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**DISABLED VOLUNTEERS: AN ANALYSIS OF  
THE EXPERIENCES OF WHEELCHAIR-USERS  
WHO VOLUNTEER.**

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## **DEDICATION**

**This thesis is dedicated to my parents, Patricia & Ronald Andrews without whose continued love and support it would not exist; and to my nephew Stephen Isaac whose unexpected appearance in December 2002 brought sunshine and laughter into our lives.**

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# DISABLED VOLUNTEERS: AN ANALYSIS OF THE EXPERIENCES OF WHEELCHAIR-USERS WHO VOLUNTEER.

**Submitted by Jane Andrews: For the Degree of: Doctor of Philosophy: Aston University: January 2006**

## **SUMMARY OF THESIS**

Following grounded-theory methodology, this thesis provides an analysis of the volunteering experiences of 47 wheelchair-users. It challenges the traditional image of volunteering which tends to conceptualise non-disabled people as the instigators of voluntary action (the helpers) and disabled people as the recipients of volunteerism (the helped). It also begins to fill a notable gap in academic knowledge about the volunteering experiences of disabled people.

The literature review showed that contemporary conceptualisations of disability were unsuitable for this thesis. Thus, an organising framework is proposed which acknowledges that disabled peoples' experiences may be influenced by medically and socially constructed factors – or by a combination of both acting simultaneously (medical-social factors).

Having conceptualised disability for the purposes of the study, the thesis then provides an account of the research methodology used. This is followed by a presentation of research findings. An analysis of the volunteers' demographic, epidemiological and background characteristics is provided and their perceptions of the benefits of, and barriers to, volunteering highlighted. This is followed by an analysis of their volunteering experiences.

Theory is developed in order to explain the volunteers' experiences from the approach outlined within the organising framework. The final part of the thesis adopts a reflexive approach to contextualise the research processes from the writer's own perspective as a disabled person conducting research into the lived experiences of other disabled people.

The thesis concludes by highlighting the implications of the study for future social research.

### **Key-Words & Phrases:**

Disability:  
Reflexivity:  
Volunteers:  
Volunteering:  
Wheelchairs.

**WORD COUNT: 66, 477**

## **CHAPTER 1: INTRODUCTION**

This thesis provides an analysis of the volunteering experiences of 47 wheelchair-users. It represents the culmination of almost four years' work; a time of my life that may best be described as tumultuous, manifested by periods of great enthusiasm and optimism as well as by episodes of complete isolation and depression. Each stage of the research process brought with it a distinct set of difficulties and issues. Having worked through such issues, it is possible to look back in retrospect and envisage the part played by each small set-back and achievement in the formulation and completion of this thesis.

This introductory chapter is divided into two main sections. The first consists of a narrative depicting my own personal journey from complete antipathy towards volunteering to my present-day enthusiasm for volunteerism and the voluntary sector. It also outlines my personal motivations for undertaking research into the experiences of disabled volunteers. The second section provides a brief overview of the subsequent chapters.

The importance of the 'self' and the place of reflexivity to the research process is depicted within the academic literature (Alvesson & Skoldberg: 2000, Giddens: 2001, Harris: 2001, Wengraf: 2001). The following narrative therefore explores my own personal experiences of the voluntary sector and in doing so contextualises the thesis whilst explaining my motivation for undertaking this study.

## SECTION 1: BACKGROUND TO THE THESIS: A PERSONAL NARRATIVE

### - From Antipathy to Volunteerism:

It is difficult to determine from where my interest in volunteering and the voluntary sector originally stems. As a child born into a working-class family the antipathetical manner in which the concept of charity was perceived within the community in which I was raised was matched only by an in-built aversion to the idea of working without pay. Thus, although I grew up unaware of the existence of the voluntary sector, in retrospect it loomed large on the edges of my life, hidden behind a culture that thrived on the certainties of family and neighbourhood. Within this culture there existed youth clubs, church based groups, sports clubs, special interest groups and numerous other smaller 'grass-roots' agencies. Like many other youngsters I joined such groups, acquiring valuable social and communication skills along the way.

At the age of seventeen I enlisted in the RAF, an environment in which the concepts of volunteerism and voluntarism were greatly confused with coercion and discipline. Upon enlisting all recruits were told they would 'voluntarily' donate a single-days pay each year to the Royal Air Force Association (RAFA). At the time I had little idea that my unwitting donation would be repaid to me at least a hundred-fold in later years. Donating to the service charity was not my only 'voluntary' action during the time I served in the RAF; over a five year period I 'volunteered' for numerous non-duty related activities including taking part in several charity based sports events, acting as an unpaid waitress at special events for commissioned officers and acting as a guard for Princess Diana's wedding dress when it 'toured' the country for public viewing.

Thus by the time I was discharged from the RAF my previous antipathy towards the concept of volunteering had increased markedly. With few transferable skills, I decided that my future career path was destined to be in the public sector and so, like many ex-military personnel joined the Police Force. I found myself immersed within a macho and patriarchal culture that was institutionally both racist and sexist. I was persuaded by my family that the best way in which I could hope to change such a culture would be from the inside. This was a mistake and I spent the following five

years unhappily pretending to fit in. However, it was whilst in the Police Force that I became acutely aware of the extreme social and economic divisions within British society. The majority of the people I dealt with were socially excluded, living in poverty, with little or no hope for the future. Many were also living with apparent mental health problems. Feeling the need to 'do something', I resigned from the Police Force, took an 80% drop in wages and applied to become a student psychiatric nurse.

I spent almost 3 years training to be a psychiatric nurse. During this time my awareness of the important role played by the voluntary sector within the community grew. I observed how organisations such as MIND and the National Schizophrenia Fellowship provided a safety net for those people, who, upon being discharged from hospital care continued to need help and support. Unfortunately, six months prior to qualifying as a psychiatric nurse I awoke one morning to find myself in extreme pain and unable to walk. It was May 1994.

At the time I wasn't too concerned. Like most people I assumed my GP would identify the source of the problem and that I would soon recover. This expectation was not totally unreasonable as research suggests that the majority of working age people who experience disability recover fully within two years (Burchardt: 2000). This was not to be in my case and I was later diagnosed with Multiple Sclerosis (MS).

Following the onset of disability I experienced a process of grieving for my old life (Kubler-Ross:1970) and slumped into a deep depression. Such depression was augmented by the fact that I had been forced to resign from nurse training and suddenly found myself struggling to survive on income support. The inadequacies of the welfare state were brought home to me when, upon applying for a wheelchair, I was told that I was not 'disabled enough' to fit the prescription criteria. This was despite the fact that I was housebound and could only walk a few steps. With nowhere else to turn, and in desperation I approached the Royal Air Force Association (RAFA) and asked for assistance. Within weeks I was supplied with a 'mobility scooter' and a manual wheelchair. For the first time in months I was able to leave home independently.

The philanthropic actions of the RAFA gave me a new lease of life. After being almost totally housebound for over six months the mobility scooter enabled me to get out of the house independently. I was prompted to re-evaluate my life and enrolled on a part-time Open University course. I also took the decision to seek voluntary work within my local town. At the time my motivations for wanting to volunteer were almost entirely selfish. I had become socially isolated and withdrawn; unsure as to the cause of my disabling symptoms the future looked extremely bleak. Thus, I decided to seek out voluntary work in anticipation that it would afford social opportunities whilst providing mental stimulation.

I first contacted an advice and information centre for disabled people which was advertising for trainee benefits advisors. I was sure that, as a reasonably intelligent person, I had much to offer such a position. The organisation in question, which I now know to be was an organisation of disabled people (Oliver: 1997, Taylor: 1997) was firmly embedded in a culture that promoted certain types of disability above others. The person who interviewed me for the position looked at my wheelchair and decided I was too ill to volunteer. Without even being given the opportunity to try, I was denied the chance to access volunteering.

I was extremely surprised by such negative attitudes, particularly as the organisation in question claimed to promote a culture of equality and inclusion within society. Having faced such seemingly impenetrable barriers, it took over twelve months before I felt psychologically strong enough to try again. On this occasion I decided the local Volunteer Bureau would be the most appropriate place in which to identify suitable voluntary opportunities. Again I was immediately confronted by negativity; the young woman advisor looked at my wheelchair and asked if I could read and write. Having assured her that my literacy levels were quite reasonable, I was given the standard application form and asked what areas of volunteering I thought I might be able to cope with. I left the Volunteer Bureau without being offered a place.

At the time MENCAP was running an advocacy scheme and was seeking individuals to volunteer with people with learning disabilities. Here, despite the fact that all the paid staff were able-bodied, I was welcomed with open-arms. I spent over 2 years



volunteering a few hours a week at MENCAP and at the same time became a volunteer counsellor and listener for MIND.

I found MENCAP to be a forward-thinking organisation that was willing to listen to the views of the people it was there to serve. However, at the time, the local branch in which I was placed did not have any people with learning disabilities in positions of authority or influence; it was managed by a parent of a person with learning disabilities. The failure of such organisations to involve disabled people in their management has been criticised by Oliver (1990) who argued that they 'serve to institutionalise disabled people and create dependency' (p 90). Read (2000) also criticised organisations for disabled people such as MENCAP and argued that they 'seek to exercise control over disabled peoples lives, keeping them in a dependant situation whilst 'reproducing inequality and maintaining injustice' (p 104).

My own experiences however, lead me to question the validity of such arguments. Although the branch of MENCAP in which I was deployed did not have any people with learning disabilities in positions of authority, it strove to empower its members by promoting a culture of independence and equality. As a volunteer with MENCAP my duties entailed, for example, assisting a young woman in acquiring the necessary skills to live independently within the community. Thus we spent many hours practising the skills of daily living until she reached the point where she felt ready to live independently and was able to move into a home of her own.

My experiences as a volunteer counsellor and listener within MIND were totally different from those as an advocate with MENCAP. The branch in which I was engaged was essentially an independent self-help group (Brenton: 1985) that offered its members a varying degree of help and support. It had no paid staff and was totally reliant on volunteers for its day-to-day management. With no single designated individual in charge, it appeared to be managed on an ad-hoc basis, with little direction or strategy. As a volunteer I found such a chaotic environment extremely difficult to cope with and subsequently slowly withdrew my services.

I left MENCAP in October 1998 and enrolled full-time at University. Later that year I was approached by an organisation of disabled people and asked if I would accept a

place as a volunteer on their management board. This organisation, a CIL (Centre for Integrated Living), offered a variety of services to disabled people within the local area. I accepted the offer and remained a trustee of this organisation until funding shortages forced its closure in 2003. During this period I also volunteered on the management committee of a local branch of the MS Society. I ceased this activity in the summer of 2003 after being asked to apply for a position on the Society's national voluntary board. Upon attending an interview for the position, I discovered that the Society was managed and governed by a majority of people who had no personal experience of MS – I did not accept the position as trustee.

At present I am a volunteer within two different types of 'service-user' organisation. The first of these is a local wheelchair-user group the function of which is to liaise with NHS wheelchair services with regard to the provision and supply of wheelchairs to service-users. I find volunteering in such a position extremely frustrating and am frequently left feeling disturbed and angered by a system which appears to only be paying 'lip-service' to the users. Despite such frustration, I continue to attend meetings whenever possible in the hope that such user-consultation may one-day become user-involvement.

The second group I am involved with currently was originally founded by a local speech therapist who identified a lack of public sector provision for people living with speech impairments within the local area. This group, which has grown considerably since being established, now functions along the lines of a self-help organisation. Its management committee, which was originally formed to satisfy the demands of external funders, consists entirely of disabled people, all of whom, with the exception of myself, have speech impairments. The supportive nature of the group is manifested by high levels of mutual support and empathy which is offered to all members irrespective of the nature of their disability. The most important part of the voluntary work I undertake within this group involves giving assistance in applying for welfare disability benefits. Many of those whom I have helped later become volunteers' themselves, offering support and advice to other newly disabled members of the group. Thus group members support each other practically, socially and psychologically and it is through my activities as a voluntary benefits advisor and fundraiser within this group that I feel I have found the true meaning of volunteerism.

## - Why Research Wheelchair-Users who Volunteer?

The voluntary work I have undertaken in various organisational settings over the past ten years has undoubtedly influenced my own ontological perspective. Having volunteered within organisations of and for disabled people I have gained a distinct insight into the similarities and differences between the two types of organisation. Moreover, I have become increasingly aware that disability is itself a highly contestable issue. In discussing such controversy Alcock (1996) has argued that 'fundamentally there is no clear agreement about what constitutes disability, or what degree of disability is likely to lead to disadvantage' (p. 243). Over the past eleven years I have encountered many people who perceive themselves to be disadvantaged by disability. I have also learned that disability does not have any social, ethnic or economic preferences; it can and does strike anyone at anytime.

