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'YOUNG ADULTS AND DISABILITY: TRANSITION TO INDEPENDENT LIVING?'

by Nicola Hendey, B.Sc., MA

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for the degree of Doctor of Philosophy, June, 1999

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ABSTRACT

The study aims to explore young disabled peoples' concerns about independent living, and how they view the source of that independence.

The transition to adulthood poses particular problems for young physically disabled adults and independent living is a widely shared goal. The independent living movement has spearheaded an increasing awareness amongst disabled people of their rights as human beings and citizens and has brought together ideas on independent living and ways of achieving it. The philosophy of independent living is based on four assumptions: that all human life is of value; that anyone, regardless of their impairment, is capable of exerting choices; that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have a right to have control over their lives, with whatever assistance they need to do so; and that disabled people have the right to participate fully in society. Government policy is consonant with the aims of the independent living movement: to keep individuals in the community and to address their needs more appropriately.

This study, which is based upon data from 42 young physically disabled adults uses qualitative methods which were inspired by the ideals of the Emancipatory Research Paradigm. Interviews were in-depth and informal and focussed on the periods before, during, and after transition. The work was conducted from the

standpoint of the seven fundamental needs outlined in the social model of disability.

To what extent had the young people achieved independent living? None of the sample had achieved independent living in its fullest sense in terms of employment, independent housing, financial and personal control of assistance, life style, relationships, educational qualifications or transport. A minority had achieved some of these. The majority had low self-esteem and had received inadequate support from families and the education system and had poor employment prospects. Most were reliant on benefits which were insufficient to meet the extra costs associated with disability and few had received support from social services. Most appeared destined for a life on the margins of society.

INTRODUCTION

The principal focus of the research was to ascertain the experiences, expectations and priorities of young adults with profound physical disabilities who had recently undergone transition from special needs education to living in the community.

Although physically disabled people were designated a priority group in the Government's policy document 'Care in Action' (1981), work that has been carried on this area from the standpoint of service provision (Anderson & Clark, 1982; Beardshaw, 1988; Fiedler, 1988; Wagner, 1988; Bax & Smyth, 1989; Morris, 1990; Audit Commission, 1992; Chamberlain, 1993), has highlighted deficits in provision for this group. Services for younger physically disabled adults those aged 16 - 65 years are at the lower end of the spectrum of services for disabled people in terms of quantity and quality (Beardshaw, 1988).

It is acknowledged that young adults with profound physical disabilities face particular problems when making the transition from childhood to adulthood and from living in the parental home to living independently in the community. The transition from school to adult life is acknowledged to be a time of particular stress (Court Report, 1976; Warnock Report, 1978).

This period has been largely neglected in the literature and there has been little attempt to ascertain the experiences, expectations and priorities of a group of physically disabled young adults who had recently undergone transition. Why is the period so stressful? What are the difficulties faced? What impact does the lack

of services have on the lives of young disabled adults? These questions have been neglected in the literature and will be explored in subsequent chapters of this thesis.

Professionals (from the fields of medicine and social work) have played a predominant role in the delivery of health and social services to this group since 1945 (Oliver, 1990; Barnes, 1991; Morris, 1994). Whilst the literature suggests that this may be problematic as it reinforces the idea of inadequate disabled people who are incapable of making basic decisions about their individual service needs and therefore need expert 'care' (Oliver, 1990; Barnes, 1991), there has been no attempt to investigate the extent to which this is the case or the ways in which it may disadvantage young disabled people who are attempting to make the transition from full-time education to living in the community. This issue will be investigated later in the thesis.

Critics from the disability movement have argued that the central role played by professionals in service delivery has legitimated the individual model of disability which:

> Locates the 'problem' of disability within the individual and sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability (Oliver, 1996:32).

There has been little attempt to explore the extent or nature of the impact of this model on the lives of young physically disabled adults. This will be explored in terms of the disability literature and literature on transition from the fields of Psychology, Sociology and Social Policy and the experiences of the young disabled adults themselves.

The assumptions underpinning the individual model of disability have not gone unchallenged however. The origins of the independent living movement in Britain lie in disabled people's attempts in the 1950's and 1960's to leave the paternalism of long - stay institutions. Organisations of disabled people mushroomed during the 1970's and 1980's and the resistance to residential care spearheaded an increasing awareness amongst disabled people of their rights as human beings and citizens. (Morris, 1993). The formation of the British Council of Organisations of Disabled People in 1981 provided a national forum which brought together ideas on independent living and ways of achieving it. Centres for Independent Living aiming to provide advice and support for people who wished to live independently were a crucial development. These were inspired by the centre at Berkeley, California and later American Centres. These identified five basic needs which, if met in full, would enable disabled people to achieve independent living: appropriate housing, personal assistance, transport, access to their environment, advocacy and training. The Derbyshire Centre for Integrated Living added another two basic needs to the list, information and counselling and equipment or technical assistance (Crosby & Jackson, 1988; Kestenbaum, 1996).

There are four assumptions on which the philosophy of the independent living movement is based, namely: that all human life is of value; that anyone, regardless of their impairment, is capable of exerting choices; that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have a right to have control over their lives, with whatever assistance they need to do so; and that disabled people have the right to participate fully in society (Morris, 1993; Kestenbaum, 1996). This definition of independence has been adopted in the current study.

The 1990 NHS and Community Care Act is consonant with the aims of the independent living movement: to keep individuals out of institutions and to address individuals' needs more appropriately. Community care featured increasingly strongly on the political agenda from the 1950's onwards, fuelled by financial concerns, and a number of studies and scandals which illustrated the damaging effects of institutionalisation (Goffman, 1961). The dominance of the New Right version of welfare pluralism in the political arena since 1979 may pose new difficulties for young physically disabled adults. The emphasis has been on a reduction in the role of the state as provider at central and local levels accompanied by financial and service rationing (Johnson, 1987; 1990), and a mixed economy of welfare has been encouraged. The burden of care upon the state has been reduced by the promotion of a positive element of choice and competition leading to self - reliant rather than dependent service consumers befitting Right wing ideology (Johnson, 1990). The 1990 NHS and Community

Care Act, implemented in full in April 1993, is the basis of current policy:

> Instead of users and carers being subordinate to the wishes of service providers, the roles will be progressively adjusted....Users and carers will be enabled to exercise the same power as consumers of other services (Department of Health, 1991).

Have disabled people experienced these developments as service cuts or as a move from service led to needs led provision? This will be investigated from the standpoint of the young physically disabled adults in the research sample.

The research carried out on disability has been largely quantitative in nature and has been based on the individual as opposed to the social model of disability. Whilst it has made a valuable contribution in terms of knowledge of current levels of service provision for young physically disabled adults, it has been criticised for having had minimal impact on policy and little effect in terms of improving the lives of disabled people. The process of research production has alienated both the researched and the researcher in that disabled people have been treated very much as 'research subjects' with their priorities taking second place to the research plan and the researchers priorities. (Oliver, 1987, 1992; Barnes, 1992; Zarb, 1992). Research carried out by Social Services Departments has been criticised for relying too much on head counts which fail to acknowledge the social causes of disability, and are unreliable due to the subjectiveness of measures and definitions

of disability (Oliver, 1987; Beardshaw, 1988).

The use of emancipatory research has been advocated in order to prevent the alienation of disabled people during the research process by fundamentally changing the social relations of research production so that research is based on empowerment and reciprocity, and focuses attention on society rather than the disabled individual (Oliver, 1992; Zarb, 1992).

The methods employed in the study were qualitative and were inspired by the ideals of the emancipatory research paradigm (Oliver, 1992). Disabled people were asked about their experiences of education, employment, social security and social services support with the aim of ascertaining the ways in which support from each related to the achievement of independence.

To ensure that the young adults had maximum involvement in the setting of the research agenda the interview schedule was adjusted to reflect concerns generated by young adults in early interviews. Fifty young adults aged 17 - 31 years with profound physical disabilities were interviewed. Forty two of the interviews were usable. All needed assistance with the tasks of daily living, none had a severe learning disability. The research was conducted by a researcher who is herself disabled and as far as possible, reflects the expectations, priorities and experiences of the young people in the research sample.

Consonant with the social model of disability, which locates the causes of disability squarely within society and its organisation, the following definitions of disability will be employed in this thesis: 'Impairment' alludes to the physiological limitation(s) which affect an individual's body, whilst 'Disability' refers to the disadvantage experienced due to social, physical and attitudinal obstacles (Morris, 1993). To reiterate the point, the term 'disabled people' as opposed to 'people with physical disabilities' will be utilised as the former phrase highlights the extent to which society, by its reaction to impairment, disables people (Morris, 1993). The expression 'non disabled people' will be used as it draws attention to the difficulties faced by impaired individuals every day.

Chapter 1 will review the literature which focuses specifically on disability and in particular, physically disabled young adults. The major themes will be outlined and the strengths and weaknesses of this body of work will be discussed.

Chapter 2 will focus on the transition from youth to adulthood. Contributions from the fields of social psychology and sociology will be discussed and the challenges faced by non-disabled young people in transition will be documented. Finally, the comprehensiveness of the contributions will be assessed with regard to young people as a whole.

Chapter 3 will discuss the rationale behind the use of qualitative research methods, for the current study of young physically disabled adults in terms of the

disadvantages and advantages associated with this approach. The use of the Emancipatory Research Paradigm (Oliver, 1992) in the field of disability research will be evaluated. This raises a number of fundamental issues; epistemological, technical and ethical, centring on the relationship between research and social policy.

Chapter 4 has three functions: it will give a descriptive account of the sociological and psychological well - being of the respondents, it will introduce the independence measure used throughout the thesis and the individual action/ social context explanations of respondents' lives will be discussed.

Chapter 5 will discuss the background to the role of the family in the transition of young physically disabled people to independent living in terms of the policy process, and the way in which family support has become increasingly important for a successful transition will be outlined. The chapter will then document the ways in which the families of the young people in the study helped or hindered their transition to independence.

Chapter 6 will explore the role played by education in preparing young people for adult life and full participation in society. The extent to which parents influenced this process will be discussed together with the contributions made by the various professionals involved with disabled children. The benefits and disadvantages of segregated education from the standpoint of the disabled young adults in the study

will be outlined, and the degree to which they achieved or underachieved will be explored both in terms of educational qualifications and the degree of career choice open to them. The role of personal agency (in this context this refers to self-motivation) on the part of the young people will also be considered. Finally, the availability of adequate resources for the education of profoundly physically disabled people will be outlined with reference to the research sample.

Chapter 7 will explore the degree of success that the disabled young people experienced in the employment market. Recent policy developments will be outlined. This will be followed by an exploration of the research sample's perceptions and experiences.

Chapter 8 will explore the support available to disabled people living in the community in terms of the social security benefits available and the role played by personal social services. Attention will be paid to the realities of life for people reliant on such provision, with both positive and negative aspects outlined. In each case the data will be set in the context of recent policy developments.

Chapter 9 concludes the thesis and will explore the extent to which the young disabled adults in the research sample achieved independent living. The role played by education, employment, the benefits system, and personal social services will then be discussed with the aim of explaining the way in which support from reach related to independence. The most important elements in

young adults' achievement of independence will be identified and the implications outlined.

CHAPTER ONE

DISABILITY IN SOCIETY?

This chapter will review the literature which focuses specifically on disability and in particular on physically disabled young adults. The major themes will be outlined and the strengths and weaknesses of this body of work will be discussed.

This literature has focussed on society's attitude to disability in general, and in particular, the degree of credence attached to the individual model of disability (Oliver, 1990, 1992; Morris, 1992). Most of the work has been conducted from a service provision perspective with the aim of documenting levels of provision for this group (Beardshaw, 1988; Fiedler, 1988; Bax, 1989; Chamberlain, 1993). Much critical attention has been paid to the effectiveness of the research that had been carried out in terms of its ability to fundamentally improve the quality of disabled people's lives, and the appropriateness of the research methodology employed (Oliver, 1987, 1990, 1992; Barnes, 1992; Zarb, 1992).

The literature has also addressed the role of current political ideology with its emphasis on reducing the role of the state at central and local levels, and the impact of this on levels of service provision. The way in which the New Right's definition of citizenship with its emphasis on the protection of the individual from state intrusion and the promotion of active citizenship, where individual citizens are encouraged to contribute to their own welfare in order to ensure optimum welfare for all, has been a special concern (Oliver, 1987).

Government policy has served to reduce dependency on the state by shifting dependence on to other sectors of society. What effect has this had upon the lives of young physically disabled adults? This question will be addressed later in the thesis.

Defining Disability

To date, all attempts to officially define disability have been based upon the tripartite distinction originally developed by Harris in 1971 and refined by Wood in 1981, which was accepted by the World Health Organisation as the basis for the international classification of Impairments, Disabilities and Handicaps (ICDH). This has been used in much disability research (OPCS, 1988; Beardshaw, 1988); and has formed the basis for the registers which local authorities are obliged to keep under the 1970 Chronically Sick and Disabled Persons Act. This classification constitutes the only available source of numerical data on physically disabled young people and offers a number of advantages over the use of diagnostic labels to identify numbers. The clear terminology aids communication between different professional groups, and there is emphasis on *'handicaps'* as disadvantages *resulting* from disabilities (Philip and Duckworth, 1992).

There has been much criticism levelled at the tripartite distinction of impairment, disability and handicap by disabled people and their organisations. This has centred on the fact that the distinction was based on non - disabled assumptions

of disability, and as a result is not representative of the personal experiences of disabled people:

> This lack of 'fit' between non - disabled and disabled people's definitions is more than just a semantic quibble for it has important implications both for the provision of services and the ability to control one's life (Oliver 1987).

It has also impacted on the way that social research on disability has been undertaken. The core of the debate on definitions is the issue of where the problems of disability are located, whether the functional problems of the impaired individual are the focus of attention, or whether the problems are seen as originating from the wider social and physical environment. The definition advocated by Wood (1981) has also come under criticism because it was developed without reference to disabled people who daily experience the problems of disability. Also, whilst this classification does acknowledge the social dimensions of disability, the basis of the problems faced by disabled people is firmly located within the individual. These issues are discussed in greater depth in chapter three.

The Individual and Social Models of Disability

The emergence of two distinct models of disability can be seen, i.e. the individual model and the social/social oppression model.

The individual model is characterised by a focus on the individual rather than the environment and it is this which has formed the basis of much disability research. From this standpoint, the difficulties experienced by disabled people are viewed as resulting directly from physical impairment. The studies have been characterised by structured observation with medical and psychological assessment of respondents. Medical and service provision issues have been the primary focus of such work. This model of disability has not only had wide currency in medical and disability research, it has been widely used in education and psychology. These issues will be discussed in greater depth later in this thesis.

There is a role for methodological individualism in disability research as disabled people can and do face problems as a direct result of their physical impairment. There is a need for adequate medical review of young people with physical disabilities as they can deteriorate from the orthopaedic point of view (Bax, 1989; Chamberlain, 1993). In addition to disorders such as cerebral palsy and spina bifida there may be degenerative disorders such as osteo - arthritis, and scoliosis and contractures may become more severe. There may be circulatory disorders due to immobility, urinary tract infections and pressure sores and other skin disorders.

Individuals can also develop painful muscle spasms and respiratory tract disorders (Bax, 1989; DCDP, 1992; Morris, 1989; Chamberlain, 1993). These may place a severe burden upon the individual in terms of pain, reduced mobility and increased dependency and associated difficulties in achieving adult status through employment, having an active social life and enjoying a relationship with a partner. It is important to remember that not all the problems that disabled people encounter are social in origin. Some are directly linked to an individuals impairment and the 'management' of such.

Severe chronic pain can have a devastating effect on an individual's life and can dominate every waking (and sleeping) moment, thus imposing many restrictions on their daily life. The whole day can become geared to just surviving the pain:

> I've always maintained that if they could control the pain there would be no problem as the wheelchair is no big deal (Morris, 1989).

Disability does have a personal cost and the individual model ensures that this is not omitted from the equation. It is also the case that it is not the sole cause of the difficulties encountered by disabled people. The picture is much more complex with a multitude of interrelating factors, which stem from the macro processes of society.

Disabled people have been highly critical of the individual model of disability with its narrow focus. Disability is seen as a tragedy and disabled people are treated as if they are victims of tragic circumstance in terms of everyday interactions. This approach encourages the development of social policies which attempt to compensate victims for the misfortune that has befallen them and which do not accord them many of the basic rights of citizenship, thus encouraging dependency. Segregated education and the benefits system are cases in point (Oliver, 1996). Also, the problem with the individual/medical approach to disability is that problems faced by a disabled individual are viewed as treatment for a 'patient', as stemming from individual impairment and failing to take into account the broader aspects of disability.

Disability, in the context of the social model, refers to the oppression which all disabled people face as a result of negative attitudes inherent in society resulting in prejudice and discrimination. The central point is that people are not disabled by a particular impairment but by society's reaction to that impairment. It is for this reason that the disability movement encourages the use of the term *disabled* people rather than *people with disabilities.* The former term has maximum political power since it firmly places the emphasis on how society oppresses people with a whole range of impairments. This terminology will be utilised throughout this thesis. The implication implicit in the latter term is 'people with impairments', with the focus very much on the individual disabled person.

With regard to the issue of acknowledging the personal cost of disability, proponents of the social model of disability argue that the social model is not denying that some medical conditions result in disability, and they acknowledge that many disabled people will experience illness at some point in their lives. They concede that doctors may have a role in treating disabled people, stabilising their initial condition, treating any illnesses which may arise and may or may not be disability related. They argue that there is a danger inherent in emphasising the personal at the expense of the political because of the credence still accorded the individual model of disability, and such a stance would serve to strengthen its hold by re-emphasising the link between disabled people's bodies and their social situation. (Shakespeare, 1992; Oliver, 1996).

Service Provision

As outlined in the introduction, there has been much criticism of the lack of provision for young physically disabled adults (Beardshaw, 1988, Fiedler, 1988; Wagner, 1988; Bax et al, 1989; Morris, 1990; Audit Commission, 1992; Chamberlain, 1993; Oliver, 1996) with the problems faced by members of this group embarking on the transition from childhood to independent living acknowledged as being particularly acute. (Court Report, 1976; Warnock report, 1978; Rowan, 1980; Anderson et al 1982; Hirst, 1986; Beardshaw, 1988; Bax & Smyth, 1989; Chamberlain, 1993; Stalker and Reddish, 1996).

On one level there is evidence that a few service planners are beginning to recognise the importance of the social model of disability. One County Council has commissioned a number of reports consonant with this (The Right to be Able, 1987; Silburn, 1988; Silburn and Winfield, 1993; Vincent, 1994). The 1987 report sets out a philosophy of care for younger disabled people aged 16 - 65 years with detailed recommendations for service provision.

Some Local Authorities have utilised the model of seven fundamental needs outlined in the introduction. Derbyshire adopted the standpoint that in the case of individual difficulty with any of these, the fault would not lie with the individual but with social organisation and provision. The approach to planning services was to ask 'What changes would be necessary to enable all people to live ordinary independent lives?' Each of the seven needs were considered. Despite this progressive approach to service planning and delivery there is still a long way to go. Whilst there appears to be limited endorsement of the ideology behind the social model of disability, to what extent has it been implemented in the case of the young physically disabled adults in the sample?

The issue of fostering self - advocacy skills in young physically disabled school leavers has been raised in the literature (Hirst 1986). How well is the policy of teaching these skills matched by the choice available in the community?

Whilst the work on service provision has provided a valuable insight in to the

levels of service provision for this group, it has a narrow focus which neglects the role of other agencies in determining the degree of independence which young physically disabled adults will eventually experience, and it fails to address the degree to which those agencies roles are interrelated. Transition has to be viewed as an holistic picture. This thesis will attempt to address that omission.

The Role of Legislation

Government legislation does exist with the explicit aim of affording disabled people full integration into society namely: The 1944 Disabled Person's (Employment) Act, the core of which was the belief that the majority of disabled people were capable of working in ordinary employment with the proviso of appropriate training and services to facilitate this (Morris, 1993). The 1944 Education Act was based on a philosophical commitment to the idea that disabled children, where possible, should be educated in mainstream school (Oliver, 1996). The 1970 Chronically Sick and Disabled Person's Act was an attempt to ensure the provision of local authority services to disabled people in their own homes, and that adequate records were kept of the disabled people within their catchment area. The 1981 Education Act was meant to speed up the integration of disabled children into mainstream provision, and the Disabled Person's (Services, Consultation and Representation) Act 1986 was intended to give disabled people a voice in the planning, design and delivery of services proposed for them. The NHS and Community Care Act (1990) was intended to enable disabled people to

remain in their homes by giving them choice about the support provided.

This legislation is fundamentally concerned with altering welfare state provision for disability. Has this been achieved? Was the basis for the legislation appropriate? This will be explored later in the thesis.

Whilst legislation has recently been passed to protect disabled people against discrimination by employers and to allow local authorities to make direct payments enabling them to purchase their own personal assistance packages (the 1995 Disability Discrimination Act and the 1996 Community Care [Direct Payments] Act respectively), disabled people's organisations have expressed concern about the effectiveness of the new legislation. With regard to the Disability Discrimination Act difficulties of enforcement are envisaged (Paton, 1995). This is discussed in chapter seven. A number of anxieties are being voiced about the Community Care (Direct Payments) Act. Although payments will be targeted at individuals aged 16 - 65 years, there is disappointment that direct payments are only meant to be an option for those individuals who have had a needs assessment and for whom the local authority would be otherwise providing a service. Another concern is that direct payments may be used as a cheap option by failing to take account of the full cost of employing personal assistants (i.e. holiday and sick pay, unsocial hours and administration costs), when calculating the amount to be paid (Kestenbaum, 1996). This is discussed in chapter eight.

Whilst much has been written about the policy, politics and bureaucracy of disability legislation, there has been little attempt to ascertain how those affected feel about it or about its impact on their lives. The current study addresses those issues.

The Role of Professional Need Assessors

Services for disabled people were criticised by Blaxter (1979) as being hypocritical in that they set out to 'care for' vulnerable people but have played a large part in the creation of the difficulties that disabled people face. Examples include the provision of segregated residential accommodation such as Young Disabled Units and Cheshire Homes and also segregated schools and day centres (Davis, 1990; Oliver, 1996). These services replaced accommodation in hospital wards and in homes for the elderly. Some assessment procedures invade disabled people's privacy in that they are obliged to disclose their financial details in order to qualify for necessary aids. Factors such as these have not only hindered the delivery of full citizenship rights to disabled people, they have actively served to reduce some rights thus contributing to the social creation of dependency. The period since the Second World War has seen the development of a powerful ideology regarding the inadequacy and dependency of disabled people. This has been perpetuated by the central role played by the medical profession in the 'management' of impairment. The rapid expansion of disability charities 'for' disabled people also served to undermine the position of disabled people in society

as autonomous individuals and citizens.

The NHS and Community Care Act (1990) has lead to fundamental changes to the delivery of care and support to adults in the community. From April 1993 social services departments were required to assess the needs of disabled individuals and arrange with them individually tailored services to meet those needs and commission those services as appropriate. The key aims behind this legislation are to empower service users by giving them choices about the support provided so that their needs can be met in ways and at times convenient to them, thus enabling them to remain in their own homes. There have been examples of innovative schemes which have enabled disabled people to move out of residential accommodation, which are sensitive to disabled people's needs and have greatly enhanced the quality of their lives (Audit Commission, 1992).

To the disability movement, the aims of the Act have a hollow ring. This is due to the emphasis placed on the role of informal carers by the Act, thus reinforcing the ideology that disabled people need 'care', are inadequate and therefore dependent, seriously undermining a rights based approach to meeting peoples' needs. Under the Act it is intended that those who need some form of assistance with the tasks of daily living will be assessed by a care manager whose role will be the purchase of services in line with the needs assessment. What role have community care policies and services played in enabling disabled people to lead full and independent lives? These issues will be explored later in the thesis from

the standpoint of the young physically disabled adults.

The need for the education of health professionals has been highlighted as they too play a large role in the provision of services to disabled people:

> Assessments for benefits and equipment [are] still widely delegated to doctors....The real problems are the need for assessment at all, and that doctors who undertake the responsibility may not be adequately trained (or experienced) for the task (Harrison, 1993).

Some medical literature does exist on the transition of young physically disabled adults to independent living but the majority of it pays little attention to the social factors which impinge on disabled people's lives. A minority of it does partly consider such factors (Bax, 1989; Chamberlain, 1993), but on the whole the field is a neglected one.

Disabled people have been highly critical of the medical profession for a number of reasons. A conceptual gap currently exists whereby a person with a disability is viewed as a victim of a particular impairment or accident and not as a disabled person with rights and entitlements. There is a relatively poor understanding of disability in hospital and medical practice. There is evidence of the low priority given to disability medicine in that there is little information on the medical problems encountered by this group. This situation is compounded when one

considers the paucity of information on the problems young physically disabled people face during the transition to adult life and particularly on information regarding disabled peoples' own perceptions of the transition process. The medical treatment of disabled people still lacks a generally agreed term with which best to describe it. The term 'disability medicine' has not found wide support as it has wrongly been interpreted to imply the medicalisation of disability. 'Rehabilitation Medicine' is less negative but it is not suitable for individuals with congenital impairments who will find it impossible to recover a function that they never possessed. Unfortunately, similar to geriatric medicine, rehabilitation medicine has been viewed from within the profession as a soft option bringing limited benefits and being boring and barely medicine. Such attitudes are hardly conducive to the encouragement of high calibre progressive practitioners. Of course, this situation is indicative of the medical culture, where students quickly learn to distinguish acute from chronic conditions and are trained to diagnose, treat and either cure or admit defeat. It is a poor environment for learning the correct approach to disability. Not only have disabled people been disadvantaged by a lack of medical treatment, they have had to contend with the other extreme - aggressive, inappropriate treatment:

> The problem arises when doctors try to use their knowledge and skills to treat disability rather than illness. Disability is a social state which is not treatable medically and is certainly not curable. Many disabled people experience much medical intervention as,

at best inappropriate, and at worst, oppressive (Oliver, 1996).

Disabled people have been highly critical of the emphasis placed by the medical and paramedical professions on the 'ideology of normality' with its aim of restoring the disabled person to normality regardless of physical or emotional cost (Oliver, 1996). They argue vociferously that it is society that has to change and not disabled individuals. Has the medical profession or the disability movement got the right approach? There has been no attempt to explore the social costs of such interventions which may extend far beyond the period of treatment. This issue will be addressed later in the thesis from the standpoint of the young disabled people themselves.

Defining 'Independence'

As outlined above, the particular definition of disability which is utilised has had a huge impact on the nature of services provided to disabled people. This can be seen with reference to the concept of independence. The definition' that is adopted has crucial implications in terms of the quality of a disabled person's life. It has been governed by the professionals working in the health and social service field and, in turn, by their reliance on the individual model of disability. From the professionals' point of view the definition of independence is narrow:

Independence is a word which has come to have narrow meaning, that of

the completion of physical tasks without assistance (Chamberlain, 1993).

The term 'independence' or independent living varies in meaning depending on the context in which it is used. In a professional health, or social services context the term has been used to describe initiatives that they have developed in the context of the community care policies. For example, to move from institutional to community provision for disabled people. For occupational therapists it means the acquisition of the necessary skills or use of equipment to enable individuals to carry out some self care. Disabled people have been extremely critical of the assumptions behind the process of 'rehabilitation'. One of the main criticisms has been of the narrow meaning given to the attainment of independence and the emphasis given to the restoration of 'normal' function. Whilst it is undeniable that both rehabilitation professionals and disabled people would agree that independence is an important goal for most disabled people, there is a discrepancy between the views of professionals and the independent living movement. The majority of the literature on health and social services provision utilises the narrow professional definition of independence outlined above.

The Independent Living Movement in Britain was born out of disabled people's desire to leave residential care which they accused of paternalism. During the 1960's and 1970's disabled people made increasingly vociferous demands for more control over their lives and the institutions in which they lived. The adopted notion of independence has a fundamental impact on the type of service on offer.

However, the debate ranges further than this (Oliver, 1987). It is also about the politics of control, whether disabled people or professionals should be in charge of the rehabilitation process, and whether individual need should be defined by disabled people or professionals and the extent to which professionals are qualified to define such needs (Harrison, 1993).

The concept of independent living is broad, covering the whole range of human and civil rights. For example, the right to have personal relationships, the right to be a parent, equality of access to education, training and leisure activities as of right extending to full participation in the community. The philosophy of the independent living movement is based on the assumption that all human life is of value; that anyone, whatever their impairment is capable of exercising choices, that people who are disabled by the reaction of society to the various types of impairment have a right to assert control over their lives, and that it is the right of disabled people to participate fully in society. That is the definition of independence adopted in the current study. The development of this philosophy has led to the redefinition of the term 'independence' by disabled people with its resultant move away from the negative connotations associated with the narrow professional definition and application of the term which has contributed to the construction of disabled people as dependent and subordinate.

There has been little work done on the attainment of independence from this standpoint and there is a need for investigation of the factors which enable the

attainment of independent living in its broadest sense. What is the role of personal assistance in this context? And to what extent is interaction with other agencies required for the attainment of independence? It is noticeable that despite the fact that wider choice and control are central themes in the disability movement, the importance of choice over work opportunities has been omitted from the discussion. How important is choice over work opportunities? Does employment lead to independence? The debate around the attainment of independent living is polarised when a young physically disabled person enters the transition to adulthood.

The Role of Disability Research

As outlined above, the majority of the work in the disability field has focussed on the provision of services, has been largely based on the individual model of disability, been driven by professionals and not disabled people and has been quantitative in nature. It is argued that the process of research production has been alienating both for disabled people and for the researchers themselves (Oliver, 1992). The disabled people being researched have been placed very much in the role of 'research subjects' and used very much for the researchers ends in that the research plan takes precedence over individuals actions. Much of the research on disability has been criticised for viewing disability at an individualistic level rather than as a consequence of a particular social system and because it was carried out by able-bodied researchers (Davis, 1990; Abberley 1993).The OPCS National

Disability Survey has been criticised on these grounds:

> .....The OPCS surveys both in terms of overall approach and of method....indicate by negative example some of the things that good research in this area....requires (Abberley, 1993).

The Disability Movement argues that: from an epistemological point of view, if disability is socially caused, and for research to be beneficial, it should aim to identify the social causes so that they can be removed as opposed to individualising disability. The reliability of head -counts has also been questioned (Oliver 1987, Beardshaw, 1988) due to the arbitrariness of definitions and measures of disability.

The use of emancipatory research has been advocated in order to prevent the situation where disabled people experience disability research as alienating (Oliver, 1992). This can only be achieved via a fundamental change in the social relations of research production which are:

> .... Built upon a firm distinction between the researcher and the researched; upon the belief that it is the researcher who has the specialist knowledge and skills; and that it is they who should decide the topics for research and be in control of the whole process of research production (Oliver, 1992).

The key to achieving such a change is via research which is based upon empowerment and reciprocity, changing the focus of attention away from disabled individuals and on to a disablist society with the onus very much on encouraging the self - understanding of disabled people and thus providing a re - definition of the problem and facilitating empowerment (Oliver, 1992; Zarb, 1992).

It can be seen that there are parallels between the factors impinging on the way that health and social care services are provided and the way that the majority of research on disability has been conducted. The predominance of the individual model rather than the social causes of disability is apparent in both spheres together with the predominance of the professional 'expert' with the result that disabled peoples perceptions of the problem whether it be issues for research, or their needs with regard to health and social services provision, have largely been ignored.

A number of concerns are mirrored also. For example, the issue of the extent to which a disabled researcher's experience of disability can be typical of the experiences of disabled research subjects given that individual experience and methods of coping with disability is so subjective. There is also the possibility that individuals might have multiple disabilities. Researchers and respondents could have experiences that are poles apart. These issues will be explored in chapter three.

However, it can equally be argued that there is bound to be more common ground between a disabled researcher and the research subjects in disability research than with a non - disabled researcher if only in terms of 'breaking the ice'.

There are questions that could be asked regarding the typicality of respondents taking part in emancipatory research as, by definition, they would have to be reasonably articulate and able with good self - advocacy skills. There is the issue as to the extent to which the majority of disabled people currently possess the skills necessary to participate in research on an equal basis with the researcher (Barnes 1992). What about the disabled people who do not have the opportunity to get their voice heard?

But again, it could equally be argued that a disabled person's view is more representative than that of a professional:

> It is axiomatic that if we [disabled people] do not define ourselves for ourselves, we will be defined by others - for their use and to our detriment (Morris, 1992).

The current study gave individuals a chance to air their views and a welcomed opportunity to 'get their voice heard'. As a result, it paints a picture of transition from the young disabled people's point of view. Individuals from the most articulate and able through to those at the opposite end of the spectrum described

their experience of transition with astonishing frankness and great clarity and many mentioned that they felt more at ease with a researcher who was herself disabled.

The extent to which the fundamentals of emancipatory research, reciprocity and empowerment, can be achieved in disability research is neglected in the literature. This is because the development of emancipatory research within the disability field appears to be at a very early stage. There has been very little attempt to suggest or develop an appropriate methodology for such research. (Zarb, 1992). The current study addresses this.

There are likely to be special problems with regard to attaining reciprocity between the researcher and the research subject where the issue under investigation involves young, relatively inexperienced research subjects (Barnes 1992). It is inevitable that research subjects will require some guidance with regard to research design, and once the research moves away from a non - directive stance, the power base reverts back to that between 'expert' and 'subject'. It is suggested that a degree of reciprocity can be built into the research by using open ended and reflexive methodology. The current study went some way to achieving this. This will be explored in greater detail in chapter three.

There are questions to be asked regarding the extent to which emancipatory research can empower disabled people and who such research is empowering. The

researcher? a radical minority? Zarb (1992) acknowledges that whilst some progress has been made with regard to reciprocity within the research process, the research carried out by him to date has contributed nothing to the empowerment of disabled people.

Whilst it would be a positive step forward to have disability research carried out by disabled people following as closely as possible the ideals of the emancipatory research paradigm, this in itself is not enough. The research findings must be accessible to disabled people. Ironically, much of the work has been criticised for being inaccessible to disabled people because it was too academic (Oliver, 1996). Admittedly, disability issues are extremely complex, but for disability research to be truly empowering the results must be amenable to dissemination to a wide audience. This is already being achieved with the current study by the publication of journal articles in the disability press.

The advantages and disadvantages of emancipatory research will be discussed in detail in chapter three.

In conclusion, there are a number of common themes apparent in the literature on disabled people in general and young physically disabled adults in particular. These are: the importance attached to the individual model of disability, the low priority given to health and social services provision for this group, and the way in which these services when they are provided are delivered. The way that

disability research has been conducted is also an issue. It is argued that it has been alienating for disabled people, and has had little impact on policy and failed to make any contribution to the improvement of disabled people's lives. The role of government policy has also been questioned. Within the young physically disabled adults priority group there is a sub - group which is virtually ignored. i.e. individuals making the transition from education to independent living in the community. The literature that is available on this group consists very much of research done from a medical standpoint (Bax, 1989; Edwards and Warren, 1990; Chamberlain, 1993) with a focus on service provision. There has been little attempt to look at transition from the standpoint of the social model of disability or to investigate the impact that the lack of services has. Also the young physically disabled adults' expectations and priorities with regard to transition have been neglected.

The current research focuses on the transition of physically disabled young adults from full - time education to living in the community and has been conducted utilising the social model of disability. The current study has given credence to the role of the disabled person as opposed to the professional expert and the methodology employed has given the most disadvantaged disabled people a voice. As a result it presents a picture of the young peoples' feelings about the current levels of service provision and its impact on their lives. Due to this, it has a much broader focus than previous work as it considers the role of other factors (including personal assistance and employment), in determining the degree of

independence that the young people will experience, and explores the extent to which the transition to independent living depends on a network of support from different sources. Also, this work discusses how disabled people feel about disability legislation and considers its impact on their lives.

CHAPTER TWO

TRANSITION - A SMOOTH ROAD TO ADULTHOOD?

This chapter will focus on the transition from youth to adulthood. Contributions from the fields of social psychology and sociology will be discussed and the challenges faced by young people in transition will be documented. Finally, the comprehensiveness of the contributions will be assessed with regard to young people as a whole.

The debate around the transition from youth to adulthood hinges on issues of cause and effect i.e. the extent to which behaviour is determined by structure. Theories range from those with an individualistic approach found in social psychology, through to a focus on the broader structural context of youth, characteristic of sociology. It is widely acknowledged that theoretical development in youth research is problematic and that there is a need for work which locates the transition to adulthood and independent living in the wider social context. (Hutson and Jenkins, 1989; Jones and Wallace, 1992; Brannen and Dodd, 1994; Irwin, 1995; Jones, 1995). Detailed discussion of the theories pertinent to youth from the disciplines of social psychology and sociology is beyond the scope of this chapter. However, the main themes will be outlined.

At the outset it is important to define the terms 'youth'(adolescent) and 'young adult'. 'Youth' refers to a stage in the life course which leads to adulthood. This period extends from puberty to the age of eighteen years which in Britain is the legal age of majority and is associated with independent adulthood. (Jones and

Wallace, 1992). However, there are problems with this definition which will be explored later in the chapter. Young adulthood in the social psychology literature refers to the period between the ages of eighteen to forty years (Bee, 1996). The primary focus of the thesis is on young disabled people aged from eighteen to thirty one years; who are defined as young adults as they are over the age of eighteen.

The term 'transition' refers to a period of growth, and change between two relatively stable but different stages in the life course (Kimmel, 1990).

The Social Psychological Perspective

Psychologists have attempted to envision the processes by which individuals make the transition from childhood to adulthood. Briefly, the theoretical perspectives are first, an early formation approach which is based on the assumption that the personality structure is established in the first few years of childhood and thereafter is essentially unchanged through adulthood. This theory assumes that the character of the adult is largely determined by events occurring during the first five years of childhood. Second, there is a stage theory of development which proposes that development is reflected in reactions to a succession of conflicts between choices of life goals. The way that each conflict is resolved influences the strategy that is adopted during future conflicts. Adolescence is conceptualized as a period of emotional turmoil, identity formation, and conflict with parents and

other adults. The theory developed by Erikson (1958) has been the most influential theory of adult development. His work has influenced the majority of stage theories of adulthood and his terminology has been widely adopted (see Loevinger, 1976; Kohlberg, 1964; Gould, 1978, 1980: cited in Wrightsman 1994; Bee, 1996) Erikson conceptualised eight stages through from infancy to late adulthood and stated that an essential requisite for a complete, stable identity is the passage through and resolution of eight 'crises' or dilemmas during a lifetime. Each dilemma emerges as the child or adult has to cope with new relationships, tasks or demands. Third, there is the dialectical approach which views development in terms of on going tension between pairs of goals. This approach is based on the idea that no goal is ever fully achieved, due to the existence of a continuous tension which pulls the individual towards the opposite goal (Wrightsman, 1994; Bee, 1996).

Erikson's theory suggests that psycho social development continues throughout life as a result of the interaction between inner characteristics (drives and instincts) and external cultural and social demands leading to the development of identity via a number of stages. Central to Erikson's theory is the view that development follows a basic built in 'blueprint' that shapes a chain of "potentialities for significant interaction" with those around the child or adult" (Erikson, 1958; cited in Bee, 1996:43). Also, he believes that individuals are compelled through the series of dilemmas by a combination of factors; biological maturation, social processes and the demands of social roles. (Erikson, 1958; cited in Bee, 1996).

Thus, Erikson is of the view that the stages come along at roughly the same age for all individuals and regardless of the extent to which the previous dilemma has been resolved, the prescribed order of the stages must be adhered to.

From the standpoint of young adults; three of Erikson's eight stages of psycho social development are pertinent to this age group:

Table 2.1 Stages of Psycho social Development - Young Adults

Age	Stage	Gain	Description
13-18	Identity v role confusion	Fidelity	The teenager or young adult must achieve a sense of identity - both who she is and what she will be in several areas: occupation, gender role, politics and religion.
19-25	Intimacy v isolation	Love	Young adult must risk the immersion of self in a sense of "we", creating one or more truly intimate relationships, or suffer feelings of isolation.
25-65	Generativity v self-absorption and stagnation	Care	In early and middle adulthood, each adult must find a way to satisfy the need to be generative, to support the next generation or turn outward from the self toward others.

Source Erikson, & Kivnick, 1986; cited in Bee, 1996, p 56

The theories briefly outlined above share a common characteristic in that they all assume that behaviour comes from within the individual and not from outside. However, psychologists have stressed that the transition to adulthood is based around biological events and individual developmental tasks.

The main developmental tasks constitute the demands placed on a young person during adolescence (youth) and young adulthood. The tasks associated with a particular life stage are the skills, knowledge and functions that a person must

acquire or master in order to progress to the following stage. These tasks are faced by all individuals according to psychologists. The difference between an individual who is physically mature and one who is truly adult is that as well as meeting the physical characteristics he or she must establish an identity, gradually become independent of parents, adjust to sexual maturation, establish social networks and develop the social skills necessary to maintain them, and decide on and prepare for a meaningful career (Conger, 1991:30; Heaven, 1994).

In general, psychologists have emphasised the importance of a shared 'psychological clock' that leads to common inner changes (Brannen, 1994; Bee, 1996). This is reflected in the way that the causes of transition are viewed in the psychological literature.

The Causes of Transitions

There are a number of types of transition that can occur in human development which can be caused by either internal changes or external events or a combination of the two:

Table 2.2 Transition Type and Cause

	TYPE (Normative)	
	Changes that are expected according to the social norms for individuals at particlular times of their lives i.e. leaving school, marriage.	
CAUSE (Internal)		(External)
Involving individuals feelings, physical reactions, etc. reflecting endogenous pressures within oneself - puberty, menopause, dissatisfication with lifestyle, etc.		Reflect social or environmental forces i.e. promotion at work, winning lottery.
	(Idiosyncratic) Changes in life ptterns that are unique to an individual i.e. divorce, illness.	

The types and causes of transitions are not mutually exclusive. However from a theoretical standpoint emphasis is placed on internal factors as the primary cause of transitions. The theories of Erikson, Levinson and Gould mentioned above fit into this category. These theorists also assume that there is a common goal orientated direction towards which all adults move and as a result are categorised as developmental stage theorists. (Kimmel, 1990; Bee, 1996). The key point is that the changes in adult development espoused by the stage theorists, ie. the movement from one stage to another, is essentially an internally motivated change. However social norms are internalized, and social interaction plays a role in Erikson's eight stages of life; but the role of this is secondary to that of a programme of inner development. It can be seen that the emphasis is very much on the characteristics of the individual as opposed to the influence of society, as

with the disability literature reviewed in the previous chapter.

All individuals reach adulthood having been strongly influenced by inherent characteristics such as gender and race, internal characteristics such as intelligence and personality, cultural factors and structural conditions such as family background and the amount of education received. These factors shape the path that individuals take in early adulthood which is usually the one most congruent with their life experiences (Bee,1996). The influence of intelligence testing on educational practice will be explored in chapter six. With regard to the effects of intelligence on adult life patterns, psychologists argue that it influences the number of years of education (Brody, 1992; cited in Bee, 1996:46), and the degree of interest in intellectual pursuits such as reading, completion of crossword puzzles and playing of intellectual games. All of which have an impact on life patterns. The consensus is that differences in intelligence among young adults may give an indication of the direction of their future lives in a number of ways; the higher an individuals intelligence, the greater the number of years completed at school, which has a fundamental impact on adult life. Psychologists argue that higher intelligence adults are more likely to end up in higher prestige occupations and earn higher incomes (Brody, 1992; Clausen, 1993; cited in Bee, 1996:46).

However, these arguments are based on a model which equates intelligence with IQ test measurements. This is seriously contentious and psychologist's use of these strategies has often been challenged. Critics argue that intelligence

measurement may be affected by cultural factors. Physical disability may also impede the measurement of intelligence.

Intelligence and personality differences are a product both of heredity and environment (Bee, 1996). The term *personality* refers to:

> ...Each person's distinctive, consistent patterned methods of relating to the environment (Bee, 1996:47).

Personality is well established by adolescence or early adulthood and plays a major role in terms of shaping adult experience. Options, choices, as well as levels of life satisfaction, are influenced (Bee, 1996). Evidence for this has come from a study which was designed to identify stable personality traits in adults and discover whether adults with differing personality traits have dissimilar life patterns. The study advanced four personality dimensions which have been widely adopted as the fundamental description of individual personality (McCrae and Costa, 1987; cited in Bee, 1996:47):

Table 2.3 Personality Traits as described by McCrae and Costa

Trait	Descriptive Adjectives
Extraversion	Active, assertive, energetic, enthusiastic, outgoing
Agreeableness	Appreciative, forgiving, generous, kind, sympathetic, trusting
Conscientiousness	Efficient, organised, planful, reliable, responsible, thorough
Neuroticism	Anxious, self pitying, tense, touchy, unstable, worrying

Source: Bee,1996, table 2.4, p 48

Psychologists argue that the above traits have multiple implications for individuals lives in that they affect the type of occupation that the individual chooses, and they may also contribute to job success or failure once a person is in post (Bray and Howard, 1993; cited in Bee, 1996:48). Also, personality affects the extent to which individuals feel satisfied with their lives. Research has shown that adults who score highly on the neuroticism trait have a much lower level of satisfaction with their lives whilst those who score highly on extroversion are consistently more satisfied. It is claimed that longitudinal effects of these traits can be demonstrated in that measures of neuroticism or extroversion at one point can predict happiness or satisfaction some twenty years later:

> ...Psychologists are not prophets, and we cannot predict whether life will hold wealth or poverty, health or illness, love or loss...If our model is correct, we can predict how individuals will evaluate whatever life circumstances they encounter, whether they will be happy or unhappy with their lot (Costa & McCrae, 1984; cited in Bee, 1996:48).

Personality is viewed as having a dual impact, on occupational and life success, and it also provides a framework for emotional competency in adult life, i.e. whether the individual will have an optimistic or depressed response to life. It is seen as exerting an influence on individual life trajectories to the extent that riches are accumulated (or not) in both a psychological and an economic sense. The general argument is that if a person starts off on the right path, achievement is likely which in turn leads to an increase in self - confidence and the attainment of further knowledge and skills which opens the door to further success. The extent to which this applied to young physically disabled adults will be explored later in the thesis.

On the other hand, if an individual follows an inappropriate path from the start, resultant failures will undermine the individual's self confidence and make him or her less inclined to try. Things that others would view as a challenge he or she views as a threat and applies his or her energies in defensiveness rather than constructive coping. This in turn, leads to the loss of an increasing amount of ground in terms of the acquisition of the knowledge and skills that are prerequisites for success on the occasions when he or she does try (Bee, 1996).

There has been much debate within psychology as to the extent to which people who lack control over their daily lives can learn 'helplessness' i.e. the expectation and belief that they are powerless in terms of initiating and changing events in their lives; that events are independent of their actions and beyond their control.

Learned helplessness theory originated from a study that showed that dogs who had learned helplessness would passively continue to receive high levels of electric shocks (Overmier and Seligman, 1967, Seligman, 1975; cited in Brechin and Walmsley, 1989:109).

The theory is based on the idea that powerlessness results in three negative effects on individuals; there is a loss of motivation to try and control events, people believe that there is no point in trying to solve problems or overcome barriers; this in turn can lead to emotional problems such as resignation, depression and anxiety; and also disruption to learning in that an individual may find it hard to assimilate that his or her own actions actually affect outcomes or events even when the results are positive (Brechin and Walmsley, 1989).

Proponents of the theory maintain that learned helplessness does not stem from one particular situation, it is viewed as the result of a series of learning experiences over which an individual has had little control or choice and it can begin in the first few days of life (Seligman, 1975; Watson and Romney, 1972; Newson, 1979). The basic argument is that a child's sense of mastery or helplessness is rooted in early interactions and from the information provided by parents' responses to the child's actions. The role of the parents of disabled children is particularly critical and the extent and ways in which they contributed to the individuals sense of mastery or helplessness will be explored later in the thesis.

Psychologists faced a major difficulty in explaining why some individuals in powerless situations do not appear to be helpless in terms of initiating change, and directing life shaping decisions. The theory was reformulated and situations such as the one above were explained in terms of individuals perceptions of the origin of the difficulties faced and the reasoning behind their explanation for their situation. According to the theory, this hinges on the following:

Table 2.4 Origin of Difficulties

Causes	Definition
Internal - External	Personal or dependent on the environment
Stable - Unstable	Of long or short duration
Specific - Global	Unique to one or applying to various situations

Source: Garber & Seligman, 1980; cited in Brechin & Walmsley, 1989; p 110

Learned helplessness is associated with internal, stable and global explanations for negative events i.e. individuals feel that their lack of competence is to blame and positive outcomes are associated with unstable global explanations. Individuals do not award themselves credit for the outcome but attribute it to 'chance' (Brechin and Walmsley, 1989).

These theories are diametrically opposed to the social interaction perspective which emphasises the centrality of close relationships with friends and family together with social roles. Great emphasis is placed on a 'social clock' which defines a sequence of normal adult life experiences, such as the timing of marriage

and childbearing, or retirement for example. The social roles related to age are considered to be essential and these have tremendous bearing on major decisions and life patterns as well as emotional well-being and relationships with others (Kimmel, 1990). Whilst emphasis is placed on the operation of an inner social clock in the theories outlined above, from a social interaction perspective the question would be asked as to whether stages are anything more than expectations for what individuals should be involved in at a given age (Wrightsman, 1994).

The social interaction perspective advocated by Kimmel (1990) and others is grounded in a symbolic interaction approach to the study of the relationship between the mind, self and society. Mead, the father of symbolic interactionism argued that:

> ...humans evolved as social beings and that their ability to interact with one another through symbols (such as language or gestures) was particularly important for understanding the nature of the human self (Mead, cited in Kimmel, 1990:57).

Symbolic interaction is viewed as having an important role by psychologists, writing from a social interaction perspective, in terms of its usefulness as a perspective for describing human interaction. Although it does not enable the prediction of human behaviour, it does allow description of human functioning in society and, in terms of the study of adulthood, it offers a number of advantages

from a psycho social standpoint: namely: the focus on the individuals' inner experience; the emphasis on the continual capacity for change; and the fact that social processes are viewed as having a major impact on human functioning. Essentially, the approach encourages the examination of the interaction between individual development and social influences and an understanding of this is viewed as central to comprehension of the age related changes that occur in adulthood (Kimmel, 1990).

These age related changes are influenced by age norms (Kimmel, 1990) which are a set of expectations about behaviour which individuals use to regulate their own behaviour and respond to others' behaviour and these are learned via the socialization process. Pressure is brought to bear on an individual who violates norms or expectations and this takes the form of social sanctions. Norms prescribe roles for individuals in different social positions and informal as well as legal sanctions may be used to maintain expected behaviour. Age norms are the expectations of appropriate behaviour for people at various points in the life span. Awareness of such norms is universal although they may be culturally specific. There are stereotypes about people based on age, which are used as a basis for a response to individuals of different age groups.

For example, 'expected age' with regard to various age related life events such as marriage will vary to some extent across cultures and time (Kimmel, 1990). It has also been suggested that society has less rigid norms now in terms of the best age

for people to finish school and start work, and to marry (Kimmel, 1990:68). Individual perception is significant in terms of what constitutes appropriate and inappropriate behaviour at a given age and this is essential to the operation of age norms (Kimmel, 1990).

Psychologists writing from a social interaction perspective place great emphasis on the importance of social roles and age norms in influencing human behaviour (Kimmel, 1990). Social role encompasses both the individuals social position and the norms of society. *Roles* refer to the behaviour that is expected of individuals who are occupying a particular social position, and *norms* dictate the expected role behaviour, for example, the roles of mother and employee. Roles and their accompanying 'scripts' are seen as essential to human interaction, and deviation from a role may result in social discomfort and the employment of a social sanction. The interaction between a doctor and patient is reliant on both playing their roles correctly. It is acknowledged that individuals do exercise a degree of licence, and that all roles played by individuals are idiosyncratic in some respects. However, if a person deviates too far, then social constraints are applied.

There are cases where individuals step outside prescribed social roles and ignore social constraints. Examples include members of oppressed groups who make a point of highlighting oppression sometimes to the extent of provoking confrontation and civil disobedience. The action of Luther King and Gandhi are cases in point. The Disability Movement is increasingly adopting such tactics in

Britain through the growth of organisations 'of' disabled people, albeit on a smaller scale, in order to protest about the oppression of disabled people in society, although there has been no emergence of a leader to date. This is due to a number of factors such as the heterogeneity of disabled people and their experiences, and the extent to which they are marginalised within society. Also, to a lesser degree there is the issue of the extent to which a vociferous disabled person is seen to deviate from the 'script' which accompanies the passive role associated with being disabled. This is one factor which has discouraged people from having a voice. Questions are raised as to the extent to which disabled people on the one hand have to work to a different 'script' to rest of society, and the existence of opportunities to deviate from it on the other. These issues will be discussed later in the thesis. Social norms can have a negative role in that they can be used to undermine individuals and discriminate against groups of people (Kimmel, 1990). Individuals can be discriminated against for a number of reasons; on the basis of age, race, gender and disability. People may suffer multiple disadvantage, with a number of social biases interacting in complex ways. The definition of ageism offered in the psychological literature i.e that it:

> ...Involves prejudicial attitudes, discriminatory practices, and institutional policies and practices (Butler, 1969; cited in Kimmel, 1990:72).

can be applied to all discrimination experienced by oppressed groups in society including young people whether non disabled or disabled. These issues will be

discussed in greater detail in subsequent chapters.

The interaction of age norms, age constraints and age status systems (i.e. where society awards rights, duties and privileges to individuals differentially on the basis of age) together with age related roles has highlighted the existence of a 'social clock' to psychologists (Neugarten, 1968). This is an internalized sense of the appropriate time to attain social milestones. These are based on the age related factors outlined above. This clock navigates the individual through the events and milestones associated with the attainment of, and progression through adulthood. The process of internalization occurs when:

> The norms and expectations of society (the generalized other) are internalized by taking the attitude of the generalized other towards oneself. One then compares one's own developmental progression with these norms and expectations...Consider the social clock as "Big Ben". We set our individual watches (internalized age norms) to Big Ben (Kimmel, 1990:74).

The emphasis is very much on the individual being responsible for the timing of his or her particular 'social clock'. Individual behaviour as opposed to structural constraint determines the achievement of the major milestones. This is illustrated by the comment:

> ...Some of our watches keep better time than others, so there is some variation in the timing of major milestones, but most of us have a reasonably similar sense of the 'right time' to marry, change jobs, become a parent...(Kimmel, 1990:75).

