Sachdev 1997). The *Code* emphasised the importance of Local Education Authorities working in partnership with parents and reinforced parents' right of appeal (Statham and Read 1998).

The *Education Act* (1996) was a consolidation of all previous Education Acts and provided a framework for schools to develop and review their policies and procedures for the identification, assessment of, and provision for, pupils with special educational needs, including disabled pupils (Sebba and Sachdev 1997). One aspect of this *Act* focused on improving the efficiency of the statementing process by extending the rights of parents (Wolfendale 1999). This *Act* introduced a more efficient one tiered Special Educational Needs Tribunal, to which parents could appeal if they were not happy with decisions regarding their children's education.

To facilitate a more efficient service to meet the educational needs of the young person, the *Education Act* (1996) and *Code* (Department for Education and Employment 1994) encouraged the promotion of interagency working so that statutory agencies and voluntary groups worked more effectively together (Statham and Read 1998, Wolfendale 1999). In addition, the importance of involving the young person in the development of any Individual Educational Plan was also stressed in the belief that young people have the right to be heard and should be encouraged to participate in decision-making about provision to meet their special educational needs (Read and Clements 2001).

The *Education Act* (1996) and the *Code* (Department for Education and Employment 1994) have been criticised for taking only a moderate stand on the issue of inclusion as both emphasise the importance of a continuum of provision to meet the needs of all students, including segregated schools (Hornby 1999). Special education is still marketed to parents as a safe option for disabled young people who are considered vulnerable in mainstream schools (Middleton 1999). This suggests that mainstream schools are not being pushed to ensure that disabled young people are fully included within the schools. It is also the case that the potential to improve the provision for disabled young people is hampered by inadequate funding for schools and for teacher training (Middleton 1999).

The implementation of the *Special Education Needs and Disability Act* (2001) finally provides real impetus towards inclusive education, specifically the education of disabled young people within their local mainstream schools. This *Act* supports the notion that there are strong educational, social and moral grounds for educating disabled young people in mainstream schools, as put forward by the *Salamanca Statement on Principles, Policies and Practice in Special Needs Education* (United Nations Education Scientific and Cultural Organisation 1994).

Summary of the Policy Background

There has been a huge shift in emphasis and focus of national and international legislation regarding disabled young people since the early 1980s. Whereas most of the earlier legislation had a Medical Model of Disability influence and tended to see disabled young people as the responsibility of parents and other adult figures, this is not the case with more recent developments (Kenworthy and

Whittaker 2000, Burr and Montgomery 2003). More recent legislation appears to recognise young people as a separate social group, who have distinctive rights and who can be active participants in the decisions that affect their lives. Further, there is a move towards including disabled young people in the decision-making process that affects their lives ensuring that they have opportunities equivalent to their non-disabled peers. Although legislation is becoming more rights focused, it will take a longer time for public attitudes and prejudices to change, to create a truly inclusive environment that is accepting of the diversity of human abilities.

Family Experiences of Disabled Young People

Each family with a disabled young person is unique. As a group, however, these families experience a range of inequalities that families with non-disabled young person do not experience, despite the considerable improvement in social care provision over recent decades (Case 2000, Dowling and Dolan 2001). Lack of funding, inflexible care arrangements and the prejudices of others not only disable young people with impairments, but also disable their families (Dowling and Dolan 2001). This may cause stress to the parents and siblings and have an adverse affect on family welfare. As the family has a significant impact on development, the inequalities experienced and the strategies families use to cope will affect the disabled young person.

The unequal opportunities and consequences affect many facets of family life such as work, leisure, finance and quality of life. A research programme funded by the Joseph Rowntree Foundation (1999) found that the standard of living of families with disabled young people fell below that necessary for these young people to achieve adequate physical, mental, spiritual, moral and social well-being as outlined in the *United Nations Convention on the Rights of the Child* (United Nations 1989). Many families were living in unsuitable housing. The cost of raising a disabled young person was found to be at least three times greater than the cost of raising a non-disabled young person. This financial burden is further complicated by the finding that parents of disabled young people were less likely to be able to meet these higher costs because the primary carers were unlikely to find a job that will fit in around their caring responsibilities. As a result of this reduction in earning power these families are less able to pay for or contribute towards adaptations, equipment, transport or child care. Dobson *et al.* (2001) and the Joseph Rowntree Foundation (1999) found that even the maximum financial benefits available to families raising disabled young people fall far below the extra costs involved. This finding has been supported by other research investigating the financial cost of having a disabled young person within a family and offers a clear example of how attitudes and systems prevalent in society disabled the whole family (Lewis *et al.* 2000, Curran *et al.* 2001, Dobson *et al.* 2001, Dowling and Dolan 2001).

Employers rarely take into account a parent's caring responsibilities and local child care support services are inadequate for many parents to combine paid work with looking after a disabled young person (Dowling and Dolan 2001). The lack of options for work is also complicated by the general restructuring of the labour market and high levels of unemployment making it much more difficult to compete with adults who do not have the extra responsibilities of raising a disabled young person (Read and Clements 2001). Even when both parents do work usually one, if not both, has to compromise their working patterns in order to be available for their disabled child (Lewis *et al.* 2000).

It is important to note that financial incentives are not the only, or even the main, reason underlying why parents want to work. Lewis *et al.* (1999) found that in addition to the economic benefits of working, there are also psychological and social benefits, particularly for mothers who are usually the main carer. They interviewed 40 working parents of disabled young people. The mothers, who usually had the main caring role and worked part-time, enjoyed working because it improved their self-esteem by giving them another role and some time away from the care needs of their children and as such relieved their stress level. In addition, working enabled mothers to socialise, talk and mix with others. So, if the primary carers are unable to work they will be unable to benefit from the companionship and release from stress associated with caring that work may bring (Dowling and Dolan 2001).

Having a disabled young person is often portrayed as resulting in stress within the family. The Social Model of Disability proposes that the stress is not caused by disabled young people but is a result of societal barriers and attitudes towards them and the family (Dowling and Dolan 2001). Both professionals and the general public are responsible for these barriers and attitudes. This is not to deny that the upbringing of a disabled young person often makes demands that exceed that of the upbringing of a non-disabled young person (Statham and Read 1998, Roberts and Lawton 2001). For example, parents may have to continue assisting their disabled young person with more intimate aspects of care, such as washing, toileting, dressing and eating, long after non-disabled young people require assistance (Bereford 1995, Read and Clements 2001). What is suggested, is that the removal of the unnecessary societal barriers and attitudes could significantly reduce the stress experienced by a family with a disabled young person.

When describing how mothers deal with their emotions of having a disabled child, Larson (1998) found that parents had an 'embrace of paradox'. She describes how parents experience contradictory emotions of grief and joy, hope and fear and tensions between their children's present circumstances and what their future might hold.

> The embrace of paradox was the management of the internal tensions of opposing forces between loving the child as he or she was and wanting to erase the disability, between dealing with the incurability while pursuing solutions and between maintaining hopefulness for the child's future while being given negative information and battling their own fears. The tensions created by the paradox promoted an internal striving to maintain a tenuous hopefulness despite "crashes" in their maternal work, and promoted an extension of maternal skills working toward a hopeful life trajectory for the mother and her child. In the embrace of paradox mothers created a positive bias and regained a sense of control that fuelled their optimism in maternal work.
>
> (Larson 1998, p. 865)

The embrace of paradox metaphor highlights the difficulties that mothers, and possibly fathers, have in creating a positive family environment. Larson (1998) suggests that they are battling with their internal acceptance of their disabled child and the belief in a positive future. This itself must be difficult enough but it is further complicated by the generally negative attitude of society towards disabled young people. A positive acceptance of the disabled young person within the family is essential, as secure and affectionate family relationships provide a sound foundation for the young person's psychological, social and emotional development (Baker and Donelly 2001).

It is not uncommon for parents to feel that people outside the immediate family cannot see past the disabled young person (Dobson *et al.* 2001). In public people often stare and pity a family with a disabled young person. Friends of the family might start to exclude them from social outings because of the perceived difficulties of including a disabled young person. Even health, education and social services professionals ignore the privacy usually given to families without a disabled young person and repetitively ask personal and sensitive questions. Rarely do people consider that the family with a disabled young person can have the same ordinary hopes, desires, ambitions, concerns and feelings as other families.

Parents use a variety of coping strategies to deal with raising a disabled young person. Some parents use problem-focused strategies to help to alter the cause of the stress, while others regulate their emotional responses to the stressors (Judge 1998, Selway and Ashman 1998, Taanila *et al.* 2002). One coping strategy commonly used by parents is to seek respite care (Morris 1997, 1998c). Often, this type of service is over-subscribed and as such the service may be inflexible and not meet the needs of the service users. Interruptions to services, long waits, badly planned access and poor facilities increase the stress and inconvenience already experienced by families. Parents state that regular respite care, either formal or informal, is essential to enable them to focus on their own lives and the needs of other family members (Widdows 1997).

Respite care, however, is not without its drawbacks. Significantly, it may reinforce the difference and the stigma of being a burden that a disabled young person may feel (Middleton 1999). Some may feel homesick, rejected or abandoned as it is unusual for non-disabled young people to be sent away for care in a segregated institution when the parents require a break (Morris 1997). Non-disabled young people would usually stay with relatives or friends. Usually disabled young people are not consulted in the respite care process (Morris 1998c). Read and Clements (2001) suggest that for respite services to be more centred toward the young person and his or her family they would need to offer short-term breaks in a more innovative and flexible way. Breaks outside the home may be an option, but respite care should also include the possibility of homecare and support workers, which may be seen as offering a more positive experience for the disabled young person and family.

The issue of respite care is a main concern for parents because the traditional child care services and play and leisure activities open to non-disabled young people frequently exclude disabled young people (Dowling and Dolan 2001, Read and Clements 2001). Specialist provision often means segregated provision and this can affect the social skills development of disabled young people (Morris 1997).

Friendships and Relationships

Read and Clements (2001) found that disabled young people aspired to a quality of life comparable to that enjoyed by their non-disabled peers, even though it is difficult to have access to the same basic social and human rights as their peers. Their childhoods can be made up of countless negative incidences in which they are constantly reminded of their differences. The cumulative effects of this negativity may lead to low self-esteem and expectations, fostering a dependent attitude in which disabled young people are denied control over their own lives (Middleton 1999, Davis and Watson 2001). Additionally, it can be difficult for disabled young people because there are few positive roles models for them to aspire to and the images of disability created by the media and society perpetuate pitiful pictures. This can lead to 'infantising' disabled young people in spite of their abilities.

In part, the negative images and incidents confronting disabled young people can be attributed to the medical interventions to which they are subjected. Middleton (1999) believes that there is a real risk of the medical needs of the young person becoming the main focus and thereby other areas of life that may contribute to greater self-esteem and happiness are ignored. The problem with having this medical focus, and hence an upbringing underpinned by the Medical Model of Disability, is that disabled young people are continually reminded that they are 'not normal'. They are encouraged to work towards 'being normal', a target which they are unlikely to achieve.

Feelings of acceptance and belonging are issues that are important to most people, including disabled young people. Shakespeare and Watson (1998) reveal that many disabled young people become isolated probably because there are no other disabled people within their family, no role models within the community and no positive images in the media or general culture. Baker and Donelly (2001) suggest that when compared with non-disabled young people, they generally have a poorer quality of social experience. Disabled young people have few, if any non-disabled friends, are rejected and victimised more than their non-disabled peers, and have more unstable, uncooperative and non-emotional relationships. During the teenage years, the visible nature of a young person's impairment may make integration into groups where uniformity and similarity are important very difficult (Lepage *et al.* 1998). This can be further complicated by environmental factors, such as architectural barriers or lack of appropriate transportation, which can impede integration even though the person may have the potential to develop friendships.

The ability to make friends is possibly one of the most meaningful skills a young person can learn (Erwin and Guintini 2000), yet Mulderij (1997) found that for many disabled young people, family members often substitute for friends or are involved in trying to find suitable friends for the disabled family member. Practise at mixing socially with a diverse range of people is important from an early age. Disabled young people are often hampered from developing relationships early on in their lives and as a result do not necessarily develop appropriate social skills for when they are older. A young person's history of relationships is an important factor in developing skills for making and retaining friends later in life (Mulderij 1997). Disabled young people are generally hindered in this process, partly as a result of their impairment and other people's attitudes and reactions to this impairment, but also as a result of constant adult company and therapeutic interventions. Some disabled young people will have the skills required for social interaction but may lack the experience or strategies required for applying these skills in unfamiliar contexts (Roberts and Smith 1999). As a result, they may experience higher levels of social and emotional difficulty and experience loneliness and a lack of friends, particularly when this involves socialising outside of school (Mulderij 1997). In addition, there may be many obstacles to overcome for a disabled young person to socialise freely with peers (Tamm and Prellwitz 2001).

The opportunity to play provides a good example of the different social opportunities available to disabled and non-disabled young people (Rodger and Zivanni 1999, Tamm and Prellwitz 2001). Ferland (1997) proposes that through play young people experienced feeling of discovery, mastery, pleasure and fun, and as a result develop their curiosity, creativity and self-expression. Disabled young people are more constrained in their play because their impairment and the resultant lack of certain abilities can be a serious obstacle to exploration, manipulation, experimentation and socialisation. Their play experiences will be diminished which may impact on their ability to problem-solve, adapt to future challenges and socialise. As a result disabled young people may have limited experiences of feeling mastery and control that are intrinsic in many play activities. Widdows (1997) suggests that this is the case for disabled teenagers who have limited opportunity for leisure activities outside the home at a period in their life when leisure and spending time with friends is important and the norm for their non-disabled peer group.

It would be easy to feel that the social experiences of disabled young people are mostly negative and as a result they will have a negative view of life. However this is not necessarily the case. Connors and Stalker (2003) conducted a two-year study exploring young people's experiences of impairment. They examined the impact of impairment by interviewing 26 disabled young people (aged between seven and 15), 24 siblings (aged between five and 19) and 36 parents. They found that the majority of the disabled young people were happy most of the time and this happiness stemmed from feeling a sense of achievement related to success at school or in sports and through spending time with friends. No participant adopted a tragic view of themselves and most accepted their impairment and got on with their lives in an average, ordinary way, not in an against-the-odds way.

Educational Experiences of Disabled Young Person

Given the large amount of time young people spend at school their educational experiences will have a profound impact on their academic development, self-concept, self-worth and attitudes to life in general (Lightfoot *et al.* 1999). For disabled young people there is much debate about whether they should attend a segregated special needs school or be included in a mainstream school. Legislation, from the *Education (Handicapped Children) Act* (1970) which made the State responsible for the education of disabled young people, to the more recent *Special Educational Needs and Disability Act* (2001), has progressively moved towards increasing the emphasis on inclusion, although there remains little empirical evidence to support this move (Sebba and Ainscow 1996, Sebba and Sachdev 1997, Wolfendale 1999, Llewellyn 2000, Lindsay 2003).

Although the Warnock Report (Department for Education and Employment 1998) introduced the term 'integration' into the British educational system, the preferred term is 'inclusion'. Farrell (2001) states that integration only referred to the type of setting into which disabled young people might be placed but said little about the quality of the education they might receive. Integration describes the placement of a disabled young person into a mainstream class, in what Corbett (2001) refers to as a 'dump and hope model'. The emphasis is on changing the disabled young person to fit into the social and academic life of the school. Integration leads to an emphasis on the structural changes to buildings without the corresponding changes necessary in the school ethos and culture (Davis and Watson 2001).

Many educationalists feel that this emphasis is wrong. For integration to be effective, there has to be a fundamental shift in the ethos and culture of the whole school (Barton 1998). The term inclusion found favour as it describes the process that schools undergo to ensure the participation of all students, no matter what their abilities, by considering curricula and organisational changes (Sebba and Ainscow 1996, Barton 1998, Booth 1999, Bishop 2001). The term encompasses a broader range of young people than just those who are considered disabled, it encompasses all students who experience barriers to learning and participation (Graves and Tracy 1998, Booth 1999, Thomas and Tarr 1999, Booth *et al.* 2000). The more inclusive schools are developing dedicated support systems to enable each disabled young person to fully participate in a mainstream environment (Sebba and Sachdev 1997, Thomas 1997).

Although there is little empirical evidence that supports inclusion over segregation, there is agreement between educationalists on what is necessary for inclusion to work. Of prime importance is an inclusive ethos within the school and the commitment of all staff members, followed by the provision of appropriate structural and material resources and adequate funding (Hadley and Wilkinson 1995, Corbett 2001, Lindsay 2003). These are required if there is going to be the establishment of a 'connective pedagogy' in which the unique needs of each individual learner are recognised and then connected to the curriculum and wider school community (Corbett 2001).

Considering what makes inclusive education work does not address the fact that many disabled young people still attend, and in some cases choose to attend, segregated special needs schools, although it is acknowledged that this number has decreased over the last two decades (Alderson and Goodey 1998, Abbott *et al.* 2001). There are pros and cons to both educational approaches. Indeed some educationalists believe that no single type of education can fit all pupils (Llewellyn 2000, Butler 2001). Pitt (2003) separates the debates into ethical, social and educational concerns, indicating that the arguments centre on the human rights ideology and philosophy, and the social experiences and the academic achievements of disabled young people.

Human Rights Ideology and Philosophy

Much of the current push towards inclusion is based on the human rights ideology (Feiler and Gibson 1999, Hornby 1999). Kenworthy and Whittaker (2000) state that ending segregation of young people within education is above all a human rights issue and refer to special schools as twentieth century gulags that create a system of apartheid. Fundamental to this is the belief that all young people have the right to learn and play together with their peers in their local community so there is no legitimate reason why they should be separated (Florian 1998). Thomas (1997) and Tomlinson (2001) believe that segregated education has played a key role in maintaining the unequal access to services and resources prevalent within society and perpetuating the stigmatised labelling and categorisation of disabled young people. The use of labels and categories is considered to be a barrier to inclusion as the focus is on what is wrong with the young person rather than what can be changed about the school (Johnstone 1995, Farrell 2001).

As persuasive and emotive as human rights arguments are, several authors feel that to use these arguments to justify inclusion is naïve. Firstly, a human rights ideology is thought to ignore the difficulties a disabled young person might have (Llewellyn 2000). This is similar to the limitations of the Social Model of Disability. By creating a homogeneous group of young people and saying that they all have a right to be educated in mainstream school, it is possible to dismiss each disabled young person's impairment. Llewellyn (2000) believes that mainstream schools are not always the best option because in their current state they are discriminatory and do not allow full access to the curriculum, resources and, perhaps most importantly, friendship networks.

This leads onto the second argument against using a human rights basis for inclusion. The human rights perspective maintains that inclusion will reduce prejudice and promote positive attitudes towards disabled people in general (United Nations Education Scientific and Cultural Organisation 1994, Carro 1996, Leicester and Lovell 1997). By interacting with a diverse, comprehensive array of humanity at school all young people will be better equipped to engage with society in general. Llewellyn (2000) believes that because mainstream schools are generally discriminatory, a reduction of prejudice and a greater acceptance of diversity is not overwhelmingly evident. Placing disabled young people in mainstream schools has not automatically resulted in attitude change (Yude and Goodman 1999, Farrell 2001). Llewellyn (1995) suggests that there may be acceptance of disabled young people in school based activities but this does not necessarily evolve into personal friendships. So using the human rights agenda to include disabled young people into mainstream school may not lead to the expected positive acceptance of all.

A further argument against the human rights perspective is with regards to whose rights are being considered. With regard to school there is a conflict of rights (Corbett and Norwich 1997). Within the competitive nature of education and the implementation of the National Curriculum schools have a right to maintain their quality and standards. In addition, parents have the right to select which school their child attends and to go to a tribunal if they are unhappy with the selection process. Finally, the young person has rights, but as Lindsay (1997) suggests, surely this is a right to good education, not the right to decide where to be educated. Hornby (1999) agrees that a right to a good education is the most important right, followed by the right to be fully included in the community. He suggests that inclusion can only be justified if both rights can be guaranteed.

Hegarty (2001) believes that a focus on inclusion distorts the purpose of education. He argues that being included is not why parents send their children to school. They send their children to school to be educated. Some young people, he claims, are not able to be educated in mainstream schools. These young people may require a specific special environment or the cognitive gap between them and their peers is too great that there would be no advantage to placement in a mainstream school. The argument here is that a disabled young person's impairment and abilities should play some part in the decision of whether to go to a special needs school or mainstream school, it cannot just be based on a human rights assumption that all young people have a right to attend their local mainstream school.

Social Concerns

The majority of young people, including disabled young people, report friendships as the most important aspect of school life (Swain and French 2000). It is believed that positive relationships with peers contribute to feelings of social acceptance and a healthy development of self-esteem (Pitt 2003). Inclusion provides the opportunity for all young people to mix with a diverse array of peers, in an environment that reflects the 'real world' (Graves and Tracy 1998, Pitt 2003). Through inclusion disabled young people can feel that they belong in their community (Cook *et al.* 2001) and their family can be more involved with the school (Graves and Tracy 1998). In essence, one of the key reasons given for inclusion, after the human rights argument, is that disabled young people have a better opportunity to form friendships with a variety of peers, and hence become known, within their local community. The social experiences available through inclusion are thought to enable disabled young people who attend mainstream school to be far more socially competent than their peers attending special needs schools (Kliewer 1998).