As a wheelchair-user living with MS I am particularly interested in the volunteering experiences of other wheelchair-users. The barriers I encountered whilst attempting to access volunteering blocked my participation for over a year and made an indelibly negative impression both on my sense of self and my views of volunteer management. Such barriers have not disappeared. Practical, environmental and attitudinal barriers continue to arise in all areas of my life including volunteering. Thus, from a personal perspective, volunteering is not an 'easy' option; whilst I enjoy it, it is something I undertake out of a sense of social-duty and commitment.

Having developed several personal coping strategies to deal with the extant barriers to volunteering, I was interested to learn whether other wheelchair-users who volunteer have encountered similar barriers; and if so how they have dealt with such barriers. I quickly found that previous research has tended to conceptualise disabled people as being the recipients rather than the providers of voluntary action; as such disabled people constitute an invisible group of volunteers. My main motivation for undertaking the study was to 'do something' to balance this.

There have been no previous studies specifically examining the volunteering experiences of wheelchair-users. Moreover, stereotypical views of disability mean

that most people continue to believe that wheelchair-users are incapable of volunteering. It is hoped therefore that this study will highlight the role played by wheelchair-users within contemporary society and in doing so will make a considerable contribution to academic and practitioner knowledge. Furthermore, I hope that this study will not only encourage other disabled people to volunteer their services, but will also encourage volunteer managers to overcome any preconceptions they may have in respect of disability and actively promote volunteerism amongst wheelchair-users and other disabled people within their organisations.

## SECTION 2: AN OVERVIEW OF THE CHAPTERS

### - Chapter 2

Chapter 2 provides a critical discussion of the academic literature relevant to the research topic i.e. wheelchair-users who volunteer. It starts by drawing attention to the two dominant conceptualisations of disability within contemporary society – the medical and social model of disability. Following a critical discussion of each of these approaches, other disability related issues are discussed including the stigmatisation of disability, employment, social exclusion and poverty. The literature about wheelchair-users is also discussed. Following this the chapter reviews the voluntary sector and volunteering literature and includes a discussion focusing upon volunteer activities, volunteer motivations and volunteer management.

The third section of Chapter 2 draws attention to the sizeable gap in academic knowledge about the experiences of disabled volunteers. It is noted that there have been no previous studies examining the volunteering experiences of wheelchair-users.

The final section of Chapter 2 draws together the literature reviewed in the previous three sections to develop an organising framework. This framework, which comprises of medical, social and medical-social approaches to disability, contributes to academic knowledge by suggesting that the experiences of disabled people are influenced by both medically and socially constructed factors – or by a combination of the two acting at the same time.

### - Chapter 3

Chapter 3 provides an overview of the research methodology. The first section draws attention to the pre-field work undertaken prior to the commencement of the pilot study and fieldwork. This includes identifying the emergent research questions and conceptualising the term volunteering for the purposes of the study.

The second section of chapter 3 outlines the methodological approach adopted including the role of grounded theory. The research design is explained with

particular consideration given to the various methodologies considered for use within the study. Following a brief discussion of the pilot study, issues relating to the fieldwork are examined including difficulties encountered in accessing the research field; matters pertaining to the interviews and interview processes; and the role of reflexivity within the research process.

Having outlined the methodological issues encountered prior to and during the fieldwork, attention is given to matters of validity and reliability. Chapter 3 concludes by highlighting the contribution made within the chapter to academic and practitioner knowledge.

#### - **Chapter 4**

Chapter 4 is the first of the analysis chapters. It provides empirical data about the demographic, epidemiological and other characteristics of the volunteer study participants. Various aspects of the volunteers' experiences are discussed including the nature of their activities and their motivations for volunteering.

Having analysed the volunteers' background characteristics the chapter focuses on matters pertaining to the organisations in which they were engaged. This is followed by an analytical discussion of the issues raised throughout the chapter. The conclusion to Chapter 4 suggests that the high levels of vocational skills and expertise brought to volunteering by the wheelchair-users interviewed as part of this study constitutes a sizeable contribution to both the organisations in which they are engaged and to society as a whole.

#### - **Chapter 5**

An analysis of the volunteers' perceived day-to-day experiences is given in Chapter 5. This reveals that the perceived beneficiaries of the volunteers' activities were: the volunteers' themselves; other disabled people; the general public; the organisations in which they were engaged; and external organisations and agencies.

The second section of Chapter 5 highlights the perceived barriers to volunteering identified during the course of the study. Such barriers can be divided into four main areas: environmental; personal; attitudinal; and organisational.

The third section of the chapter concentrates on the volunteers' general and routine experiences of volunteering. This section looks at wider issues including: dealing with the general public; issues around governance and management; office relationships; impairment related issues; and familial support when volunteering. It is noted that many of the volunteers, including those engaged as trustees, were reluctant to discuss in detail any matters relating to governance or management.

The final section of chapter 5 contextualises the volunteers' experiences by providing a critical discussion of those experiences. This discussion notes the highly personal and individual nature of the volunteers' perceptions of their experiences. Thus, what some volunteers described as a barrier to volunteering, others perceived as a challenge to be overcome.

## **- Chapter 6**

Chapter 6 commences by explaining the volunteers' experiences using the original organising framework depicted within chapter 2. The second half of this chapter adopts a reflexive approach to contextualise the research process from my own perspective as a disabled researcher conducting research into the lived experiences of other disabled people. The thesis concludes by highlighting the implications of the study for future research.

## **CHAPTER 2: LITERATURE REVIEW**

The aim of this chapter is to provide a review of the academic literature relevant to this study. Prior to undertaking this review it was first necessary to ascertain which issues were relevant to the volunteering experiences of disabled people. Such issues were identified during an extensive period of pre-fieldwork undertaken during the early stages of the research process in which several disabled volunteers and managers of disabled volunteers were consulted. This pre-fieldwork is discussed further in chapter 3.

Each of the first three sections of this chapter focuses upon a different area of the literature. The first comprises a review of disability theory commencing with a critique of two different conceptualisations of disability within contemporary society; the medical and social models. The second section provides an overview of different conceptualisations of the voluntary sector before examining various definitions of volunteering, volunteerism and voluntarism. The third section of this chapter draws together the literature pertaining to disability and volunteering.

The final section of this chapter uses the literature reviewed in the previous three sections to synthesise the two dominant approaches to disability. Thus a conceptualisation of disability that combines the medical and social models of disability is formulated and depicted within the organising framework. This organising framework is used to frame the research process and as such is utilised throughout the study. It provides a solid framework upon which the research process is built and the experiences of disabled volunteers investigated, analysed and explained. Moreover, by suggesting that both medically and socially grounded factors can impact upon the experiences of disabled volunteers, either as single influences or as a combination of the two acting together, this chapter adds to both disability and voluntary sector literature.



## **SECTION 1: DISABILITY**

The aim of this section is to provide a critical overview of the disability literature relevant to this study. The first paragraphs provide an analysis of the two dominant conceptualisations of disability– the medical and social models. The critique then focuses upon other relevant literature about: the stigmatisation of disability, employment and disability; poverty, social exclusion and disability; and wheelchair-users.

### **1.1 Conceptualising Disability**

#### **- The Medical Model of Disability**

The medical approach to disability was reflected historically in the institutionalisation and incarceration of those people deemed to be sick, mad, or handicapped (Gooding: 2000, Roulestone: 2003, Woodhams & Corby: 2003). Reflecting dominant ideological perspectives that medical intervention is the both the normative and correct response to disability (Brisenden:1986, Oliver: 1990: Coggin & Newell: 2004) contemporary medical sociological approaches to health and sickness build upon Parsons (1951) functional application of the ‘sick role’ model. Parsons’ contention was that in adopting a persona based upon illness, the sick were abdicated from ordinary day-to-day social responsibilities and obligations. For several years this view was considered pivotal within disability theory (Donoghue: 2003). It perceived illness to be an undesirable and temporary state and reinforced the medical hegemony by placing the onus upon the sick person to seek medical advice and take all appropriate steps to ensure recovery. Moreover, by legitimising the relinquishment of daily responsibilities and by reinforcing the notion of temporariness, the sick-role approach discounted the daily living experiences of disabled people living with chronic illnesses and impairments.

More recent medical sociological approaches to disability have been framed within the World Health Organisation (1980) International Classification of Impairment, Disability, and Handicap:

- **Impairment:** Any loss or abnormality of psychological, physiological or anatomical structure of function...
- **Disability:** Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner considered normal for a human being...
- **Handicap:** A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual...

Adapted from Wood (1980:27-29)

In short, the medical model of disability views a person's functional limitations as the root cause of any disability. Moreover, any disadvantages caused by that disability can only be overcome by medical treatment or cure (Oliver: 1990, Oliver & Barnes: 1998, Hurst: 2003).

#### - **Critique of the Medical Model**

Leading disability theorists argue that it is the medical model which continues to dominate contemporary conceptualisations of disability and that the resultant medical hegemony results in disabled people being alienated from society and thus excluded from everyday activities, (Oliver: 1990, 1996, Barnes et al: 1998). This perspective was supported by Gooding (1995) who drew attention to the sustained influence that the medicalisation of disability had in negatively shaping public perceptions of disability. Negative attitudes towards disability reflecting the medicalisation of society were also highlighted by a study examining the link between disability and social exclusion conducted by the Fabian Society (1999). This found that whilst many physically disabled people had experienced indirect discrimination (indicative of the inaccessible nature of the built environment) the main perceived cause of social exclusion was reflected in prejudicial social attitudes towards disability.

This issue was also discussed by Field and Taylor (1998) who argued that disabled people are 'defined almost exclusively with reference to their medical diagnosis' (p.14). Thus someone living with diabetes becomes "a diabetic", someone living with

arthritis is described as “arthritic” and a person living with a spinal cord injury is labelled “paraplegic”. Defining people in terms of their medical condition not only reflects the medicalisation of popular culture but also reinforces negative perceptions and stereotypes of disability. Such negative conceptualisations can result in disabled people being perceived as being different from ‘normal’. This perspective was supported by Ettore (2000) who conducted research into pregnancy and disability and found that women’s desires to have ‘normal babies’ are reinforced by the medicalisation of disability to the point that:

‘...the general attitude in society is that we are trying to get rid of the handicapped people and they are just useless people...’

(Ettore:2000: 409).

The desire for normality within the human psyche is augmented by popular media images promoting beauty and perfection. Such generally unattainable images, which are reinforced by a popular culture that promotes biological sameness and physical perfection, are integral to the medicalisation of society (Carey: 2003, Mitchell & Snyder: 2003). In fact, notions of biological perfection and sameness formed the basis of the eugenics movement during the first half of the twentieth century – the abhorrent ramifications of which are well documented (Gould: 1996, Carlson: 2001).

Although the historical repercussions of medically based conceptualisations are recorded in the academic literature, the continued influence that the medical profession plays in the lives of disabled people is the subject of much debate. One controversial perspective has argued that the medicalisation of disability is reflected in the denial of basic human rights for those people deemed by the medical establishment to be too handicapped, incapacitated or disabled for medical treatment or intervention (Pal: 2000). This perspective reflects recent highly publicised court cases regarding the right to life for severely disabled and ill individuals (Luscombe & Young: 2005, Dyer: 2005). However, it also contradicts equally controversial arguments about euthanasia made by some severely disabled people who believe in their own right to choose to die (Meikle: 2005, Doward: 2005).

The medical approach to disability continues to be widely utilised to conceptualise disability throughout much of Western society (Charlton: 2000, Donoghue: 2003). One of the main strengths of this model is that it encapsulates the experiences of the majority of disabled people whom are living with chronic health or degenerative conditions. Moreover, the three-fold typology proposed by Wood (1980) takes account of the fact that for many people, disability is a fluid, rather than a state condition. Despite such strengths the medical models failure to acknowledge that some aspects of disability are socially constructed is a major weakness

Although the medical approach to disability is criticised by writers on disability, literature aimed at those living with chronic illness adopts a different stance arguing that there is a clear need for medical intervention in the form of diagnosis, treatment and rehabilitation (Shepherd: 1992, Thomas: 2002). Whilst not actually discounting social causes of disability, impairment focused literature emphasizes the need for disabled individuals to develop meaningful relationships with the medical profession in order to promote their own health and well-being (Fallon: 1987, Robinson et al: 2000). Such advice is challenged by writers on disability who argue that the medicalisation of disability has resulted in 'health care professionals [playing] a significant role in the oppression and marginalisation of disabled people' (Bricher: 2000: 782).