The literature does concede that there are slight differences in the settings of the 'social clock' according to socioeconomic class. In western societies social class is generally defined on the basis of education, income and occupation. Individuals with the highest social status are highly qualified, well paid and have a prestigious occupation. Every family occupies a position in this status hierarchy, and this influences the progression of children towards and through adulthood. It is well documented that family background determines education levels, life expectations and attitudes and influences the pathway that individuals are likely to follow throughout their lives. Families teach attitudes towards work and self, foster or inhibit confidence, and encourage or discourage achievement (Kimmel, 1990; Bee, 1996). A study of a representative sample of persons aged fifty to sixty years in a Midwestern American city in the 1950's, found that persons from higher socio-economic classes experienced family related events later than persons from lower socioeconomic classes (Kimmel, 1990).

The literature does not explore the extent to which differences other than social class affect the setting of individual social clocks. The question of the influence of disability is ignored together with the possibility of inherent conflict between

the non- disabled social clock and the one enforced in the 'disabled world'. This can be a source of great distress to the individual as will be illustrated in the thesis from the standpoint of the young physically disabled adults themselves.

Psychologists have also pointed out that events that occur abnormally early or late according to the social clock can be problematic in that planned transitions are not generally associated with psychological change whilst events that disrupt the expected sequence can be a source of extreme stress (Pearlin, 1982; cited in Kimmel, 1990; Bee, 1996). Being 'off time' is perceived as carrying a price:

> ...Every culture...shares some set of expectations about the 'normal' or 'expected' pattern of adult life. We may not be consciously aware of these expectations, but violating them involves some kind of price...Any time you experience some life event or acquire or lose some social role at a time that is not typical for your generation, you are likely to experience heightened depression or distress (Hurwicz, Duryam, Boyd - Davis, Gatz and Bengtson, 1992; cited in Bee, 1996:216).

The effects of such events are not all negative however. The literature cites the example of women returners to education who undertake further or higher education upon completion of child bearing (Neugarten and Hagstead, 1976; cited in Kimmel, 1990). It is recognised that there is some scope for individual autonomy as the power of age norms decreases enabling people to exercise choice

and delay marriage or parenthood or bring retirement forward in line with current trends (Kimmel, 1990). The emphasis is on the individual's responsibility for setting internalised age norms and deciding whether the pace needs to be speeded up or slowed down in order to stay synchronised with the 'social clock'.

On one level it could be argued that there is greater freedom than ever before to 'skip some time' i.e. delay family life events or advance occupational ones (Kimmel, 1990). However this assumes that all individuals have an equal degree of choice in such matters, and that structural constraints are not part of the equation. These issues will be discussed in more detail later in the chapter. Again there is no acknowledgement that choice and autonomy are not universal and disability is absent from the equation.

Problems with the Social Psychological Approach to Transition

There are a number of difficulties associated with this approach when viewed from the standpoint of the broader structural context of 'youth' rather than adolescence:

Similar to the disability literature reviewed in chapter one, the focus has been very much on the characteristics inherent in the individual and focuses on the role of inner characteristics (drives and instincts) and the operation of social norms. There is no consideration given to the effect of structural factors on transition.

There is a problem in defining the terms 'youth' and 'adolescence' as alluded to at the beginning of the chapter. Psychologists have defined adolescence (youth) on the basis of age (Kimmel, 1990, Bee, 1996) and whilst this provides a starting point, there are a number of difficulties associated with this approach. Although the physical and biological changes associated with adolescence are universal, the demands placed on a young person during adolescence or youth are culturally specific and can vary over time. For example, adolescents today have to master much more complex sexual, social and occupational roles than was the case in the 1950's. These terms encompass the areas of both physical and socio-economic development as well as legal status:

> To a great extent, youth and adolescence are social constructions, varying between cultures, and subject to reconstruction over time (Jones & Wallace, 1992:3).

From the standpoint of sociology, youth and adolescence are very much influenced by life course events and social relationships and the association with age is a weak one. This is graphically illustrated by the literature which outlines the way in which transitions have become more extended (Jones & Wallace, 1992; Jones, 1995).

The psychological literature reviewed on adult development appears to have neglected young adults (i.e. those between the legal age of majority and forty

years). This is related to difficulties in defining young adulthood. In the service provision literature reviewed in chapter one, young adults were defined as individuals between the ages of sixteen to sixty four years (Beardshaw, 1988), and sixteen to thirty years (Chamberlain, 1993); whilst the social psychological literature defines young adulthood as the period from eighteen to forty years (Bee, 1996). In the context of this thesis, young adulthood is defined as the period from eighteen to forty years. Considerable attention has been focussed on childhood, adolescent and elderly development but there is a paucity of information on development during young adulthood and as a result little literature to account for the extension of transition from a social psychological perspective.

The research on which the above theories were based was mostly small - scale. Erickson's work is based primarily on limited clinical observations. And whilst the use of small scale research is not unacceptable per se, and has an extremely important methodological role to play (Bee, 1996), the problem in this case is that the results (i.e. developmental stages) are generalized to the population as a whole with inadequate consideration of such limitations.

Linked to the previous point, stage theorists have been criticised for:

> ...Several marked biases [that] are built into many (but not all) of the data sources and the theories themselves. Most theorists have studied primarily white middle class adults. Virtually all have studied only Western culture.

(Bee, 1996:78).

Criticism has been widely levelled at the degree of reliance on interviews with men only (Kimmel, 1990; Brannen, Dodd, Oakley, 1994; Bee, 1996). In describing the developmental stages of adolescence:

> ...Traditional psychological accounts have paid little attention to gender...the notion of individuation in adolescence, and adolescents' progress towards autonomy and the exercise of individual rights is largely based upon a male model of development (Gilligan, 1982 cited in Brannen, Dodd, Oakley, 1994).

Erikson is singled out for particular criticism in this respect because although he acknowledged sex differences, his model of the life cycle is explained in terms of male experience. It is also the case that disabled people are omitted from the equation by all the theorists. These factors further question the generalizability of such theories and the inherent assumption that all adults develop exactly the same way following an identical sequence. This applies to social interactionist approaches also:

> ...The period from eighteen to twenty five years is dominated by the social clock...Role demands are still extremely powerful...This fact tends to make the lives of those in early adulthood more like one another than they

> will be at any later point...[they] enter into the broad river of family and work roles in their early twenties and are moved along with the common flow as their children grow older and their work status progresses (Bee, 1996:392).

Disability is neglected in the psychological literature. Whilst personality is viewed as having a dual impact on occupational and life success, with achievement leading to an increase in self-confidence and further success, and failure having the opposite effect leading to a state of perceived powerlessness and ultimately learned helplessness, there has been no attempt to explain this process in terms of events outside the individual, or from the standpoint of different social groups. This thesis will explore the cause and effect of powerlessness from the standpoint of young physically disabled adults.

Disability is also neglected in the psychological literature written from a social interaction perspective. No consideration is given to the effect of disability on the operation of the social clock, both in terms of the extent to which the non-disabled and disabled worlds operate to different social clocks (due to the influence of external factors), and the existence of conflict between the two from the standpoint of the disabled individual. Also, the costs of being 'off-time' in terms of the social clock are ignored. These issues will be discussed later in the thesis with reference to young physically disabled adults.

The literature also assumes that there is universal scope for individual autonomy and control regarding the attainment of major social milestones. This is not the case for all social groups as will be illustrated in later in the thesis.

A strong emphasis is placed on the importance of biological events and individual developmental tasks in structuring the passage to adulthood. The focus is very much on the individual as opposed to the social and economic facets of transition. This is particularly apparent in the work on intelligence and personality. Much criticism has been levelled at learned helplessness theory on similar grounds.

This theory is based on the idea of 'helplessness' as a condition of the individual, and it has medical connotations in that it has been described as a 'syndrome'. The relationship between the individual and his or her social environment is ignored with the emphasis placed on the person's inability to control that environment. This has an extremely negative effect on the individual concerned:

> ...By concentrating on the attributes of the individual (including whether they blame themselves), learned helplessness theory becomes part of the ideology for blaming the victim...the stigma, the defect, the difference although derived in the past through environmental forces - is still located *within* the victim, inside his or her skin (Ryan, 1977; cited in Brechin & Walmsley, 1989:112).

This theory offers a model of the psychological price of powerlessness i.e. the internalization of oppression. Apathy, fatalism, depression and pessimism are categorised as characteristics of the individual when in fact they arise as a result of powerlessness. Helplessness is a direct result of that power imbalance between people and those who control their lives.

There is a strong argument for focus on the relationship between the individual or groups and the social environment. These issues will be explored below.

The Sociological Perspective

Whilst the social psychological literature on the transition from childhood to adulthood depends to a large extent on biologically based models of adult development where there is a strong association with age, sociologists have approached the question from a very different perspective.

The first task is to define the term 'youth' in the context of the sociological literature. "Youth" has been defined as:

> ...An interstitial phase in the life course between childhood and adulthood (Jones & Wallace 1992; cited in Coles, 1995).

However defining the beginning and end of youth has proved to be extremely

problematic. The general consensus of opinion is that age is only loosely associated with the attainment of adulthood as youth is a process of continual re-definition which is guided by interactions between individuals, their families, peers and societal institutions. (Jones & Wallace, 1992; Coles, 1995). The tenuousness of the link between youth and chronological age is illustrated by the fact that certain legal rights and responsibilities are endowed upon the individual at age thirteen, such as the legal right to engage in part-time employment, whilst other such as full entitlement to adult income support are delayed until the age of twenty five (Harris, 1989; cited in Coles, 1995). Also, the rights and entitlements of young people have not remained constant over time in response to alterations in social and economic circumstances.

There is also the issue of whether sociologists should attempt to define the age at which young people become adults. It is argued that the focus of sociology should be on the mechanisms by which dissimilar groups of young people attain adulthood in different social contexts (Jones & Wallace, 1992).

As age has proved an unsatisfactory definition for youth, sociologists have described the phase in terms of a series of transitions and the term 'post - adolescence' has been coined which it is claimed identifies a new stage in life (Gaiser, 1991; cited in Jones & Wallace, 1992). This term applies to the period of dependence on parents which extends into the twenties and sometimes the thirties. The most important transitions of youth are:

Table 2.5 Youth as a Series of Transitions

School - Work transition from full - time education and training to full - time employment.
Domestic transition from family of origin (Usually the biological family) to the family of destination.
Housing transition from parental or surrogate parental home to living in separate accommodation.

Source: Jones & Wallace, 1992; Jones, 1995; Coles, 1995

Explanations of youth have differed over time. Both the focus of researchers and commentators and the theoretical perspective utilised has been subject to change. Functionalist theories placed central importance on the role of the family which was responsible for the primary socialisation of children. This role consisted of:

> Families teaching children to conform to social norms and learn culturally prescribed social and familial roles...For this to be successful it was deemed necessary for the child to be dependent on its parents...temporarily in order to learn the parents role models....It was recognized that in time, the family must fulfill another function and help in emancipating the child from that dependency (Parsons, 1956; cited in Jones & Wallace, 1992:9).

However, it was believed that primary socialization alone would be insufficient to adequately prepare young people for their future roles in society, so it was suggested that secondary socialisation would be necessary to rectify this. This was provided in state institutions such as schools which would share responsibility with the family for the development of the young persons

independence (Eisenstadt, 1956; Reuter, 1957; cited in Jones & Wallace, 1992). This function is of critical importance to disabled people. The extent to which the family and education system were able to fulfil this function will be explored later in the thesis from the standpoint of young physically disabled adults.

With the development of youth cultures, social change and challenges to the idea of inflexible normative roles, and the increasing demands for social change and self - determination characteristic of the 1960's and 1970's, functionalist theory lost credibility as the possibility of a smooth transition to adulthood became increasingly improbable. Their explanation that the increasing marginalization of young people was due to a failure of the socialization process was insufficient.

Attention switched in the 1970's to the transition from school to work, and explanations were sought for the situation where the 'normal' process of transition from school to work was disrupted for a large number of mostly working class teenagers (Hutson & Jenkins, 1989). It was recognised that the scope of research had to be broadened beyond the generational focus characteristic of earlier studies on youth cultures (Berger, 1963; Zweig, 1963; Parsons, 1973; cited in Jones & Wallace, 1992) to consider the impact of social class and eventually gender and race (Willis, 1977; Corrigan, 1979; Cashmore & Troyna, 1982; Dex, 1982; Cross & Smith, 1982; cited in Hutson & Jenkins, 1989). This work focussed on the reproduction of power structures such as class inequalities through the peer group.

The work outlined above is written from the perspective of social reproduction theory, and although the roots of this are in a reaction to the perceived inadequacies of functionalism, there are a number of overlaps which can be identified and these can be seen in the work of Willis (1977) which outlined the centrality of the role played by peers and schools in ensuring that employment roles are perpetuated from generation to generation (Jones & Wallace, 1992). Both theories fall into the category of structural explanations of youth.

There is an extensive literature on 'the youth unemployment problem' covering areas such as post - secondary school education and training provision, (Finn, 1987; cited in Hutson & Jenkins, 1989), the culture or life-styles of young people, (Wallace, 1987; cited in Hutson & Jenkins, 1989), aspects of the labour market for young workers (Roberts *et al*, 1981, 1987 cited in Hutson & Jenkins, 1989), the psychological consequences of youth unemployment (Braithwaite & Garcia, 1985; cited in Hutson & Jenkins, 1989). Researchers have also examined the social consequences of unemployment for individuals from ethnic minorities (Silitoe & Meltzer, 1986; cited in Hutson & Jenkins, 1989).

Since the 1970's the nature of the youth labour market and training provision has altered and this together with a deepening economic recession led to calls for a different perception of the problem. It became obvious that social researchers focus on the transition from school to work alone was too narrow as the work

was generally based on white working class males. These days attention is largely targeted on the *transition from youth to adulthood*. This shift to a more holistic approach is also indicative of a change in the way *the problem* of youth is viewed from:

> ...Looking at youth as a problem, towards an analysis of the problems of youth...and a concern with ordinary as opposed to troublesome young people (Hutson & Jenkins, 1989).

This broader focus has led to a wider debate on the consequences of unemployment for the transition. On one hand certain commentators argue that:

> ...We are still failing to get to grips with the implications of unemployment...most of the adult unemployed are already *culturally formed*. ... They are workers without work, wage earners without the wage, consumers without money. ... But for young adults the situation is qualitatively different, and in my view more open; both positively and negatively. ... Because they are not yet fully formed. For them there are only broken transitions into the possibilities of adult roles. They have never experienced them. They are in suspended animation (Willis, 1984; cited in Hutson & Jenkins, 1989).

In this quote employment status is taken to be pivotal in determining successful

transition to adulthood. This is viewed as the starting point from which individuals gain access to independent housing, parenthood, and the consumer market. However, this portrayal of adulthood has been criticised for being ill - defined and simplistic (Hutson & Jenkins, 1989; Jones & Wallace, 1992).

From the mid 1980's onwards a number of studies were published which acknowledged the role played by both gender and locality in moderating the impact of class. An example of such work was the Economic and Social Research Council project which became known as the 16 - 19 initiative. The aim of this project was to outline youth transitions from full - time education to employment during the late 1980's (Banks et al. 1992; cited in Coles, 1995). The report outlined the balance between structure and agency which characterises youth. Whilst it defined youth as a time during which critical choices are made, it was also acknowledged that structural constraints also impacted upon this period:

> ...Social class, gender, ethnicity will all play a part in shaping aspirations, as do the characteristics of the locality in which a young person lives ... these influences are 'mediated' through informal networks of social relationships involving parents, friends and peer groups, as well as the more formal guidance received by teachers and careers advisers (Coles, 1995:13)

The extent to which the socio-economic circumstances of young people's upbringing reproduces social structural advantage and disadvantage has been the subject of much debate in the sociological literature. The areas of social class, gender, locality and ethnicity were highlighted as areas of potential disadvantage although the impact of disability has been largely neglected.

Trajectory, Career Path or Life Course?

On review of the literature, it is apparent that sociologists have used a number of different terms to describe the process of transition and this also has been the subject of debate. Whilst some talk in terms of young people's "careers" being influenced by structural constraints (Bates & Risebrough, 1993; cited in Coles, 1995), others talk of "trajectory" which gives a sense of individual's being pushed along an established path towards a set destination due to the influence of social class and locality (Roberts, 1993; cited in Coles, 1995). Other authors use a Life - Course model to analyse the transition to adulthood (Hutson & Jenkins, 1989; Jones & Wallace, 1992; Jones, 1995). There appears to be considerable overlap between the life course perspective and the concept of career. The concept of career has been favoured by some sociologists because it allows a much wider scope than that implied by the term "trajectory" as it acknowledges the role played by agency and therefore presents a less deterministic picture of transition as choice may be exercised on a number of levels. In theory young people may make choices with regard to the career

options followed or abandoned, adults may make decisions in their role of 'youth professionals' and steer young people in a certain direction (Coles, 1995). The concept of career is defined as:

> ... The complex interactions between young people and their parents and other agencies responsible for their welfare... it is these negotiated or imposed decisions which determine each discrete stage in a status sequence, and which set in train a whole range of social and psychological processes associated with the incumbency of each status position (Coles, 1995:20).

Although the sociological concept of career was first developed in the 1960's (Becker, 1963; cited in Coles, 1995) and applied to the study of deviance, it has been adapted by Coles (1995), and used in the context of transition. There is a marked similarity between the life course perspective (Hutson & Jenkins, 1989; Jones & Wallace, 1992, Jones, 1995) and the concept of career in this context. It could be argued that the terms are interchangeable.

It is essential that both sides of the structure/agency equation are recognised. Whilst "trajectory" is too weighted towards the structure side and does not acknowledge the possibility of change, there is the danger that "career" places too much emphasis on the influence of individual choice and agency. There is another danger associated with the broad scope of a life course/career

perspective. Because the focus is biographical, there is a danger that it could be narrowed to individuals rather than social groups due a process of reduction. Thus the work would possibly be exposed to accusations of myopia and victim blame and would have gone full circle. However it is widely acknowledged that a broader scope is preferable (Hutson & Jenkins, 1989; Jones & Wallace, 1992; Jones, 1995, Coles, 1995).

This has been advocated on the grounds that:

> The models of adult status which are current in society must be the starting point inasmuch, as adulthood, is a culturally and socially defined status a facet of the (*life - course*) rather than a biologically determined condition (*a phase of the life cycle*) (Hutson & Jenkins, 1989).

The life - course perspective has opened up the possibility of work which unites the sociology of youth and the sociology of family life. Such work has highlighted the importance of economic independence in allowing individuals to fully participate in society via access to, and acquisition of, the full rights and responsibilities of citizenship (Jones & Wallace, 1992; Jones, 1995; Coles, 1995). This literature has outlined a number of barriers to the achievement of economic independence by young people. These will be briefly outlined below.

Economically Independent Young Adults?

Much of the recent literature has utilised the concept of citizenship as a framework for understanding youth and transition. It is favoured over adulthood because it allows the consideration of both process and inequality i.e. the way in which citizenship rights are acquired during youth, and the extent to which *access* to those rights is governed by social inequality such as social class, gender, race and disability (Jones & Wallace, 1992).

Modern writing about citizenship draws heavily on Marshall's analysis but criticises the limitations of his arguments to social class, suggesting that citizenship's relation to gender, race and disability is also problematic.

It is generally acknowledged that there have been substantial changes in transitions to adulthood over recent decades, with transitions becoming extended and increasingly complex (Jones & Wallace, 1992, Jones, 1995, Coles, 1995). This development is due to a longer period spent in education and training, decreasing employment opportunities for youth and reduced state support and changes in the structure of families and the nature of family support. Thus young people are disadvantaged on a number of levels in terms of making the transition to a independent living These will be briefly outlined below:

The Extension of Education and Training

These changes have particularly affected the working class school leaver as there is no longer a smooth transition from the status of pupil to worker. Increasing numbers of school leavers are spending time as trainees or students. This has had an impact on the achievement of the other stages of transition such as the transition from the family of origin to family of destination (domestic transition) and also the transition from residence with parents (housing transition) since a wage is of central importance. The education system has expanded markedly since the 1970's and as a result new patterns of dependency have been created:

Table 2.6 Expansion of the Education System

Higher Education	*Secondary Education*
Increased University places	Higher school leaving age
Polytechnics	F.E. colleges
Open University	Vocational qualifications
Access courses	

Source: Jones & Wallace, 1992:29

The length of dependency has been increased due to the above expansion of education and a reduction in the youth labour market which has resulted in an increasing number of young people adopting the intermediate status of students or trainees. Although this has meant increased opportunities for a large number of students, these advantages have been undermined by the reduction of state support for students at the same time as parental responsibilities have been highlighted. Student grants have decreased in real terms, and the new emphasis

on student loans has resulted in large - scale debt for the majority on completion of higher education (Jones and Wallace, 1992). The position of students was further undermined by the withdrawal of the right of students to claim income support during vacations and the removal of housing benefit. Students with poorer parents, and those living away from home have been particularly disadvantaged (Jones, 1995). However the long term prospects of students are much brighter than individuals forced to enter youth training schemes. Students undoubtedly face short - term relative poverty in youth but there is the possibility of getting a highly paid job with equivalent status in society (Jones & Wallace, 1992). The extent to which this applies to disabled graduates will be discussed later in the thesis. Of course there are a number of young people who failed to attain sufficient educational qualifications to gain entry into higher education and enter youth training. They may face the prospect of a life time pattern of second class citizenship (Jones & Wallace, 1992).

With regard to trainees, it was assumed during the 1980's that all 16 - 18 year olds would either become students or trainees due to the shrinkage of the youth employment opportunities. However the various youth training schemes instituted have been of limited effect as the status of "trainee" has never been widely recognised and training allowances are extremely low and fail to cover housing costs. The basic YTS allowance contained no rent or board element (Jones, 1991) with the result that many working class young people are remaining dependent for longer.

The Reduction in the Youth Labour Market

The increase in youth training not only reflects a reduction in employment opportunities but has led to the alteration of the structure of the labour market itself. With the growth of training schemes characteristic of the 1980's, some forms of youth employment and apprenticeships disappeared as employers took increasing advantage of government subsidized schemes which made it cheaper to employ trainees rather than the unemployed. It was the case also that some jobs disappeared due to advances in production techniques. Apprenticeships reduced in number from nearly a quarter of a million places in the mid 1960's to 55,000 by the end of the 1980's. The proportion of young men in apprenticeships also fell from 6% to 2% (Ashton et al, 1989; cited in Coles, 1995). Youth unemployment had reached such a high level by the 1980's that training schemes were extended to take individuals out of dole queues and train them for jobs although, in reality, they have only served to launder the unemployment statistics. (Hutson & Jenkins, 1989; Jones, 1995). There is a danger of this happening with the present government's 'Welfare to Work' initiative.

The increase in youth unemployment has to be viewed in the context of a decline in the traditional manufacturing sector which started in the 1970's. As companies took advantage of cheap labour available overseas, temporary and performance related contracts replaced the guarantee of a regular 'job for life'. This occurred in the steel industry of South Wales where unemployment, part-time work, home

working or temporary work became commonplace (Jones & Wallace, 1992). The decline in heavy industry led to the increase in youth training outlined above and considerably weakened the trade unions which had offered employment protection to workers. The election of a Conservative government in 1979 added further impetus to this process with policies to reduce public expenditure and de-regulate the labour market. State services were reduced and sub - contracted out in order to reduce costs and 'roll back the state'. The public utilities were privatised. The introduction of structured flexibility (laying people off, low wages, short time and wage cuts), into the labour market has rendered marginal members of the workforce the most vulnerable i.e. young people, disabled people, women, and workers from ethnic minorities (Jones & Wallace, 1992). Transition is more protracted in a climate where there are fewer young people in work, and the number getting training allowances rather than wages has increased. It is an employer's market where those in work have little bargaining power and this is especially the case with young people who have relatively little 'voice'. The 1992 Employment Labour Force Survey estimated that 125,000 of 16 - 17 year olds were unemployed; 10% of the age group (ELFS, 1992; cited in Coles, 1995:53). The problem was found to be even more acute among 16 - 24 year olds. In 1996 it was estimated that 15 percent were unemployed (Social Trends 1998:88). These figures and the changes outlined above present a bleak picture when one considers that:

> ...A wage from work has traditionally been important as the means

> through which economic independence has been achieved in youth and it has been described as 'the key to citizenship'...leaving home and all other transitions to adulthood, such as the formation of partnerships and families all depend on a viable income from work (Allat & Yeandle, 1992; Jones, 1995:10).

The sociological literature assumes that this applies to all social groups. Does an earned wage constitute the key to citizenship for young disabled people? This issue will be discussed in chapter seven.

The Reduction in State Support

The security of state support is becoming less available to young people, making parental support during transition even more crucial. Their position in the welfare system had always been tenuous because of their intermediate status i.e. from the inception of the welfare state, there has always been a strong relationship between an individual's contributions and the right to receive welfare assistance. This notion of deserving and undeserving poor has its roots in the Poor law. The irony is that as transition is prolonged, young people remain in a position of enforced economic dependency if they are unemployed, as they are denied the rights of those who pay income tax. This situation is paradoxical, because on the one hand, the previous government urged citizens to 'stand on their own two feet' whilst extending the period of dependence in youth (Jones, 1995). There

have been numerous changes since 1979 which have served to slow down transition out of the parental home:

Table 2.7 Reduction in Access to State Support (Social Security)

Year	*Change*
1983	Right of 16 - 17 year olds on supplementary benefit to claim an allowance for their housing costs (Non - Householders rent addition) was withdrawn if they were living in their parental home. Basic YTS allowance contained no rent or board allowance.
1984	Non Householders rent addition withdrawn from 18 - 20 year olds.
1984	Families on low incomes or where family members were unemployed faced the loss of the non - householders rent addition, but the non - dependent deduction (the assumption that working children would make a contribution to their parents housing expenses; and the prescribed amount was duly deducted from the parent's benefit) was greatly increased. Parents were expected to collect rent of £3.30 from all employed 16 and 17 year olds and £8.80 from each employed child over 18 years.
1985	Board and Lodgings regulations meant that those living away from home and on supplementary benefit had the amount which could be paid and the time period for which they could claim limited.
1986	Abolition of exceptional needs payments (which met minimal and equipment needs of those on social security) This demand *has not* been met by Severe Hardship Payments or Social Fund loans.
1988	Withdrawal of Income Support from under 18's (Replaced by the *training guarantee*) and the introduction of a lower than adult rate of income support for 18 - 25 year olds; Withdrawal of unemployment benefit from the under 18's.

Source: Coles, 1995; Jones, 1991, 1995

These changes have effectively made young people economically dependent on their families of origin for a longer period. Young people are now assumed to be dependent until the age of 18 and semi - dependent up the age of 25 (Jones,

1995). This was seen as preferable to dependence on a 'nanny state'. The underlying ideology is that:

> ... Non - householders are dependents, have no housing costs and are not entitled to benefits in their own right (Jones, 1995).

This is despite the fact that it is well - documented that young people pay board (Hutson & Jenkins, 1989; Jones, 1991; Jones, 1995). The benefit changes have affected young people still living in the parental home as well as those trying to leave home. The changes have meant that poorer families (particularly those in receipt of low incomes but not on housing benefit) are doubly disadvantaged if their adult children became unemployed as it is clear that parents are expected to subsidise them (Jones, 1991).

Changing Family Structures

Family support has now become more crucial than ever as a result of the changes outlined above. However, the responsibilities of the family have increased at a time when family support may be less available than before due to an economic recession and resultant unemployment and the increase in part - time working. The private sphere of the family has been the focus of public debate and has undergone much change and legislative regulation over the last twenty years. The roles and responsibilities of the family have considerably altered. A number of

family structures are now apparent with an increase in single parent families; lone parents headed nearly 21 percent of all families with dependent children in Great Britain in 1996, which was nearly three times the proportion in 1971 (Social Trends, 1998:41). Many more young people are leaving single parental homes and the increased likelihood of poverty in such homes has been the subject of much attention in the literature (Jones, 1995). Remarriages have also considerably increased from 37,000 in 1961 to 148,000 in 1991 (Coles, 1995:59). As a result more young people are living with step - parents and there is evidence that step children experience particular difficulties. Step children tend to leave home at an earlier age because of family conflict and are more likely to experience homelessness and there may be difficulty in identifying which parent is responsible for financial support (Jones, 1995; Coles, 1995).

In the traditional nuclear family the responsibility and dependency were clearly defined in the model of breadwinner husbands supporting dependent wives and children. However, the changes outlined above together with women's increased participation in the labour force means that families are less likely to conform to the model of the patriarchal nuclear family (Jones & Wallace, 1992). Despite these changes the traditional family is still considered to form "the building block of society" (Jones & Wallace, 1992). The ideology of the traditional nuclear family has formed the bedrock for government policy during the last eighteen years. They have placed the blame for increasing juvenile crime and delinquency on the 'nanny state' which has served to weaken the family. Their solution to 'the

problem of youth' has been to place increasing responsibility on the family by withdrawing social security benefits thus ensuring young people's economic dependence on parents:

> ... Young people need the support of their families and the family is seriously weakened as an institution if it loses its responsibility for young people. But genuine family responsibility for young people is make believe unless at least some of the costs of their care are shifted back from the state to the family (Marsland, 1986; cited in Jones & Wallace, 1992:80).

This type of thinking does not allow any scope for young people to embark on the road to freedom from parental control and become economically independent. It is well documented that the family plays a crucial role in *assisting* emancipation (Jones & Wallace, 1992; Jones, 1995). The associated increase in the period of dependency creates serious difficulties and tensions for both young people and their families. What kind of conflict does this create? This will be explored later in the thesis. The changes in family structure on the one hand and the increasing emphasis on family responsibilities can have a devastating effect on young people making the transition to adulthood:

> ... for most young people, their families are their major source of emotional, material and financial support as they attempt the precarious

> first steps towards adulthood. For a significant number of young people this support is far from secure, and in such circumstances they may experience unemployment, homelessness and destitution with little state support (Coles, 1995:78).

Many young people are being excluded from participation in society as full adult members, due to the increasing prevalence of extended transitions which have resulted from the socio-economic changes outlined above.

The structural constraints faced by young people attempting to leave the parental home have increased markedly over the last three decades. And it was concern about the effects of these on transition that led to the first group of studies which examined the effect of formal structures on transition (Willis, 1984; Wallace, 1987; Hutson & Jenkins, 1987). These studies documented how failure to negotiate the path through formal structures (i.e. the labour market) and to make the transition into employment, can have a fundamental impact on the degree to which domestic and housing transitions are achieved. The picture has been further complicated by the increasing role played by the market in structuring inequality (Jones & Wallace, 1992; Jones, 1995). No effort has been made to discuss the impact of disability on young people's employment prospects.

Whilst on the one hand structural constraints are increasing for young people trying to live independently, on the other there is international evidence of

agency or self - determination on the part of young people. This can be seen in the prevalence of leaving the parental home in order to live independently (i.e. in a single household) which has become the main reason for moving out amongst the under 18's in Australia, West Germany, Britain and France (Jones, 1995:31). This period has been labelled as a period of post adolescence during which individuals have the opportunity to establish their "social identity and construct a social destiny" (Galland, 1990: cited in Jones, 1995).

Whilst this may be true for some individuals, the reality is that for many young people the picture is not so clear cut. On one level choice has increased for young people via the expansion in higher education and training places outlined above, on another level, it is the case that students entering higher education have a higher earning potential on completion of their courses and better employment prospects than trainees. There is evidence that youth training schemes are geared more to internal labour markets than external ones (ie. training for a particular job in a particular firm); that they socialize young people into low skilled work, with low pay; and that one third of trainees are unable to find employment upon completion of a scheme (Jones & Wallace, 1992; Bates & Risebrough, 1993). Trainees are economically disadvantaged whilst on the schemes as are students in higher education, but the difference is that the students are increasingly likely to be from a middle class background. In the light of grant cuts and social security changes and the possible introduction of tuition fees, parental financial subsidy is becoming crucial (Jones, 1995). Again, the impact of disability has

been omitted from the equation.

It can be seen that whether or not housing transition is achieved is dependent on success in gaining access to the structures outlined above; the labour market and an income, access to adequate social security benefits and access to family support all of which play a crucial part in determining whether young people make the transition to independent living.

Choices are limited for many young people. Access to adequate economic resources has become more important across the spectrum in the light of the current economic crisis. Even individuals who are living in their own households face difficulties.

> ... For those under 18 years of age who may be on low incomes from student grants, wages or training allowances, and no entitlement to social security in Britain, choice depends on the extent to which they can mobilize personal or family resources and 'advantage' comes in the form of emotional and economic support supplied by the family...This may or may not be forthcoming. (Pickvance & Pickvance 1994; cited in Jones, 1995).

Their lives may be severely restricted due to inadequate economic resources which may inhibit participation in social and leisure activities. This situation

applies to both individuals living independently and those still resident in their parental home.

Choices have also decreased for young people in terms of their access to independent housing. This is due to a number of factors: at a time when there are greater and more diverse demands on the housing market which is due to increases in the number of single young people setting up independent homes over the last few decades, a decline in the private rented sector, and a substantial increase in student numbers, young people are encountering ever greater difficulties competing for a declining amount of housing stock (Jones, 1995). The shift from the public rented sector to owner occupied housing, encouraged by the previous government's subsidies, has resulted in an attitudinal shift where owner occupation is much coveted, and social housing stigmatized. When considered against a background of decline in local authority new build programmes and a rise in the general level of homelessness (Morris, 1991), the scenario is one of increasing polarization between those wealthy enough to enter owner occupation or poor enough to qualify for social housing (Jones, 1995).

If non - disabled young people's lives are restricted by the above factors, what is the reality for disabled young people?

Problems with the Sociological Literature on Youth

The sociological literature on youth has approached the issue of transition from childhood to adulthood from a very different perspective to that of social psychology. Rather than focussing on biologically based models of adult development centred strongly on age, sociologists have mainly concentrated their attentions on the paths that young people take through the formal structures of society such as education and the labour market as documented at the beginning of this section. And whilst there is evidence of attempts to adopt a more holistic approach to the study of youth by focussing on both the formal and informal (i.e. family) structures that influence the transition to adulthood and independent living; and the roles played by structure and agency (Jones & Wallace, 1992; Jones, 1995) this literature is limited.

The literature leaves a number of important questions unanswered: such as do different groups of people have dissimilar experiences of transition? Does success or failure in one dimension of transition determine whether another will be successfully negotiated? How is success or failure in transition defined? (Jones, 1997; cited in JRF Young People & Families Committee Report 1997:3).

It is only recently that race (Hewitt, 1988; cited in Brannen, Dodd & Oakley, 1994) and gender perspectives (Griffin, 1985; McRobbie, 1991; cited in Brannen et al, 1994) have been incorporated into the study of youth. It is also the case that

the difficulties faced by the young people aged over 18 have been neglected and this group is particularly likely to suffer unemployment and associated disadvantage (Hutson & Jenkins, 1989).

Current work largely ignores the impact of disability on the transition process; the potential difficulties faced by disabled people are only given passing reference (Jones & Wallace, 1992; Bates and Risebrough, 1993; Coles, 1995). The most attention given to disabled people in the sociology literature is in the form of a single chapter (Coles, 1995). All the literature reviewed is based on the experiences of non - disabled youth. The ESRC's 16 - 19 Initiative did not include disability in its frame of reference (Bates and Risebrough, 1993). The difficulties experienced by disabled people during transition have been ignored despite the acknowledgement in the service provision literature that:

> ... For those with special educational needs (which includes physically disabled youth)... the transition from school to adult life is likely to be a period of particular stress (Warnock Report, 1978; cited in Chamberlain, 1993:2).

Important questions remain unanswered with regard to the role of the family and education system in preparing young disabled people for independence and the extent to which successful transition depends on a network of support involving a number of different agencies. The impact of disability on employment

prospects and the extent to which an earned wage is the key to citizenship has also been ignored in this literature. These areas will addressed in the thesis.

Conclusion

In conclusion: whilst the social psychology literature outlines the transition from childhood to adulthood, this is done from the standpoint of physical and biological processes and a great deal of emphasis on age. This is illustrated by the emphasis placed on developmental stages. The work is centred on the individual's response to society and assumes that all individuals reach the same developmental stages at the same time regardless of gender, race or disability. It is the case that disability is totally ignored in this literature. Any deviations from these stages are assumed to be the result of a dysfunction on the part of the individual. For example, learned helplessness is viewed as a condition of the individual rather than a result of the interaction between individuals and the social environment. The broader structural constraints which impinge on the transition process are absent from the equation and a number of questions are left unanswered with regard to young disabled people. To what extent is powerlessness social in origin? What effect does it have on individual disabled people? Do disabled people experience a different social clock and if so, how does it relate to the one in the non-disabled world? Considerable attention has been focussed on childhood, adolescent and geriatric development but the development of young adults has been neglected in the social psychology

literature and disabled young adults in particular.

The sociological literature on 'youth' has focussed on the transition from youth to adulthood in terms of specific dimensions of young people's lives usually in terms of the path taken through formal structures such as education and the labour market. There has been little holistic exploration of the experience of transition. The literature has neglected young people's transitions in the context of the informal structure of family life. Work is needed which examines the dimensions of transition in the context of both formal and informal structures and this is best achieved using a life course approach which draws on the biography of the individual (Jones & Wallace, 1992).

As with the social psychology literature, the difficulties faced by the over 18's have been neglected as a category, and disabled young people are only given passing reference in the literature; their existence is largely ignored in the social psychology, sociology and social policy literature. This is a serious omission given the difficulties faced by non - disabled youth in making the transition from full time education to independent living and a number of important questions remain unanswered: What is the role of the family and education system in preparing disabled young adults for independent living? To what extent is the role being fulfilled? Are other agencies important to the transition process? Is an earned wage the key to independence? These issues will be explored in subsequent chapters of this thesis from the standpoint of young physically

disabled adults themselves using qualitative methods which were inspired by the ideals of the emancipatory research paradigm.

The following chapter will evaluate the use of the emancipatory research paradigm (Oliver, 1992) in the field of disability research. The rationale behind the use of qualitative research methods which followed the ideals of emancipatory research as closely as possible will be explained in the context of the current study.

CHAPTER THREE

EMANCIPATORY RESEARCH FROM RHETORIC TO REALITY?

THE METHODOLOGY AND METHODS OF THE RESEARCH

The rationale behind the use of qualitative research methods, for the current study of young physically disabled adults will be discussed in terms of the disadvantages and advantages associated with this approach. The use of the Emancipatory Research Paradigm (Oliver, 1992) in the field of disability research will be evaluated. This raises a number of of fundamental issues; epistemological, technical and ethical, centring on the relationship between research and social policy.

Placing Disability on the Agenda

Research on disability in the UK has played a positive role in terms of illustrating the difficulties faced by disabled people and putting some of their problems on the policy agenda. A wide range of health, educational and support services have been advocated. However, much of this work whilst valuable, has examined the medical and social aspects of disability in childhood (Warnock Report, 1978; Rowan; 1980; Younghusband, 1970; cited in Bax, 1989; Court Report, 1976; Anderson and Clarke, 1982). The focus has been on specific disabling conditions such as cerebral palsy and spina bifida, (eg. Anderson and Clarke, 1982), neglecting the difficulties faced by individuals with a wide range of physical disabilities (Bax, 1989). This has had important implications as it has led to much of the research on both children and young adults being supported by funding or pressure groups who feel a responsibility for 'their' children or young adults (Philp and Duckworth, 1982; Bax, 1989). It is important to reiterate that

this work has made an important contribution in furthering understanding of the medical needs of these disabled people, and the personal experience of impairment.

There have been benefits in the form of changes in type of services provided. A few Health Districts have developed specialist services for young disabled people. In 1993 there were ventures in seven towns: Stoke, Leeds, Newcastle, Nottingham, Pontefract, Exeter and Hereford (McBride and Ward, 1991; Chamberlain, 1993).

The difficulties faced by young people who have reached school - leaving age and are facing transition to adulthood have been relatively neglected as outlined earlier in the thesis. The work that has been done is from a health care needs/service provision perspective (Hirst, 1983, 1984, 1985, 1987; Beardshaw, 1988; Silburn, 1988; Bax, 1989; McBride and Ward, 1991; Audit Commission, 1992; Chamberlain, 1993; Silburn and Winfield, 1993; Vincent, Gaskin and Dobson, 1994; Stalker and Reddish, 1995). There has been no published qualitative work done on physically disabled young adults transition from education to independent living in the UK.

A distinct change is apparent in the way that the studies viewed the causes of the disability experienced. For example, the earlier work saw the causes of disability as being rooted firmly in individual impairment. Later studies increasingly

acknowledged that disability is also related to the response of the social environment (Anderson and Clarke, 1982; Bax, 1989; Hirst, 1989; McBride and Ward, 1991; Chamberlain, 1993; Silburn and Winfield, 1993; Vincent, Gaskin and Dobson, 1994; Stalker and Reddish, 1995). Three of the studies of service provision for young adults were structured with the social model of disability in mind (Silburn and Winfield, 1993; Vincent, Gaskin and Dobson, 1994; Stalker and Reddish, 1995).

Defining Disability

All attempts to define disability officially have been based on the tripartite distinction originally developed by Harris in 1971 and accepted by the World Health Organisation as the basis for the international classification of Impairments, Disabilities and Handicaps (ICIDH) and used in much disability research (OPCS, 1988; Beardshaw, 1988); including the registers which local authorities are obliged to keep under the 1970 Chronically Sick and Disabled Persons Act.

The current International Classification of Impairments, Disabilities and Handicaps is as follows:

- **Impairment** is an abnormality of psychological, physiological or anatomical structure or function. Impairments refer to organs eg.

paralysed muscles or legs.

- **Disability** is the restricted ability to perform an activity. Disabilities refer to persons eg. person cannot walk.

- **Handicap** is the restriction faced by a person with a disability in fulfilling normal roles due to social barriers. Handicaps refer to the interaction of people and their societies eg. a person is unable to get a job because employers do not want someone who cannot walk (Cited in Goerdt, 1995:4).

The above classification is scheduled for revision in 1999 by the WHO (Goerdt, 1995). All the studies cited above with the exception of one (Silburn and Winfield, 1993), have utilised this classification because, it is argued, there is no alternative source of numerical data available on physically disabled people (Beardshaw, 1988). Even the most vociferous critics of the tripartite classification have been forced to rely on the estimates of disability it generates:

> ....Writers such as Barnes and Oliver use this type of social research themselves...They have recently...spoken of 'the struggle' for equal rights and opportunities for Britain's 6.5 million disabled people....thereby using estimates of the extent of disability from the 1988 OPCS study, which elsewhere they, and others have been at

such pains to criticise (Bury, 1996).

This approach was developed as an improvement on the use of diagnostic labels to estimate numbers. The advantage of the ICIDH scheme is clear terminology which aids communication between the different professionals who may have different perspectives on disability issues. Whilst there is still a medical orientation, it has a useful role to play in clarifying the roles of medical and social workers in this field (Philp and Duckworth, 1982). The separate classification of handicap with its six specified dimensions; orientation, physical independence, mobility, occupation, social integration and economic self - sufficiency serve to ensure that there is less chance of social and psychological perspectives being ignored which was the case with diagnostic labelling schemes. There is a clear emphasis on 'handicaps' as disadvantages *resulting from* disabilities (Philp and Duckworth, 1982). The manual describing the WHO classification states:

1. Some value is attached to departure from a structural, functional or performance norm, either by the individual himself or by his peers in a group to which he relates;
2. The valuation is dependent on cultural norms; so that a person may be handicapped in one group and not in another - time, place, status and role are all contributory;
3. In the first instance, the valuation is usually to the disadvantage

of the affected individual (WHO, 1980; cited in Philp and Duckworth, 1982:6).

There are other advantages associated with use of the classification namely, that it serves as a tool for measuring the effectiveness of policies for people with disabilities; and it is possible to assess cross - national differences (Krouse, 1995). The classification does allow generalization in that samples defined by ICIDH categories are said to lend themselves to the development of hypotheses and data gathering facilitating the emergence of general conclusions (Philp and Duckworth, 1982).

Quantifying Disability

The concerns and characteristics associated with quantitative research are strongly in evidence. The exception was one qualitative piece of work which evaluated services for younger physically disabled people in North Derbyshire (Silburn and Winfield, 1993).

Quantitative research is associated with a range of data collection methods, with the social survey a favourite. It is widely used because it is possible to generate substantial amounts of quantifiable data from large groups of people who are representative of a wider population. (Hirst, 1983, Parker and Hirst, 1987; Anderson and Clarke, 1982; Hirst, 1986; Bax, 1989) In other words, it is possible

to make generalisations from the findings of such research (Bryman, 1990). The ICIDH classification is widely used and studies based on this are used as a measure of the sample in terms of its representativeness of disabling conditions (Philp and Duckworth, 1982; Stalker and Reddish, 1985). Structured observation is a characteristic of such research and can be seen in the classification and medical examination of individuals in the disability studies. Many of the interviews involved a form of assessment; albeit medical and psychological (Bax, 1988, 1989), Interviewees in one study had to also fill in a Malaise Inventory, and their teachers had to complete a Rutter Teacher Scale (Anderson and Clarke, 1982). A particular language is associated with quantitative research in which terms used to describe the way scientists investigate the natural order, variables, control, measurement, experiment are central (Bryman, 1990). This language features strongly in the disability studies with the use of control groups being mentioned (Anderson and Clarke, 1982; Hirst, 1986).

Most of the studies of physically disabled young adults omit detailed discussion of the methodology employed other than references to the use of the international classification, their primary focus being on service provision issues. Whilst use of the classification has introduced an element of standardisation, it is difficult to comment on the sample selection as the methods employed are omitted from many of the reports (Beardshaw, 1988; Chamberlain, 1993).

Quantitative research does have advantages and views of this method of enquiry

are changing. In the past academics working in the fields of victim research, violence and feminist research have stressed the ways in which individuals can be empowered by qualitative research. However, it is now acknowledged that people sometimes find it easier to reveal traumatic events via a closed questionnaire than in a face to face interview. It can be seen that quantitative methods have their uses in certain contexts but qualitative research methods have been under used in the field of disability research hence their use in the current study.

The Relationship Between Theory and Data in Quantitative Research

The scientific research paradigm appears to imply that theory always precedes data and that it is not modified by the data collection process. However in practice the relationship between theory and data may not be as not clear cut as it seems in quantitative research. Some commentators have argued that theory is often developed at the end of the research process (Cicourel, 1982; cited in Bryman, 1988), This is problematic as whilst theory can follow data collection in quantitative research this can only follow a controlled scientific experiment. (Heron, 1996). Not all quantitative research falls into this category as it may not be theoretical. Its purpose my be information gathering i.e. ascertaining the numbers of people behaving in a certain way etc.

Quantity or Quality? The Critique of Disability Research

There has been much academic debate about the merits and demerits of quantitative and qualitative research. It is a debate in which both epistemological and technical issues have become intertwined as is apparent above. From the late 1970's onwards, philosophical issues have featured increasingly hinging on the appropriateness of *a natural science model* to the social sciences. This was a considerable change as earlier writers had rarely questioned the suitability of natural science procedures (Bryman, 1990).

Social scientists have used qualitative research methods for many years, initially in social anthropology where participant observation was widely used. This strategy was encouraged by Malinowski:

> ...With his plea for the social anthropologist to come down from the verandah and to mix with the natives (Bryman, 1990:45)

The importance of the influence of anthropology is acknowledged in the adoption of the term 'ethnography' by many qualitative researchers to characterise their strategy. The term means:

> ..Literally, an anthropologists's "picture" of the way of life of some interacting human group (Wolcott, 1975; cited in Bryman, 1990:45)

Qualitative research operates from a different epistemological position from that of quantitative research. The former follows a positivist model of how knowledge about the social world should be generated whilst the epistemology of the latter reflects the influence of phenomenology, symbolic interactionism, *verstehen*, naturalism and ethogenics. Qualitative research has been strongly influenced by phenomenology and symbolic interactionism. A phenomenological approach to the study of the social world is characterised by rejection of the idea that scientific methods of study can be applied to the natural and social worlds regardless of any difficulty. Great emphasis is placed on the idea that people and their social reality, the subject matter of the social sciences, is totally different from the subject matter of the natural sciences;

> The world of nature as explored by the natural scientist does not 'mean' anything to molecules, atoms and electrons. But the observational field of the social scientist; social reality, has a specific meaning and relevance structure for the beings living, acting and thinking within it. By a series of common - sense constructs they have pre-selected and pre-interpreted this world which they experience as the reality of their daily lives...The thought objects constructed by the social scientist, in order to grasp this social reality, have to be founded upon the thought objects constructed by the common - sense thinking, living their daily lives within the social world (Schutz, 1962; cited in Bryman, 1990:51).

Phenomenology, symbolic interactionism, verstehen and ethogenics all denote a similar approach i.e. a strategy for the study of the social world the aim of which is to describe and analyse the culture and behaviour of human beings from the point of view of those being studied.

The academic debate has focussed on the following core issues: the role of qualitative research, the relationship between researcher and subject, the researchers stance in relation to the subject, and the relationship between theory and research (Bryman, 1990). These concerns have been reflected in criticisms of quantitative research on women and disabled people and the plea for the use of emancipatory research.

Researchers in the human sciences believe that there is no neutral research (Hall, 1975; Reason and Rowan, 1981; Westkott, 1979; cited in Lather, 1986; Oakley, 1993). The approach is based on the realisation that knowledge is socially constituted, and that one way forward lies in "scholarship that makes its biases part of its argument" (Lather, 1987).

Over the last twenty years women have striven to highlight the ways in which the constitution of knowledge itself has exacerbated their oppression. At the core of the conflict between feminism and knowledge is:

> The perspective of the knower, and the purpose of knowing. In the

> conventional model, the knower is separable from what is known, and the purpose of knowledge is knowledge. From the feminist perspective, the person who knows, what they know and what is to be known are joined in a nicely heretical confusion...there is no point in knowledge for its own sake. Knowledge must serve social ends. It must improve the human predicament either directly or indirectly, either concretely or diffusely (Oakley, 1993:208)

As the criticism of positivist approaches to social research has intensified, it is feminist researchers and researchers in the field of co-operative inquiry who have progressed furthest along the road towards emancipatory research (Oakley, 1981, 1993; Ribbens, 1991; Heron,1996). It is beyond the scope of this thesis to give a critique of feminist research. To do so would involve repetition as the principles inherent in this approach underpin much of the thinking and debate around the emancipatory research paradigm which is explored later in the chapter. Contributions from feminist researchers are discussed in this context.

As alluded to in chapter one, research on disability has been criticised for alienating disabled people and researchers themselves, failing to influence policy, and not improving the lives of the research participants or their peers (Oliver, 1987, 1992; Barnes, 1992; Zarb, 1992). These criticisms mirror comments by feminists regarding research on women. Alienating social research is characterised by:

> Treating people as fragments. This is usually done by putting people into the role of 'research subject' and then permitting only a very restricted range of behaviour to be counted...Using the person for someone else's ends; the persons actions do not belong to that individual but to the researcher and the research plan (Rowan, 1981).

The 1989 National Disability Survey carried out by OPCS has been heavily criticised on the above grounds (Abberley, 1993):

> ...Attempts to depoliticise the unavoidably political, to examine the complex and subtle through crude and simplistic measures, indicate by negative example some of the things that good research in this area...requires (Abberley, 1993).

This survey constituted the most extensive and costly research on disability ever carried out in Britain and although extensively used by its critics (see above), the work has been attacked for failing to lead to any coherent policy developments and it has been either ignored or disputed on the grounds of reliability and validity by disabled people. The critics argue that this outcome was inevitable given that disabled people were not consulted about the research in advance; the issues they felt should be investigated, and how the research should be conducted (Davis, 1990; Abberley, 1993).

The issue is raised as to the extent to which it is possible to conduct research on disability without direct (or indirect) assessment of physical disability. Classifications such as ICIDH play a crucial role in that they enable the extent of disability nationally to be quantified. It is not the fact that such scales exist that is problematic, but the manner in which they are used. This will be explored further below.

Much disability research is viewed as inappropriate by disabled people on the grounds that it relies too much on methodological individualism. This is apparent on two levels, epistemological and technical, i.e. it relates 'handicap', solely to impairment and thus to the functional limitations of individuals, failing to focus on the social and environmental limitations which disabled people face daily thus further 'handicapping' them (Finkelstein, 1984; Oliver,1987); and in the way that the research has focussed on individual disabled people whose responses have been aggregated with those of the others in the sample perpetuating the individualisation of disability by treating social reality as an external object (Oliver, 1987; Bryman, 1988).

The ICIDH and similar classifications have been criticised on epistemological grounds. Whilst these classifications do acknowledge the social dimensions of disability, the problems faced by disabled people are not seen as arising from social causes as their basis is the impaired individual. Disability and handicap is seen as arising as a direct result of physical impairment.

Research in the personal social services has been censured for being unreliable and wasteful (Oliver, 1987). Estimates of the number of disabled people in Britain vary widely ranging from 3 million (Harris, 1971; cited in Oliver, 1987), 10 million was advanced in a survey that was carried out at the same time but published later (Townsend, 1979, cited in Oliver, 1987), two other studies came up with figures of 3,887 thousand and 5,856 thousand respectively (Knight and Warren, 1978; Patrick et al, 1981). Based on the evidence of these earlier studies, a figure of four million disabled people has also been advocated (Beardshaw, 1988). Local authority registers differ greatly to the local estimates made by Harris in that it was found that they were only able to identify one third of the disabled people who had been included by Harris (Knight and Warren, 1978; cited in Oliver, 1987; Beardshaw, 1988). These studies used different definitions and methods, and some were conducted in one local area only (Patrick et al, 1981). For example the latest Community Care Plan for Nottinghamshire states:

> ...It is not possible to have reliable figures on the incidence of people having a disability in Nottinghamshire because of the continuous nature of the concept of disability. A mixed range of census data and estimates exist (NCCSSD, 1996).

The major problem encountered when attempting to estimate the prevalence of disability is actually defining disability itself. This is illustrated by the alternative estimates documented above. The definitions and measures that can

be used are inconsistent and can be subjective. Proponents of the social model of disability stress that it is the physical and social environments that disable individuals; an individual may be able to carry out a wide range of tasks in one environment whilst being severely constrained in another. And differences in the phrasing of survey questions can alter total numbers (Beardshaw, 1988; Chamberlain, 1993). These difficulties have serious implications for policy and service planning and may be an underlying factor in the failure to focus on physically disabled people as a priority group (Oliver, 1987; Beardshaw, 1988). This situation is self - perpetuating in that is difficult to plan services adequately without a reliable data base that correctly identifies disability as being socially caused. Without this, services will be inadequate and low priority. It also means that few disabled people will be aware of their existence or choose to use them and local authorities will have an even more distorted picture of demand.