These are laudable claims and there is research that indicates that disabled young people do mix with non-disabled young people (Sebba and Sachdev 1997, Alderson and Goodey 1998, Bax 1999). There is however other research which indicates that a disabled young person is more likely to be ostracised, lack friends and be bullied when compared with their non-disabled classmates (Yude and Goodman 1999, Llewellyn 2000).

Indeed, there are several reasons why disabled young people may find it difficult to make friends with non-disabled classmates. Firstly, there is the issue of public perception and preconceived ideas. Non-disabled classmates may have little, if any, experience mixing with disabled young people. They may make incorrect assumptions about a disabled classmates' abilities, often having low expectations (Farrell 2001). Further, it is not uncommon for classmates to be initially curious about the disabled young person because of their novelty factor. This curiosity can be a problem because the disabled young person may spend a considerable time answering questions, some of which are quite personal, and still have very few friends once the 'interrogation' has ceased (Lightfoot *et al.* 1999).

Disabled young people may be perceived as different, and their impairment will mean that they have to do some things in an unconventional way to the mainstream. As a result they are more prone to being verbally and physically bullied, in ways ranging from teasing to being physically pushed or hit. More important, however, is the covert bullying, through exclusion from social groups leading to social isolation and loneliness (Llewellyn 1995, Dorries and Haller 2001). This view of inclusion reflects that of some parents, who feel that their children will be mistreated by other pupils and by some staff in mainstream schools. These parents choose to send their children to special schools for peace of mind as they are felt to be in safe and secure environments (Leicester and Lovell 1997). They value the perceived protective environment of a special school (Hadley and Wilkinson 1995) and feel that the environment of a special school provides a valuable pool of friends with whom their child may feel more comfortable (Mulderij 1997, Widdows 1997). This peer support is considered to be essential and for the most part is felt to be missing from mainstream schools as there are substantially fewer disabled young people to mix with, who might understand and share similar concerns and issues. The counter-argument is that there is a reduced option to mix with non-disabled young people in their community because of the wide catchment area of special needs schools. As disabled young people are unlikely to live near a special needs school this limits the possibility of developing and maintaining friendships with fellow pupils outside of school time (Cook *et al.* 2001).

A second reason why it may be difficult for disabled young people to make friends with non-disabled peers is that they are under constant surveillance from staff members (Allan 1996, Pitt 2003). These young people are watched and observed in the classroom and at break so that information is available for formal review meetings as part of the requirement of Statements of Educational Need. Allan (1996) claims that the degree of scrutiny for disabled young people is much greater than for other pupils at the school. This surveillance and the constant presence of adult assistants may make other pupils wary about beginning a friendship with disabled classmates (Ainscow 2000, Pitt 2003). It may also inhibit disabled young people so that they temper their emotions, behaviour and interactions.

The third reason for disabled young people finding it difficult to make friends at mainstream school is they are often absent from class because they have frequent health and social welfare appointments to attend (Lightfoot *et al.* 1999). Johnstone (1995) and Alderson and Goodey (1998) claim that a disabled young person's education can be severely disrupted by the interventions provided by a range of health and social welfare professionals, which may even include extended stays in hospital. Apart from the obvious difficulty of making friends, these absences and interruptions to learning can result in the risk of the disabled young person being academically disadvantaged (Lightfoot *et al.* 1999).

Educational Concerns

Although one of the prime foci of the segregation versus inclusion debate is education, there has been little research conducted that focuses on the educational benefits of either approach. Research remains inconclusive when comparing the educational performance of disabled young people attending mainstream and special needs schools (Farrell 1997, Pitt 2003). Nevertheless, in their review of the literature Sebba and Sachdev (1997) found a small to moderate positive effect of inclusive education on the academic achievements for disabled young people. They also claim that the presence of a disabled young person in a classroom is not detrimental to the academic performance of other pupils. They suggest that a further benefit of disabled young people attending a mainstream school is that they have access to a wider and more varied curriculum than they would have in a special needs school. The research projects of Butler (2001), Kliewer (1998) and Bax (1999) support these conclusions by revealing that disabled young people make better academic progress within a mainstream setting even though the differences may only be slight in some circumstances.

Wishart and Manning (1996) counter these claims suggesting that it becomes increasingly difficult in secondary school to meet the educational needs of disabled young people in a mainstream class. Further, staff often feel they are not skilled enough or have the time to adapt the curricula to accommodate the needs of disabled people (Llewellyn 2000, Wedell *et al.* 2000, Hemmingson and Borell 2002). In some schools disabled young people do not have access to the entire curriculum. Physical education is one particular subject where participation may be problematic (Simeonsson *et al.* 2001). This can extend to difficulty participating on school trips and extra-curricular activities connected to the school (Llewellyn 2000).

Wedell *et al.* (2000) found that a school's commitment to inclusion, may affect the school's position in the league tables. Schools that attract a relatively high proportion of disabled young people saw a lowering of their position on the league tables. Whether this was a direct result of disabled young people lowering the academic standards or the decision by some other academically able pupils to choose a less inclusive school to attend, is unclear. Dorries and Haller (2001) suggest that this may be because disabled young people require a relatively large number of educational resources to remain in a mainstream classroom, which may mean that there is proportionally less available for other pupils.

Hornby (1999) reviewed the literature available on the trend towards inclusion and suggests that many of the proposed goals of inclusion have not been met, including greater educational attainment. In line with some of the earlier discussion, he states that greater educational attainment, increased social skills, reduced stigma, increased self-esteem and improved parental involvement have not been realised through inclusion. His review is not negative towards the movement, but he, like other educationalists, encourages more research around the topic. This is particularly pertinent when the results of a later study in which he was involved are considered. Hornby and Kidd (2001) followed up pupils who participated in research investigating the outcome of an inclusion project conducted ten years previously. They interviewed 24 of the original 29 participants who had moderate learning impairments and who were moved from special needs to mainstream schools. Some went into special units within mainstream schools and others were included in mainstream classes. In the follow-up study all 24 students had completed their schooling and were between the ages of 18 to 25 years old. The authors found that at the time of the interviews, only three participants were employed full-time, one was employed part-time and the others were unemployed. Seventeen lived with their parents, one with her sister, one with her partner and two lived alone in rented flats. Two were in residential care and one was in a psychiatric unit. Three had been convicted for various criminal offences and one had served a brief prison term. Eleven participants reported having no friends, six had one friend, four had two or three friends and three had more than three friends. When reflecting on their transfer from a special needs school ten years previously, 11 out of the 12 who attend a special unit and only four out of the 12 who attended a mainstream class viewed this favourably.

The authors acknowledge that this is only a small-scale unrepresentative study. However, it did show for the 24 participants that there were low numbers in employment and in general their quality of life could be considered poor. In the light of their views about the transfer it seems that those that went to a dedicated special needs unit, viewed this more favourably compared with those moved into a mainstream class. Unfortunately no criteria are provided as to the decision for placing the participants into different settings. The results, however, question whether for these participants, the move into a mainstream class was beneficial. Indeed, it appears that for most the goals of inclusion were not met.

A Summary of the Educational Experiences of Disabled Young People

The evidence to support inclusive or segregated education is inconclusive. Much of the research is small-scale and unable to account for the many variables that need to be considered. This makes comparative studies and generalisations difficult (Pitt 2003). Llewellyn (2000) states that most studies also occur at one point in time and so do not capture the development of young people or the affects of the continually changing educational environment.

It would appear at this stage that the decision to include disabled young people in mainstream schools is predominantly a moral and ethical one. In this respect the view that people have of inclusion will depend on whether they are looking at it through a 'positive or negative lens'.

> With a positive lens, it is seen as something intrinsically good, about social justice and fairness, about recognizing the unique contribution of every individual learner and about the power of the human spirit. With a negative lens, it is seen as impractical, unrealistically utopian and a form of misguided liberalism which can only lead to failure and frustration.
>
> (Corbett 2001, p. 117)

Whichever view is adopted a young person's educational experiences will influence his/her development. It is too simplistic to state that one approach offers greater potential to develop more healthy and rounded attitudes as this will depend on many factors, perhaps most importantly, the intrinsic motivation of the young person. The influence of the family, peer groups and teachers will also play a key role in the development of a disabled young person's life views.

Summary and Research Focus

Disabled young people are subjected to many influences. Like most other young people, disabled young people's families have the most significant influence on their development, particularly in the opportunities offered. The other major influences on disabled young people are their school environment, social groups and experiences to which they are exposed. They are further affected by legislation focusing on disability issues and the national and international movements aimed at changing the negative attitudes within society towards disabled people. These factors will not only influence the young people's physical development, but perhaps more importantly, their emotional, social, psychological and cognitive development (Bronfenbrenner 1979). The acquisition of relevant learning and communication strategies, prerequisite knowledge and the motivation to learn and develop accounts for the individuality of each young person and the variation in their development (Rogoff 1990).

All these factors influence each young person's life story (Fox 1983, Denzin 1989, Frank 1996, Habermas and Bluck 2000). The inner world of the person and the outer influences of the physical, social, spiritual and social environment are intertwined in the development of a unique personal life story. Disabled young people's life stories, however, are generally ignored by researchers and as a result their views are often not heard (Morris 1997, Shakespeare and Watson 1998). It is predominantly professionals and parents who present their views about disabled young people or the disabled person when they are an adult reflecting back on their childhood. The voice of disabled young people themselves is usually absent (Barnes 1996, Morris 1997, Kitchin 2000).

The aim of this research therefore is to investigate the life stories of a small number of young people with a motor impairment by writing and analysing their biographies. In focusing on these biographies the intention is to identify what is important for each young person. This research rests on the premise that each disabled young person is unique and cannot be grouped with other disabled young people on the basis of their impairment label.

CHAPTER 3 METHODOLOGY AND METHOD

Introduction

In order to elicit the voices of disabled young people and to hear their views and opinions research located within the interpretive paradigm was conducted over a one-year period commencing in February 2002. Auto/biographical research methods were used to gather the life stories of disabled young people. This chapter explains the auto/biographical methodology used in this research. A rationale for the choice of methodology is followed by a description of the investigation method, an explanation of the data analysis procedure and, finally, a discussion of the ethical issues that arose from the research.

Rationale

Auto/biographical research focuses on the life experiences of a person (Denzin 1989, Erben 1998). This type of research is concerned with individuality, with the dynamics of change and how knowledge is culturally and historically situated (Sparkes 1994, Preece 1996). It allows the participants to describe their experiences in their own words and ascribe their own personal meaning to those experiences (Pollock *et al.* 1997). This type of research is appropriate for investigating disability issues because it offers 'counter-narratives' to dominant narratives and is a way of reconstructing alternative realities from the viewpoint of marginalized groups, such as disabled people, and in the case of this research disabled young people (Preece 1996, Thomas 1999).

The importance of giving voice to disabled young people is identified by Morris (1997) and Kitchin (2000). They believe that much disability research is unrepresentative of the views of disabled people because it tends to be researcher oriented and based around the desires and agendas of researchers and funding bodies, rather than disabled people who are the subjects of the research. This approach to research can be exploitative and as a result the researcher and participants are in an unequal relationship. Kitchin (2000) argues for the adoption of research strategies that are both emancipatory and empowering. Disabled people should play an active part in shaping the course of research projects and the researcher needs to be a respectful participant who continuously analyses the effects of his or her participation (Finlay 1998, von Tetzchner and Jensen 1999, Bricher 2000, Davis *et al.* 2000, Finlay 2003).

Atkinson and Walmsley (1999) state that auto/biographical research has the greatest potential for self-representation. The auto/biographical text can convey a more authoritative account of the life experience of people who have often been represented in stereotypical ways by others. Narrating one's life story is one way in which a person can make sense of their life, and at the same time, claim a self-identity (Frank 1996, Habermas and Bluck 2000). Denzin (1989) stresses that life stories are always open-ended, inconclusive, ambiguous and subject to multiple interpretations. The linking of events or actions is not a reflection of the chronological order of events but a reflection of the purpose of the story. The past is not fixed. Completely different narratives may result at different times from the same event and the meanings related to these stories may be different. How people see and interpret their past depends on why they are reflecting on it. It is partly due to this that every life story is made up of multiple stories that could be told. People create stories that reinforce their sense of who they are and who they want to be (Thorne *et al.* 1998).

Thorne *et al.* (1998), Baerger and McAdam (1999) and Habermas and Bluck (2000) believe that young people do not have the cognitive abilities or the motivation necessary to narrate coherent life stories. These authors propose that life stories do not become integrated until the more cognitively sophisticated forms of causal and thematic coherence develop during adolescence when teenagers begin to interrelate past and present selves by identifying causal links between life circumstances and events and their own personal development. They start to recognise the relationship between their past and their current personality, and have moved from believing that knowledge statements are an absolute truth, to realising that knowledge is uncertain and that truth is dependent on the context and the integration of a variety of sources (Kitchener and Fischer 1990). This enables teenagers to account for context and different perspectives, and realise that past events are not fixed but can continuously be reinterpreted.

Although complex and coherent life story narratives do not emerge until adolescence, autobiographical memory involving temporal and cultural coherence begins in early childhood (Gathercole 1998). The stories of young people need to be personally told, as they are the ones who are most knowledgeable about their own lives. Adults recalling their childhood memories will not recall the same stories nor give the same emphasis and meaning to stories as they would have done when telling those stories when they were young people. Adults will only provide an adult perspective of the stories they recall (Nelson 1992). The best people to inform researchers about childhood are young people as they are the ones experiencing that stage of life (Fine and Sandstrom 1988).

Plan of Investigation

Sample Selection and Recruitment

The plan for this study was to recruit a small number of young people with a motor impairment so as to investigate their views of their lives. Focusing on a small number of disabled young people allowed time to listen to and write their biographies, learning from their individual narratives. Although aspects of the life stories of the young people shared many similarities, it was anticipated that each life story would be unique. Hence the plan was to collect a divergent array of life stories, rather than life stories that converge on particular issues to reinforce a hypothesis, and to explore each life story in depth.

In order to recruit a small number of young people with motor impairment two special needs schools were contacted. These schools were contacted because I was familiar with both through my professional occupational therapy contacts. One was an early development centre and primary school that admitted young people from between the ages of six months to 12 years. Some attended part-time while spending the remainder of the week at a mainstream school, while others attended on a full-time basis. For the purposes of confidentiality, this centre is called Cloudberry School.

The second school was a residential primary and secondary school that accommodated young people who had primarily a physical impairment. Most attended this school on a residential basis although a small number were day students. Students were admitted from many different parts of the country. For purposes of confidentiality, this school is called Juniper Hills School.

Contact was made initially with the Director of Cloudberry School and the research proposal was discussed. A copy of the draft parent letter, parent and young person information sheet and parent and young person consent form was left with the Director, who required this information to discuss the research with the Board of Trustees. The Board of Trustees approved the research on the proviso that the young people recruited would be either close to leaving the school or would have already left the school. The reason for this was that they were in the process of recruiting a member of staff who would be involved in internal research and they did not want the research to conflict.

Contact with Juniper Hill School was initially through the Head Teacher, who then introduced me to the Head Occupational Therapist. The Head Teacher had approved the research but because I was an occupational therapist handed over the responsibility for co-ordinating the research to the occupational therapy department. The Head Occupational Therapist was given draft copies of the parent letter, parent and young person information sheet and parent and young person consent form.

Each school was asked to suggest ten students with motor impairment who might be interested in being involved in this research. The only selection criteria was that the young people should be between the ages of ten and thirteen (an age band selected bearing in mind the earlier discussion about the development of autobiographical memory – these young people should have the language and life experiences to start to begin to narrate complex life stories (Pollock *et al.* 1997)) and they should not have a significant cognitive impairment.

A further reason for the schools being responsible for the selection of young people was that ethically I only needed to have contact with those who indicated that they would like to be involved in the study. The Director of Cloudberry School and the occupational therapy staff at Juniper Hills School undertook the selection of the young people. The number of ten young people from each school was chosen on the assumption that less than half the people approached would respond.

Each school sent an information pack to the parents of the ten young people that they had selected. Within each pack there was a cover letter from the school, a letter from myself (Appendices 1 and 2), a parent information sheet (Appendix 3) and an expression of interest form (Appendix 4). The cover letter from the school indicated their support for the research whilst clearly stating that the research was independent from the school and the decision to be involved in the research was up to the parents. The letter from me introduced the research and invited the parents to read the information sheet and consider letting the disabled young person within their family be involved in the research (Appendices 1 and 2). The information sheet included more detail about the study, a brief biography about me, what would be involved if the young person participated, what would happen to the information and an explanation that participation was entirely voluntary (Appendix 3). The expression of interest form was included for the parents to complete and return to me if they were willing for me to come and talk to them and their disabled child further about the research (Appendix 4). This expression of interest form was not a commitment to take part in the research. Completing and returning the expression of interest form only meant that the parents had agreed to one visit from me to discuss the research further.

This visit enabled me to discuss the research in more detail with parents and the disabled young people to ensure that they knew what was involved before they committed themselves to further interviews. Generally seeking parental permission is considered to be the proper way to access young people in Britain. Young people are rarely free to decide entirely by themselves whether to participate in a research (Masson 2000, 2004). Masson (2000, 2004) points out that there are usually several adult gatekeepers who control access to young people. Within my research, the gatekeepers were the Director and Board of Trustees of Cloudberry School, the Head Teacher and occupational therapy staff of Juniper Hills School, and the parents of the young people approached. Usually, these gatekeepers have a positive responsibility in protecting young people within their care and checking out the motives of people who want access to the young people (Masson 2000, 2004).

However, as I was going to work with the young people to write their life stories, and planned to work with the young people as co-researchers as much as possible, I had to be sure that they were choosing to be involved in the research of their own accord rather than because their parents thought it would be a good idea. This is in line with the move for young people to be considered active participants who have a right to say what they will be involved in as outlined in the United Nations Convention on the Rights of the Young person (United Nations 1989) and the New Sociology of Childhood (Prout and James 1997, Burr and Montgomery 2003, Stainton Rogers 2003).

A date was set for the return of the expression of interest form. Parents were asked to return this form in the enclosed stamped addressed envelope. The date was approximately two weeks after the parents received the information pack on the assumption that if the parents were interested they would return it relatively quickly and for those who were not interested the information pack would either be binned or put to the bottom of a 'things to do' pile.

Nine parents, five from Cloudberry School and four from Juniper Hills School, indicated they were willing to discuss the research further. They were contacted by telephone and an appointment made at a time that was convenient for them and the disabled young person. At this informal appointment the parents and the disabled young person were encouraged to ask any questions they wanted about the research. This process enabled me to find out a little about the family.

At these meetings I tried to engage the disabled young person in as much conversation as possible to ensure that they understood what the research was about and what would be expected of them. I gave each young person a research information sheet, which contained the same information as the parent information sheet but in slightly simpler language (Appendix 5). In general these meetings were of approximately one-hour duration. At the end of each meeting, the young people were given the option to be involved in the research. All nine young people and their parents agreed to be involved. This was then formalised by the parents and the young people completing and signing a consent form indicating that they had read and understood the information sheet, they acknowledged that their participation was voluntary and they could withdraw at any time without explanation, they understood the research was part of a doctoral programme, and they agreed to the interviews being audio-recorded (Appendices 6 and 7). Once the young person and a parent completed their respective consent forms, an appointment was made for the first interview. Table 1 shows the name, place of recruitment and ages of each of the participant.

Table 1 Overview of the participants and interview information
(CB – Cloudberry School, JHS – Juniper Hills School; mar – married, sep – separated, div – divorced; br – brother, sis – sister; I/V – interview; m - minutes)

Name	Recruiting School	Parents marital status	Siblings	Age at last I/V	Date initial meeting	Date first I/V	Date last I/V	No. of I/V	Total time for I/V	Average time per I/V
Alex	CB	mar	---	11	23/02/02	23/03/02	30/11/02	4	198m	49m
Anne	JHS	mar	1br	12	16/02/02	24/04/02	31/10/02	4	140m	35m
James	CB	mar	2sis	11	16/02/02	26/03/02	28/10/02	5	216m	43m
Lucy	CB	sep	1sis, 1br	11	2/02/02	16/03/02	11/01/03	5	204m	41m
Riley	CB	mar	1sis	10	2/02/02	16/03/02	30/11/02	5	241m	48m
Ronald	JHS	mar	1sis	14	12/02/02	24/04/02	20/12/02	5	98m	20m
Simon	JHS	div	2br	12	17/02/02	1/05/02	19/02/03	8	288m	36m
Tony	JHS	mar	1br	12	12/02/02	13/03/02	30/10/02	3	129m	43m
Xanthe	CB	mar	2sis	13	2/02/02	16/03/02	23/11/02	4	255m	64m

Interviewing: A Tool for Data Collection

Interviews were used to collect the participants' life stories as this method was considered appropriate for discovering young people's perceptions of their experiences of their social and physical worlds (Yarrow 1960, Fine and Sandstrom 1988, Ginsburg 1997). Kitchin (2000) argues that rich data can be accessed through interviews as interviewees can express and contextualise their feelings. This supports the contemporary emphasis on narrative and auto/biographical research approaches in the construction of knowledge and understanding of marginalised voices, such as disabled young people (Leicester and Lovell 1997). The interviews were open-ended, unstructured and non-directive, allowing the participants to lead as significance was attached to the way the participants reported, presented and made sense of their lives (Plummer 1995, Frank 2002). Further, to ensure that the interviews were conducted at an appropriate level Bowden's (1995) guide for communicating with young people was followed.