#### - **The Social Model of Disability.**

The social model of disability originated within the disability movement of the 1970's and 1980's. It was developed by disabled activists and academics in response to the medical hegemony they perceived dominated the lives of ordinary disabled people. Founded upon the premise that people living with impairments are disabled by society, this approach argues that issues surrounding disability should be dealt with by social change; and should not be addressed solely by medical intervention and rehabilitation (Oliver: 1990, Hasler: 1993, Barnes et al: 1999).

An early expression of this approach was formulated by the Union of Physically Impaired Against Segregation (UPIAS), a British-based disability organisation which argued that:

‘Disability denotes the disadvantage caused because society is organised in such a way that excludes people who have physical impairments from mainstream activities.’

(UPIAS:1976: 3-4).

Although this perspective focused attention away from the medicalisation of disability, its emphasis on physical impairment excluded the experiences of those living with sensory disabilities, mental health problems and learning difficulties and disabilities. Thus it failed to encapsulate the experiences of the majority of disabled people.

An alternative, more detailed definition of disability was formulated by the Disabled People’s International (DPI):

‘A Disabled Person is an individual in their own right, placed in a disabling situation, brought about by environmental, economic and social barriers that the person, because of their impairment(s), cannot overcome in the same way as other citizens. These barriers are all too often reinforced by the marginalizing attitudes of society. It is up to society to eliminate, reduce or compensate for these barriers in order to enable each individual to enjoy full citizenship, respecting the rights and duties of each individual.’

DPI (1994: 14)

This definition reflected Oliver’s (1990) social constructionist approach which drew attention to the role played by society in excluding and disabling individuals. From this perspective disability is socially constructed; people living with impairments are not disabled by their illnesses or medical limitations, but are instead disabled by the manner in which society is constructed and organised. Disabling social factors include: ‘an inaccessible built environment; negative social stereotypes of disability; deficiencies in the availability of accessible reading material for visually impaired people; the inability of the general population to use sign language; and antagonistic public attitudes towards people with invisible disabilities’ (Oliver: 1990: 11).

## - A Critique of the Social Model

The influence that the social model has played in changing widely-held perceptions regarding disability is the subject of much debate. Leading disability theorists postulate that a wide acceptance of the social-constructivist paradigm has had positive implications for the manner in which disability is perceived throughout contemporary society (Wilkinson: 1999). Moreover, the social models emphasis on oppression and discrimination has resulted in changes to the way in which disabled people are supported to live independently within the community (Beresford: 1993).

Despite such positive endorsements, any influence that the social model approach may have had within contemporary society is mostly restricted to the UK. Notably, its failure to make an impact within the USA contradicts arguments that a social model approach can by itself promote equity and equality throughout society. Moreover, the strength of the Americans with Disabilities Act (ADA:1990), which is rooted within the medicalisation of disability (Donoghue:2003), suggests that any significant changes to the manner in which disability is perceived within society will not occur without prompting from the law. In addition to addressing disability discrimination the ADA (1990) also covered areas such as housing, employment, public buildings, education, transportation, communication, health services and access to public services (Davis: 1996). The result of such wide-ranging legislation was an increase in the accessibility of American society for disabled people; furthermore, disabled Americans currently have far more civil and social rights than their British counterparts (Charlton: 2000, Donohue: 2003).

One of the main criticisms of the social model is that it fails to fully acknowledge the impact that chronic ill-health may have on an individual's personal lifestyle and overall well-being (Morris: 1991). Leading feminist disability theorists have questioned how symptoms such as pain, fatigue, depression and chronic illness which are a fact of life for many disabled people, can be seen as being irrelevant (Crow:1996). Even when all of the socially determined disabling barriers have been removed, many disabled people will continue to encounter barriers caused by illness and impairment.

Taking a practitioner perspective Ridley (2001) has also questioned the relevance of the social model for people with degenerative conditions such as Multiple Sclerosis. She argued that there is a need for an alternative biographical model which:

‘...recognises that individuals lives will be directly and sometimes adversely affected by their impairment, and that this will be dependent upon the prognosis of the condition, the level of severity and the prevalence of the symptoms at any one time...’

(Ridley: 2001: 23).

One problem with the biographical model is that by concentrating mainly on the negative impacts that impairment and illness can have on an individual, there is a danger that a tragic image of disability could become the dominant view of a disabled person. From this perspective disability is viewed as an individual tragedy that can only be overcome by medical treatment or cure (Oliver: 1990); thus there is no need for society to remove any social barriers or deal with episodes of discrimination and prejudice experienced by many disabled people on a daily basis.

The need for the social model to be widened in order to take account of the effects that impairment can have upon an individual was also highlighted by Swain and French (2000) who suggested an affirmation model of disability. Such an approach would essentially consist of a ‘non-tragic view of disability’ that is both grounded in disability culture whilst promoting the ‘benefits and life style of being impaired and disabled’ (Swain & French: 2000: 569). By affirming the positive nature of being impaired, disabled people can actively repudiate the ‘dominant value of normality’ (Swain & French: 2000: 578).

However, not all disability theorists support the argument that any conceptualisation of disability should encapsulate individually experienced medically-grounded experiences. Shakespeare (1992) argued that:

‘...to admit pain, to confront our impairments has  
been to risk the oppressive seizing of evidence  
that disability is ‘really’ about physical limitations after all...’

(Shakespeare: 1992: 40).

Whilst this perspective may reflect Shakespeare’s personal experience of living with disability, its narrowness in discounting the experiences of those living with painful, life-limiting medical conditions does little to promote understanding and acceptance. Thus, it reinforces the prejudicial barriers faced by many disabled people within contemporary society.

**- Conceptualising Disability: A Comment on the Two Dominant Approaches.**

It would appear that the medical and social models of disability are two separate and opposed perspectives.

The medicalisation of disability has resulted in medical professionals having considerable power and influence over the day-to-day lives of disabled people. Such power and influence results in medical intervention in numerous areas of disabled people’s everyday lives including: ‘the prescription of wheelchairs; eligibility assessments for social benefits; decisions about driving ability; as well as measuring suitability for work or education’ (Oliver: 1990: 59). Although Oliver’s work is somewhat dated, much of his argument is still relevant within contemporary society as medical professionals continue to play a largely unregulated role in the day-to-day lives of disabled people. However, although medical intervention may be inappropriate in some areas of disabled people’s lives, the role played by medical professionals in reducing disability and the disabling symptoms of ill-health should not be underestimated.

Whilst medical science continues to influence the daily lives of some disabled people, it is evident that the social model of disability has resulted in some positive changes to the daily experiences of many disabled people. Such changes, which include a shift towards independent living for disabled people as well as moves to make public



transport more accessible, have not been made in isolation of the law. However, the influence that social model conceptualisations of disability have played in shaping public and social policy is difficult to determine; current disability legislation refers to social issues and socially constructed barriers but defines disability solely in medical terms (McClellan: 2003).

What seems to be needed is an approach which acknowledges the disabling impact that both medically and socially constructed barriers can play in shaping disabled people's lives. This argument forms the foundation of the organising framework outlined in the final section of this chapter.

## **1.2. Stigma and Disability.**

Some writers on disability have argued that the dominant medical-tragic view of disability has resulted in the stigmatisation of disabled people and that this stigmatisation has resulted in disabled people developing a 'group consciousness and identity' (Oliver: 1990: 4). From this perspective, we might expect to find similar experience amongst disabled people. Assumptions of homogeneity of experiences were identified in Goffman's (1963) study "Stigma" in which he argued that by applying assorted stigmatising labels, society places people into various categories. Such categorisations reflect: 'abominations of the body – the various physical deformities, blemishes of individual character, and the tribal stigma of race, nation and religion' (Goffman: 1963: 14).

One weakness of Goffman's (1963) study is its emphasis on the psychological aspects of stigma. Moreover his conceptualisation of stigma ignored issues around power inequalities and inequities within society. Thus his book reinforced political arguments that any existing power inequalities within contemporary society are both unavoidable and inevitable (Abberley: 1993: 110-111). Another study examining the stigmatisation of disabled people was conducted by Hunt (1966) who concluded that problems related to disability are not only the result of functional impairments, but also reflect intemperate relationships with 'normal people' (p146). Disabled people are presumed to be unfortunate because they 'are set apart from the ordinary [and thus appear] unfortunate, useless, different, oppressed and sick' (Hunt: 1966: 146). One of

the weaknesses of this study was its emphasis on normality, the meaning of which was not established.

Other social studies examining stigma and disability have argued that the stigmatising effect of disability is manifested by a fear of the unknown; this fear is then used to justify the continued social exclusion of disabled people (Ainsley et al: 1986, Finkelstein: 1980, Abberley: 1993). Despite such studies it is difficult to establish the exact nature of any link between disability and stigma. Literature in this area is limited and the representativeness of studies examining stigma and disability questionable. Furthermore, by assuming that disabled people form a single homogenous group, studies linking stigma and disability fail to take account of the individual nature of personal life experiences and perceptions.

### **1.3. Employment and Disability.**

One of the direct results of the impact of stigma is a high incidence of unemployment amongst the disabled population (Oliver: 1990). Recent statistics regarding the percentage of the UK disabled population who are unemployed are difficult to find. However, previous estimations of the proportion of (the American) disabled population who are out of work vary from a half (Lonsdale: 1986) to a third (Martin et al: 1989); suggesting that in the 1980's between a half and two-thirds of disabled Americans were unemployed. More recent US studies suggest that little has changed over the past quarter of a century despite extensive legislation pertaining to the employment of disabled people. Seventy percent of Americans with disabilities are unemployed – compared with the official national unemployment rate of 4-5% (Russell: 2002). The subjective nature of disability means that such figures are unreliable – many disabled people do not inform their employers of their impairment or claim state benefits; thus they are not included in any statistical data. Other literature suggests that between 6% and 16% of the working age population in the UK have a long-term illness or disability (McClean: 2003: 51). However, these figures fail to say what percentage of disabled people are actually in paid employment.

The importance of employment to the quality of life for disabled people has been articulated thus:

‘The decisive decision between hope and no hope among the disabled is between working and not working. Those who work by and large feel they are part of the human race. Those who do not work feel left out, alone and largely useless’

Harris (1987: 195-196)

From this perspective purposeful occupation is linked to feelings of usefulness and optimism. Apparent high levels of unemployment amongst the disabled population would suggest that many disabled people are denied the opportunity to remain in, or acquire, paid employment. For such people volunteering may be the only link they have with the world of work.

Although statistical evidence regarding the percentage of disabled people who are unemployed is somewhat limited, research into unemployment and disability has found various demographic and epidemiologic disparities in the employment of disabled people. Research conducted by Smith-Randolph and Andresen (2004) found that in the USA women with disabilities were at higher risk of unemployment than their male counterparts, whilst a study by McClean (2003) concluded that people with acquired disabilities or impairments were more likely to be in paid employment than those who were born disabled. Such studies suggest that women who are born disabled are the least likely to gain paid employment. Writers on disability argue that such inequalities reflect the medicalisation of disability and result in many employers refusing to employ disabled people.

One detailed study analysing the experiences of disabled people within the workplace was undertaken by Vickers (2003) who drew attention to variations both in how the chronically ill experienced work, and in how they dealt with the long-term effect of disability and illness. Vickers’ study highlighted how many people living with chronic illness felt the need to hide the true nature of their condition from their employers;

‘It is no surprise, then, that people with stigma (visible or invisible) feel the need to hide their true selves. Those who exist on the fringe of organisations – for whatever reason – continue to cover their perceived flaws, to hide and mask.’

Vickers (2003: 138)

Whilst it is apparent that many disabled people may have good cause to hide the true nature of their impairment from employers, this option is not available to wheelchair-users – it is impossible to hide a wheelchair. Thus the percentage of wheelchair-users who are unemployed is likely to be higher than other groups of disabled people living with ‘hidden disabilities’.

#### **1.4. Poverty, Social Exclusion and Disability.**

Research suggests that unemployment amongst the disabled population is linked to high levels of social exclusion and relative poverty (Townsend: 1993, Bradley et al: 2004, O’Grady et al: 2004). Such relative poverty has been defined thus:

‘...[a lack of] resources to obtain the types of diet, participate in the activities and have the living conditions and amenities which are customary or at least are widely encouraged or approved in the society in which we live.’

Townsend (1979: 3)

In suggesting that disabled people constitute a disproportionate percentage of the population living below the (relative) poverty line, Townsend (1979) pointed to a significant positive correlation between severity of impairment and levels of social deprivation. This correlation was also identified by Oliver (1990) who argued that there is a link between the distribution of poverty and the epidemiology of impairment.