The disability movement considers that disability research to date has failed disabled people on a number of counts: it has alienated disabled people, led to the generation of inaccurate data for planning and policy purposes, and its emphasis on methodological individualism has further oppressed disabled people (Finkelstein, 1985; Oliver, 1987, 1992; Barnes, 1992; Zarb, 1992). This applies equally to both positivist and interpretive research paradigms. It is for these reasons that disabled people have been given the following advice with regard to co - operation with research based on the ICIDH:

> ....When the researchers or users of the ICIDH try to impose it on us we should either refuse to co - operate or should only provide answers which draw attention to the way which our societies handicap us by the way they are organised for able - bodied persons (Finkelstein, 1985: cited in Oliver, 1987:11).

The emphasis is on highlighting disability as a form of social oppression, focussing on the social rather than the individual causes of disability. This has fundamental implications as it implies a move away from methodological individualism, a complete change in the social relations of research production, and a break from the positivist tradition (Oliver 1987). The plea is for research that involves disabled people at every stage: from planning to report writing. The critics of disability research are arguing for a move away from the 'rape model of research' where the researchers have achieved career advancement via the use of alienating and exploitative research methods (Reinharz, 1979; cited in Lather, 1986).

Emancipatory disability research has to focus on:

> ...the disablism ingrained in individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society (Oliver, 1992:112).

Emancipatory research has to be based upon the essential elements of reciprocity, gain and empowerment (Lather, 1986; Oliver, 1992). This stance has important implications for research design in that the emphasis on reciprocity raises questions regarding the role of the researcher, the relationship between data and theory and ultimately the validity of such research. These issues will be addressed from the standpoint of research carried out on young physically disabled adults who had recently undergone the transition from special needs education to living in the community.

There are problems associated with the use of qualitative research methods per se in social research and when the methodology employed is both qualitative and emancipatory, the difficulties are compounded. Concerns focus on the problem of interpretation, the relationship between theory and research, and generalization. In emancipatory research where the key fundamentals are reciprocity, gain and empowerment, the tensions are more acute. These difficulties were reflected in the study.

With regard to the problem of interpretation, focus on the research subjects interpretations of social reality is the basis of all qualitative research (Bryman, 1990). However the extent to which researchers are capable of seeing through other people's eyes has been the subject of much debate. For example the conception of a study on a particular aspect of social life is reliant on the identification of a problem in the first place and this is likely to have been

influenced by earlier research.

A classic illustration of the problem of interpretation in qualitative research is to be found in Freeman's (1983) critique of Mead's (1928) study of child rearing in Samoa. Mead described Samoan adolescence as being free from the conflict and stress of its American parallel. She concluded that nurture was a greater determinant of human behaviour than nature; Freeman visited Samoa twenty years after Mead and he found the opposite to be true of Samoan adolescence. Freeman concluded that Mead's interpretation of the situation had been overly influenced by cultural as opposed to biological theories of human behaviour. Another anthropologist who restudied Mead's findings in the same Samoan village concluded that her findings were correct. (Holmes, 1983, 1984, cited in Bryman, 1990). There are considerable differences in the anthropologists' interpretations of the nature of Samoan life as viewed by the Samoans themselves.

This is a difficulty with emancipatory research. In deciding that this research method is merited, the researcher will have been influenced by a prior realisation that a particular group was being oppressed. This standpoint may stem from the researcher's membership of that group plus the influence of earlier research. Also, emancipatory research calls for an approach whereby:

> ...Both the researcher and the research become the changer and the

> changed...the research process enables people to change by encouraging self reflection and a deeper understanding of their particular situations (Williamson cited in Lather, 1987:263).

The decision to undertake research on the transition of profoundly physically disabled young adults from full time education to independent living was influenced by personal experience of congenital physical disability and visual impairment and by the difficulties highlighted by previous research on this group plus the growing critique of the methodological individualism inherent in those studies.

Linked to the problem of interpretation is the issue of the researcher's stance in relation to the research subject. For qualitative researchers a central concern is to get as close as possible to the research subject; to be an insider as this facilitates a view of the world through the participants' eyes. This standpoint has its drawbacks as it can lead to the researcher 'going native' ie. forgetting that their role is to carry out research and becoming completely immersed in the participants perspective. The experience of 'going native' has vividly been described by Oakley:

> At three forty five after two hours of a busy antenatal clinic I too would sigh with the doctors as we jointly peeped into the corridor and saw waiting another row of abdomens...(Oakley, 1984; cited in

Bryman, 1990).

Whilst 'going native' is a problem associated with qualitative research, in emancipatory research the nature of the relationship between the researcher and the researched is fundamentally changed. It is based around the notion of reciprocity which is important on two levels, between the researcher and the research subject and between data and theory (Lather, 1986). To critics of qualitative research per se, the emphasis on reciprocity implies an approach to social research far removed from that of the objective scientific method of interviewing advocated in most textbooks and the threat of interviewer bias looms large over such work.

Modern sociology has been described as the 'science of the interview' (Oakley, 1993) and textbooks make a powerful demarcation between appropriate and inappropriate interview techniques. The social research interview is viewed as a mechanical instrument of data collection, a specialised form of conversation in which there is a strict demarcation in terms of who poses and who replies to questions, interviewees as viewed as passive and the interviewer's role is solely question asking and rapport promoting (Oakley, 1993). There are limits on the extent of the rapport that can be established. Rapport in this context is defined as:

The acceptance by the interviewee of the interviewer's research

goals, and the interviewees' active search to help the interviewer by providing the relevant information (Oakley, 1993:224).

The emphasis is on a passive 'respondent' who has been socialized into the correct interviewing behaviour i.e. answering questions and no more. The researcher's stance in relation to the subject is that of an outsider; the detached scientific observer who views research subjects as 'merely fodder for the examination of his concerns' (Bryman, 1988:96)

The intention is to reduce the risk of interviewer bias as much as possible in order to ensure the validity of the research. Interviewer bias is defined as the way that research interviewers can influence responses via their *attitudes*; *expectations*, and *characteristics*; the effect of interviewer attitudes was demonstrated by a study where two interviewers collected data from people living in poverty. In one interviewer's data overindulgence in alcohol emerged as the most common cause of poverty, whilst the results from the other interviewer showed that social and economic conditions had played the largest role. It transpired that the first interviewer was a prohibitionist and the second a socialist (Rice, 1929; cited in Kidder and Judd, 1985) Expectations on the part of the interviewer can introduce an element of bias into research i.e. he or she may have expectations about what a particular category of respondents may say or think which may bias the data collected. There is also the issue of reactivity on the part of research subjects. This problem was illustrated in randomized laboratory experiments:

> ...[This problem occurs] when subjects know they are being studied and want to create a good impression and when experimenters are in direct communication with their subjects and can communicate their expectations verbally and non - verbally (Rosenthal, 1966; cited in Kidder and Judd, 1985:96).

The respondents' perceptions of the interviewer's characteristics, ie. age, sex, race, class etc, may bias their answers and is an example of reactivity (Bryman, 1988). Research has shown that blacks show less hostile attitudes towards whites when interviewed by white interviewers than by black (Singer, Frankel and Glassman, 1983; cited in Kidder and Judd, 1985:271).

The interviewer's perception of the respondent is also a significant source of bias (Kidder and Judd, 1985). This is a difficulty regardless of the degree to which the questionnaire may be standardised, and how rigidly the interviewer may have been instructed. There is still considerable scope to exercise freedom of choice during the actual interview and it is often their view of the respondent which dictates the manner in which the questions are asked, answers probed, ambiguous answers classified, and verbatim answers recorded. It is also the case that interviewers do not approach each new respondent in an identical fashion. Strong expectations and stereotypes may come into play which get stronger as the interview progresses. As a result of previous answers to questions, and the judgements formed, an unconscious association may be made between variables,

and such expectations are detrimental to performance (Kidder and Judd, 1985).

Critics argue that in the interview context reciprocity is operational on three levels; how the researcher responds to direct questions put by the interviewee, that the researcher takes the same risks of self exposure that are requested of the interviewee, that the development of long - term friendship between the researcher and the researched is not discouraged (Ribbens, 1989; Oakley, 1993). This is the opposite of the 'hygienic' interview which has been viewed as legitimate in social research:

> In order to do their job, *both kinds* of interviewer (i.e. structured and depth interviewers) must "switch off" their own personality and attitudes (Oppenheim, 1979; cited in Ribbens, 1989:583).

Doubts have been expressed about the concept of emancipatory research both in terms of its potential to engender large - scale social change and undermine academic integrity:

> ..Ideas clearly have a role, but actions decide the day, and whilst it is possible to make the research process more balanced, grandiose claims for its revolutionary potential seem to me to be over - optimistic...While few would now argue in terms of objectivity, a notional independence and balance is still seen as crucial to the

> academic endeavour...There is little point developing research which is rejected out of hand by government and media as being contaminated by ideological prejudice...The reality is that academics cannot be perceived as having axes to grind (Shakespeare, 1996:118)

With regard to the above quote, it highlights the basic tensions which exist between 'hygienic' academic research and emancipatory research as advocated by the women's and disability movements. On the one hand academics have to present both sides of an argument (as in an academic thesis), whilst proponents of emancipatory research believe that the views of the oppressed group being researched should be given prominence. In an academic thesis which is also committed to following the ideals of emancipatory research as far as possible, a balance has to be struck between the two extremes. The strategy employed goes some way to giving the disabled people in the study the opportunity to air their views and not the presuppositions of the researcher. The ways in which this was achieved are outlined below. As a result, this thesis presents a picture of transition as seen through the eyes of the young disabled adults themselves.

Tensions also exist between the individual and social models of disability. Whilst it is argued that:

> The social model does not deny the problem of disability but locates it

squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation (Oliver, 1996:32).

This is problematic when viewed in the context of the key words associated with this model:

3.1 Disability Models

Individual Model	*Social Model*
personal tragedy theory	social oppression theory
personal problem	social problem
individual treatment	social action
medicalisation	self-help
professional dominance	individual and collective responsibility
expertise	experience
adjustment	affirmation
individual identity	collective identity
prejudice	discrimination
attitudes	behaviour
care	rights
control	choice
policy	politics
individual adaptation	social change

Source: (Oliver, 1996:34)

Whilst this approach might be appropriate for some disabled people it cannot be

assumed that all people would want to or be able to identify with it. The extent to which individuals may relate to the social model is dependent on the nature and extent of their impairment, age at onset and subsequent life experience.

For example a disabled person with a painful, deteriorating impairment might find it difficult to concede that their disability is socially caused. All their time and effort is taken up coping from day to day. In this context individual limitations can cause disability. The picture is further complicated if the impairment is congenital as they will have been socialised into the 'disabled world' of segregated education, day centres and leisure pursuits from a very early age. As a result they may have received a poor basic education and had little opportunity to develop the social skills necessary to take on a campaigning role. They may not have the necessary skills to enable them to take control of their lives or not wish to. It is extremely difficult for people in this situation to place their limited life experiences in the broader social context.

The model is more appropriate for young, fit wheelchair users whose impairment began in their late teens due to illness or injury. They may have the advantage of not suffering pain or deterioration and spent their formative years as a non disabled person. They are likely to have received a better education, and have the appropriate social skills and life experience to enable them to articulate their experiences in a campaign setting and take control of their lives. They also have the benefit of hindsight as they are able to compare their life as a non- disabled

person with their current existence.

There is also an issue regarding the role of the medical aspect of the individual model of disability. Medicalisation is only a part of the individual model. Individuals do have the ability to institute change and act for themselves. To what extent did the young adults in the research sample view the cause of their disability as social?

The Relationship between Theory and data in Qualitative Research

The relationship between data and theory in qualitative research is complex and has been viewed as problematic by quantitative researchers. In quantitative research the relationship between theory and research is one of confirmation, whilst in qualitative research the theory emerges from the data. Grounded theory has its basis in analytic induction and was developed by Glaser and Strauss (1967) as a means of generating theory from data. Theory is grounded in fieldwork. The process is one of continual refinement and testing leading to maximum abstraction at the end of data collection. However the extent to which this is possible in reality has been questioned. Can a researcher totally suspend knowledge of theories or concepts until such a late stage in the research? To what extent is it possible to conduct research from a theory neutral stance? (Bulmer, 1979; cited in Bryman, 1990). The extent to which the constant interweaving of categories and data advocated in the grounded theory approach can be achieved given the time needed to collect and transcribe data is also questioned (Bryman,

1990).

As with quantitative research this is problematic and views have changed in recent years. It was thought that a lot of qualitative research relied on the development of theoretical framework after the data collection phase. Rather than the theory developing in distinct stages alongside data analysis, due to the length of time involved in interview transcription, and the completion of the remaining interviews, the theory is developed when data analysis is complete and in this sense does not constitute true grounded theory (Bryman, 1988).

Bryman's assertion that theory follows the completion of data analysis in qualitative research is problematic. It is increasingly acknowledged that this is not the case as researchers inevitably enter a research setting with ideas in their heads. This is particularly the case with emancipatory research as by simply deciding that such research is merited for a particular social group the researcher has identified that they are oppressed. The key is that the theory is refined as the research progresses.

In emancipatory research difficulties in terms of the relationship between data collection and theory building are more marked and revolve around the extent to which the research relationship can be reciprocal. Whereas in grounded theory building the theory follows from the data, in emancipatory theory building there is tension between the use of theory that precedes the data (i.e that a particular

group is being oppressed and need enlightening as to the nature, reasons for, their difficulties and how to empower themselves), whilst at the same time ensuring that the researcher is sticking to the principle of seeing through 'the subjects eyes' and not from the standpoint of a priori theory or prejudice:

> In the name of emancipation, researchers impose meanings on situations rather than constructing meanings with research participants (Fay, 1977; cited in Lather, 1986:265).

The generalizability of qualitative research is problematic in that is not possible to apply the findings to the wider population.

The issue of the relationship between data and theory in emancipatory research has been extensively covered in the literature on co-operative inquiry (Heron, 1996). However, involving the young adults in the sample in interpretation and theory building proved problematic. Their circumstances made this degree of reciprocity extremely difficult. Whilst they were eminently capable, the majority were constrained by their limited life experience and consequent difficulty making decisions. Of course this means that true reciprocity was not achieved between the researcher and the researched but the disabled people did find the interviews illuminating:

> It has been good for me, taking part, because I have never been

asked these questions before. It really made me think (Robert).

The Strengths of Emancipatory Research

The research concentrated solely on the views of young physically disabled people in order to redress the balance. Research in the field had been dominated by the professionals (service providers) definitions of disability. In this sense the current study is deliberately subjective.

A number of the young adults interviewed stated that they would not have participated in the study had I not been a physically disabled researcher. One individual commented:

> "I couldn't remember whether you were physically disabled or not. I was really relieved to see that you are because I would not have let you interview me otherwise" (Lisa).

The snowball sampling method utilised had a number of advantages. It proved to be extremely productive as it resulted in the location of thirty six people from a variety of backgrounds all of whom were enthusiastic participants. It also enabled contact with individuals who were not regularly in touch with services or voluntary organisations and had 'fallen through the net'. People were volunteering right up to the end of the data collection period and regrettably I had

to turn five away as there was not sufficient time to interview them.

The success of this method is attributable to the fact that potential volunteers were assured before I had contact with them that I was physically disabled myself and 'one of them' that the interview format was informal and as far removed from an assessment as physically possible and most importantly enjoyable. Snowball sampling overcame the problems of research fatigue, illiteracy and lack of confidence in that the ice was broken before I contacted the individuals directly. There was no other way that I could have accessed the young physically disabled adults. In the interests of validity I did ask interviewees not to divulge the interview questions to potential participants and this request seems to have been was adhered to.

The key to the success of the snowball sample was the interview method. As outlined above the interviews were in depth and semi structured. They were tape recorded and lasted for approximately ninety minutes and yielded extensive and rich data about the most personal aspects of people's lives. With two exceptions interviews were carried out on a one to one basis.

The findings from each group of interviews were used to develop the subsequent group's interview schedule in an attempt to reflect the concerns and priorities of the interviewees as closely as possible. This strategy proved to be extremely successful in that the interviewees identified increasingly strongly with the

interview questions as the study progressed.

In order to reduce interviewer bias, and congruent with the open - ended and reflexive methodology, the questions were formulated using data collected from the previous group's interviews. This ensured that the interviewees concerns were being voiced as far as is possible, and not those of the researcher. The questionnaire was structured with a positive and a negative quote for each area and the interviewee was asked which quote was closest to their experience and why. If neither quote reflected their experience they were encouraged to say why and to relate what happened to them. In order to further reduce bias and to prevent the development of a response pattern the questions were structured so that where a question started with a negative quote followed by a positive one, the subsequent question would begin with a positive quote and so on throughout the questionnaire. Individuals were always asked the same questions in the same order with no omissions. An example of a question is given below:

> 'Lots of people meet socially or through work and I don't have the chance to do that. I don't go to nightclubs so its very hard to meet anyone. Also, you have to be confident about yourself...that you are attractive to other people and valuable as a disabled person.'

> 'I have had several relationships with people with disabilities and non disabled people. I have no problem at all.'

Which is closest to your experience and why?

This question covered some highly personal and difficult issues yet not one interviewee refused to answer it. Although many admitted in the 'de-briefing' session at the end of the interview that they had found it the hardest to answer. They talked about how they felt about their appearance and being physically disabled and the factors which helped or hindered them in terms of establishing personal relationships. As a physically disabled woman I was fully aware of just how difficult these issues were for people.

During the course of the interviews, in line with the ideals of emancipatory research, the relationship between the interviewees and myself as interviewer was reciprocal on a number of levels. Firstly I was asked numerous questions, some of a deeply personal nature and I was very conscious of the fact that to answer these questions could bias what the interviewee said to me subsequently, and also that it would significantly lengthen the time taken to complete the interview and as three interviews were scheduled per day with people in a variety of locations, this was an important consideration. Time was an issue with the young adults interviewed at Day Centres in that many relied on 'ambulances' to take them home and had to be ready by a specific time.

However, I was very conscious that I was asking them to divulge the most personal aspects of their lives whilst I was in the safe haven of the researcher's

role and they were learning nothing about me. It seemed a very unequal exchange. Also, some of the individuals lacked assertiveness skills and which made approaching people for information quite daunting and I took it as a sign of their acceptance that they felt able to ask me. As Oakley (1993) commented:

> The mythology of 'hygienic' research with its accompanying mystification of the researcher and the researched as objective instruments of data production [must] be replaced by the recognition that personal involvement is more than dangerous bias - it is the condition under which people come to know each other and admit others into their lives (Oakley, 1993:242)

My approach to interviewee's questions echoed that of Oakley but with a compromise. When I was asked questions during the course of the interview itself I explained to the interviewees that if I stopped to answer their questions we wouldn't be able to complete the questionnaire but that I would be happy to answer their questions after the interview had finished. This is a similar approach to the one taken by Hobson in her research on the social isolation experienced by housewives (Hobson, cited in Oakley, 1993:239). Where the requests concerned access to specific services or pieces of equipment I had a selection of leaflets which I gave to people or I advised them to contact their GP, social worker or the Young Adult Community Health Team or a local Women's Aid organisation for further assistance. These discussions always took place after the interview had

been concluded. Where the questions concerned my experiences of disability I always answered them fully with the proviso that I was speaking from personal opinion. Where questions concerned interviewees' treatment I always stated that I wasn't qualified to comment and suggested they contact their GP or health visitor. With regard to the individual who asked me to look at her oven I felt obliged to comply with her request although I made it very clear that really I was not qualified to comment and could only give my personal view and I advised her to contact her social worker. I was asked by one individual who was setting up a social group for young physically disabled adults in the locality if I would distribute flyers advertising the groups events on my travels. This I agreed to do after consultation with my supervisors. These were given to interviewees after the conclusion of their interview. In return the group leader enlisted six participants for my study.

With regard to *volunteering* information about myself, I did not find this productive for the reasons that the young adults were only too happy to have somebody to talk to about their problems and have the benefit of a listening ear as many were socially isolated, they viewed any contribution by me as an intrusion which interrupted their flow. This echoes the experiences of Ribbens (1989). The second reason was that the questionnaire proved to be an excellent 'trigger' so intervention apart from controlling the focus of the interview was unnecessary and unwanted.

In terms of the third level of reciprocity achieved by Oakley (1993); my experiences with the young adults were different in that I only interviewed them once although I did maintain contact with some of them through the snowballing process. They all had my telephone number. One individual contacted me about neighbour problems and I interviewed her about these subsequently. I cannot say that any long term friendships have developed although I have received invitations to various meetings as a result of the interviews. This absolved me from the thorny question of friendships and confidentiality (Wise, 1987; cited in Ribbens, 1989).

The degree of reciprocity fundamental to emancipatory research does pose a number of ethical problems as the relationship between the researcher and the researched has to be so close. This is further compounded when both parties belong to the same minority group be it a feminist interviewing women or a disabled person interviewing disabled people. In such a situation there may be many similarities between the life experiences of both parties and a hygienic interview approach seemed acutely inappropriate and inadequate for understanding the reality of disability in terms of the subjective situation of disabled people. Whilst there are disadvantages in terms of potential bias, with regard to the minority group being studied, these were far outweighed by the advantages of a non - hierarchical approach.

As mentioned above the young adults were already extremely wary of researchers

due to previous experience and many lacked self - confidence and found the prospect of being interviewed extremely daunting even by a disabled person. One interviewee commented:

> I have been dreading this interview. I have lain awake for the last two nights worrying. It hasn't been nearly as bad as I thought. I've enjoyed it.

It is possible that no other method would have yielded such rich and vivid data with regard to this group. It paints a picture of their lives in terms of the difficulties disabled people face as a result of the attitudes of society in general whilst, at the same time articulating the personal aspects of disability. The interviewers role is one of "a data collecting instrument for those whose lives are being researched" (Oakley, 1993:295).

The fact that this type of interview does not deny the subjective situation of a minority group has a particular salience in the disability field where a powerful critique of the individual model of disability has been gathering pace (Oliver, 1987a, 1990b, 1992c). Whilst there is merit in the argument that what appears to be an individual experience of disability is in fact socially constructed Morris (1992) makes the important point that:

> In our attempts to challenge the medical and personal tragedy models of disability, we have sometimes tended to deny the personal experience of disability....It is not inherently distressing to be black it may be to suffer from painful arthritis (Morris, 1993:164).

The methodology employed enabled young adults' experience of transition to be explored from the standpoint of the social model of disability whilst at the same time not denying the individual, personal experience of disability as in reality the two are not mutually exclusive. At the same time there is a move away from the methodological individualism characteristic of previous quantitative, and some qualitative studies (Oliver, 1987). This occurs both on epistemological and technical levels. The emphasis given to the social model ensures that social reality is not reified and the snowball sampling method meant that the individuals were in contact, providing an indication of the relations among individuals and the extent of social networks (Coleman, 1958). The use of a focus group reinforced this. Also there was an occasion where individuals were interviewed together. The one to one format of the interviews reflected the participants' choice not the inflexibility of the research design.

Reciprocity was achieved on a number of levels. Initially two groups of disabled people were consulted regarding the research design. The methodology employed was open ended and reflexive and allowed the young adults to influence the interview schedule used, resulting in a closer understanding of the perception of

the disabled people themselves. In the interview situation they were able to ask questions of the researcher which were answered as fully as possible either verbally or in the form of leaflets so there was a two way exchange of information and mutual benefit.

They were not involved in data transcription or analysis, simply due to the time and resource constraints of the project. A number of the interviewees did offer to help with transcription. There were difficulties in that the assurances given to participants regarding the anonymity and confidentiality of the data would not have been honoured. Also, it would not have been possible to offer payment for such work.

The methodology and framework of investigation has the potential to empower the participants as it offers the means whereby the social relations of research production can be examined and acknowledged; and the empathetic understanding essential for this approach engendered positive feelings amongst the majority of the participants i.e. that their experience is of value and being used to help others in the same situation. The research process itself can be seen as positive and empowering (Munn - Giddings, 1993).

The young adults were very positive about the interview schedule and were extremely helpful both in terms of suggesting amendments and providing me with further participants. The only reservations expressed regarded the section

on personal relationships:

> I felt uncomfortable when you asked me about my personal life. Its been fantastic though (Sophie).

> I found the questions very liberating. The other student used tick boxes and I felt like I was being assessed and we are assessed enough. I don't think we should be assessing each other (Vera).

Rationale For the Study

The transition of young physically disabled adults from special needs education to living in the community was of interest for a number of reasons: because young physically disabled adults have been neglected in the literature and the experiences of this group during transition particularly so; the work that has been done has been conducted from the standpoint of professionals working in the disability field, utilising the individual model of disability, and has focussed on medical and service provision issues; the growing criticism of the work carried out from both the positivist and interpretative research paradigms, the call for the use of emancipatory research, and the lack of such research in the disability field. There has been no emancipatory research on the transition to independent living, and as a physically disabled person the issues around transition to independent living were of personal concern.

The Study

The focus of the research was to ascertain the experiences, expectations and priorities of young adults with profound physical disabilities who had recently undergone transition from special needs education to independent living in the community. Why in the young adult's eyes were they living or not living independently? Could this be explored using emancipatory research?

Methods

The research methods utilised aimed to get as close to the ideal of emancipatory research as possible while attaining appropriate standards as a thesis which needs to be acceptable within an academic community. Qualitative research was used with semi structured interviews. Each interview lasted approximately ninety minutes. Two organisations of disabled people were consulted regarding research design prior to commencing the study. The priority was to consult disabled people at all stages of the research. The open ended and reflexive methodology encouraged a process of continual refinement, which it was hoped would approach an understanding of the perceptions of disabled people themselves.

In accordance with the ideals of emancipatory research, in an attempt to move away from methodological individualism, all references to individual impairment

and resultant disability are based on respondent's own interpretation. Official estimations have not been utilised in this study.

Fifty young adults aged 17 - 31 years with profound congenital impairments were interviewed; 42 of the interviews were usable. All had severe mobility disabilities, while none were severely visually or hearing impaired. It proved impossible to avoid assessment of physical impairment in the selection of the sample. However, this was done indirectly and in a way that intended to avoid alienating the young people. This was achieved via a definition based on the need for personal assistance rather than levels of physical function. The criteria used was that all needed a high level of assistance in their daily lives in the community. People with multiple impairments were not excluded providing that their degree of learning difficulty did not prevent them understanding the interview situation. Two of the sample had severe speech difficulties and communicated via the use of a touch talker. Most of the individuals had been resident in the East Midlands all their lives. Eight had spent their childhood in other parts of the country but were attending a Further Education College. The sample ranged from young adults who were living in the parental home, and those actually in the process of moving to independent living, to individuals who were living in their own homes in the community.

Setting up the study proved to be extremely difficult and it became obvious that a systematic sample was not going to be possible so snowball sampling was

utilised. Initially a number of avenues were explored in the hope of setting up a systematic sample but this proved unsuccessful.

Two Social Services Departments (A and B), were approached with the intention of accessing a systematic sample of 25 physically disabled young adults from each department's register aged between 17 - 25 years, who needed a high level of personal assistance in their daily lives, but who did not have severe learning difficulties. Despite a number of meetings with Social Services Department A, it proved impossible to locate any young adults. The department indicated that it would be willing to send out initial letters outlining the study, with consent forms, on my behalf to any young adults that they located in their registers. They were supplied with 25 letters, the draft of which they had approved in December 1995. Unfortunately repeated phone calls to ascertain whether the letters had been received and sent out, failed to elicit any response and there was no further contact with them. Attempts to directly elicit the co - operation of Social Services Department B failed. Eight introductory letters were handed to one of their Disabled and Young Peoples' Disability Information Register Administrators at a conference. As a result of this, letters were forwarded by Social Services Department B to all the Disabled Persons Act Workers dealing with individuals with physical disabilities in the area. They were extremely helpful and offered to forward the letter to agencies dealing with young adults with visual and hearing impairment as well, but these individuals were beyond the scope of the study. The letters forwarded by department B resulted in the

location of two individuals in total who subsequently participated in the study. A Further Education Training College for Physically Disabled People with a national catchment area was approached. A briefing meeting was held with a Senior Occupational Therapist who selected and approached ten individuals from the past and current student registers who agreed to participate. The Independent Living Fund was contacted, a meeting was arranged and they sent out 15 letters to individuals on their registers. This resulted in three individuals agreeing to take part. One subsequently participated in the study. One was moving away from the area the following week, and the other could not be contacted to arrange an interview time. The organisation Arthritis Care was contacted, and the section of the organisation dealing with young adults with arthritis was extremely supportive and agreed to send out 15 letters to young adults on their registers resident in the East Midlands. This resulted in one response. The individual concerned subsequently participated in the study and her help in terms of further contacts was invaluable.

Thirty six individuals were located from a variety of sources. Local organisations of disabled people were approached. Briefing meetings were held at a Centre for Integrated Living and a Coalition of Disabled People. Both organisations were extremely supportive of the project and provided valuable advice. These meetings resulted in contact with two further individuals. An article and an invitation to participate was placed in the Coalition's monthly news publication 'Info Exchange'. Unfortunately this failed to elicit any response. A local PHAB

(Physically Handicapped and Able - Bodied) group was contacted and following a meeting with the group leader and members, a number of individuals were approached independently of the researcher and seven subsequently participated in the study. Three Day Centres for Physically Disabled Adults also co - operated with the study. One centre manager was already aware of the research due to contact with the PHAB group, all were initially approached and briefed by the researcher, and introductory meetings arranged with centre members. These approaches yielded a further eighteen participants. A further nine individuals were contacted via 'word of mouth'.

Location of the sample had illustrated a number of problems specific to the study of young physically disabled adults. The first problem encountered concerned the difficulty in obtaining a systematic sample. The Social Services Departments contacted admitted that their records with regard to this group were incomplete, and that a number of individuals 'fell through the net' during the transition from childrens' to adult service provision (the reasons for this are explored in chapters six and eight). Also, due to concerns about confidentiality, I was not allowed direct access to the registers so the young adults had to be contacted indirectly via a letter sent out by Social Services staff which was unsatisfactory as it only resulted in four participants. Other researchers conducting work on this group have encountered similar difficulties (Anderson, 1982; Bax, 1989). The low response rate to my letter was surprising as I clearly stated that I was physically disabled myself and that the aim of the research was to get <u>their</u> experiences and

views of transition and I had assumed that potential participants would be more willing to talk to a disabled researcher. The low response rate was attributable to a number of factors which became apparent during the course of the research as a number of the participants contacted via snowball sampling stated that they had received a copy of the letter but did not feel inclined to respond positively to it. They gave a number of reasons; that the letter looked 'too official'; it was on University headed paper, and they were afraid that it was 'another assessment'; linked to the previous point was 'research fatigue' particularly in the case of the individuals who were living independently who complained that they were always being approached for interviews. A number commented that the interview just consisted of the researcher 'ticking boxes' and they didn't feel able to get their point across, and the quantitative nature of the interview made it seem like an assessment. This had made them disinclined to participate in further research.

Other difficulties mentioned included literacy problems, rendering the letter useless. Linked to this was the fact that a significant number of the young adults living in the parental home were participating in the research covertly, some after being told by parents that they could not take part. There were difficulties where individuals relied on relatives to decipher their mail and the relative took a negative view of the study. Some of the recipients of the letter found the physical task if writing impossible or exhausting, or did not have the use of a telephone; others lacked the self confidence to participate despite positive encouragement from parents. One parent wrote to say that she had begged her daughter to

participate but to no avail. Some just did not want to become involved, and some never received or lost the letter. Age emerged as an important factor in deterring some potential participants. One individual responded who was too old for the study. This incident, and subsequent conversations with research participants revealed a problem with the sample selection criteria in that allowance had not been made for the fact that young physically disabled adults are likely to be two or three years behind their peers in terms of social and emotional maturity (Anderson and Clarke, 1982). As a result major difficulties were encountered in locating young adults within the age range 17 - 25 years who had achieved independent living. It was for these reasons that the decision was taken to utilise snowball sampling and to increase the sample age range to encompass individuals aged from 17 - 31 years.

Snowball sampling resulted in a further thirty six individuals agreeing to participate in the study. After completion of their interview, participants were asked if they knew of any individuals who would fit the sample criteria, and who might be interested in taking part. A copy of the initial letter was left with the interviewee to show to potential participants. It was always the case that initial approaches were made by friends or acquaintances of the individuals concerned and not by the researcher. If agreement to participate was obtained then the individual's telephone number was passed on to the researcher and an interview time arranged.

This sampling method was not without difficulty however. The sample obtained via this route were all resident in the East Midlands. There were problems when it was found at interview that the individual fell outside the scope of the study i.e. that their impairment was not congenital. There was also a potential validity problem in that there was a risk that individuals would discuss the format of the interview with potential participants. This was a particular risk with the interviews carried out in the three Day Centres.

Locating the sample was extremely time consuming since I was reliant on other people to contact their friends and acquaintances, and the tight time schedule of the study was not as crucial to them as it was to me. Another difficulty was that as the sample was dispersed throughout the East Midlands and the majority of the interviews took place in individual's homes. I do not drive, the use of public transport would not have been practical as it was too infrequent and inaccessible and would have limited the number of interviews manageable in a day, and the cost of using taxis was prohibitive. I am indebted to my father for driving me to and from the interviews.

Interviewing Young Physically Disabled Adults

The interview technique chosen for the study was in - depth and semi structured. At the start of each interview the purpose of the research was outlined and the format of the questions explained. Participants were told that the interview would

last for approximately ninety minutes and that all information given would be anonymous and remain confidential to the University of Nottingham. Participants were asked to choose a pseudonym. This served a dual purpose in that it involved them in the research design from the start and it also provided reassurance regarding anonymity. Interviewees were told that there were no right or wrong answers to the questions and that what I wanted was their views. They were asked if they minded the interview being tape recorded. I explained that only I would listen to the tape and that their anonymity would be guaranteed. No one objected to this. I also told them that I planned to run a focus group to discuss the preliminary findings from the research and to ascertain their views on the best way to disseminate it for the benefit of young physically disabled adults and that I would contact them at a later date with further details. Participants were then asked if they had any questions or worries about taking part in the research. Any worries were addressed and reassurance offered. The concerns voiced by a number of people were firstly that they wouldn't have anything to say (this was certainly never the case!), and that they wouldn't be able to understand the questions. They were told to say so if this was the case and the question was repeated.

The interviews aimed to obtain individuals experiences and views on their education from school to college (academic attainment, independent living training and physiotherapy were discussed), employment current living situation, leisure and personal relationships and contact with the National Health Service.

The intention was to build up a picture of the transition process to independent living. At the end of each interview they were asked if they had any comments on the questions, whether I had missed anything off, if there were any questions they found difficult to answer, and what they thought of the interview per se. This took the form of an informal chat which served a dual purpose. It allowed the interviewee some direct involvement in the research design and it also served to allow the individual to recover from any aspects of the interview which they may have found upsetting (Oppenheim, cited in Ribbens, 1979).

The interview schedule was informed by the results of previous interviews so that it increasingly reflected the priorities and concerns of the interviewees. The data from the first group interviewed led to substantial changes being made in terms of the focus of the research and the interview agenda.

The dynamics of the interview situation proved to be exceptionally difficult and hinged upon my identity as both an interviewer and a physically disabled person. During the course of the interviews I was asked numerous questions ranging from: 'What is the best way to contact a social worker/ orthopaedic surgeon?' 'How do I get a new wheelchair?' 'How do I get a more accessible oven? Will <u>you</u> have a look at it?' to; 'How do I go about getting my own flat?' 'What is wrong with <u>your</u> foot? Have you had the same operations as me?' 'Did <u>you</u> have problems with teachers?' 'Where can I go to talk about the time I was raped?'

Some of the above questions would be difficult under any circumstances but doubly so given my role as an interviewer and a disabled woman. I found the questions about my personal experiences very daunting as I was aware of the fine line between establishing rapport and 'going native'. I felt empathy towards the participants as there were some similarities between their experiences and my own. The picture painted by some of the young adults was bleak. There was one occasion when an interviewee recounted serious sexual abuse and became very distressed in the process which was traumatic for both parties.

There were instances where contact was maintained outside of the interview situation. One interviewee phoned at 11pm one evening to say that she was being intimidated by a neighbour who was an ex - psychiatric patient. Another interviewee clearly saw my role as that of a counsellor. This was an example of the tension between the elements of power and empathy which is characteristic of depth interviews in that, for the interviewer, empathy is the key that unlocks the door to the other person's world, and the research relationship is a transient one. To the interviewee, listening to such an extent is associated with long - term caring relationships (Ribbens, 1989). This was a particular problem with the young physically disabled adults whose life experience was limited to segregated provision in terms of school, college and finally a Day Centre and who, by definition, had limited social contact. It could be argued that expectations were being created that were not compatible with the research relationship.

The degree to which reciprocity can be attained in an interview situation has been questioned by critics of emancipatory research. Whilst the young adults 'placed' me as a disabled person, and the disabled women interviewed identified most strongly with me, there were differences between my life experiences and theirs just by virtue of the fact that I was there interviewing them for a Ph.D thesis and that the work was being carried out under the auspices of the University of Nottingham. However one views it, research is a privileged activity and one is increasingly a member of a different group (Ribbens, 1989).

The degree of equality achieved in the relationship was further lessened in the case of the interviewees who attended the three Day Centres who co - operated with the study in that, because they were aware of the public support of the management for the work, my status as a 'person in authority' was further increased.

Critics of emancipatory research argue that the relationship between the interviewer and the interviewee will always remain one sided due to the fact that by its very nature an in - depth interview will have encouraged the interviewee to talk about very personal issues. Yet, at the end of the day the interviewer departs with the data which is then objectified into an interview transcript.

The study highlighted issues of power and manipulation when interviewing vulnerable research subjects. These concerns have been echoed by feminists with

regard to interviewing housewives as such women have little contact with the public domain and therefore are unlikely to be in a position to anticipate the outcome of any research (Ribbens, 1989). The young physically disabled adults who had spent their lives in one form of segregated provision or another and had no experience of the 'outside world' epitomized vulnerability in the sense that, because they were powerless in society generally, and lacked assertiveness skills and relevant research training they found the prospect of power over the research process daunting.

Ethical Considerations

The fact that I was interviewing a vulnerable group of people raised a number of ethical concerns which had implications for my role as a researcher. Specifically these were the possibility of distress being caused to the young adults as a result of their participation in the research, and what to do in the case of revelations which indicated that an individual was at risk. I also had to consider how to feed the results back from my research.

I was acutely aware that I was asking people about the most personal aspects of their lives which could cause distress. I felt that the use of a snowball sample was an advantage in this respect as it meant that the subject of participation in the study was broached by friends of the young people which helped to 'break the ice' and also gave people the opportunity to refuse to take part without direct

contact with the researcher. I also made a point of meeting all participants to introduce myself and explain the nature of the project prior to interview dates being arranged. I made it clear that people did not have to take part and were free to leave the project at any time. On the day of interview I again explained the nature of the project and asked them if they had any worries about it before the interview commenced. If this was the case these were addressed.

The issue of interviewee distress posed a dilemma for me in the role of researcher. I had to balance up the need for research on a group of people who had 'fallen through the net' and had little opportunity the have their voice heard, with the prospect of casing distress to some participants. I had decided that if people became upset I would stop the interview and ask them if they wished to continue. All participants were to be 'de-briefed' on completion and were asked for their comments on the questions and interview technique.

As a researcher, I found distress on the part of interviewees very traumatic particularly where serious sexual abuse was revealed. I will never forget that particular interview as it highlighted a dilemma faced by all social researchers who work with vulnerable people. On the one hand I was a researcher and had to adhere to that role in terms of the level of involvement that I had with interviewees but, at the same time I was aware of my role as a disabled woman and on that level I emphasised with the individual. I also felt degree of responsibility and wanted to be of some practical help particularly in cases of

physical and sexual abuse.

A further dilemma was posed as the young people had agreed to take part in the study on the understanding that their comments would be anonymous and confidential to the University of Nottingham. I knew that if this agreement was broken by the researcher divulging information to an outside agency, further help from participants in terms of locating additional participants for the study would cease. In cases of risk individuals were given the name and telephone number of agencies that could help so that they had access to practical and emotional support without the researcher having to break any confidences as I was not qualified to approach agencies on the young people's behalf.

I was also aware of my personal safety as a disabled woman. This was a serious issue as the majority of the interviews were carried out in individuals' homes due to mobility problems and/or a lack of accessible transport. Whilst the young adults were profoundly disabled, in most cases their partners/ personal assistants were not. In one instance I had to leave an interview situation quickly. The disabled woman had reported serious physical abuse by her partner. The partner returned home and strongly objected to the interview with the result that I felt compelled to leave. Most of the young adults lived in deprived areas and a number reported harassment from neighbours who were ex-psychiatric patients, and drug dealers. I felt at risk walking through estates to reach individuals' homes.

The problem was solved by the presence of my father who drove me to all the interviews. He remained outside in the car but timed the interviews meticulously. If I ran markedly over time he would knock on the door to check that everything was alright. I could not have done the research without him.

I was acutely conscious of the limitations to any help which I could offer the young people and the extent to which the exchange was an unequal one. I was only with them for a limited period of time during which, they had talked about the most personal aspects of their lives. I would very much have liked to have improved their daily lives but this was impossible. Many people said that having a 'listening ear' had helped, but from my standpoint this was small consolation. The best that I can do is to get the major issues highlighted by the project on to the Government policy agenda. The work will be made available to participants, groups of disabled people and government bodies. The aim is also to publish in academic journals.

With regard to the current study, as far as possible, theory emerged from the field work process and was refined and tested, reaching greater levels of abstraction. A thematic framework was developed which led to the formulation of categories and the associations between them were identified and an explanation given in the context of the transition of yong physically disabled adults from full - time education to independent living. The starting point for analysis was the question What enables young physically disabled adults to make the transition to

independent living? The data was analysed using the QUALPRO code and retrieve computer programme.

Conclusion

In conclusion disability research conducted from within the quantitative tradition has furthered understanding of the difficulties faced by young physically disabled adults on one level. Its focus on the individual model of disability has served to emphasise the personal costs of physical impairment. However this cannot be viewed in isolation as society plays an important role in restricting the lives of these young people. There have been calls for the epistemological assumptions underpinning disability research to change with a move away from the methodological individualism characteristic of previous research towards a non hierarchical, emancipatory approach based on the social model of disability. This is particularly important with regard to young physically disabled adults who had been subjected to a large amount of quantitative research which has examined service provision and health needs, while their perceptions experiences and priorities regarding transition to independent living have been ignored. The use of emancipatory research methods with their emphasis on reciprocity may have provided the only means of access to this group.

Whilst the study is subjective both in terms of its focus on the young adults views only and the fact that the researcher is disabled; it is this subjectivity which

has yielded rich and vivid data on individuals' experiences and views and why individuals achieve independent living, whilst at the same time placing the process in the wider social context. Although the interviews were very different from those characterized in methodology textbooks, the critical criterion was the appropriateness of the method employed for the issue being studied.

Subsequent chapters in the thesis will draw on research data gathered from interviews with forty two profoundly physically disabled young people. The issues explored in the chapters directly reflect the concerns voiced by the respondents during the course of the interviews and represents a unique opportunity to view transition through the eyes of the major players in the process i.e. the young disabled people themselves.

Chapter two outlined the extreme difficulties faced by young people trying to make the transition from the parental home to independent living. For young adults with profound physical disabilities the hurdles to be overcome are even greater. The remainder of this thesis will identify those hurdles and offer an explanation for their existence

The chapters will attempt to fill gaps in the current literature on transition which have been outlined above. They will present a holistic picture of the transition process which has been attained via the use of a life course perspective and they will explore how transition is experienced by young people and their families.

The life course perspective is useful in this context because it allows an examination of the biographies of the individuals in the sample. It involves situating them within two strings of events; one belonging to the young person and the other belonging to wider society which interact to form a life history (Cohen, 1986; cited in Biehal & Clayden et al, 1986:106). The lives of the sample are viewed as an integrated whole which allows an appreciation of the structuring effects of social institutions and the way in which individuals negotiate a path through those institutions (Jones & Wallace, 1992).

CHAPTER FOUR

YOUNG DISABLED PEOPLE

This chapter has three functions: it will give a descriptive account of the sociological and psychological well - being of the respondents, it will introduce the independence measure used throughout the thesis and the individual action/ social context explanations of respondents' lives will be discussed.

From Dependence to Independence

The concept of independence is difficult to define in the context of human relationships and transition as, on one level, it can be argued that very few individuals would wish to live a totally independent life since it would necessitate complete social isolation. This is not the norm for most young people (Biehal and Clayden et al, 1995). On another level, very few people achieve independence because even the act of moving out of the parental home may not constitute a move away from parental authority and to independence. Research has shown that those young people who leave home for non - marriage reasons were more likely to return home again (Young, 1984; cited in Jones, 1985:25). As a result of such work the relationship between leaving home and adult independence has been questioned. There are a number of reasons for this. First, young people do not always become independent householders when they leave home. They may move to intermediate accommodation such as a University hall of residence, residential college etc. Second, they may not leave from choice but due to constraint. This is often seen when there has been family breakdown and reconstitution. Increasing numbers of young people are living with a lone parent

or step parent; a situation which gives much scope for family conflict (Jones, 1995). It is estimated that 1 in every 65 children was affected by divorce in England and Wales in 1995, which was twice as many children as in 1971. (Social Trends 1998:41). Third, young people may not make a clean break with the home of origin and may return if things do not work out. (Jones and Wallace, 1992). Also, parents and the extended family may continue to play an important role in supporting the young person even though he or she may live in separate accommodation (Biehal and Clayden et al 1995). Their role may be of central importance if the individual is reliant on benefits for the reasons outlined in chapter two.

Conversely, it is possible for young people to live in the parental home and have a very independent lifestyle particularly if they are fortunate enough to be in full employment. However, as outlined in the previous chapter, in recent years it has become increasingly difficult for young people to find employment and this is particularly true of the sixteen to twenty four age group, for whom unemployment is the highest of all the age groups. In 1996 15 percent were unemployed (Social Trends, 1998:88). The wages earned may open up the possibility of paying a realistic board rate to parents for example. In the UK it is the norm for children living in their parent's homes to pay board money, with young people paying a fixed amount for board but retaining control over the money they earn. (Jones and Wallace, 1992). For individuals fortunate enough to be in a well paid job they will have the financial means to run a car or use

public transport or taxis and enjoy an active social life if they so wish. Individuals in this situation are able to exercise a great deal of control over their lives.

As illustrated by the previous discussion, leaving home does not necessarily guarantee independence just as remaining in the parental home does not mean that the young person will inevitably be dependent. Leaving home is not a reliable indicator of independence when taken in isolation. It needs to be considered alongside the developmental tasks and stages of transition outlined in chapter two. It is for this reason that the experiences of young profoundly physically disabled people who took part in this study are viewed from a life course perspective. The respondents were asked about their lives in detail in order to build up an holistic picture. This and subsequent chapters will examine disabled young adults, their families; their education, employment, benefits and support from social services departments. The experiences of disabled individuals will now be explored.

It was necessary to assess the individuals in the sample in order to distinguish those who led the most independent lives and in an attempt to explore the differences between groups. Individuals were classified as either independent, intermediate, or dependent on the degree to which they scored positively on each of the criteria outlined below. A positive response merited 1 point whilst a negative one resulted in 0. Each individual could score up to a maximum of 8

points. Those who scored 5 - 8 were considered to be independent, 2 - 4 intermediate, and those who scored 0 - 1 were dependent.

The extent to which the research sample led independent lives was assessed on the basis of eight criteria:

These were living accommodation i.e. whether they were living with their parents or in independent accommodation, the degree of financial control they exercised over their personal assistance and their lives, and the extent to which they were able to control their personal assistance. The availability of accessible, affordable transport was also included as an indication of the degree of personal control as it was mentioned by the research sample as being a central determinant of the amount of control and freedom they were able to enjoy in their daily lives. The importance of transport to the quality of disabled people's lives was illustrated by a survey which found that four out of five of the people interviewed had problems with transport, and two thirds said that difficulty using public transport was the reason for not going out more and travelling further afield (Barnes, 1991; cited in Gooding, 1996:4). Lack of transport can lead to social isolation and feelings of failure to match up to peer group norms and thus lower self - esteem (Hirst and Baldwin, 1994). Lifestyle was considered from the standpoint of the degree of social activity and its range in terms of whether social networks were narrow and did not extend beyond occupation or daily activity. Social life has an important role to play in terms of self - esteem as a dearth of

social contact can lower self - esteem, which can undermine an individual's ability to develop close, fulfilling relationships. Whether individuals were in a relationship was a criterion as it was frequently mentioned by the sample and also because girlfriends and boyfriends confer status, valued heterosexual identity, and the promise of a lifestyle that approximates some norm (Hirst and Baldwin, 1994). Educational qualifications gained at age sixteen are a key predictor of future career routes in that they influence the likelihood of avoiding unemployment and also, if continuing in education or training, the kinds of courses and schemes that young people can join (Biehal and Clayden et al, 1995). Occupation or daily activity is also an important determinant of the degree of autonomy that an individual is able to enjoy and thus self - esteem, as the perception of feeling valued, acceptable and useful is dependent on the ability to participate fully in society, and employment provides status and identity (Hirst and Baldwin, 1994).

DISABLED INDIVIDUALS

The issues outlined in this chapter reflect those highlighted by the young disabled people during the course of the interviews. They are expectations, fearfulness, social interaction, politicisation, self-esteem and self-confidence.

Expectations

The extent of and focus of the young people's expectations were explored to find out whether they were high or low and what their hopes for the future were. The young people talked about their expectations in terms of educational attainment, future career and living accommodation. These will be outlined below.

Educational Attainment

During the course of listing their educational qualifications all the respondents gave an indication of whether or not they felt that the levels obtained were a true representation of their ability. There were two types of comment; those who were happy with the way that they had performed at school and those who thought that they could have achieved substantially more. The relationship between educational expectations and attainment will be explored in chapter six.

A minority of the sample were satisfied with their educational performance. For eleven people their achievements were in line with their expectations and one had done better than he had expected.

One individual who had done better than he expected admitted that he had not realised the importance of qualifications whilst he was at school: Robert said:

> I eventually got eight GCSE's, the highest being a grade D. But I took the opinion that at least I had passed them. I feel I could have done better had I known then what I know now because at sixteen you haven't got the same attitude that you have aged twenty four or twenty five. I did my eighth GCSE when I was twenty three and it was completely different. I put the work in. At school I thought I would get away with doing a bit of work. I wanted to pass but I wasn't motivated.

The majority of the sample had high expectations in terms of their own ability to attain GCSE's. Thirty people felt that they were capable of sitting an examination, and many strongly voiced their feelings to teachers. This area was a source of considerable frustration. Some individuals were successful in getting their voice heard. Lisa's comments were typical:

> ....The main people in my life were the doctors, occupational therapist and physiotherapist. They had a firm belief that special education was very good because I would get the physio. I had to be very strong and it was quite a fight to have my wish to go to either the Grammar or Private school recognised. It was a real fight. I won.

Other people were less successful than Lisa and their attempts to speak out were unwelcome. Ian said:

> ..I did maths and English. It wasn't very clever in the sense that it didn't stretch me. I didn't do exams. There were a lot of head injuries there and the school gradually got worse and worse and I was stuck there. I know I could have done a lot, lot better. It was incredibly frustrating because there wasn't a lot I could do about it. As soon as I spoke out I was told I shouldn't do that.

Many respondents could not understand why, when they expressed a desire to sit an examination, the staff were unwilling to let them try. Dorothy's comments echoed those of a number of people. She said:

> Basically, I told my maths teacher that I wanted to try a maths exam. She just told me to my face that I wasn't good enough. I don't know why she wouldn't let me try...at least I would have tried. I think I could have done it. They did exams at my school. I also asked if I could do a cookery exam but I got the same response. I felt inadequate and let down because if they didn't think I was good enough then it was their fault because they weren't teaching me properly.

Kevin also felt very strongly that individuals should have the right to sit examinations if they so wish and are prepared to do the work:

> ...I didn't think I was getting the best education in the world. I didn't do

> any exams at school because they didn't do them basically. I felt I could have done exams if I had got the right education. You should be able to do exams whatever school you go to really. You should have the right to go for exams whether it is an ordinary or special school.

Out of the thirty individuals who felt that they were capable of sitting and passing examinations, eight were allowed to do so and gained passes. The remaining twenty two were not entered for examinations whilst at school although some went on and gained GCSE's and A - Levels at further education college. Angela who was nineteen was typical of this group:

> ...I had an assessment which showed I'm dyslexic and the school didn't help at all. The just sat me in a corner and wouldn't let me do any exams. They just didn't want to know. I am at college now where I am doing GCSE's in English and Maths. I take my exams tomorrow. I used to get so frustrated at school. I enjoy the work at college. They said I couldn't do anything at school but I knew I was capable. I could have done a lot better.

The majority of the sample had, during their school years, high expectations with regard to their own ability and many had expressed a willingness to sit some examinations. On leaving school the majority had never been entered for any examinations and many were lacking basic literacy and numeracy skills and this was a source of considerable distress and embarrassment to them, and further

hampered an uncertain future.

It is acknowledged that these accounts of disabled people's expectations with regard to educational attainment are subjective in that they are based on the individual's judgements only. It was beyond the scope of the study to obtain the opinions of teachers, and the use of formal intelligence testing was inappropriate for the methodology as the aim of the research was to obtain disabled people's experiences and perceptions of transition. Many indicated very strongly at the start of the interview that they would not be prepared to co-operate with a formal assessment. However, the interviews were rigorous and respondents had to answer complex questions which necessitated the assimilation of opposing quotes and the ability to compare their own experience with them. One individual was unable to do so due to severe problems with short term memory, and it was unfortunately not possible to include him in the study. The questions would have been difficult for anyone. The majority of the sample answered the interview questions in an articulate manner as the quotes demonstrate, which suggests no serious level of learning disability.

It is also possible that a number of the sample may have had unrealistic expectations with regard to their own ability. It is extremely difficult to judge given that the majority received a poor standard of education. There was no relation between the level of disability and the level of expectation in this study and a number of the most profoundly physically disabled individuals achieved

examination passes.

Future Career

The sample were asked to describe their career expectations during their final years at school. These were as follows:

Table 4.1 Career Expectations	
Expectation	*Number (n = 42)*
Work with Children	8
Further/Higher Education	6
Voluntary Work	7
Clerical Work	13
Day Centre	5
Don't Know	2
Nursing	1

As with educational attainment, the majority of the sample, had high career expectations. They intended to go on to higher or further education in order to gain academic or vocational qualifications, or to work in a nursery or an office and one wanted to enter nursing.