Bowden (1995) suggested that prior to interviewing, researchers need to build a trusting and workable relationship with the young people. This can be difficult for adults researching young people due to their perceived position of authority, so spending time building a rapport prior to any interviews was essential (Kitchin 2000). The initial informal meeting with both the parents and young people was part of the process aimed at building a workable relationship in addition to ensuring that each young person was as fully informed as possible and in a position to freely choose to be involved in the research. I spent an afternoon at Juniper Hills School helping out in the classrooms of the young people to be involved in the research so they could see me at the school before I started any of the interviews with them. Before and after each interview I always allowed time to talk with each young person about things not necessarily related to the research. I spent time talking with the young people's parents and siblings before and after any of the interviews conducted in the young people's homes.

Bowden (1995) suggested that for a young person to be placed in a position of expertise and therefore able to actively engage in the research the interviews must be structured around themes that are familiar. The interviewer must not display too much prior knowledge as this may intimidate the young person (Moston 1990). In addition the interviewer must become skilled at asking appropriate open questions as young people generally did not respond well to direct questions (Dockrell *et al.* 2000). The participants for this research were placed in the position of experts because the topic for the interviews was their life stories (Curtin 2001). Each interview was relatively unstructured so that the participants could focus on what they saw as important. I asked questions to clarify anything that was unclear but basically the interviews were lead by the young people themselves. I displayed my respect and interest by listening to what they were saying (Lloyd-Smith and Tarr 2000, Curtin 2001). I also trusted their version of events and did not clarify various factual details with their parents.

Although Bowden (1995) suggested that during the interview young people should be given a choice of familiar or fun activities in which to participate, I did not find this to be essential during my interviews. Perhaps this was because the participants were reasonably comfortable with an interview format (Dockrell *et al.* 2000). I did however always offer each participant the choice of what they wanted to do, but on the whole they were happy to just sit and talk. They did show me some of their possessions, photographs and video clips but they did not feel the need to be active while we were talking.

I conducted all the interviews in a place where each young person would feel comfortable as Bowden (1995) and Masson (2000, 2004) suggested that this would reduce any anxieties and enable the young person to demonstrate their initiative and spontaneity. All the interviews with the young people recruited through Cloudberry School were conducted at their homes, usually on a Saturday or during school holidays. Most of the interviews with the young people recruited through Juniper Hills School were conducted at the school during the period between the end of formal lessons and the start of the evening meal.

As the nature of this research was the gathering of biographical information, each participant was interviewed several times to ensure as much material as possible was collected (Bowden 1995). They were informed that the interviews would stop when they felt they had told me all they wanted to. This allowed the participants greater control over the information they told me during the interviews.

After the initial meeting with the five young people recruited through Cloudberry School an appointment was made for the first interview. The interview appointments were made through each young person's mother. The initial meetings occurred during the month of February 2002 and the first interviews started in the following month. After this first interview I saw each young person about once every four to six weeks until the summer holidays.

Following my initial meeting with the four young people recruited through Juniper Hills School I arranged further appointments, either through one of the occupational therapy staff members or through the staff in the house to which the young person was assigned. The interviews for these young people started in March/April 2002. After the first interview I saw each young person about once every four weeks until the summer holidays.

Prior to the start of the first interview, the young people were reminded of the aim of the research, what the interviews were about and that they could withdraw at anytime without explanation. For this interview I began with an open question, loosely based on Wengraf's (2001) suggestion, that participants be asked to speak freely about their lives. When interviewing the young people there was a varied response to using this open question. All but two required some guidance in the sort of things to talk about. I provided this guidance by repeatedly adding questions and statements like, "Talk about things that have been important to you in your life" or "What are your earliest memories?" and "Anything else?" I needed to add these prompts to encourage the participants to talk more fully about their lives and to assist them to engage in the interviews.

In each subsequent interview the participants were always asked if there was anything else that they remembered about their life that they would like to talk about, in addition to various questions encouraging them to expand on the detail that they had talked about previously. Hence the focus of each interview was negotiated at the beginning and where necessary at appropriate intervals during its course. Later interviews were used to clarify issues raised and stories told in earlier interviews and to cover any outstanding themes.

Although pilot interviews are recommended (Fontana and Frey 2000, Silverman 2001), I felt them to be unnecessary in this research. This was because each participant was interviewed several times, so each interview conducted was used as a learning experience for all subsequent interviews.

A breakdown of the dates, number and length of each interview can be found in Table 1. The interviews with the participants recruited through Cloudberry School were usually longer than those conducted with participants from Juniper Hills School. This was because the length of each interview with the participants from Juniper Hills School was restricted by the school timetable. When the interview was conducted during the after-school activity timeslot then the time available for the interview was between 40 to 50 minutes. When the interview was conducted in the time period between the end of the after-school activity timeslot and dinner, then the time available for the interview was between 10 to 15 minutes.

The summer holiday break provided a convenient period in which to halt the interviews while I completed the transcriptions and the first draft of each young person's biography. During this time each young person was sent a £10.00 book voucher to thank them for participating in the study. Payment was made as a means of both acknowledging their contribution to the research project and compensating them for their time (Dowling and Dolan 2001).

When I completed and returned the first drafts of the participants' stories, appointments were made for a follow-up interview. Prior to this appointment, each participant was asked to read the first draft so that we could discuss it at the interview (Appendix 8). These interviews were conducted between November 2002 and January 2003 at the home of each young person, apart from one, which was conducted at Juniper Hills School. The focus was on correcting the first draft of the biography and adding any further information that the young person wanted to include in the biography. For all the participants, apart from Simon, this was the last interview as they were generally happy with their biographies, pending the changes and additions that were discussed in the interview. Simon, however, wanted to add more information so requested more interviews. He was seen a further five times.

Following the final interviews, a second draft of the biographies was completed and sent to the participants for their comments in June 2003. In the cover letter with this second draft the young people were given the option of either seeing me again or talking with me on the telephone or contacting me by email (Appendix 9). Alex emailed me to suggest some minor changes and to say there was no need to meet up. I telephoned the other young people in July 2003 and spoke with their mothers. Some mothers informed me of some changes required but each said that the disabled young person was happy with the draft. I only spoke with Ronald directly who said that the draft was fine.

It was important to ensure that the participants had the opportunity to comment on the final drafts of their stories. This was one way to ensure that the stories were a valid representation of what they had told me about their lives and was a sign of my commitment to work in collaboration with the young people as recommended by Morris (1997), von Tetzchner and Jensen (1999), Bricher (2000) and Davis (2000).

Each young person was again sent a £10.00 book voucher and a bound copy of his/her story as a final thank you for participating in the research.

Data Analysis

There were several stages to the data analysis. Firstly, each interview was transcribed as soon as possible after its completion. Where possible a young person's interview was transcribed prior to the following interview. However, this was not always possible due to several interviews being conducted around the same time. If an interview could not be fully transcribed prior to the next interview it was listened to and notes taken so that I was aware what had been discussed and could ask for further elaboration or clarification. The first stage involved the completion of all the transcripts of the interviews conducted prior to the summer holidays in 2002.

The second stage of the data analysis involved reading and re-reading the transcripts for each young person to sort out what topics the young people were talking about so as to achieve some insight into their biographies. To assist in this process, the text of each transcript was cleaned up. Nespor and Barber (1995) suggest that transcripts can be cleaned up to make them more flowing and to ensure that thoughts are expressed clearly. My intention in cleaning up the transcripts was to remove all the "umms" and "ahhs" and the repetition of words, sentences and topics, while maintaining the integrity, meaning and actual words the young people used.

After cleaning up the text, each young person's transcripts were separated into general topics, such as family, friends, schools and medical treatment, depending on what was appropriate for each young person. Then, by using predominantly the words the young person used in the interviews, the transcripts were turned into the first draft of their biography. I occasionally put in linking words but, as much as possible, only the young person's words were used.

When the first drafts of the biographies were completed they were arranged into A5 book formats that were held together by a ring binder. Each draft had a cover page with the young person's name on it. The contents of each was laid out in sections related to the topics identified and where possible in chronological order. These draft biographies were printed in 14 point Arial and were double line spaced. There was a lot of white space on each page so that the text did not look too dense. This was to make the first draft easy to read. To limit any confusion in reading the first draft, the real names of the young people and any other person or place that they had mentioned were used. An example of the cover page and text lay out can be found in Appendix 10.

The third stage of analysis involved the follow-up with each young person after they had read the first draft of their biographies. This generally involved a long interview in which amendments and corrections were noted and additional material was added. This stage was completed when each young person indicated that they had said all that they wanted to say.

The fourth staged involved the full transcription of the final interviews and the production of the second draft of the biographies. Amendments and corrections were made and additional material inserted. Although the young people did not comment on the layout or style of the first draft, I decided to lay the second draft out differently. This was based partly on the suggestion that the order in which an interviewee talks about issues is important (Wengraf 2000, 2001). Coffey and Atkinson (1996) also emphasise the importance of how the story is organised and developed, and where and how the narrative begins and ends. They state that the interest

> is not solely in the formal analysis per se but also in using the structures to identify how people tell stories the way

> they do: how they give the events they recount shape; how they make a point; how they "package" the narrated events and their reactions to them, and how they articulate their narratives with the audience or audiences that hear them.
>
> (Coffey and Atkinson 1996, p. 58)

Firstly, I decided to print the second drafts on A4 size pages and, rather than ring bind the book, it was stapled down the left side. The cover page had the young person's pseudonym on it plus an indication of when the interviews occurred. The text was still laid out in double-spaced 14-point Arial and there was lots of white space on each page. The major difference between the second and the first draft is that the sub-section headings were removed. Instead, I rearranged the text so that the order it was presented in followed the order that the young person had narrated their life throughout the interviews. Where a young person returned to a topic at a later interview, this information was added to where the information was initially raised.

The second drafts were returned to the young people for their comments and corrections. When each young person agreed the second drafts, the final drafts were written and used for the next stage of analysis. The final drafts of each story can be found in (Appendices 11 to 19). These have been reformatted to fit with the thesis layout; 12-point Arial and one and a half line space.

The next stage of analysis involved the identification and interpretation of the dominant themes in each young person's biography, using a thematic field analysis (Wengraf 2000, 2001). Preece (1996), Polkinghorne (1995) and Chase (1996) stated that aspects of the interviewees' stories may be presented thematically and be supplemented by the researcher's analysis identifying how each young person described and evaluated their experiences.

Ethical Issues

The responsibility I felt in the construction and analysis of the participants' biographies was immense because I was potentially making young people's private lives public (Ribbens 1993, Bakan 1996). I was open about this issue with the participants and their parents. I ensured that participation in the research was voluntary and that the young people were fully informed about what to expect. This was one reason why the initial meeting was essential as it was at this meeting that each young person could ask questions and decide whether they wanted to be involved. Those who agreed to be involved had the right at all times to withdraw from the study without giving a reason or to withdraw or change what they have said. This was formally recognised in the consent form that both the young people and their parents were asked to sign and the young people were reminded at each interview of their right to withdraw.

The vulnerability that the young people might have felt has been recognised by other researchers who noted that participants may feel unsettled as they reflect on and tell their life stories (Josselson 1996). Bar-On (1996) and Chase (1996) suggest that auto/biographical research explores each participant's concepts of self-identity and as a result they may disagree or feel uncomfortable with what is printed about them. To deal with this, I worked towards the written biography being a collaborative effort in which the young people controlled what they wanted to tell me and had the final say on what stayed in the written biographies. By giving them control of the final product meant that anything that they felt uncomfortable about was removed. Several wanted aspects of their biographies changed. At times this was because they were correcting an inaccuracy, but it also included the removal of swear words and ensuring that one of the references to a father was more favourable. Enabling the participants to have control over their final biography was also an important way of dealing with the issue of confidentiality. Although the names of people and places were changed, it is the nature of auto/biographical research that it would not be possible to disguise the identity of the participants completely. At the very least the staff at the two schools would be able to identify the participants.

As I was writing the biographies of the participants, I had to consider the issue of speaking for others. Although I tried to work with the young people in the production of the biographies and use their words as much as possible, I acknowledge that I had a major influence in how they were laid-out and presented, and I did not consult the young people with regard to my analysis. I was very involved in the construction of these biographies (Richardson 1995, 2000), which was why I have used the term auto/biography as suggested by Stanley (1993). Stanley stated that the construction of a biography was a collaborative effort between the researcher and the participant. In this way, I am acknowledging that my voice was not silent within the biographies because my agenda and personal priorities have contributed to their construction (Meloy 1993, Sparkes 1995, Josselson 1996). I made decisions about the text of each biography in terms of what was presented to the young people for their comments. So although I was trying to give voice to the young people, I was accountable and responsible for the voice and point of view that was written, and as such I recognise that I may have misrepresented the true voice of the participants (de Vault 1990, Alcoff 1991).

I also acknowledge that the stories told to me were only partial stories of the young people's lives. The young people constructed stories according to what they felt I wanted to know. These stories would likely be different to the ones they would tell others and would change as they reflect back on the events in later life (Hatch and Wisniewski 1995). Hence, the narrative identity of the young people will constantly change as they continuously revise their stories. My way of dealing with this issue was to acknowledge that these biographies reflect only what the young people wanted to tell me during the course of our meetings. On the cover page of each biography I clearly stated the period in which the stories were told to me. I was aware that by the time my dissertation was completed all the young people's stories would have changed, at least to some degree. I accepted that all the young people had multiple and continually changing interpretations of their lives and that they provided me with one of these interpretations, one way of looking at their lives. This was a valid interpretation and provided some insight into their lives during the time the interviews occurred. I also acknowledged that my analysis of their stories was only another interpretation, another point of view. My interpretation was valid as long as I took responsibility for my point of view and provided detailed explanations as to how I came to that particular point of view (Richardson 1990). This issue is related to evaluating the credibility of the research (Hatch and Wisniewski 1995, Sparkes 1995).

Evaluating the Credibility of the Research

The integrity of this auto/biographical research can be judged in the following ways. Firstly, according to Gitlin (1990) the degree to which the disabled young people were able to participate in the research process provided some evidence of the integrity of the process. As the interviews were relatively open, the young people controlled the direction of each interview and the content of what they told me. They also were involved in deciding whether the content of the written biography was accurate, making corrections and adding further information. In this way, I attempted to collaborate with the young people in the writing of their biographies, ensuring the biographies were a reflection of their voices (Stanley 1993, Richardson 2000). All the young people were satisfied that the biographies reflected what they had said. This affected them in different ways, with Simon summarising the general feeling by stating,

> When I read the first draft of the book, I was embarrassed about what I said because it was like reading your own thoughts. It's a bit strange.

Although the young people were engaged in the production of their biographies, they were not involved in the analysis of their life stories. As already noted this raised the issue of whether my analysis was an accurate reflection of their thoughts (de Vault 1990, Alcoff 1991, Richardson 2000). The credibility of this aspect of the research can be judged by the explanations provided of the analytical process, particularly via my engagement with reflexivity.

Reflexivity involved the direct acknowledgement that I was an active participant throughout the research process and had a significant influence on the development of the research and the engagement of the young people (Finlay 2003). I sought to ensure that I was conscious of my interactions and thoughts by keeping a research diary, thus turning my subjectivity into an opportunity to enrich the research findings (Davis *et al.* 2000, Finlay 2003, Gough 2003).

CHAPTER 4 HEARING WHAT THE YOUNG PEOPLE SAID: FINDINGS AND DISCUSSION

Introduction

My aim in conducting this research was to focus on the individuality of the nine disabled young people as depicted through their personal life stories. My belief was that disabled young people should not be defined by their impairment, rather they should be considered as people first and foremost. In this chapter, I explore their biographies and interrogate what they have to say about their lives. Although the interviews were non-directive and open-ended, allowing each young person to talk about their life in a way they found comfortable, they all talked about family, friends, school, and having an impairment. These topics have been used as a framework for the structure of this chapter.

Ideally, the analysis of each story would be presented separately as the aim of this research was to highlight the individuality of each young person in an attempt to move away from homogenising this group just because they all have the same medical condition. However, due to the word restrictions of a thesis, I discuss the data under the four main themes raised by the young people, emphasising the different perspective each brought to these themes. It is my contention that the different perspectives would be related to the way in which each young person had interacted and engaged in the variety of environmental contexts that they had experienced (Bronfenbrenner and Morris 1998).

In this chapter, I focus first on briefly describing each young person in order to provide some background as well as some indication of our interactions. This is followed by an examination of what the young people said about their family, friends, schools and impairment. To allow the young people to speak for themselves, the text is illustrated with quotes from their biographies as suggested by Kitchin (2000).

Description of the young people

Lucy

Lucy chose her pseudonym but gave no reason for her choice. She was born in 1991, 10 weeks premature, and spent a period of time in a special care baby unit before going home. She was 11 years old by the last interview. She lived at home with her mother and brother Guy, who was exactly 13 months older than her. Coincidently, her brother was also born prematurely. Her father worked in another European country during the week and came home at weekends. During the course of the interviews, her parents separated, and planned to divorce. Lucy also had a sister Trudi who was 16 years older than her, who had lived nearby but during the course of the interviews moved, with her partner, to another part of England.

Lucy's main interest was spending time with her friends, but she also enjoyed playing practical jokes, listening to music, making robots out of junk materials and looking after her pets. In the future she wanted to walk, be a disc jockey and work as an archaeologist. She originally attended the same mainstream primary school as her brother. She completed her primary education, years five and six, at Cloudberry School. She began her secondary schooling at a mainstream school but a different school to the one her brother attended.

Lucy was friendly and easy to talk with during our meetings. She showed no sign of being bored, apart from when we were watching videos of her childhood with her brother and mother. Often she asked questions about my family and I felt comfortable answering as I sensed her genuine interest. She nearly always finished her sentences or her thoughts even on occasions when I interrupted to ask a question.

Lucy walked with the aid of sticks or a walking frame. She used a manual wheelchair when travelling a distance and a powered wheelchair when she was in a hurry. She also had clear but slightly slow speech.

<u>Xanthe</u>

I chose Xanthe's name as she could not decide on a pseudonym. She was born in 1989 and was 13 years old by the last interview. She was one of twins. Her twin sister Liberty had no impairment. She lived at home with her parents, her twin sister and her younger sister Matilda. The family also had a pet dog. Both sets of grandparents were supportive. Her paternal grandparents paid for her private physiotherapy. She had a particularly close relationship with her maternal grandfather and was very upset when he died. She loved being involved in dramatic performances and singing in a choir. She did not state what she would like to do in the future although she did like writing.

Xanthe had always attended a mainstream school. She went to the local primary school with her twin sister but had to move to a different secondary school because of her special needs.

When I first met Xanthe she was having difficulty making friends at her mainstream secondary school. Her difficulties were possibly more acute because her twin sister went to the local secondary school with most of their primary school friends. She had no difficulty expressing her views and came across as intelligent, thoughtful and reflective, presenting herself as older than her chronological age. As she suggested she had had to grow up and think about things more than most other girls her age had to. Xanthe referred to herself as a bit of a 'boff' and thought this might be one reason why she had difficulty making friends.

Riley

Riley could not decide on a pseudonym and did not quite understand why his name had to be changed. I chose to call him Riley. He was born in 1992 and by the last interview was 10 years old. He lived at home with his parents and his sister Tilly, who was three years younger than him. He attended a mainstream primary school, with a large special needs unit, four days a week and Cloudberry School one day a week. Tilly attended a different primary school. His father worked as a graphic designer and was partially responsible for Riley's interest in computers. Riley also had reasonably frequent contact with both sets of grandparents. His paternal grandparents lived locally while his maternal grandparents lived some distance away. Riley saw these grandparents mainly during the holidays. He enjoyed reading, watching television, drawing and using his computer. He also collected toy frogs. In the future he wanted to be able to walk and have a job that involved working with computers.

On meeting Riley, I noticed that he did not look directly at me, something that he was unable to do throughout all the interviews. In addition to not looking at me when we were speaking, Riley tended to provide short quick answers to any questions. At times it appeared that he was not really thinking through his answers as he required a lot of prompting to talk about his life. This made the interviews more difficult as he was unable to elaborate on what he was saying. The impression I gained was that he had not yet reached the stage of reflecting on his life and tended to consider only the here and now; perhaps not surprising as he had only just turned 10 prior to our first interview. He was, however, very co-operative and willing to be involved and always appeared to be ready and willing to see me.

During the interviews, he would only talk to me when there was no other member of his family present in the same room as him. He wanted what he said to be kept between him and me. He was also concerned about some of the things he said, as he did not want certain people to find out.