Other writers have suggested that disabled peoples increased risk of experiencing poverty is augmented by ineffectual welfare policies, high levels of unemployment and commonly held misperceptions of disability (Howard: 1999, Borsay: 2005). Such commonly-held negative misconceptions and stereotypes aggravate experiences of social exclusion and culminate in high levels of dependency on state welfare (Oliver: 1990). Moreover, within contemporary society many disabled people continue to experience unemployment and the resultant social and economic exclusion. Recent government figures suggest that 60% of disabled people claim 'safety-net' welfare benefits such as Income Support and Housing Benefit, and 47% of disabled people claiming such benefits do not have sufficient income to meet minimum costs (Davey Smith et al: 2003). This would indicate that in comparison to non-disabled people, 20% of whom live in a state of relative poverty (Hills: 1998), disabled people are more likely to claim subsistence welfare benefits and more likely to struggle financially. Thus poverty is a considerable factor influencing the lives of disabled people and determining their quality of life (Hughes: 2002).

It would appear then that there is a self-reinforcing 'circle' of disability and poverty: impairment results in disability; this is then followed by unemployment and a reliance on state welfare benefits; inadequacies in the benefit system mean that many of the claimants are forced to live in a state of relative poverty; such poverty results in ill-health; ill-health aggravates impairment and thus causes increased levels of disability.

### **1.5. Wheelchair-Users**

There are no statistics regarding the percentage of wheelchair-users who are living on supplemental or subsistence benefits. This lack of statistical knowledge is indicative of the literature pertaining to wheelchair-users as a whole which is extremely limited. Moreover, there have been no previous studies analysing the lived experiences of wheelchair-users who volunteer.

Although the daily life experiences of wheelchair-users have not been subjected to rigorous academic investigation, the diagrammatic symbol of the wheelchair is a universally accepted conceptualisation of disability (Sapey et al: 2005). Because this symbol is used to depict what are frequently conceptualised to be 'special' facilities

for disabled people (such as wider parking spaces, different entrances to buildings and accessible toilets) it is generally negatively perceived as being associated with difference and otherness. Thus the symbolic meaning attached to the use of a wheelchair reinforces commonly-held negative social stereotypes of helplessness and dependence that are frequently linked with disability (Barnes et al: 1998).

Such negative perceptions do not necessarily reflect how wheelchair-users themselves feel:

‘A wheelchair is freeing, not confining, (the reason many wheelchair users hate to be described as ‘wheelchair bound’ or ‘confined to a wheelchair’). It is a devise that supplements lost leg muscle exactly as eye glasses replace lost vision. The right ‘assistive device’ can turn passive patients into independent consumers, able to go to school, work, rear families and live on their own.’

Shapiro (1993:219)

In fact, the majority of wheelchair-users view their chair positively (Sapey et al: 2005), often perceiving them to be:

‘..... a symbol of freedom not confinement. They are an alternative to walking and provide independence for users. My wheelchair is my best friend – I wheel it with pride. It takes me into the world...’

Slack: (1999: 3).

Whilst many wheelchair-users may have a positive self-image, non-wheelchair-users, including other disabled people often have an entirely different view regarding what it means to be disabled and to be in a wheelchair. Swain & French (2000) for example argued that able-bodied people feel ‘threatened and challenged’ by wheelchair-users who appear to be pleased and proud with whom they are (p 570).

Such fears which reflect medical and social constructions of disability may result in wheelchair-users experiencing prejudice and discrimination. An example of this was given by Walker (1995) who described the inappropriate treatment he received from an airline whilst en-route to an academic conference. Because he was travelling unaccompanied the airline deemed it appropriate to ask a number of highly personal questions. Thus it soon became clear that, like many organisations, the airline in question did 'not know culturally how to deal with disabled people' (Walker: 1995: 39).

Research suggests that attitudinal barriers are frequently encountered by disabled people, including wheelchair-users, in all areas of their lives including access education, employment and public services (Zarb:1995, Tremblay et al: 2005). It is a combination of physical, environmental and social barriers that continue to exclude wheelchair-users from mainstream society. Such barriers prevent access to: the built environment (Oliver: 1990, Walker: 1995, Tremblay et al: 2005); the external environment including the countryside (Griffin: 2002); and public transport (Heiser:1995, Reeves:1999, Pickall:2002). In addition to this a combination of medically and socially constructed barriers prevent wheelchair-users from taking part in everyday social activities (Lenney & Sercombe: 2002) thereby increasing social exclusion and isolation.

Whilst only a small minority of disabled people use a wheelchair on a permanent basis, the universally recognised wheelchair symbol means that disability is generally perceived in terms of the use of a wheelchair whilst other impairments are frequently overlooked or ignored. Despite such generalisations, the practical and environmental barriers faced by wheelchair-users are often aggravated by social ignorance and stereotypes of helplessness and dependence. Furthermore, a lack of academic study in this area reflects the hidden nature of the social isolation experienced by many wheelchair-users many of whom are excluded by a frequently hostile and inaccessible environment.

## **1.6. Concluding Points to Section**

The literature reviewed thus far has discussed some of the issues relevant to the everyday lives of disabled people in general and wheelchair-users in particular. In providing a critique of the social and medical models of disability attention has been focused upon the limitations of both. There is a clear need to develop a model of disability that encapsulates both socially and medically constructed approaches. This is particularly important given the daily experiences of disabled people. The fact that both medically and socially derived influences impact upon an individual should not be disregarded or undervalued and must be considered when investigating the experiences of disabled volunteers.

The final section of this chapter addresses this issue by developing a organising framework with which to conduct this study. It is first necessary to examine and analyse volunteering and voluntary sector literature relevant to this study.



## SECTION 2: THE VOLUNTARY SECTOR AND VOLUNTEERING

### 2.1 Conceptualising the Voluntary Sector.

#### - Definitions

The 'voluntary sector' is a complex concept that is intangible in nature and problematical to define. Difficulties in conceptualising the sector are well documented and are reflected in various explanatory labels within the literature including: 'the "third sector", the "non-profit sector", the "independent sector", the "social economy", and "non-government organisations" ' (Harris: 1998: 9). Such functional and descriptive characterisations all encapsulate the ethos of the sector thus:

'... they all have in common a focus on the way  
in which people can do things for themselves  
and for others through collective action which  
is not dominated by the state...'

Harris (1998: 9-10).

Independence from the state is frequently perceived to be one of the defining features of the sector. However, within contemporary British society, the contract and partnership culture indicative of New Public Management, which is manifested by an interdependent relationship between the state and the voluntary sector, means that any conceptualisation of the third sector as being totally independent of the state does not reflect reality (Wolch: 1990, Straw: 1998, Craig et al: 2002). Moreover, whilst much of the activity within the sector may involve people doing things for themselves, a requirement for managers of voluntary sector organisations to work in partnership with professionals from other agencies means that many rely in practice on external advice and expertise.

One of the most frequently adopted methods of conceptualising the sector is to describe it in terms of what it is not. Billis (1993) for example, described voluntary organisations as 'non-governmental and non-profit seeking' (p.156); whilst Harris (1998) argued that the voluntary sector is one sphere of public space that is occupied

by 'those organizations which are part of neither the government, for-profit (market) nor informal spheres of activity' (p.9). An American perspective was given by Van Til (2000) who asserted that the third sector is 'composed of a special category of organizations, those that are non-state and non-capitalist' (p.19).

Such traditional conceptualisations of the sector were criticised by Marshall (1996) who argued that widely held perspectives viewing the sector as being that which is 'not for profit (private) and not statutory (public) [are] unsatisfactory as [they] fail to define what the sector actually is' (p.45). Moreover, by framing the sector in negative terms such definitions fail to assert its positive nature, suggesting it is in some way secondary to the public and private sectors.

Billis (1989: 1993) provided an alternative conceptualisation of the voluntary sector describing it as an associational zone that overlapped with three other 'worlds' – government, business and personal. Billis' organisational explanation of the sector contests that much of the activity within these zones is either associated with government or private agencies or is entrepreneurial in nature. Moreover, the distinct manner in which each of the zones of activity overlaps with the others creates distinctive organisational problems within the sector. Despite such difficulties the overlap between the zones is manifested by acts of voluntarism and volunteerism across all three spheres of economic activity, and is not just restricted to the voluntary sector.

This perspective was further developed by Evers (1995) who in proposing a theory of the voluntary sector argued that it is an intermediate area placed between the market, state and private households; and by Pestoff (1992) who described the sector in terms of associations placed in the middle of the state, community and market sectors. By placing the voluntary sector in the middle of state, public and private sectors, such conceptualisations suggest that the sector is a central feature of society. Thus it is vital to the continued functioning of contemporary society.

The following paragraphs build upon the issues discussed thus far and draw attention to literature pertaining to the composition and functions of the sector.

## - **The Composition and Functions of the Voluntary Sector.**

One frequently adopted method of conceptualising the voluntary sector is to examine the manner in which it is structured. In some respects this structure is manifested by the diverse range of activities undertaken within the sector (Osborne: 1996). Such diversity was also highlighted by Wolch (1990) who drew attention to the various roles performed by individuals and organisations within the sector. Another widely used method of depicting how the voluntary sector is structured is to utilise a functional analysis. Figure 2.1, overleaf, provides a diagrammatic representation of the International Classification of Non-Profit Organisations (Salamon & Anheier: 1993).

Although Figure 2.1 does appear to be an all-encompassing functional description of the activities undertaken within the sector, it fails to incorporate the various activities undertaken by numerous grassroots and community groups. Furthermore, its classification of 'disability' as being part of the social services genre is both oversimplistic and inaccurate. Whilst organisations which provide social and welfare services to disabled people may be accurately classified as social service organisations, many organisations "of" and "for" disabled people do not fit into this classification. Such organisations provide a plethora of services based upon a wide variety of different activities including: recreation and sports; advocacy and advice; philanthropy; and campaigning for civil and human rights. Moreover, many of the other functions placed within particular groups (such as youth services, education and emergency relief) may be placed within more than one group.

**Figure 2.1: The International Classification of Non-Profit Organisations**



*Adapted from: Salamon & Anheier (1993: 190-191)*

An alternative perspective was proposed by Alcock (1996) who depicted four different types of organisations found within the voluntary sector:

- **Protective Organisations;** established by their members for the purpose of mutual support or benefit:
- **Representative Organisations;** promote or represent the self-interest of members via external activities such as campaigning:
- **Campaigning Organisations;** do not specifically act on behalf of their members but campaign on more general issues effecting large numbers of people:
- **Service Organisations;** motivated by altruism and providing services to others.

*Adapted from: Alcock (1996: 86-87)*

Whilst Brenton's five-fold functional typology distinguishes between the different types of 'social services' provided by the voluntary sector as follows:

- **The Service Providing Function:** typified by voluntary agencies that supply a service directly to people. Such services may be in the form of information, advice or support:
- **The Mutual Aid Function:** includes self-help groups that organise around a common interest. Such groups tend to be non-professional in nature and are based around specialised interests:
- **The Pressure Group Function:** based upon campaigning, lobbying and direct action as well as advocacy – aims to bring about change:
- **The Resource Function:** acts as a resource base for other organisations:
- **The Coordinating Function:** includes 'umbrella' organisations that represent other voluntary organisations – liaising between them and other public and/or private bodies:

*Adapted from: Brenton (1985: 11-13)*

Although this typology was primarily intended to categorise the activities of those organisations providing social services, it is equally applicable to other areas of activity within the voluntary sector.

## - **Conceptualising the Sector: Comment**

This section has thus far drawn attention to the complex and ambiguous nature of the voluntary sector. It has highlighted how difficult it is to define and conceptualise the sector and has argued that attempts to frame the sector within different functional typologies have failed to fully encapsulate its diverse and complex nature. It is perhaps the intangible nature of the voluntary sector that is its most distinctive feature: The sector is unique, yet diverse; it strives to remain independent of the state whilst being increasingly reliant upon various agencies of the state for funding; it acts as both a welfare ‘safety net’ whilst having to limit its services to particular groups of people. In recent years the voluntary sector has become an integral part of welfare provision within the UK. It currently provides many services previously the sole responsibility of the public sector – this is particularly so in the case of provision of social and welfare services for disabled people.