A minority of the sample had low expectations in terms of a future career. They either saw themselves as doing voluntary work, attending a day centre, or had no idea what they wanted to do on leaving school. The least surprising were the two

individuals who stated that they had no idea what they wanted to do when they left school for it is not uncommon for young non-disabled people to lack direction at this stage of their lives, due to the growth in further education and training opportunities and the contraction of the youth labour market (Coles, 1995). It is also the case that many school leavers do not reach a decision on future careers until they have completed further or higher education. One of the sample had completed a degree and had been unable to reach a career decision. Twelve of the sample of forty two had mentally ruled themselves out of the labour market whilst they were still at school by opting to go to a day centre or undertake voluntary work. The reasons behind these decisions will be explored later in the thesis.

To What Extent had their Expectations Been Fulfilled?

A brief overview will be given of the career destinations of the sample at the time of interview. The reasons behind the various destinations will be discussed in depth in subsequent chapters of this thesis.

A minority of the sample had managed to fulfil or were in the process of fulfilling their career expectations. Out of forty two people nineteen were in this category. Out of those nineteen people two had gone on to higher education and obtained degrees although both were moonlighting whilst on benefits. One person was employed full time in a clerical post, and two others were employed

part - time carrying out administrative duties. Three were in further education and were working for A - levels, and three were studying for GCSEs.

Table 4.2 Career Destination	
Destination	*Number (n = 42)*
Full Employment	1
Part Time Employment	2
Moonlighting on Benefits	2
Voluntary Work	4
Mainstream F.E.	7
Segregated F.E.	6
Day Centre	17
At Home Only	3

The majority of the sample had not fulfilled their expectations at the time of interview. The majority of this group were attending a day centre. The remainder were either engaged in life skills courses at college, a small amount of voluntary work or were at home during the day.

The data was based on interviews with disabled young people only and it could be argued that their career expectations were unrealistic given the severity of their impairments as some were quadriplegic with severe communication difficulties. For example, an individual with very limited use of her limbs and communication difficulties said that she had always wanted to become a nurse. However, all were able to participate fully in the interview situation as the use

of a computerised touch talker removed any communication difficulties. With the advent of such technology there is little reason why individuals with speech impairment and mobility impairment should not be able to gain employment. In theory, the advent of the 1995 Disability Discrimination Act has made it illegal to discriminate on the basis of disability (Gooding, 1996). Unfortunately, the legislation came after the completion of data collection. The effectiveness of disability employment legislation to date will be discussed later in the thesis.

The young adults generally had high expectations with regard to their ability to sit and pass examinations and the majority also expected to have some sort of career when they left school. Unfortunately, for the majority, their expectations remained unfulfilled in that many not only lacked qualifications but basic literacy and numeracy skills and were unemployed. The reasons behind this will be explored in chapters six, seven and eight.

The over - estimation of individual abilities was the exception rather than the rule. The majority of the sample were extremely realistic about their career prospects. For example the five who said that they expected to go to a day centre said that they felt that they were 'too disabled to work and wouldn't be able to cope'. The tendency was for individuals to under-estimate their own employability given that all were articulate and that the technology exists to overcome the severest communication difficulties. There is no reason why mobility difficulties should exclude individuals from <u>all</u> forms of employment.

It is difficult to comment on the extent to which their assessment of their own capabilities was accurate as to do so would have necessitated a clinical examination to assess physical functioning, which was beyond the remit of the researcher, and would have alienated the research sample. It would also have introduced a misleading element into the research in that it would have placed an undue emphasis on the medical aspects of disability which would be at odds with the principles of emancipatory research.

Fearfulness

The young people's lives were further constrained by number of serious concerns which will be explored below.

Broaching the Subject of Independence

Non - disabled sons and daughters usually raise the issue of leaving home and take the initiative by moving away and this is usually a part of the developing of independence which arises in a person's late teems or early twenties (Richardson and Ritchie, 1989).

A minority of the sample had no difficulty with this and had moved to independent accommodation or were in the process of doing so.

For the majority of disabled young people in the study the process of leaving home was proving to be much more difficult. Some people were extremely concerned that if they contacted an outside agency for assistance their parents would be hurt or angry or both. They stated that this was the main reason why they had not taken the initiative and contacted their social services department. In some cases, where there had been contact, the young people instructed staff not to telephone them at their homes out of concern about parental reaction. It is important to state at this point that only the young adults perceptions of parental attitude are given in this study. There were instances where this concern extended to information leaflets handed out by the researcher at the end of each interview. Barrie was very concerned that his parents might find his leaflets on independent living:

> ...I have to be careful where I put these things [leaflets]. I can't put them in certain places because my parents will find them...If they find numbers and things that I have taken from people they will get suspicious.

Some people just could not bring themselves to broach the subject of independent living with their parent's for fear of hurting their feelings, whilst others had managed to air their views but were discouraged from pursuing them any further. Violet said:

> ...I have wanted to leave home. I think it was just before Christmas that I

> told my Dad that I was thinking of leaving home. The only reaction that I got back off him was that he would have to sell the house if I went. He didn't really explain why. My parents own their own house. He said I didn't think much of them and didn't respect them just because I wanted my own independence. I thought at the time that they would be pleased about me wanting to make a life of my own but, no. It upset me the way he said that. Since then I have not tried again.

Some of the sample showed no concern about the reactions of their parents. They hadn't got that far. The prospect of picking up a telephone or writing a letter or asking staff at their day centre or college for help was just too daunting. Others were hampered by lack of access to a telephone, speech impairment or illiteracy, or an impairment that made it physically difficult for them to write a letter and the lack of such basic skills undermined their self - confidence.

Abandonment by Family

Some of the sample stated that the main thing that had stopped them initiating a move to independent accommodation was the worry that they would never see their families again if they moved out. Sophie said:

> ..I would love to live on my own but I am scared of hurting her [mother] and myself. If I leave home they won't have nothing to do with me, that

> is what I'm afraid of. That's what I feel. I am scared of being abandoned. I daren't talk to them about anything because I know there will be obstacles.

Living Alone

Many people were also extremely concerned about the prospect of living alone for a number of reasons. They did not want to be lonely and they also worried about their ability to cope with bills, in an emergency, with cooking etc. Philip was worried about being alone:

> ...I have got my brother and parents at home, but living on my own there would be nobody around all day so I just think I would rather have somebody to talk to at the moment.

Andrew was worried about not being able to cook:

> ...The thing that worries me about living independently is cooking because I can't cook at all and I can't do much with one hand so that's why I am staying at home as long as possible.

Many people worried about what might happen in an emergency if they were living alone and this was of particular concern to the sample members with

epilepsy who worried about injuring themselves during a fit. Olivia's comments were typical:

> ...I am scared of living on my own because of my illness really. Sometimes when I have bad fits I have nasty falls and hurt myself.

Relying on Strangers for Personal Assistance

The prospect of having to rely on strangers for personal assistance was a major source of worry to many people. They did not know how to go about organising the personal assistance they would need to live independently, they worried about trusting strangers and some were embarrassed about the prospect of having a non family member carrying out personal care. All of these concerns were disincentives to further action.

The amount of social activity and the extent of social networks was an area of great concern to the young adults in the study and the importance of social interaction for individual well - being has been documented in the literature:

> ..Lack of social interaction can lower self - esteem which can in turn, limit an individual's ability to develop close, fulfilling relationships (Hirst and Baldwin, 1994).

This will be discussed below.

Social Interaction

Social participation was an issue frequently raised by the research sample. The degree social contact enjoyed by individuals was assessed on the frequency of social contact and the extent of social networks. Social contact refers to that which took place in the evening outside daily activity. The pattern of social activity was as follows:

Table 4.3 Social Interaction	
Type and Extent of Activity	*Number (n=42)*
Spontaneous lifestyle involving a wide circle of friends in a variety of contexts.	11
Goes out with disabled friends frequently.	7
Attends a PHAB Club weekly.	3
Goes out with friends from college/ Day Centre on organised visits.	5
Goes out with parents/ relatives to a limited extent.	4
Does not go out at all apart from attendance at a Day Centre or College.	11
No formal daily activity and no social interaction.	1

A minority of the sample, eleven people out of forty two, enjoyed an active social life which was spontaneous and involved a wide circle of friends both disabled and non - disabled from a wide variety of contexts. They were happy with their lives in general. Ian's comments were typical of this group:

> ...I'm quite outgoing and sporty, and do my own thing. I have no problem mixing with non - disabled people at all.

Seven people out of forty two had a moderately active social life. The difference between this group and the one above was that in general their social activity was less spontaneous. The social networks of this group were much more limited with social interaction limited to the disabled worlds only.

The majority of the sample had a very restricted lifestyle. The amount of social interaction they experienced (i.e. apart from their formal daily activity) ranged from attendance at a PHAB club once a week to no social activity at all. One individual gave cause for concern because not only was she not involved in any formal daily activity but she had no social contact either. The reasons for their lack of social activity were varied and will be explored later in the thesis.

Henrietta found her opportunities for social interaction severely limited:

> ...I'm a really shy person and I can't just jump in and start having a conversation with a person because I'm scared they will not understand me because of my speech and that they are just laughing underneath. That's why I won't make the first move...Another reason why I don't go out is because I have to be in bed by a certain time because my carers...I am supposed to be in bed by half past ten because I am always told that

> my carers need between seven and eight hours sleep. I can go out sometimes but when I do I can't have a shower because I should have been in bed.

Many had been to segregated school and on leaving school had transferred with other ex - pupils to the local day centre. They had been with the same group of people all their lives and this made social interaction with a variety of people more difficult. For a minority this was quite acceptable and they enjoyed being with their friends from school and they felt comfortable with other disabled people.

For the majority their exclusion from the non - disabled world was a source of great frustration. The feeling of isolation from the local community was voiced by residential college students and individuals who attended day centres. Marjorie said:

> ...The day centre and the PHAB club go very much hand in hand. They are both institutionalised. They are very similar. I was going to the day centre until 3.30pm and then going out in the evening to PHAB club and seeing exactly the same people that I had seen in the day time and sat with all day. And we would sit there at night talking about the same things....We couldn't meet anybody else. You feel like you are going potty.

Out of a sample of forty two people only eleven had any non - disabled friends. For the remainder of the people interviewed their leisure time was either spent in the company of other disabled people or their parents. And whilst there is nothing intrinsically wrong with this, as disabled people can offer mutual support, and leisure time spent with parents can be positive, when this is occurring in the late teens and twenties, as it was for the individuals in the study, it can signal exclusion from non - disabled society and also a lack of autonomy, and self - confidence (Hirst and Baldwin, 1994).

As outlined in chapter one, historically the approaches of professionals in the social and health care fields have been focussed around the individual model of disability (Oliver, 1990). The difficulties faced by young disabled people during their transition to adulthood and independence have been blamed on their physical impairment which it was thought limited the scope for the attainment of independent adult status. The appropriate response was thought to be that of teaching disabled young people skills to enable them to overcome these limitations. In other words, the root of the difficulty has been firmly located within the individual. The learned helplessness hypothesis was part of this approach and served to further embed difficulties as emanating from *within* individual disabled people.

The learned helplessness hypothesis states that:

> ...If people are frequently in situations over which they have no control they can learn 'helplessness' that is the expectation and belief that they can do nothing to affect or change events. People can learn that events are independent of their action and beyond their control (Overmier and Seligman, 1967 cited in Brechin and Whalmsley, 1989:109).

Health, education and social care professionals play a large role in influencing the lives of young disabled people during their formative early years, so the individual approach to disability is inevitably given much prominence. There is a possibility that the more socially isolated individual disabled people are, the less opportunity they have to internalize the alternative approach to the causes of disability advocated by the disability movement who argue that:

> ...It is not individuals' medical problems or functional limitations that determine their quality of life. Social forces and institutional structures present disabled people with social, economic and physical barriers that deny them equal opportunities and full citizenship (Oliver, 1990; cited in Hirst and Baldwin, 1994).

This approach offers a conceptual change about the nature of disability and changes the location of blame from the individual to the social context within which disabled people live. Exposure to the politicization of disability can change disabled people's perceptions of themselves and their lives. A major

factor in this process was individuals realization that they were not inadequate but that society's attitudes to disability were. These issues will be discussed below.

Politicization

Did respondents' blame themselves for their difficulties or perceive the source of their problems as lying in the attitudes of society? This information was gathered from comments made by individuals during interview and the aim was to ascertain the extent to which the social model of disability had wide currency amongst the young disabled people in the study, and where it was recognised, the route by which individuals became aware of it whether through education, media or other disabled people.

A minority of the sample demonstrated an awareness of the social model of disability. The source of their information also varied and was as follows:

Table 4.4 Source of Politicization

Source	*Number (n=15 out of 42)*
Disabled Friends	7
Day Centre Staff	3
Disability Rights Group	4
Development Course	1
Education	0

Other disabled people were the most important source of information regarding the social model of disability. This is contrary to the literature, which states that the existence of disabled friends only may be a sign of exclusion from non - disabled society (Hirst and Baldwin, 1994:77). They played several roles: they acted as role models and mentors during the transition to independence and they provided information, personal support and advice.

In three cases individuals had been influenced by day centre staff who were committed to raising disability awareness, and this influence, in two cases, had directly led to a move to independent accommodation. In another case it had led to a young person becoming actively involved in an organisation of disabled people by helping other people to achieve independent living.

Four people attended a PHAB club whose leader was very active in the disability awareness field. She had set up and was running a disability awareness group with the help of club members. The group visited schools committed to raising disability awareness. Membership of the group not only did much to educate non - disabled people about disability issues, it also had positive benefits in terms of self - confidence. Pam's comments were typical:

> Until I joined the group I used to be terrible with my confidence. Now I can't believe it. It used to be nerve -wracking in front of children but I've built my confidence up by that.

One individual had attended a personal development course which had changed her life Lisa said:

> I am very political now. I went on a Personal Development Course in November 1991. The lead up stuff was about becoming more assertive, self - confident and all that - knew that I needed that desperately, didn't really realise that it was a course that taught me about social model of disability and your own identity. That was it. It changed my life - December 14th 1991. To say 'it's not me it's the system, I can't change me'. It's the attitudes, the environmental barriers, the system and institutions. We can do something about them but we are always going to have disabled people and we either get rid of them or we create a different world. Taking that blame that I've carried around for years, was basically incredible for me.

The majority of the sample, twenty seven people out of forty two displayed no knowledge of the social model of disability and blamed their impairment for the lack of autonomy in their lives. Two people out of this group did display some signs of politicisation due to attendance at a day centre where a member of staff was enthusiastic about promoting disability awareness but they lacked the self - confidence and the support necessary to put the ideas into action. The issue of support from both family and the statutory services will be discussed fully later in this thesis.

Despite the existence of the social model of disability, it is important to remember that not every disabled person would necessarily want, or be able to cope with the lifestyle adopted by the most autonomous members of the sample. And the fact that this may be the case does not imply that they are lesser people. Some people were quite happy with their lives as they were. They were content that others were in control as they did not feel able to cope with the responsibilities that a more autonomous life would entail due to illness or pain. Disability sometimes had a personal cost.

Self - Esteem

A sense of self - esteem is an essential for meeting the challenges inherent in adult life. An individual with a sense of self - esteem feels valued, accepted and useful (Coopersmith, 1967; cited in Hirst and Baldwin, 1994:52). Individuals with high or low self - esteem demonstrate distinctive traits:

> ..Individuals with high self - esteem judge themselves to be capable, significant and effective whereas low self - esteem creates feelings of inadequacy, inferiority and being unwanted (Hirst and Baldwin, 1994:52).

An important influence on the degree of self - esteem that an individual has is their perception of the degree to which they match up to peer group norms. As outlined in the chapter two social norms have a great deal of influence on

individuals lives. Psychologists have documented the existence of a 'social clock' which is an internalized sense of the appropriate time to obtain social milestones, such as leaving school and entering employment, marriage and parenthood for example. (Neugarten, 1968). It is the case that individuals are acutely conscious of the degree to which they match up to, or fail to match these norms and failure to do so can be a source of much distress. Being 'off - time' is perceived as carrying a price:

> ...Every culture...shares some set of expectations about the 'normal' or 'expected' pattern of adult life....Any time you experience some life event or acquire or lose some social role at a time that is not typical for your generation, you are likely to experience heightened depression or distress (Bee, 1996:216).

The degree to which an individual has a sense of personal control over their lives also has an important impact on the amount of self - esteem that a person feels. Personal control is an integral part of having the opportunity to participate fully in society and an important part of this is being 'on time' in terms of the social clock.

For example, individuals with no role in society such as those who are unemployed and dependent on benefits through no fault of their own, are relatively powerless and disabled people in this position even more so. It is

recognised that there is a psychological price to be paid for such powerlessness and this is in the form of apathy, fatalism, depression and pessimism. Thus, helplessness is *not* a condition of the individual but is a direct result of powerlessness. (Brechin and Whalmsley, 1989)

The amount of autonomy or personal control that an individual feels they exercise over their lives has a direct influence on an individuals sense of self - esteem (Hirst and Baldwin, 1994). This will now be explored in relation to the research sample.

A minority of the sample had high self-esteem. Lisa's comments were typical:

> ..I never dreamed that I would have the sort of life that I have now. I never dreamed that I would have a car and a home, live on my own, be spontaneous and have fun. When I was doing physio and studying like hell I never thought that this could be me and it can...

Self - image is not static, and as Lisa and the others see their significance, capabilities and effectiveness continuing to improve, their self image will climb accordingly. The individuals with high self - esteem were very much in a minority. They constituted eleven out of forty two people.

The degree of autonomy enjoyed by the remaining thirty one sample members

ranged from moderate to extremely low. Nine people out of this group had moderate amount in their daily lives. The majority had low self-esteem.

Some were able to exercise a degree of control over their lives. For some the fact that they had made and acted upon, their decision to attend a residential further education college was very significant and had increased their self - esteem. Zoe's comments were typical:

> ..I put myself in here [college]...Now I do feel more capable, more practical in society. I've made a break.

The fact that individuals were engaged in a formal daily activity which they felt was worthwhile was extremely beneficial. Marjorie commented:

> ...When you are sat in a day centre all day you are tired but you can't be bothered to do anything else. You are just so sluggish that your brain has gone to sleep and you just don't want to do anything...I'm not like that anymore. Sometimes I come home from college and I'm buzzing. It's amazing because you are still thinking about what you have done.

The majority appeared to have little control over their daily lives. The twenty two individuals with the lowest autonomy were the most disadvantaged in the sample. Only two lived in independent accommodation, and this was the only

autonomy that they had and they were at pains to stress that their lives were extremely limited in every other respect.

The self - esteem of this group was extremely low and many were very frustrated and depressed by their circumstances. Some resented the limitations placed on their lives and in particular, relationships. Quentin's comments were typical:

> ..I feel as if I am in school because I can't go out on my own. Its like you are a child. Its in case I did anything to myself, they would be responsible. I am allowed to go out on my own in Kent [parental home] any time that I want. I am engaged but we can't do anything we are not allowed.

Sometimes, daily activity in the form of attendance at a day centre did not lead to an increase in self - esteem. Sixteen out of the twenty two people in this group attended a day centre.

Sophie's comments were typical of this group:

> ..I come to the day centre two days a week. I get up at half - past six, spend the day there and come home dead tired due to boredom. But I am bored at home. All of my life is totally boring.

Henrietta who had her own home felt helpless. She said:

> ..Every little job its like....say I do the washing up and drying in one go, I have a sit down afterwards, and maybe the next thing that comes around is lunch. Then I sit down and clean up afterwards. Its like I can't even manage a simple task. I am putting myself down, it's a shame but that's the way I feel...My day consists of television addiction, afternoon sleeping that can last too long....I'm sitting around....It's a crime.

The young people with a low level of self - esteem were acutely aware that they had not fulfilled the social norms for young people of their age and appeared depressed. Marjorie's said:

> ..I might as well be six because I don't feel as adult as I should. I don't feel that I have experienced enough to be adult. I'm twenty six and I'm almost that teenager who is learning things....just starting out and there are people who are thirty and worse than me....

It is the case that the type of self - image that a person has, whether it be positive or negative, impacts on other areas of their lives. It has a direct effect on the level of self - confidence that they possess:

> ..Our image of ourselves, and the beliefs we have about ourselves, help to shape not only what we think we are, but what we think we can do and what we think we can become (Hirst and Baldwin, 1994:51).

Self - Confidence

The transition from full time education to independent living is not easy for anyone but it was particularly difficult for young physically disabled adults who not only faced the task of identity formation, but they also had to cope with the extra difficulties imposed by severe levels of impairment on a daily basis whilst at the same time negotiating their way through a society which lacks disability awareness.

The literature suggests that:

> Young people with neurological impairment (i.e cerebral palsy and spina bifida with hydrocephalus) are particularly likely to have emotional or behavioural problems.... Such as a lack of self - confidence resulting from self - consciousness about their impairment; fearfulness of new situations and meeting new people, worries about incontinence, marked or frequent misery or depression and difficulties in getting on with peers (Anderson and Clarke, 1982:107,124).

Eleven respondents possessed a high degree of self - confidence. These individuals all enjoyed a high degree of autonomy in their lives and had high self - esteem.

Of the minority of individuals with the highest level of self - esteem and self confidence, all but one had a severe neurological impairment, and some were doubly incontinent, but they did not view their impairments as the primary source of any difficulties in their lives. As far as they were concerned the problem lay with the attitude of society and not with them as individuals. These people were involved in a variety of activities and were certainly not fearful of new situations. Generally they lived life to the fullest extent possible. Lisa's life was typical:

> I'm a volunteer, an advice worker and they are mainly the things that keep me going. I work all over the Midlands so I'm constantly driving. I am also a trainer who works in training young people in employing personal assistants, confidence building and that is the work that I enjoy most.

The degree of self - confidence possessed by these people had played an important part in enabling them to make the move to independent living in the first place, and they all acknowledged this whilst admitting at the same time that the move had been difficult. Cassie's stressed the importance of having the self - confidence to fight the system:

> ...You have got to fight the system. If it was up to most people, disabled people wouldn't live independently. They would either be at home with their parents or in institutions. That is the way they see it. You have definitely got to fight the system. That is where self - confidence comes

in. You have got to have enough self - confidence to sit there and fight.

Self - motivation was also viewed as essential both to acquire the information for the initial move: Eleven respondents possessed a high degree of self - confidence. These individuals all enjoyed a high degree of autonomy in their lives and had high self - esteem.

> ..You need to be motivated yourself. You have got to want to do it. It is no good being unsure or it is no good being definite that you want to spend the rest of your life with your parents. You have got to be prepared to investigate and to find out (Tina).

And also to persevere at independent living when times were difficult:

> ..You need enough confidence to start running your own life. Because at home things were done for you that you wouldn't necessarily think of yourself and you have got to have the confidence to do that. You have got to stick at it and learn to start thinking for yourself. Organising your own life takes a lot of doing and for that you need confidence (Theresa).

The individuals described above all exercised a high degree of control over their lives and possessed the self - confidence in order to be able to do so. And of course as their competence in managing their daily lives increased, so did their

level of self - confidence.

The majority of the sample ranged from having a little self - confidence to none at all. Out of this group nine people had some self - confidence this was assessed on the grounds of them having taken responsibility for some decisions in their lives, often against opposition from others. Examples included deciding to leave a day centre in order to enter further education, initiating the move to residential further education college, deciding to learn to drive or moving into independent living in the community. What distinguishes these individuals from the ones described above is the degree of autonomy that they experienced in their daily lives. In general they had less opportunity to influence major decisions and they also found the process of decision making much more difficult due to a lower level of self - confidence.

One individual described how successfully making the move to her own flat had given her the confidence to seek other avenues in life:

> ..I would have been conditioned if I had stayed in the day centre. I wouldn't have even thought of going to college. I thought to myself if you can go in a flat on your own you can go in to a different place [college]. If you can move on in one direction you can move in another. (Marjorie).

A number of other individuals echoed this sentiment. However, although people

were making decisions, some of them major, many people in this group still lacked self - confidence in some situations in particular meeting new people and having to deal with outside agencies and care staff. This group were still coming to terms with having to make choices. Robert described some of the difficulties:

> ..I'm still learning, it is ever so hard to get the hang of it when you have had somebody in control. I have had to learn how to make business phone calls, how to ring the electricity board, the doctor, the police if anything happens. Those sorts of things you need to learn. I have to write it all down before because I get nervous.

Whilst some individuals were taking active steps to improve their self-confidence, the remaining twenty two people who had the lowest level of self - esteem, totally lacked self confidence.

These people led extremely restricted lives. They had no self - confidence and little chance of improving it. Their lack of social skills was far more limiting than their physical impairment. Many of the young people felt that their difficulties stemmed from a lack of opportunity to participate in society.

The next section will explore the relationship between individuals and independence utilising the index described at the beginning of the chapter.

INDIVIDUALS AND INDEPENDENCE

The Independent Group

These individuals constituted a minority of the research sample. In line with the majority of the research sample the independent group had high expectations both in terms of educational attainment and career development. This group were the most likely to have fulfilled their expectations for educational attainment, but the situation was reversed with regard to career development.

This group were the least likely to have had any difficulty in initially broaching the subject of a move to independent accommodation and were the most likely to have been in their own accommodation at the time of interview or to be about to make the move. A minority were living in the parental home.

This group enjoyed the most active spontaneous social life with a variety of friends in a number of contexts.

These individuals also had the highest awareness of the social model of disability via their disabled friends.

They also had the highest degree of self-esteem and self-confidence of the entire sample.

Intermediate Group

These also had high expectations in terms of educational attainment and career development, but were less likely than the independent group to have fulfilled their expectations.

The majority of this group were living in the community in their own accommodation but a substantial minority of them were either residential college students (who lived in the parental home during vacations) or were living in the parental home full-time.

This group had a moderately active social life but on the whole it was with a smaller circle of friends and was less spontaneous than that of the independent group.

These individuals has some awareness of the social model of disability but not the same extent as those above.

The self-esteem and self-confidence of this group was moderate but some individuals were taking active steps to improve their situation.

The Dependent Group

The dependent group consisted of the majority of the research sample. Although the majority of this group had high expectations in terms of educational attainment and career development, none had fulfilled their expectations in terms of education or career path. The minority of this group who had the lowest expectations of the whole sample in terms of career development were paradoxically the most successful of all the young adults in the study in terms of fulfilling them as, all the young people who stated that they expected to spend their adult life in a day centre achieved this.

This group were the most fearful of broaching the subject of independent living and of the consequences of doing so. The reasons for this will be explored later in the thesis.

These individuals had little or no social life. The most active members of the group attended a Physically Handicapped and Able-Bodied club once a week in the evening. One individual was not involved in any formal daily activity and had no social contact.

These young people had no knowledge of the social model of disability and they were the most likely to blame their impairment for the lack of autonomy in their lives.

This group who constituted the majority of the sample had the lowest levels of self-esteem and self-confidence. Many were frustrated and depressed by their circumstances but felt helpless to improve the situation. They were also acutely aware that they were 'off -time' in terms of the social clock for their age group.

In conclusion, this chapter has illustrated the limitations that the young physically disabled adults were experiencing in their daily lives. The majority of the sample had high expectations in terms of educational attainment and career prospects and which were largely unfulfilled. To what extent did this occur? What were the reasons? Most of the young people had moderate to low self-esteem and little or no self-confidence. Why was this? These questions will be addressed later in the thesis.

Some of the sample demonstrated high self-esteem and were clearly very happy with their lives, and held a positive view of themselves. Despite having profound physical disabilities, these people were in control of their lives and their futures illustrating that disability does not automatically imply self - rejection. They were in a minority which consisted of eleven people out of a sample of forty two.

This chapter has examined the importance of the roles played by disabled people in facilitating their transition from full time education to independent living in the community. It has drawn on the disabled peoples' own perceptions and

experiences of this period of their lives and it is on their accounts only that the study is based, in line with the ideals of emancipatory research. Individuals can have both positive and negative influences on both the rate of progress towards independent living and the extent to which it is eventually achieved. These issues will be explored below.

The concept of independence has been defined and discussed in this context. Where independent living was achieved the extent was discussed from the standpoint of the individuals with reference to the roles played by personal agency and structural constraint. These differed significantly from those who were still living in the parental home in terms of personal characteristics. The purpose of this chapter is not to evoke victim blame or focus on an individual model of disability; the aim is to illustrate the extent to which individuals are constrained by wider societal processes. It is argued that individuals do possess a degree of agency and personal characteristics do play a part in deciding who will become independent. However, personal characteristics are influenced to a degree by social and economic factors. The extent to which lives choices and development are constrained by social factors will be discussed in subsequent chapters.

The majority of the sample were seriously lacking in self - esteem which was serving to limit lives which were already very constrained. This in turn, resulted in a further reduction of their self - confidence leading to feelings of helplessness.

They had little or no control over their lives and were excluded from society. This thesis will attempt to explain the differences between the most and least advantaged sample members. Did they start out with higher self - esteem and self - confidence or did they develop as a result of experiencing greater autonomy in their lives? Or was it a combination of both? Also what was the 'catalyst' that put them on the road to an independent lifestyle? Both groups started out with high expectations both in terms of their ability to attain educational qualifications and in terms of a future career. A minority of the sample had their expectations fulfilled. The reasons for the differences between the two groups will be outlined starting with the role of the young disabled people's families which will be explored in chapter five.

CHAPTER FIVE

FAMILY SUPPORT?

This chapter will discuss the background to the role of the family in the transition of young physically disabled people to independent living in terms of the policy process, and the way in which family support has become increasingly important for a successful transition will be outlined. The chapter will then document the ways in which the families of the young people in the study helped or hindered their transition to independence.

The Role of the Family in the Transition Process

As outlined in chapter two, the family plays a very important role in the transition of non-disabled young people to independence and its influence is apparent on two levels: in western societies social class is generally defined on the basis of education, income and occupation and every family occupies a position in this status hierarchy. This influences the position of children through and towards adulthood. There is much evidence of the way in which family background determines education levels, life expectations and attitudes, and guides the path that individuals are likely to follow throughout their lives. (Kimmel, 1990; Bee, 1996) This is a major source of sociological debate which is beyond the scope of this thesis. The family's role has become even more crucial in recent years (again as outlined in chapter two) due to changes in the support available to young people. These are apparent in the way that the period of child-like dependence has been extended via the raising of the age of access to state benefits to eighteen years, and the failure of eighteen to twenty five year

olds to qualify for adult levels of state benefits or, frequently, adult levels of income from employment. In addition, the economic responsibility for this "dependent" group of young people has been largely shifted from the state and placed on their parents, leaving increasing numbers of young people to seek assistance from their families (Jones, 1995). It can be seen that the transition to independent adulthood has become much more difficult for non-disabled young people who have been forced to rely increasingly on family support.

Profoundly physically disabled young people face considerably more difficulties in making the transition to independent adulthood. Gaining employment and financial independence are key goals of adulthood yet disabled people face considerable inequalities of access to the labour market (Hirst and Baldwin, 1995) and a survey carried out by the Office of Population Censuses and Surveys found that there were two million disabled adults of working age in Britain. Only about 700,000 had a job. Non disabled adults were twice as likely to be in paid work. (OPCS, 1989 cited in Rawlingson and Berthoud, 1996:1). The reasons behind this will be explored in chapter seven. Does employment lead to independence for young physically disabled adults?

Disabled young people are also disadvantaged by the way that the social security system operates. It can be argued on one level that this group has a number of advantages over non-disabled young adults in terms of benefits. At age sixteen the social security system grants adult status to this group (Hirst and Baldwin,

1995) but in reality, disabled people's benefits are set at a level which is inadequate to meet both mobility and personal assistance needs (Morris, 1993) and financial independence is often negotiated with parents, with social security income often controlled by them. This limits the income at the young people's disposal and increases their dependency on parents. (Hirst and Baldwin, 1995). The inadequate level of social security provision for young people as a whole, and disabled young people in particular, reflects the major thrust of government policy in recent years i.e. that of reducing welfare spending and the shifting of financial and moral responsibilities on to families. The community care policies are central to this approach. This policy has been adopted by successive governments throughout the 1960's, 1970's and 1980's; indeed by the 1970's the emphasis was firmly on care *by* rather than *in* the community. (Bayley, 1973; cited in Morris, 1993:5) and the emphasis on individual and family moral responsibility was articulated by Thatcher, in her role as leader of the Opposition in 1978:

> We know the immense sacrifices which people will make for the care of their own near and dear - for elderly relatives, disabled children and so on....Once you give people the idea that all this can be done by the state, and that it is somehow second-best or even degrading to leave it to private people....then you will begin to deprive human beings of one of the essential ingredients of humanity - personal moral responsibility. (Thatcher, 1978; cited in Morris, 1993:6)

It was assumed that the community care policy, by aiming to keep people out of institutions, would ensure that people's needs in terms of independent living would be met to a higher degree. However, concerns have been expressed as to its effectiveness:

> Although the rhetoric about helping people to live independent lives in the community and the philosophy of needs-led rather than service-led assessment are very helpful, the financial realities tend to pull in the other direction, presenting barriers to independent living rather than promoting it. (Kestenbaum, 1996:4)

Fiscal constraints on Social Services have placed a double burden on families because on one level it is well documented that young disabled people are failing to get the help that they need to enable them to live independently in the community (Chamberlain, 1993; Hirst and Baldwin, 1995) which means that they are increasingly dependent on the family. On another level there is evidence to show that families with disabled members are not getting the statutory support that they need in order to support and promote independence on the part of their disabled children. Paradoxically, whilst the family is being actively encouraged to take responsibility for the lives of its members, the extent to which this can be achieved is at the same time being undermined by a lack of statutory support for families with disabled children.

Recently, the focus of attention has moved away from disabled children placed In long-stay institutions to recognition of the need to develop better social care for disabled children living with their families. The 1989 Children Act provided a new legal framework for the provision of services for disabled children because it consolidated the basis for services provided by local authorities and slots in with duties resulting from the National Assistance Act 1948, The Chronically Sick and Disabled Persons Act 1970, the National Health Services Act 1977, the Child Care Act 1980, the Education Act 1981, and the Disabled Persons (Services, Consultation and Representation) Act 1986.

Unfortunately, despite the legislation, families with disabled children are still experiencing serious disadvantage:

> The experience of many parents who have disabled children is that they receive a low priority from Social Services Departments. Although a number of Acts of Parliament have enabled or required Local Authorities to make assessments or provide services, very often parents have been left alone to deal with a multitude of emotional practical and social problems. (Social Services Inspectorate, 1994)

Whilst the study focussed on the experiences of young physically disabled adults during transition who were aged from eighteen to thirty one years, the plight of disabled children and their families today is of relevance because if support is

patchy after the implementation of the 1989 Children Act it must have been considerably worse when the research sample were children, placing even greater emphasis on the resources of individual families. Given that the 1994 Report of the National Inspection of Services to Disabled Children and their Families acknowledged that there was a lack of comprehensive information, there was little attempt to collect information on the needs of disabled children in a given authority area, and there were serious shortcomings in the provision of respite care. Assessment procedures for establishing the needs of disabled children were inadequate and lacking in clarity regarding responsibility for the implementation and review of care plans. These shortcomings meant that the resources available within individual families were increasingly important particularly when a member of the family was disabled.

In summary, inequality of access to the labour market, social security provision that does not meet mobility and personal assistance needs, and the emphasis placed on family responsibility by community care policy whilst at the same time failing to support families in the carrying out of those duties, means that growing emphasis is placed on the resources which individual families can muster albeit emotional, intellectual, practical or financial in determining the degree to which a disabled person can make the transition to independent adulthood. The importance of the role of the family in the transition of non-disabled young people has been acknowledged:

> For most young people their families are their major source of emotional, financial and material support as they attempt the precarious first steps towards adulthood. (Coles, 1995:87).

For young physically disabled people this is even more the case and the ways in which families helped and hindered the transition to independent adulthood will be discussed below with reference to parental expectations, dependence, parental anxiety, letting go and the relationship between care and abuse.

Parental Expectations

Families teach attitudes towards work and self, foster or inhibit confidence, and encourage or discourage achievement. (Kimmel, 1990; Bee, 1996). Parents expectations of their children are at the core of this process. Participants in the study were asked about their parents attitude towards their living independently in the community and during the course of the interviews the young people frequently referred to their parents' expectations with regard to education, employment and independent living. All the interviewees stressed the extent to which their parents expectations had influenced their lives. These issues will be explored below. The data reflects the disabled young people's views only. Some parents had high expectations of their children with regard to educational achievement from an early age. This was demonstrated by parents pushing to have their child enrolled in either the most academic segregated school in the

area, a mainstream school or private provision. In some cases their efforts proved to be expensive in terms of time, effort and money in the case of private education. Other parents had very low expectations of their children in terms of educational attainment. These issues will be explored in detail in chapter six.

Employment

A number of the young adults reported that their parents had always encouraged them to seek employment. The level of assistance offered ranged from verbal encouragement through to practical help in obtaining a job. Oliver's parents had always been positive about the prospect of employment. Four other people were in some form of employment at the time of interview and also had been encouraged to find employment by their parents. Oliver said:

> I have never been discouraged as such. I had some people in my early school life saying that's all that's good for you is weaving baskets....but I haven't heard that for a long time and I have never seen a sheltered workshop in my life. Mostly I have been told to buck up and do it more so being disabled.

Other parents had become actively involved in seeking employment for their child via social networking. Christopher described how he found employment:

> My father got in touch with the Managing Director who I'm working for and asked if there was a job going for me because I was told that I would not be able to get a job because of my disability as employers may not want me, because I wouldn't fit in. I was really disappointed and never want to see a social worker or careers officer again. They said people wouldn't want me because I'm disabled, so my father contacted some people to see what he could do for me.

There were other examples where parents who lacked social contacts had tried to find employment for their child via a more formal route unfortunately without success. Olivia said:

> My mum used to work at the local factory and she tried to get me a job there but they wouldn't let me go because of my epileptic fits and the machinery. They said I couldn't go. I was a bit upset. I think I could have worked there. I could have done easy jobs. My mum was really upset.

Family members were seen as trying to find work for a disabled sibling. Andrea recalled:

> I wanted to get a job when I left school working in the factory with my twin sister. We both thought that I would be able to work there. But the factory people wouldn't let me work there because they said that I would

> be a fire hazard and that really got up my nose because disabled people do get jobs - that I know. My sister said there was another disabled person working there who was deaf and dumb. I can walk and I wouldn't have used a wheelchair in the factory.

The irony about the three cases documented above was that they had the lowest degree of physical impairment of the whole sample. One had limited mobility and the functioning of one hand was slightly impaired, the other two had limited mobility, full use of their hands but had a history of epilepsy. None had any learning difficulties. Despite the best efforts of parents or other family members two out of the three were unemployed at the time of interview.

In one case a young person recalled how family members had tried to encourage her to seek employment but the individual concerned had resisted their efforts due to a lack of self - confidence. Wilma admitted:

> I did typing and cookery at college. I enjoyed typing and I wanted to be a typist. When I first came here [to the day centre] I did a lot of typing but the woman has left now. My auntie thinks that it would be a good idea for me to get a typing job but I don't know....I'm faster on an electronic than a manual. I don't know what's stopping me getting a job.

Unfortunately, the majority of the research sample (37 out of 42) had reported

that in their opinion their parents did not think that they were employable and this was often at odds with the young persons assessment of their own abilities as illustrated in the previous chapter. Violet said:

> I wanted to do a BTEC to train towards getting a job but they said no because they didn't think that I would be able to manage. I wanted to go just to see if I could do it. Both the careers officer and my Dad said that you are going to a day centre. I don't know why. I tried to put my view across but they wouldn't listen so I just gave up in the end and went to a day centre.

Other people painted a similar picture. Irma recalled:

> I have been told that I will never be able to work because I am disabled. The careers officer said that and my parents went along with it. The one thing I would like to do is what the careers officer was dead against, like he was with most of us, is to work with children.

There were cases where a careers officer felt that vocational training would benefit a young person but this was blocked by parents who were present at the careers interview. Wilma recalled:

> A careers officer came to see me and he was on about me going to

> Hereford College for two years to learn further typing skills. My dad said what was I going to do after two years and then he went on about the local day centre and felt that it would be better for me if I went there because Hereford is too far away. I started at the day centre on August 2nd 1989.

Some parents just felt that their child was not capable of work and made their reasons quite clear which undermined self - confidence. Sophie said:

> I felt I was thick. Mum and Dad said that you won't be able to work because you can't concentrate - your brain is not working which I don't think it is. They said you are not going to be able to do things....I would have loved to have gone and worked. I love typing. I can't use this hand very much, but yes, in an office. People stopped me and then the careers officers did by saying that you will not be able to work. How the hell do they know? They don't know what I am feeling or thinking.

Some of the disabled people interviewed maintained that their parents worried about whether they would be able to 'cope' in employment or whether they would be looked after properly in the workplace. A number of the sample said that their parents had never discussed employment prospects with them. Philip's comments were typical:

> When I was at school I had this expectation of getting a job but it wasn't

> to be. I never discussed it with my parents, what I would do when I left school. I have never had any work experience at all. I went to college to get more education, in my maths and they thought you've been to college and that's it.

It can be seen from the above examples that the parents of the young people in the sample had very different expectations with regard to their child's employment prospects. Some of the parents encouraged their child every step of the way but did not have the means to offer practical help. Two young people who were in employment at the time of interview said their parents positive attitude had helped greatly. A minority of the parents were very ambitious and became actively involved in tying to secure employment for their son or daughter against the advice of some of the professionals in the field, with some success. Others tried their best but did not have the social contacts necessary for success. Some gave their children every encouragement to find employment but the young person lacked the self-confidence necessary to make the first move.

The majority of the sample said that their parents had low expectations of their gaining employment. The parents of these individuals were more likely to agree with professional's negative assessment of their child's capabilities and there were examples of parents disagreeing with a positive assessment of a young person's ability to obtain work. In some cases parents made it clear to their son or daughter that they didn't think that they were capable of work. Some parents

had never broached the subject of their son or daughter's employment prospects. The reasoning behind the different expectations will be discussed more fully in a later section of the chapter. Parental expectations with regard to independent living will now be explored.

Independent Accommodation

The young people in the study were asked about their parents attitude to them living in independent accommodation in the community. A variety of views emerged during the course of the interviews and these will be explored below. Some of the sample said that their parents had always been very supportive of their wish to live independently. These parents although understandably anxious had helped their son or daughter prepare and make the move to independent accommodation and were very often continuing to provide practical help. Some of the most severely impaired individuals had been supported by their parents in making the move. Theresa's comments were typical:

> They [parents] were very supportive and positive. They said you have got to do this [move out] because we are not going to be here for ever and its a good move. You are going to be secure when something does happen to us. You are perfectly able mentally and physically and we have full belief in you.

The importance of their parents support was stressed by a number of the young people not only in terms of enabling them to move into independent accommodation but also in terms of enabling them to lead a more independent life whilst they were still living in the parental home. Marjorie said:

> My parents had a lot done to the house to make it easier for me...You know, the grants for alterations, my parents had them all done. I had a downstairs bedroom with a shower on it, I had adaptations to the kitchen so that we had half low and half high units. I have got very, very pushy parents who are not satisfied with being told no..my dad especially. That's how you have got to be. You have got to fight. It's a pain but its worth it because you get what you want.

As a result of the adaptations to her parent's home Marjorie was able to learn the independence skills necessary to enable her to move into her own home where she was at the time of interview.

There were instances of parents forcing young people out of the family home in order to make sure that they would be able to survive when they (parents) were no longer alive. Henry recalled his move:

> My mother has always pushed me to do what I wanted and she has always been happy about independent living. She has never been soft on me and

> it was her who made me take the decision to go for independent living...I think I've got a lot to thank my mum for. If it weren't for her pushing me I wouldn't be living independently now.

There were cases of parents having every expectation that their child would be able to cope with independent living but despite every encouragement the young person lacked the self - confidence necessary to even begin investigating the possibilities. Barbara admitted:

> I don't want to have to live on my own at the moment. My Dad says it's up to me when I want to leave. The problem is that you are not safe these days are you. I don't want to leave yet.

Some parents forced the young person to leave the family home because of family conflict or breakdown and offered no help in terms of arranging a move, actually moving or day to day living in the community. These cases were in a minority. Felicity described the reasons behind her move:

> My parents couldn't cope and that was the easiest option or putting me in a home...Coming here [to her flat] wasn't a problem because there wasn't any parental involvement. I did it all by myself...my parents are not interested so there was no point getting them involved. I can't ring up my parents and say my carer hasn't come because their attitude is "why

> should we help you we aren't paying for it they are" so I had to fight for it. My parents live locally. I don't know what my parents think of me living independently because they have only visited twice and I have lived here two years.

The individuals described above all had parents who were ambitious for them to live independently in the community. For the majority, this approach stemmed from a concern for the best interests of the young person concerned. A minority of the research sample felt that their parents ambitions stemmed from self-interest. The reasons behind these different approaches will be explored later in the chapter.

The majority of the sample faced a very different problem in that they had parents who had extremely low expectations of their ability to live independently in the community to the point of actively blocking any move to independent living in some cases. These issues will be explored below.

Some parents had never broached the subject of independent living with their son or daughter. Josie said:

> I have not discussed my wish to live independently. I know it is something that I really, really want to do...We have never discussed the future. My Dad probably thinks I am going to stay at home.

Some of the parents had not only failed to broach the subject of the future with their child, but had reacted angrily when the young person had taken the initiative and raised the issue of their living independently. The experience of Violet, documented in the last chapter is a case in point.

There were instances where parents flatly refused to co-operate with their son's or daughter's wish to leave home. Even to the extent of trying to prevent their attendance at a residential college. Zoe said:

> My parents obstructed every move that I made towards independent living. They didn't want me to go to residential college; they didn't want me to be independent. When I came to college they felt like they had lost a part of themselves because they couldn't keep their eyes on me. My parents didn't come with me to look around because they weren't interested.

One individual recounted how his parents took extreme measures to prevent him having any independence. Barry said:

> I live at home with my parents at the minute and my parents aren't willing for me to live independently...When my mum and dad and brother have gone out I'm left locked in the house answering the telephone. That is about all I do.

The majority of the sample were either still living with their parents or were residential college students who returned to the parental home during the holidays. Four people returned to home to their parents at the end of term. All of this group were either actively striving for greater independence in their lives or indicated that they would like to be more independent in the future even if they admitted that they found the prospect daunting. Only one person stated that she had no desire for independence in any aspect of her life. Jane said:

> My Dad does everything and me and my Dad get on very well so I am quite happy with that. I don't want to be independent I am happy where I am.

The individuals in the sample who reported that their parents had low expectations of their ability to live an independent life often faced a double difficulty in that, in many cases, not only were parents reluctant to countenance any move to independent accommodation but they also placed a number of restrictions on their sons or daughters whilst they were still living in the parental home, which further disadvantaged them in terms of learning the necessary independence skills. The nature of this restrictiveness and the reasons behind it will be explored in the next section of this chapter.

Mutual Dependence

The majority of the young people interviewed who were living in separate accommodation at the time of interview stressed that their parents had been extremely supportive of their decision before, during and after their move. The young people were full of praise for their parents who had helped them to the best of their ability. Whilst the young people were still living with them parents had ensured that their son or daughter was in receipt of, and had control of, all the money (in the form of benefits) to which they were entitled. This issue had important implications for the degree of autonomy which the young person was able to enjoy. This will be explored below. Theresa's comments were typical of this group:

> Me personally, I had the benefits from the age of sixteen anyway whilst I was still at home with my parents. I always controlled all my own money. My parents always said that it was my money.

Parents had helped them to fill in the necessary forms, helped them to locate suitable properties and then accompanied their son or daughter during the viewing process, they had contacted social services in order to ensure that the necessary adaptations were done to the property and in some cases they had helped to decorate their son or daughter's new home. There were also examples of parents supplying furnishings and being available to deal with any problems

once the move had taken place. At this point it is important to mention that whilst some of the young adults were living independently of their parents, the extent to which they enjoyed an independent lifestyle with an equivalent degree of autonomy to that of non-disabled young people of the same age varied greatly. This issue will be explored later in the thesis.

Whilst a minority of the sample had managed to become independent of their parents and were running their own lives, a move which for most had the full blessing of the parents, the majority of the sample (25 out of 42) were dependent on their parents for the roof over their heads, their personal assistance needs, the provision of meals, in fact, almost every aspect of their daily lives. Some of the young people were unable to leave the house unaided. Three individuals in this group were less dependent than the rest in that they were all in some form of employment and were drivers so they had no transport problems. However, these were in a minority. The majority were entirely dependent on their parents and faced a number of restrictions as a result of this. In some cases their lives were further complicated by the fact that their parents were dependent on them both financially and for the roof over their heads. These issues will be explored below. With the exception of three people who were in legitimate employment, the remaining thirty nine people were dependent on social security benefits. Particular concerns were raised with regard to benefits during the course of the interviews by people still living in the parental home. Taken at face value, the fact that some parents were financially dependent on the young person's income

could be taken to be a sign of financial independence on the part of the young people in that they were using their benefit income to contribute to the household in the form of board payments which:

> Although the amounts may be small, and bear little relation to the full cost, many parents regard such payments as one of the more important ways in which young people learn financial responsibility and the obligations of adult life. (Allat, 1988; cited in Hirst and Baldwin, 1995:32)

Given the centrality of financial independence as a symbol of adult status, in theory, the payment of board money should be viewed as a positive development by parents and young people alike marking a step towards adulthood. As outlined above, on the surface, young disabled people were relatively advantaged in terms of benefit income when compared to their non-disabled peers in that this group is accorded adult status by the social security system at age sixteen, two years earlier than the rest of the population. The assumption is that benefits claimed after that age should be controlled by the young person and treated as their money where possible.

It emerged during the course of the interviews that entitlement to benefits at age sixteen and the payment of board money did not always mean that the young person had a degree of financial independence. Concerns were raised over the control of money from benefits.

Board Money

Some of the young adults interviewed who were still living in the parental home and reliant on social security benefits were clearly in control of their own money and the arrangement was that they physically handed over a set amount of board money to their parents each week. This process was described by Pam:

> My step mum keeps my benefit books you see and she collects my money and just puts it in my drawer and that's it. I hand her my board money. She has my attendance allowance and I pay board on top of that.

For other people the situation was very different with parents totally controlling benefit money and deducting board payments at source in some cases leaving the young person with a small amount of 'pocket money' to spend which they viewed as inadequate for their needs. Henrietta described the difficulties that this had caused her before the death of her mother had forced her to move out of the parental home:

> When I was living with my parents I got to an age where they wanted not all my money but a certain amount of money. I will always remember this. I said to my mum I should have the money for my needs because I wasn't allowed to go out by myself I would always have to take somebody with me. I said to her that the money is mine, but she said we give you £10 a

week.

Henrietta's parents were reliant on her benefits to the extent that her contributions to the household economy only left her with £10 a week to live on, an amount that would not allow for any participation in the community or personal autonomy.

Barrie's experiences were similar:

> I don't control my own money my parents do. My parents hold on to you know, the benefit side. I get bits of spending money - five pounds a week enough for me to buy coffee and dinner and things like that at the day centre.

Barrie's parents were both unemployed so the income from his benefits was particularly important as reflected by the amount deducted in lieu of board payments. In one case the parents retained control of the young persons benefits even after they had moved into residential provision. Henrietta described her experiences after the death of her mother:

> I went into a residential home after my mum died and my dad had my benefit books and I had a social worker and I said to her that I couldn't live on the money that my dad was giving me to live on and that she could

> go and tell him that I would like my benefit books. Well, you never heard anything so bad in your life. He came to see me because I wanted my benefit books off him. He was swearing in front of all the residents. He said that I didn't need the money and he was earning more money than me...because...then he took my money. OK, He and I used to go on holiday once a year but I couldn't live on £10 a week. He refused to talk to me for nearly two months because they took the money off him and he resented it.

Sometimes, the parents' reliance on the income from their son or daughter's benefits led to a situation where they were seen as actively discouraging a move to independent accommodation. Dorothy described some of the difficulties:

> They were worrying about losing my benefits. Even if I mention about leaving home my dad goes barmy. He flips the roof. I don't know why that is...He has never discussed the future, he can't even bring the subject up. They get a bit of money for looking after me... and if I moved out all that would stop and I think that is one of the big problems.

In some cases, parents relied on their son or daughter for the family home. It seemed as if Violet was making an important contribution to her parent's mortgage:

> I told my Dad that I was thinking of leaving home and the only reaction that I got back of him was that they would have to sell the house if I went. He didn't explain why. My parents own their own house.

Young people who lived with their parents in social housing which was adapted for their needs were not immune from such dilemmas. Josie was very aware of the difficulties that her family would face if she moved into a home of her own:

> I would like to live on my own...I have said it to my friend and sister and they were all for it. Where I live my home has been especially adapted for me. It has been built for a disabled person really. It would be difficult because I wouldn't know where they stood....they would lose the house. It's a local authority house and it is the main reason why I won't broach the subject.

The examples given above clearly illustrate that in some families the payment of board money by the young disabled people was far more significant than the comment by Allat, 1988 (see above) implies. The amounts paid were not small in relation to the young person's overall income and as far as possible did bear some relation to the cost. They were clearly essential to the household economy. It is important to acknowledge at this point that the amounts that the young adults were able to contribute, issues of who was actually controlling the money aside, are determined by benefit levels which are set by the government. Given that it

is widely acknowledged that disabled people's outgoings are higher than their non-disabled peers, and that benefit incomes do not adequately cover the extra costs incurred (Hirst and Baldwin, 1995) it may be that the board levels required by some parents reflect their struggles to make up the shortfall and cope with the extra costs of having a disabled child. These issues will be explored in greater depth later in the thesis. In a number of cases the young people believed that their parents were mainly motivated by self-interest (as was illustrated by the cases where parents were actively preventing a move to independent accommodation) and there was a strong suspicion that the extent of the problem is much greater than the examples given here suggest. However, this would require further study.

With regard to the issue of parents controlling benefits, this was clearly an area which was of great concern to the young people in the study and many resented the situation. Economic dependency on the part of parents aside, there are issues of the parents perceptions of their son or daughter's ability to cope with responsibility in the equation (this will be explored in the next section) which in turn hinges on the level of education received. This will be discussed in the next chapter.

The fact that some parents were reliant on the young person for the family home needs further investigation. Particularly the instances where the family was housed in local authority accommodation, and again there was a suspicion that this was the tip of the iceberg, but further study would be required to verify this.