Up until a year prior to our first meeting, Riley had been able to walk with sticks. He had an operation which resulted in him having to relearn how to walk. He had made a considerable improvement since his operation but he was not yet back to the level of mobility he had prior to the operation. He walked a short distance with either a frame or an adult helping him and used a manual wheelchair for longer distances. At home, his bedroom had been moved downstairs to make it more easily accessible.

Ronald

Ronald chose his pseudonym, saying that he just liked the name. He was born in 1988 and was 14 years old by the last interview. He used a powered wheelchair to enable him to move around. He was interested in playing wheelchair football and being involved in a variety of other wheelchair sports. He was also interested in music, with a preference for the heavy metal style. Ronald was not sure what he would like to do in the future although he was considering going to college and being involved in the development of wheelchair football. He would like to drive and if he did not have an impairment, he would be an RAF pilot.

When at home he lived with both his parents and sister Tina, who was two years younger than him. His father worked for the railway and his mother had a part-time job as a dinner lady at a school. His sister attended the local secondary school. His family depended on social services to assist with his caring when he was not at Juniper Hills School where he boarded during school terms. Prior to moving to Juniper Hills School for his secondary education, Ronald had been in a special needs primary school. He had never attended a mainstream school.

Although Ronald was relatively friendly and initially had agreed to be involved, I suspected that during the course of the interviews, he was not really engaged with this research. This manifested in several ways. Ronald was always late for our arranged meetings, even to the extent of missing one. This meant that the four interviews held at the school were short, with the longest lasting for approximately 17 minutes. Throughout the last interview, which was conducted at his home, he watched a black and white war movie. During this interview, he rarely acknowledged me and gave the impression that he did not want to talk. The conversation was very much one way, as I asked all the questions and Ronald answered in as brief a way as possible, usually with a 'yes' or 'no' or the equivalent paralinguistic expression.

Finally, when I phoned to ask him his opinion of the second draft of his story, his mother told me that he had won one of the events in the National Wheelchair Games and would possibly be representing Britain in that event at the next Para-Olympics. When I mentioned this to Ronald, he acknowledged that this was the case but did not say anything more about this.

During each interview Ronald appeared to have difficulty elaborating on what he was saying. He focused mainly on his time at Juniper Hills School, seeming to find it difficult to talk at any length about his earlier life. This meant that I was more directive and asked more questions than I had originally intended.

Tony

Tony chose his own pseudonym but gave no reason for his choice. He was born in 1990 and was 12 years old by the last interview. He was interested in Formula 1, fast cars and rugby. Tony stated that his ideal job in the future would be to return to Juniper Hills School and work as a physiotherapy assistant. He lived at home with his parents and his brother Jonny, who was two years younger than him.

Tony was born three months prematurely and had to spend the first six months of his life in a special care baby unit. He suggested that it was only because of the technology available at the time that he survived. He had always attended a special needs school. During the interview period, he was a day pupil at Juniper Hills School.

Tony had quite a marked perceptual impairment. He was unable to use both his eyes together and as a consequence lacked depth perception. This affected his ability to write and form letters. He had, however, started to read and was able to use a word processing package on the computer with the help of the software package, Penpal. Tony also stated that he has Asperger's Syndrome.

Judging by his detailed story of the long process his parents went through to ensure he was admitted into Juniper Hills School, he appeared to have a good memory for factual information. In addition, he always included the names of people and places when telling his stories to provide a fuller picture. At times he talked in an elaborate style which required considerable concentration to follow, indicating that his command of language was quite good.

It became clear that Tony worried about things and became anxious, particularly in new situations. His mother said that he was very worried during the summer break prior to starting at Juniper Hill School, wondering what it would be like to be at his new school. He fidgeted with his hands during the interviews and occasionally rocked backwards and forwards. He was unaware that he was doing these things.

Tony was a thoughtful and kind person, full of genuine enthusiasm for other people and for the things that he did in his day-to-day life. Even when he was describing a difficult incident or experience he continued to portray it in a positive light.

James

James chose this pseudonym based on his favourite movie hero, James Bond. He was born in 1991 and was 11 years old by the last interview. He was a passionate Arsenal and England football supporter who liked to collect video/DVD movies, particularly James Bond movies, go to theme parks and play on his game console. In the future, he would like to be a football manager. He lived at home with his parents and two sisters; Jessica who was three years older and Nina who was three years younger. He attended a mainstream primary school that included disabled young people, although not the one his younger sister attended. Although he did not agree with the decision, he was moving onto Juniper Hills School for his secondary schooling, where he would be a weekly boarder.

During our meetings, James was enthusiastic, his face was expressive and he radiated a zest for life. He had a manual wheelchair that he used at school and at other times when crawling along the floor was not appropriate. Although he was unable to speak clearly, this did not prevent him from talking. I was able to understand most of his speech and when I did not understand something, he either repeated what he was saying or his mother intervened on his behalf. He was friendly, funny and willing to talk about most things. He seemed to say what he wanted to even though his mother disapproved of some comments he made. His decision not to talk about his granddad, who died about 18 months prior to the first interview, while his mother was in the room suggested a certain sensitivity. Indeed, his mother sent me an email, following this particular interview, stating that he did not talk about his grandad because he was worried he would upset her, as the death of her father had been traumatic for her. James had a good sense of humour and he was much more talkative when asked about recent and current events.

Anne

Anne chose her pseudonym but gave no reason for this choice. She was born in 1990 and was 12 years old by the last interview. She enjoyed going on shopping trips with her mother and being involved in research projects to show non-disabled people how clever disabled people can be. In the future, she would like to go to college and perhaps university. She would like to work as a presenter or as a computer designer and earn lots of money. She would also like to walk. She was born nine weeks prematurely and stated that, as a result of her birth, she had to be resuscitated and her brain was damaged. This resulted in her alternating between using a manual and powered wheelchair to enable her to move around. Apparently, she also had some spatial awareness problems which affected her ability to read small print and some aspects of her mathemathics.

When I met Anne, she was a weekly boarder at Juniper Hills School, where she had been a pupil since the beginning of year five. Prior to this, she had attended two mainstream primary schools and a special needs nursery. At weekends and during holidays, she lived at home with her parents, her brother Hugo, who was about two years older than her, and her pet cat. Her father worked with a car dealership and had in the past worked very long hours but now has more time to spend with his family.

Throughout the interviews, Anne remained friendly and interested. She was at ease talking about herself and sharing her life experiences and appeared to have some good insights into her own attitudes and feelings. She had a genuine interest in the various research projects she was involved in and appeared to relish the opportunities given because she was in a wheelchair. She acknowledged that there were times when she got down but on the whole she believed that she was a positive person.

Simon

Simon chose his pseudonym because he liked the nasty judge on the television series 'Pop Idol', Simon Cowell. He was born in 1990 and was 12 years of age by the last interview. He was a boarder at Juniper Hills School where he had been a pupil since starting secondary school. His parents were divorced. When he was not boarding at school, at weekends and school holidays, he spent his time shared between his mother and father. He had two older brothers. One brother was studying music and the other had joined the armed forces.

Simon used a powered wheelchair with a special supportive seating system for his mobility. To reduce extraneous movements and to assist him to have more control, Simon wore a Lycra body suit and had straps to secure his feet to the wheelchair footplates.

Simon's speech was initially difficult to understand, although this did not prevent him from being very talkative. He had a Lightwriter, an electronic communication aid, which he used to supplement his spoken speech but he preferred not to use it. He never tired of repeating what he was trying to say until I understood, even when he was telling a joke. At times I had to ask him to say it another way or as a last resort to type a key letter or word on his Lightwriter to help me to understand what he was saying. I often repeated what he said so that he knew that I understood. Simon used this to play tricks by swearing to see if I would swear when I repeated what he had said.

In spite of his enthusiasm, he seemed to have difficulty telling his life story. The first four interviews centred on his fixation with the Eurovision Song Contest and the Children in Need event. It was not until the fifth interview that these two events were no longer mentioned. Initially he avoided talking about his life and seemed more concerned with trying to portray a certain image. He often swore, although I am sure that this was for affect, and he would also change topic without warning. Simon avoided any talk about how his parent's divorce had affected him, saying that he did not really care about it.

There was little sense of chronology in Simon's story. He provided vignettes and brief stories that showed him in an individual way and provided him with the opportunity to display his humour. He seemed to like to be thought of as an individual who was a bit radical and a bit of a 'dodgy' character.

Alex

Alex chose his pseudonym after the hero in the Anthony Horowitz series of novels about a teenage spy called Alex Rider. He was born in 1991 and was 11 years old by the last interview. He was born three months prematurely and had to spend the best part of the first three months of his life in a special care baby unit. His condition was so serious that there were some days when his parents thought he was not going to live. He was able to talk in some detail about this period of his life because his father had taken a photo of him everyday and had written a brief comment, such as his age and weight or 'first bath' for each photograph. He also had a permanent scar on his wrist caused by an accident with a drip during this time in hospital which provided a constant reminder of this period of his life.

Alex was an only child and lived at home with his parents. He had tried a variety of activities including, horse riding, singing, keyboard lessons, drama and scouts. He also liked to play on his computer and games machine. He attended a local mainstream primary school four days a week and Cloudberry School one day a week. His family had a dog and cockatiel as pets.

Alex wore two hearing aids which his mother said allowed him to hear at a near 'normal' level. He could walk short distances with a frame but tended to use either a manual or powered wheelchair for moving around outside. He used a powered wheelchair for moving around his school.

Alex's was keen to be involved in this research. When I first met him he had prepared some questions to ask me that were concerned with his anonymity and who would be reading the book. He was chatty and friendly throughout all the interviews. Often he was not able to expand on his answers or go into depth about his feelings. He didn't always understand what I was asking but felt confident enough to ask for clarification. He was distracted at times during the interviews, and would often pause for long periods before answering a question. Alex demonstrated his initiative further by being the only young person to contact me via email after reading the second draft of his story to inform me of some minor corrections.

The Young People's Views of their Families

Several issues concerning the family were raised in the literature review. These included the marital status of the parents, the cost implications and the stress of raising a disabled young person and the effect disabled young people have on their siblings. This section relates the young people's comments on their family to these issues.

Marital Status

Read and Clements (2001) found a greater proportion of disabled young people were brought up in single-parent households compared with non-disabled young people. Single parents were usually women who had to carry the full responsibility of the care and upbringing of their disabled child, more often than not with little support and a greatly reduced option of being employed. This proportion of single parents was not represented in the sample of disabled young people in this study.

Of the nine young people involved in this study, seven lived with both parents. Of the other two, Simon's parents divorced prior to the start of the study and Lucy's parents separated during the study, although as her father had worked overseas for several years, there were frequent periods when he was not at home.

Financial Costs of Raising a Disabled Young Person

The costs of raising a disabled young person have been found to be significantly greater than that of raising a non-disabled young person (Lewis *et al.* 2000, Curran *et al.* 2001, Dobson *et al.* 2001). This caused a financial burden for parents who usually had the added complication of compromising their employment prospects to satisfy the care needs of the disabled young person in the family. Lewis *et al.* (2000), Dowling and Dolan (2001) and Read and Clements (2001) found that one parent was usually in full-time paid employment (normally the father) and the other (normally the mother) either did not work or worked part-time. Only Ronald and Simon mentioned that their mothers were in part-time paid employment. The other young people mentioned only their fathers being employed. None of the young people provided any evidence in their stories that they were an economic burden to their families.

Stress of Having a Disabled Young Person in the Family

Statham and Read (1998) and Roberts and Lawton (2001) found that having a disabled young person in the family could lead to stress because the demands involved in raising him or her exceed those for a non-disabled young person. Although the young people could not remember their early lives, Alex, Tony and Anne recognised this period as a time of stress. Alex had a photographic record of his first 90 days of life. Although he did not directly say so, it was clear from this record that his parents were worried because his survival was uncertain, particularly in the first few weeks. Several of the young people were born prematurely, and although they did not have a photographic record, the period when they were in the Special Care Baby Unit would have been a very emotional and draining time for their parents.

Tony and Anne stated that another period of stress for their parents was when they were told that they had a disabled child. They indicated that their parents were shocked. Larson (1998) described how parents experienced contradictory emotions around the time of being informed of their child's diagnosis. They were usually torn between feelings of both grief and love for their child as they began to rebuild their concept of what family life would be like. As Dobson *et al.* (2001, p. 25) stated, when parents have a disabled child they have to

> construct a new paradigm of family life so as to accommodate and include all aspects of their 'new' lives. Within this new paradigm, relationships, obligations, aspirations, responsibilities, as well as one's sense of self, had to be redefined and renegotiated.

For Anne's parents, her early years were a difficult time because they were not informed that she had to be resuscitated after her birth. Instead, they sought a paediatrician's opinion when they noticed Anne was unable to hold her head up or sit straight. Anne's parents were initially left to find out information about her condition and the services she required. She stated,

> I'm surprised my mum and dad didn't have a nervous breakdown when I was little. My mum and dad didn't know what to do at first because they didn't know anything about cerebral palsy and what could help. They didn't know about the Peto Institute until it was suggested. They didn't know about physiotherapy until it was suggested. So when I was little, I was very stiff and I couldn't do much that the average toddler could do. Mum and dad soon looked into this and started phoning and writing various letters or statements or whatever and got to know more. They got some magazines from companies like Scope and they told us about the *special needs nursery* that was near where we lived. So we went and had a look and liked it and it's all progressed from there really.

Although Tony was born prematurely and spent the first six months of his life in a special care baby unit, his parents did not realise he had an impairment until he was about three years old. Tony said that both his parents were shocked about this news and had to deal with more because it turned out that he also had Asperger's Syndrome and some perceptual problems. Tony stated that there were two other times in his early life when he almost died. The first time was when he was young and had to go to hospital because of a chest infection. The second occasion resulting from his chronically infected tonsils and adenoids, seemed to be more serious. His mother did not want him to go to hospital and, according to Tony, said, "I'm not having my child die in hospital, I think he would rather die at home".

Tony saw both these occasions as major turning points in his life and as with his initial prematurity, felt that it was good that he actually pulled through and fought to survive. He also had some notion of the effect his death would have had on his parents by stating, "My mum was so upset because if I had of died it would have caused a lot of bother to the family". This reflects the roller-coaster of emotions that parents go through because of the often uncertain futures of the disabled young people (Larson 1998, Dobson *et al.* 2001).

Tony mentioned that he wore nappies until he was six, demonstrating how the demands of caring for him exceeded those of caring for a non-disabled young person, and would have added to the potential stress of raising him. Bereford (1995) and Read and Clements (2001) pointed out that having to care for a disabled young person beyond the age when they would be usually expected to do more for themselves was a major cause of stress for parents.

Xanthe provided an example of how her mother dealt with the stress of caring for three daughters when the older two started secondary school. To spend more time with her other two daughters, her mother arranged for carers to help Xanthe get ready in the morning and have a bath in the afternoon. Although Xanthe did not like having carers she saw it as necessary as her mother was under a lot of pressure and this was one way of helping her cope. She remarked,

> Mum was the one who decided that I should have carers … She was probably a bit desperate because we didn't have an au pair and I'm hard to live with sometimes when I'm depressed. Mum decided I should have carers because she wasn't getting a chance to do normal things with Liberty and Matilda … So I don't blame her for organising carers because she had a lot of extra, a massive amount, to think about.

Larson (1998) and Taanila *et al.* (2002) suggested that in order to cope with the stress of raising a disabled young person, parents used a range of coping strategies. Problem-focused strategies were a common form of dealing with the stress (Judge 1998). In Xanthe's case, her mother sought external support to ensure that all three daughters could be ready to go to school within the limited time available in the morning.

Respite care has been reported as being the most common service requested by parents as a means of coping with the stress of raising a disabled young person (Morris 1998a, c). Interestingly, none of the young people mentioned respite care. This may be because the support and resources that the families already had, particularly from their extended families, negated the need for respite care. Indeed, seven of the nine young people lived with both parents. Of the remaining two, Lucy's father remained in frequent contact and for most of Lucy's life her older sister had lived nearby and actively supported her. When Simon was not boarding at Juniper Hills School, he split his time between his mother and father. Although not considered as such by the young people boarding at Juniper Hills

School was a form of respite care during school term. Simon, Ronald and Anne's parents may not have felt the need for respite care as their children were away at school for long periods of the year, therefore reducing the potential stress at home. It was also possible that the degree of impairment each young person had may not have been at a level that required the parents to seek respite care, even infrequently. This appeared to be the case from the insight gained into the lives of the families.

The fact that respite care was not used, may also reflect the stigma of this facility, reinforcing the difference the young people and their families may have felt because they lived with an impairment (Middleton 1999). Alternatively, it may reflect that the families felt the service provided was inappropriate for their needs as it lacked the flexibility to suit their different lifestyles (Read and Clements 2001). Morris (1997) felt that by not using respite care facilities parents were reinforcing the normality of the disabled young people's lives because they would not usually send non-disabled young people to an institution to be looked after.

Siblings

Brothers and sisters provide opportunities for including disabled siblings in activities, extending their everyday experiences (Widdows 1997). Cate and Loots (2000) found that siblings may feel anxious, withdrawn, aggressive, embarrassed and guilty about their own health. They may also feel resentful towards their disabled sibling who may have more parental attention and restrict the activities of the family (Widdows 1997). These findings tended to focus on the uni-directional impact disabled young people had on their non-disabled siblings, from the point of view of the non-disabled siblings, rather than the interactive impact the siblings had on each other. Research has not focused on how a disabled young person felt about their non-disabled siblings. The young people in this study talked about their feelings for their siblings, with only Anne considering the impact she may have had on her brother.

Apart from Alex, all the participants had one or two siblings and were generally positive about their relationship. They talked of the support their siblings provided. Lucy talked of her close friendship with her older sister Trudi who often looked after her or had Lucy stay at her house for sleep-overs. Xanthe said that her twin sister Liberty had always been there for her and that her younger sister Matilda had been particularly sensitive during her low moments. Tony stated that his brother Jonny looked after him when he was anxious and worried.

Research suggests that the support provided by siblings was only one way. However, the findings from this study indicated that some of the disabled young people felt that they supported their non-disabled siblings. Although Lucy was younger than Guy, she was protective of him as she felt he did not stick up for himself. She saw herself as more able to take care of herself, especially when bullied. Tony was older than his brother Jonny and because of this he felt that he could offer him advice, particularly on the importance of doing his homework.

There were times when the young people's relationship with their siblings was not so supportive, perhaps reflecting the ordinariness of their relationship. Xanthe found the relationship she had with her twin sister changed when they went to different secondary schools.

This seemed to be at the root of some of the arguments they started to have.

> Then sometimes we have a massive argument about something that is not stupid but is something that would perhaps not be as big if you didn't have a sister in a wheelchair. I think we have probably had more arguments since we have gone to secondary school because there's so much I envy because she has gone to the school I wanted to go to with our primary school friends.

Riley's younger sister got on his nerves because she was always inviting her girlfriends home and would do dangerous things such as climb the door-frame, making him anxious. He described how he felt when he said,

> Sometimes I like having a sister and sometimes I don't. I do like her being around sometimes but sometimes she does things that annoy me or some things that are really bad and mum does not even notice ... She also climbs up the walls by putting her hands on either side of the doorframe ... It is really dangerous ... I am worried that she will hurt herself but she just says, "Oh I won't hurt myself" ... My sister has loads of friends ... I hate the way she invites all her friends around and sort of runs around the house. She runs around the house so much ... I normally go in my room because I don't really like it when Tilly's got all her friends running around.

James found his two sisters annoying because they teased him. Anne, on the other hand, complained that her older brother did not show her any signs of affection.

> I don't spend much time with my brother, Hugo. I'm sure he does love me really but I wish he would admit it. There is a picture of him giving me a cuddle. He was about four years old and I was about two or three ... We don't dare hug each other now. I want to hug him but he wouldn't hug me.

This may have been because he was embarrassed about having a disabled sister as Widdows (1997) found in her study but it could also have been a factor of his age. Anne was the only young person to acknowledge that having a disabled sibling must have had some impact on her brother. Widdows (1997) and Cate and Loots (2000) found that having a disabled sibling may have positive and negative effects on the non-disabled brothers and sisters. Anne felt that her brother must have been through difficult times as the family came to terms with her impairment, although she did not think that this was still the case.

> My brother, who is only a year older than me, used to get frustrated when we were growing up because he couldn't understand why our parents were spending so much time with me. You know when you are young, if your parents spend attention on somebody else for too long you get jealous but he's learnt to live with it. Now he doesn't mind because really I don't get treated any differently to him.

Extended Family Members

Previous research made little mention of extended family members and their impact on disabled young people. Indeed, where it was mentioned, the focus was on the negative reaction of these family members rather than the support they provided. Dobson *et al.* (2001) found that people outside the immediate family often could not see that the family wanted to be considered ordinary and would have appreciated others supporting them in a way that acknowledged that they basically had the same needs as other families.

Some of the extended family members of these young people had a positive impact on their lives. These members supported the parents of the young people by being around, becoming involved in therapy programmes and offering regular everyday experiences. In particular, the maternal grandfathers of both Xanthe and James played a significant role in their lives. Xanthe spoke fondly of her maternal grandfather.