### **2.2 Volunteering & Related Concepts.**

The traditional image of volunteering is that it is undertaken by white, middle-aged, middle class women (Smith et al: 1995, Lukka & Ellis: 2001), a representation which is rooted in the philanthropic activities of middle and upper class women during the nineteenth century (Prochaska: 1988). However, recent studies suggest that whilst this may be an accurate depiction of volunteering in some fields of activity, volunteering now attracts people of both genders, many of whom originate from a wide range of social and economic backgrounds (Knapp et al: 1995, Davis Smith et al: 2004, Haddad: 2004, Hustinx & Lammertyn: 2004).

The following paragraphs provide a brief overview of the literature pertaining to volunteering, volunteerism and voluntarism. Each term is separately defined and discussed.

## - Volunteering

Often depicted as one of the most fundamental building blocks of civil society (Van Til: 2000) volunteering has recently become a ‘hot’ political issue frequently used to promote images of a cohesive and caring society (Locke & Davis Smith: 1999, ODPM: 2002, Brown: 2005, SKILL: 2005). Despite widespread political usage of the term, volunteering is a complex concept that is difficult to define (Cnaan et al: 1996). The following paragraphs draw attention to some of the most frequently utilised definitions of volunteering. Such definitions are later referred to in the methodology chapter where the term “volunteering” is operationalised for the purposes of this study.

One detailed and widely utilised definition of volunteering was proposed by the Volunteer Centre UK (1983):

‘Work undertaken on behalf of self or others  
outside the family; not directly in return for  
wages; undertaken by free choice; not required  
by the state or its agencies...’

Volunteer Centre UK (1990) in  
Davis Smith (1992: 76).

This definition was later updated to incorporate volunteering that benefited the environment:

‘Volunteering is any activity which involves spending  
time, unpaid, doing something which aims to benefit  
someone (individuals or groups) other than or in  
addition to close relatives, or to benefit the environment’

Davis Smith (1998: 13-14)

One weakness of both these definitions is that they failed to take account of differences between organised voluntary work requiring considerable personal

commitment, and one-off acts of altruism that in some respects may also be considered voluntary (Clary & Snyder: 1991).

An alternative perspective differentiated between formal volunteering and helping:

‘Volunteering is an unpaid activity which is undertaken by free choice, organised through a formal agency and done for the benefit of others, the environment or oneself. It is not the informal help given between family, friends and neighbours, nor is it work undertaken on behalf of self-help, religious or leisure based groups,’

(Sheard:1995:115-116).

In many respects this somewhat lengthy definition failed to accurately conceptualise volunteering; by discounting the activities of volunteers within self-help, religious or leisure based groups it failed to recognise the valuable work undertaken by volunteers within such groups – most of which would cease to function without volunteer labour. Moreover Sheard’s assertion that volunteering may be undertaken to benefit ‘oneself’ contradicted other recognised definitions of the term.

An alternative approach was adopted by Cnaan et al (1996) who collated 11 widely used definitions of volunteers and identified the four most frequently utilised dimensions of volunteering thus: ‘volunteering is a formally organised activity that is uncoerced, undertaken without remuneration for the benefit of others’ (1996: 372).

One difficulty in placing volunteering within the context of formal organisations is that it excludes those activities undertaken within smaller grassroots community or self-help groups. Such groups are often reliant on the goodwill of volunteers and volunteer members; many of whom freely donate their time and energy to the group on a regular basis.

The value of volunteering within smaller community groups has been depicted thus:



‘The unpaid time, freely given, of volunteers is in a sense the essence of voluntary activity. It is virtually the sole resource of many, [ ] community based organisations...’

Alcock (1996: 79).

This perception of volunteering as a valuable resource is particularly relevant when considering the activities of those community based and grassroots agencies providing activities such as childcare, luncheon clubs for the elderly and disability related activities such as wheelchair-user groups.

Volunteering then, can be seen as comprising of actions that are based upon freedom of choice and the free contribution of an individual volunteer’s time and energy. Difficulties associated with such freedom of choice are reflected in the variable and inconsistent nature of volunteering. Unlike paid employees, volunteers are not bound by legal contracts or motivated by the payment of wages (Brudney: 1990, Mason: 1996).

#### - **Volunteerism**

Volunteerism, which refers to the act of volunteering, was described by Van Til (1988) as being at the hub of all human activity including civil society. He saw it as:

‘...a quality of participation, which at any time and in any institution empowers the individual and enriches the organisational setting in which the individual is sited,’

Van Til (1988: 83).

Van Til continued to argue that volunteerism is the ‘hallmark of both an authentic person and an active society’ (1988: 83). However, in referring to the activities of the Ku Klux Klan, Van Til also drew attention to the ‘darker side of volunteerism’ and pointed out that idealists tend to assume that all volunteering is for altruistic reasons resulting in social benefit (1988: 83-85). As a social phenomenon, the secretive nature

of such 'negative' volunteerism means that it is a largely unresearched and undiscussed area of voluntary activity.

The concept of volunteerism was also discussed by Brudney (2001) who distinguished between the voluntary activities of those who contribute their time for a specific purpose (such as to acquire or hone job skills) and one-off acts of ad hoc volunteerism whereby a person reacts on a short-term basis to a specific need. Whilst this distinction differentiated between volunteerism and helping, it failed to include short-term or episodic volunteering. Such episodic volunteerism appeals to those individuals not attracted to more traditional forms of volunteering (MacDuff:2005).

In noting the instrumental nature of some volunteering activities Brudney (2001) suggested that not all voluntary work is undertaken for purely altruistic reasons. This argument was previously expressed by Smith (1981) who defined volunteerism as being 'the contribution of services, goods or money to help accomplish some desired end, without substantial coercion or direct remuneration' (p 33). Such perspectives suggest that whilst volunteerism does not always promote public good, it is usually undertaken in response to a particular situation or need. Whilst the uncoerced nature of volunteerism suggests an element of freewill, the desire to achieve a certain purpose or fulfil a predetermined goal indicates that volunteerism is not always a totally unselfish activity. Moreover, the hidden nature of negative (or darker) volunteerism means that some activities undertaken whilst volunteering may be illegal and/or immoral.

#### **- Voluntarism**

An alternative approach focuses upon the concept of voluntarism:

'Actions undertaken freely by individuals, groups or organizations that are not compelled by biological need or social convention, mandated or coerced by government, or directed principally at financial gain, regarded as beneficial by participants or larger society'

Brudney (2001: 320).

This definition differs from the conceptualisations of volunteering and volunteerism discussed thus far because it encompasses the actions of groups and organizations which Brudney believed are at the heart of many of America's pre-eminent non-profit educational, medical and cultural institutions (2001). However, Brudney's assertion *that voluntarism is not compelled by social convention or mandated by government* is not entirely accurate. Shifts in UK government policy in respect of welfare and social service-provision have meant that an increasing number of services are now provided by the voluntary sector under the terms of service-level agreements or other contracts. In this respect such services, which may be provided by volunteer labour, are mandated by government (Wolch: 1990, Straw: 1998, Craig et al: 2002).

Whilst the concept of voluntarism does include volunteerism, it also encapsulates other philanthropic actions such as donating money or other tangible goods. The degree to which this perspective is applicable to the contemporary UK voluntary sector varies greatly between voluntary organisations. That many such organisations now provide services on behalf of the state, not only brings into question their independence, but also means that many are operating for financial gain – even if that gain is not directly distributed to share-holders.

The place that voluntarism plays within society was also highlighted by Turniansky & Cwikel (1996) who described it as being 'a feeling of commitment towards society and others'. They argued that such a commitment is 'translated into an assumption of responsibility for what happens in society and a feeling that one has to take action' (1996: 303). A good example of voluntarism was seen in the immediate public response to the Tsunami disaster in December 2004 (Hawkes: 2004, BBC: 2005, Honigsbaum & Jinnan: 2005).

This part of the chapter has provided an overview of conceptualisations of volunteering, volunteerism and voluntarism. They are discussed further within the methodology section where a working definition of volunteering for the purposes of the study is proposed.

### 2.3 Volunteers' Activities

Various studies have drawn attention to the different activities undertaken by volunteers. Figure 2.2 depicts the results of the 2001 Citizenship Survey in which 3828 people were asked about their volunteering activities. The table shows the distribution of volunteers by field of interest, gender and ethnicity.

**Figure 2.2: 2001 Citizenship Survey: Participants in Formal Volunteering at least Once in Previous 12 Months by Gender: Field of Interest**



Attwood et al (2003: 104).

Figure 2.2 reveals that voluntary activity occurs in a wide-range of different areas of interest. It shows that, within the research sample, more women than men were involved in volunteering and that different numbers of each gender volunteered in similar fields of activity. For men, sports and leisure based activities were the most popular, whilst more women volunteered in children's education. Of the other popular areas of activity, males were more likely to volunteer in hobby-based activities whilst females were more likely to be involved within religious groups.

Although the numbers differed slightly, the above survey confirmed the findings of an earlier survey which found the main fields of volunteer activity were:

- Religion (28% of volunteers):
- Sports and Exercise (25%):
- Children's Education/ Schools (25%):
- Youth/ Children (Outside School) (25%):
- Health and Social Welfare (21%):
- Hobbies/ Recreation/ Arts (21%)

Lynn & Davis Smith (1991) in  
Kendall & Knapp (1996: 115).

Whilst the above studies outlined the main areas of voluntary activity they did not depict what people actually do. Figure 2.3 shows participation in volunteering by voluntary activity and gender as revealed by the Citizenship Survey (2001). This table reveals that volunteers undertake a wide variety of tasks, with raising money and organising an event or activity being the most frequently undertaken. Other popular tasks involved giving practical help, advice or information and leading a group or sitting on a committee. Women were more likely to be involved in befriending activities than men who were more likely than women to act as representatives.

**Figure 2.3: 2001 Citizenship Survey: Participants in Formal Volunteering at least Once in Previous 12 Months by Gender: Voluntary Activity.**



Attwood et al (2003: 102)

Whilst previous research has highlighted the wide range of activities undertaken by volunteers few studies have analysed the volunteering activities of disabled people.

## 2.4 Why People Volunteer

Previous studies have identified several key motivations as important factors shaping why people volunteer including: altruism; religious concerns; personal reasons such as the desire to fill spare time; and social reasons including the need to fill a perceived social gap or the desire to meet new people (Davis Smith: 1992, Fenton et al: 1993, Liao-Troth & Dunn: 1999, Wardell et al: 2000). Such studies suggest that people volunteer for a wide variety of reasons and are influenced by a complex mixture of individual altruism and personal or social motivations.

From a historical perspective Smith et al (1995) argued that during the 19<sup>th</sup> Century one of the most influential motivational factors promoting middle-class women to volunteer was the opportunity to break free from the confines of the dominant patriarchal culture. This could be seen as analogous with the experiences of disabled volunteers within contemporary society who may choose to volunteer in order to break free from the restraints of the current dominant culture in which they often feel stigmatised and alienated (Coleman: 1997, Hogan: 1999, Watson: 2003). Because there have been no previous studies analysing the motivations of disabled volunteers it is difficult to ascertain to what extent this is the case.

Although there is a notable gap in knowledge about disabled volunteers other literature has analysed the motivations of other groups of volunteers. One such study into volunteering by young people between the ages of 16 and 24 found five different motivations for getting involved. Such motivations included: a desire to gain personal satisfaction and to meet new people; social needs associated with peer group involvement and recognition; altruism, the desire to help others; the opportunity to gain work experience; and the chance to gain vocational qualifications and other rewards (Ellis: 2004). Whilst some of the above motivations are similar to those identified by previous studies (Davis Smith: 1992, Fenton et al: 1993, Liao-Troth & Dunn: 1999), the instrumental motivations expressed by the young people in respect of a desire to gain work experience or vocational qualification differ greatly from those identified in other research. However, high levels of unemployment amongst the disabled population (Oliver: 1996, Abberley: 2002, Bradley et al: 2004) means that

some of the 'work' related motivations of young people may be similar to those of disabled volunteers.

Research conducted by Horne and Broadbridge (1994) examined the motivations of volunteers working in a Scottish charity shop. The reasons for volunteering uncovered during this study were similar to those described in Figure 2.4 overleaf, with the most popular reason being to meet people and make friends (32.6%). Such social motivations may reflect the age of the volunteers included within the study. A more recent study by Yeung (2004) investigating the connection between religiosity, volunteering and social capital in Finland and also identified social reasons why people volunteered: a desire to spend time with peers; concern for others; and a willingness to help others.

An alternative approach which analysed individual volunteer's initial reasons for volunteering is depicted overleaf in Figure 2.4. This study found that being asked to get involved was an important motivational factor (Davis Smith: 1992). Other reasons for getting involved were associated with altruism, personal circumstances and social motivations.