This situation is a reflection of the national policy to promote owner occupation and private rental at the expense of local authority new-build programmes. This has further increased pressure on scarce purpose built housing for disabled people (Morris, 1990; Kestenbaum, 1996). Disabled people are particularly disadvantaged by this situation given that 45% of disabled adults are local authority or housing association tenants compared to 31% of the general population. (Morris, 1990). The shortage of social housing per se, further complicates the issue when the family home has been purpose built for a disabled person and the disabled member of the family wants to live in independent accommodation. They either face having to 'evict' their families or trying to find scarce alternative housing in the locality for themselves in the knowledge that their family will lose their home anyway, a situation which places intolerable strains on disabled people and their families. Many of the young people were acutely aware of the upheaval that would be caused particularly in cases where there were younger siblings. As with the issue of benefit levels, the situation with regard to social housing for disabled people brings questions of levels of state support for disabled people and the families in to the equation.

A major theme which emerged during the course of the interviews with the young people was their perceptions of the extent to which their parents anxiety about their ability to cope with the responsibilities inherent in living independently in the community had coloured parents support (or otherwise) of independent living. Parental anxiety was mentioned in two respects, firstly with

regard to the young adults ability to cope on their own and secondly, the parents own ability to adjust once the young adult had left home. These issues will be discussed in the next section.

Parental Anxiety

All parents have a difficult role to play given that it is argued that:

> It is one of the functions of families to help in emancipating the child from dependency. (Parsons, 1956; cited in Jones, 1995:80).

As they mature, the assertion of individual identity becomes increasingly important to the majority of young people and parents have to be flexible enough to adapt to the changing relationship with their children and accept that the desire for emancipation from parental control and economic independence is a normal part of the transition to adulthood. This process is fraught with dilemmas:

> It is not easy to be a parent. Whatever the many joys of bringing up children, there are also considerable difficulties along the way...As children become adolescents and develop their own interests, parents have to make decisions about how much independence to give them, how much to enable them to do what they want, rather than what they believe to be best. Throughout this process, many parents find it difficult to be

sure that the course they chose was 'right'. (Richardson and Ritchie, 1989:92)

Central to this process is the concept of risk and what constitutes an *acceptable risk*. In order to fulfill their role of helping to emancipate their child from dependency they have to weigh up the desire to protect a child from harm against the necessity of teaching the skills essential for managing daily life. This process begins once the child leaves babyhood and develops walking skills which enable it to move around unaided. Parents progress from teaching the child basic skills right through to managing complex human relationships. There are no hard and fast rules governing when a certain stage will be reached. It is up to the parents to decide when the benefits of allowing a bit more independence outweigh the risks incurred. This issue is a major source of tension in families both between spouses and between parents and their children. On the one hand, parents worry about allowing their child to achieve the next 'milestone' in terms of the teaching of key skills such as allowing them to boil a kettle on their own, use the oven, cross the road, go out in the evening, learn to drive etc in case their child comes to some harm, whilst on the other hand the young person may resent the restrictions imposed and feel that they are unjust even though in the long run they may be in their best interests. There is a tension between the realisation that increased autonomy is an essential part of growing up, and the desire to protect from harm. This is a normal part of the parent - child dynamic. At this stage parents have a dual role. They have to teach independence skills and also develop

sufficient emotional detachment to allow the child to cope on his or her own. Usually, this process is helped by the child who increasingly takes the initiative in terms of demanding more autonomy culminating in the completion of full - time education and a move into the adult world of work with its associated responsibilities.

For parents with a disabled child the situation is much more complex, with a host of competing emotions, which are even more intense whilst at the same time their role in terms of emancipating their child from dependency is of even greater importance as the initiative in terms of promoting autonomy may rest firmly with them for reasons which will be explored later in the thesis. Their role is an extremely difficult one and the reasons for this will be explored below.

As outlined above all parents are anxious for their children and this anxiety is an integral part of being a responsible parent. In the case of parents of disabled children their anxieties are heightened by the fact that their child is disabled whilst at the same time it is even more imperative that they teach their child the necessary independence skills and allow them some autonomy. In this situation the tension between the need for autonomy on the part of the child (and its parents) and the desire to protect from harm is even greater. Parental anxieties are heightened on both the macro and the micro levels.

On the macro level, despite the increasing emphasis placed by government policy

on the role of the family in caring for its sick and disabled members, there is a paucity of support for the family and, in particular, the families of disabled children in carrying out this role (as outlined above). The majority of parents are acutely aware of this and the lack of provision for their child once he or she reaches adulthood. This will be explored in chapter eight.

On the micro level, in order to enable their child to achieve independence, parents of disabled children have to overcome a number of emotional hurdles the majority of which centre on the concept of acceptable risk.

With regard to disabled people, the literature defines three types of risk; physical, social and emotional which are associated with independent living in the community (Stevenson and Parsloe, 1993):

Physical Risk ranges from the possibility that certain disabled people may attempt suicide or attack others (this applies mostly to individuals with a history of psychiatric disorder) through to the problem of physical and sexual abuse of young adults by their carers or personal assistants. This issue will be discussed in greater depth later in the thesis. Another area of potential physical risk concerns the standard of personal and domestic hygiene that the individual is able to maintain and it is a particular concern if the impairment involves double incontinence.

Social risk concerns the effect of an individual's behaviour on others and the difficulties faced by that person if his or her behaviour alienates him. (eg if they are very smelly) the authors acknowledge that this is a difficult area:

> How far should social workers seek to influence or persuade users to behave in ways which are generally socially acceptable, in a word, to conform? (Stevenson and Parsloe, 1993).

Another area of potential social risk is the financial abuse of young people by carers, cases of which were described above. The issue of financial abuse by personal assistants will be covered later in the thesis. At this point, a note on terminology is needed. The term 'care' is being increasingly rejected by disabled people because of its connotations with compassion rather than civil rights. It ignores the principle that the disabled person should retain control of how their daily living tasks are carried out. However, the term 'care' continues to be used as it is entrenched in the current community care policy. Nevertheless, in recent years the term 'carer' has been used in the context of an unpaid relative or friend such as a parent (payment can be involved although it is usually in the form of 'board money'); a care assistant in the case of workers employed by a statutory or voluntary agency, and a personal assistant in the case of a one - to - one relationship. (Kestenbaum, 1996). The term will be used in the manner above throughout the thesis.

Emotional risk is the most ambiguous type described thus far. In the context of the current research it is taken to imply emotional abuse of a disabled individual by a carer, care assistant, or personal assistant. Carers keeping a disabled individual in isolation is an example of emotional abuse. (Stevenson and Parsloe, 1993:19).

It seems as if parents of disabled children are acutely aware of the types of risk outlined by Stevenson and Parsloe, (1993) although they may not articulate them as such. Parental knowledge of the risks that their child may face in the community may substantially increase anxiety levels and make their role in promoting independence on the part of the child considerably harder as they wrestle with the protection versus autonomy dilemma.

As acknowledged by Parsons 1956 (above), parents' principal role is to empower their child to live independently in the community. However, empowerment is more than a goal it is *a process*. Although the point is made with reference to social workers, the quote below could just as easily be applied to parents:

> Judgements will be made by workers as to the stages by which greater autonomy should be achieved and in what areas of daily living. For some users, for example young people with mental and physical disabilities, there is a fine line between discouragement through failure and the

> learning which has to take place from experience even if negative. (Stevenson and Parsloe, 1993:22)

In order to enable their children to live independently, parents have to set a number of modest intermediate goals and the level and type of goal which is heavily influenced by the degree of anxiety which the parents feel about their child's future. It is acknowledged that parents can 'make or break' their child's transition to independence:

> The biggest enemies [disabled young people] have got are their parents....Over-protective. Won't let them go, won't let them make their own mistakes, I've realised this for many years and fought against it and that's why we have taken so many chances with our son. (Parent, cited in Richardson and Ritchie, 1989:42).

For parents who have cared for a disabled young person the urge to overprotect is a very strong one. This operates on a number of levels including the teaching of practical tasks and social skills. The situation can be further complicated when the parents have had a negative experience of professionals and the wider community who may have made their low expectations of disabled people quite clear.

With regard to the teaching of practical tasks, parents may worry that the young

person may injure him or herself in the kitchen for example and there is also the issue of parents being able to sit back and allow their child to struggle to complete a task as the urge to intervene and do it in half the time can be very strong. Parents also have to overcome their worries about the vulnerability of their son or daughter in order to allow them to develop the necessary social skills for participation in adult society. Whilst it is acknowledged that all parents are anxious for their children, whether they are disabled or not, for the parents of a disabled child the anxiety is likely to be more intense and its consequences much more serious in terms of the disabled individual's life chances if it is allowed to limit the achievement of independence. The degree of anxiety that parents feel influences the extent to which they feel able to encourage their son or daughter to become independent. Confident parents are more likely to feel able to promote independence whilst fearful parents are likely to be restrictive. These issues will be explored below with reference to the research data.

The current study explored young disabled peoples' perceptions of their parents' attitude to their living independently in the community. Other work has been done on the carer's perspective (eg Richardson and Ritchie, 1989) but little work has been done on disabled peoples' perceptions of parental attitudes to their attainment of independence. It is argued that the point of emancipatory research is to empower disabled people (Oliver, 1992), to obtain the views of parents in this context would have been disempowering and at odds with the methodology.

The experiences of the sample ranged from individuals who stated that their parents had always been confident of their abilities (if a little anxious) and had gone out of their way to encourage their son or daughter to be independent through to individuals who stated that their parents had always been fearful of the consequences of encouraging their child's independence and had therefore severely restricted the disabled young person's daily life. There were also some individuals who had experiences which fell between the two extremes. The range of experiences will be discussed below.

Some of the individuals in the sample said that their parents had always encouraged them to be as independent as possible although they were understandably anxious. Cassie's comments were typical:

> I didn't really have much trouble. I actually lived with my sister who is my guardian. I didn't have much trouble because she is actually not that much older than me so she understood. I mean she was frightened for me and didn't really want me to go, but she also understood that it was really something that I had to do...She had a lot of fears at first, she used to ring me every day, sort of like every hour on the hour she was on the telephone to check that I was alright. She was just fearful.

Other young adults described similar experiences with regard to parental anxiety continuing but diminishing once they had moved to independent accommodation

in the community. Theresa remembered:

> Yes, it got better. They [parents] do improve. The telephone calls got down to every other day then once a week.

In general, the young adults with parents who had encouraged independence understood that their parents anxieties were not unreasonable and a normal part of the parent - child relationship. Marjorie explained:

> They were worried about me moving out but any parent is I suppose, able - bodied or not.

Parents had made every effort possible despite their worries, to encourage the young person to be independent from an early age. Marjorie described her childhood:

> I was lucky. I've got really, really good parents that pushed me. If there was a holiday going at school it was like: 'you are going, it will do you good'. I was told that from the age of eleven.

Parents had a number of anxieties ranging from worries about how the young person would cope with the practicalities of employing personal assistants i.e. with the role of employer, and the perceived vulnerability of a disabled person

in this situation, through to concerns about the practicalities of independence involving cooking, cleaning and managing money. However, these parents had not allowed their understandable anxiety to override their role in emancipating their child from dependency. Many of these parents had encouraged independence from an early age by allowing their child to attend residential school, a decision which a number of the most independent young people said had helped both them and their parents as their life was 'less home centred'. Ian said:

> I have been away from home at boarding school and college since the age of seven so I am not a home type person really and I have never thought of living at home.

A minority of the sample had parents who were confident enough to promote maximum independence in terms of encouraging the young people to live independently in the community. The remainder of the sample were either residential college students (6) or still at home with their parents (20). Four people who were still living in the parental home faced few restrictions and were very much in control of their daily lives.

A majority of the sample reported that they had extremely anxious parents and as a result, the majority led extremely restricted lives. Restrictiveness ranged from not being allowed out after a certain time in the evening, a situation which

was a source of as much frustration as it is for non - disabled young people. Dorothy aged 25 said:

> My parents treat my brothers and sister differently. My middle brother can do what he wants, come in when he wants. I'm just blocked because they say that I wouldn't be able to reach the light switches. I think that's an excuse. I can get in and out of the house by myself O.K.

This was not the only restriction that Dorothy faced. In common with the majority of people she was not allowed out unaccompanied at all. When a member of her family or boyfriend were not present her parents only allowed her to travel to and from her day centre on social services transport.

Not only were some young people not allowed out unaccompanied but their parents also refused to let them stay alone in the house. Olivia said:

> We are supposed to be going on holiday soon. I didn't want to go but I am now because my mum didn't want me to stay at home on my own. She worries about my fits. I am on medication for them.

Some parents anxieties were such that they would not let their son or daughter into the kitchen to learn cooking skills. Angela's comments were typical:

> My mum is very strict. She won't allow me in the kitchen. She worries about me in the kitchen and that.

There were also cases of parents refusing to co-operate with social workers who called at the house to discuss independent living with their son or daughter and parents who either actively prevented or made it as difficult as possible for the young person to attend residential college. One individual was not allowed out at all apart from attendance at a day centre and was left locked in the house when his parents went out.

The young people interviewed all said that their parents had worried about allowing them more independence. The parents who had promoted the development of independence in their disabled child had not let their understandable anxiety about risk undermine the family's most important role i.e. that of emancipating children from dependency.

In the case of the young people with the most restrictive parents, these parents had allowed extreme anxiety (in most cases) to undermine their role of promoting independence on the part of their disabled son or daughter. Many of the sample said that their parents made it clear that they didn't think that the disabled young person would be able to cope with a greater degree of independence. Wilma summed up the worries of many parents:

> I have always wanted to live on my own but my stepmother doesn't think that I will be able to manage because I can't cook and she thinks that I will be hopeless with the bills and that because I am no good with money.

Some of the sample had not been taught the most basic skills by their parents. A number were totally unable to tell the time and had been to ashamed to admit the fact at school. The reasons behind this will be explored later in the thesis.

As outlined above, empowerment cannot be just a goal it is a *process* (Stevenson and Parsloe, 1993) and for the goal to be achieved it has to be acknowledged as such. A minority of the sample were fortunate to have parents who recognised it as such and had the courage to start their son or daughter on the difficult road to independence and adult participation in society. This was achieved via a number of intermediate stages each leading to greater autonomy.

The majority of the sample were severely restricted by their parents and had not been allowed even the most basic level of independence. This situation had stemmed from their parents fear of allowing their child to take risks, one of the sample described this as the 'cotton wool syndrome'. According to the sample these parents clearly thought that they were acting in their son or daughter's best interests even if the young person did not agree!

These parents felt that they had their child's best interests at heart. Unfortunately, as outlined in the section on mutual dependence, there was a significant number of parents who may have been motivated by self interest in keeping their child dependent on them. Dorothy, Henrietta, Barrie, and Violet all believed that although their parents expressed worries about their ability to cope with more autonomy, the dominant factor was the fact that their parents were dependent on their benefits (see above).

It became apparent during the course of the interviews with disabled young people that there were instances where parents had made every effort to encourage their son or daughter to be independent but could not bring themselves to let go emotionally. These issues will be discussed in the next section.

Letting Go

The majority of the restrictions outlined above stemmed from caution on the part of parents, a trait which although viewed as inappropriate by the majority of disabled people interviewed, is nevertheless understandable given the fact that *all* parents are anxious about their offspring's future and the parents of a profoundly physically disabled child doubly so.

For most parents the most difficult aspect of their role is coming to terms with the fact that eventually their son or daughter will have to leave home. For some,

the major feeling may be a sense of relief and opportunity as they have more time for themselves and a sense of freedom. Others may feel a profound sense of loss. Some may feel a combination of the two and struggle with the dilemma that this presents. This period in a family's life is one that calls for a major change in family relationships. These changes particularly affect mothers who have put their parenting role before a career.

In the case of mothers of profoundly disabled children, this period can be one of particular difficulty especially if they have had sole responsibility for the daily care of the child. The caring role will have occupied a large part of the day especially if the child or young adult has required toileting and changing. In such a situation parents inevitably feel a strong sense of protectiveness towards their child and the relationship between parent and child may have become very close. All these factors can make it extremely difficult to let go:

> If you have a child, you have to let go don't you? It's very tough if you can't. It's a measure of your love to let them go. But it isn't easy, believe you me it isn't. It is very difficult. (Parent of disabled child cited in Richardson and Ritchie, 1989:1)

Different groups of parents are likely to view the prospect of letting go differently. It is generally the case that younger parents are more likely to view the change from the standpoint of new freedom whilst older parents may see it

as the 'beginning of the end' with little to devote themselves to for the rest of their lives (Richardson and Ritchie, 1989).

With regard to the current study, a minority of the sample had parents who had been able to muster the courage to let go. Irma's comments were typical:

> My mum was frightened a bit at first but now she knows that I am alright she just comes and sees me twice a week to make sure that I am O.K. and I am quite happy with that. She was frightened of how I would cope with the work; the cooking, cleaning and all that because I am a bit slow physically. I think she thought it would be a bit too much for me but I seem to be O.K. My mum used to do everything for me before I moved out and I am quite surprised that she has left me alone. My mum has more or less just left me to it not being selfish or anything...she has left me to stand on my own two feet.

There were instances where parents were only too pleased to let go as in the case of Felicity described above. Her parents were unable to cope with her disability. Even though they lived within a ten mile radius of her flat she had only seen them twice in three years.

Sometimes parents attempts to make their son or daughter stand on their own two feet could be misinterpreted by friends or neighbours, making the difficult task

of letting go even harder. Elizabeth said:

> My parents were very encouraging. They let me do what I wanted...let me make my own mistakes. Some people called it neglect you know.

The parents who had been able to let their son or daughter go had all made strenuous efforts to encourage their child to be independent including encouraging their attendance at residential college etc.

The majority of the sample reported that their parents had the greatest difficulty in letting them go and this was a source of some frustration. The extent of difficulty ranged from parents who had gone through the process of empowerment (sometimes to the extent of physically helping them to make the move to independent accommodation) but still found themselves unable to let go, through to parents who had made no effort to even discuss their son or daughter's future. The range of experience will be discussed below.

In one case parents had offered their daughter every assistance in moving into her own flat and had encouraged her to be independent throughout childhood. However, once the move was completed the mother appeared quite unable to let go emotionally much to the frustration of her daughter and her care assistants. Marjorie said:

> I think really I have been too close to my mum...She will come into the flat and insist on cleaning and choosing the clothes that I am to wear. She does that every day. It drives me mad.

It is the norm for parents and their offspring to stay in touch once the son or daughter has left the parental home and the level of contact depends on the way that families negotiate dependence and independence (Jones, 1995). However, too much support can be stifling and unhelpful. Whilst the parents in the case above had been sensitive up to a point to the changing needs of their daughter as she grew older up to a point, they had failed to adjust the level of support in accordance with her growing independence. As a result she felt that it was a form of control.

There were some instances where young people had a great deal of autonomy even though they were still living in the parental home, but when it came to them moving to independent accommodation they found it extremely difficult to get their parents to discuss the issues. Oliver's comments were typical:

> My parents don't want me to rush into anything stupid. I mean I am all ready for moving out but they are worried....they don't want me to move into anything that has got rising damp, that makes my legs act up...I can't get them to talk about it.

The majority of the sample had parents who were unable to let go. These included the cases outlined above plus some individuals who had parents who had blocked their attendance at residential college and who made it quite clear to their son or daughter that they would be returning home once they finished college. Sixteen individuals stated that their parents had never raised the issue of the future with them let alone begin to let go.

The parents of disabled children do face a much more difficult task in terms of preparing their child to lead an independent life because quite often the impetus for independence does not stem from the child as it does with non-disabled children. Whereas non-disabled children will seek out new activities and friends as they mature, disabled children often have less opportunity to do so for a number of reasons which will be explored later in the thesis. If the parents have low expectations in terms of their child's developing maturity and as a result are over-protective, then the young person's chance of becoming independent is seriously undermined. There were instances in the study where the disabled young people did take the initiative and also examples of parents being strict and forcing their child to be more independent but these were in a minority.

The majority were still facing extreme difficulty in this respect. This was due to a variety of factors. There were cases where young people had tried to raise the subject of independent living but had literally been shouted down by their parents.

There were instances where parents felt that they had to do everything for their child in terms of personal care. What was the motivation for this? This will be explored in the next section.

The Relationship Between Care and Abuse

> There is no doubt that most parents with disabled sons and daughters feel a great love for them. While their lives may revolve heavily around looking after their child, the every day tasks of this care comes to be seen as wholly natural. They are undertaken as part and parcel of the parental role...as with any family the looking after and the loving are frequently bound up together. (Richardson and Ritchie, 1989:14)

Parents can decide to care for their child at home for a number of reasons, not least is a desire to do the very best for their child. Where the young person is profoundly physically disabled, the relationship between parent and offspring is fundamentally altered and is similar to the one which exists between parents and very young children as everything is home - centred at a time when the majority of non - disabled young people would have moved or be moving towards independence. (Richardson and Ritchie, 1989:19).

There are a number of reasons why parents may decide to keep a disabled young person at home. It may be out of a sense of parental responsibility which hinges

on the parent's duty to the child; it may stem from the parent's determination to be self-reliant and also as a result of pressure from family, friends and neighbours. Some parents just enjoy having a caring role. They like the sense of purpose, and companionship associated with this role. This aspect can be particularly important for elderly, widowed or divorced parents. Unfortunately, parents can become emotionally dependent on their children (Richardson and Ritchie, 1989:26). Sometimes if parents have had a bad experience of statutory provision for the child their resolve will be strengthened to keep the young person at home. Given that paucity of information and support for disabled children and their families, it is likely that some parents were unaware of the existence of alternative approaches (Social Services Inspectorate, 1994) The inability to let go can lead to a situation of over - care which can be extremely negative in terms of the amount of autonomy that the disabled person is able to exercise over his or her life. These issues will be explored below from the standpoint of the disabled people themselves.

All the young people in the study who lived in the parental home had their care carried out by their parents. There was no outside care assistance. Twenty six out of the forty two people in the sample were still living with their parents. Twenty lived in the parental home full - time whilst six attended a residential further education college but returned home during the holidays. Out of this group, four people with profound disabilities were happy to have their parents acting as carers and felt that this did not impinge on their autonomy at all. Richard's

comments were typical:

> There are no barriers anywhere. I go away on my own, I go out on my own and I drive. My parents are extremely supportive in that way.

The remaining twenty two people were unhappy with the situation and felt a combination of suffocation and anxiety about the extra strain that caring placed on their parents. The quote from Sophie in the previous chapter illustrated this **See page 176.**

There were instances of fathers being the sole provider of their daughter's personal care including showering, toileting and catheterization. These were fathers who were either divorced or widowed and had been left with sole responsibility for the care of their disabled daughters and were trying to do the best for their child whilst remaining self - sufficient. Jane summed up this attitude:

> I have got a shower....me dad does....helps me get on that and everything...We don't have anybody else coming in because we can manage.

Josie said:

> My Dad does all my personal care because there wasn't any other option. My parents divorced when I was eleven so my dad has been with us. He washes all my bottom half and I have a catheter and he has to put that in as well. Nobody else comes in to do it because it is easier.

Neither respondent directly described this situation as abusive, though they appeared stressed and anxious in talking about it. These respondents were exposed to abuse whether or not it occurred. In the case of Josie, where her father was reliant on her for the family home (see above) there was further scope for abuse.

Where the young disabled person was totally reliant on parents for personal care and the parents also managed their benefit income, it left the young person with little scope for autonomy and meant that parents were totally in control. Also, the fact that there was little or no outside involvement meant that an extremely vulnerable person was isolated if difficulties arose. Many individuals complained that the parental care situation kept them as children despite their years. As mentioned above, in one case parents locked their disabled son, Barrie, aged 22, in the house when they went out.

Given the lack of statutory support for disabled children and their families outlined above, a tremendous responsibility rested on the shoulders of parents. This was exacerbated by the fact that in many cases it fell to the parents to

initiate moves towards independence.

Four individuals were still living in the parental home and had a lot of control over their daily lives because their parents had encouraged them to be independent although they had not let go emotionally.

The majority of the sample had parents who had made little or no effort to encourage them to be independent and as a result the disabled people had little control over their daily lives and faced an uncertain future. The extent to which the family played a role in determining the lifestyle of the research sample will be summarised below.

FAMILY SUPPORT AND INDEPENDENCE

As outlined at the beginning of the chapter an index was devised against which the research sample was assessed as being dependent or independent. In this section the three groups will be discussed in relation to the attitude of their families to independent living in the broadest sense.

The Independent Group

Eleven individuals scored 5-7 and were classed as independent. This group had a number of advantages when compared with the remainder of the sample. These

individuals were the most likely to have parents who expected and encouraged them to seek employment and to offer practical help in doing so.

The parents of this group had also made the maximum effort to encourage independence on the part of their son or daughter. The support ranged from teaching independence skills whilst the young person was still living in the parental home through to help with the move in to independent accommodation and practical help afterwards.

The young adults in this group were most likely to say that their parents had played an important role in initiating benefits system and social services support. It was also the case that the disabled people had full control of their benefit income.

The young people in this group stated that although anxious, their parents had always had confidence in their abilities. They had not allowed anxiety to undermine the process of encouraging their child to be independent. This had led to a situation where parents had been able to summon the courage to 'let go' both physically and emotionally.

None of the individuals in this group had personal assistance carried out by parents.

The Intermediate Group

In terms of parental expectations, some of the young people described how their parents had encouraged them to seek employment. In general this was to a lesser extent than the group above and had not been as successful.

The parents of these people had also made some effort in empowering their child although to a lesser extent than the group above.

These individuals retained limited control over their benefit income but it was not totally in their hands. Also parents had played a smaller role in initiating benefit system and any social services support.

With regard to the issue of emotionally letting go, some parents had gone through the process of empowerment, up to and including helping their child to move to independent accommodation, but they were seen as unable to emotionally 'let go'.

The majority of this group had care carried out by parents part-time as the young people attended residential college.

The Dependent Group

This group constituted the majority of the research sample. Most of the young adults in this group felt that their parents had low expectations of their ability to obtain work and/or live independently in the community. These young adults were most likely to say that their parents had gone along with a careers officer's negative assessment of their ability to work or, conversely, actively blocked suggestions arising from a positive assessment. The reasons for this will be explored later in the thesis. This stance was often at odds with the expectations of the disabled young people as outlined in chapter four.

In most cases the young people described how their parents had made little effort to encourage them to be independent. There were two exceptions one involved family breakdown and conflict and the other was a situation where, despite the parent's best efforts, the young person lacked the necessary self-confidence to become independent. The whole situation raises the question of the extent and role of support for disabled young people and their families. This will be discussed later in the thesis.

All the young adults were still living in the parental home at the time of interview and were dependent on benefits. A number of individuals raised concerns about the control of benefit money. This group was the most likely to report problems with parents totally controlling benefit money to the extent of only allowing the

young person a small amount of 'pocket money'. Did this situation arise out of parental selfishness or was it due to the inadequacy of disability benefits? This issue will be explored later in the thesis.

This group also described their parents as extremely anxious. This resulted in the young people leading very restricted lives. There is evidence that parental anxiety was not the only factor which restricted the sample's lives. What role did other agencies play in this context? This issue will be explored later in the thesis.

Most of the young adults said that their parents had never raised the issue of the future with them let alone begun the process of physically and emotionally letting go. Again, this raises the issue of the amount of outside support available to young disabled people and their families which will be explored later.

All the individuals had their personal assistance carried out by their parents. None had any outside assistance which further added to their lack of autonomy. Most were extremely unhappy with the situation and a number of issues were raised ranging from worries about the burden on parents through to concern about fathers providing their daughters personal assistance. This situation was especially difficult where the parent was also reliant on the child for the family home.

In conclusion, this chapter has outlined the importance of the role that all

families play in emancipating their children from dependency and the families of disabled children even more so. This role is played out against a backdrop of policy initiatives which stress the family's obligation to care for its sick and disabled members, whilst failing to provide the necessary statutory support to enable it to adequately carry out its role. In such a climate, the quality of family support which is on offer is more important than ever, particularly in the case of individuals who for reasons which will be explored in subsequent sections of this thesis, may not be able to take the initiative themselves in terms of demanding independence.

It can be seen from the material above that parents played a large part in enabling independence. However, this is not the whole picture as there were exceptions to the rule in that some disabled people became independent despite their parents, and others refused to accept more autonomy in spite of their parent's best efforts. What was the role of education, employment, the benefits system and the personal social services in enabling independent living? This will be discussed in subsequent chapters beginning with education.

CHAPTER SIX

EDUCATION FOR THE FUTURE?

This chapter will explore the role played by education in preparing young people for adult life and full participation in society. The extent to which parents influenced this process will be discussed together with the contributions made by the various professionals involved with disabled children. The benefits and disadvantages of segregated education from the standpoint of the disabled young adults in the study will be outlined, and the degree to which they achieved or underachieved will be explored both in terms of educational qualifications and the degree of career choice open to them. The role of personal agency (in this context this refers to self-motivation) on the part of the young people will also be considered. Finally, the availability of adequate resources for the education of profoundly physically disabled people will be outlined with reference to the research sample.

As with the rest of the thesis, the data is based entirely on the research sample's accounts of their experiences in the education system.

This section will briefly discuss the development and role of segregated education in terms of the policy process and the increasing influence of various professional groups. The chapter will then document the young people's perceptions of the ways in which the education system influenced their transition to independence.

The Development of Segregated Education

Provision for children experiencing difficulties began with a school for deaf children in 1760, and for the blind in 1791. Schools for those with learning difficulties and physical impairment were founded in 1847 and 1865 respectively. These were all created by charitable initiatives and emphasis was placed on training rather than education in order to enable them to gain employment and contribute to society (Solity, 1992). The 1870 Education Act led to the extension of elementary education, and school boards were required to set up special classes for those with physical and sensory handicaps. It was not until the early part of the twentieth century that it became mandatory for school boards to make provision for those with physical impairments.

Early formal state education was characterised by a 'payment by results' scheme which further influenced the development of segregated education. Teachers salaries were linked to the educational achievements of their children with the result that those children whose performance was below par were perceived as posing a threat to the wage packet. Many teachers responded to this by stating that the cause of difficulty lay with the child, in that he or she was having difficulty learning, and that other forms of provision were indicated which were preferably outside the mainstream setting (Solity, 1992)

The growing currency given to intelligence testing as:

> A major 'educational' instrument aimed at ascertaining children's learning potential (Solity, 1992:4)

further legitimated the view that poor progress was attributable to the personal characteristics of the child. Intelligence testing was advocated in Britain by Burt, who used such tests to identify which children should be withdrawn from mainstream education and placed in segregated schools. The tests were based on the notion that children with an IQ of less than 70 would not be able to make sufficient progress in mainstream education and would therefore be better suited to segregated provision.

It can be seen that the strength of the individual model (i.e. that difficulties arise due to the characteristics of the child, rather than the type and level of provision on offer), has its roots in the earliest forms of voluntary sector provision outlined above which was established on the basis of clearly identifiable medical conditions.

The focus on individual characteristics was strengthened by the advent of the 1944 Education Act. Intelligence testing and differential forms of education were integral to the act within which those with difficulties were described as having 'disabilities of body or mind', (cited in Solity, 1992:5) clearly implying that problems were a result of a defect in the child. This Act established the framework for the education of disabled children which operated until new

legislation, in the form of the Education Act 1981 came into force. The 1944 Act defined ten categories which merited segregated education: blind, partially sighted, deaf, partially deaf, delicate, educationally subnormal, epileptic, maladjusted, physically handicapped, and speech defects. There was a further category for children who were considered to be 'uneducable' in the opinion of doctors, and were the responsibility of the health authority (Sandow, 1994).

During the 1950's and 1960's segregated education expanded steadily. Educational psychologists increased in number and the intelligence test was the main instrument for assessing children's learning. However, reservations about the legislation and the practice were increasingly voiced. The ten categories of handicap were increasingly derided and scepticism increased about their usefulness in describing the needs of disabled children due to the heterogeneity of impairment which made the labels very difficult to apply. Also, the concentration on the impairment following the medical model of assessment was increasingly criticised (Sandow, 1994).

It was not until the mid 1970's that the validity of offering segregated provision for those categorised as experiencing difficulties was increasingly questioned. Educationalists concerned about promoting equal educational opportunities realised that segregation was incompatible with the aim of offering:

> All children equal educational opportunities irrespective of their gender,

race, social class, or perceived level of ability (Solity, 1992:6).

The emphasis was increasingly on integrating children with difficulties into mainstream school. The Warnock Report which had been commissioned in 1974, was published at the end of the 1970's and it effectively shaped attitudes and practice in the 1980's. Some of the Warnock philosophy was in the 1981 Education Act on Special Needs, which came into force in April 1983. Briefly, the report:

- Suggested that the aims for children with special needs be the same for all children;
- Replacing notions of handicap with that of children's special needs;
- Promoted the concept of integration;
- Saw assessment as a gradual process taking place over time. (Cited in Solity, 1992).

The 1981 Education Act resulted in changes in four areas of special educational provision. These were the concept of special educational need, provision in ordinary schools, identification and assessment, and statements. These will be briefly outlined below:

The Concept of Special Educational Need

Under the Act a child is categorised as having a special educational need if he or she has:

> A learning difficulty which calls for special educational provision to be made (Haskell & Barrett, 1989:175).

A 'learning difficulty' is defined as the situation where a child has a greater difficulty in learning than the majority of children of their age, or if they have an impairment that hinders or prevents them using mainstream educational facilities generally available to their peers (Haskell and Barrett, 1989). Special educational provision under the Act is defined as 'educational provision which is additional to, or otherwise different from, the provision made generally for children in schools maintained by the local educational authority concerned' This group is sub-divided into children who remain the responsibility of the school and who are in mainstream provision, and a minority of disabled children in segregated education who are the responsibility of the Local Education Authority (Haskell & Barrett, 1989).

In terms of assessment, there is very little said about the majority of disabled children who are in a mainstream setting. Schools are supposed to 'use their best endeavours to provide an appropriate education for them'; and teachers must be

told about the special educational needs of their pupils and make the necessary provisions. Children in segregated education must be formally assessed according to rigid procedures and the results communicated, in theory, with a similarly strict adherence to the rules (Haskell & Barrett, 1989). The local authority also has a responsibility to provide a nursery place for all children with special needs whether formally assessed or not. Formal assessments can be invoked from the age of two years onwards.

In terms of the concept of special educational needs, the 1981 Act has had a major impact in that it moved the assessment criteria away from a medical focus to an educational one.

Provision in Mainstream Schools

The mainstream school is viewed as the optimal place of education for all pupils except in special circumstances. The school has a duty to ensure that 'the child engages in the activities of the school, together with children who do not have special educational needs' (Cited in Haskell & Barrett, 1989:176) The Act also states that the wishes of the child's parents should be taken into account.

There are however some provisos to these requirements. These are that the child is receiving the special education that he or she needs; that this arrangement is compatible with the efficient education for the children with whom he or she will

be educated; and that it constitutes efficient use of resources. (Haskell & Barrett, 1989).

Identification and Assessment

For children educated in a mainstream school, assessment takes place within the school setting with the help of external specialists as necessary. The Act stipulates that parents must be involved and informed at every stage and it should be a continuous process which determines class teaching and monitors progress.

Where segregated educational provision is indicated, a formal assessment has to be made. This follows strict guidelines and is multi - disciplinary in nature. Medical, psychological, educational and specialist personnel are involved. It is stipulated that parents must be actively involved at every stage and have the right to request a statement of special educational needs. The statement specifies the child's special educational needs in detail and the provision made to meet those needs. In cases of dispute, parents have the right of appeal to the Special Educational Needs Tribunal which is an Independent body set up in September 1994. Prior to this, parents could appeal to the Secretary of State for Education (Haskell & Barrett, 1989; Department of Education, 1994).

Statements

Local Authorities are required to review the statement every twelve months and inform the parent of any changes made. If a person is still the subject of a statement of special educational need at age fourteen a further assessment is mandatory when he or she leaves full-time education. This review is described as being of particular importance:

> In preparing for the move to further education and adult life. This review will involve all those people and organisations who will play a major role when the child leaves school....Including the careers service and the local social services department and [it] will produce a transition plan for the child's move to adult life. The child and its parents will be asked to help draw up the plan. (Department of Education, 1994:31).

This multi - agency co-ordination should mean that relevant information is transferred thus ensuring that young people receive the necessary specialist help and support during any continuing education, vocational or occupational training after leaving school. With regard to young disabled people, the role of social services departments is of particular importance which is reflected in the legislation. Under Sections 5 and 6 of the Disabled Persons (Services, Consultation and Representation) Act 1986, the Local Education Authority (LEA) is required to seek information from social services departments as to

whether a child with a statement under part III of the Education Act, 1993 is disabled and may require services from the local authority upon leaving school. The LEA must inform the appropriate officer at the local social services department of the date of the child's first annual review after his or her fourteenth birthday, and must also inform social services of the disabled child's expected leaving date eight to twelve months prior to the date in question. (Department of Education, 1994).

The Local Education Authority's responsibilities are as follows:

Table 6.1 The First Annual Review At Age 14
The LEA convenes the meeting and must invite the child's parents and other people it considers appropriate.
The LEA must ensure that other providers such as social services, are aware of the review and the procedures to be followed. It must invite social services to the review to ensure the pooling of information from other assessments under the Disabled Persons Act (1986); the NHS and Community Care Act, 1990; and the Chronically Sick and Disabled Persons Act, 1970.
The LEA must invite the careers service to be represented at the review to enable all options for further education, careers and occupational training to be given serious consideration. The careers service will also be able to identify specific targets which should be set as part of the annual review to ensure that independence training, personal and social skills, and other aspects of the wider curriculum are addressed during the young person's last years at school.
The LEA prepare the review report and the Transition Plan after the meeting, and circulate these to the young person's parents, the head teacher, all those from whom advice was sought, all those attending the review meeting and any others the LEA consider appropriate. It is important that the LEA consider passing the review report and Transition Plan to the Further Education Funding Council, particularly in cases where a decision might need to be taken about specialist college provision outside the further education sector.

Source: Department of Education, 1994:117

The transition period is acknowledged as being of critical importance:

> As [it] may be associated with increasing levels of disability in some young people. It may be necessary to plan for future increased special needs and for the provision of aids and adaptations both in a home or an educational setting. (Department of Education, 1994:120).

Some children with statements of special educational need will remain in school beyond the age of sixteen, in which case, they remain the responsibility of the Local Education Authority until they are nineteen. Others may have moved to further education or to social services provision. Regardless of future plans, the annual review at age fourteen is of particular importance.

The local education authority also has particular responsibilities with regard to the provision of information to children and their families on the point of transition. They have to ensure that the young person is aware of the power of the social services department to provide assistance beyond the age of 18 .They also have a duty to provide any relevant information to the local social services department in order to alert them of any future special needs.

To what extent is this put in to practice? Social services themselves are duty bound under Section 24 of the Children Act 1989 to make arrangements for young people over the age of eighteen who are regarded as 'being in need' and who have been looked after by the local authority or who have been in receipt of services from them prior to that date. It is of course the case that some young

people may choose *not* to be assessed as disabled under sections 5 and 6 of the Disabled Persons Act and may also choose *not* to request help through the local authority community care arrangements. In this instance the LEA has to provide details of voluntary organisations and professional counselling services if such advice is needed. Schools should also have information on local sources of help, including disability organisations in the area which can provide information on services and offer independent advice and advocacy if needed. (Department of Education, 1994).

In cases where a child has attended a residential school outside his or her local authority, the LEA still has specific responsibilities, namely that of seeking liaison between all relevant LEAs and social services departments. (Department of Education, 1994).

The 1981 Education Act has been described as:

> Marking a milestone in special education. The whole emphasis of categorising children and designating where they should be educated has altered. Parents have a positive, legal role to play. Voluntary organisations are brought in for advice. A multi - disciplinary approach to assessment is assured and Statements of Special Educational Need are legally binding. Regular review is compulsory and nursery education must be provided. (Haskell & Barrett, 1989).

It could be argued that children with special educational needs are better catered for than the majority before the 1981 Act. Many examples have been chronicled of individual integration in various settings. (Cole, 1989).

However, whilst the situation has undoubtedly improved, a number of concerns have been raised with regard to the efficacy of the legislation. These will be outlined below.

The 1981 Act: Rhetoric or Reality?

The legislation has been criticised for failing to recognise and address the important social function played by segregated education; that of maintaining a homogenous and controllable population within general education. (Tomlinson, 1982; Christensen and Rizvi, 1996). A number of writers have commented that the exclusion of children from any form of education for reasons of physical condition, and the segregation of other children in special schools or classrooms, constitutes a violation of fundamental human rights. As such practices are:

> Stigmatizing and deterious to student, and, given the demonstrable lack of efficacy of the segregated setting, indefensible in terms of serving student's interests. (Christensen & Rizvi, 1996).

Concerns have also been voiced about the extent to which the legislation,

although less medically orientated, still focuses attention on individual failings in that professionals, writing advice for statements, still tend to concentrate on the child's difficulties rather than considering his or her strengths and weaknesses and the individual's relationship to the environment both in the home and at school. (Evans and Goacher, 1989).

It has also been found that statements are being used as a means of removing children from mainstream education, rather than looking at the provision of extra support in the child's present setting to enable his or her needs to be met there. (Evans & Goacher, 1989). The numbers of children in segregated education are increasing; in particular, fifty two week placements in residential schools. (Russell, 1994; cited in Morris, 1997:254). There is evidence to show that disabled children are being placed in segregated education for social care reasons rather than educational ones, and that this can sometimes be a response to family breakdown and/or parental rejection. (Morris, 1997).

The picture was further complicated by the 1988 Education Reform Act which has been described as 'the most comprehensive piece of legislation to be directed at education since the 1944 Education Act'. (Clough and Lindsay, 1991:154). It laid down the direction for education for at least the next forty years. Unfortunately it is considered by many to have undermined the 1981 Education Act, as special educational needs are not a major concern of this legislation. (Clough & Lindsay, 1991; Sandow, 1994).

The most damaging elements of this legislation from the standpoint of special needs relate to the way in which schools are funded. Funding is dependent on the number of pupils and this, in turn, is affected by the schools performance in terms of its position on the league tables of aggregate achievement in the National Curriculum. Thus there is a potential disincentive for schools to take pupils with special needs and the situation has been worsened by the fact that LEA budgets have been reduced by Community Charge Capping, loss of funds allocated to 'opted-out' grant maintained schools and the cut-backs in monies available for central services to support pupils with special educational needs. This has resulted in an increase in the percentage of pupils with statements of special educational needs in LEAs, as this procedure offers financially straightened schools an alternative means of resourcing special needs since money can then be obtained from the LEA. (Sandow, 1994). A survey carried out by the Institute of Education found that 50% of LEAs reported an overall increase in the numbers of pupils placed in segregated schools. (Lunt & Evans, 1991; cited in Sandow, 1994:21)

Linked to the above point, concerns have also been voiced as to the extent to which a market driven education system will exclude disabled pupils from the National Curriculum:

> There is a bleak consequence of the market-led concept of education and that is the inescapable fact that in the market-place some are

> losers....What if a 'bad' school fails to come up with the proper examination results because it has a lot of 'bad' pupils who are unable to pass examinations? What will happen to such pupils in the future? We are already told that schools may 'exempt' certain pupils from the National Curriculum tests. There is a real danger that such pupils may also be 'exempted' from the National Curriculum itself (Warnock, 1991; cited in Sandow, 1994:29).

There has been concern that the battery of tests associated with the National Curriculum which have to be carried out at ages 7, 11, 14 and 16 will lead to the marginalization of the pupils who do not do well in the tests. (Barton, 1988; Clough & Lindsay, 1991). Some pupils may unfortunately be labelled a 'level 1 child'.

Problems have been highlighted with regard to the use of the concept of 'ability' within education, a trend which has been further fostered by the emphasis on assessment associated with the National Curriculum. Some commentators have argued that even though intelligence tests are no longer used to ascertain ability, the language of this procedure still abounds in the form of tests associated with the National Curriculum, and that this may:

> In the most negative instances, lead to children quite arbitrarily being identified as lacking intelligence or ability, with the consequence that

expectations for their future learning are low. (Solity, 1992)

On a similar vein, the fact that there has been a basic assumption that there is a foolproof assessment for ascertaining that a child has special needs has come under scrutiny. As mentioned above, in recent years faith in the objectivity and scientific validity of mental testing has markedly reduced, and for disabled children the most crucial time in terms of their educational career is the period when they are assessed. It is this which sets them on a different path through the education system. (Tomlinson, 1982).

The power of the professional experts, who work in the special education field, to make judgements and decide what is best for others has been increasingly questioned. The view has been taken that it is the power of the older established professions (medical and psychological) which has legitimated the assessment process within special education. The number of professionals working within special education has increased greatly, and some commentators argue that professionals have a vested interest in expanding the number of children assessed as having special needs. (Tomlinson, 1982).

Professional's power is bolstered by the individualization of need, i.e. the notion that 'you are the problem' and 'I, the professional expert, am the answer' (McKnight, 1987, cited in Barton, 1988:201). This removes people and their difficulties from any social context, and the multi-disciplinary approach to

special education further increases the powerlessness of the individual as their life becomes increasingly compartmentalised. The fact that professionals are members of socially dominant groups and maybe distant from the working class further enhances their mystique and makes questioning their decisions more difficult. (Tomlinson, 1982).

Apart from the assessment process in special education being dominated by professional power, the situation is further complicated by the ad hoc nature of the process. The process of assessment varies in efficiency and sensitivity amongst authorities. Long delays between the start of procedures and the completion of statements have been documented (Evans & Goacher, 1989). Parents have not been informed of the reasons for delay or given any indication of the length of time they will have to wait. There is evidence of a lack of feedback to other departments and services about the outcome of assessments with Health authorities and social services departments not informed of the decisions made about children about whom they had given advice. The wording of statements was found to be vague and imprecise. (Evans & Goacher et al, 1989).

Whilst guidance is lacking on the statementing procedure for the minority deemed to need statements under the 1981 Education Act, advice is even more scarce with regard to the majority of children with special needs which could be met within the mainstream system. This impacts at both LEA and teacher level,

and makes the process of establishing which category children fall into much more difficult. (Solity, 1992). It is also the case that special educational provision varies from one local authority to the next and from one school to the next. (Solity, 1992).

With regard to the involvement of parents in decision making, whilst the 1981 Act gives parental involvement a high priority, in reality there have been a number of problems. These will be briefly outlined below.

The 1981 Act states that parents should be given the name of an 'officer' from whom they can obtain information about the procedures involved in assessing their child's special needs. However, there is evidence that few parents use this point of contact, preferring to use a person known to them such as the head teacher or educational psychologist. And it is also the case that many parents feel isolated and unsupported during procedures. (Evans & Goacher, 1989). Many of the information booklets designed for parents have been found to be misleading, incomprehensible or incomplete and do not encourage parental participation in the assessment process. (Evans & Goacher, 1989).

Also, because the majority of statements tend to be worded in an imprecise manner without the aims of any intervention specified, and the resources offered to achieve aims do not relate to needs in any specific way, it is very difficult for any parent to challenge the provision offered to their child. When one considers

that parents are often unaware of the timescales involved (see above), active participation in the assessment process is problematic.

Added to these difficulties are the resource constraints faced by LEAs which may lead to a limited range of provision on offer which means that there is little choice about the final placement for a child. There has been a lack of frankness on the part of LEA officers with parents about the limitations of provision and instances where officers have tried to manipulate or coerce parents into accepting provision for their child which they considered to be unsatisfactory. (Evans & Goacher, 1989).

Some parents may be further disadvantaged by the increased professional involvement in the assessment for special education. Whilst the professionals benefit from this in terms of more clients and therefore more work, it may place parents and children at a disadvantage with ever more experts trying to persuade them that they have special needs. (Tomlinson, 1982).

There is evidence from empirical investigation of various special education programmes which has shown that a number of labelled students demonstrate no detectable evidence of impairment, disorder or disability. Many special education students deviated from the norm on social, cultural, ethnic and economic dimensions rather than on sensory, intellectual, physical and emotional dimensions. Special education was shown to comprise disproportionately large

numbers of students from poor or minority backgrounds. (Mercer, 1973; Algozzine & Ysseldyke, 1983; Barton, cited in Christensen & Rizvi, 1996; 1988). Given that it has been documented that professional behaviour does vary with the social class of the client (professionals are more likely to take note of the wishes of middle class families) (Tomlinson, 1982), many children and their parents may be disadvantaged.

In conclusion, the 1981 Education Act has been a stimulus for change in the provision of services to disabled children and their parents. There is an emphasis on parental involvement in decision making, change in the way in which children with special needs are categorised, and the act seemed to focus attention on more children with special needs remaining in ordinary schools. However, the impact of the act has been undermined, to a large part, by the resource constraints faced by local education authorities which makes the choice of provision open to disabled children and their parents very limited.

Special education has not only been a low priority with regard to government funding. Although people with special needs could be regarded as one of the most disadvantaged groups in society, the issue of equal opportunities with regard to special education has been ignored by policy makers. (Barton, 1988). There is evidence to show that it is a neglected area within sociology too. (Tomlinson, 1982; Barton, 1988). Also, with regard to the literature that is available on special education, whilst some focuses on parents experiences

(Evans & Goacher, 1989; Solity, 1992; Sandow, 1994), exploration of the disabled child's view of the system is extremely scarce. It is this which the next section will address.

EDUCATION FOR THE FUTURE?

This section will focus on the young disabled adults' perceptions of the education that they received. The issues covered were ones which the disabled people indicated were of great concern during the course of the interviews. The following issues will be explored: parental role, professional assumptions, encouragement by parents and teachers, interruptions to education, achievement and underachievement, career destination, the role of personal agency, and the impact of resource levels on the classroom situation.

The interviewees ages ranged from 17 - 31 years at the time of interview during 1995. 4 out of the 42 (those aged 19 or under at the time of interview), had begun their education after the introduction of the 1981 Education Act. The remaining 38 had begun their education prior to the Act and therefore would not have had access to the statementing procedure, and the decision about their education was made at a time when education in mainstream schools was considered to be less of an option. All but five of the sample had attended segregated school on a day or residential basis. Out of the five, two had attended private (mainstream) schools, one had attended a local Comprehensive school on a fully integrated

basis, and two had attended special needs units in Comprehensive schools out of the study area.

Parental Role

The importance of family support in preparing disabled young people for the transition to adulthood and independent living in the community has been documented in the previous chapter. However, it became apparent during the course of the interviews that parents had an important role to play in terms of securing the most appropriate educational provision for their child. This was particularly so prior to the 1981 Education Act, and is still the case today given the shortcomings of provision documented above. Examples ranged from parents who had been determined to secure the best provision for their child to those who had shown little or no interest. Unfortunately, most of the individuals had little idea as to whether they had been given a statement of special need. However, the range of experiences will be outlined below.

A minority of the sample stated that their parents had played an active role in determining the type of school that they attended. Lisa described how her parents had opted to send her to a private girl's school:

> The local grammar school said....we don't want you to come here and interrupt the schooling of the rest of the pupils...at which point my

> parents told them to get lost. We opted for a private girl's school and I stayed there until I did my A-levels.

There was an example of parents who were teachers making every effort to ensure that their son did not enter segregated education despite being told that he would be unable to cope in mainstream provision. Christopher said:

> When I was born, my parents were told when I was four months old that I wouldn't be able to walk, speak, read or write. I have proved them all wrong. My mother and father sent me to private school. It was not a disabled school. They have supported me all the way and still are. My mother knows all about it because she is a teacher.

There were examples where parents had fought to have a Local Education Authority decision about their child's education overturned. Zoe said:

> They wanted to send me to a mentally handicapped school somewhere near Leicester and I'm not mentally handicapped. My mum hit the roof. I went to another school.

There were other examples given where parents had used the local radio station to secure a place for their child in the local segregated school. There was also an example of parents moving their child from a segregated school because they

were unhappy with the provision. Clare said:

> When I first started school, right from the age of two, I went to a totally disabled school. Then my parents took me out of there and put me in the local co-ed school.

Other parents had wanted their child to go to segregated school as they had been unable to cope. Felicity said:

> My Dad was in the Air force so we were abroad a lot. My parents couldn't cope and that was the easiest option or putting me in a home.

This was an example of a disabled person being placed in residential segregated education for social care reasons rather than educational ones. There were examples of parents wanting their son or daughter to go to a segregated school because they thought that it would ensure that they got an education plus any necessary physiotherapy and personal care. Irma said:

> My parents were forming the idea that ' she should go to special school she does need this treatment, she does need protecting, she couldn't cope'.

There were instances where parents were persuaded by the professionals in the

field that segregated education was the best option for their child. Vera acknowledged:

> My parents always fought for me and did what they thought was best. Of course that isn't always right because what they think is best isn't best. If I put myself in their position, they were told by professional people teachers, physiotherapists and occupational therapists, who surround disabled babies and children, that segregated school was the best course of action so they did that.

The rest of the sample were unclear as to how they came to be in segregated education. There was no mention of parents taking one stance or another as with the cases above. It seems that these parents went with the system whether happy or not.

Professionals' Assumptions

Professionals such as teachers make assumptions about the ability of the children they teach. The type of assumption made (whether positive or negative) determines their level of expectation with regard to a certain child or group of children. As documented above, in education there has always been a strong emphasis on the individual model i.e. if a child is having difficulties, those difficulties stem from a problem inherent in the child. No consideration is given

to the possibility that difficulties might be a result of a particular learning environment. Teachers' assumptions have been based on the result of intelligence tests which led to certain children being labelled as having a low intellectual capacity which resulted in an inability to learn effectively. (Solity, 1992). Teachers have been informed by a number of myths that pervade special education. (Solity, 1992). These are that:

> The number of children experiencing difficulties during their school careers may be as high as one in five, that children with difficulties need one -to-one tuition, that they cannot concentrate for long periods etc. These commonly held views set the agenda for how we think about children, how they learn, how they can be taught, and where they should be taught. (Solity, 1992:24)

Teachers are also informed by the literature that has been produced on the types of impairment experienced by disabled children. For example the literature describes cerebral palsied children with hemiplegia as likely to experience a loss of vision on either the left or right half of the visual fields of both eyes. This is found in approximately 25% of children. (Tizard, et al, 1954; cited in Haskell & Barrett, 1989:27).

The literature also states that:

> The abnormal patterns of behaviour frequently associated with cerebral palsy (CP) children, which are considered organic, must be mentioned. These include hyperactivity, emotional liability, attention peculiarities (short attention span or perseveration), low frustration tolerance, impulsivity and distractibility. (Haskell & Barrett, 1989:28).

On one level, it is an inescapable fact that visual impairment is the child's problem and whatever the quality of the teaching, this situation will remain unchanged. However, it is important to acknowledge that:

> It is dangerous to infer that these are homogeneous groups of children who inevitably experience problems. It is now recognized that children adapt and respond in a variety of ways to potentially handicapping conditions, and the curriculum and teaching approaches are just as important in determining learning outcomes as for any children thought to have difficulties. (Solity, 1992:19).