> I have memories of him bouncing around on the floor and lifting me up on his shoulders. He was 60 years old and was cantering around the garden and everything. He took us to Thorpe Park and those sorts of places ... He was the one who was always there for me.

James spoke of his maternal grandfather in a similar vein, emphasising how he treated him like any other grandson and was not bothered about his impairment.

> I was very close to my granddad, my mum's dad. He was a lot of fun. I used to stay with him every weekend ... I would stay there without my sisters. I used to sleep downstairs and he would sleep downstairs with me. My grandmother slept upstairs. We would stay up late and play football and stuff like that ... He was a good friend.

Both Xanthe and James were devastated when their respective maternal grandfathers died. Xanthe said that it was "like the worse thing that had ever, ever happened".

Simon spoke of his relationship with his uncle, his father's brother. It appeared that Simon liked this uncle because he could have fun with him.

> I want to stay with my uncle ... I see my uncle every holiday. I work for my uncle as an undercover agent, making deals. I am working undercover here at the school. What I am finding out is top secret.

Alex spoke of his visits to his cousin's house. On these occasions his older cousins looked after the younger ones, including Alex, while their parents went out for a "booze". Alex enjoyed going to his cousins' house, as he was able to stay up late and have some 'older' experiences.

Anne, Tony and Lucy did not mention any support they had received from their extended family.

Not all the extended family members were supportive. This was the case for Xanthe who described her paternal great-grandmother as "utterly insulting ... one of the worse people I have ever met ... disgusting ... not a nice person ... horribly cruel and completely bitter". From Xanthe's perspective, her great-grandmother made no effort to accept her.

> She talked to me like I was some sort of object, like I was a nuisance. She said a lot of rude things. The last time I saw her she said, "What are you going to do with her then?" It was like she did not want me to be part of the family.

Ronald revealed that not all his extended family were initially supportive. He felt, however, that this was normal behaviour for people when they first heard that someone had a disabled child, supporting the findings of Dobson *et al.* (2001) who suggested that it was not uncommon for people outside the immediate family to be unable to see past the disabled young person.

> Some of the family were a bit put off when mum and dad told them that they had got a disabled son ... I don't know anybody who has got a disabled child who isn't a bit touchy about it but I'm 14 years old now, that was 14 years ago, and I get on with everyone in my family, my relatives, now.

The Young People's Views on Friendships

Swain and French (2000) stated that friendships were an important aspect of disabled young people's lives. This was borne out by most of the young people as they talked at length about their friends. Having good friendships, in the majority of cases, lead to young people feeling good about their lives, perhaps contributing, as Pitt (2003) suggested, to feeling socially accepted and having a healthy self-esteem.

The majority of the friends mentioned were school friends, indicating that the school environment provided opportunities for them to feel socially accepted. The young people who talked about their various friendships focused on two distinct categories, disabled friends and non-disabled friends.

Friendships with Disabled Young People

The four young people who attended Juniper Hills School had friendships predominantly with other disabled pupils at the school. Ronald and Anne talked more fully about these friendships, describing their friends as true and close friends. Prior to moving to Juniper Hills School, Ronald was restricted in the friendships he developed and the activities that he was involved in by the lack of facilities at the special needs primary schools he attended and by his own family's lack of resources. He saw himself as popular at Juniper Hills School and enjoyed being with his school friends so much that he chose to stay at the school on the weekends rather than go home to his family. He explained,

> On the weekends that I stay at the school I stay with my mates and even though it can be boring and half the time we are just sitting around doing nothing, it's good because I am with my friends.

Anne chose not to stay at Juniper Hills School on the weekends but felt very contented with her friendships at the school. Her school friends were very important to her, particularly as she had felt lonely and left out by her peers at her mainstream primary school.

Tony did not identify any specific disabled friends at Juniper Hills School, preferring to talk about his concerns for his classmates, demonstrating his caring and thoughtful nature and indicating how comfortable he felt at school. He described his school as a "disabled community" and went on to state that "it's just lovely to be with people who get the same help as you ... It's just lovely that I'm with people I know now and who I have got used to".

Simon did not talk in detail about his friendships at Juniper Hills School. He did however state that his best friend, Tom, and girlfriend, Kylie, were at the same school.

Juniper Hills School provided a valuable pool of people who shared similar experiences to the young people in this study. Mulderij (1997) and Widdows (1997) revealed that disabled young people found it easier to mix with other pupils who understood each other because they all had an impairment. Within a school dedicated to disabled young people, an environment was created in which they felt accepted and comfortable because they did not feel different from the other pupils at the school (Shakespeare and Watson 1998, Davis and Watson 2001). Ronald, Anne and Tony were clear that, in their opinion, the peer support they experienced at Juniper Hills School would be missing if they went to a mainstream school.

Only Ronald and Anne specifically mentioned the difficulty of keeping up with their friends during the holidays. Cook *et al.* (2001) stated that this was a common experience as special needs school had a wide catchment area so the pupils were unlikely to live near each other. Attending a residential special needs school also had the drawback of pupils not living near their community and so reducing the option to mix with non-disabled peers in their home neighbourhood (Baker and Donelly 2001). Even Tony, who was a day pupil, only mentioned one non-disabled friend in his local community with whom he played. Possibly this was because he went to a special needs school, whereas most of the other young people in his neighbourhood went to their local school.

Although Ronald had a full social life at school, his contact with his school friends was non-existent during the school holidays. He did not live near any of his friends. This absence of friends and the lack of facilities and resources available to this parents meant that Ronald had little opportunity to socialize actively at home and most of the time he felt bored. Anne, on the other hand, with the assistance of her mother, tried to maintain contact with her close friends during the school holidays.

> When I am on holidays I try to see some of my friends from school ... Sometimes I go to their house and sometimes they come to my house ... To keep in touch with my friends over the holidays, I usually phone them up and see if they want to come up for lunch or something. Sometimes we meet at a pub halfway between the two houses ... I do try to keep in touch with my friends because I think it is nice.

Lucy mentioned that her closest friend, Dawn, was a disabled pupil whom she had met at Cloudberry School. Dawn did not attend the same secondary school as Lucy, but when talking about her, Lucy stated that it was "nice to have just one close friend to see outside of school". Interestingly, it was difficult initially for Lucy to make friends when she started attending the special needs primary school.

> On my first day at the special needs primary school I remember going up to this girl called Jo-Jo, who is one of my close friends now, and I said to her, "Can I play with you?" And she said, "No you can't play with me, I don't want to play with you, I want to play with Dawn". I felt

> really upset because it was my first day there. There was no one to stick up for me because I had none of my friends from my other school there. It took me about six months to make friends at the special needs primary school. So I had to play by myself.

She eventually developed good friendships and enjoyed attending the special needs primary school so that she "could see [her] friends every day". It has often been expected that disabled young people should get along together because they all have an impairment and are generally 'in the same boat' (Mulderij 1997, Widdows 1997). However, Lucy's experience demonstrated that this was not the case, and some friendships took time to develop.

Although Riley attended a mainstream primary school he preferred to play only with other disabled young people, stating that he didn't "have any friends at school who [weren't] in wheelchairs." He stated that he only had two friends, called Patrick and Peter, but when he provided more detail he seemed to be ambivalent about these two friendships. He said of his friend Patrick,

> I never get Patrick over. I normally go to his house ... I don't go very often ... I don't really like having friends over ... I just don't feel comfortable about it really. I just don't like people to see what I do at home. I don't really want to go to other people's places. I get nervous with other people.

When talking about Peter it seemed that they had different interests. He said,

> I don't actually see much of Peter because I've told him not to devote himself to the football pitch every single day but that is what he does ... I think it's a bit strange to go on the football pitch and not do anything else.

As if to emphasise that he felt fine with his own company, he added, "When I am by myself I often make up a song or write a story in my head ... I don't always need someone to play with". Riley was unusual in comparison with the other young people, as he was quite happy being by himself. Erwin and Guintini (2000) argued that making friends was possibly one of the most meaningful skills a young person could learn as it was essential for developing relationships throughout life. It was unclear how Riley's views on friendships might affect his relationships in later life but at this stage of his life he appeared content.

Investigating the diversity of relationships and preferences for friendships was missing from previous research. When exploring the issue of friendships and disabled people, it is important to consider the personality and preferences of the individuals. The personalities of disabled young people, like other young people, vary from the gregarious to the very shy and it should not be expected that they all want to have lots of friends or indeed consider friendships important.

James and Xanthe did not talk about having any disabled friends. They both attended mainstream schools which admitted other disabled pupils but both chose to mix with non-disabled pupils. James did not like to be associated with any of the other disabled pupils in his school. He hated sitting at what he called the "disabled table" with the other five disabled pupils in his class whom he referred to as "brain damaged". He felt sitting at this table was uncool and showed him up. James resented the expectation that he should mix with the other disabled pupils.

> When I'm in the playground, I play with undisabled children. I would be really angry if they made me stay with the other disabled children. I would be so angry they would have to put chains on me.

This view of friendship has not been discussed in the literature. In his efforts to just get on with his life, it was reasonable for James to want to mix purposefully with non-disabled pupils rather than to feel he had to mix with other disabled pupils. He did not seem to consider his impairment a hindrance to socialising with non-disabled young people.

Although Xanthe did not talk about being friends with other disabled pupils, she felt it was important that all the disabled pupils at her school were friendly and polite to each other, perhaps as recognition that they had some things in common (Mulderij 1997, Widdows 1997). She was annoyed with another disabled pupil with whom she shared the same taxi to and from school and the same mini-bus on school trips, because he did not acknowledge her in any way.

> He is the only person in a wheelchair that I have a problem with ... I've made a massive effort to be sociable with him. I think I sort of understand why he's not sociable ... He can be a bit of a shy person towards certain people. I still find it annoying that I can't talk to him ... He can talk ... but he just doesn't bother with me. So I don't bother with him.

Friendships with Non-disabled People

Apart from Riley, the young people who attended mainstream schools had predominantly non-disabled friends, even though in some circumstances these friendships took a long time to develop. The views of the participants in this study supported research that suggested disabled young people mix with non-disabled young people (Sebba and Sachdev 1997, Alderson and Goodey 1998, Bax 1999) and the converse findings that disabled young people were ostracised by non-disabled young people (Yude and Goodman 1999, Llewellyn 2000).

Xanthe valued having non-disabled friends but, since moving to her mainstream secondary school, had struggled to develop friendships. This came as a surprise because of her very positive experiences of friendships in her mainstream primary school. She went to a different secondary school to her twin sister and her primary school friends and did not know anyone at her new school and had to start making new friends. By the end of her first year in secondary school, she was very disillusioned because, although she had tried hard to make friends, she felt that she had very little return for her efforts. This even involved her accepting how she was treated so that she could be with the group of pupils she wanted to be with.

> At my secondary school they didn't really try to be my friend. They would just dump their bags near me and expect me to look after them while they all went and played ... I tried to be friends with everybody but they just didn't generally think that I was worth being with.

By the end of her second year at secondary school, some friendships began to develop. Xanthe was unsure of the reason, although she stated that it coincided with the time when she was just about to give up trying to make friends. She felt her approach of trying to be friendly had paid off eventually. With the help of her mother she was meeting up with some of her school friends outside of school.

James only had non-disabled friends as he disassociated himself from the other disabled pupils at his school. He had a best friend and a girlfriend at school, Jack and Katie respectively. He saw them occasionally outside of school and during the school-holidays, although this was difficult as they did not live near each other because James did not go to his local school. He enjoyed playing and being active with his friends at school.

> We play chasing games in the playground. My friends push me around in my wheelchair. I liked being pushed by them because it helps me get out and about. I can push my wheelchair by myself but not as fast and not a long distance, like three miles. We also play football at lunchtime.

Alex mentioned several non-disabled young people that he played with at school. Although he referred to these pupils as friends, he was unsure whether they considered him a friend.

Although Lucy did not mention anyone specifically, she had some friends at the mainstream primary school she attended. She chose to attend an after school club called Music Makers so as to spend extra time with her friends. She had not kept up these friendships once she moved full-time to Cloudberry School. She was concerned, prior to moving to her mainstream secondary school, about whether she would make friends as none of her special needs primary school friends were moving to the same school. She found, however, that she was able to make friends quickly, although she saw these friends as school friends rather than friends to meet up with outside school. It was possible that Lucy felt like this because she had not long been at the secondary school and, although she had made some friends, those friendships were still developing.

Although most of Tony's focus was on his concern and good wishes for his classmates, the friend he talked about in some detail was his neighbour David.

> David's not a school-friend, he's just a friend. I was getting bored one summer because there was no one to play with me. Then the doorbell rang and David came in, switched on the Playstation, switched on everything because he knew I couldn't do it. That was a major help to my mum because then she could get on with her jobs.

One issue that was identified by some of the young people in relation to friendships with non-disabled young people, was that of being considered a curiosity or novelty. Lightfoot *et al.* (1999) and Farrell (2001) revealed that this was a common occurrence when a disabled pupil was admitted to a mainstream classroom. They stated that disabled young people were perceived as being different because they may have had to do things in an unconventional way. As a result, they were often subject to considerable interest and questioning. The young people stated that it was common for other pupils to take an interest in them because they were in a wheelchair. For Xanthe, at her secondary school, this interest was not all positive.

> So for the first term I was in my manual wheelchair and I was fought over so much in that term. I was even a bit frightened that I was going to be pushed off a kerb at times ... Somebody had threatened to push me off a kerb and I was force fed Rolos and things like that, as if I was some type of animal.

This initial interest did not result in Xanthe developing friendships with other pupils. Lightfoot *et al.* (1999) found that often when the initial interest had subsided the disabled young person was left with very few, if any, friends.

This was also the case for Anne when she went to her local mainstream primary school. She initially had many non-disabled friends when she started at her mainstream primary school and as a result was very happy and felt accepted by her peers. This changed after the first few years and she began to feel lonely and excluded.

> ... eventually the people just began to think I was weird ... The problem was that there was no one else in the same position as me. I was the only person in that school in a wheelchair. Everyone thought it was a bit of a novelty at first but I didn't like being thought about like that. I wanted to be with people who were in the same boat as me ...

> Things began to change because (a) I got older and (b) quite a few new people had joined my school and I got a bit lonely. At playtime I couldn't find anyone to play with because they wouldn't let me into their games … I used to have some friends in the beginning but I hardly was invited to parties and other things.

Lucy was aware that one of the possible reasons she made friends quickly at her mainstream secondary school was because the other pupils felt it was novel to assist her. She was conscious that the novelty might wear off and felt that she had to make sure that her friends did not become helpers. In illustrating her concerns, she referred to a story of a disabled friend who had lost friends because they became helpers. Lucy suggested that she would require some assistance from her friends but to keep them as friends she decided that she could not ask too much of them.

Although mixing with a diverse range of young people was considered a goal of inclusion (Graves and Tracy 1998, Cook *et al.* 2001, Pitt 2003), Ronald raised a pertinent issue about playing with non-disabled peers. He spoke of an earlier period in his life when he played with some of the other young people in his neighbourhood. He saw this as a period in which he started to understand that he was different because he was limited in the activities he could be involved in compared with the other young people.

> When I was at my primary school and staying in a different house to the one we live in now we used to play football with some of my next-door neighbours. That was cool but I always felt that I was a little left out because I was always put as a referee or goalkeeper or stuff like that. I was never an attacker or something like that which was a bit of a put down. It was then that I started to realise what I was and what I couldn't do.

It seemed that playing with non-disabled young people had a negative impact on his self-perception and self-esteem, even though he was included in a variety of activities.

The Young People's Views on Education

There has been a general move toward inclusive education since the Warnock Report (Department of Education and Science 1978) and this has more recently been supported nationally by the Disability Discrimination Act (1995), Education Act (1996) and the Special Education Needs and Disability Act (2001). In spite of the move toward inclusion, the young people in this research had varied educational experiences in different educational settings. Their experiences and views support Norwich's (2002) notion that full non-separatist inclusion in which the full participation of disabled young people can be achieved without any dedicated systems to enable participation in the mainstream was an idealistic human rights position. Not only did all nine participants experience different combinations of education systems from mainstream to special needs, including a mix of the two, but the delivery of each system was different for each young person.

Only Xanthe had her primary and secondary education within the mainstream educational system. James had been to a mainstream primary school but was to go to Juniper Hills Schools for his secondary education.

Ronald and Tony had been in special needs primary and secondary schools. In primary school, they both attended as day pupils. In secondary school, Ronald was a residential pupil and Tony was a day pupil at Juniper Hills School. Riley and Alex attended a mainstream primary school four days a week and went to Cloudberry School one day a week. Both were expecting to move onto a mainstream secondary school full-time. Simon went to a mainstream primary school full-time until he was moved to Juniper Hills School where he boarded. Lucy and Anne both initially attended mainstream primary schools but completed their primary education at special needs schools. Lucy attended her mainstream primary school four days per week and went to Cloudberry School one day a week up until year five when she changed to being a full-time pupil at Cloudberry School. She then moved to a mainstream secondary school. Anne attended a mainstream primary school full-time but moved to Juniper Hills School as a residential pupil to complete her primary education and had stayed on at the school for her secondary education.

For inclusion to work research has indicated that an ethos within the school, a commitment from all staff members, the provision of appropriate structural and material resources and adequate funding were essential (Corbett 2001, Farrell 2001, Lightfoot *et al.* 2001, Lindsay 2003). Within the young people's stories there were examples of inclusion working where the individual's learning needs were connected to the curriculum and the wider school community (Corbett 2001). There were also many examples where this was not the case and where it appeared that the young people were integrated into a mainstream school rather than included, as the schools did not cater for their specific needs (Sebba and Ainscow 1996, Booth 1999, Davis and Watson 2001).

Inclusion Experiences

Through listening to the young people talk about their mainstream school experiences it became clear that there were several reasons why inclusion did and did not work. A factor in this, not necessarily recognised in the literature, was an individual's personality because what worked for one young person did not necessarily work for another.

School Friends

Xanthe experienced an ideal inclusive experience when she was in primary school. She went to her local mainstream primary school with her twin sister. She felt that it made a difference starting school with all the other pupils because they all got used to her from the start. Although Xanthe did not explicitly say so, having a twin sister attend the same school probably helped her become more readily accepted by her peers. As a result of the ethos of the school and her relationship with the other pupils, her various medical appointments did not interfer with the development of her friendships. This was contrary to the argument put forward by Lightfoot *et al.* (1999) and Alderson and Goodey (1998) who found that frequent health and social welfare appointments made it difficult for disabled young people to make friends. Xanthe did not feel there were any barriers to her participation in primary school and this led to her forming friendships and being involved in her local community. Belonging to the local community and being accepted by non-disabled peers was one of the arguments for inclusion (Alderson and Goodey 1998, Kliewer 1998, Llewellyn 2000, Cook *et al.* 2001).

Anne went to her local mainstream primary school but did not experience the same degree of friendships as Xanthe. Her experiences were mixed as initially she was very happy and felt accepted but this changed after a few years. Supporting the findings of Lightfoot *et al.* (1999) that the initial interest by other pupils towards a disabled student usually wore off, Anne eventually felt lonely and more excluded by her fellow pupils. She was the only disabled young person at the school and felt that no one understood her. Anne's experience was not unique as several research projects found that disabled young people were often not accepted and lacked friends in mainstream schools (Sebba and Sachdev 1997, Lightfoot *et al.* 1999, Yude and Goodman 1999, Llewellyn 2000). Anne became increasingly unhappy and, with the support of her parents, completed her primary school education at Juniper Hills School. The response of the other young people at her mainstream primary school caused Anne to feel like an outsider (Llewellyn 1995, Dorries and Haller 2001), and pushed her to consider special needs education. This may be attributed to the fact that she did not start at that school at the same time as others in her class as she had moved from another school because her parents moved house.

However, in James' situation he neither attended the local mainstream primary school nor did he start at his primary school with the rest of the class yet, he was popular and felt accepted. This probably had to do with his enthusiastic personality, his decision not to mix with the other disabled pupils and his eagerness to be involved in many school activities.

The different experiences of Xanthe, Anne and James suggest that individual personality played some role in the development of friendships at school and the feeling of being included. This view was generally absent from previous literature focusing on inclusion. The issue of agency and the role an individual has in an event, however, was recognised in the New Sociology of Childhood, which emphasised that young people actively engaged and interacted with their environment (Prout and James 1997, James *et al.* 1998). However, Xanthe and James' primary school experiences support research that found disabled and non-disabled young people can form friendships (Sebba and Sachdev 1997, Alderson and Goodey 1998, Bax 1999). Xanthe's secondary and Anne's primary school experiences, on the other hand, demonstrate that disabled young people may feel ostracised and excluded by their non-disabled peers (Yude and Goodman 1999, Llewellyn 2000).