It is evident from these studies that motivations for volunteering vary greatly and that most people are motivated to volunteer by a mixture of different personal and social reasons. Whilst altruism may play a small part in promoting volunteering, other reasons such as enjoyment or the desire to utilise or gain a particular skill are equally important.

The studies included within this section have not identified which, if any, of the volunteer participants were living with chronic illness or disability. Thus, the reasons why disabled people volunteer remain unresearched and undocumented.



**Figure 2.4: Why Volunteer? Initial Motivations as Described by Volunteers.**



The Volunteer Centre UK (1990): In Davis Smith (1992: 84)

## **2.5. Benefits of Volunteering**

Although the motivational literature identifies the positive aspects of volunteering for the volunteers themselves, the benefits for the recipients of volunteerism are generally more difficult to determine. Studies by Hustinx & Lammertyn (2004), Yeung (2004) and Hadden (2004) all suggested that volunteering benefits the individual volunteers themselves, the organisations within which volunteers are engaged and the different communities in which the voluntary work takes place.

Another study identified the beneficiaries of volunteering within a Canadian hospital: various hospitals and hospital departments in which the volunteers were engaged; users of the hospital in which the volunteers were engaged; and the volunteers themselves who benefited from the opportunity to socialise whilst acquiring new skills (Handy & Srinivasan: 2004).

From these studies it would appear that in addition to benefiting the organisations in which volunteers are engaged, voluntary action also benefits the service-users of those organisations, the wider community and the volunteers themselves.

## **2.6. Barriers to Volunteering.**

Whilst literature pertaining to the benefits of volunteering is somewhat limited, there is a notable body of literature examining the barriers to volunteering. One such study by Thomas & Finch (1990) found that the most frequently described barrier to volunteering was the stereotypical image associated with volunteering:

‘Many of the non-volunteers had a negative view about the type of people who become volunteers ..... “do gooders”... volunteering was done for altruistic [reasons] or solely for personal gain.’

Thomas & Finch (1990: 58)

Such negative stereotypical images were also identified as an obstacle to volunteering by Hannagan (1992) and by Davis Smith et al (2004) who argued that:

‘In the UK, a long standing stereotype of volunteering has been that it is a formal, organisational-based activity that is carried out by white, middle class and middle aged people.’

Davis Smith et al (2004: 24)

An earlier study identified various psychological and attitudinal barriers to volunteering for people from black and ethnic minority groups (Obaze:1992). This perspective was also supported by Hedley & Davis Smith (1992) who argued that other factors such as lower social class, gender and age also impact upon volunteerism:

‘Fewer people from lower socio-economic groups volunteer; fewer men volunteer; and fewer people from ethnic minorities volunteer...’

Hedley & Davis Smith (1992: 5)

An alternative method of identifying barriers to volunteering is to examine why regular volunteers stopped volunteering. A study by Davis Smith (1998) found that the most frequent reason for withdrawing from volunteering was that previous voluntary activities were no longer deemed relevant to the individual participants. The second most frequently expressed reason for ceasing to volunteer was linked to geographic location – the volunteers had moved away from the area in which they had previously participated. Other reasons for stopping volunteering included health related difficulties and problems finding the time to spare (Davis Smith: 1998).

From these studies it is possible to speculate that the barriers to volunteering take three main forms; psychological, cultural and practical. Psychological barriers are related to self-image and personal choice; whilst cultural barriers are linked to social class, gender and ethnicity. Practical barriers which, from the literature, appear to be the most difficult to overcome, reflect issues related to finance and geography.

It is also evident that difficulties encountered by one individual may not necessarily prevent others from volunteering. However, the stereotypical images associated with volunteering may prevent disabled people from becoming involved – particularly as disability is associated with low socio-economic status (Townsend: 1979; 1993, Bradley et al: 2004, O’Grady et al: 2004). Moreover, disabled people are usually perceived to be the recipients rather than the givers of voluntary assistance (Barnes et al: 1999). Such stereotypes may discourage non-disabled managers from offering voluntary posts to potential volunteers whom they perceive to be incapacitated because of a particular impairment or disability.

## **2.7 Managing Volunteers**

The uncoerced nature of volunteering suggests that unlike paid employees, volunteers are free to come and go as they please without fear of financial penalty or other retribution. This can result in a somewhat tentative relationship between volunteers and the organisations in which they are involved:

‘By definition volunteers have more options than a typical employee. At will volunteers may enter an organisation or depart it, and vary the amount of resources they contribute.’

Mason (1996: 216)

The tenuous nature of organisational and volunteer relationships was also noted by Brudney (1990) who argued that volunteers ‘can be far more selective in their choice of activities than paid workers’ (p 109). He continued:

‘Volunteers are less dependant than paid staff on the agency, and for this reason, managerial styles must adjust to accommodate a more autonomous workforce.’

Brudney (1990: 112)

The fact that volunteers are not subjected to the normal rules of paid employment would suggest that those responsible for their management need to be skilled communicators as well as administrators. For those organisations totally or partially reliant upon the utilisation of voluntary labour the importance of skilled volunteer management has long been recognised:

‘It is very necessary for any service using volunteers that there should be some form of organisation of their work. By organisation we mean the provision of a system within and through which the volunteers are enabled to carry out their work..... effectively, smoothly and with satisfaction to their clients, themselves and the services which need their help.’

Aves (1969: 93)

The importance of formalised policies and procedures was also highlighted by Bowgett et al (2002) who provided detailed guidance regarding the management of volunteers. Such guidance included advice relating to organisational administration and volunteer management.

Whilst the importance of formal organisation to volunteer management is reflected within numerous conceptualisations of volunteering (Alcock: 1996, Cnaan et al: 1996, Davis Smith: 1998) formal volunteer management is not without criticism:

‘Critics have argued that the new management culture imported from the paid workplace is inappropriate and at odds with the culture and values of volunteering. Moreover, the heavy emphasis on formal management processes has been held to deter volunteers from marginalized groups from coming forward...’

Davis Smith (1996: 187)

Such criticisms of volunteer management fail to take into account the perspectives of the volunteers themselves many of whom prefer to have organisational cohesion and managerial direction including defined tasks, roles and job descriptions (Tihanyi: 1991, Mason:1996).

## **2.8 Concluding Points to Section**

This section has analysed some of the literature pertaining to the voluntary sector, volunteering, volunteerism and voluntarism. It has drawn attention to the ambiguous nature of the voluntary sector and has discussed the complex nature of volunteering and volunteerism. The following section builds upon this by drawing attention to the literature about disability and volunteering.

## SECTION 3: VOLUNTEERING AND DISABILITY

### 3.1 Gap in Academic Knowledge

Research studies examining the daily living experiences of wheelchair-users are extremely limited: moreover there exists a notable deficit in the academic literature linking the concepts of volunteering and disability generally. Previous research into the experiences of disabled people in relation to the voluntary sector tends to focus upon non-disabled people providing services to those living with a disability; whilst studies into volunteering have tended to overlook the possibility that volunteering might be an activity undertaken by those perceived to be severely physically disabled.

Thus there exists a considerable gap in the academic literature regarding the experiences of disabled volunteers; furthermore, previous literature analysing the experiences of wheelchair-users who volunteer is non-existent. This study is therefore unique in that it provides a detailed analysis of the volunteering experiences of a group of wheelchair-users within Great Britain. However, the lack of previous studies means that only a small amount of literature relates to both disability and the voluntary sector. This section now provides a review of such literature commencing with a critical discussion about disability organisations.

### 3.2 Disability Organisations

Oliver (1990) argued that disability organisations within the contemporary UK are divided into two distinct groups; organisations *of* disabled people and organisations *for* disabled people. It is often postulated that each type of organisations reflects a different ideological stance towards disability:

‘... in the case of disability organizations there is a veritable chasm between traditional voluntary organisations and contemporary democratic and representative organisations of disabled people, committed to the social model...’

Barnes et al: (1999: 172)

In developing a typology of disability organisations Oliver (1997) argued that such differences are manifested both in the organisational ethos adopted by particular organisations and in the activities undertaken. This typology, which is depicted below in Figure 2.5, distinguished between the activities undertaken by organisations of and for disabled people and identified 5 distinct type of organisation:

**Figure 2.5: Typology of Disability Organisations**



*Adapted from: Oliver (1997:42-45)*

Although this typology was intended to be all-encompassing it did not incorporate the activities undertaken in the numerous organisations and agencies in which disabled and non-disabled people work together to promote a particular disability related cause. Another weakness was its failure to acknowledge that the boundaries between organisations of and for disabled people are becoming increasingly blurred as some of the more 'traditional' organisations endeavour to become representative of the populations they 'serve'.

Whilst a few of the larger organisations for disabled people are in the process of changing their philosophy and management structures, many such organisations

continue to be managed and governed by non-disabled professionals and as such are often criticised as being philanthropic and patriarchal in nature (Oliver: 1990, Barnes et al: 1999). Some writers argue that the ideological nature of such traditional charitable organisations reinforces negative stereotypes of helplessness and dependence associated with disability (Morris:1991, Barnes et al:1999). Moreover, many organisations for disabled people tend to concentrate on one particular group of disabled people; consequently their ideology and ethos is usually impairment focused.

Organisations of disabled people have their roots in the American disability movement of the 1960's and 70's (Charlton: 2000). Oliver (1990) argued that such organisations promote equality and equity whilst providing disabled people with the opportunity to become involved in political and campaigning issues. Although many disabled peoples' organisations were originally established out of a desire to change public and political perceptions of disability, the politicalisation of the disability movement is the subject of much debate:

[The disability movement] 'is neither one thing nor the other; in fact it is a movement which incorporates both revolutionary and reformist politics...'

Campbell & Oliver (1996: 179)

The ambiguous nature of disability means that not all sections of the disabled population either engage with, or are represented by, the 'disability movement'. Rather than criticise the lack of representation within the disability movement leading disability theorists contest that it is better for disabled people to be represented by non-representative disabled activists and academics (such as themselves) than by non-disabled medical professionals, politicians, voluntary sector managers and civil servants (Morris: 1991, Barnes et al: 1999). One difficulty with this perspective is that it fails to acknowledge the interdependent nature of relationships between disabled and non disabled people in disability politics (Goodley: 2003).

The effectiveness that voluntary sector disability organisations have in promoting equality and equity within contemporary society is not recorded in the academic literature. In fact, the activities of volunteers within such organisations remains a



largely unknown phenomenon. It is anticipated that this study will go some way to addressing this issue.

### **3.3 Self-Help Groups.**

Many of the more established organisations of disabled people were originally founded in the 1980's by a small groups of disabled people with the aim of challenging political policies and social attitudes towards disability. (Morris: 1991, Charlton: 2000). Such organisations, which have since grown extensively, empowered and supported disabled people whilst raising public and political awareness (Barnes et al: 1999). In discussing self-help groups, Kendall & Knapp (1996) argued that they consist of a 'group of individuals who experience a common problem [ ] and who simultaneously help and are helped' (p 70). Such 'common problems' attracting members of self-help groups are frequently associated with medical conditions or other health related problems:

'...self-help groups appear to be groups of people with a common condition or problem – a chronic disease or disability, an addiction or phobia or some situation in their life with which they are less than happy...'

Richardson & Goodman (1983: 2)

'Self-help groups are formed of people who share a particular condition or problem. Within these groups, there is no meaningful distinction between givers and receivers, the relationship is reciprocal.'

(Rochester: 1992: 121)

Thus self-help groups are based upon a culture a social reciprocity and mutual support.

A study by Bond et al (1979) drew attention to the valuable role played by medically related self-help groups in assisting disabled people come to terms with disability and

deal with the symptoms associated with their medical conditions. The ethos of self-help organisations is generally manifested in a culture of empathy and support. The value of such support to those people seeking advice and reassurance following the onset of, or sudden deterioration in, a disabled condition whilst being difficult to quantify, is nonetheless important (Hatch: 2000, Robinson et al: 2000). The diverse range of activities undertaken within medically and impairment related self-help groups was highlighted by Richardson (1983) who drew attention to five separate kinds of help provided within such groups: 'emotional support; information and advice; direct services; social activities; and pressure group activities' (p 33). The degree to which volunteers are involved in offering such services is not recorded in the literature.