As with physical impairments, it is the case that blanket assumptions have been made with regard to the level of attention deficit experienced by cerebral palsied children. (See above). And it is from this sort of comment that the myth, that children with special educational needs have greater difficulties in concentrating, has been generated. (Solity, 1992).

Research which examined children's learning experiences in primary schools has found that whilst teachers were able to ascertain when the work they gave pupils was too difficult because children became distracted and did not concentrate on the task to hand, they *never* estimated that the work was too easy, because the children were able to concentrate on the easy tasks. (Solity, 1992). The children in the study did not have a concentration problem per se, as they would have found it impossible to concentrate on the easy tasks too. The study concluded that:

> It is likely that the extent to which they can concentrate is closely associated with the work that they are given. Where it is purposeful, meaningful and stimulating, children are more likely to display suitable levels of concentration than when this is not the case. (Solity, 1992).

Children with special needs face an uphill struggle against such myths which exert a powerful hold on educational culture. They influence the thinking about disabled children, the ways in which they learn, their behaviour, and how and where they can be taught. (Solity, 1992). These issues will be explored below with regard to the research sample.

The disabled young people interviewed voiced strong views that the level of expectations held by teachers had a great deal of influence over whether they achieved or underachieved in the education system.

Some of the sample were very satisfied with the teaching that they had received and had done well educationally. Lisa's comments were typical. She said of her private school:

> They pushed the pressure to be good, to be academic on to all their students. They expected me to do well regardless of my disability.

There were other individuals who had not done well in terms of educational qualifications but, nevertheless, were happy with the teaching that they had received. Robert, who had been fully integrated into a local Comprehensive school said:

> I had help as and when needed. The teachers that took the time to understand the difficulties that I had and that had the patience to help me overcome them and help me to achieve the same as everybody else were good compared to the ones who said 'oh, well'. I did eight GCSE's the highest I got was a grade D.

Andrea said of her segregated school:

> I am very slow at writing because I am left handed. But the teachers did take their time with me and sat and helped me. I did all the subjects that I could have done at school and I did quite well with them. I didn't do

> any exams because they thought that it would be hard work for me and I was happy with that.

However, the individuals who were satisfied with the teaching they had received were in a minority. Most of the sample were extremely dissatisfied and felt the low expectations of their teachers had seriously undermined their future prospects. Marjorie's comments were typical:

> I thought I was slow. You grow up thinking you are slow...that you aren't as fast as everybody else. It turns out it is not that at all, it's the way I have been taught. I was taught at such a slow steady pace at my special school.

Sophie said of her segregated school:

> Everybody said that I couldn't concentrate on anything. I used to sit there in class wishing it was all over because I was so bored. I wanted to get out and do something else.

The low expectations of some of the segregated school staff were made painfully apparent to some of the sample when, in line with the 1981 Education Act, segregated schools started integrating some of their pupils into local Comprehensive schools for a limited period during the week. Irma's comments

were typical:

> I think it was just like certain people said I was slow and you start thinking it. When I joined the classes at the Comprehensive school, I did find out that I couldn't really keep up very well. I think my special school slowed me down you know. Some of the teachers told me I was slow. I think my slowness had a lot to do with the way I had been taught. I don't think special schools are a good idea really because it is mostly all physio.

The assumptions made by professionals in the special education field were not the only concern of the research sample. In many instances professional assumptions, whether positive or negative, may have influenced the amount of encouragement that disabled people received with regard to their education from both parents and teachers. These issues will be explored below.

Encouragement

Some of the sample were very positive about the encouragement that they had received from parents and/or teachers. Examples of encouragement ranged from motivating pupils to succeed at particular subjects whilst at school, and/or directing them on to further education. There were examples given of lecturers in further education colleges encouraging students to try particular courses or

subjects. The role played by teachers will be discussed first. Robert who attended a local Comprehensive school on a fully integrated basis said of his teachers:

> The teachers were brilliant. They put me in the right direction, put me to college. They didn't push me into it, they helped me into it really so I did pretty well.

Christopher said of the teachers at his private school:

> My view is that I was given the best possible treatment that I could get. They told me that I could do any subjects that I wanted, that I felt comfortable with and I picked my four best subjects and tried to get good grades. They did help me. The state schools didn't want to know me.

Some individuals commented that their teachers only encouraged them in the subjects that they were perceived to be good at and that they got little or no support in the weaker areas. Vera said of her segregated school:

> I really did get a lot of support from the teachers....in the subjects I was good at or was told that I was good at.

Examples were given of teachers actively encouraging individuals to go on to further education because they thought that the young person would benefit. Josie

said:

> They did encourage me and tell me about the college in Coventry which they thought would benefit me more than the local ones. It was residential.

There were instances where individuals had not been encouraged by their teachers whilst at school but were encouraged by the lecturers in the further education colleges which they were attending. In general, the sample were more positive about their experiences at college than they were at school. Kevin said:

> I was happy at college because I thought that I needed more education and at college I got more education than I did at school. I got better maths and I was encouraged to do computers which was more interesting.

Nigel commented:

> I wasn't encouraged to do any exams whilst I was at school but when I first went to college they allowed me to do what I thought I could do. I did O-levels and got five O-levels and two A' levels grade C.

Karl recalled:

> They didn't think I was capable of doing exams whilst I was at school because they thought I was slow. I was very, very, disappointed and basically since I have come to college I have proved them wrong. I have got qualifications in typing, English, and office administration.

Angela said:

> I had an assessment which showed that I am dyslexic and the school didn't help me at all. They just sat me in a corner and wouldn't let me do any exams. I am at college now where I am doing GCSE;'s in English and Maths. I take my exams tomorrow. I used to get so frustrated at school. I enjoy the work at college. They said I couldn't do anything at school but I knew I was capable.

There were few criticisms of the further education sector in terms of encouragement offered by staff. A few individuals felt that the college had been too directive in terms of the courses that they had been allowed to do (this issue will be explored later in the chapter), but negative comments were in the minority.

The individuals who said that they had been encouraged by their teachers at school were in a minority. Most of the sample felt strongly that they had received little or no encouragement to do well at school as some of the quotes above

demonstrate. Jane who had attended a segregated school said:

> They didn't give me the level of support I needed at school because I think that they had their favourites...If they didn't think you were good enough they would go to somebody who they thought could basically get on. They just didn't want to spend the time. I know I was slower than everybody else but I didn't have any real problems.

There were instances where encouragement from parents had been as important as that received from teachers and this became of central importance where support at school was lacking. Parental encouragement ranged from helping with homework to motivating their child to continue trying. Marjorie's comments were typical:

> I was ready to pack up. I had no support at school, but my mum and dad said 'you are better than that. Instead of letting it bother you, you have got to think sod you, I'm going to do it anyway' so I did.

The majority of the sample were not as fortunate as Marjorie in that they had parents who either felt that their child was incapable of achieving at school, or felt that education was the sole province of the school or they felt unable to offer encouragement. Some parents felt that education was unimportant. Comments by Zoe and Violet graphically illustrate these points. Zoe said that her parents:

> Had lower expectations than the teachers. They didn't think that I would get any GCSE's [she got two grade C's]. Dad's got me down as a bit of a no - hoper really, because my English and maths are so bad.

Violet recounted:

> I was always the only one in the class aged 15 who could not tell the time. Nobody has ever taken time out to teach me. My mum and dad said that it was the responsibility of the school to teach me those things. Nobody tried to teach me until the second year of college...I was so embarrassed. My parents knew I couldn't tell the time.

During the course of the interviews the effect of interruptions to individual's education was frequently mentioned and were a cause of great concern to the young people. Their experiences will be explored below.

Interruption to Education

The causes of interruptions were hospitalisation, often for corrective orthopaedic surgery, or time lost in class due to having to attend physiotherapy sessions. Many of the young people could not see the point of the sessions and resented the fact that they had been made to walk to no avail. The need for physiotherapy had never been adequately explained to the young people and all physiotherapy had

ceased once the individual had left full-time education. There were examples where great effort had been made to avoid interrupting schooling, with operations scheduled for school holidays and/or physiotherapy timetabled out of school hours. The problem was particularly acute with regard to segregated schools. However, there were examples of segregated schools making great efforts to minimise disruption: Anthony said:

> I had physiotherapy every day of the week after school. As soon as the bell went I was dragged out for a half an hour session.

One person had physiotherapy during her lessons. Felicity said:

> We never went out to physio, the school didn't believe in that because you missed lessons. We used to have physio during the lessons. I think this was good because you were still there, and it also meant that the physio was consistent. It didn't affect my concentration because I had been brought up with it since age five.

Physiotherapy was less of an issue for the minority of the sample who had attended private or mainstream schools. In all cases it was scheduled out of schools hours with academic work made a priority.

The majority of the sample attended segregated schools and experienced great

difficulty due to physiotherapy interrupting their lessons and the issue was contentious. Whilst a minority felt they had benefited from physio, the majority felt that they had received little benefit from having physiotherapy. Most felt that the disadvantages from interruption far outweighed any benefits the physiotherapy may have brought. All were wheelchair users or had severe mobility difficulties at the time of interview. Three out of forty two people felt that physio had helped. Debbie's comments were typical:

> I missed out on a lot of education through having physio. I had too much physio all day long. As soon as I went into school in the morning I had to go straight into the physio room. You would have physio for an hour or so and then go back to your class. A few hours later you would be called back to physio...I had no schooling!

Sophie said:

> I missed out on a lot of education because I spent most of my time in physio. From the time I got to school the teachers didn't know I was there because I went straight to physio. I didn't make my legs any better either.

Irma said:

> I haven't walked for ages. They used to make me walk all the time in

> calipers when I was a child and it was very tiring. I don't really think it did much good...and it was disruptive to my education although, saying that, in most of the groups at my school you could do more or less what you liked as long as it was some sort of education...I don't think I would like to walk again. I cope alright in a chair. I wouldn't be able to live in my own flat without my wheelchair as my balance is so bad.

Many of the disabled people interviewed felt that the curriculum had been weighted too heavily on the side of physiotherapy. The balance of the curriculum was not the only concern of the young disabled people interviewed. Many felt that they had been disadvantaged by their attendance at segregated school for other reasons which will be outlined below.

Segregated Education - Benefits and Costs

Whilst some of the research sample said that they were pleased that they had attended a segregated school, many of the young people interviewed who had attended segregated schools said that they felt that they felt socially isolated and cut off from the outside world, and the lack of opportunity to mix with non-disabled people was a source of great frustration.

Segregated schools have been viewed as playing a positive role in that:

> Segregated schools can limit the anxieties and frustrations and sense of failure arising from comparisons with non-disabled peers. It is argued that because their disability is understood and accepted a more positive self-concept can be fostered....on the other hand, a fully segregated school with...lower expectations of the child than mainstream education, can present an unrealistic view of the world....and can leave a young person ill - prepared for adjusting to adult society. (Hirst & Baldwin, 1994:58).

Some of the sample felt that segregated schools did offer some advantages. Lisa, who had been to a private girl's school commented:

> I always used to have a debate with a guy who had been to special school who said that he would have done anything to have gone to a mainstream school and I was so shocked because he was wonderfully confident, he liked himself. He was all the things I wasn't. I hated myself, I didn't like being disabled, I disowned it. I was very, very unhappy with life and I think he had a very good life. He'd gone to special school, I hadn't and I realised that I needed to be with other disabled people for the sake of my identity. And that is the only benefit special schools have - a sense of identity.

Pam said:

> I didn't mind being at special school. I enjoy being with disabled people because they are one of me sort of thing.

Some individuals considered special education to be the only option for them due to the nature of their impairment. Felicity said:

> Thinking about it now, if I had gone to mainstream I wouldn't have got an education because I was too slow physically because of my speech. It was a lot worse then. I would have got left behind. I benefited educationally.

The people who viewed their attendance at a segregated school in a positive light were in a minority. Most of the sample felt that it had been a negative experience which had left them ill - prepared for life outside school. Vera commented:

> When I was at segregated school I wasn't politicised so I didn't think of myself in terms of a disabled person and being proud of that. I wasn't aware of the barriers that I faced. I thought it was my fault because all of us at segregated school internalized the ideas that non disabled people had about us. I mean, we even had this hierarchy with people who had invisible impairments such as haemophilia at the top and those who were able to do the least for themselves in terms of function were at the bottom of the pile.

Elizabeth complained about the lack of opportunity to mix with non-disabled people:

> Being at special school hindered me because now I can't imagine anything except interacting with disabled people, no offence, but it is hampering when you are trying to get on with what you have to do - you have got to do a job, something that normal people have to do.

Many of the disabled people described the way that segregated school had made them dependent. Vera's comments were echoed by the majority of the sample:

> I think that segregated school doesn't really prepare you for life because although the teachers pretend that you are making decisions, you are not. You are placed in a position of dependency where you feel that you can't actually make those decisions and you lack confidence because the way the system treats you, and my school was one of the more academic ones. That feeling stays with you.

Many people felt that attendance at segregated school had prevented them from learning to form relationships. This was even more the case when they had attended a residential segregated school. Felicity said:

> Being brought up in an institution didn't give you the opportunity to form

> relationships, the others got in the way, I haven't had any relationship even with my parents and that has been more of a disability than the disability itself.

Many people were at pains to stress that the schools made no attempt to prepare them for adult relationships and this was a source of great anger. Marjorie's comments were echoed by many people during the study:

> We didn't get sex education until we were sixteen at my segregated school and then they sent letters home to the parents asking permission. It was so embarrassing. I mean no able-bodied teenager would have stood for that. It was really humiliating. The amount of parents that sent back and said no because they thought that we were not going to meet anyone anyway....I mean we have got no feelings from the waist down so we have obviously got none of those feelings either.

The young people also complained about the lack of opportunity to develop the social skills necessary for forming relationships with the opposite sex. Henry summed up the feelings of many:

> Its quite a hard thing to explain. When I go out I don't know how to go up to a woman and chat her up. I have never had all them social skills to do it. You see all these people in relationships and you think well, they

do it how come I can't?

Vera summed up the negative effect of segregated school:

> I think that it is the kind of messages that you get about being a disabled person at segregated school. They don't encourage you to think positively about yourself and that is the key to having a relationship...thinking that you are valuable and that somebody else is going to find you attractive and want to be with you. I'm not in one at the moment but I'd like to be.

The problems of a lack of social skills and isolation from the 'non-disabled world' were not the only disadvantages which many of the research sample felt they were experiencing as a result of their education. Literacy and numeracy problems were highlighted as a source of great concern. These issues will be explored below.

Educational Achievers?

As outlined in chapter four some individuals in the sample were achievers in terms of educational qualifications. Eight individuals had attained one or more GCSE grades A* - C with one individual going on to achieve A' levels and two people achieving A' Levels and then degrees. Five people achieved their exam passes whilst still at school whilst three people gained their qualifications at

further education college. The location where the qualifications were attained is outlined below:

Table 6.2 Qualifications Gained by Institution GCSE Grades A-C	
Type of School	*Number (n = 42)*
Private (Mainstream)	2
Mainstream (Fully integrated)	2
Mainstream (Separate Unit)	0
Segregated	1
F.E. College	3

However, the individuals who achieved were in a minority with only eight out of forty two people falling into this category. Of the remaining thirty four individuals, seven had managed to attain one or more GCSE Grades D - G only, with the remaining twenty seven achieving no qualifications at all. The location where qualifications were obtained is outlined below:

Table 6.3 Qualifications Gained by Institution GCSE Grades D-G	
Type of School	*Number (n = 42)*
Private (Mainstream)	0
Mainstream (Fully integrated)	2
Mainstream (Separate Unit)	0
Segregated	5
F.E. College	0

The majority of this group were not only concerned about their lack of

qualifications. Many stated that they had experienced severe problems with basic literacy and numeracy and were distressed by this. This situation has not been helped by the relationship of segregated schools to the national curriculum.

Concerns have been expressed in the literature about the lack of academic emphasis in segregated schools and, in particular, with regard to the operation of the National Curriculum:

> The new curriculum's attainment targets, tests, and a subject range which seemed to exclude the development of personal and social skills, pointed to a competitive educational system in which there would not be the time or inclination to meet the needs of special children other than un-segregated provision. (Cole, 1989:138).

Although segregated education has historically been presented as a helpful variant of mainstream education, the reality can be otherwise:

> It is to remove children from the credentialing, examination orientated system. (Tomlinson, 1982:113).

The disabled people's perception of their literacy and numeracy problems will be outlined below.

The entire group said that they had great difficulty with mathematics. Oliver and Felicity's explanations for their difficulties were very different: Oliver said:

> I found Maths very hard but, apparently Spina Bifida's have problems with maths. It's not an excuse but a reason.

Felicity's comments were typical:

> I found maths difficult so I didn't like it. I think it was the way it was taught because now I am doing A-level maths at college.

Whilst it may be the case that some people would never be capable of academic achievement, as stated earlier in the chapter, the onus has to be on teaching staff to find a way around the difficulties faced by children with special needs. It cannot be assumed that <u>all</u> children with a particular impairment will face a particular problem or the same level of problem.

There was one example of a Further Education College taking an innovative approach to an individual's literacy problem. Angela said:

> I do have problems because of my dyslexia, but at college in the exams the teacher reads all the questions to me and then I dictate my answers so we get around it.

Many of the sample were unable to read and write and were extremely embarrassed about their situation. Debbie was making strenuous efforts to rectify her problems. Her comments were typical:

> I am now doing my Word power Foundation Level City and Guilds at college and the work that I have put in has come from me. They said I was thick at school because if somebody doesn't teach you to read and write you do look thick to the average person. They just left me in a corner with a paint brush and some paints. People used to ask me to read something and when I couldn't they just used to stand back. When I left school I did voluntary work in a nursery and I explained to the Nursery that I found it difficult to read and write and they said that was O.K. Then I was asked by a new teacher to read a book to the three year olds and when I said I couldn't do it she was amazed. I was so ashamed. I think a lot of it is also if you can't do something at school and you say so, instead of saying 'we will do this another way' they used to fling the chalk at me and then I used to go and lock myself in the toilet.

The young people were very aware of the extent to which their lack of literacy disadvantaged them. Zoe said:

> My average reading and writing age is that of an eight year old because at primary school they used to leave me lacking. I lack reading, writing

> and maths skills. My problems with English and Maths knock on to every other subject and cause me problems with everything I do.

There were instances of disabled people with severe communication difficulties being disadvantaged by a lack of access to suitable microcomputer technology. The importance of such provision is stressed in the literature:

> The interchange of information is the basis of human communication but any children with physical and sensory impairments have severe communication problems because they are not able to enjoy a full exchange of information with those around them...The inability to handle information sufficiently fast enough has frequently led to children being segregated because they 'cannot keep up' in an ordinary classroom. (Reiser & Mason, 1990:94).

Such equipment is of particular importance to children with neuromuscular disorders such as cerebral palsy, muscular dystrophy etc. who may find speech or writing or a combination of both very difficult. Quentin who had severe speech problems said:

> I didn't get my touch talker until I was sixteen so I couldn't communicate until that time. I had to use my body to talk. I couldn't do lessons.

There were other examples of individuals being held up by lack of access to a typewriter or computer which considerably slowed their progress in the classroom.

The young people also cited class sizes as a reason for their lack of achievement at school. Henrietta's comments were typical:

> I don't think I was given the best education because I'm dyslexic. I do miss not being able to read because there is so much you miss out on. I didn't have enough support at school, because there were so many people in my class that they didn't have the time to give me the extra attention that I needed and I think it is a poor state that its like that. Its like that wherever you go. You can't get the help to do something with your life. I didn't do any exams at school because I can't read and write very well it takes me so long to put pen to paper.

Many of the sample felt that their lack of achievement at school had affected their future prospects and a frequent complaint was that they did not have enough options open to them when they left school in that they were directed towards day centres or particular courses at further education college. Their concerns will be outlined below.

Career Choices?

Some of the disabled people had very positive experiences in terms of the amount of choice that they were able to exercise at college and the careers guidance they received. Clare said:

> I discussed my future before I left school with my parents, teachers and careers officer and they all agreed with my decision not to do sewing up work or be a beautician like my friends. I decided to do office or secretarial work.

Karl said:

> My contact with every single careers officer has been fantastic. They have helped me every single step of the way. A careers officer suggested that I could do clerical work and I have always wanted to do clerical so it fitted in with what I wanted to do.

Oliver commented:

> I have never had somebody come to me and say you are working in a sheltered workshop because that is all you are fit for - accept it.

A number of the young people were satisfied with the amount of choice that they were allowed to exercise in terms of college courses. Josie's comments were typical:

> My experiences at college were very positive. I did what I wanted to do my GCSE's and a business and administration NVQ.

However, the individuals who were happy with the careers advice they received were in the minority. Most of the sample were very dissatisfied with the help that they had received from the careers service. Another concern, outlined briefly above, was that although the comments regarding further education in terms of support offered by staff were extremely positive, many people expressed frustration at the extent to which they were 'channelled' on to particular courses by college staff. Their concerns will be outlined below.

Most of the sample were scathing about their contact with the careers service: Henry's comments were typical:

> The careers officers were all for you are disabled, you have got to go to a day centre, you can't work.

Marjorie too was very disappointed:

> When I told the careers officer that I wanted to work with children he said that was impossible because what if there was a fire, what if the children fall over? He put up barriers and then started to go on about allowances and things. He said it wouldn't be worth my while working.

Kevin too was disillusioned with the careers service:

> It was so pathetic. He sort of said you are going to a college and to a day centre and that's it. I didn't mind the college so much, but when it got to the day centre they didn't give you any option. I said to him that I would like to work with computers when I left school. He said no chance. You just get pushed into a day centre. I think he thought I wasn't capable.

There were only four positive comments about the careers service from the entire sample of forty two people. Many people were also unhappy about the degree of choice that they had been allowed to exercise at college with regard to courses. Many objected to being directed on to clerical or business administration courses. Marjorie's comments were typical:

> I didn't choose to do what I did at college, I was told to do it. There was no 'you can have a choice of courses'. Normally, you find a career you are interested in and you go for the course that involves it. We were told we were going on a business course and that is exactly what we did.

Many of the sample who were attending college worried about what would happen when they finished. Henrietta's comments were echoed by many:

> I go to college twice a week but there is nothing at the end of it only day centres. You just leave school and if you have got no qualifications you are lost. There is nothing at the end of it.

Zoe was worried about the value of the certificates that she had gained whilst at further education college:

> I have got certificates but I don't think that employers are going to want to know about them. I don't think they are recognised.

The chapter thus far has painted a bleak picture of disabled people passively doing and going where they were told in the context of schooling and further education. However, this was not always the case. There were examples of people challenging the system and going in the direction that they wished. Examples of this will be outlined below.

Determination to Succeed?

Some of the sample refused to be pushed along with the crowd and made strenuous efforts to achieve against the odds. Zoe, who achieved two GCSE's

was typical of the three people who stood their ground:

> The teachers didn't have much say in what I was going to do when I left school because I told them 'on your bike!' I am going on to further education.

Tina who achieved GCSE's at college said:

> My reading and writing are fine now but I have had to work at it. I still can't spell too well but I put that down to having the physio rather than the schooling again, because it is too late. I should have concentrated on that stuff when I was seven. The basic building blocks weren't there.

Five people had achieved due to a combination of parental support, support from teaching staff and self - motivation. In one instance a social worker had provided encouragement and support. This will be discussed in greater detail in the next chapter.

The remaining thirty four people had allowed their lives to be directed by other people in terms of their education. Irma offered an explanation as to why this happens:

> I think it is mostly down to parents and schooling because everybody

> seems to make decisions for you. I think it makes you scared to make decisions. I think they should leave it more to you.

For most people in the sample the deficits in their education had a tremendous impact on their lives. Tina's comments were echoed by many:

> My difficulties now all stem from when I was younger. If I had got better education then maybe I would have been in my own flat two years ago because I wouldn't have been catching up on stuff that I should have learnt when I was seven.

The extent to which individuals were able to avoid the influence of the education system will be explored in the next chapter which will focus on the young disabled people's experiences of the labour market and benefits system.

The chapter so far has shown that the research sample feel extremely disadvantaged both within, and by, the education system, blame the situation on the professionals within special needs education. However, it is the case that class teachers do not operate within a vacuum. Classroom interaction is heavily influenced by the amount of resources available to special needs education per se, and whilst inadequate resources do not excuse low standards in the classroom, they are an important influence. This area will be discussed below.

Resources Within Special Needs Education

The research sample did acknowledge some difficulties in the classroom such as class sizes (see above). These will now be explored in more detail.

Whilst some of the sample reported no difficulties in this area in particular the two who attended a private school and three out of the four pupils who were fully integrated into mainstream schools, the picture was very different for the majority of the sample.

Their issues highlighted during the course of the interviews were the provision of micro technology support, one to one support in the classroom, and the issue of whether financial concerns on the part of colleges were determining the courses to which disabled people were allowed access.

Quentin and Henrietta had been denied touch talkers even though they had severe speech problems because of a shortage of money. Quentin said:

> I didn't get a touch talker until I was fifteen years old because they didn't want to give the money. I had to use my body to talk.

Kevin's comments about a lack of support in the classroom were echoed by many:

> There were a load of kids in one room and only one teacher. You got stuck at the pace of the slowest, and you just seemed to be going slower and slower and I didn't think I was getting the best education in the world.

A number of the sample highlighted fears that financial concerns on the part of further education colleges were determining the courses to which they were allowed access. This was mentioned with regard to segregated and mainstream FE provision. Zoe who was struggling on her business studies course said:

> The college gets paid a lot more money if you are on the business studies course part-time as opposed to straight further education. It also gets paid more if you are a boarder rather than a day student.

Quentin said of the same segregated FE college:

> It is a business and the business concerns come before the academic ones. They are being paid £21,000 to educate me and I did not decide the courses that I went on.

Oliver had similar worries about his mainstream FE college:

> When I went to college I got on the wrong courses. I was misdirected. I

> found the BTEC National too hard. They persuaded me to do the course just to fill in the numbers plus with me being disabled they would get access to extra money.

The issue of resources at the macro level was beyond the sample's sphere of experience. The way that resources are allocated reflect the priorities both outside and within education at a given time and it is acknowledged in the literature that important changes need to be made to special needs education if:

> The special school and the children and staff within it are not to remain a Cinderella dimension, attracting marginalised pupils as well as teachers. (Sandow, 1994:140).

The quality of the training which teachers in special education receive is central to the success or failure of their pupils in the classroom and concerns have been expressed with regard to this particularly in relation to the National Curriculum which was implemented with the 1988 Education Act. This resulted in teacher training institutions having to change their initial teacher training courses (ITT) to encompass the new curriculum. As a result, the time available for the teaching of subsidiary subjects and other themes has been reduced.

The issue has been further complicated by the requirement of the Department of Education that the bulk of initial teacher training should take place within

schools. (D*of*E, 1992; cited in Sandow, 1994:130). Increasingly school based work has resulted in less time for supporting or subsidiary activities such as special educational needs. There is concern that SEN training has been pared down to such an extent that only the most basic awareness of SEN issues can be provided by training institutions. (Sandow, 1994).

This paints a bleak picture when one considers that prior to the 1978 Warnock Report it was not considered necessary for special educational needs teachers to have a further qualification. (Tomlinson, 1982). Up until 1959 teachers in segregated schools in England and Wales were not required to have even an ordinary teaching qualification and by 1977 only 57% of teachers of the blind, 67% of teachers of the deaf, and 74% of teachers of the partially hearing had obtained such a qualification. (Tomlinson, 1982:131).

The low priority given to teacher training in SEN, together with the pressures that have been placed on schools by the changes on the way they are funded as a result of the 1988 Education Act, where funding is dependent on the number of pupils in the first instance, and in turn, on the schools performance in the National Curriculum (see above) will further disadvantage disabled pupils. Also, the reduction in Local Education Authority budgets has further undermined support for disabled children within education.

Again the lack of fit between the 1981 and 1988 Education Acts is underlined.

If one argues that:

> There can be little doubt now that the basic educational system for all should be one which is integrated with the mainstream. (Clough & Lindsay, 1991:150).

a stance which was advocated by the 1981 Education Act, it is obvious that teacher training is of central importance in that integration is not just about removing children from, or not placing them in segregated schools. It is about supporting disabled children and their teachers in mainstream schools so that the issue of disabled children leaving mainstream education does not arise. As outlined above this has been severely jeopardised by the reforms to education introduced in 1988.

A minority of the sample had a positive experience in terms of education. Eight individuals had managed to achieve one or more GCSE's at grades A*- C. Three of these went on to obtain two or more A-levels and two were educated to degree level.

Out of the remaining thirty four people, seven had managed to attain one or more GCSE's grades D - G. Twenty seven people had never been entered for any examinations. The chapter paints a picture of a disadvantaged group of people moving through a part of the education system that is itself under-resourced and

marginalised. The problems that the young people faced seemed to stem from failings in this system and not from within the disabled people themselves.

The next section will explore the extent to which education influenced independence using the index outlined in chapter four.

EDUCATION AND INDEPENDENCE.

The Independent Group

The young people in this group constituted a minority of the sample. They were the most likely to stress that their parents had played an active role in securing the best education possible. They challenged negative professional assessments of their children's capability and also any decision to place their children in segregated school. Parental action ranged from withdrawal from the state system through to campaigning to get their child in to the best segregated school available.

This group had the most positive comments about professionals' assumptions. The type of assumption made (albeit positive or negative) determines the level of expectation with regard to a certain child. The majority of the group were satisfied with the teaching they received and stated that their teachers expected them to do well.

The individuals in this group were also positive about the level of encouragement they had received from both parents and teachers. They had motivated people to succeed in particular subjects and directed them on to further or higher education.

This group suffered the least interruptions to education due to medical treatment. This did not mean that they had experienced less treatment, but that their schools were more academically orientated. This meant that physiotherapy sessions were timetabled out of school hours with academic achievement priority. Also, hospitalisation was arranged for the school holidays.

The majority of individuals who attended segregated school felt that the experience had been beneficial and they had achieved academically. Six out of the eleven people in this group had achieved one or more GCSE's at grades A-C, with three of the six educated to A-level standard and two to graduate level. The remaining five people had no qualifications. Whilst there were no problems with literacy, all reported some difficulty in terms of numeracy.

This group were also the least likely to report difficulties with regard to resources in the classroom.

The Intermediate Group

The majority of the people in this group did not know how they came to attend

segregated school. One individual stated that she was sent there because her family was unable to cope. It seemed as if the majority of parents had abided by professional decisions whether happy or not.

Some of the individuals in this group were satisfied with the quality of teaching they had received but they were fewer in number than the group above.

Some individuals in this group stated that they had been encouraged by their teachers but they were in a minority.

A substantial number of people had suffered interruption to their education due to attendance at physiotherapy sessions during school hours and time lost due to hospitalisation.

A minority of the individuals in this group were positive about their segregated education in that they felt this type of school was able to cope better with their impairment, but on the whole the group were less positive than the individuals above.

Out of this group two people had achieved one or more GCSE's grades A*-C, and two people had managed to attain one or more GCSE's at grades D -G. The remaining five people had not been entered for any examinations. Numeracy was more problematic than literacy.

A number of individuals reported difficulties with regard to Further Education colleges restricting access to courses on the basis of financial gain rather than of potential benefit to the young people.

The Dependent Group

The experience of this group who constituted the majority of the sample, was the same as the one above with regard to parental role.

Almost every individual in this group was extremely dissatisfied with the quality of teaching they had received and felt that the low expectations of teachers had seriously undermined their future prospects.

This group felt that they had been offered little or no encouragement whilst at school. For a minority parental support had been of central importance as it enabled the young people to 'keep going' when encouragement from teachers was absent.

The individuals in this group suffered the highest degree of interruption to their education of the whole sample. They frequently had to leave the classroom for physiotherapy sessions and many felt that they had received little benefit from the treatment and that the disadvantages in terms of missed education far outweighed any benefit.

The majority of this group viewed their attendance at segregated school as a negative experience which had left them ill prepared for life outside full-time education. They felt that their education had encouraged dependence, and had offered little opportunity for the formation of relationships and development of social skills. The young people also felt that it had severely undermined their self-esteem.

Twenty one people out of forty two were classed as being dependent based on the index. None of this group had been educated to GCSE level and the majority were experiencing difficulties with literacy and numeracy.

This group was most likely to highlight serious difficulties with regard to resources. There were cases of individuals with severe communication difficulties denied the use of a touch talker due to insufficient funds, and many people expressed concern about class sizes which further undermined their education.

In conclusion, this chapter has presented a bleak account of the disabled people's path through the education system. They are disadvantaged by entrenched attitudes and assumptions on one level and by being educated in an under-resourced sector of education on another. All of this is against a backdrop of policy changes which will further disadvantage the education of disabled people and the staff who teach them. The extent to which their poor education

disadvantaged them in the employment market has yet to be seen and their experiences of this and the benefits system will be explored in the next chapter.

CHAPTER SEVEN

FROM SCHOOL TO WELFARE?

This chapter will explore the degree of success that the disabled young people experienced in the employment market. Recent policy developments will be outlined. This will be followed by an exploration of the research sample's perceptions and experiences.

As with previous chapters, the data is based entirely on the research sample's accounts of their experiences of the labour market.

EMPLOYMENT

This section will consider the issue of access to the labour market from the standpoint of government policy. It will then go on to explore the experiences of the young adults themselves in terms of the roles played by educational qualifications and careers officers in their success or failure in the labour market.

Setting the Scene

Recognition of the employment needs of disabled people in the UK was a direct result of the first World War which created strong political, moral and economic grounds for getting the war disabled back into employment. There was also a labour shortage as a result of mobilisation. Rehabilitation and employment services were established for this group from 1919 onwards. (Lonsdale and Walker, 1984). The Tomlinson Committee was established following the second

World War and it published a report which became:

> The bedrock of policy concerning the employment of disabled people for the next forty years. (Lonsdale & Walker, 1984:5).

The Disabled Person's (Employment) Act 1944

The report was based upon the premise that disabled people are capable of mainstream employment and that they should be given every assistance in fulfilling that potential. (Lonsdale & Walker, 1984). The recommendations of the Tomlinson Committee were incorporated in the Disabled Person's (Employment) Act 1944. The act made the following provisions:

- Assessment;
- Rehabilitation and retraining;
- A specialised placement service;
- A register of disabled people;
- A quota scheme to offer protection for registered disabled people in open and sheltered employment;
- Establishment of the National Advisory Council on the Employment of People with Disabilities which advises the Secretary of State on issues concerning the employment and training of disabled people;
- Establishment of local advisory committees whose role is to advise on

local employment issues, including performing certain roles under the quota scheme (Lonsdale and Walker, 1984; Gooding, 1996).

The 1944 Act, although amended by various acts of parliament, was the key legislation regulating the employment of disabled workers until the introduction of the Disability Discrimination Act 1995 which legally came into force in November 1996.

The most significant aspect of the 1944 Act in terms of employment protection for the disabled, was the operation of the Quota Scheme which required firms of more than twenty employees to ensure that at least 3 percent of their employees were registered disabled and to keep records of their operation of the quota. Disabled employees also had protection against unfair dismissal if its effect was to bring the employer below quota. Employers who failed to fulfil the requirements of the Act were in theory liable to a fine or a term of imprisonment.

The main advantage of the quota scheme as a form of positive discrimination, was that it was an example of a policy which aimed to promote employment of disabled people as a group. The 1944 Act represented a social obligation, discharged by government to oversee the translation of the principle into practice and monitor its effects. The Act placed a duty on employers to ensure that disabled people were fairly represented in their workforce, and there were mechanisms and penalties to ensure that this was adhered to. The policy was

quite successful in the post-war period when there was an interest in protecting the war disabled. There was evidence that the scheme was working as the percentage of eligible employers meeting the three percent quota was 61 percent in 1961 (Thornton & Lunt 1995:10). In short, the responsibility for actively promoting the employment of disabled people rested firmly with the state under this Act. (Thornton & Lunt, 1995). The quota scheme encapsulated a range of values:

> Collectivist notions like the right to work and state intervention...integrative assumptions based on egalitarian values...which did not discriminate between people...and individualistic concerns with merit which were linked to notions of normality and independence. (Bolderson, 1980 cited in Thornton & Lunt, 1995:12).

In summary, the scheme offered a degree of 'protection' to disabled people in employment, and gave them a small advantage when seeking work in a poor economic climate (Lonsdale & Walker, 1984). It also gave employers a degree of incentive to employ disabled people. It played a stronger role in terms of principle in that:

> It was a tangible reminder of the right to work and to a fair share of the available employment (Barnes, 1991; cited in Thornton & Lunt, 1995:13).

And it was also a reminder that the responsibility of ensuring those rights is a collective one 'which can be consciously exerted on behalf of the nation as a whole' (Townsend, 1981; cited in Thornton & Lunt, 1995:13).

There was evidence that the system did confer some advantages on registered disabled people as opposed to the non - registered:

> In the three years up to June 1982 unemployment among those registered as disabled rose by 28 percent and among the unregistered by 69 percent (Lonsdale & Walker, 1984:15).

A national survey of employers which examined the recruitment and retention of people with disabilities reported that 40 percent of the sample stated that it was difficult to attract applications from disabled people because no disabled people applied for vacancies (Dench, Meager & Morris, 1996).

On paper, the 1944 Act, and in particular the quota system, appeared to be an extremely positive development in terms of the employment prospects of disabled people. The rhetoric was not matched by reality and there were a number of difficulties associated with the quota system which will be outlined below.

The operation of the quota scheme has been undermined by past governments'

economic policies beginning with Thatcherism in 1979 and extending up to May 1997, which have emphasised supply side responses i.e. that non-interference in the labour market and the promotion of individual enterprise and competition are the most appropriate solution to economic problems (Thornton & Lunt, 1995; Thornton, Sainsbury & Barnes, 1997). Collective legislative provisions such as those in the 1944 Act do not fit well with this process which hinges on minimal intervention by government in the economy and the labour market. There has been an emphasis on 'deregulation' and the reduction of the administrative burden faced by firms. There is a dislike of control by government and also a commitment to 'rolling back the frontiers of the state' (Thornton & Lunt, 1995).

Governments in the UK have followed the road of educating and persuading employers as opposed to compulsion, and this stance explains the policy vacuum that surrounded the 1944 Act where no sanctions were imposed on employers who failed to comply with the quota. The maximum penalty of £100 introduced fifty years ago was never increased; and there have only been ten prosecutions for quota offences with the average fine being around £60 (Massey, 1994).

Another weakness of the scheme was the availability of permits to employers. Under the system every employer with more than twenty employees, if below quota, was supposed to offer every vacancy to a registered disabled person. However, if a registered disabled person could not be found, the employer was entitled to be issued with a permit to employ a non disabled person. It was an

offence to employ such a person without a permit and employers ran the risk of prosecution. Penalties included a fine of not more than £400 (£2,000 if the employer was a body corporate), or a term of imprisonment of not more than three months (Lonsdale & Walker, 1984; Thornton & Lunt, 1995). There is evidence that the system was widely abused by employers. The percentage of eligible employers meeting the 3 percent quota declined with the advent of the Thatcher period. It stood at 0.7 percent in 1993 (Thornton & Lunt, 1995:10). Employers routinely applied for exemption permits, which had been issued in bulk since the early 1960's and covered all appointments. These were valid for six months. The practice became so widespread that compliance with the Act came to be seen as obtaining an exemption permit prior to employing non disabled people. From 1973, the number of employers issued with exemption permits exceeded that of those complying with the scheme (Thornton & Lunt, 1995:11). It is estimated that in 1986 fewer than 17 percent of those not meeting the quota had no permit and were as a result, in breach of the law (Barnes, 1991; cited in Thornton & Lunt, 1995:11).

Given the dearth of prosecutions outlined above, employers rapidly realised that the threat of enforcement was weak. Responsibility for initiating prosecution of an employer rested with the Secretary of State for Employment and between 1945 and 1975 there were six prosecutions (Thornton & Lunt, 1995).

There were other problems associated with the scheme. The obligation of

employers to meet a quota was not adequately publicised, and research was published to show that a substantial minority of employers were ignorant of the obligations under the scheme. One quarter of respondents to a study in 1990 were unaware of the scheme with a further tenth unfamiliar with its requirements (Morrell, 1990; cited in Thornton & Lunt, 1995).

Also, insufficient staff resources were committed to the scheme. It was found that Employment Services staff lacked the resources to monitor every vacancy and propose suitable disabled candidates. Their duties were split between policing the quota and inducing attitudinal change toward disabled employees on the part of employers (Thornton & Lunt, 1995).

The effectiveness of the scheme was further hampered by problems with the registration process for disabled people. The numbers of registered disabled people declined from 936,196 in 1961 to 374,182 in 1994 (Thornton & Lunt, 1995). There were a number of reasons for this which will be outlined below.

Many disabled people were unaware of the existence of the register and had not realised that it was a prerequisite to finding work. An inquiry into disabled people's failure to register found that 41 percent were unaware of the register (ED, 1990: cited in Thornton & Lunt, 1995). There is evidence that the registration rate fell during periods of high unemployment when it was viewed as pointless both by employment service staff and disabled people. The failure

of the quota scheme reinforced that opinion (Walker & Townsend, 1981; Lonsdale & Walker, 1984; Thornton & Lunt, 1995).

Some disabled people were discouraged by the perceived stigma associated with registration:

> The very real experience and fears of stigmatisation and stereotyping which many people with disabilities worry that registration brings, cannot be denied... If people with disabilities perceive themselves as having a deviant or 'abnormal' social status, then they are less likely to want to acknowledge it (Lonsdale & Walker, 1984:32).

It is also the case that organisations of disabled people rejected the principle of registration on the grounds that it added further credence to external 'professional' judgements of disability which hinge on medical diagnosis (Thornton & Lunt, 1995).

It was outlined above that registration had secured some individuals advantages over the non - registered in terms of the rate by which unemployment increased for these two groups. (28 and 69 percent respectively). However, the figures are inaccurate as they were based on registration for employment and it is estimated that a minority of disabled people were registered:

> It is widely accepted that the official register of employment does not include between one fifth and one quarter of those without and seeking jobs (Lonsdale & Walker, 1984:15).

It is often argued that the failure of disabled people to register was a major factor behind the failure of the quota system and this is justified by the evidence that there were not enough disabled people on the register to allow employers to satisfy the 3 percent quota. But the reluctance of disabled people to register was a reflection of macro societal processes such as rising unemployment and the failure of government to properly enforce the scheme. A lack of commitment to the scheme is evident from the apathy with regard to enforcement even during periods of high employment:

> [There was] unwillingness to prosecute employers during the 1940's, 1950's and 1960's when unemployment was low as a whole but relatively high among the registered disabled, failure to make sufficient grants for training and the adaptation of premises and equipment... (Walker & Townsend, 1981:64).

Given the lack of success of the quota system there was increasing pressure for a change in employment policies for disabled people. This came from two sources. As mentioned above, government economic policy has increasingly shifted towards deregulation and this applies to the economy, labour market and

individual's lives. This has resulted in disability policy which is weighted on the side of individually - based solutions to employment (Thornton & Lunt, 1995). Pressure for change has also come from disabled people themselves in the form of the disabled people's movement which has argued:

> ...Against patronage policies, challenging the dominant view that disabled people 'need' care and 'deserve' special provision. The Independent Living Movement has campaigned for individual rights to self-determination and the crusade for 'civil rights' has helped justify the retreat from policies of social obligation and the dismantling of practices which, in theory at least, protected the collective employment position of disabled people (Thornton & Lunt, 1995:1).

The Disability Discrimination Act (1995)

The Disability Discrimination Act (1995) was a direct result of the factors outlined above and it marked a substantial move away from collective disability employment policy. This Act firmly placed responsibility for obtaining fair access to the labour market on the individual rather than the state. Much of the 1944 Disabled Persons (Employment) Act has been revoked. The emphasis now is very much on individual responsibility for action and self - policing (Thornton & Lunt, 1995). Whilst the Disability Discrimination Act came into force after the completion of data collection, it is argued that the assumptions on which it is

based are flawed. This issue will be explored below starting with the advantages of the new legislation.

The Disability Discrimination Act is the first legislation to address discrimination against disabled people in Britain and as a result is something of a watershed (Gooding, 1996). Specifically the act:

- Makes all employers of twenty or more employees and all UK providers of goods and services legally liable for discrimination against disabled people. It confers the right of disabled people not to be treated less favourably because of disability, unless there is a justification. The employment provisions include a duty on employers to take steps 'as it is reasonable' to alter the working conditions or working environment to facilitate the employment of an identified disabled person.

- It contains extensive provisions regarding the accessibility of public transport services - taxis, trains and buses (Gooding, 1996:149; Thornton, Sainsbury & Barnes, 1997:104).

When the Act came into force in November 1996 it seemed to hold a lot of promise:

> It represents a historic step towards the recognition of disabled people's

> rights...As the Act's requirements for the removal of the institutional and environmental barriers which confront disabled people progressively come into force, the Disability Discrimination Act may, (If adequately enforced), play a significant role in opening up society to the talents of this disenfranchised minority (Gooding, 1996:1).

There is evidence that the Act has helped some disabled people. Harry Barnes, sponsor of the 1994 Civil Rights (Disabled Persons) Bill commented at a conference on the DDA in 1997:

> It had been used successfully in some cases, and had led many employers to review their practices (Barnes, 1997 cited in Info Exchange, November 1997:1)

However, serious doubts have been expressed about the effectiveness of the Act. A major concern has been the lack of any principle obligating employers to employ disabled people. The Act is based on the principle of persuasion and although in theory it offers a statutory right of non discrimination against disabled people, this right is only supported by a statutory code of practice. The onus is on employers to set their own targets and monitor their own progress. There are no targets set by Government. And although a National Disability Council was set up to advise Ministers on discrimination issues, no Equal Opportunities Commission comparable to those on race and gender was

established (Thornton, Sainsbury & Barnes, 1997; Thornton & Lunt, 1995).

The Act has a number of other failings. It relates to the treatment of a *specific* disabled person whether seeking or in employment. It is weighted on the side of the employer:

> Whether the obligation has been met depends on the employer's judgement of what is reasonable for that person...It is the duty of the employer to take such steps as it is *reasonable*, in all circumstances of the case, for him to have to take in order to prevent the arrangements or features that have that effect (Disability Discrimination Bill, 1995; cited in Thornton & Lunt, 1995:20).

As with the Sex Discrimination Act (1975) and the Race Relations Act (1976), the responsibility is on the individual to instigate action if he or she considers that they have been discriminated against. The grievance then goes to tribunal where action or compensation may be obtained. The important point is that the *individual* has to take action against a *particular* firm. Also, there is little in the Act to force the employer to make the environment less discriminatory as the onus is on the firm settling with the *individual,* so the scope for any adjustments being applied to the working environment as a whole is extremely limited (Thornton & Lunt, 1995). Of course, disabled people have a wide range of impairments so adjustments for one person may not be suitable for another. It is

also the case that the individualistic focus of the Disability Discrimination Act does little to combat the social construction of disability in the workplace.

There is another problem which has been ignored by the disability movement in its campaign for individual rights to self-determination. Most attention has focussed on the way that official definitions of disability have disadvantaged disabled people and campaigners have been highly critical of the individual model of disability. However, despite the fact that wider choice and control are central themes in the disability movement, the importance of choice over work opportunities has been neglected in the discussion (Thornton & Lunt, 1995). As a result, whilst the Disability Discrimination Act is on the one hand giving individuals greater control over their lives in theory, by placing the responsibility on the disabled employee to instigate action against an employer, the Act lends itself very easily to focussing on the disabled individual as the source of a problem. The Act was intended to be part of a civil rights crusade, ironically, its individualistic focus is not only in danger of going 'full circle' in terms of locating 'the problem' firmly within the individual, but it is also at odds with *aims* of the disability movement. It could be argued that in order to afford individuals maximum choice and control over their lives equality of access to the labour market is crucial, and an essential prerequisite to this is strong political commitment to policy with a collective focus which obligates employers. The Act as it presently stands disempowers disabled people in the labour market.

The Act excludes certain groups of disabled people, namely those who do not have sufficient education and support to initiate proceedings against an employer, those who are not in or seeking employment are denied protection under the legislation, as are those who are not considered to be 'competitive' in labour market terms. Those individuals deemed to be capable of supported (subsidised) work in mainstream employment do not fall with the remit of the act and these individuals are likely to be in low status, poorly paid jobs (Thornton & Lunt, 1995). It is also the case that firms with less than twenty employees are also exempt. This means in practice that 95 percent of private sector employers and almost a quarter of all disabled workers are not protected (Disability Now, January 1998:1). However, the present Government's new Disability Rights Task Force is committed to reviewing this (Disability Now, January, 1998:1).

The Act has also attracted wide criticism for being contorted and vague and for failing to establish the clear principle of equal treatment which is central to anti - discrimination legislation:

> [The Act] is riddled with vague, slippery and elusive exceptions making it so full of holes that it is more like a colander than a binding code (Hansard, 22 May 1995, cited in Gooding, 1996:1).

The impact of the legislation is also undermined by isolation. It is the only legal protection for disabled people in employment and the only obligation on

employers is towards individual employees. No other country operates such a system (Thornton & Lunt, 1995).

In summary, it can be seen that the history of disability employment policy in the UK has been marked by ineffectiveness due to a lack of political commitment in the form of adequate enforcement by successive Governments, who have put the needs of the economy before those of disabled people. The position of this group in the labour market has been further weakened by a move from policies which imposed limited obligations on employers to employ disabled people, to legislation which places the onus for instigating proceedings against an employer firmly on the disabled individual concerned assuming that they are seeking, or in employment in the first place.

The Access to Work Scheme

However, there is support available for disabled people seeking work or who are already in employment with the aim of improving their labour market position by making them more 'competitive'. The Access to Work scheme was introduced by the Department of Employment in June, 1994 and is unique in that all the financial help that is available through the scheme is targeted at the disabled individual rather than employers (Thornton & Lunt, 1995). As with the Disability Discrimination Act (1995) the onus is on the disabled individual seeking support via his or her local Job Centre which is the first point of contact. The process is

not instigated by the employer. This guarantees that disabled individuals benefit. To be eligible for help individuals must be:

Table 7.1 Eligibility for the Access to Work Scheme
Disabled people whose disability or health problem affects the kind of work they do, and is likely to last for 12 months or more.
Disabled people who are unemployed, self-employed or in a job.
It applies to any job, part-time or full-time, permanent or temporary.

Source: Employment Service DS4, July 1997:1

The scheme offers the following benefits which are tailored to an individual's needs for a particular job up to a ceiling of £25,000 per person over a five year period:

Table 7.2 Access to Work Services
Communicator for the deal or hearing impaired at job interviews.
Communicators for the deaf or hearing impaired. In the workplace.
Part-time readers or assistance at work for the blind or visually impaired.
Support workers for those at work who need practical help at work or getting to work.
Job coach or temporary support worker where needed to assist a new employee in becoming familiar with job-related tasks.
Finance is also available for changing the workplace i.e. adapting or changing equipment in accordance with an individual's needs; alterations to premises so that a disabled person can work there; and adaptation to cars or additional transport costs.

Source: Thornton & Lunt, 1995:38; Employment Service DS4, July, 1997)

As cost ceilings relate to individual disabled employees, the amount of assistance that an employer may receive is unlimited. The budget for 1994-95 was £14.6

million. (Thornton & Lunt, 1995). The Access to Work scheme operates on a number of levels:

Table 7.3 Degree of Help Available
Unemployed people with a job to go to, or who have just taken up a job or are starting self employment are eligible to have the full amount of approved costs of help met by the scheme.
Those in employment for six weeks or more are eligible to have 90% of the approved costs of help after the first £100.
If total approved costs are more than £10,000 over 3 years, Access to work will pay 100% of the approved costs between £10,000 and the actual cost.
If an individual needs help with travel to work or communicator support at interview, the scheme will meet all of the approved costs whether the person is unemployed or employed.
Help is available up to a maximum of three years after which renewal is considered.

Source: Employment Service DS4, July, 1997:3

The range of help available is comprehensive, and the scheme is streamlined (it is administered by the Employment Service), and easy to access compared the systems in operation in other countries (Thornton & Lunt, 1995).

The scheme also affords the disabled worker more control over the best way of meeting his or her needs in the working environment and in this sense is in line with the disability movement's campaign for increased self-determination.

However, there have been a number of problems identified with the scheme. The Access to Work programme as introduced with the aim of simplifying and extending the scope of services available to disabled people and their employers. It incorporated the Adaptations to Premises and Equipment scheme, targeted at

the employer, for which take-up was extremely low (Thornton, Sainsbury & Barnes, 1997). However, the problem of low take-up has not been solved by the introduction of the new scheme as there is evidence to show that the programme is under-utilised by disabled people. For example, the aim of the Access to Work programme was to increase the number of disabled people in employment, and as a result, it was intended that half the entrants would be unemployed. In the event, a survey one year after the introduction of the scheme found that:

> 92 percent of the entrants were already in work when they applied (Bienart et al, 1996). In the quarter ending September, 1996, Access to Work supported 4,233 people in work with continuous help, helped a further 456 new users in work, and helped 334 people to obtain work (Hansard, 11/11/96 cited in Thornton, Sainsbury & Barnes, 1996:119).

There is a central contradiction apparent in the scheme: whilst on the one hand it offers disabled employees a greater degree of choice and control in terms of their working environment, on the other hand, as with the Disability Discrimination Act, the locus of the 'problem' is placed firmly within the disabled individual and not with their employer. The programme will not improve the general working environment for disabled people. (Thornton & Lunt, 1995).

Whilst the scheme was introduced with the aim of getting disabled people into

employment, the emphasis is on helping individuals who are actively seeking work (i.e. attending job interviews) or who are already in work. Information on the level and type of training on offer for unemployed disabled people is very thin on the ground and concern has been expressed that insufficient effort has been made to offer adequate training for disabled people seeking work:

> The challenges facing training are to reorientate it towards openings in the service industry, to increase variety in programmes to serve a more heterogeneous target group, and to improve job seeking skills (OECD, 1992; cited in Thornton & Lunt, 1995).

These issues will be explored later in the chapter with reference to the Government's 'New Deal' Programme for the long - term unemployed.

This is an important omission, as there is evidence that many disabled people face discrimination by employers at the job application stage (Spastics Society, 1990).

It is also the case that there is no mention of disability awareness training for non - disabled workers which is essential for disabled people to be fully accepted in the workplace.

Disability Working Allowance

There have been other developments in terms of disability employment policy in the form of Disability Working Allowance which was introduced in April, 1992. This benefit was intended to encourage disabled people into work by topping up low earnings. It was introduced following growing concern in the late 1980's about the potential financial disincentives to work facing disabled people and the cost to the country of maintaining so many people on benefits:

> Public expenditure on benefits for sick or disabled people now accounts for almost a quarter of the total spent on social security benefits, is second only to that for people of retirement age and is considerably more significant than provision for the unemployed (Thornton, Sainsbury & Barnes, 1997:110).