Riley showed agency by choosing only to mix with disabled young people at his mainstream primary school. Like James, this raised the issue of choice and providing opportunities for disabled young people to decide with whom they would like to mix. Although disabled young people may attend a mainstream school, it does not automatically mean that they want to mix with non-disabled pupils. They may feel, like Riley, more comfortable mixing with pupils with whom they feel they have more in common, appreciating this peer support and sense of belonging that Mulderij (1997) and Widdows (1997) consider essential for developing social skills and a healthy self-esteem.

Learning Support Assistants

Xanthe stated that being the only disabled pupil at her mainstream primary school and having dedicated learning support assistants were two reasons why her primary school inclusion experiences were successful. Norwich (2002) suggested that meeting the unique needs of each pupil is essential if inclusion is to work. In Xanthe's situation her primary school was able to develop a dedicated support system to enable her to participate in the mainstream environment. Within this system Xanthe did not find her learning support assistants a barrier to making friends. This was contrary to the findings of Ainscow (2000) and Pitt (2003), who found that a number of disabled pupils described learning support assistants as 'friend-repellent'.

> I remember everybody wanted to be with me especially because [one of my learning support assistants] was fun and they knew they weren't going to get into trouble.

Xanthe's experience was different to that of James, who stated that having help from the learning support assistants made him feel different to his non-disabled classmates. Although they were friendly, he did not want their help. For James, it was not so much that the constant presence of the learning support assistants made it difficult for him to develop friendships with others, as suggested by Ainscow (2000) and Pitt (2003), but rather he felt their presence prevented him from being seen as 'normal'; they identified him as being different. To make this help more acceptable James referred to his learning support assistants as "bodyguards", changing the perception of why he needed them. When he was provided with a laptop computer, he felt liberated because he did not have to sit on the "disabled table" and he thought that he would no longer need his "bodyguards". He felt angry when they continued to seek him out.

> But the helpers still come up to me. I get annoyed at that. They even come up to me even though I am in year six. I thought I told them in year five, in the exact words, "I do not want helpers", but oh no, they think I am a poor unintelligent child, a mentally child. My mum hates that word. So they still come over.

In contrast to her primary school experience, Xanthe did not like the learning support system in her secondary school because she did not have dedicated learning support assistants and had to share the assistants with other disabled pupils. She felt that her unique needs were no longer considered and instead she became just another disabled pupil that required assistants and resources. This conflicted with Norwich's (2002) assertion that when focusing on the needs of disabled young people, each of them had to be considered unique, so that the assistance and resources provided were specifically tailored rather than generally distributed. In addition, she complained that there was an imbalance in the distribution of assistants such that she was not given the same priority as some of the other more disabled pupils.

> I felt that I was not considered. I was made to feel that I was not worth helping as much as anybody else in a wheelchair because I didn't need as much support work done for me ... I felt that they just did the minimum ... for almost everything.

Xanthe thought that her needs would be better met if she went to a secondary school where there were fewer disabled pupils. She felt that one of the possible problems with her current secondary school was that there were too many disabled pupils at the school which spread the learning support services too thinly.

> I know this is different at Liberty's school because I have a friend with hemiplegia who has helpers and she has control over when she needs them. It's because she's the only one, out of a possible two, at her school that needs helpers whereas I have to share the helpers with so many other people at my school ... It really doesn't work at our school.

In addition, Xanthe thought that one of the reasons she was not popular at school, particularly in years seven and eight, was because her helpers were "all rules and regulations". She had to be a "Miss Goody-two-shoes the whole time" because she was "never going to get away with anything". She considered some of her helpers to be a barrier to developing friendships with non-disabled pupils, a situation also found in the research of Allan (1996), Ainscow (2000) and Pitt (2003).

Accessing the Curriculum

For inclusion to work the curriculum should be tailored to enable each young person to have access to the full curriculum offered by the school. Llewellyn (2000) believed that many disabled pupils attending mainstream schools did not have access to the full curriculum and, as a result, many schools that promote inclusion are discriminatory. Riley liked that his education was tailored for his needs and that he did not have to do the whole curriculum. He was put into the B-stream classes because although he was bright, the pace of the curriculum in the A-stream classes was a bit fast for him. He often missed his physical education lessons, using these periods as a time to see his physiotherapist or occupational therapist. He felt that this was better use of his time as he did not have to miss many of the more academic periods. Simeonsson *et al.* (2001) found that physical education was often a subject that many disabled young people missed or did not become involved in.

Xanthe on the other hand was frustrated that she did not have access to the full curriculum at her secondary school, even though the school was supposed to be fully inclusive. Her experiences were reflected in the research findings of Hemmingson and Borell (2002), Llewellyn (2000) and Wedell *et al.* (2000), who showed that schools and staff were not always skilled enough or had the time to adapt the curricula to accommodate the needs of disabled young people. Xanthe criticised the inclusive nature of her school, providing two examples of how she was not included on school trips. Llewellyn

(2000) also found that participation in school trips was one area that mainstream schools had difficulty in being fully inclusive. Xanthe was unable to go on the French Encounters trip with her French class because the accommodation was not accessible. In addition, on school trips disabled pupils had to travel in a separate bus and were put in the awkward position of nominating one or two non-disabled pupils to travel with them.

Xanthe argued that the inclusive nature of her secondary school tended to encourage the staff and pupils to have pre-conceived ideas about disability and the needs of each disabled pupil. In addition, the school had a policy of treating everyone the same and as such did not focus on the individual needs of each pupil which was contrary to Norwich's (2002) argument that for inclusion to work the individual needs of each pupil must be considered.

Lucy did not have any of Xanthe's concerns and felt that her needs were being catered for at her inclusive mainstream secondary school as the school made sure that she had full access to the curriculum and a good learning support system. More importantly, she appreciated the freedom and autonomy she felt when she entered secondary school. She no longer felt that she was being continually scrutinised and surveyed by adults, a factor which Allan (1996) suggested was usually a constant problem for disabled young people at school.

School Staff

The commitment of staff at the mainstream school had an impact on the inclusive experiences of the young people. Various educational commentators stated that this was of prime importance for inclusion to work (Hadley and Wilkinson 1995, Hornby 1999, Corbett 2001, Lindsay 2003). Riley found that his mainstream education was negatively affected because of the behaviour of a previous head teacher.

> She told my mum that I couldn't have a full-time learning support assistant. So my mum had to fight and fight and fight to get a new statement to get a full-time learning support assistant for me.

Lucy also had a problem with her class teacher in year five who was neither supportive or empathetic, and the predominant reason for her move into full-time special education.

> There was this really silly lady called Mrs. Jones and if I didn't get a sum right in like a minute of two, she'd go, "Come on quickly", and like when I got it right she would bang her head down on the desk and she'd go, "Alleluia, alleluia". She would start singing that and the whole class used to be like staring at me because she used to be like that all the time ... She used to make fun of me. I used to think, "You know you could at least teach me properly and you could be slow with me and be like patient and even if it does take me a minute you don't start banging your head down on the desk and go alleluia, alleluia".

Lucy had difficulty keeping up with her schoolwork because she could not write at the same pace as her peers. She felt the class was rushing ahead and because the number of pupils in her class was large her needs were not being recognised. She stated, "if you couldn't keep up you wouldn't learn anything and they couldn't be bothered with you". Llewellyn (2000), Wedell *et al.* (2000) and Hemmingson and Borell (2002) stressed that staff have to be committed and skilled for inclusion to be a positive experience. It appeared that Lucy's teacher had neither the skill nor the commitment to successfully accommodate Lucy's needs.

Special Needs School Experiences

The young people raised more issues with education in mainstream schools compared to special needs schools. Those pupils that went to a special needs school, even on a part-time basis, saw it as appropriate and did not mention feeling segregated or excluded. On the contrary, the special needs school experiences were generally considered positive, particularly as the students were encouraged to try different things and as Anne put it, feel 'less disabled'.

Ronald described Juniper Hills School as "the best disabled school there is in the country", while Tony stated that it was "like a community, a disabled community with lots and lots of pupils wanting help and support with their educational needs". Ronald and Anne mentioned that they had made lots of close and true friends at school. They were also pleased with the variety of activities they had access to. Anne stated that,

> There is also always plenty of things to do at this school like football, discos, remote control car racing, water fights in summer, barbeques and parties. It's never quiet around this place as there is always something going on.

They were also pleased with the therapy they received. Tony felt that the regular physiotherapy he was receiving was definitely improving his ability to walk. Anne talked about how the school had improved her independence.

> I have come on in leaps and bounds ... I feel I have come a step closer to not having a disability. I know I've got a disability and I always will have one but this school has helped me get that little step closer to being an average person.

For Ronald, Tony and Anne, special needs education had been very positive. Although their environment did not reflect the 'real world', a criticism levelled at segregated education by Graves and Tracy (1998), they felt a sense of community at the school where they were accepted by their peers and did not have to constantly explain themselves (Mulderij 1997, Widdows 1997). In addition, they were happy with the curriculum as their individual needs were catered for (Llewellyn 2000). This all had a positive impact on their view of themselves and their relationships.

None of the participants who attended a special needs school mentioned any stigma attached to being segregated. This stigma was suggested as one of the drawbacks of special needs schools by Leicester and Lovell (1997), Florian (1998) and Kenworthy and Whittaker (2000). Anne referred to being in a "bubble of protection", acknowledging that she was in a protective and safe environment but felt that this was where she needed to be at this point in her life. Hadley and Wilkinson (1995) and Leicester and Lovell (1997) found that one reason parents chose to send a disabled young person to a special needs school was for peace of mind as they felt these schools provided safe and secure environments. For Ronald, Tony and Anne, being at a special needs school had enabled them to minimise the effect of their impairments and get on with enjoying their life.

Unlike Ronald, Tony and Anne, Simon did not comment on his experience at Juniper Hills School. Although he was not critical of the school, he resented having to board because he felt it was uncool and limited what he could do.

While James had not started at Juniper Hills School, he had visited the school three times with his parents to determine whether it would be suitable for his secondary education. Considering James' negative view toward the other disabled pupils at his primary school, it was not surprising that he did not want to move to a residential special needs secondary school. He equated attending this type of school with being sent to prison; an image consistent with Kenworthy and Whittaker (2000) description of these schools as twentieth century gulags.

In spite of the predominantly positive experiences of the young people who attended Juniper Hills School, attending special needs schools was not without problems. Tony had an upsetting experience when he was in years five and six that showed that, even at special needs schools, individual needs may be overlooked and teachers may lack the skills to accommodate disabled pupils.

> When I started my special needs primary school, they only took people with cerebral palsy. But when I was in years five and six everything changed. They took people with all kinds of disabilities. I didn't think that was fair because they had lots and lots of people and we weren't looked after.

His dissatisfaction was exacerbated because his teacher changed, causing everyone in his class to struggle. Tony indicated that even in a perceived protective environment (Hadley and Wilkinson 1995), he was bullied by a girl who tore up his good merit sticker. Being bullied at a special needs school was also mentioned by Lucy.

> At my special needs primary school, there were children whacking at you that were mentally and physically disabled. I used to be sitting or walking up to a door and this girl would stand behind me and she used to scrub my hair or hit me across the face. It really used to hurt. You used to be sitting next to her and she would pinch your arm or something. Once she made this massive black bruise come up on my arm she pinched me so hard.

Views on Education and Disabled Young People

Llewellyn (2000) and Butler (2001) argued that no single type of education fitted all pupils. They stated that just as it was indefensible to segregate all disabled young people into special needs schools, it was equally indefensible to place them all into mainstream education. Lindsay (2003) stated that disabled young people had a right to good education, not strictly a right about where to be educated. This supported Hegarty's (2001) argument that parents did not send young people to school to be included rather they sent them to school to be educated. Inclusion was considered a secondary function.

The young people held mixed views on whether mainstream or special needs schools were the most appropriate for disabled young people. Their personal school experiences undoubtedly influenced their points of view, although the link was not always clear. Ronald and Tony had never been in mainstream education so had no personal experience on which to base their opinions. Both looked at mainstream education through a negative lens and felt that they would not be accepted within such an environment. Ronald stated that he would be an outsider and would not have any friends because there would be no one else at the school like him. Tony added that he would probably be bullied because he would not fit in and he would be unable to keep up with the other pupils. Anne had been to a mainstream primary school where she felt excluded and lonely and considered that special needs education was the best system for her. Their views were consistent with that of Llewellyn (1995) and Dorries and Haller (2001) who found that disabled young people were more prone to being mistreated at mainstream schools because they were perceived as being different. Ronald, Tony and

Anne's views have all been influenced by their very positive experiences at Juniper Hills School. Although Simon had been to a mainstream primary school, and he disliked boarding at Juniper Hills School, he made no comment about whether he preferred a mainstream or special needs school.

Even though Xanthe had a very difficult and lonely two years at her mainstream secondary school and had concerns about the inclusive nature of the school, she was a strong advocate for inclusive education. She appeared to have been strongly influenced by her positive primary school experiences. For her, there was no alternative to inclusion. She argued that, although a segregated education might equip her to get through life, it was morally wrong to place disabled young people in separate schools. In addition, she felt that a special needs education would be less academic and would not allow her to reach her academic potential. James shared a similar view to Xanthe; he stated that going to a special needs school would be like being sent to prison. Although Lucy's mainstream primary school experience was not positive and she completed her primary education happily in a special needs school, she agreed with Xanthe and James, suggesting that being put in a special needs school was the equivalent of saying she was not normal.

Xanthe, James and Lucy put forward opinions about their educational preference based on a human rights ideology, as well as, in Xanthe's case, the academic standard of each system. Feiler (1999), Hornby (1999) and Kenworthy and Whittaker (2000) felt that inclusion had a strong moral foundation, believing that it was fundamentally wrong to segregate disabled young people. They believed that segregated education maintained the stereotyped attitudes society holds about disabled young people rather than supporting the acceptance of diversity. This stand for inclusion underpinned the Salamanca Statement (United Nations Education Scientific and Cultural Organisation 1994). However, Llewellyn (2000) argued that inclusion predominantly based on a human rights ideology was naïve in that it did not account for the individuality of each person nor did it recognise each person's unique needs.

Alex made no comment related to which education system he preferred. He was content going to a mainstream primary school with special needs support and intended to go to the mainstream secondary school with similar support.

Riley was the only one who commented on the choice more broadly. He indicated that disabled young people should go to the school that best suits their needs. He wanted to stay in the mainstream school system as long as he had the learning support he required.

The difference in the young people's opinions highlighted the difficulty with trying to have one education system for all. On the whole, the young people that attended a special needs school seemed to have benefited from that experience. It may be that they felt they were in a "bubble of protection", as suggested by Anne, but they were also able to make positive steps in their emotional, psychological, social and physical development. More issues were evident for those pupils who attended a mainstream school. Possibly this was a reflection of how each school interpreted its commitment to inclusion (Norwich 2002), as well as the general attitudes within society towards disabled people (Davis and Watson 2001). However, it also reflected the personalities of the young people as illustrated by Xanthe and Lucy. Although Xanthe had a difficult time in her secondary school and Lucy had a tough time in her primary school, they both fundamentally believed that inclusion was the right approach for them. It would seem that these findings support Pitt's (2003) study in which she found disabled pupils needed to be involved in deciding where they attended school but that the choice should include a range of options including mainstream education, special needs education or a combination of each.

Views of Impairment

Middleton (1999) and Davis and Watson (2001) suggested that, as a result of the attitudes prevalent within western societies, disabled young people were subjected to countless negative experiences. The dominance of the Medical Model caused stereotyped perceptions of disabled people to emerge and created the stigma of being impaired (Harper 1999, Dowling and Dolan 2001, Watson 2002). Imrie (1997) suggested that within this Model, disabled young people were not considered to be individuals but tended to be grouped together according to their diagnosis and condition. This resulted in them being considered 'abnormal' and requiring various interventions to make them 'normal', to enable them to fit into society (Llewellyn and Hogan 2000).

Middleton (1999) believed that the medical needs of disabled young people unjustly overrode all the other needs and resulted in a continual focus on what was different rather than on their attributes and abilities. Rarely were services constructed and provided from the perspective of the young person and family, in spite of more recent legislation stressing the importance of working in partnership (Dowling and Dolan 2001). Although partnership was considered essential, the young person central and the parents knowledgeable

(Murray 2000), it was more common for professionals to retain their aura of expertise, fostering an unequal relationship and, in the process, disempowering the family (Case 2000, Read and Clements 2001). The stress placed on families of a disabled young person to attend the constant stream of appointments with a variety of different agencies was in addition to the constraints placed on all parents by school hours and holidays. Although these appointments may have been for the well-being of the disabled young person, the number and frequency were disruptive and caused great inconvenience, leading to a reduction in the quality of life for the family as a whole (Dowling and Dolan 2001).

Within the Medical Model, there was a prevailing theme that it was tragic to be disabled, and an assumption that disabled people could not lead fulfilling lives (Llewellyn and Hogan 2000, Swain and French 2000). The experiences and views of the young people in this study did not match this tragic view of disability. Dowling and Dolan (2001) found that the Medical Model did not match the experiences of many disabled people and as such could not be considered a useful way to explain disability. The young people in the current study did acknowledge that it was, at times, difficult having an impairment and gave examples of this but most of their stories were positive and showed that they lead fulfilling lives. They also gave examples of 'impairment effects' as defined by Thomas (1999), in which they acknowledged that their impairment could not be ignored because it was a part of who they were and contributed to their experiences (Davis and Watson 2002). Their stories showed that they had agency and were able to influence their own lives, demonstrating that it was not just medical or social influences that controlled their lives (Read 1998, Swain and French 2000).

Alex focused his story predominantly on the activities he had experienced and the holidays he had been on. Simon concentrated on presenting an image of himself as a bit of a "dodgy" character, "another Del Boy", who related to "nasty" people such as Simon Cowell from Pop Idol: "I liked his rudeness". When he spoke about what life with an impairment was like he took the opportunity to display his sense of humour.

> I couldn't really care less that I have cerebral palsy but being in a wheelchair has stopped me from becoming a pop star and a film star.

In addition, he gave a brief list of what was "good" and "bad" about having cerebral palsy. The "good" things included: "... I have to be fed ... I get free access in a car park ... I can get a job". Although his brief list of "bad" things was more serious, he still included a throw away comment: "I'm stuck in this contraption and this school ... I can't climb trees or get a builder's bum ... I can't get upstairs without help". Even his reason for wanting to speak more clearly had an aside: "... because I can't get the swear words out". It was uncertain whether the humour and superficial content of Simon's story was a sign of difficulty coming to terms with his impairment or whether it was a sign of feeling comfortable and an ability to laugh about any difficulties he had or differences he perceived.

Xanthe stated that she was a smiley, chatty and outgoing person, but was oppressed by her experiences, particularly those that had occurred during her first two years at secondary school. She was influenced by many factors in her life, particularly having a non-disabled twin sister, a close peer with whom she could compare her life. Her story was littered with words and phrases that suggested her experiences of having an impairment were not positive. Examples of these words and phrases were: "hit me hard";

"punished"; "tortured"; "scars"; "I wanted to scream at them"; "I got stuck with"; "I had no other choice"; and "make so many sacrifices".

Throughout her story Xanthe referred to herself as "sensible" and "organised". She felt this about herself because coping with her impairment had caused her to grow up faster than her peers. She believed that the negative reaction of people and systems toward her had forced her to reflect on and comprehend her life. She was frustrated by the negative reactions of others because she held that, apart from some specific concerns related to her impairment, she had the same worries and concerns to think about as her peers.

> I have found the attitudes towards disabled people has hit me hard. I have had time to think about how people don't listen. I have thought about every little detail because there is only so long that I could keep living in a sort of fantasy when there are things going on around me all the time. I have become incredibly aware of everything ... At the moment if you are disabled you have normal experiences on top of the rest of the load that you get from being disabled. Being in a wheelchair and all the appointments and everything else gets me particularly stressed at the end of every day. Nobody really understands that, they don't understand why I feel stressed.

Xanthe clearly saw her disability as being caused by society's attitudes towards her. This sits with the essential premise of the Social Model of Disability, which proposed that disability was caused by the barriers and negative attitudes prevalent in society, not by a person's impairment (Rieser 1992, Morris 1997, Shakespeare and Watson 2002, Connors and Stalker 2003). Xanthe felt that society did not truly accept or listen to disabled people and as a result her school, social and family life had been affected. She indicated that, in her experience, some of the least accepting of disabled people had been medical and educational professionals who tended to have an expert rather than a collaborative approach. Medical professionals have talked over her, treated her "like a specimen", been responsible for her "horrendous" stay in hospital and have indirectly caused her back pain which had the potential to completely incapacitate her. She believed that educational professionals were responsible for the lack of true inclusion in schools, so that disabled young people did not have a fair choice of which school they attended. In addition, even schools that claimed to be inclusive, did not necessarily cater for the specific needs of each disabled pupil and did not consult with them.

Xanthe's strong views were in contrast to the generally positive attitude portrayed by the other young people. Lucy saw herself as someone who just got on with things. She was the only one who mentioned a role model, reinforcing Shakespeare and Watson's (1998) assertion that disabled people lack role models.

> I know this person with one leg. She's got a false leg and one real leg, one proper leg. Her name is Suzie and she doesn't care, she just gets on with it. I know that it is going to be hard but I have to get used to it.