The diverse range of activities undertaken by organisations of disabled people in relation to self-help activities and governance has resulted in the disabled members of such groups reassessing and challenging medicalised and paternalistic approaches to service provision (Oliver: 1990). By empowering their members, self-help organisations, led by service users, have promoted new approaches to service delivery (Taylor: 1997b). Such changes in service delivery are mirrored by changes in how disabled people view both themselves and what they expect from the services provided. For those health care professionals responsible for providing services to disabled people such changes in attitude may prove to be both disconcerting and challenging (Wistow & Barnes:1993). Furthermore, studies have found that many such professionals, unable to comprehend service-user empowerment, question whether representatives of user-groups are too articulate to be truly reflective of 'real' service-users (Bewley & Glendinning: 1994, Hastins et al: 1996). Although such studies identified attitudinal difficulties encountered by disabled people in the course of volunteering within self-help groups, they did not consider to what degree resistance from professionals might actively impinge upon disabled people becoming involved and might thus form a potential barrier to participation.

Whilst there is in existence considerable literature examining the nature of activities undertaken within self-help and user-led groups, there remains a significant deficit in research analysing volunteerism within such groups – particularly if that volunteerism is undertaken by disabled people. There is also a considerable gap in knowledge about

the services provided to disabled people by disabled members of organisations of disabled people including self-help groups.

### **3.4 Disabled Volunteers & the Generic Volunteering Literature**

The traditional image of volunteerism as comprising of those who ‘help’ and those who are ‘helped’ places disabled people in the role of recipients rather than providers of volunteering (SKILL: 2005). Moreover, health related issues associated with chronic illness and disability are perceived to be a determining factor influencing an individuals ability to volunteer:

‘One third measure of human capital is health status... The ability to do volunteer work, or to assist those in need of help, depends on one’s physical capabilities...’

Wilson & Musick (1997: 699).

Although considerable research has been conducted analysing the experiences and motivations of non-disabled volunteers, very little research has been undertaken examining the experiences of disabled volunteers, thus it is necessary to consider to what degree some of the generic volunteering literature may apply to the experiences of disabled people. One study by Granville (2004) which examined the experiences of older volunteers engaged in intergenerational school based activities drew some interesting conclusions which may be applicable to wheelchair-user who volunteer. Although this study did not specifically note how many of the volunteers were disabled, some of the volunteers’ experiences discussed in the paper in relation to the barriers to volunteering and motivation for volunteering may be analogous to the experiences of disabled volunteers. More specifically, one of the barriers to volunteering identified by Granville, reflective of negative social attitudes and stereotypes towards older people, may well be similar to the barriers to volunteering experienced by disabled people (2004). The literature suggests that disabled people are excluded and isolated from mainstream society by negative social attitudes and stereotypes towards disability (Oliver: 1990, 1996, Napolitano: 1996, Barnes: 1998,

2000), thus it is reasonable to postulate that they may also be excluded from volunteering by such attitudes and prejudices.

In discussing the motivations of the older volunteers, Granville (2004), noted that they were similar to those identified in previous generic studies of volunteering (reciprocity, the opportunity to contribute to society, altruism and other individually centred benefits). The lack of previous research into disabled volunteers means that it is difficult to envisage to what degree such motivations apply to wheelchair-users who volunteer. However, a study into volunteer motivation by Brooks (2002), which argued that volunteer motivation is reflective of certain cultural orientations, may be applicable when considering the reasons why disabled people volunteer. Brooks highlighted the complex and multifaceted nature of volunteerism and suggested that individual's motivations for volunteering reflect intricate and introspective reasoning that is both culturally sensitive yet individually grounded (2002).

A study by Howlett (2004) which analysed the literature about the volunteering activities of people with mental health problems may also, in some respects, be applicable to the experiences of disabled volunteers. Howlett's (2004) argument that lack of previous social investigation in this area suggests that volunteering by those living with mental health problems and disabilities is a largely 'invisible' phenomenon. Like physically disabled people, those with mental health problems are simply not conceptualised as being able to volunteer. Thus, stereotypical views of volunteering being an activity that is mainly undertaken by white, middle-class, physically and mentally able individuals remains on the whole, unchallenged.

One exception to this was a study undertaken by Roker et al (1998) who sought to challenge the stereotypical image of young disabled people in the UK by exploring the different types of voluntary and campaigning activities they were involved in. In order to do this Roker et al (1998) divided their study into two halves; the first consisted of a national survey exploring the different types of voluntary and campaigning activities young disabled people were involved in; the second took the form of two case studies in which the researchers adopted ethnographic methods such as participant observation and qualitative interviews. This research, which considered the experiences of young disabled people with both physical and mental impairments,

revealed that far from being the passive recipients of care, young disabled people are actively involved in various types of voluntary work and are thus making a considerable contribution to their communities.

Whilst Roker et al's (1998) study did highlight the volunteering experiences of young disabled people, it did so from the perspectives of their carers and helpers. Thus, despite its positive outcomes, this study's methodological approach reinforced negative stereotypes of helplessness and dependence associated with disability. Moreover, the fact that the researchers ignored the personal perspectives of those people whose views the study claimed to represent brings into questions the validity of the study findings.

Stalker et al (1999) analysed the correlation between theory and practice in NHS and Social Services based learning-disability user-groups and voluntary organisations providing services for people living with learning disabilities. This study aimed to explore the implications of the 'learning society' for adults with learning difficulties. However, as with the study by Roker et al (1998) one major weakness with this work was that it failed to encapsulate the personal perspectives of disabled people themselves – but instead focused solely on the views of the professionals providing services for them. Such research is typical of many studies purporting to represent the views of disabled people; rather than investigate the perspectives of disabled people themselves much social research has concentrated upon the viewpoints and opinions of non-disabled professionals and carers.

Barlow & Hainsworth (2001) took a different stance and looked at the motivations of older volunteers training to become lay-leaders on a 'Challenging Arthritis' course. All of the volunteers in this study had arthritis, and all were of retirement age. Their study found that volunteering in 'later life' can help compensate for the negative health and social impacts often associated with retirement or growing older. Another study, which identified the positive health benefits of volunteering by older people living with depression, was conducted by Musick & Wilson (2003) who found that prolonged volunteerism had positive psychological benefits for those people over the age of 65. Although these two studies looked at the experiences of older volunteers, they did not draw a distinction between those volunteers who perceived themselves to

be disabled and those who did not. Thus it is not possible to draw any conclusion regarding the experiences of disabled volunteers from them.

A recent study conducted by Davis Smith et al (2004) analysed the volunteering experiences of three different 'socially excluded' groups of people: ex-offenders, people from ethnic minorities, and people with living with disabilities. Although this study identified various psychological and practical barriers to volunteering its presumption that disability equates to social exclusion was a considerable weakness. Moreover, it failed to acknowledge that as volunteers, the disabled participants included within the study were unlikely to perceive themselves as socially excluded.

Despite such weaknesses the study undertaken by Davis et al (2004) was unusual in that there remains a large gap in academic knowledge pertaining to the volunteering experiences of disabled people. By providing a detailed analysis of the volunteering experiences of wheelchair-users, this study aims to address this gap.

### **3.5 Concluding Remarks to Section**

This section has drawn attention to the academic literature relating to disability and volunteering. Much of that literature focuses upon user-led and self-help organisations – although this does not necessarily relate only to disability. The notable gap in literature pertaining to the experiences of disabled volunteers reflects frequently held conceptualisations of disabled people as being the recipients rather than the instigators of voluntary action. This is particularly the case when considering the experiences of wheelchair-users – who are rarely perceived to be able to volunteer. This thesis is the first study to provide a detailed analysis of the volunteering experiences of wheelchair-users.

The final section of this chapter now draws together the literature discussed in the previous three sections and develops a organising framework the empirical study.

## SECTION 4: DEVELOPING A FRAMEWORK WITH WHICH TO ANALYSE THE EXPERIENCES OF DISABLED VOLUNTEERS

The literature reviewed in section 2 of this chapter drew attention to the fact that, within contemporary society, there are two dominant approaches to disability – the medical and social models. These two seemingly opposite perspectives conceptualise disability in terms of it being medically or socially constructed. Figure 2.6 below summarises the main points of each model; whilst Figure 2.7 overleaf assesses each model's appropriateness as an ideological and theoretical approach for use within this study:

**Figure 2.6: Conceptualising Disability: Two Dominant Approaches**



Adapted from: Oliver (1990), Moon & Gillespie (1995); Finkelstein & Stuart (1996) Jakubowicz & Meekosha (2003).

**Figure 2.7: Assessment of Each Model’s Suitability for Use Within the Study.**

	<b>SOCIAL MODEL</b>	<b>MEDICAL MODEL</b>
<b>APPROPRIATENESS FOR USE WITHIN STUDY:</b>	<p><b>UNSUITABLE AS A SINGLE APPROACH BECAUSE THIS MODEL:</b></p> <ol style="list-style-type: none"> <li>1. Ignores experiences of those living with chronic or degenerative medical conditions (which are not socially constructed).</li> <li>2. Does not acknowledge that even if all the socially constructed barriers were removed some people would still be disabled by their medical conditions</li> <li>3. Assumes homogeneity of disabled people’s experience.</li> </ol>	<p><b>UNSUITABLE AS A SINGLE APPROACH BECAUSE THIS MODEL:</b></p> <ol style="list-style-type: none"> <li>1. Ignores socially constructed causes of disability.</li> <li>2. Places responsibility for disability onto individual disabled people and believes disadvantages caused by disability can only be overcome by medical intervention.</li> <li>3. Assumes homogeneity of disabled peoples experiences</li> </ol>

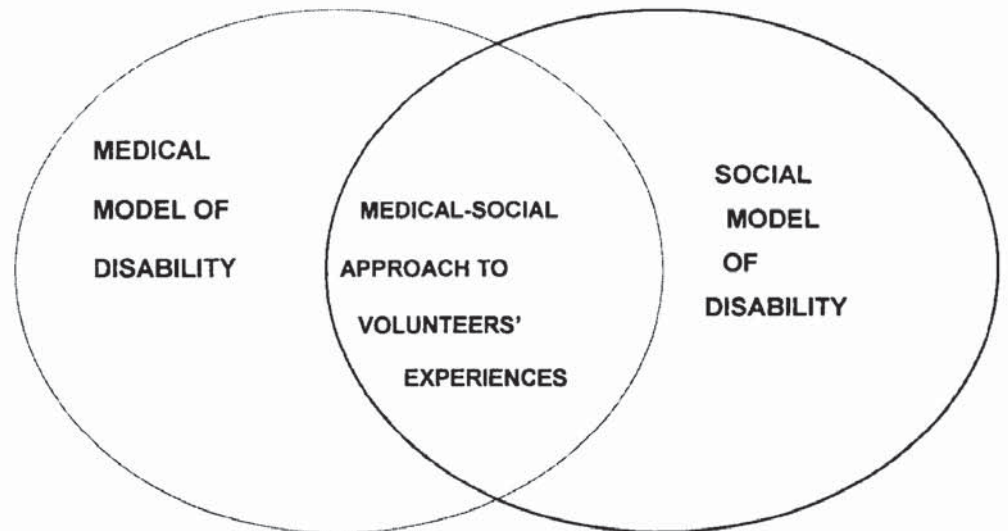
Both socially and medically constructed approaches to disability tend to articulate any links between volunteering and disability in terms of *helper* (the volunteer) and *helped* (the disabled person) (Morris: 1993, Blakemore: 2002, Swain & French: 2002). Consequently, disabled people are usually conceptualised as being the recipients rather than the providers of voluntary services (SKILL: 2005). This frequently held perception has not been adequately challenged within either the voluntary sector or disability literature.

As single approaches neither the social or medical model is appropriate for use with this study as neither one provides a comprehensive explanatory framework of the experiences of disabled people within contemporary society. The medical model of disability fails to incorporate socially constructed barriers and issues; whilst the social model does not account for medically rooted difficulties and barriers.



Thus it is proposed to develop an approach that takes into account the main points of both perspectives. Figure 2.8 depicts a method of organising the main points made in the literature in such a way that suggests the impact of both medically and socially constructed factors may act together to influence the experiences of disabled volunteers. This suggests that in addition to taking account of social and medical influences, an approach which also accepts that the volunteers' experiences may be influenced simultaneously by a combination of socially and medically constructed factors would be an appropriate starting point for investigating and analysing the experiences of disabled volunteers:

**Figure 2.8: The Medical-Social Approach to Disability: An 'Organising Framework':**



The above framework has been developed for use within this study to encapsulate, analyse and explain the volunteering experiences of disabled people. In developing this approach several methodological questions were raised in respect of whether it represents a 'conceptual' or 'organising' framework. The literature suggests that concepts depicted within a conceptual framework are linked by a causal relationship

and are thus interconnected (Cepeda & Martin: 2005, De Dominico & Morrison: 2004). Conversely, the organising framework depicted in figure 2.8 is heuristic in nature, allowing the research themes to be organised and managed, and the diametrically opposed social and medical influences on disabled volunteers to be considered both separately and concurrently.