The primary aim was to encourage disabled people off benefits and into work in order to offset the situation where those who were out of work received higher social security benefits than the non-disabled unemployed whilst at the same time there was evidence that disabled employees earned less than non-disabled workers in equivalent jobs. It was also intended that Disability Working Allowance (DWA) would act as a partial capacity provision i.e. disabled people who are capable of some work but who are not fully able to support themselves. Also, the benefit was designed to encourage disabled people to try employment

without losing their former rate of incapacity benefit, if the return to work is unsuccessful within two years providing that the individual is still incapable of work. (Rawlingson & Bethoud, 1996; Zarb, Jackson & Taylor, 1996; Thornton, Sainsbury & Barnes, 1997).

To qualify for receipt of Disability Working Allowance individuals must be:

Table 7.4 Qualifying Rules for DWA
Working for more than 16 hours a week in a paid job that is expected to last more than five weeks provided that they are at a disadvantage in getting a job due to illness or disability (despite the fact that they have to be in work or have the offer of a job).
***Either** In receipt of or received within the last 56 days before the claim Incapacity Benefit, Severe Disablement Allowance, or a means-tested benefit with a disability premium such as Income Support (Isdp), Housing Benefit or Council Tax Benefit.*
***Or** the Higher Rate of Disability Living Allowance (DLA) Mobility Component, or the higher or middle rate of the DLA Care Component, or similar payable under the war pensions or industrial injuries scheme.*
Be aged 16 years or over.
Be earning less than the DWA income threshold (after household composition and income has been taken into account) and have £16,000 or less family savings.

(Source: Adapted from Zarb, Jackson & Taylor 1996; Howard, 1997).

From 1995 the financial incentives associated with DWA were improved. The following measures were introduced:

Table 7.5 Improvements to DWA
Automatic exemption from NHS charges for people with savings of £8,000 or less.
Increase in the rate of benefit for couples and lone parents.
An increase in the earnings threshold for single people.
The introduction of a new disabled child's allowance.
The extension of DWA to people undertaking training for work.
The allowance of £10 per week for people working 30 hours or more a week.

(Source: Zarb, Jackson & Taylor, 1996:2)

There is evidence that the improvements to this benefit have had a positive effect as the caseload for DWA increased from under 6,000 in April 1995 to 11,942 in January 1997 (Thornton, Sainsbury & Barnes, 1997:115). It has enabled some disabled people to take up and stay in paid work (Rawlingson & Berthoud, 1996).

Disability Working allowance has offered disabled people who are trying out work a distinct advantage. The two year 'linking rule' means that if the job does not prove to be suitable, the person can return immediately to long-term incapacity benefit without having to endure 28 weeks at lower rates. This has avoided the risk of loss of long term benefit entitlement and in theory, reduced the risks associated with employment (DIG Journal, Autumn, 1996).

It is the case however, that the introduction of DWA has had limited impact in terms of encouraging disabled people into work and it is argued that in terms of helping disabled people move into and stay in employment, DWA is just the 'tip of the iceberg' as:

> In 1993, of the 1.6 million disabled people who were, or had been on disability benefits, only 425,000 had some attachment to work. Of these only 60,000 were working 16 hours a week or more. Only 17,500 people were eligible for DWA and only 3,500 were receiving the benefit. A handful, 200 people, had been encouraged to work by the benefit (Rawlingson & Berthoud, 1996:212).

The benefit has had limited success for a number of reasons which will be briefly outlined below.

Many individuals had been discouraged from applying for fear that they would be declared capable of work. They would thereby risk losing their incapacity benefits and associated 'passport benefits' and be financially worse off. (Rawlingson & Berthoud, 1996).

> The benefits system traps people in categories of 'sick' or 'fit' which have shifted over time as more of the 'sick' have to sign on as 'fit'. People on incapacity benefit are effectively discouraged from having any contact with the labour market (Howard, 1997).

There is evidence that many disabled people view their impairments as a major barrier to work (Rawlinson & Berthoud, 1996). A lack of awareness about DWA amongst disabled people has been found to be a major problem (Zarb, Jackson

& Taylor, 1996), together with the complexity and difficulty of claiming benefit. There is also evidence that some disabled people fail to claim the benefit because they do not want to be labelled disabled when they had gained employment. They did not want to be in work and reliant on benefits (Zarb, Jackson & Taylor, 1996).

There are other problems associated with DWA. The benefit is withdrawn at a steep rate as income rises. It is reduced by 70 pence on the £ and if other means tested benefits such as housing benefit are claimed, people may see a 4 pence net gain for a £1 increase. The unemployment trap has constituted a powerful disincentive to the take-up of DWA. For example, individuals may lose out as a result of travel to work costs, the removal of Council Tax and Housing Benefits as income increases and possibly any mortgage interest payed whist they were on Income Support (disability premium) (Rawlingson & Berthoud, 1996). It is also the case that there is a lack of awareness of the extra incentives introduced with regard to DWA (documented above), which were introduced in April, 1995 (Howard, 1997).

The other problems with this benefit are that as with the other measures outlined in this chapter, the emphasis is on the disabled individual taking responsibility for his or her situation:

> There is a clear view in the policy [underpinning DWA] of economic,

> rational actors acting at the margin to take up opportunities that were previously not worthwhile. Underlying the DWA is the assumption that job opportunities do exist which persons on the margin can be persuaded to take. 'Seek and ye shall find' (and be appropriately rewarded into the bargain) would seem to be the underlying maxim (Thornton & Lunt, 1995:41).

The New Deal for Disabled People

Although the present government's New Deal for Disabled People was introduced after the completion of data collection, the basis of the policy is open to question.

The emphasis on individual responsibility is reiterated in the present Government's green paper 'A New Contract for Welfare' which was launched in March 1998:

> At present the welfare state concentrates on supporting people rather than helping people to support themselves. While the rules of some benefits require some claimants to look for work, and in return offer them help to do so, others fail to encourage claimants to enter the labour market or to undertake training or voluntary work (Cm 3805:11).

The Green Paper sets out the present government's plans for getting the long-term unemployed back into work including specific help for disabled people. The intention is to:

Table 7.6 The New Welfare State and Disabled People
Introduce effective civil rights for disabled people
Via the Disability Rights Task Force which will recommend the way forward, and the Disability Rights Commission which will protect, enforce and promote the rights of disabled people. It is also intended that the remaining provisions of the Disability Discrimination Act will be implemented.
Help disabled people into work
Via the New Deal for Disabled People which involves support for innovative schemes to test a range of ideas for helping people with a disability or long term illness move into, or remain in, work. The bidding process for innovative schemes is at present underway and the first contracts will be awarded in early autumn 1998. Funding has been made available for pilot work on the effectiveness of personal advisers whose role will be to offer individualized help to disabled people who want to move into work. They will co-ordinate a range of services ranging from action planning, job preparation and job placement, through to advice on benefits for the disabled when they want to move into work. The first pilots will begin in October 1998. It is intended that the pilots will supply more information on the difficulties faced by disabled people in relation to the labour market.
Tackle the Barriers to Work which Disabled People Face
In particular the Unemployment Trap where disabled people are worse off in work because of the loss of benefits. More financial help will be provided to disabled people who find work. From October 1999, a new Disabled Person's Tax Credit will replace Disability Working Allowance. This will provide more generous help and support to a larger number of individuals. The limit on the amount of work that disabled people can do before loss of benefit will be increased. For example the period for which people can take up a job and return to benefit if the job fails will be increased from 8 weeks to 1 year and the 16 hour restriction on voluntary work will be abolished. Pilots are proposed which would allow people on Incapacity Benefit to remain on benefit whilst undertaking work for a trial period, do some paid work up to a weekly limit of £15 without affecting benefit, have access to job finders grants and job match payments for the first six months of part-time work to ease the transition into work. Employer discrimination will be addressed through the implementation of the Disability Discrimination Act and establishing the Disability Rights Commission.

Source: Adapted from Cm 3805 'A New Contract for Welfare-54)

The polices advocated in the Green Paper for disabled people constitute positive action at this early stage of their development. On one level, they provide evidence that this government has put the problems faced by this group in achieving full civil rights and access to employment on the policy agenda, and the scheme does represent:

> The first programme ever to provide disabled people who want to work with the opportunities to do so and the assistance they need. It marks a clean break with the past, when disabled people were left for years on benefit without help or advice on how to return to work (Cm 3805:52).

The availability of personal advisers will be a positive step in helping people negotiate the benefits maze and the barriers to employment. Also, there will be opportunities to learn new skills. The Government is also planning an information campaign to:

> To improve knowledge of the existing help available to help people into work and to change the attitude of benefit recipients, employers and the public (D*of*EE Brief March, 1998).

Equally important is the Government's acknowledgement that some disabled people will never be able to work:

> Our commitment to their welfare is unwavering, The Government will work to ensure that they are not left on society's sideline (Cm 3805:51).

However, there are problems with some of the support that is being advocated for disabled people. The Disability Rights Task Force which has been charged with the role of recommending the best way of securing civil rights for disabled people has been criticised by organisations of disabled people for a lack of disabled representation with 50 percent rather than the 75 percent originally asked for. Also, people with learning difficulties are excluded and come under a separate reference group (Info Exchange, February, 1998:1).

The Green Paper is unclear on how the remaining provisions of the Disability Discrimination Act will be implemented. This may give cause for concern that the Act is based upon persuasion rather than social obligation on the part of employers.

Linked to the above point, is the possibility that, as with non-disabled young people (see chapter two), the government urges people to 'stand on their own two feet' whist extending the period of dependence in youth. There is a commitment to tightening up the eligibility criteria for incapacity benefit, disability living allowance and attendance allowance which will affect all new claimants (Guardian, March 27, 1998:21;28). In these circumstances, the onus will increasingly fall on families. Concern has been expressed by the

Disablement Income Group about the logic behind tightening up eligibility for incapacity benefit before a proper programme of welfare to work has begun (Disability Now, January, 1998:3).

The merit of youth training in this context is also debatable, given that there is evidence that such training schemes for non disabled people are geared for internal labour markets rather than external ones (i.e. training for a particular job in a particular firm) and that they socialize young people for low skilled, low paid work with little hope of employment at the end (See chapter four). This is of particular concern with young disabled people given the ineffectiveness of the Disability Discrimination Act, and the current high rate of unemployment with 24 percent of the male working population non - employed in 1996 (Walker, 1997:vii). It seems as if the Government's goal of reducing the numbers of people on benefits is out of kilter with disability employment policy.

There is also the risk that some employers may be enticed into the New Deal by the opportunity for cheap subsidised labour and would offer low paid poor prospect positions (Gold, The Times, 14 April 1998:21).

In summary, the New Deal does offer some promise for disabled people the extent of which is difficult to judge at this early stage of the programme. The acid test for the programme will be the degree to which Government is prepared to obligate employers not to discriminate against disabled people. As the law stands

at the moment, the onus is on the individual disabled person instigating action against a particular firm using a Disability Discrimination Act which is full of loopholes and the key to the success of the New Deal is to make employers change their practices. Unless that is achieved the programme can be no more than window dressing.

The chapter thus far has critically reviewed disability employment policy from the 1944 Disabled Person's (Employment) Act up to, and including, the introduction of the New Deal for Disabled People in April 1998 with the result that the focus has been on the macro issues associated with employing disabled people.

The next section of the chapter will explore the employment of disabled people from the micro perspective that is, the young adults own perceptions of their experiences. Literature does exist on school-leavers experiences in the labour market (Walker, 1981), but this work although comprehensive, is not recent and was quantitative rather than qualitative in nature. The data outlined below reflects a research agenda which was set by the disabled people themselves, and as a result highlights their major concerns as expressed in interview.

FROM SCHOOL TO WELFARE?

This Section will focus on the following issues which were of great concern to

the young disabled adults in the study: access to the employment market both in terms of the attitude of employers and physical access to buildings, the role played by careers officers, qualifications, and the invisibility of disabled people in the labour market.

Access to Employment

Society places great emphasis on the importance of paid work which is viewed as providing a number of benefits for the individual namely: a social identity, meaningful and interesting activity, social contact and financial independence from the state (Thornton & Lunt, 1995, Rawlingson & Berthoud, 1996). It is also the case that:

> Most people in Western Society expect to work. The question often asked of young people 'What do you want to be?' is not seeking to know what kind of person they want to be but what kind of work they want to do... The stigma attached to unemployment serves to strengthen the links between job and social status, job and sense of self-worth. We expect, and are expected, to make a contribution to society through the work we do (Smith, in Hales, 1996:145).

Access to employment both in terms of the opportunity to gain a job and the issue of physical access to premises were issues which caused great concern to

the research sample and their range of experiences will be explored below.

Getting a Job

Some of the sample were in employment at the time of interview and the breakdown was as follows:

Table 7.7 Occupational Status of Sample	
Type of Employment	(n = 42)
Full-Time Employment	1
Part-Time Employment	2
*Informal Employment**	2
Unemployment	37

** 2 individuals were moonlighting whilst on benefits*

The three individuals who were in formal employment had found their jobs through a variety of routes from the local paper, through the employment service, and via parental contacts. The comments were generally positive about employers. Christopher's remarks were typical:

> My work colleagues are very supportive as are my employers. I am the only disabled employee and I haven't met any problems. I want to become a manager.

Oliver, whilst reasonably happy at work had some reservations about the nature of the tasks allocated to him and the level of wages on offer. He said:

> My work is roughly what I want to do. I'm working with computers but I mean it's pretty basic stuff entailing data capture and data entry. For the money you get it is really underpaid. It is also very menial stuff. It's not great but it is experience.

Oliver had managed to secure a better job with another organisation but was having the greatest difficulty in getting his new working environment made wheelchair accessible which was a source of great stress:

> I have got a new job, it is permanent and with more pay. At the moment I am having fun and games with PACT because in the contract that my new employer has offered me, they have stated that they will only offer me the job providing that I get funding for a chairlift because the place that I will be working is inaccessible for a wheelchair. PACT have turned around to me and said they will only fund me for the chairlift if I have been unemployed for weeks beforehand. It is worrying me to death.

All the individuals who were in employment were in office jobs.

Sadly, the individuals in employment were in a minority as 37 out of 42 people were unemployed with two other individuals in informal employment (i.e. moonlighting whilst on benefits). The reasons behind this will be explored below.

In two cases, contributory factors to the decision to leave employment were the nature of the job and a lack of support in the workplace. Vera recalled:

> The job was horrible. It was clerical and just very boring and there were only two people with disabilities there, myself and the telephonist. I didn't have the right support in the workplace and I struggled and I worked full-time and found it very tiring. I changed my hours to part - time but it still didn't work out.

Lisa said:

> I decided that I wanted to work in the publications department of a National Charity. I got the job in the July but I decided that I could not work there as I had a lot of conflicts as a political disabled woman working for a charity. I was being asked to write booklets on pain relief and I thought I was going to be doing them on personal assistance and housing...that was very shocking to me I couldn't take it.

Other people had tried to obtain employment and attended interviews. They felt that their lack of success was due to the employer's attitude to their disability. Felicity said:

> I feel that I am not too disabled to work but that society says that I am.

> I am qualified to be a secretary but there is no way I can get a job because of my image. I put in applications, and I nearly always get an interview but I always get the same excuse that I am too slow. I think it is more than that; it is because of my speech because of the image. You can hide a wheelchair but you can't hide from the waist upwards.

Andrea said:

> ...The factory people wouldn't let me work with my sister because they said I was a fire hazard and that really got up my nose because disabled people do get jobs like that I know. I can walk and I wouldn't use a wheelchair in the factory and I have grown out of my epileptic fits.

Olivia recalled:

> I wanted to work in the factory after I left school but they didn't want me because of my epileptic fits they said I couldn't do the machinery...but I could have done easy jobs. I was a bit upset.

Other people felt that their difficulties lay in employers' perceptions that they would be more expensive to employ because of their impairment. Freddie commented:

> I have been blocked by employers who have said that it would be too expensive to adapt the building or that I am too slow.

For eleven people their first experience was via work experience which was a short-term placement arranged with a local employer whilst they were still in full-time education. This was either arranged by their school or college or by the employment service. This was viewed as an important event by the young adults and left a lasting impression.

Five people felt that their work experience had been positive. Angela's comments were typical:

> I had some work experience which I enjoyed. It was office work, going through exam papers to make sure that they all said the same. I also worked in accounts and had to fill in the details of cheques in the log. They were all helpful and friendly.

However, the majority of the group felt that their work experience had been negative. Christopher recalled:

> I had work experience in a bank and a library. The bank said that there was no point in me applying for a job there because I wouldn't be able to cope as you need two hands to count money and I can't use my left arm

at all. That was the only reason they gave.

In some cases employers showed little commitment to the training needs of the young person and made no effort to adapt to their needs. Tina's comments were typical:

> I couldn't do work experience. I was just sitting there because they didn't make any effort adapting to my needs. Everything was too high and all we did was fill in my training booklet because I actually couldn't carry out the tasks. I had to watch people lie on the form because it wasn't physically possible for me to do the task, and they weren't prepared to make it physically possible for me to do the task.

Interestingly, out of the eleven people who had been on work experience, only one was in employment at the time of interview, and that person was Christopher whose experience had been negative. None of the individuals who said that their work experience had been positive were in employment. None of the others in employment at the time of interview had been on work experience. It seems as if in the case of the individuals in this study, work experience whether positive or negative had little practical impact on employment prospects and was viewed as something of a lottery by the young disabled people. Robert's comments were typical:

> I had some work experience when I was at college but it was all office based, just data input on the computer nothing else. They didn't even tell me what the data related to. The review about me wasn't very good. The employer said that I was methodical but slow....Work experience seems to be purely pot luck. I know people who did their work experience and the company offered them a job when their course had finished. The ones that get the jobs are very much in a minority though.

In some cases, work experience even when viewed positively had not led to employment. Barbara's comments were echoed by others:

> I had a load of work experience with children which I really enjoyed but I don't know why I never ended up doing that. I would like to do it but I think it is getting up the confidence to do something about it.

Work experience could have a damaging effect on individual's self-confidence about their ability to work. Josie said:

> I underestimate my abilities due to my speed. I am not very good or quick at things like typing. It was pointed out to me during work experience.

Some people were determined to keep trying to get a job. Freddie said:

> I have been for numerous job interviews and would do whatever came along. It is other people who have underestimated me.

Others did not feel that it was worthwhile even trying to get a job. Henrietta's comments were typical:

> I'm sorry to say this but it all depends on whether you fit into their category. If I wanted to go for an interview to work in a shop or something I would get discriminated against straight away because of my disability; because of the way I talk; the way I am. It's where your face fits.

The young people also felt that there were other factors which influenced their employment prospects apart from the attitudes of employers and the issue of physical access to buildings. These will be explored below.

As outlined in the previous chapter, careers officers were perceived as having played an important role in determining the young person's suitability for employment.

Careers Officers

As mentioned in Chapter Six, a minority of the sample reported that their careers

officer had been helpful. Zoe recalled:

> The Careers Officer helped me to apply to this college and actually drove me up here to have a look around because my parents weren't interested.

As highlighted earlier in the thesis, there were also examples of careers officers encouraging a disabled person to go to college but being overruled by parents. Jane said:

> A careers officer came to see me and he was on about me going to Hereford College for two years for typing but my dad said what will I do after that two years. My Dad said I would be better off in a Day Centre so that is where I went.

The importance of the disabled person knowing their own mind was stressed when dealing with careers officers. Tina said:

> I have never had a bad experience with careers officers but you have got to be straight on what you want because they will try to put you in Day Centres. If you are positive and know what you want and get that across then you shouldn't be put in one.

But for the majority of the sample, their experience of careers officers had been

extremely negative with numerous barriers erected to employment. These took the form that the individual was incapable of work due to the nature of their impairment. Andrea remembered:

> I told the careers officer that I would like to work but he said that I was not fit enough.

Others were told that it would be too dangerous for them to work in their chosen occupation. A number of individuals recalled the reasons why they were not considered suitable to work with children. Irma's comments were typical:

> The one thing that I would have really liked to do, the careers officer was dead against like with most of us, was working with children. He said what if there was an accident and you had all these children running around. He just didn't think we could cope with it. I don't agree with his view. I don't think it would be that hard as there would probably be other staff around. I have a friend who works in a creche and she is a wheelchair user and she enjoys it.

Sometimes careers officers hinted that it might not be financially worthwhile for the young person to work: Marjorie's experience was typical:

> He started to go on about allowances and things. He said it wouldn't be

worth my while working.

It was often felt that careers officers had not been trained to relate to the disabled people they were supposed to help. Robert observed:

> The careers officer wasn't helpful really until it was made known to him that 'this is what I want to do' and then he slowly came around to trying to achieve those goals. He found it difficult to comprehend the fact that I was actually telling him what I wanted to do. I think careers officers have a problem with that. They think they know what's best.

Of course, there were some disabled people who were unable to work due to the extent of their impairment and who had accepted the situation. Jenny said:

> I have never seen a careers officer in my life. I don't even know what they do. I went straight to the Day Centre from school and I am very happy here.

Unfortunately negative attitudes on the part of employers and careers officers were not the only factor which the sample felt undermined disabled people's chances of gaining employment. Educational qualifications were highlighted as a major determining factor and this will be explored below.

Educational Qualifications and Employment

A third of young people in the general population were managing to obtain five GCSE's grades A - C (Biehal & Clayden et al, 1995). In 1997 the GCSE averages for special schools (attended by the majority of the research sample) were as follows:

Table 7.8 GCSE Averages For Special Schools 1996	
Qualification	***% of all Pupils aged 15 years***
5+ Grades A* - C	**1**
5+ Grades A* - G	**5**
1+ Grades A* - G	**20**

Source: DofEE September 1997

A minority of the research sample gained high examination passes ranging from one GCSE grade A-C up to degree level as is illustrated below:

Table 7.9 Educational Qualifications	
Level Attained	***Number in Sample*** (n = 42)
Degree	2*
1+ A-Levels Grades A-C	**3***
1+ GCSE's Grades A-C	**8**
1+ GCSE's Grades D-G	**7**
No Qualifications	**27**

*Note:** These individuals were also included in the GCSE A* - C figures

A lack of educational qualifications is a serious disadvantage in an increasingly competitive youth labour market where educational qualifications have ever

more currency. It is the case that young people and older workers disproportionately face the worst unemployment and there was a substantial increase during the 1980's due to recession and an increasing youth population. For example, for immediate school leavers aged 16 - 17 years:

> The unemployment rate was as bad in 1996 as it was in the 1980's. Then, 13 per cent of the entire age group were unemployed by spring 1993 it was nearly 9 per cent...and by the spring of 1996, just over 10 per cent (142,000) were jobless, despite the promise of a guaranteed place on YT (youth training). This represents a percentage unemployment rate of 18.6 per cent (almost one in five of all economically active 16 and 17 - year olds (Chatrik and Coventry, 1997 cited in Walker, 1997:180).

Official figures show that one in ten people of working age have a disability and that disabled people are more than twice as likely as the general population to be without a job and to suffer long-term unemployment (Howard, 1997).

It is documented in the literature that the lowest levels of unemployment are recorded for individuals holding a degree or vocational qualification (Walker, 1997) illustrating the importance of educational qualifications in determining labour market position. In the case of the minority of the sample (eight individuals), who gained one or more GCSE's at grades A-C or above, their employment situation was as follows:

Table 7.10 Educational Qualifications and Employment GCSE Grades A-C	
Type of Employment	(n = 8 out of 42)
Full-Time Employment	1
Part-Time Employment	1
Full-Time Education	2
Informal Employment	2
Unemployed	2

Two out of the three people in the entire sample who were in formal employment at the time of interview had a high level of educational qualifications. Interestingly, the two most highly qualified individuals, who were educated to degree level had been in full-time employment but had left their jobs partly due to a lack of support from their employers (as outlined above) and were in informal employment (moonlighting whilst on benefits) at the time of interview. The other factors behind their decision to leave employment will be explored in the next chapter. Two people were in full-time further education at the time of interview but had already gained higher examination passes and expressed a strong desire to enter employment upon the completion of their course. Clare said:

> I'd like to move on to either a full-time or a part-time job because at the end of the day I don't want to be stuck at home looking at four walls, housebound all the time like a lot of women are. It's not right.

Two others were unemployed at the time of interview but although actively

seeking work, the prospect of full employment was a source of worry the reasons for which will be explored in the next chapter. The overriding characteristic of these individuals is that they all thought themselves capable of work. Freddie's comments were typical:

> I am hoping to go to University and to eventually start my own business.

Of those people above who had attended segregated school, only one had obtained any qualifications there. The majority of the examination passes had been attained whilst at Further Education College or as a result of private education.

Of the remaining thirty four people in the sample, seven had lower examination passes i.e. one or more GCSE's at grades D - G, and the remaining twenty seven people had no qualifications. Their employment situation was as follows:

Table 7.11 Educational Qualifications and Employment GCSE Grades D-G

Type of Employment	n = 7 (out of 42)
Full-Time Employment	0
Part-Time Employment	1
Unemployed	6

The majority of the sample had obtained no educational qualifications and were unemployed at the time of interview. Most felt that they had been disadvantaged by the nature and level of education which they received. They felt that

segregated schools were less orientated to preparing their pupils for the labour market. Henry's comments were typical:

> They [the school] probably think that you are never going to bother working. They don't prepare you for work. They were alright with independence but they never gave you any preparation for work and you need that as well. My friend works for the BBC and she was fortunate to get that because she went to a different sort of school.

The one person in employment out of this group had attended a large Comprehensive school.

The young adults were acutely aware of their lack of qualifications and how it had undermined their competitiveness in the employment market. Debbie said:

> I said to the headmaster as I was coming up to leaving 'I don't know why you are telling me I can leave school because I haven't had any schooling. I am going to be in a right mess when I go for a job aren't I!'

Similar sentiments were expressed by Henrietta and Kevin:

> You just leave school and there is nothing at the end of it. Without qualifications you are lost.

Kevin explained:

> When I was at school I had this expectation that I would get a job but it wasn't to be. I didn't get the education - maths and things like that.

Oliver, the only individual in this group who was in employment said:

> a lack of qualifications and work experience have really blocked me in terms of job prospects.

For some people a lack of educational qualifications wasn't the only barrier to employment they faced. As mentioned in chapter six, some of the sample lacked the most basic literacy and numeracy skills and these individuals were all unemployed at the time of interview. Henrietta's comments were typical:

> I like children but with me not being able to read...I was down to do work experience in a creche but to put it bluntly I didn't go because I thought it was pointless with me not being able to read all that good...I felt like a child myself.

Debbie who was illiterate had also been offered work experience in a nursery and had struggled, related how her partner who was seventeen years her senior, had faced similar barriers when he left school:

> My boyfriend can recognise the odd word so we get by. They said to him 'it's no good teaching you to read and write because you will never get a job' If they were saying that to someone born in 1951, what were they doing saying the same to somebody born at the end of the 1960's? Nothing has changed.

Lack of literacy and numeracy skills seriously disadvantages a non - disabled person but for a disabled person who may have limited mobility and perhaps poor co-ordination, the disadvantage is much greater as the options in terms of alternative employment utilising physical skills are non-existent due to the nature of the individuals impairment and the restricted labour market.

Due to the factors outlined above, the majority of the research sample were likely to become long-term unemployed with its associated disadvantages:

> Long-term unemployment itself becomes a barrier to employment as it erodes work related skills and repeated unsuccessful job-search and rejection can undermine self-confidence and motivation (Walker, 1997:179).

For many of the sample, their situation had become a vicious circle of disadvantage where their employment prospects were initially undermined by a poor education, the results of which were amplified by a restricted labour market

and weak disability discrimination legislation where the emphasis is often on poorly educated individuals initiating action against powerful employers. Also, frequent rejection had engendered a sense of hopelessness in the majority of the sample and they had simply given up trying to find work.

The lack of prominence of disabled people in the labour market both in terms of employment generally and high profile jobs in particular, means that disabled people are largely invisible in this context and this further undermines their employment prospects because if they are not seen to be in employment, and therefore capable of work, there is little incentive for attitude change on the part of employers. The stark reality for the majority of the sample was that they had indeed gone from school to welfare and the implications of this will be explored in the next chapter.

When individuals in the sample did manage to obtain employment it was in low paid, low skilled jobs with few opportunities in terms of career development and this severely restricted individual's options in terms of independent living. Ironically, all the individuals in employment in the sample were still living at home with their parents and the reasons behind this will be explored in the next chapter.

The next section will explore the extent to which employment and related factors

were linked to independence or dependence using the index outlined in Chapter four.

EMPLOYMENT AND INDEPENDENCE

The Independent Group

Whilst the individuals in this group were the most likely to be in employment, a minority of the group had achieved this status. Three people were formally employed at the time of interview. The remainder were reliant on benefits.

All of the people engaged in formal employment at the time of interview stressed that they had extremely supportive parents. This support ranged from instilling in their children that they had every confidence in their ability to achieve in life through to actively helping their child to secure employment through social contacts. None of the individuals in this group stated that their parents had ever expressed a negative opinion about their ability to work and, in some cases, had actively encouraged their child to achieve in the face of professional opposition. In one case parental encouragement had motivated an individual to search for a job despite a very negative experience whilst on work placement.

The presence of supportive parents or other relatives, was also significant in the

lives of the remaining six people in the independent group with four out of the six stating that this had influenced their lives to a great extent. All six were full-time students at further education colleges at the time of interview. Two of the six said that their parents had always had a negative opinion of their ability to achieve but that they as individuals had been determined to do as well as possible.

The members of this group were the only ones to remark positively on the advice that they had received from careers officers. A minority were satisfied with the guidance they had received. These individuals stressed that they had 'known their own mind' when dealing with careers officers.

The most highly qualified individuals in the sample were in this group. The majority had gained one or more GCSE's at grades A-C or above. However, only three people were in employment at the time of interview. Two individuals who had been educated to degree level were unemployed.

Because the research is based on a very small sample it is only possible to make very tentative suggestions from the data. However, it seems that in the case of the group of individuals in the study, educational qualifications added little to the employment prospects of the disabled people in that, the most highly qualified people were unemployed at the time of interview and although they had been employed in the past, they had been engaged in low status, poorly paid work. The

same can be said of the individuals in employment at the time of interview in that, they too were in low status, poorly paid jobs.

Whilst educational qualifications added little to the employment prospects of disabled people, literacy and numeracy problems brought still worse prospects as they undermined every aspect of the young peoples' lives. Limited employment opportunities were further reduced and life in general was made much harder. This will be explored further in the next chapter.

Another factor worthy of discussion in terms of this group is that all three individuals in formal employment were living in the parental home at the time of interview, whilst the people who had been in employment but had decided to leave their jobs were living independently in the community and therefore responsible for organising their own care and running their own homes. In fact, the majority of the independent group (8 out of 11) were living independently in their own homes in the community and all were technically unemployed. Whilst employment brought a measure of independence, the extent to which it was achieved was undermined by that fact that all the individuals were still resident in the parental home at the time of interview. Independence via employment was at the cost of domestic dependence, whist domestic independence was only be achieved via benefit dependence. The reasons behind this will be explored in chapter eight.

The Intermediate Group

None of the individuals were in employment at the time of interview. Four individuals were not available for employment as they were full-time further education students.

Five out of the ten individuals stated that they had very supportive parents who had always encouraged them and this support ranged from encouragement to achieve academically through to arranging a work placement. Seven individuals in this group had gained GCSE passes at grades D-G.

The remaining five people had parents who appear to have offered little or no encouragement. In two cases, parents had shown no interest in the child's future career and in one case had attempted to stop their daughter attending further education college. Ironically both individuals had done well academically compared to the rest of the sample in that one was due to sit A-levels at the time of interview and the other had gained some GCSE passes.

This group reported a negative experience of careers officers who they felt stressed their inability to work.

Members of the intermediate group who were not in full-time education were more likely to report severe literacy and numeracy problems as the barrier which

had prevented them from applying for jobs and this was a source of great distress.

In terms of educational qualifications, although seven members of the group had obtained examination passes at GCSE level, none were in employment. Three people were full - time students at further education college whilst two others attended day centres. Both of these people had supportive parents who had encouraged them to work. So again, possession of educational qualifications seems to have had little bearing on the young peoples' experiences in the labour market in the context of this small scale study. However, a lack of basic literacy and numeracy skills was perceived as an enormous barrier to employment by the research sample.

A high proportion of this group although unemployed at the time of interview, were living independently in the community and were responsible for organising their own care and running their own homes. Two people were at residential further education college, and two people were still living at home with their parents.

The Dependent Group

None of this group had any experience of the labour market and all attended day centres during the week with the exception of two who were at a residential

further education college.

This group were the most likely to report problems with their parents ranging from low expectations in terms of academic and occupational achievement, often leading to over- protectiveness which the young people found stifling, through to complete disinterest. The parents of these individuals were the least likely to have fought for their child and in many cases were incapable of doing so. In general they were very much guided by the professionals in the disability field. However, the reasons behind parents' attitudes need further exploration. To what extent did the young people's perceptions of their parents reflect the levels of support available to the parents of disabled children? This will be addressed in chapter eight.

This group also stressed that their experience of careers officers had been negative. They had been told that they were too severely impaired to work and that it would not financially beneficial to do so.

In terms of educational qualifications, none of the individuals in this group had ever been entered for any examinations whilst at school and this was a source of great frustration. This group were the most likely to report the lack of a basic education and as a result, severe literacy and numeracy problems.

One individual lived independently in the community and two others were at

residential further education college during term time but returned to the parental home during vacations. However, the majority of the group lived permanently in the parental home and all were reliant on state benefits.

In conclusion, the young disabled people in the study faced serious disadvantage on a number of fronts in terms of the labour market. First, the majority of the sample lacked encouragement from their parents with regard to their ability to achieve academically and ultimately to work. Second, when the young people did achieve qualifications this seemed to have little bearing on their employment prospects. Labour market access was discriminatory in that if they did manage to secure employment the job was low status and poorly paid. This was one of the most damaging aspects in terms of the achievement of independence as even if people had obtained employment, the wages were insufficient to support independent living. Tina summed up the difficulties:

> You have to earn loads a week to pay for your assistance and run a flat as well. What job would pay that? Not a job that a disabled person would get anyway.

Third, even if they had managed to get to the stage of entering the employment market, there is little protection available against disability discrimination under the current legislation. The removal of the only obligatory disability employment policy has seriously undermined the rights of disabled people in the labour

market as the onus is now on the disabled individual instigating action. Disabled people who lack a basic education, and self confidence are not in a position to argue with powerful employers even if they get that far. The onus of disability employment policy is on a move from collective to individual solutions to problems and this is out of kilter with the promotion of employment for all for the reasons outlined above. Part of the blame for this situation must rest with the Independent Living Movement and its campaign for individual rights to self-determination as this has added weight to the retreat from policies of social obligation and the removal of much of the protection for disabled people in the employment market.

The realities of life for disabled people solely reliant on benefits will be explored in the next chapter.

CHAPTER EIGHT

SUPPORT IN THE COMMUNITY?

This chapter will explore the support available to disabled people living in the community in terms of the social security benefits available and the role played by personal social services. Attention will be paid to the realities of life for people reliant on such provision, with both positive and negative aspects outlined. In each case the data will be set in the context of recent policy developments.

THE POLICY BACKGROUND

The experiences of severely disabled young adults reliant on social security benefits and support from the personal social services must be set against a backdrop of recent social policy. The common themes running through recent policy changes with regard to the benefit system and personal social services have been on the one hand, a desire to promote individual rights and independence whilst on the other concern to reduce public expenditure. These issues will be explored further below.

Disability Benefits

The National Insurance and National Assistance schemes introduced by Beveridge following the second world war made few distinctions between different types of claimant. The qualifying factor was that the individual was unemployed and the reason was not important. Benefits were paid at a flat rate

regardless of individual and family circumstances (Berthoud, 1998).

Benefits targeted specifically at disabled people were introduced by the 1974 Conservative government and these were at higher rates than those available to other groups apart from pensioners. These benefits were designed to afford disabled people a degree of financial independence, which is essential both in terms of adult status and the opportunity to participate fully in the community (Hirst & Baldwin, 1994).

On one level it can be argued that social security provision has conferred a degree of independence on disabled people. In certain circumstances disabled young people have been found to have a higher income than that of young people in the general population. This was particularly so of young people still in full-time education and those with no formal weekday provision. However, non-disabled young people in employment were found to have the highest incomes of all (Hirst & Baldwin, 1994). Some disability benefits are generous especially the war pension and industrial injuries schemes (Berthoud, 1998). Disabled people are also advantaged in the benefits system as they are able to claim benefits in their own right from the age of sixteen (Hirst & Baldwin, 1994), whereas social security support for non-disabled young people who are unemployed has either been withdrawn or reduced, with income support withdrawn from nearly all 16 - 17 year olds, and reduced rates have been introduced for young people between the ages of 18 and 25 (Coles, 1995). It is

also the case that the present government has promised the most severely disabled an above inflation increase to benefits in its recently published Green Paper (Editorial, The Guardian 27/3/98).

Whilst the introduction of disability benefits was a positive step in many ways, their impact has been undermined by an underlying policy initiative of reducing public expenditure. It is beyond the scope of the thesis to document the policy changes to disability benefits in depth so a brief overview will be given. Evidence of fiscal concerns was apparent in November 1980, when long-term invalidity benefit was increased at 5 per cent below the governments estimated rate of inflation (Walker & Townsend, 1981) and the first Social Security Act of 1980 abolished the statutory obligation to increase long-term benefits each year in line with prices or average earnings whichever was the higher (Walker & Townsend, 1981). In 1981 the revised supplementary benefit scheme was introduced with a reduction in single payments for exceptional needs which further disadvantaged disabled people. Attention has also been focussed on disability benefits during the 1990's with the Major government introducing the 'benefits integrity project' at the end of its term of office. This project was designed to check the validity of Disability Living Allowance and Attendance Allowance claims following a recent investigation by the Disability Living Allowance Advisory Board and the Department of Social Security which suggested that in two thirds of cases there was insufficient evidence to support the benefits claim, and that one third of the awards made to people for life, (two

thirds of all awards) were made to people whose condition could be expected to improve (Cm 3805 1998).

The Green Paper 'A New Contract for Welfare' whilst stating the government's commitment to the continuing provision of Disability Living Allowance (DLA) and Attendance Allowance (AA) as universal, national benefits, makes it quite clear that eligibility for these benefits is likely to be tightened up in the form of more stringent medical tests:

> There is a question about whether some people receiving these benefits are entitled to them and whether others who are entitled to them are getting the help that they need...We now want to undertake a review of the gateway to DLA and AA. (Cm 3805 1998:55).

The following disability benefits are currently available:

Table 8.1 Current Disability Benefits			
Current Benefits	*Purpose*	*Type*	*Date*
Incapacity Benefit	To replace the earnings of those incapable of work, who had previously paid NI contributions.	Contributory	1995
Severe Disablement Allowance	To replace the earnings of those incapable of work, who do not have a contribution record.	Contingent	1984
Invalid Care Allowance	To replace earnings for those who do not work because they are caring for a disabled person receiving DLA or AA	Contingent	1976
Disability Working Allowance	To supplement the low pay of those working at least 16 hours per week, whose employment prospects are affected by disability.	Means tested	1992
Disability Living Allowance	To meet the extra costs of disabled people with special needs for care or mobility. Can be claimed only up to age 65.	Contingent	1992
Attendance Allowance	Equivalent to the care component of DLA, for those who claim over 65.	Contingent	1971
Industrial Injuries Disablement Benefit	To compensate people who were injured or who became sick in the course of employment.	Contributory	1948
War Disability Pension	Similar to above for those injured in the armed forces.	Contingent	1918
Income Support	To maintain a minimum level of income for non-working claimants and dependents. A 'disability premium' raises level of entitlement above basic rates.	Means-tested	1988
Housing Benefit and Council Tax benefit	To contribute to rent and council tax liabilities of claimants and dependents. A disability premium similar to income support.	Means tested	1983

Source: Berthoud, 1998:3

Social security benefits are either contributory (ie. Based on the national insurance scheme. The retirement pension is an example. To qualify claimants must have paid contributions in the period before they left work); means tested,

(i.e. Where assurances have to be given by claimants and their families that their income is low); or contingent (i.e. based primarily on the claimants needs only. DLA is an example) (Berthoud, 1998).

There are three main objectives underpinning disability benefits and these are to replace lost earnings, cover extra cost of living associated with disability, and to provide compensation for those whose impairments were a result of their occupation albeit in the forces or some other form of employment.

As mentioned above, by far the most generous benefits are those associated with industrial injuries and war claims which can add up to hundreds of pounds a week for seriously disabled people and can more than double the income paid by the same social security system. For example, a maximum non-means tested payment to a single person under the war pension scheme amounts to £386 compared with £160 for incapacity benefit and disability living allowance (Disability Alliance, 1997 cited in Berthoud, 1998:25). However, the benefit rate available to other disabled people is far less generous, given that many of these individuals are likely to have severe congenital impairments with all the associated social disadvantages including a lower level of education, little or no employment experience and a lack of opportunity to build up any financial capital.

There is evidence of difficulty with regard to Disability Living Allowance (DLA)

and the extent to which the current levels of benefit were intended to, and in reality can, cover the extra costs of living which are associated with severe disability. The total amount payable to the most severely disabled claimants is £87 per week. The rate was based on estimates of extra costs (including care and transport) by the OPCS Disability Survey, and the rate of benefit is significantly higher than the OPCS average of extra costs which amounted to £20 per week at today's prices. (Martin & White, 1988 cited in Berthoud, 1998:44). However, disability organisations claim that the true figures could be as much as six times higher and amount to £120 per week at today's figures. (Berthoud, 1998).

The extra costs which Disability Living Allowance was intended to cover consist of goods and services which are specific to disabled people such as personal support. In this context personal support covers two types of task: housework (including cleaning, shopping, cooking and home maintenance), and 'intimate' personal tasks such as getting in and out of bed, dressing, bathing, toileting and feeding, all of which constitute personal assistance. The benefit was also intended to cover the cost of general household items such as transport, heating and chemist's goods.

Current benefit levels have to be set against a backdrop of increasing concern over public expenditure and in particular the cost of disability benefits which has soared. This process began in the 1970's with the introduction of new benefits and increases in the rates of existing benefits as a result of both Conservative and

Labour government policies. During the 1980's most benefit rates were frozen or cut by overt or covert means but the cost of disability benefits increased markedly between 1979/80 and 1989/90 from £5.4 billion to £22.4 billion in 1997 (Berthoud, 1998:11).

Fiscal concerns have also impinged on the provision available to severely disabled people from Social Services Departments. As outlined earlier in the thesis, the implementation of the NHS and Community Care Act 1990 lead to fundamental changes in the delivery of care and support to adults in the community. Briefly, from April 1993 departments were required to assess the needs of individual people, arrange with them individually tailored services to meet those needs and commission those services as appropriate. The expressed aims behind this legislation were to empower service users by giving them choices about the support provided so that their needs can be met in ways and at times convenient to them and to enable people to remain in their own homes where appropriate (Audit Commission, 1992). There have been examples of innovative schemes which are sensitive to disabled people's needs and have greatly enhanced the quality of their lives.

However, in recent years Social Services Departments have faced an increasing battle against budget cuts resulting in services which:

Tend to be limited and inflexible. There are clear indications of how

> disabled people would like to see them improved, but user involvement in policy making is now having to take place against a background of stringent financial cuts (Kestenbaum, 1996:17).

There is another side to this. Since 1990, the Government has actively encouraged local authorities to charge users for community care services via the Health and Social Services and Social Adjudication Act (1983). However, the act did afford local authorities some discretion in terms of whether and how to use this power. Increasing pressure on local authority budgets has undermined any discretion offered by the act and the Association of Metropolitan Authorities revealed that:

> When the Government decided its revenue support to local authorities for 1993/1994, it assumed a recovery of seven per cent of the costs of domiciliary and day care through charging (AMA 1994: cited in Kestenbaum, 1997:8).

There is increasing evidence that Local Authorities are taking this route with a recent survey by the National Association of Citizens Advice Bureaux confirming:

> That there has been a dramatic increase not only in the numbers of authorities imposing charges but also in the levels of those charges

(NCAB 1997: cited in Kestenbaum, 1997:8).

Local authorities are increasingly assuming that social security benefits, especially Disability Living Allowance should be taken into account when assessing individual ability to pay even for those on income support (Kestenbaum, 1997). Concern is mounting that people who rely on such services are cancelling them on the grounds of cost. The situation is further complicated by the lack of any Government guidance on how the poorest and most vulnerable disabled people can be protected from the impact of such charges. It also the case that charges vary widely between authorities (Chetwynd & Ritchie, 1986; Kestenbaum, 1997).

The policy background both in terms of disability benefits and the personal social services demonstrates a history of competing priorities. On one level the aim was to promote individual rights and independence whilst at the same time acknowledging wider fiscal concerns.

The remainder of this chapter will focus on the realities of dependence on disability benefits and the personal social services at the micro level utilising interviews with the forty two young adults who took part in the research reflecting as far as is possible their major concerns.

SUPPORT IN THE COMMUNITY?

The first part of this section will explore the extent to which advice on available benefits was available to the young adults, and the source of such advice. Subsequent sections will focus the sample's income source and whether or not it was felt to be adequate, and the final section will look at the degree to which individual's lives were restricted and examine the degree to which the sample blamed the benefits system for any restrictions.

Benefits Advice

Some of the sample had experienced little difficulty in obtaining advice on benefit entitlement from the statutory authorities. Four people out of forty two in the sample said that their social worker had been extremely helpful in this respect. Theresa's comments were typical:

> My social worker kept an eye on me for the first six months after I had moved into the community and I found out through her the benefits that were available.

For the remaining thirty eight people, advice on benefits had been obtain via a variety of informal routes including parents, other disabled people and personal assistants. The young people felt strongly that the underlying expectation was

that they had to find the information by themselves. It was not automatically offered formally and this was a source of great resentment. Vera's comments were echoed by many:

> The emphasis is on the individual to find out by themselves and I really resent that because I know people that are struggling and why should they have to struggle for it? It should be a right.

As a result of this situation the onus was very much on parents taking the initiative and finding out about benefits. Oliver's situation was typical:

> My parents have dealt with all my benefits. They told me that I would have to apply for them as an individual and then they would deal with it.

Elizabeth's experience was similar:

> My first benefit began before I started college and my parents passed it on to me. They found out about it by themselves.

Marjorie too had relied heavily on her parents in this regard:

> I have had very good parents. I have never worried about how to get allowances. They have always dealt with all of that for me, found out and

filled in forms for me.

Other people had been forced to rely on personal assistants for information. This had proved to be invaluable for Tina:

> One of my carers has worked with disabled people virtually all her life and she knows a lot about benefits. She came up to me and said 'I think you should be getting this benefit'. It was quite nice to have somebody there who could say that.

For many of the sample, their friends had played a crucial role in enabling them to claim their benefit entitlement. Lisa summed up their importance:

> The factor that can make the difference is friends. You are either extremely fortunate in terms of having a good social worker, but your best friend should be your friends who are disabled people or your family - you need their support.

The most striking factor with regard to the sources of benefit advice is the paucity of input from formal sources and the extent to which a very vulnerable group of people, who were clearly in need from an early age, relied on informal sources of information. Given that the whole sample had congenital impairments, it was difficult for some individuals to recall exactly how their benefits had been

obtained as they had been in receipt of them from an early age. However all were able to describe their experiences from the age of sixteen onwards and it is quite clear that they were very poorly informed.

Income Source

It proved extremely difficult to ascertain exactly the young adults income source in terms of the benefits they received for the following reasons:

First, many of the young people had been in receipt of benefits from an early age. Obviously, the arrangements were out of their hands as was the control of the money with the result that in many cases, individuals could not say which benefits they received. Other researchers in this field have encountered similar problems:

> Although benefits should remain in the control of parents only where the young person is incapable of managing his or her own affairs, a change of status for those who can manage may not be so abrupt in practice. Disabled people rarely have more than a vague understanding of social security provision (Anderson & Clarke, 1982; cited in Hirst & Baldwin, 1995:39).

The picture is further complicated by the literacy and numeracy problems

experienced by many of the sample which made identifying and managing benefits almost impossible. There is also the issue of the complexity of the benefits system:

> Disability benefits are a potentially bewildering sector of an already confusing social security system (Berthoud, 1998:84).

In a few cases, fear of the loss of their benefits (despite reassurances from the researcher) prevented individuals from disclosing the exact nature of the benefits they received.

However, the income of the sample was low. As outlined earlier in the thesis, only three out of forty two people were in formal employment. One was in full-time employment, and two were in part-time employment. The income of the individuals who were working was low enough to qualify for Disability Working Allowance (i.e. the same as or below the 'applicable amount' for a single disabled person which constitutes £56.40 a week) (Disability Alliance, 1996). The remainder of the sample were reliant on disability benefits obviously without entitlement to the more generous war pension and industrial injuries provision as they all had severe congenital impairments.

The next section will examine the extent to which the young people felt socially excluded in terms of being able to participate fully in the community as a result

of their reliance on the benefits system.

Inclusion or Exclusion?

A minority of the sample (one person) was satisfied with the level of income that they received and did not feel that their life was restricted. Theresa said:

> Living independently in the community you are entitled to more money and income support and all of those kind of things. I was provided with ILF money when I was at home but it was only a very small amount whereas now I am entitled to a lot, lot more.

The majority of the sample (thirty eight out of forty two people) felt that their lives were severely restricted as a direct result of their reliance on the benefits system. The young people reported difficulties in all areas of their lives and their major concerns were as follows:

Employment

The extent to which the benefits system acted as a disincentive to individuals seeking or obtaining employment was highlighted. Vera's comments were echoed by many who were living independently in the community for whom it was a particular concern:

> I have got the issue of not being able to work because of money for personal assistance.

Tina was even more concerned:

> There are some jobs that you could do, but you can't afford to do them because you would lose your benefits, but in another way people don't think you can work and that is why you have your benefits. They haven't said we will give you this much benefit on top of your income if you want to get a job. I mean if I worked I would lose my independent living money which I think I should have whether I work or not. O.K. you lose your income support, but independent living money, you don't stop needing personal assistance because you are employed.

Robert explained how working would affect his entitlement to passport benefits:

> I'm on the housing tax benefit and council tax benefit but if I was working I would lose those and also my severe disability allowance. I would have to earn a substantial amount to cover the amount that I was losing and cover what I have to pay out. At the moment it is just not feasible.

Lisa who was educated to degree level and was moonlighting whilst on benefits

was extremely unhappy with her situation:

> I'm working illegally, because of the benefits system. I would love to work properly because some weeks get very quiet. I think it is a waste of the education I got. Last Christmas a lot of work came in and I was very busy, and having that from thinking that I would never be wanted or have skills that were valued was quite a wow thing really.

All the individuals who were living independently in the community at the time of interview voiced the same concerns. This is despite the fact that they were all in receipt of the highest care and mobility component of Disability Living Allowance due to their need for twenty four hour care and restricted mobility. The interesting point here is that disability living allowance is a non-means tested benefit which was meant to cover the extra costs associated with having a physical impairment. It is clear from the comments above that the benefit rate is insufficient to do so given that the total cost of a care package of support for a severely disabled person averages around £250 a week and the higher rate care payment in DLA is only £50 per week (Phillips, 1993 cited in Berthoud, 1998:43). By entering employment, the young people would have been forced to rely on DLA alone to pay for personal assistance.

Most of the young people living independently in the community were also in receipt of money from the Independent Living Fund which was set up in 1988

to cover the abolition of domestic assistance payments under the now defunct supplementary benefit regulations. The scheme was greatly oversubscribed as it was estimated that it would help a few hundred people, but by the time the fund closed in 1992 23,000 had received assistance and the budget had been increased to almost £100 million per year (Berthoud, 1998). This fund was superseded by the Independent Living (1993) Fund which has much tighter eligibility criteria. To qualify, individuals must receive support services of at least £200 per week from their local authority and have care needs whose total cost is no more than £500 per week to the local authority and the Independent Living Fund, and be receiving income support or have income at approximately the income support level. Any income in excess of income support has to be contributed towards the cost of care. For those individuals in receipt of income support half their disability living allowance has to be contributed towards the cost of their care (Disability Alliance, 1996).

To the young adults living independently in the community the way that the benefits system operates proved to be a major disincentive to paid employment. The majority were keen to work but it did not prove to be economically feasible, which explains why every individual who lived independently in the community in the study was unemployed. Ian spoke for many:

> The benefits are naff, horrible. The government just doesn't want you to work basically. If you could keep your benefits and work part-time or

> full-time without them being taken off you then that would be fine.

All the individuals who were in employment in the study were still living in the parental home where, although their earnings were low, they did not have to worry about meeting out-goings to the extent that the people with their own homes did.

It also became apparent that the young people had been aware from an early age that employment was not the best option for them. Tina said:

> I knew all the way along the line that when I left school a career would have to be well paid because you lose all your benefits and things but I planned to do voluntary work.

There were cases where young people had been encouraged by parents and careers officers not to work because of the risk of losing their benefits regardless of whether they were living in the community or the parental home. Pam's comments were typical:

> My parents thought and I agreed actually, I had my head screwed on at this point, that it would be best for me not to work because I would lose my benefits.

Andrea said:

> My mum and dad said it would be better if I didn't go to work so I would get more [money]. I don't get a lot but I think that I have done the right thing not going into work. He said if I did have a job they would take everything off me and he said that I wanted some money behind me.

As outlined earlier in the thesis there were instances of parents discouraging their offspring from working in some cases in order to prevent a reduction in the family income.

Paying for Assistance

The sample faced other restrictions to their lives as a result of their dependency on benefits. People living independently in the community were critical of the level of payments from the independent Living fund which were felt to be inadequate. Concern was voiced over the amount of help available from the fund to meet the costs of assistance for people still living in the parental home. Lisa said:

> You can't get the assistance you need and live at home. Even if I wanted to live back with Mum and Dad and have people coming in to have an independent life within the family home, you can't get assistance from

> somebody independent and live within the family home. You can only get the level of assistance by making a total break and moving away.

Some of the sample, resident in the parental home at the time of interview, were extremely unhappy with a situation where they had been forced to rely on their parents for intimate personal care, and this was particularly the case where daughters were having to rely on their fathers.

Tina, who lived independently in the community, was unhappy with the fact that she was unable to pay her personal assistants a decent wage which had implications for the calibre of person she was able to employ and also staff turnover. She explained:

> I employ three personal assistants at any one time and they provide twenty four hour cover, seven days a week. For lots of reasons you don't get very much money from the Independent Living Fund. I have the maximum and that is still not enough to pay a non-exploitative minimum wage, it is not enough to cover holiday pay or emergency cover.