She saw herself as someone who was positive and who had control over her life. Some of the setbacks in her life, such as her unsupportive teacher in year five, had helped her to deal with her frustration and to control her anger. She did not want people's pity and she did not appreciate people staring at her, particularly adolescents and adults, whom she felt should know better. She stated that it was not until she was about six that she realised she "was different from other children", but it did not bother her, she just got on with life.

> I won't let having cerebral palsy affect my life. I got to get on with my life as I have only got one life … Some children get really upset and all tense … It's not worth being like that

> because it just makes you depressed about your life. If people are like that they are not going to have a very good life.

Riley saw himself as a bright, talkative boy who chose to be a loner but who was basically content with his life. He disliked being the centre of attention, being fussed over and people feeling sorry for him. He was pessimistic about the public's opinion of disabled people changing, accepting that that was just the state of things.

> Nothing will ever change because everyone must have the image in their minds. You know they just get the basic things in their minds automatically. You can't tell how clever you are by looking at people, that's the trouble.

He thought that people would always have stereotyped negative views of disabled people and that there was little that he could do to change that. He did not think of himself as different to other people. He did not like having to use a wheelchair but he just got on with life and didn't wish to be someone else.

> I don't look at other children and wish I wasn't in a wheelchair. I'm not one of those who ever wished to be anything else, anyone else. I've never been anything else so I don't know anything else. Maybe people think I want to be like other children but I don't ... I just live with what I can do. I don't mind. I am what I am and I have just got to live with it and accept it.

Riley was the only young person who talked extensively about his therapy. Apart from having physiotherapy and occupational therapy at both his primary schools, he attended conductive education classes during his school holidays. He considered his therapy to be very important and was confident of it's benefits.

> Physio is very important to me because it helps me to progress ... it's the time that I cherish more than anything because I get to improve ... it has helped me to walk and to use my hands better.

Riley saw this therapy as an important means of reducing the impact of his impairment. This view of therapy was shared by Shakespeare and Watson (2002) who argued that there was nothing wrong with working towards improving function and reducing the "impairment effect". Thelen and Smith (1998) and Ketelaar *et al.* (2001) found that when a disabled young person improved their functional abilities and had more control over their bodies, they were able to do more for themselves, become involved in more activities and develop a healthy self-esteem.

Ronald viewed himself as a person who was enjoying the opportunities he had access to at Juniper Hills School. He saw himself as disabled and, as a result, not fitting in with non-disabled people. He indicated that he liked to keep busy because being active allowed him to forget about his impairment and focus on what he could do rather than not do.

Tony was a happy person who tried to find good in most people and situations. He was caring and thoughtful about others and appeared to experience great enjoyment in his life. Tony was able to express his contentment for his life in his wishes for the future.

> In the future, I'm hoping to have a good adult life. I believe there's hope for the future for everyone you know. I would just like everyone to be happy in my family and that is all I can ask for right now. You don't know what's next in your life. I would just hope that people have the same success that I have had. It's all going really well at the moment. Everything is getting better.

He was also accepting of how his impairment had affected his life. For example, although he had to wear nappies until he was six, he did not see this as a problem, just something he had to do.

> It was not a major problem and no one took the mickey. There were some other people who used the same

> strategy for their child. I believe that children learn to go to the toilet gradually, learn one step at a time.

Although Tony did become worried and anxious at times, his story was not one of tragedy but one of acceptance and being happy with what he had and was able to do.

Anne shared Tony's positive view and was happy and enthusiastic about the many opportunities she had had so far in her life. She saw herself as just like any other young person, except that she used a wheelchair. She also had the confidence to be involved in a number of research projects because she saw it as an important way of informing people about what having an impairment was like. Throughout her story, she stated consistently that she just wanted to be treated like any other young person because she did not feel different. She didn't mind people helping her but she preferred to ask for help when it was needed. Anne was clear that her impairment had affected her development but she was very positive about the improvements that she had made, particularly since starting at Juniper Hills School. Anne also stated that she had days when she wished she did not have an impairment.

> On down days I sometimes think why am I in this stupid wheelchair? Why me? If God was such a nice man he wouldn't do this to all of us and there would be no need for a special school. I feel as if I have done something wrong before I was even born. I feel like it's my fault ... Sometimes I get a bit fed up because I wish I could be climbing trees with my brother and his friends ... I do kind of wish I could walk and was kind of normal.

On a positive note, Anne felt that her impairment had provided her with a lot of opportunities. This included meeting Princess Anne who opened a new hydrotherapy pool at the centre Anne attended; talking with the Duchess of Devonshire; meeting Ant and Dec; winning a trip to Lapland to see Santa's grotto and meet Santa Claus; and being selected to go on a 10-day trip to Orlando courtesy of British Airways.

Anne and Tony were happy with the surgery they underwent and with the treatment they had received but both complained about the pain physiotherapists caused. Anne felt her therapists sometimes ignored her. However, these thoughts did not detract from feeling contented overall with her medical treatment. She thought her consultant did a "top job" and her operation had been successful beyond her initial expectations. Tony was grateful that medical technology enabled him to survive three times, once when he was born prematurely and two other times when his health was critical. He was also happy with the operation he had to straighten his foot when he was in year six, stating that if it had not been for the surgeon, he would not be as mobile as he was. Neither Anne nor Tony felt their surgeons were trying to make them 'normal' as suggested by Llewellyn and Hogan (2000). Rather they felt that their surgeon had improved their function and this had lead to them being able to do more for themselves and become involved in more activities.

James did not see himself as disabled nor did he want to be associated with other disabled young people. He saw himself as a usual boy of his age, with usual interests, who did not want to be treated any differently than his non-disabled peers. As a result of his views, he did not see his impairment as affecting his life to date.

> I feel that I have just got on with my life. I haven't let my cerebral palsy stop me from trying to fit in. I like to try to do everything for myself. I even try to wash, dress and feed myself if I don't have to rush. I don't need help with anything and if I do mum helps me a bit.

Swain and French (2000) suggested that these positive views of impairment were not uncommon amongst disabled people and that the tragic view of disability portrayed by the Medical Model did not reflect real life experiences. Further, they argued that the Social Model failed to acknowledge the positive life experiences of disabled people as well. Both models deny the personal experiences of disabled people, their enjoyment of life and their identity and self-awareness as disabled people. There was a tendency to believe that disabled people must always be dissatisfied with their life as they were not 'normal' and hence it was difficult to accept disabled people as being contented. Yet, six of the nine young people in this study suggested that they were happy with their lives. This does not mean that occasionally they would not want things to be different or that they never have 'down' days, but it suggests that generally they valued their experiences as disabled people. They accepted that they had an impairment but did not consider this a barrier to having positive experiences.

Anne indicated that she would like to have some 'normal' experiences like climbing a tree, but none of the young people stated that they wanted to be 'normal'. This was in line with Swain and French (2000) who found that disabled people rarely state that they want to be 'normal'. These researchers felt that the experiences of disabled people indicated that a newer model of disability was essential, and they proposed that this model be called the Affirmation Model of Disability. This model promoted the message that having an impairment was not tragic and could enhance or provide a lifestyle of satisfaction and worth. This was not to say that the removal of societal barriers was no longer required. In fact, the removal of these barriers continues to be essential for disabled people to achieve a lifestyle of their choice. For the young people in this study, their current lifestyles allowed them to lead fulfilling lives. Xanthe was an exception and this might be a reflection of her having reached a stage in her life where she had begun to experience more societal barriers, resulting in her not being able to lead her chosen lifestyle. Removal of some of the barriers she had been experiencing and a greater acceptance of diversity, particularly at her secondary school, would probably enable her to feel more positive about her life. It is likely that the other young people will go through periods where their lifestyle choices become restricted. For example, all the young people who attend Juniper Hills School will at sometime in the future have to leave their “bubble of protection” and enter the ‘real world’ (Pitt 2003). This may be a time when they will have to reassess their lives and their lifestyle choices in the light of their individual means, unique situation and the available resources in their community.

The Affirmation Model proposes that disabled young people should be seen as people with a range of hopes, wishes and dreams like non-disabled young people (Middleton 1999). They need to have the same opportunities to live their life for today, not for the future adult that they will become. In this way, they can learn to have positive self-esteem and feel good about who they are.

Summary

In this chapter, I have discussed the young people’s biographies in the light of current research. A description of the nine young people with motor impairment involved in this research was provided at the start of the chapter to highlight their individuality and to present the different ways we interacted. I then illustrated throughout the discussion that, although these nine young people talked about similar themes within the stories they told, they gave individual perspectives that were personally relevant. They all talked in varying detail about their families, friends, education and views on having an impairment. On the whole, although some were aware that raising a disabled young person could be stressful, they did not feel the impact of the stress their parents probably felt at various times in their life. They indicated that their parents were very supportive and provided them with opportunities to experience life. Relationships with siblings were described as 'normal' in the sense that the young people were not treated differently because of their impairments. More importantly, it was recognised by some that they at times supported their non-disabled siblings, a factor that has been overlooked within previous research. The extended family also played an important role by accepting the disabled family member and offering everyday experiences as well as helping with medical and therapy interventions. In particular, the maternal grandfathers became important figures in the lives of two of the young people.

The young people considered friendships to be important. Those who attended Juniper Hills School generally felt comfortable interacting with peers who also had impairments. They preferred mixing with others who understood them and did not treat them as different. The others, who attended mainstream schools, had mixed views ranging from only being friends with non-disabled peers to only being friends with disabled peers. The reasons behind this appeared to be partly related to the personalities of the young people. What was important was that they were included in a peer group that they wanted to be with. An interesting issue that arose from the stories was that putting disabled young people together did not necessarily mean that they would become friends.

The young people at Juniper Hills School spoke positively of their segregated education. They felt they were understood, their needs provided for and there were plenty of opportunities to be active. Those that went to a mainstream school had mixed experiences from being totally included to feeling excluded. There were issues with the staff and student attitudes and school systems that affected the inclusion experience. The young people differed as to their opinion on the inclusion-segregation debate.

In spite of the difficulties that some of the young people had experienced, they were relatively positive about their life. They did not view having an impairment as a tragedy but they did have some issues with the attitude of some members of the public. The stories indicated that they just got on with life rather than became stressed about their impairments. They were also reasonably positive about their medical interventions, although complaining a little about the attitude of some health professionals, indicating that they felt an improvement in their own functioning was worthwhile. They saw themselves as ordinary for their age except that they used a wheelchair for mobility. Their positive outlook adds weight to the development of an Affirmation Model of Disability as proposed by Swain and French (2000) an extension of the Social Model of Disability.

The following chapter reflects on the study and presents some overall conclusions and recommendations for future research.

CHAPTER 5 REFLECTION, RECOMMENDATIONS AND CONCLUSION

Introduction

The biographies of nine young people with motor impairment were written and analysed to gain insights into the views and issues that were important to them. An auto/biographical approach was used to enable them to talk about their lives in their own words, thus giving them a voice (Prout and James 1997, Qvortrup 1997, James *et al.* 1998, Roberts 2000, Curtin 2001, McKechnie 2002). In this chapter I will reflect on the methodological issues inherent in the study and provide future research recommendations and an overall conclusion.

Reflection on the Research Methodology and Method

When reflecting on the research three issues became evident as potential limitations of this study. Firstly, the issue of the degree of collaboration with each participant; secondly, the ability of each participant to tell 'coherent' stories; and thirdly, the difficulty of grouping together the nine voices into general themes.

The intention from the beginning of this research was to work collaboratively with the young people to produce and analyse their biographies. Whereas I was able to partially achieve this in the production of each biography, the participants were not involved in the analysis of their stories. This raises the important ethical issue of representation and whose voice took precedence. Within the methodology chapter, I recognized that I was in the main responsible for the final content and layout of each biography and I acknowledged that I may have misrepresented or suppressed the very voices that I was attempting to make heard. Nevertheless, as Denzin (1989), Stanley (1993) and Richardson (1995, 2000) state it is not possible to silence the researcher's voice from the text, rather the construction of a biography should be a collaborative effort between the researcher and the participant. This is consistent with Alcoff's (1991) view that researchers need to develop the skills of writing with participants to ensure that what is written is representative of the people being researched. Accordingly, in order to further facilitate hearing the voices of the disabled young people the collaborative nature of the research method used in this study requires further development. Arvay (2003) proposes using a collaborative narrative method to make the relationship between the researcher and the participants equal, as a way of dealing with issues of voice and representation. Whereas my attempt at collaboration focused on the production of agreed biographies, Arvay (2003) extends this by collaborating with research participants, whom she refers to as co-investigators, in the analysis of the data. She provides her co-investigators with the interview transcripts and a reading guide as an aid to analysing the transcripts. Both she and the co-investigators read the transcripts independently, following the guide, and develop their interpretation. Once this is completed, they meet together for the interpretive interview, in which they both share their interpretations of the text. This interview ends with the summarising of the interpretations into one blended text. The researcher then writes the story as a first person account. The co-investigator edits this account and has the final word on the form and the content of the narrative account. Arvay (2003) contends that the inclusion of each participants' analysis and interpretive interview enhances the credibility of narrative type research.

However, what is important to note here is that Arvay (2003) uses the collaborative narrative method with adults. The challenge for my research is to engage disabled young people in the interpretation process. Strategies to enable this to happen require careful thought, particularly in light of the fact that in my study the young people only offered spelling, grammatical and the occasional factual error corrections. None challenged the content, layout or presentation of their stories even though they were encouraged to do so. To work with this group more collaboratively involves a greater commitment on their part, in both time and effort, and an ability to work more closely with the researcher. Building the necessary rapport would take time and require the participants/co-researchers to have a greater understanding of the research, perhaps even being involved in the development of the research project. Time would be required to develop the disabled young people's skills and ability to read transcripts and to use the reading guide for analysing the transcripts. Further, the development of a reading guide would likely need to be a collaborative task as a method of enhancing the disabled young people's understanding of, and participation in, the research process. Lewis and Kellet (2004) suggest that this is important for the continued development of emancipatory disability research in which disabled young people become intrinsically involved throughout the whole research process. The effort involved in adapting the collaborative narrative method to engage disabled young people more in the production and analysis of their biographies would be worthwhile as it has the potential to ensure that the final stories are more representative of their voices.

A second potential limitation of this study concerns the ability of the participants to tell coherent stories. Thorne *et al.* (1998), Baerger and McAdam (1999) and Habermas and Bluck (2000) believe that young people do not have the cognitive abilities or the motivation necessary to narrate coherent life stories. They propose that life stories do not become integrated until the more cognitively sophisticated forms of causal and thematic coherence develop during adolescence. During this period teenagers begin to connect past and present selves by identifying links between life circumstances, events and their own personal development. Accordingly, when applied to this study, their proposition suggests that the majority, if not all, of the young people would not be able to tell a coherent life story. This is because most of the young people are between the ages of 10 to 12 years, with only Xanthe and Ronald beginning their teenage years, being 13 and 14 years old respectively. The young age of the participants may be considered a limitation in auto/biographical research where the narration of causally and thematically coherent life stories is key to the research. The disabled young people in this study showed a marked variation in their ability to talk about their life. For most the focus was on the present and little detail was provided about past events. This does not, however, seem to be specifically related to their age. It may, in fact, have some connection to gender as the three girls, aged 11, 12 and 13 years, talked in some depth about their lives, even providing some basic forms of causal and thematic coherence while the boys, aged between 10 and 14 years, in the main, concentrated on the present. Gathercole (1998) believes that the differences in the ability to narrate coherent life stories may relate to the relationships young people have with adults. She argues that positive interactions with adults who gradually introduce young people to richer and more complex ways of talking about earlier events is important to the development of coherence. Perhaps young people who tell their life stories more coherently have parents who actively demonstrate and encourage the ability to reflect on and talk about one's life (Rogoff 1990).

Within this study, the ability to tell coherent life stories was not an inclusion criteria as I felt that stories that lacked coherence were still worthwhile stories. Their worth lies in seeing them as one interpretation of how disabled young people perceive their lives at a particular point in time. The present may be what is important to a disabled young person during the period of telling his or her story. Indeed the way a disabled young person talks about life provides some insight into the development of his or her cognitive and emotional abilities, and identifies areas which may benefit from further development. Thus I remain convinced that an auto/biographical approach is an appropriate means for accessing the life stories of this group of young people. The approach, however, needs some adaptations, such as using more directed rather than open questions, in order to accommodate the lack of causal and thematic coherence evident in the stories the disabled young people tell.

To understand each young person's story more completely, it would have been preferable to present and analyse each biography separately within this thesis. However, the word limit restriction meant that this was not an option and, as a consequence, the discussion chapter became written on the basis of themes, as suggested by Preece (1996), Smith (1995) and Coffey and Atkinson (1996). In reducing what the young people said into general themes, their individual voices may have, in some instances, become submerged into a more general voice, particularly as it was not always possible to provide commentary on or supportive quotes from all nine young people for each theme discussed.

Recommendations

In spite of the limitations identified in this research, the findings suggest several future research directions. One recommendation, already covered in the previous section, involves the use of the collaborative narrative method as a means of increasing the participation of disabled young people throughout the research process. Other recommendations focus on specific areas of research identified by this auto/biographical approach, broadening the scope of the research and experimenting with different styles of representation.

Using an auto/biographical approach can identify areas for research that are important to disabled young people or that are absent from the literature. Within this research it became evident that more research could be undertaken to better appreciate disabled young people's views and understanding of their family. Current research tends to focus on the views of parents and siblings of disabled young people and whilst this is important, the voices of disabled people are largely missing. More research needs to focus on what disabled young people look for in friendships and, in particular, how friendships could be facilitated, particularly outside of the school environment. The evidence to support inclusive education is lacking and seems predominantly based on moral argument and expert opinion. More research focusing on disabled young people's educational experiences and views while they are young could provide a valuable contribution to this debate.

The disabled young people involved in this study are in many ways privileged, particularly in the opportunities that their parents or schools provide. It would be appropriate in future studies to focus on disabled young people from disadvantaged backgrounds, different ethic groups and who have different impairments. Thereby beginning to build a wealth of life stories with which to enhance the public perception and understanding of disabled young people.

The research for this thesis focused on each young person's life story as told during a one-year period. Denzin (1989) recognised that life stories are open-ended and subject to multiple tellings. Different narratives evolve as new experiences are continuously presented to an individual, continually challenging each person to reflect on and evaluate who they are and who they want to be (Thorne *et al.* 1998). More longitudinal auto/biographical studies would enable disabled young people's life story narratives to be analysed during different stages of their lives, thus recognising that their life is not static and that it changes as they become older. Longitudinal auto/biographical research will also provide insight into the range of influences on disabled young people throughout different periods of their lives.

The issue of representation in writing and analysing life stories remains, as I have claimed, a challenge, particularly if the narrator's voice is to be heard. Richardson (1990, 2000) suggests that researchers should experiment with writing because it is a way of analysing and engaging with their texts to greater depth and also of reaching a diverse audience. Due to the word limit and format I was unable to present the analysis of each story separately or write them in a more accessible format, perhaps fictionalising them as suggested by Ellis and Bochner (2000). Being able to write in a more meaningful way is important, as I feel an obligation to publicise the views of the young people who participated in this research project. Thus, ultimately I want to write in a way that would be more accessible to them; the concept of a thesis and research publications was foreign to all the participants. For this study to have more relevance to them and perhaps to have more impact with a wider audience, publications outside of academic journals and conferences warrant investigation. Indeed, it may be possible that some aspects of the research would be appropriate for publication in more popular journals, and further these could be written as short stories and/or presented as poems or turned into a work of fiction aimed at challenging young people's awareness and understanding of disabled people. Using a variety of methods to present and publish the life stories of disabled young people would be one way for auto/biographical research to have a greater impact and reach a wider audience.

Conclusion

According to Bronfenbrenner and Morris (1998), every young person is unique because they each have contact with different environments and grow up in different families, neighbourhoods and schools, and with different friends and peers. The essence of this individuality, however, is how a person interacts with and responds to these environments reflecting his or her abilities, attributes and personality. Focusing on these personal traits is often neglected in research, particularly research investigating disability issues, where disabled people are often wrongly thought of as a homogenised group.

Although the participants involved in this study all spoke of families, friends, school and being impaired, they each provided a different point of view, providing distinctive insights into their lives as disabled young people. These insights clearly display their diverse, complex and multiple identities and reinforce the move away from medical and educational labels, toward considering each disabled young person as an individual with specific needs (Lewis and Kellet 2004). Each participant found different things helped them to be satisfied with their lives, such as being active, having friends and a supportive family, academic success, personal interests and, for some, therapy. Their narratives supported the view proposed by the Affirmation Model of Disability, that having an impairment can enhance or provide a lifestyle of satisfaction and worth (Swain and French 2000). As Colin Cameron states in the introduction to a book of poetry written by disabled people,

> We are who we are as people with impairments, and might actually feel comfortable with our lives if it wasn't for all those interfering busybodies who feel that it is their responsibility to feel sorry for us, or to find cures for us, or to manage our lives for us, or to harry us in order to make us something we are not, i.e. 'normal',
> (Tyneside Disability Arts 1999, p. 35)

This study highlights that disabled young people with the same medical label have differing needs, aspirations, opinions, attitudes and emotional states which are as complex as those of non-disabled young people (Lewis and Kellet 2004). Considering the individuality of disabled young people brings to the forefront the issue of participation and the right they have to express views and opinions and have these listened to. Kirby and Woodhead (2003, p. 236) see the participation of young people as a multifaceted concept, describing it in the following way,

> It is about children's activity and agency being recognised; about children being treated with dignity and respect; about them being entitled to express their feelings, beliefs and ideas; about being listened to and about their voices being heard. It is about children being consulted on matters that affect them, and being given adequate

> information to be able to form an opinion. It is also about children making choices and influencing decisions, contributing to the understanding and solution of social issues.