The amount of money available from the independent living fund was in adequate in other respects. Vera's comments were typical:

> The Independent Living Fund (ILF) doesn't take into account things like

> the extra expense of having to interview personal assistants, of having to advertise and send out application forms, having to pay for people's meals when you go away with them. It doesn't take into account social needs at all. It just hinges on 'care' ....You wouldn't get the money by saying 'I need to go out, and I need somebody to help me to go out and get into the pub or get a drink at the pub' whereas you would get the money if you needed toileting.

Getting Around

The issue of transport was also raised as major restriction faced by the research sample. A minority of the sample who were drivers or who had the use of a driver on a twenty four hour basis reported few problems in this regard. Ten people fell into this category.

However for the remaining thirty two people, their lives were severely limited by the lack of affordable accessible transport. All were in receipt of the higher mobility component of Disability Living Allowance which was proving inadequate for their needs. Some disabled people were facing double disadvantage as they were being charged extra for having to use a 'London style' taxi and having to pay for out of their limited mobility allowance. Marjorie's comments were typical:

> Some people are having to use the London style cabs because they can't transfer from their wheelchair and are having to pay the five pounds surcharge....It is taking all our money and mobility allowance isn't much, and if you are relying on that for your transport you can go out twice a week maybe. It's not a lot.

The young people complained that the paucity of the mobility allowance served to restrict their lives in other ways too. Henry explained:

> I have been looking into driving but I would need a van and it is a lot of money. My mobility allowance is paying for this electric wheelchair for the next two years. They give you the choice either a motability car or a wheelchair. You can't have both. I have to pay £116 a month for my chair and even though I get quite a lot of DLA it takes quite a bit out of it. I have got to find money for new batteries for my wheelchair. How can you find money for both?

The low level of mobility allowance further restricted the young people's lives because of their access to taxis was limited due to the cost, they were often forced to shop locally without the benefit of access to the larger stores with their larger selections and cheaper prices. This again served to increase the cost of living for the disabled people.

It can be seen that individuals who are reliant on disability benefits for their income pay a high price in terms of social exclusion. They are unable to obtain employment whilst they are on benefits, and the benefit levels are inadequate to meet their needs and allow them to participate fully in society. The current rates ensure that severely disabled young adults are firmly on the margins because they do not address the extra costs of living associated with having a disability. Even though some were living in their own homes in the community, they could not be described as leading independent lives in terms of enjoying full citizenship rights.

In a similar way to the benefits system the support offered by personal social services is supposed to promote individual rights and encourage independence. The next section will examine the extent to which the young adults perceived this to be the case.

Social Services Support

This part of the chapter will focus on the amount of support received and from whom, and the level of individual financial control that the young people were able to exercise over their personal care.

A minority of the sample had received a lot of support from a particular social worker or occupational therapist who had eased their transition from full-time

education to independent living in the community in a number of ways. These will be outlined below.

In four cases social workers had proved to be an important source of benefits advice. However, there were four instances where social workers had helped individuals to find living accommodation suitable for their needs. Cassie's comments were typical:

> She [social worker] told me that there were such flats available. I knew nothing. I didn't think that there was anything like this. She said 'there are flats you know, that you can live in as disabled person, that are adapted for you with carers that live on site. They are there all the time'. So that is how I came to live here.

There were instances where a social worker had proved invaluable in persuading reluctant parents that a move to independent accommodation was in the best interests of the young person. Theresa said:

> If you have parents but don't have the support, it is just the sort of thing that you have got to do with your social worker. If your parents don't want you to do it and you are determined, you have to get your social worker's support. You have to get a social worker if you haven't got one.

Social workers had also provided much appreciated support during the first few months after a move to independent accommodation. Robert's comments were echoed by others:

> I had a social worker for a time when I first moved to independent living who helped a lot and helped me to get this place. She helped me a lot over the first few months and used to call into see if I was O.K.

Some young people had received help from their social worker or occupational therapist who had acted as their advocate. Lisa explained:

> I didn't have a social worker but had an O.K. occupational therapist who has been most supportive. When I moved in here [to her flat] the bathroom was inaccessible and so was the flat, and yet they wanted me to start paying rent before they had even adapted it and she got things rushed through very quickly. It is amazing that if you have got someone to speak with you and for you, what you will actually get.

There were also examples of social workers helping in other ways. In one case helping a disabled person to find a driving instructor. Cassie said:

> I actually found a driving instructor through my social worker. She gave me a list of suitable instructors and I got one from that.

The four individuals who said that they were happy with their social worker had not had any difficulty in contacting them when they needed help and this was viewed as very important by the young adults.

The remaining thirty eight sample members had quite different views on the level of support that they had received from social workers. Two individuals categorically stated that they had no wish for any social worker involvement. Richard said:

> I don't have a social worker because I dislike them. They tend to be a bit overpowering.

Christopher had help from another source:

> I don't have a social worker because I don't need one. My father gives me all the help I need.

Thirty six out of forty two people all stated that they required social work support but were extremely unhappy with the degree of help that they were offered. The reasons for this will be explored below.

By far the largest complaint concerned the difficulty associated with contacting a social worker for assistance. In some cases it had proved impossible. Jenny's

comments were typical. She said:

> I haven't seen her [social worker] for four years because when we want something we ring her up and she is never there.

Some people had been unhappy with the attitude of the social worker when they did make contact. Felicity commented:

> I had a social worker who was a disaster. I had problems at home and she believed my parents and not me. I've been prejudiced against social workers ever since.

Others complained that their only experience had been very infrequent contact with a succession of different people. Marjorie explained:

> I have had various social workers that come for a bit and then I don't see them again. I don't know who mine is at the moment.

Some of the young adults acknowledged that the shortfalls in provision were a direct result of the under funding of Social Services by central government. Elizabeth said:

> I have never known a social worker long term. I could really do with their

> help. I have had a little contact but it didn't last long due to cut backs in fact, I am getting legal aid about it.

Three people desperately needed social services support and were experiencing serious difficulties but had been unable to get any help at the time of interview.

The way that the assessments for people's care packages had been carried out was also a cause for concern. People had found the process very demeaning. Vera remembered:

> It was the Occupational Therapist who did the assessment for my care package. The assessment book was horrendous, it was just a book of minutes and functions and when you needed assistance.

She also felt that the assessment had not been needs led:

> It shouldn't have been like that. It should have been needs led. People should listen to what you want and be imaginative in terms of putting it in place.

All of the young adults were aware of the extent to which the assessment procedure for community care (and Disability Living Allowance) placed them in a dilemma. Lisa explained:

> Disabled people are in this dilemma of trying for jobs etc, and making out that our disability doesn't affect our capability for doing the job, but then in order to get benefits and get on the housing list we are forced to say 'oh I am terribly, terribly crippled; please help me. I am desperate for your help'. It is all part of the game which you have to play in order to survive. You can't turn round and say well, society causes my problems not my disability because that won't get you Disability Living Allowance. They want the Latin terminology.

Some of the sample reported extreme difficulty in getting essential adaptations and equipment for their homes. Debbie who was a wheelchair user recalled:

> When I moved out of the residential home I was left with no bed for three months so I had to sleep on the floor. It took them ages to do everything else I wanted. I wanted to alter the kitchen and bathroom so I could get my chair in it and it took them a year and a half to do the alterations.

Marjorie was in physical danger but still faced problems:

> I have to get a table top oven on top of a free work surface that I can push my chair underneath. I have burnt myself twice in a number of weeks by dragging hot dishes across my knees. The dish was heavy and I splashed hot gravy all over my legs. The trouble is, I have no feeling in my legs so

> I don't always know that I have been hurt. Despite my doctor writing a letter to say that I need the oven moving. I have been managing like this for four years. It is a case of wait and see.

As with information on the benefits system, the majority of the sample had relied on their disabled friends for guidance on how to negotiate 'the system' in terms of assessments by social services.

The sample highlighted another area of concern regarding the provision of transport by social services to places such as day centres and PHAB (Physically Handicapped and Able-bodied) clubs. Marjorie commented:

> The PHAB clubs are all being destroyed because of this new thing where you have got to pay for the social services buses. I don't go anywhere all week because the club has folded up. The club had four buses and the charge was forty pounds a bus. That was a hell of a lot of money for the club and they ended up increasing the subscription.

Andrea was experiencing similar problems:

> We have got a thing at our day centre that has been going twenty years. It runs once a month and is a social thing in the evenings. It is the only thing many people go to and is their only night out. Prior to the ruling

social services picked up the cost of all the buses.

When this situation is viewed in the context of a Disability Living Allowance which is inadequate to meet mobility needs (see above), it is obvious that it has seriously disadvantaged the young people who do not have the financial means to take taxis everywhere and whose social lives were already restricted.

In summary, when support was present to a satisfactory degree, it proved to be extremely effective and was much valued. However, the most striking feature of the data was the extent to which the support offered to the majority of the severely physically disabled young people in this study was minimal and this had tremendous implications in terms of the quality of their lives.

The nature and amount of restrictions which the young people faced in their daily lives was also influenced by the type and degree of personal assistance which they received. The bulk of this was provided via social services and the degree of financial control which individuals were able to exercise over their care had an important impact on the extent to which they were able to lead independent lives. These issues will be explored below.

Financial Control of Personal Care

The research sample had a variety of arrangements with regard to personal

assistance and the degree to which they were able to exert financial control varied accordingly. Support ranged from the young adult in the role of employer and having total control and responsibility for the delivery and financing of their personal assistance, through to individuals who were physically and financially dependent on their parents. The distribution was as follows:

Table 8.2 Personal Assistance	
Type of Personal Assistance	Number (n=42)
No Personal Assistance Provided.	3
In Employment and Paying Parents for Personal Assistance.	3
Disabled Person as Employer Funded by the Independent Living Fund.	3
Disabled Person pays a Personal Assistance Scheme.	4
Personal Assistance provided by Social Services Department (Via deductions from DLA).	5
Personal Assistance provided by Residential College via Local Authority.	6
Personal Assistance provided solely by relatives.	1
Personal Assistance provided by parents via board money paid by the young person out of benefits.	5
Personal Assistance provided by parents via board deducted from benefits by parents.	12

A minority of the sample had total financial control over their personal assistance and these individuals were the most satisfied with their support. They largely felt 'in control' and appreciated the flexibility which this arrangement offered. Lisa summed up the advantages which were echoed by others in a similar situation:

> I have a very flexible scheme which is built for me and it enables me to have a very spontaneous mad cap life. I don't want to be tied down. Its a variable rota.

However, the degree of funding available to pay for such arrangements was inadequate as outlined above in the section on the benefits system and this was problematic. It served to undermine the degree of financial control which individuals were able to have over their personal assistance as they were unable to pay a decent wage which led to a high staff turnover. It is the case that the advantages of this type of provision outweighed the disadvantages.

The people who were in employment and paying their parents for the provision of personal assistance reported few problems with this arrangement although they all said that their aim was to move into independent accommodation in the future. Unfortunately, because they were in employment they were not entitled to sufficient levels of benefit to make such a move economically feasible. In summary, six people were happy with their personal assistance arrangements at the time of interview.

The remaining thirty six sample members were less happy with their personal assistance arrangements. Three of these were not in receipt of any personal assistance at all although in need. The problems reported by those receiving assistance will be outlined below.

The most commonly voiced concern was over the issue of the degree of flexibility that current arrangements for personal assistance would allow. Henry paid in to a communal personal assistance scheme. He said:

> I live in this flat on my own. The personal assistance is flexible but sometimes you have to set a time to get up because there are that many people to get up. Sometimes you might buzz because you want something to eat but you have to wait because they are dealing with someone else.

There were also complaints about the attitude of the personal assistants previously employed by social services. Marjorie's comments were echoed by all the other people who paid into the personal assistance scheme:

> You can get problems where they have been employed in social services homes and have had the kind of training where there are set times for everything. They come to a place where everybody choses what they want to do and when and it is a huge culture change.

The young adults who were reliant on personal assistance provided by social services complained most vociferously about the lack of flexibility of their arrangements and none were happy. They contributed to the cost of the service via their Disability Living Allowance. Debbie's comments were typical:

> I need help to get in and out of bed. I have community care but my partner who is himself disabled put me to bed because community care start putting to bed at four o'clock. They set the times that they can come in so there isn't much flexibility.

Felicity who has very high support needs had been let down by social services on a number of occasions:

> Before I wrote to the papers, social services used to let me down a lot. I mean, people can't help being off sick but what got me was that they didn't even bother to ring up. They just left me in the lurch. Now I don't think they dare do it. They just thought there is this young girl from an institution, we can fob her off.

The lack of flexibility restricted the young people's lives in many ways. It added extra difficulty to an already disadvantaged situation. People gave examples of feeling unable to go out in the evenings because the had to be in bed for a certain time (see above) and it was also difficult to arrange holidays. Many of these concerns were echoed by the six individuals who had their personal assistance provided by their residential college during term time.

Twenty one out of forty two people had their personal assistance provided solely by parents or close relatives. Only eight people had any degree of financial

control over these arrangements via physically handing over payment to their parents out of their wages or benefit entitlement.

Some of the young people were happy with their parents or a close relative providing their personal assistance. These individuals (three out of twenty one people living in the parental home) were paying their parents out of their wages and as a result, felt more in control of the situation.

However, the majority were unhappy with the degree of control that they were able to exercise. Andrea summed up what being totally reliant on parents meant. Her comments were echoed by many:

> You can't get away from them and they are always telling you what to do. You are not in control of your life.

Josie, who was totally reliant on her father for her personal assistance including Catheterization, felt like a baby:

> I think how the hell have I lived like this for so long? What has happened to all the years? I feel like a baby. It's like you are younger than you are.

In summary, individuals with the highest degree of financial control over their personal assistance faced the least restrictions on terms of their daily lives. These

people were either living independently in the community and employing their own personal assistants or they were in employment and paying their parents to provide personal assistance (although, as outlined in the previous chapter, for individuals still resident in the parental home the price of gaining independence through employment was the sacrifice of independent living in the community). However, their lives were not without limitations which were related to the level of financial control which they were able to exercise. Benefit levels were inadequate to pay a wage which would attract and retain the right people, and for the young adults living in the parental home, the level of their wages was insufficient to allow them to live independently and employ their own personal assistants.

For individuals reliant on a communal personal assistance scheme or social services provision, the picture was bleaker. The people in the communal scheme paid for their care via contributions from their benefits and although they were relatively advantaged compared with people solely dependent on social services provision, there were limitations to the flexibility of their scheme.

The most disadvantaged group in terms of those in receipt of statutory support were the people who relied on social services provision. Not only did they enjoy the least flexible arrangements, but the fact that they, in common with the individuals above, had to pay for their assistance out of their Disability Living Allowance further disadvantaged them as it meant that the money was not

available to cover the extra daily living expenses associated with disability.

Difficulties in contacting social workers which were often exacerbated by a lack of basic education on the part of the young adults, meant that a large number of the sample were reliant on their parents for the provision of their personal assistance. Often they had little or no financial control over the situation and led extremely restricted lives as a result and again, they were reliant on meagre disability benefits which in some cases parents were retaining.

This chapter has illustrated that whilst there is some support available to young disabled adults living in the community it is on the whole inadequate. Current benefit levels are inadequate to meet the extra costs associated with disability, and the support available from the personal social services is at best, inflexible and patchy. Added to this is the situation where social services departments are charging for those services via the young people's Disability Living Allowance further reducing an inadequate disposable income.

The next section will explore the extent to which the amount of support received by the young adults in terms of the benefits system and social services was linked to independence or dependence using the index outlined in Chapter four.

This section will explore the significance of social security benefits and support from social services for independence.

The Independent Group

Eleven individuals out of forty two were classed as independent. None of the sample attained the maximum score of eight.

Within the independent group, five individuals were in one form of employment or another (two were moonlighting whilst on benefits), and the remaining six were totally dependent on benefit income. This group had the highest degree of independence of the whole sample and faced the least number of restrictions in their daily lives. Two different types of independence were experienced by these people. A minority were financially independent in that they earned a wage, although this was at the cost of living independently in the community (see chapter eight), as they were still living in the parental home.

The majority of this group (six out of eleven people) were not financially independent in the sense that they earned a wage, as they relied totally on benefit income. However, they all lived independently in the community and had full responsibility for running their daily lives.

In terms of the significance of the benefits system and social services system for their independence, although the three in formal employment were all in receipt of Disability Working Allowance, the rate was so low that it was not of central importance. Also, the inflexibility of the system meant that they were unable to

work and claim sufficient benefits to enable them to cover the extra costs associated with living independently in the community. These individuals had also had little or no contact with social services either from choice or because of failures in the system.

The picture was slightly different for the two people who were moonlighting whilst on benefits. Benefit income was of central importance in their lives and their reliance on it prevented them from entering formal employment as without it they would not have been able to live independently in the community. For the remaining six people in the sample, benefits were their only source of income.

Support from social services had also played an important role in terms of securing the independence of this group. Eight out of eleven people had been directly helped by a social worker or occupational therapist. Help included benefits advice, identifying suitable accommodation, assessment of personal assistance needs, and facilitating the provision of aids and adaptations in the home. In these instances social services staff had proved invaluable in helping the young people find their way around a very complex system. This support had made a tremendous difference to the young adults lives.

However, although the individuals in this group had the maximum support in terms of both the benefits system and social services, and they led the least restricted lives of the entire sample, their lives were still difficult due to the

inadequacy of current benefit levels for meeting the extra costs associated with physical disability and this impacted on every aspect of their daily lives as outlined above. Life was still a struggle which was further complicated by social services charging policies in some instances.

The Intermediate Group

Ten people out of forty two were classed as being in the intermediate group on the basis of the index described in chapter six. Seven people lived independently in the community, two were still living in the parental home, and one was a residential student.

None of the individuals in this group were in employment at the time of interview and all were dependent on benefit income. This group experienced greater difficulties due to their restricted income than the independent group. They were also less likely to have had consistent contact with a social worker and, as a result, found it more difficult to negotiate the benefits and social services systems and obtain the maximum provision available. This situation was complicated by severe literacy and numeracy problems in a number of cases. Ironically, the one individual who reported the most positive contact with a social worker was still resident in the parental home and was on the point of making the transition to independent living. The rest of the group had obtained advice about their entitlements from friends and relatives.

These people also experienced more difficulty with the provision of aids and adaptations and some had experienced serious shortfalls.

This group also experienced more restrictions in their daily lives due to the inflexibility of their personal assistance arrangements than the independent group. The majority of this assistance was provided by social services care staff and difficulties with these arrangements severely limited the young adults lives as outlined above.

It is undeniable that both benefits income and the support received from social services in the form of personal assistance was critical to the young people's independence because without it they would have been unable to live independently in the community. However, it is the case that the levels of support offered by both the benefits systems and social services were inadequate to meet the young people's needs, and as a result, they were experiencing great difficulty in their daily lives.

The Dependent Group

Twenty one people out of forty two were classified as dependent.

The entire group were reliant on benefit income and none lived independently in the community. They had the lowest incomes of the entire sample because

they were still resident in the parental home, and they received minimal social services support. As a result, their lives were the most restricted.

Most had never had any contact with a social worker and were totally reliant on their parents for their personal assistance needs; a situation which was a source of great distress in some cases. This group were also the least likely to be in control of their benefit income. In the majority of cases it was managed by parents, a factor which further restricted the young people's lives as some parents withheld benefits. Many had no outside agency with whom they could talk and felt totally trapped.

The process of obtaining information on benefits and social services provision was far more difficult for the individuals in this group as many had severe literacy and numeracy problems on top of their physical impairments which further socially excluded them. These individuals could not be considered independent in any sense as every aspect of their lives was restricted. They face a very bleak future under current arrangements.

In conclusion, support from the benefits system and social services is significant for the independence of severely physically disabled young adults on a number of levels. With regard to the benefits system, whilst it offered the opportunity for independent living on the one hand, its inflexibility with regard to employment trapped the young people in a dependent state on the other, having to exist on

benefits which were inadequate to meet the extra daily living costs associated with physical disability.

With regard to the support available from social services, it has its limitations but where the young people had access to a high level of support (as with the independent group), it had enabled them to live independently. However, for the majority of the sample social services support had proved to be at best inflexible and patchy. The difficulty of the situation was further exacerbated by the possibility of charging for some services. Many people had received no support at all and led completely dependent lives.

CONCLUSION

TRANSITION TO INDEPENDENT LIVING?

Transition to Independent Living?

This chapter will conclude the thesis and will explore the extent to which the young disabled adults in the research sample achieved independent living. The role played by education, employment, the benefits system, and personal social services will then be discussed with the aim of explaining the way in which support from each related to independence. The most important elements in young adults' achievement of independence will be identified and the implications outlined.

What is Independent Living?

The definition of 'independence' that is adopted has a decisive effect on the quality of disabled people's lives. Disabled people have been highly critical of the narrow professional definition and application of the term with its emphasis on functional limitations and ability to carry out daily living tasks. It is argued that this has only served to perpetuate the construction of disabled people as dependent.

The concept of independence advocated by the Independent Living Movement is broad, covering the whole range of human and civil rights including equal access to education, training and leisure with the ultimate goal of full participation in the community and it is this definition that has been adopted in

the current study. Key measures used in the study were: living accommodation, the degree of financial control they exercised over their personal assistance and their lives, and the extent to which they were able to control their personal assistance. The availability of accessible, affordable transport was included as it was mentioned by the research sample as being of central importance in terms of the amount of control and freedom they were able to enjoy in their daily lives. Lifestyle was considered from the degree of participation in social activity, and the extent to which social networks were either broad or narrow. Whether individuals were in a relationship was a criterion as it was frequently mentioned by the sample and also because girlfriends and boyfriends confer status, valued heterosexual identity, and the promise of a lifestyle that approximates some norm (Hirst & Baldwin, 1994). Educational qualifications were included as they may be a key predictor of future career routes. Occupation or daily activity was also in the index due to its influence on individual self - esteem. In order to achieve full independence individuals had to score positively on all 8 criteria outlined above. None achieved this.

None of the young adults had achieved independent living in its broadest sense i.e. full participation in society. Nobody simultaneously possessed the three criteria essential for full independence: work, an independent household and control over their personal assistance.

A minority of the sample (11 people), achieved semi - independence but still faced serious restrictions in their daily lives. Most of this group whilst living independently in the community organising their own care and running their own homes, were unemployed. The three individuals in employment were still resident in the parental home. Independence via employment was at the cost of domestic dependence, whilst domestic dependence was achieved via benefit dependence. Life was not easy for this group as they were either reliant on the income from poorly paid, low status jobs or benefits and, as documented earlier in the thesis benefit income was insufficient to meet the extra costs associated with physical disability.

Most of the sample (31 people), were totally dependent scoring 0-1 with one person scoring 2. All of this group were still living with their parents at the time of interview and were dependent on benefits. A number of individuals raised concerns about the control of benefit money. There were instances of parents totally controlling benefits to the extent of only allowing the young person a small amount of 'pocket money'. All the individuals had their personal assistance carried out by their parents and none had any outside assistance. Most were extremely unhappy with these arrangements and concern was also voiced about fathers' providing their daughters' personal assistance. This situation was especially difficult when the parent was reliant on the child for the family home. This group has also seriously educationally underachieved. Their lives were

totally under the control of other people and they were in a perpetual state of 'child-like dependency'.

The fact that only 11 people achieved semi - independence is sobering particularly when considered in the light of policy developments in recent years. Successive British governments have developed community care policy to reduce institutional provision. The first initiative occurred in the 1950's with the report of the Royal Commission which highlighted outdated mental hospitals and the stigma experienced by their patients. Also, new psychotrophic drugs became available offering an opportunity for control of symptoms rather than incarceration. The number of mental hospital beds was halved by 1975 (Morris, 1993). The growing criticism of the dehumanising effects of institutionalisation, plus cost considerations and the growing emphasis on individual and family responsibilities further motivated governments to pursue community care policies. The defeat of Labour in the 1979 elections removed any hope of an increase in resources for community care as the new Conservative Government put the responsibility for community care on the family rather than the state. Institutional care was still in evidence fuelled by the 'perverse incentive' created by the availability of social security funding for residential care. This resulted in a hundredfold increase in DHSS spending on residential and nursing home care between 1979 and 1989 while expenditure on domiciliary services increased by less than three times (Morris, 1993).

A number of reports were published during the 1980's which highlighted difficulties arising from the organisational split between health and social services responsibilities (Audit Commission, 1987 cited in Morris, 1993), the increasing cost of residential care (Working Group on Joint Planning, 1985 cited in Morris, 1993). The Audit Commission published a report in 1986 which concluded that services to the elderly, learning disabled, mentally ill and younger disabled had not improved since the Seebholm Report twenty years earlier. They were still fragmented, lacked innovation and delivery was poor (Morris, 1993). However, it was the increasing cost of residential care which prompted the Government to address the issue of community care. The 1989 Griffiths Report formed the basis for the white paper *Caring for People.* The Report recommended that social services departments should take the lead in community care in the role of enabler rather than service provider and to make maximum use of the private and voluntary sectors. It also concluded that case management should be employed. These ideas were implemented with the 1990 Health Services and Community Care Act which was implemented over a two year period. This is the basis of current policy. The key aims behind this legislation (outlined in chapter one) are to empower service users, thus enabling them to remain in their own homes.

The post-war period has seen a number of policies aimed at promoting the rights of disabled people. These were: the 1944 Disabled Persons (Employment) Act which was based on the assumption that most disabled people were capable of working in ordinary employment with the provision of appropriate training and services, and the 1944 Education Act which stated that disabled children should be educated in mainstream schools. The 1981 Education Act also promoted the concept of integration and suggested that the aims for children with special needs be the same for all children. The 1970 Chronically Sick and Disabled persons Act was based on the assumption that disabled people had the right to participate fully in society, but required action by society to make this possible. The Disabled Persons (Services, Consultation and Representation) Act 1986, requires local education authorities to obtain information from social services departments as to whether a child with a statement is disabled and may require services from the local authority upon leaving school. The Disability Discrimination Act (1995) marked a substantial move away from the collective disability employment policy enshrined in the 1944 Act. The new legislation places responsibility for obtaining fair access to the labour market on the individual rather than the state.

Disabled people themselves have campaigned for greater control over their lives. The 1970's and 1980's saw increasing numbers of disabled people trying to leave residential care and organisations run by disabled people mushroomed. The British Council of Organisations of Disabled People was formed in 1981 and this provided a national forum for bringing together ideas on independent living and

how to achieve it. Centres for Independent or Integrated living were established which aimed to provide advice and support to disabled people who wanted to live independently. The first and best resourced CIL was in Derbyshire. Its aim was to provide a system of services created by and staffed by disabled people which could provide:

> ...The magic of peer counselling and peer models serving people of all ages, whether blind, deaf or mobility impaired (Davis, 1988 cited in Morris, 1993).

From the standpoint of the current study there has clearly been a policy failure on all fronts as the young disabled people in the sample were not achieving independence as adults in the community despite all the initiatives outlined above.

A number of factors were impinging on the young peoples' lives all of which are linked. Success in one has to be matched by success in the others and policy needs to address this issue. What are the policy pieces that need to be assembled? This will be examined from the standpoint of education, employment, benefits, and support in the community.

Education

Many of the sample had no qualifications and some reported serious difficulties with literacy and numeracy which proved to be more disabling than their impairment.

Qualifications on their own were not enough to enable the transition to independent living. Whilst educational qualifications appeared to add little to the chances of disabled people obtaining employment, (the most highly qualified individuals were unemployed), serious literacy and numeracy problems brought still worse prospects.

Measures need to be introduced which ensure that disabled pupils are not excluded from the National Curriculum and pupils' eventual labour market position is not further undermined. All pupils should be taught to read and write and enabled to gain qualifications wherever possible and classroom support should be provided according to individual need. Other areas of concern were highlighted:

Most of the sample felt that interruptions to education should be kept to a minimum with physiotherapy scheduled out of school hours.

Many felt that pupils should have access to appropriate micro technology support in the classroom and this should be available from the start of education and should remain with the young person on the completion of full - time education.

There was some evidence of a potential problem with Further Education Colleges. Some students indicated that they had been 'channelled on to specific courses for financial gain regardless of individual ability or preference. It is suggested that this is addressed.

The majority of the sample had attended segregated school but only one person who had been educated in this setting had obtained one or more GCSE's at grades A - C. Most people had gained their qualifications at Further Education College.

It could be argued that disabled children should be fully integrated in mainstream school wherever possible with the provision of appropriate support. Guidance should be developed and made available to teaching staff and parents on the ways that this can be achieved. Segregated education has been shown to have a number of failings and the majority of the sample felt that they would have achieved more in a mainstream setting. The policy dilemma is whether greater resources should be targeted at segregated education or diverted to providing a higher level of support in mainstream classrooms. The research suggests that for most people the latter is the best option.

It is argued that the statementing procedure is in need of improvement. Statements should be used to consider ways in which extra support can be provided in a mainstream setting, not as a means of removing children from mainstream education. They should place more emphasis on the individual's strengths and weaknesses and the influence of the classroom environment on educational achievement.

It is suggested that communication between Local Education Authorities and Social Services Departments when disabled young people leave full - time education needs reviewing. There was evidence that many of the sample had 'fallen through the net' as a result of LEAs failing in their duties under sections 5 and 6 of the Disabled Persons (Services, Consultation and Representation Act) 1986.

Whilst it could be argued that spending more money is unrealistic, the interviews have shown that the resources available to profoundly physically disabled young adults were seriously inadequate with implications for the young peoples' futures. It is suggested that steps should be taken to reduce the resource constraints faced by local education authorities and greater priority should be given to special needs education.

Employment

Few were in employment. Most people had been discouraged from applying for work by the lack of a basic education, financial disincentives, and by the realisation that they stood little chance in the labour market.

Access to employment did not bring independence. The young people were employed in low status poorly paid work with no prospect of either training or promotion. This meant that they were unable to earn enough to pay for personal assistance and were forced to remain in the parental home. This has a number of implications for policy. It is argued that:

The Disability Movement should acknowledge the importance of choice over work opportunities in enabling individuals to take control of their lives.

An Equal Opportunities Commission similar to those established for Race and Sex should be established.

The deficiencies in the Disability Discrimination Act (1995) need to be addressed. Specifically:

Employers should be obligated to employ disabled people and the act needs to address the problem of improving conditions for all disabled people in the

workplace. Disability awareness training should be mandatory. This should be rigidly enforced. The Act should extend to those not in or seeking employment and individuals in supported work. Target setting, progress monitoring and decisions about what is 'reasonable' should not be left to employers.

It is suggested that until the above issues are addressed, the Access to Work scheme cannot be expected to make a significant difference to the numbers of disabled people entering employment. The same applies to the government's new deal for disabled people. Disability employment policy needs to be brought in to line with the government's goal of reducing the number of people on benefits.

It is argued that the scope of the Access to Work scheme should to be extended to those individuals who are not actively seeking work and that information on the level and type of training available to unemployed disabled people needs to be improved.

Benefits

The inflexibility of the benefits system discouraged the majority from seeking employment. They were aware that it would not be possible for them to be in employment and remain living independently in the community as they were unable to earn enough to make up for the benefits lost.

Benefit income appeared to be wholly inadequate to meet the extra costs associated with physical disability. This was impacting upon all areas of the young people's lives. Individuals who employed their own personal assistants were unable to pay a competitive wage and suffered a high turnover of staff as a result. This was extremely disruptive. Personal assistance during social activity and holidays was not covered. Local Authority charging policies further reduced disposable benefit income. Most people's lives were seriously restricted by the inadequacy of mobility allowance.

In terms of the benefits available to disabled people at the time of writing, the policy implications are as follows:

The benefits system with regard to independent living is complex and confusing and urgently needs streamlining. The existence of Independent Living Fund and Local Authority payments for personal assistance needs to be clarified.

The Community Care (Direct Payments) Act 1996 which enabled local authorities to make direct payments for personal assistance to disabled people should be mandatory and there should be a national protocol covering information on the Act, training and support for disabled people in the recruitment and management of personal assistants, methods of payment and charges for services. None of the sample mentioned direct payments but these

might offer more control in terms of how the money is spent as people could tailor the assistance offered by social services departments to suit their needs.

Policy needs to address ways in which the amount of Disability Living Allowance (both the mobility and the care components) can be increased. This would not only make it easier for young people to live independently in the community, but would help to relieve the financial burden on the families of disabled young people when the young person is living in the parental home. Further consultation with organisations 'of' disabled people is needed in to establish an appropriate level of payment.

Payments under the Independent Living Funds should be increased to reflect the costs of paying a competitive wage to personal assistants and outgoings for recruitment, holiday and sick pay. The current cash limit 0f £300 which is paid to individuals in receipt of £200 or more of statutory services needs to be raised in order to remove the threat of a return to the parental home or residential accommodation.

The benefits paid to disabled people in employment were also viewed as inadequate by the research sample and this has implications for policy:

It is suggested that passport benefit entitlement should not be affected by employment. Also the rate at which Disability Working Allowance is withdrawn

in relation to income should be substantially reduced to reflect the extra living costs that disabled people face.

Disabled people require substantial benefits to cover the costs of personal assistance both in the work place and at home regardless of income. This would enable them to achieve independent living and remain in employment thus contributing to society. It is also the case that it would improve work incentives and cost less than supporting large numbers of people who are totally dependent on benefits (Kestenbaum, 1998).

The assumption on which Disability Working Allowance is based needs to be reviewed as individuals cannot be expected to seek out and take up non existent job opportunities. The government's New Deal for Disabled People is based on a similar premise which fails to recognise the labour market position of disabled people. The key to the problem appears to lie in effective disability employment legislation.

Support in the Community

The support available from Social Services Departments appeared was inadequate in the majority of cases. Many people had little or no contact with a social worker despite being in serious need.

The system for identifying young people in need of services requires review with emphasis on improving communication with Local Education Authorities. Many of the sample had fallen through the net with serious consequences.

When young adults were identified as being in need, there was evidence that the social services response was inadequate. It is suggested that improvements are needed in terms of the accessibility of social workers, frequency of contact with clients, and greater user involvement in the planning and delivery of services.

Most of the sample were dependent on their parents for every aspect of their daily lives. The majority were not in control of their benefit income. This highlights two issues: the lack of a basic education on the part of many young people and the paucity of support available to the families of disabled children. There were instances where parents were dependent on the young person financially and for the family home.

The relationship between family support and formal services needs to be addressed. Support to families needs to be increased and greater emphasis placed on the role of formal services. It is suggested that the current policy of whittling away social support to families should be reviewed.

More accessible homes are needed in all sectors of the housing market in order to allow disabled people to choose where they want to live. Local authorities

need to be aware that moving to independent accommodation can be especially difficult for young people who share an adapted home with their parents and siblings. Where the home is local authority owned, steps need to be taken to ensure that the disabled person's needs are paramount.

It is suggested that the policy which allows Local Authorities to charge for community care services is reviewed as this only serves to further disadvantage disabled people. If charging is to be retained, it should be reflected in benefit levels, and there should be national guidelines on implementation and tariffs.

Linked to the above, whilst it might be argued that it is unrealistic to expect the financial constraints on Social Services Departments to be removed, it is clear from the interviews with young physically disabled adults that this group is under-resourced with serious implications for them and their families. Parents become too closely involved and the demands placed on them are too high.

Social Policy for a Social Model

The credence given to the individual model in much disability research, and in the fields of social psychology, medicine and education has been outlined earlier in the thesis. My role as a researcher was to attempt to articulate the young adults life experiences and interpret them in the context of the social model of disability and the wider social policy framework.

From the standpoint of the individual disabled person, parents and their immediate context were the factors which enabled a successful transition to independent living. They also interpreted difficulties in terms of education, employment, benefits and support from social services from a personal perspective and often blamed themselves for failure in these areas. They were unable to appreciate the wider influence of these structures on their lives and the ways in which they disabled them. Also, they were unable to appreciate the ways in which the factors were interrelated. For example, the majority of the sample blamed their parents for their failure to attain independence. Reasons ranged from low expectations and a subsequent lack of encouragement to parental selfishness in terms of the control of benefit money. Whilst families clearly play an important role in emancipating disabled children from dependency, this has to be set against a background of community care policies which have failed. Increasing emphasis has been placed on the role of the family in caring for its disabled members at the same time as support has been reduced both in terms of the level of benefits and practical support from social services departments. Families needed social service support whilst social services departments depended on families shouldering the responsibility for support. Families did play an important role in establishing links with outside agencies and services and this could be extremely beneficial. However, there were clearly factors outside the family which were preventing the attainment of independence as the individuals with the most supportive families failed to achieve independent living in its fullest sense. What were the other factors in the equation?

Education was raised as an important issue by the young adults in the sample. Their difficulties were serious. The majority of the sample had never been entered for an examination and many reported difficulties with literacy and numeracy which further undermined their prospects. It became clear that the issues were far broader than individual performance in the classroom. The most dependent individuals had all been educated in segregated schools and were victims of entrenched altitudes on the part of teaching staff who gave much credence to the individual model of disability and offered little encouragement to their pupils. The picture was further complicated by the fact that despite a number of policy initiatives to the contrary, most people had been educated in a seriously under resourced and marginalised sector of the education system. Class sizes were too large and there was a lack of micro technology support.

Respondents fared little better in the labour market as most had never experienced employment. Most blamed their impairment for their inability to obtain work i.e. that 'their face didn't fit' or a lack of encouragement from their parents. However, a lack of educational qualifications plus difficulties with literacy and numeracy had clearly undermined their prospects and there were broader issues in the equation. The minority of the sample who were employed (3 people), were all employed in low status poorly paid jobs. The most highly qualified individuals, educated to graduate level, were unemployed at the time of interview. This points to policy failure on two levels first, despite a number of initiatives, disability employment legislation has been largely ineffective for

the reasons outlined above. Second, low wages and inadequate support from the benefits system set a trap which prevented respondents from achieving both employment and independent living.

The majority of the sample who were the most dependent had received minimal social services support (most had never had any contact with a social worker), and were reliant on their parents for all their personal assistance needs. Their sole income was from benefits and they received the lowest income of the entire sample due to their residence in the parental home. Benefit income appeared to be inadequate to the extra costs associated with disability. They were the least likely to be in control of their benefits as in most cases parents were in control. Their lives were further restricted by literacy and numeracy problems which made it more difficult to obtain information on services and benefits and made it harder for them to manage their money. Again this points to policy failure on a number of levels: both in terms of support to the family (see above) and the adequacy of the benefit system in terms of meeting the extra costs associated with physical disability. The individuals in the sample all had high support needs and would have been financially worse off if they had worked as wages were insufficient to meet the benefit shortfall which would result from employment. The young people were further restricted by under-resourced social services and an inflexible and inadequate benefits system. Sadly, their plight is likely to worsen due to the increasing charges levied by social services for personal assistance which will make further inroads into a meagre income.

Individuals were more disabled by failures of education, benefits and employment policies than by their impairments and it is for these reasons that the social model of disability is more compelling. There is no way to disentangle the effects of these and this should not be attempted as they are all part of a patchwork that links together. Indeed, some policy failures are a result of partitioning the problems faced by young physically disabled adults. The research findings indicate a need for integrated social policy which addresses the difficulties faced by young disabled people on all fronts otherwise the prospects of disabled people living independently in the community, with the same degree of participation as non disabled citizens, look increasingly bleak.

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GLOSSARY OF TERMS

AA: Attendance Allowance.

CP: Cerebral Palsy.

LEA: Local Education Authority.

DDA: Disability Discrimination Act.

DLA: Disability Living Allowance.

PHAB: Physically Handicapped and Able-bodied Club. A social event attended by the young people one evening a week.

INTRODUCTORY LETTER

Dear Colleague

I am a physically disabled postgraduate student at Nottingham University researching the transition of young disabled adults from full time education to independent living. The focus of this study will be to interview a small number of people to find out their recent experiences of this phase of their lives.

The study will concentrate on people aged 17 - 31 years who are physically disabled and required special educational provision and who now need a high level of assistance in their daily lives in the community (either from professional carers or parents or both). They may also have a statement of special educational needs. Individuals who fit the above criteria but are living with their parents and thinking about moving to independent living could also take part in the study.

If these circumstances apply to you, I will appreciate it very much if you will agree to take part in this project.

Taking part will mean me interviewing you for about ninety minutes. This will be an informal one - to - one chat during which I would like to hear about your own experiences, views and priorities regarding your transition from full - time education.

Any information you give will be strictly confidential, your anonymity is guaranteed, and taking part in the study is voluntary.

I hope you will feel able to take part. Your doing so will provide valuable information on what can be a very challenging period in the lives of severely disabled people about which relatively little has been written. Your help would improve understanding of the needs of people and the problems they encounter during this time and may help service providers to improve the range and quality of their support.

Would you let me know whether or not you will take part by completing the enclosed reply form and returning it using the enclosed stamped addressed envelope.

Thank you in anticipation of your help.

Yours sincerely

NICOLA HENDEY

RESEARCH ON TRANSITION - REPLY SLIP

Should I wish to participate in the research project I understand that:

1. All my data are confidential to the University of Nottingham and anonymous.
2. My participation is entirely voluntary.
3. The time required for this study will be about ninety minutes.
4. The nature of my participation will include one interview with the above named researcher.

I agree / do not agree **(Delete as applicable)** to participate in this research project.

NAME ----------

ADDRESS ----------

TEL. NO ----------

Signed ---------- **Date** ----------

PLEASE RETURN THIS FORM TO:

Nicola Hendey
School of Social Studies
University of Nottingham
University Park
Nottingham
NG7 2RD

QUESTIONNAIRE

1) Which school did you go to? **[mainstream/special needs]**

SCHOOL YEARS - ACADEMIC v PRACTICAL SKILLS

Physiotherapy

'They gave me time for physio because they realised it was a special need. That's what we were there for. It didn't interfere with my education.'
'That school was based mainly on physio.....you missed out a lot of education by doing that.'

Which is closest to your experience and why?

'They gave me callipers to make me walk and all I could do was walk around a corridor. I couldn't have my flat if I was still walking because I couldn't manage as well as I do in a wheelchair.'

'Physio certainly helped me.'

Which is closest to your experience and why?

ACADEMIC INPUT

'I was given the best possible education I could get. They told me I could do any subjects I wanted. I tried them all and picked my four best subjects and tried to get good grades. The school helped me a lot.'

'I thought I was slow.....you grow up thinking you are not as fast as everybody else. It's not that at all....it's the way I've been taught....I know I could have done a lot better.'

How does this relate to you and why?

Literacy and Numeracy Skills

'I have problems with reading, writing and maths because at school they used to leave me lagging behind.'

'My maths isn't a strong point but whose is? My reading and writing are fine. I have no problems.'

Which best fits your experience and why?

Independence Training at School

'I think it was really good, you need skills like that before going to live in your own flat. It prepares you for life.'

'They had an independent living flat which you went into for a week to see if you could survive...but it was all about doing functional things for yourself such as cooking, cleaning and shopping. it wasn't about what you wanted to do with your life and having the assistance in order to do it.'

Which best relates to your experience and why?

Discussion of the Options available for Independent Living

'There is this basic rule that disabled people don't do things like that anyway and also in those days not many disabled people went out into the community, they were just in institutions or at home so Independent Living wasn't discussed with me at school at all.'

'The options for independent living were discussed before I left school not greatly but to a degree.'

Which is closest to your experience and why?

Teachers Expectations - Post School

'The teachers were brilliant, they put me in the right direction - put me to college....They didn't push me into it. I made the final decision.'

'The school thought they knew what you could do regardless of what you thought.'

Which relates best to your experience and why?

Career Officer Expectations

'Careers officers have been trained to tell you what you had got to do and not advise you basically....They were all for 'Oh you are disabled, you have to go to a day centre / sheltered workshop - you can't work.'

'My contact with every single careers officer has been fantastic. They have helped me every single step of the way.'

Which is closest to your experience and why?

EXPERIENCES AT COLLEGE / DAY CENTRE / WORK

What did you do when you left school?

What are you doing now?

Are you doing what you wanted to do?

College - expectations

'I'm doing a business course at college. I'm doing something that I didn't think I'd be able to do and I'm coping. I've got a very understanding teacher.'

'The attitude was that I wasn't capable of doing exams because of my disability.....they naturally assumed I wasn't capable even though I had passed my CSE's.'

The Courses Disabled People Do

'If you are intelligent you are shoved into office or typing skills. You can hide a wheelchair under a desk. Maybe its because people assume that's all we are capable of doing.'

'There is no way I would work in an office. I want to work with people....that's why I'm doing the course I am.'

Which is closest to your experience and why?

Day Centres

'I am at a day centre three days a week....I work on reception and go out and meet others. I enjoy it.'

'The majority of the people have got no idea what they want to do. You give them choices and they don't know how to chose...their only problem is that they can't walk and they are unable to make decisions. I used to be like that.'

How does this relate to you and why?

Work

Estimation of ability for

> **'I feel that I am not too disabled to work but society says that I am. I always get the same excuse that I am to slow.'**
>
> **'I have never been discouraged. I have never seen a sheltered workshop in my life. Mostly I have been told to buck up and do it - more so being disabled.'**

Which best fits your experience and why?

In Work - Attitude of Employers

> **One interviewee commented:**
>
> **'I am working in a great environment which I'm very happy about. I am doing what I want and I love it.'**
>
> **Another person said:**
>
> **'I worked for four years and it was horrible. I didn't have the right support in the workplace so I struggled.'**

Which is closest to your experience and why?

Are you registered disabled?

How did you find out about the register?

Have you ever had contact with a PACT team or DEA?

Was this useful?

Own Underestimation of Ability for Work

> **One person said:**
>
> **'I feel I could work but I don't know what I could do. I feel I underestimate my own abilities.'**
>
> **Another interviewee said:**

'I feel I could do advocacy work. I would like to teach other people that there is no need to sit in a day centre all day.'

Which best relates to you and why?

INTEGRATION / SEGREGATION

School

One interviewee said:

'I felt really comfortable in special school because I was with people with all different disabilities and I fitted in.'

Another person said:

'I didn't want to go to school with any other disabled person because I thought they may be more disabled than me and make me behind in my work. I wanted to be around non - disabled people so I could learn what life would be like in the outside world after school.'

Which is closest to your experience and why?

Day Centre

One person said:

'I felt frustrated. I felt I've got more in my head than just going to a day centre every day. You just sit on a table with the same group of people and vegetate. It's institutionalised.

Another interviewee said:

'You have this nice, safe, little disabled world that you have never had any problems in. Its very comfortable.'

Which relates best to your experience and why?

CURRENT LIVING SITUATION

What is your current living situation?

Parental Attitudes to Independent Living

'My parents worried about me needing a great level of care, as being not capable of doing anything...They also worried about losing my benefits.'

'My parents have always been supportive of my wish to live independently....they played a bigger part than the social services to be honest.'

Which is closest to your experience and why?

INDEPENDENT LIVING

Statutory Services

Previous interviewees have mentioned that their social worker / OT / ILT played a major role in helping them to move to independent living.

Others have commented that they received little or no help from these people.

Which fits best with your experience and why?

Role Models

'I always thought I'd get my own place but I didn't know how to do it. It seems through meeting other disabled people that I found out what my rights are and what I'm entitled to.'

'Most of my friends are the same. They live with their parents.'

How close is this to your experience and why?

Learning to Make Decisions

'Disability and decision making just don't go together to be honest. There is no such thing as making a decision. You don't have an opinion you just sit there.'

'I didn't find it hard moving to independent living because I didn't like it at school when people patted me on the head and said 'do that'

Which fits best with your experience and why?

Typical 24 Hours

Can you take me through a typical 24 hours? [How much PA, Who supplies it, How you work it]

Typical week?

Independent Living - Difficulties/ Fears

> **'For me it was recognising that I had the right to ask for what I want. I'm still learning that. I still agonize over asking people the simplest things.'**

How does this relate to your experience and why?

Discipline

> **'I have had to sack personal assistants/carers and that has been really hard. I sacked them because they were not working the way I wanted them to work.'**

How does this relate to you and why?

Risk

> **'When I first moved in I made the mistake of interviewing on my own. Now I don't do that. I interview with another disabled person.'**

Fears

> **'Some of the delay in moving was due to the fact that I was scared to move. I was quite scared.'**

How does this relate to your experience and why?

What advice would you give to others thinking about moving to independent living?

LIVING WITH PARENTS

> **'It was very difficult for me because I felt pressured into living independently before I was ready. People were seeing**

the physical aspect. The fear of being isolated compared to having people around me 24 hours a day stopped me going.'

'My parents are not going to be there for ever. if I was still at home with my parents I would only end up in an institution or somewhere I didn't want to be.'

Which relates best to you and why?

Carers - Trust

'I was thinking woman living on her own in a flat....scary. You are told that if you are disabled you shouldn't do dangerous or scary things. It isn't that scary, actually its not frightening at all.'

'The delay in moving was due to the fact that I was scared to move. I was worried about trusting someone to care for me. I find it intimidating, the thought of somebody I don't know coming in.'

Which fits best with your view and why?

Learning to Make Decisions

'Disability and decision making just don't go together to be honest. There is no such thing as making a decision. You don't have an opinion you just sit there.'

'I didn't find it hard moving to independent living because I didn't like it at school when people patted me on the head and said 'do that'

Which fits best with your experience and why?

Typical 24 Hours

Can you take me through a typical 24 hours? [How much PA, Who supplies it, How you work it]

Can you take me through a typical week?

Accessibility of Information on Independent Living and Benefits

'I always thought I'd get my own place but I didn't know how to do it. It seems through meeting other disabled people that I found out what my rights are and what I'm entitled to.'

'My contact with the social worker / OT / Independent Living Team was really good and helpful.'

Which relates best to your experience and why?

GENERAL SECTION

Benefits

'I can't work because I'm on them, I can't live with a partner because I'm on them, I can't be left any money by relatives who have died because I'm on them....Its creating dependency.'

To what extent does this fit your experience and why?

What benefits do you currently receive? (ILF, DLA, IS, AA, SDA HB, DWA)

How did you find out about these?

Do you manage your own money? {If not why not and who does?]

LEISURE TIME / PERSONAL RELATIONSHIPS

Leisure time

'I go out with friends, go to the cinema, play sport and go shopping. In fact I'm never in. I can do whatever I want.'

'A typical week is pretty dull. I'm at the day centre three days a week. My week consists of getting up, going to the day centre and coming back. There is nothing else.'

Which is closest to your experience and why?

Personal Relationships

Are you currently in a relationship?

> **'Lots of people meet socially or through work and I don't have the chance to do that. I don't go to nightclubs so its very hard to meet anyone. Also, you have to be confident about yourself...that you are attractive to other people and valuable as a disabled person.'**

> **'I have had several relationships with people with disabilities and non disabled people. I have no problem at all.'**

Which is closest to your experience and why?

Fears

> **Where do you get to meet them? [men] where is safe? I don't feel safe when I go out. All I have ever known is this protecting disabled society. It seems as if the disabled guys are all safe and the non disabled ones are frightening. There are some nasty creeps out there.'**

> **'I've got nobody. I don't go out at night. I'm frightened of using a taxi. Sometime I go to the cinema on my own but that's about it.'**

Children

> **'She is on her own and disabled and has children. She is a good mother and has carers to help her.'**

> **'What they [non disabled friends] are saying by saying we won't even talk about your relationships or the fact that you might want children. They are assuming that nobody would want to be in a relationship with you or that you are not responsible enough to have children.'**

Which fits best with your experience and why?

CONTACT WITH NHS

Importance of GP

'I have access to the GP for the usual coughs and colds and that's it'

'I use my GP a lot'

Which best fits with your view and why?

Level of Knowledge of GP

'I have been impressed by my doctor. He copes and he understands a little bit about CP. He is very good.'

'He asked me to explain what was wrong with me. He looked at me and didn't know what I was talking about. He had never heard of muscular dystrophy.'

Which fits best with your experience and why?

Specialist Services

'I am not very happy with the hospital. The doctors treat me like a child.'

'I have a really good doctor at the hospital. He explains everything and answers my questions. He talks to me not the person with me.'

Which is closest to your experience and why?

Medical Treatment - Disruption to Education

'I have not been in hospital much at all as there is not a lot they can do.'

'When I was little my feet turned in and I couldn't walk. I used to spend a lot of time in hospital having operations and things. I missed a lot of school.'

Which relates best to you and why?

ORGANISATIONS - DISABLED / PERSONAL DETAILS

Organisations

> **'I didn't want to have contact with any because I have got used to being around non - disabled people.'**
>
> **'We didn't know really, you don't get to find out anything. The Day Centre is my only other contact with disabled people.'**

Which fits best with your experience and why?

Is there anything you would like to add?

Personal Details

Age?

Year left school?

Are you registered disabled [If not why not]?

If so how did they find out about register?

Do you have an Orange Badge? [Who set up, if not why not]?

Nature of impairment?

DETAILS OF SAMPLE

NAME	AGE	IN EMPLOYMENT?	LIVING ARRANGEMENTS
Andrea	28	NO	Parental Home
Andrew	26	NO	Parental Home
Angela	21	NO	Parental Home
Annie	21	NO	College and Parental Home
Anthony	23	NO	Independent Accommodation
Barbara	24	NO	Parental Home
Barrie	22	NO	Parental Home
Cassie	19	NO	Independent Accommodation
Christopher	20	YES	Parental Home
Claire	19	NO	Independent Accommodation
Dana	18	NO	Parental Home
Dorothy	27	NO	Independent Accommodation
Elizabeth	24	NO	Independent Accommodation
Felicity	29	NO	Independent Accommodation
Freddie	23	NO	Independent Accommodation
Gary	30	NO	Parental Home
Helen	24	NO	Parental Home
Henrietta	25	NO	Independent Accommodation
Henry	24	NO	Independent Accommodation
Ian	21	NO	Independent Accommodation
Irma	27	NO	Independent Accommodation
Jane	24	NO	Parental Home
Jenny	25	NO	Parental Home
Josie	22	NO	Parental Home
Karl	23	NO	College and Parental Home
Lisa	23	NO	Independent Accommodation

Marjorie	26	NO	Independent Accommodation
Nigel	29	YES	Parental Home
Oliver	25	YES	Parental Home
Olivia	31	NO	Parental Home
Pam	25	NO	Parental Home
Philip	26	NO	Parental Home
Quentin	21	NO	College and Parental Home
Richard	26	NO	Parental Home
Robert	24	NO	Independent Accommodation
Sophie	25	NO	Parental Home
Theresa	21	NO	Independent Accommodation
Tina	21	NO	Independent Accommodation
Vera	29	NO	Independent Accommodation
Violet	29	NO	Parental Home
Wilma	26	NO	Parental Home
Zoe	20	NO	College and Parental Home

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