Although the United Nations Convention on the Rights of the Child (United Nations 1989) and more recent legislation and government initiatives, such as the Disability Discrimination Act (1995), the Framework for Assessing Children in Need (Department of Health *et al.* 2000) and the Special Education Needs and Disability Act (2001), formally establish the right of participation in which young people should be included in the decisions that affect their lives, there is still evidence that young people are not being listened to. Morris (1998b), Watson *et al.* (2000) and Connors and Stalker (2003) all discuss the absence of disabled young people's voices within much of the research focusing on this group of individuals. Further, disabled young people's voices are absent from the debates on major issues that influence their lives, such as inclusive education (Pitt 2003). There remains a clash between the welfare-protectionist approach to raising young people and the empowerment or participation approach (Flekkøy and Kaufman 1997, Burr and Montgomery 2003). This clash usually arises because of the issue of competence and the question of how to determine when young people are physically, cognitively and emotionally ready and able to participate.

Listening is considered essential for the right of participation to be effectively implemented with young people (Kirby and Woodhead 2003). During the course of gathering and analysing data for this study, I observed that central to auto/biographical research methods is the process of listening and telling. Through listening to and analysing the life stories of disabled young people, auto/biographical research methods can contribute to their active participation within society, through acknowledging that they are responsible, competent and capable citizens. The value of this research approach with disabled young people is that it taps into their direct experiences and perceptions of being young and living with an impairment. This is crucial as disabled young people's reality cannot be fully comprehended by the inferences and assumptions that are usually made by non-disabled adults (Lloyd-Smith and Tarr 2000).

Finally, this research has shown that auto/biographical research methods can contribute to the emancipation of disabled young people by challenging stereotyped and ill-informed attitudes held by society. Through listening to, recording and analysing the stories and views of their lives, this approach can be used to begin to unpack society's largely negative perceptions of disability and empower disabled young people by giving them a voice, contributing to their participation by treating them as valued citizens.

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APPENDIX 1 LETTER TO PARENTS OF DISABLED YOUNG PEOPLE ASSOCIATED WITH CLOUDBERRY SCHOOL

5th January 2002

Dear Parents

Biographies of Young People with Motor Impairments

This letter has been sent to you via Cloudberry School who thought that you and your child might be interested in being involved in the research described below. The director of Cloudberry School, (name), and the (relevant people) are supportive of this research. This research, however, is independent of Cloudberry School and their involvement was primarily to send this letter on my behalf to you.

I am a lecturer in occupational therapy working at the School of Health Professions, University of Southampton. As an occupational therapist I have mainly worked with young people and currently I am responsible for teaching the paediatric modules on the occupational therapy training programme at the university.

As part of my commitment to research at the University of Southampton I am interested in writing the biographies of young people with physical disabilities. The focus of each biography is to identify how each young person's current life, as well as future hopes and goals, have been influenced by his or her experiences. The biographies will give each young person the opportunity to tell his or her life stories how he or she wants to tell them and provide some insight and understanding into his or her life experiences.

One of the reasons for doing these biographies is that there is very little written from the point of view of young people with motor impairments. Most publications are written by adults, looking back on their childhood, or written from the point of view of parents and professionals. It is my belief that we can learn more about the lives of young people with motor impairments by asking them about their life while they are young.

I am writing to ask if you would allow me to talk with your child who has a physical disability with the aim of writing his or her biography. Attached to this letter is an information sheet that explains more about this study and what would be involved if you decide that your child can take part. If you have any questions that are not answered in the information sheet you are welcome to contact me. My details are given at the end of the information sheet.

I would be grateful if you could let me know your decision by completing the attached form and returning it in the stamped addressed envelope supplied. Returning this form does not commit you or your child to taking part in this study. If you indicate that you are willing to discuss further the possibility of your child taking part I will contact you to arrange a convenient time to visit you and discuss this study in more detail. After this discussion you and your child can decide whether you would like to take part.

I would appreciate it if you could return the attached form by **Friday 25th January 2002** as I would like to arrange for the initial meetings to take place as soon as possible.

Thank you for taking the time to read this letter.

Yours sincerely

Michael Curtin
Lecturer in Occupational Therapy

APPENDIX 2 LETTER TO PARENTS OF DISABLED YOUNG PEOPLE ATTENDING JUNIPER HILLS SCHOOL

5th January 2002

Dear Parents

Biographies of Young People with Motor Impairments

This letter has been sent to you via Juniper Hills School who thought that you and your child might be interested in being involved in the research described below. The staff at Juniper Hills School are supportive of this research.

I am a lecturer in occupational therapy working at the School of Health Professions, University of Southampton. As an occupational therapist I have mainly worked with young people. Currently I am responsible for teaching the paediatric modules on the occupational therapy training programme at the university.

As part of my commitment to research at the University of Southampton I am interested in writing the biographies of young people with physical disabilities. The focus of each biography is to identify how each young person's current life, as well as future hopes and goals, have been influenced by his or her experiences. The biographies will give each young person the opportunity to tell his or her life stories how he or she wants to tell them and provide some insight and understanding into his or her life experiences.

One of the reasons for doing these biographies is that there is very little written from the point of view of young people with motor impairments. Most publications are written by adults, looking back on their childhood, or written from the point of view of parents and professionals. It is my belief that we can learn more about the lives of young people with motor impairments by asking them about their life while they are young.

I am writing to ask if you would allow me to talk with your child who has a physical disability with the aim of writing his or her biography. Attached to this letter is an information sheet that explains more about this study and what would be involved if you decide that your child can take part. If you have any questions that are not answered in the information sheet you are welcome to contact me. My details are provided at the end of the information sheet.

I would be grateful if you could let me know your decision by completing the attached form and returning it in the stamped addressed envelope supplied. Returning this form does not commit you or your child to taking part in this study. If you indicate that you are willing to discuss further the possibility of your child taking part I will contact you to arrange a convenient time to visit you and discuss this study in more detail. After this discussion you and your child can decide whether you would like to take part.

I would appreciate it if you could return the attached form by **Friday 25th January 2002** as I would like to arrange for the initial meetings to take place as soon as possible.

Thank you for taking the time to read this letter.

Yours sincerely

Michael Curtin
Lecturer in Occupational Therapy

APPENDIX 3 RESEARCH INFORMATION SHEET SENT TO PARENTS

Biographies of Young People with Motor Impairment

Parent's Research Information Sheet

What is this study about?

The aim of this research is to write the biographies of young people who have a physical disability. The focus of each biography is to identify how each young person's current life, as well as future hopes and goals, have been influenced by his or her experiences. The biographies will give each young person the opportunity to tell his or her life stories how he or she wants to tell them.

The reason why this study is needed is that there is very little written from the point of view of young people with disabilities. Most publications are written by adults, looking back on their childhood, or written from the point of view of parents and professionals. It is my belief that we can learn more about the lives of young people with motor impairments by asking them about their life while they are young.

Who is Michael Curtin?

I have been working as an occupational therapist since 1983. I am Australian but have lived and worked in England since 1991. I have also worked in Botswana for four years. Most of my work as an occupational therapist has been with young people. I have been employed as a lecturer on the occupational therapy and physiotherapy programmes at the University of Southampton since 1995. The focus of my teaching is on working with young people. I am also the father of two boys, aged 10 and 7 years.

If my child takes part in the study what would it involve?

I will spend time with your child to talk with them about their life. It is expected that there will be several meetings, as it will take some time to gather the necessary details for his or her biography. Each meeting will be very informal and will last approximately an hour or for as long as your child remains willing to talk about his or her life. The meeting will usually take place at school or at your home.

What will happen to the information your child gives me in the interview?

If you and your child agree, each meeting will be audio-taped. Following each interview the tapes will be written up and I will piece together the stories your child has told. I will show your child what I have pieced together the next time we meet to make sure that I have understood what has been said and to give your child the opportunity to remove or change parts of the their story. I will treat all that your child says in strictest confidence and will only publish material that you and your child agree can be published. At the end of the research the tapes will be destroyed.

This research is being done as part of my doctorate. The stories your child tells me will form part of my thesis. I also hope to write several articles for some relevant journals and to present my findings at both national and international conferences.

Does my child have to take part in this study?

Your child is under no obligation to take part in the study. If your child does take part, he or she may withdraw or be withdrawn from the study at any time without giving a reason for doing so.

What happens now?

If you are willing to discuss this study further:

To arrange a time to discuss this study further with you and your child I require your permission to contact you. To do this I need you to complete the attached form, tick the **AM WILLING** box and then return it to me in the stamped addressed envelope. Once I receive the completed form I will phone you to arrange a convenient time to discuss the study in more detail. Returning this form does not commit you or your child to taking part in this study.

If after this discussion you and your child would still like to be involved in the research I will arrange a date to begin to meet with your child about his or her life stories.

If after this discussion you and your child would prefer not to be involved in the research I will not contact you again.

If you are not willing to discuss this study further:

If you decide that you would prefer not to meet to discuss this study further then you should complete the attached form, tick the **AM NOT WILLING** box and return it to me in the stamped addressed envelope. I will not contact you again in relation to this study.

If you require any further information you can contact me at the following address:

Michael Curtin, Lecturer in Occupational Therapy,
School of Health Professions and Rehabilitation Sciences,
Building 45, University of Southampton, Highfield,
Southampton SO17 1BJ
Telephone: 023 8059 5299 E-mail: mc6@soton.ac.uk

Thank you for reading this and for your interest. I look forward to hearing from you.

Michael Curtin
Lecturer in Occupational Therapy

APPENDIX 4 EXPRESSION OF INTEREST FORM

Biographies of Young People with Motor Impairments

Please print clearly

I, (parent/guardian name) ______________________________,

of (address) ____

____

Telephone: ______________________

am willing ...☐ **am not willing** .... ☐

(please tick the appropriate box)

to discuss further the possibility of Michael Curtin writing my child's biography.

Child's name: ____________________ Age: __________

A convenient day and time during the week to telephone me would be:

____

Please return this slip in the envelope provided by

Friday 25th January 2002

to:

Michael Curtin,
Lecturer in Occupational Therapy,
School of Health Professions and Rehabilitation Sciences,
Building 45,
University of Southampton,
Southampton SO17 1BJ.

Thank you

Michael Curtin
Lecturer in Occupational Therapy

APPENDIX 5 RESEARCH INFORMATION SHEET GIVEN TO THE DISABLED YOUNG PEOPLE

Biographies of Young People with Motor Impairment

Young People's Research Information Sheet

What is this study about?

This study is about writing your story. I will ask you about what you like and don't like doing, what are your favourite memories, what do you hope to do when you are older. I will ask you about school, what you like to play and what you do at home. This study is about you talking about things that are important to you and saying why they are important to you.

The reason I am doing this study is that many adults and young people do not understand what it is like to have a physical disability. By writing your life story I hope that we can learn more about what is important to you.

Who is Michael Curtin?

I have been working as an occupational therapist since 1983. I am Australian but have lived and worked in England for over 10 years. Before I came to England I worked in Botswana, a country in Southern Africa, for four years. As an occupational therapist I have mainly worked with young people. Now I work at a school that trains adults to become occupational therapists. I have been at this school for over six years. I teach the students about working with young people. I am also the father of two boys, aged 10 and 7 years.

If you take part in the study what do you have to do?

Basically I would like to meet with you several times and hear what you have to say about the things that interest you in your life. Each time we meet we may talk for about one hour. I hope it will be fun. We can talk while we do something that you like doing. We will usually meet at school or at your home when your parents are around.

What will Michael Curtin do with what you tell him?

I would like to record what we say using a tape recorder. This is so I can remember everything that you have said. When we are finished talking I will listen to the tape again and write out everything that has been said. I am going to try to write your life story based on the things you tell me. I will show you what I have written the next time we meet. I will also leave a copy of anything I have written. Then you and your parents can read it and see if you like it. If I have written things wrongly or written things that you don't like or that you want to change then I will write them again. I will write your story in a way that no one else will know who you are. After I have written your story I will destroy all the tapes we have recorded of our talks.

The reason I want to write your story is because I am studying at university. Your story will help me with the study that I am doing. I hope that in the future I will be able to write some books about the stories that you and other young people tell me. If I do this I will let you know. Sometimes I will talk to adults about your story so that we can all understand young people a little better.

Do you have to take part in this study?

You do not have to take part in the study. If you start to take part and then change your mind that is OK. You don't even have to say why you have changed your mind.

What happens now?

If you decide that you would like to talk with me about your life:

If you decide that you want to talk to Michael Curtin about your life stories I will arrange a time to come and visit you at school or home. When we finish one meeting we will arrange a time for the next one. These meetings should be fun but if you find that they are not then remember you can change your mind.

If you decide that you do not want to talk with me about your life:

If you decide that you do not want to talk with me about your life then you can let me know or you can tell your parents and they will let me know. I will not contact you again about this study.

If you want to know more you can write to me or phone me at the following address:

Michael Curtin
Lecturer in Occupational Therapy
School of Health Professions and Rehabilitation Sciences,
Building 45
University of Southampton,
Highfield,
Southampton SO17 1BJ

Telephone: 023 8059 5299 E-mail: mc6@soton.ac.uk

Thank you for reading this and for your interest. I look forward to hearing from you.

Michael Curtin
Lecturer in Occupational Therapy

APPENDIX 6 PARENT'S CONSENT FORM

Biographies of Young People with Motor Impairment

Parent's Consent Form

Please initial box

1. I confirm that I have read and understood the information sheet supplied by Michael Curtin for the above study and have had the opportunity to ask questions about it. ☐
2. I understand that my child's participation in this research is voluntary and that he or she is free to withdraw or be withdrawn at any time, without giving any reason. ☐
3. I understand that this research forms part of a doctoral programme of study. ☐
4. I agree that my child can take part in the above study. ☐
5. I agree that the meetings Michael Curtin has with my child can be audio taped. ☐

Name of Child ______________________________

Name of parent/guardian ______________________________

Signature of parent/guardian ______________ *Date* ______

Signature of Researcher ________________ *Date* ______

APPENDIX 7 YOUNG PERSON'S CONSENT FORM

Biographies of Young People with Motor Impairment

Young Person's Consent Form

Please initial box

1. I have read and understood the information sheet given to me by Michael Curtin for the above study and have had the opportunity to talk with him about it. ☐
2. I understand that I only need to take part in this research if I want to and that I can stop taking part at any time and I do not have to say why. ☐
3. I understand that Michael Curtin is doing this research as part of his learning at university. ☐
4. I agree that I will take part in the above study. ☐
5. I agree that my meetings with Michael Curtin can be audio taped. ☐

Name of child ______________________________

Signature of child ____________________ Date __________

Name of parent/guardian ______________________________

Signature of researcher ______________________________

APPENDIX 8 COVER LETTER TO YOUNG PEOPLE ACCOMPANYING THE FIRST DRAFT OF THEIR STORY

(Date)

Dear (Name of young person)

RE: Biographies of young people with motor impairments

At last I have completed the first draft of your story as I promised in my last letter. You should find a copy of your story for you to read, with this letter. As you read it you may find some spelling and grammatical mistakes. You may also find that I have written some things down incorrectly. When we next meet up it would be great if you could point out to me anything which is not quite right or that you would like to change.

You will notice that I have used your real name in the draft copy. When we meet up we can talk about what name you would like to use in your story so that your identity can be kept a secret. I have tried not to use the names of your schools or of other people you have mentioned. If I have done this then it will be something that we can change when we meet up. It would be great if you could think of what your story should be called and what to call the different chapters.

When we meet up I would like to spend some time filling in the gaps in your story. When you have read your story you might think that there is more you can tell me about some of the things I have written. You may also want to talk about some things that we have not talked about so far.

We could talk about your family, your friends, what you like doing, your new class, what you think about your life and your thoughts for the future. I would also like to talk more about your thoughts on having cerebral palsy.

Before my next visit you may like to think about or note down some of the things in your life that you would like to talk with me about. It might be good to have a talk with your mum and dad first so that they can help you decide what you would like to tell me.

I have arranged with your mum to visit you at your home on **(date)** at around **(time).** If you or your parents would like to ask me anything before that time then feel free to phone or email me on the numbers above.

Best wishes and I look forward to seeing you again soon.

Michael Curtin

APPENDIX 9 COVER LETTER TO YOUNG PEOPLE ACCOMPANYING THE SECOND DRAFT OF THEIR STORY

(Date)

Dear (Real name)

RE: Biographies of young people with motor impairments

At last I have completed the second draft of your story. You should find it in the envelope with this letter. I would be grateful if you could have a read through your story and see if I have got it right.

You will notice some changes in the layout and style compared to the previous version. The line numbers are included so that you can easily direct me to words or sections that might need to be changed. I have also used different names for you and for other people mentioned in your story. Just to help you follow who's who I have included the alternative names below.

Real names and alternative names used in story presented in table

I know that things will have changed in your life since we last spoke. That is why I have written the dates on the front cover so that whoever reads your story will know when it was told.

I would like to contact you within the next two to three weeks to see if you are happy with the story. I will contact your mum to see if this will be possible. If you feel that it is not necessary to meet up you could contact me by email or phone to let me know what your think of this draft version of your story.

I look forward to catching up with you again soon and thank you for the time you have already given me in being involved with this research.

Best wishes,

Michael Curtin

APPENDIX 10 SAMPLE OF THE LAYOUT OF THE FIRST DRAFT OF THE STORIES

(Note that the book was printed on A5 paper and ring bound)

Cover page

(Tony's real name) Story

23rd October 2002

My name is (real name). I was born three months premature. I was supposed to be born in July and I was born on May the 18th 1990. I was really poorly and I nearly died. Thanks to technology that they had at that time I am alive. If I had of been born earlier, before they had the technology, I would have died. I had to stay in intensive care for six months and I wasn't well at all.

When I went home from hospital I didn't get use to my home because babies have small eyes. It was hard at first to get use to being home, after being born and being away for six months. I can't remember being at home after I was born. What I can remember I have seen on tape. For my first Christmas, 25th December 1990, I got a car, which I could sit on and drive. Daddy was pushing me while I sat in this car. He was doing silly things like daddy's do to little children if you love them. He put my phone; I had a toy phone, up to his ear.

When I was about three or two I know there was one thing that I did like. I loved chocolate biscuits. I could also drink orange squash by then. I could eat normal food and didn't have a bottle or a dummy.

I didn't start walking until I was three. My parents took me to a doctor and he had a look at me.
He said, "Mr and Mrs (surname) I am afraid your child has go some condition called cerebral palsy."

My parents were more than shocked. They were really surprised. And to make things worse I also had Asperger's Syndrome, which comes with cerebral palsy. It comes with it and it was quite bad. I've also got perceptual problems, which don't allow me to see very well. I've had three eye injections in my life, which only took about five minutes, which was less time than it took to change my plaster.

I understand that my Asperger's makes me worry a lot. I also understand that my brain is a bit damaged. I had a brain scan when I was seven or eight and there were no holes in my brain but with cerebral palsy there is a bit of brain damage. Luckily for me I can still think but I am a bit slower than my brother.

My brother

When I was about three I had a little brother. My brother was only born about two days early. When he came home I was very please to have a little brother. He always cried when I hugged him. He is getting on well now he's more grown up. He's doing more stuff. There is only one problem with him. Sometimes he doesn't want to do his homework.

What I am interested in

I love Formula One motor racing. I've got a Ferrari shirt and loads of Formula One computer games that I enjoy playing. I enjoy watching motor racing. It will be interesting to see what it will be like when they bring in the new rules in 2004. You will only be allowed to bring one engine with you and if it blows up in qualifying or practices it will be tough luck. You have to fix it. I think it is a very unfair rule because at the moment you have four engines and if one of them breaks you can use a spare car. But that's the rules in the FIA regulations.

I have enjoyed riding in three Ferraris. One belonged to a friend of mine. It was a 350. The other time I rode in one was with a person I didn't know. It was in a 348. I also went to a Brooklyn weekend, where all the cars are Italian.

School

When I was little I used to go to a playgroup for children with special needs.

I used to go to a mainstream primary school in a nearby city. This primary school was not very good in my last couple of months. They didn't help me much. They didn't have the facilities. I enjoyed it there until one of my teachers left. When he left
everyone in my class struggled. We got this one silly teacher who didn't know anything. She thought she was so smart but she wasn't, to be honest. My mum perfectly agreed with me about that.

Before coming to the special needs school that I am at my parents looked at two other schools. They felt one of the schools was too normal for me.