Thus, the organising framework brings together two seemingly opposed perspectives by considering all of the medical and social determinants of disability. In addition to this the approach detailed within the approach accounts for the heterogeneous nature of the disabled population in relation to impairment and illness whilst accepting the homogeneous nature of experiences reflecting socially constructed barriers. Basically, it acknowledges that whilst many socially constructed barriers to society may result in shared experiences of disability discrimination or negative social attitudes towards disability, health related barriers such as illness, fatigue and pain are always individually experienced and perceived. The main characteristics of this framework are:

1. An acknowledgement that the experiences of disabled people are influenced by medically and socially constructed factors, and that disabled volunteers may be influenced simultaneously by a combination of both socially and medically constructed barriers and issues.
2. The idea that experiences of disabled people in general, and disabled volunteers in particular, are influenced by a complex amalgamation of: individual health related factors; medically derived belief systems; individually held beliefs and attitudes; social and economic barriers; practical and environmental barriers; socially constructed attitudinal barriers and stereotypes.
3. The idea that impairments are caused by illness, disease or injury. The approaches depicted within the organising framework suggest that whilst not all people living with impairments are disabled, all disabled people are living with an impairment.
4. The idea that disability is a permanent, not a temporary state. It does not include those people who will recover from their impairments within a short

period of time, ie. less than 9 months (Burchardt: 2000, Paterson: 2001) – but does include people living with relapsing/remitting medical conditions.

5. Because this framework has been developed as a research-tool with which to explore the experiences of physically disabled volunteers, it does not incorporate issues surrounding mental or psychological health – as these are usually framed within psychological conceptualisations of disability and health (Smith: 1999, Taylor: 2003).

The medical, social and medical-social approach depicted within the organising framework is utilised throughout this thesis to investigate and analyse the experiences of wheelchair-users who volunteer. The research protocol (Appendix 3, page X), upon which the interview questions were based, reflects the main strands of the framework and includes questions about medical and social influences on the experiences of the research participants as well as other more generic volunteering questions. Whilst the analysis of the volunteers' experiences given in chapter 6 reveals that the experiences of the disabled volunteers interviewed were indeed influenced by a complex mixture of medical, social and medical-social influences. In summary, the 'organising' framework depicted in figure 2.8 both allows the large quantities of secondary disability related literature to be organised whilst providing the ideal framework upon which this thesis built.

## **CONTRIBUTION TO KNOWLEDGE: CHAPTER 2**

By drawing together the medical and social models of disability and by suggesting a combined medical-social approach to disability, this chapter contributes to disability literature. Furthermore, because the approach within the organising framework has been developed in order to investigate and analyse the experiences of disabled volunteers the chapter also adds to voluntary sector literature.

## CONCLUSION TO CHAPTER 2

This chapter began by drawing attention to the two dominant conceptualisations of disability used within contemporary society. Each of these is a reflection of a particular perspective; the medical model reflects the ethos of the medical profession; whilst the social model promotes the viewpoint of some disabled activists and academics. Both fail to fully encapsulate the experiences of ordinary disabled people, the majority of whom are living with degenerative illnesses and are constantly frustrated both by societal barriers and the medical profession's indifference to such barriers.

The distinct nature of volunteering by disabled people made it particularly important to develop a organising framework with which to analyse the experiences of wheelchair-users who volunteer. In developing such a framework and by proposing to use medical, social and medical-social approaches to disability this chapter acknowledges the manner in which disabled people are influenced by both medically and socially derived factors. Although this approach is depicted by a Venn diagram, the influence of each 'circle of influence' is not necessarily static. It is also acknowledged that even if all of the socially derived barriers were removed, the majority of people living with impairments would still be disabled by their medical condition.

In conclusion, this literature review has identified a considerable gap in the academic literature pertaining to the volunteering experiences of disabled people in general and wheelchair-users in particular. Thus, by analysing the experiences of wheelchair-users who volunteer, it is anticipated that this study will make a sizeable contribution to both voluntary sector and disability literature.

## **SUMMARY OF CHAPTER 2:**

This chapter began by outlining the medical and social models of disability. A critique of both models was given before other issues relevant to disabled volunteers were discussed such as the stigmatisation of disability and employment of disabled people. Issues pertaining to wheelchair-users were also examined.

The second section of this chapter focused upon literature pertaining to the voluntary sector and volunteering. After conceptualising the voluntary sector, attention was drawn to the various definitions of volunteering. Literature focusing upon volunteer activities and motivations was then discussed; followed by an examination of the benefits of, and barriers to, volunteering. The final part of the second section focused upon volunteer management.

The third section of this chapter commenced by noting that literature relating to both volunteering and disability is somewhat scarce. It identified a gap in knowledge pertaining to the experiences of wheelchair-users who volunteer and highlighted the literature pertaining to disability and volunteering.

The final section of this chapter drew together the literature reviewed in the previous sections to develop an organising framework for this study. The approach detailed within the organising framework contributes to academic knowledge by suggesting that the experiences of disabled volunteers are affected by both socially and medically constructed factors.

## **CHAPTER 3: METHODOLOGY**

### **INTRODUCTION**

The aim of this chapter is to provide a broad overview of the methodology utilised during the course of this study. The chapter is divided into two main sections; the first concentrating on pre-fieldwork and the second on the methodology adopted during the pilot and fieldwork stages of the research.

This chapter commences by noting the lack of previous studies in this area. Difficulties caused by a lack of previous literature meant that it was necessary to establish which areas of the literature were relevant to the experiences of disabled people before the fieldwork could commence. Thus an extensive period of pre-fieldwork was necessary. Following the pre-fieldwork, the research questions which had emerged during the literature review were refined and the main research question proposed: *What are the volunteering experiences of those disabled people who need to use a wheelchair whilst volunteering?* In addition to the main research question, four sub-research questions also emerged out of the literature review and are thus also described within this chapter. Other matters covered in the pre-fieldwork phase of the study included the conceptualisation of volunteering for the purposes of the study and the development of a table categorising wheelchairs and wheelchair usage. Issues of epistemology and ontology are also discussed.

The second section of this chapter focuses on methodological issues encountered during the pilot study, fieldwork and analysis. Having decided to adopt an approach based upon grounded theory methodology (Glaser & Strauss: 1968), the sampling framework and strategies were then developed. The research techniques proposed during the early stages of the research process are discussed with particular attention being paid to the lessons learned during the pilot study.

This chapter concludes by discussing the issues raised and problems encountered during the fieldwork stage of the research process. It also draws attention to the difficulties encountered in transcribing and analysing the data.

## **SECTION 1: PRE-PILOT WORK**

In discussing case-study research, Yin (1993) highlighted the importance of extensive preparation and research design. Many of the points raised by Yin (1993) concerning problems of definition and the setting of objectives are equally important regardless of methodological approach. Thus, each stage of the research process was considered in great depth with attention paid to detail and logic.

In the course of conducting the literature review it soon became evident that previous studies examining the volunteering experiences of disabled people are extremely limited. Moreover, the generic volunteering literature was, on the whole, mostly not directly relevant to this study. The large amount of literature pertaining to disability made it difficult to determine which areas of the disability literature were relevant to this study. It was therefore decided that the most logical way of establishing what literature was applicable to the specific experiences of disabled volunteers would be to undertake a period of pre-fieldwork within the voluntary sector. Thus, in the early stages of the research process a considerable amount of time was spent consulting with disabled volunteers and volunteer managers, as well as with other professionals (both disabled and non-disabled) responsible for the management of disabled volunteers. A list of the organisations visited and individuals consulted during this period is included in Appendix 1 (page 312).

### **1.1. The Research Question(s)**

Having established which areas of the literature were likely to be more relevant to the experiences of disabled volunteers the initial literature review was undertaken. It was from this review that the following research question emerged:

- What are the volunteering experiences of those disabled people who need to use a wheelchair whilst volunteering?

The sub-research questions, which also emerged out of the literature review, take a wider perspective and build upon the theories discussed in the formulation of the organising framework:

- How are the volunteers' experiences shaped by medical influences?
- How are the volunteers' experiences shaped by social influences?
- How are the volunteers' experiences shaped by a combination of medical and social influences?
- What other issues impact upon the experiences of wheelchair-users who volunteer?

In general, then, the aim was to describe, analyse and explain the experiences of wheelchair-users who volunteer.

## **1.2. Defining Volunteering for the Study:**

The complex and multifarious nature of volunteering is discussed in section 2.2 of the previous chapter (pp47-50) in which various definitions of the term are reviewed. For the purposes of this study a synthesis of the definitions outlined in chapter 2 was utilised and a working definition of volunteering developed:

‘Volunteering is an uncoerced activity that is formally arranged. It involves spending time, unpaid, doing something which aims to benefit someone (other than, or in addition to, close relatives) or to benefit the environment. It includes activities undertaken within both formal organisations and smaller grassroots agencies and groups.’

*Adapted from: Alcock (1996) Cnaan et al:(1996)*

Davis Smith (1998)

Having conceptualised volunteering it was then necessary to examine the meaning of the term ‘wheelchair-user’.



### 1.3. Defining Wheelchairs & Wheelchair-Users for the Study.

There are currently over 1 million wheelchair and mobility scooter users in the UK 70% of whom are over 60 years of age (Chairpower: 2005). Of these, over 640,000 are believed to be people living with severe mobility impairments (*emPOWER*: 2004). Despite these relatively high numbers there have been no previous academic attempts to define the term wheelchair-user. Taking a literal approach a wheelchair-user may be defined simply as a person who uses a wheelchair. However, the fact that a person is seen to be sitting in a wheelchair does not necessarily mean they have a permanent disability or frequently need to use that wheelchair as means of a mobility (they may simply have a broken toe). Thus the basic conceptualisation of a wheelchair-user as being ‘a person in a wheelchair’ is not suitable for use within this study. It is more practical and acceptable to describe why people use wheelchairs:

‘Wheelchairs are what their name suggests – chairs with four wheels that can move in all directions. People use wheelchairs if they find walking difficult or if they cannot walk. A wheelchair is a piece of equipment to help you get around, just as glasses help people see...’

Spilsbury:2002:4

This definition, which was taken from a children’s educational text, provides a simplistic functional description of a wheelchair. However, it is insufficiently detailed for use within this study as it does not differentiate between those who use powered wheelchairs and those who use manually propelled wheelchairs. Furthermore, it fails to draw attention to the fact that some wheelchair-users need the assistance of a third party in order to mobilise. Thus, it was decided that in order to fully understand the concept of a ‘wheelchair-user’ a working definition of the terms wheelchair and wheelchair-usage should be developed for the purposes of this study. Figure 3.1 overleaf identifies 5 distinct categories of wheelchairs and wheelchair usages:

**Figure 3.1: Categories of Wheelchairs and Usages:**



*Adapted from: empower (2004) Best Practice Framework  
'Guidance on Wheelchair Prescriptions'*

This study included volunteers who needed to use one of the first four categories of wheelchair in order to facilitate their mobility whilst volunteering. People who used electrically powered scooters were included only if they permanently needed to use a mobility device, and chose to use a scooter rather than wheelchair. The reason for this was that mobility scooters are not supplied by the NHS anywhere within the UK (Chairpower: 2005) but are instead purchased by individual users. From my own

experiences I am aware that some scooter-users are not disabled but choose to use a scooter as a convenient mode of transportation (they are able park and walk without the assistance of mobility aids), such individuals were not included within the study. Further considerations regarding the selection of participants are discussed later in this chapter under the heading ‘sampling techniques and strategies’.

#### **1.4 Epistemological and Ontological Considerations**

Jary & Jary (1991) defined epistemology as ‘the branch of philosophy concerned with the theory (or theories) of knowledge, which seeks to inform us how we know the world’ (p201). Thus, from a personal perspective, epistemological influences impacting upon this study reflect the theoretical knowledge I have gained during childhood and adulthood both during formal education and also during my private and work-life. Such matters are discussed in the opening chapter of this thesis.

Academically, my interests lie in the voluntary sector, public policy and sociology. It is these interests that have determined the course of this study.

Ontology is described by Jary & Jary as the ‘branch of philosophy [ ] concerned to establish the nature of the fundamental kinds of things which exist in the world...’ (1991: 461). They described ontological security and insecurity in terms of it being associated with ‘feeling of emotional and intellectual security and insecurity said to arise from the effectiveness or ineffectiveness of an individual’s upbringing, especially early family relationships’ (Jary & Jary:1991:460). My own ontological approach is strongly influenced by my social class, gender and age. Furthermore, whilst my previous life experience does have some bearing on how I view the world, since becoming disabled my personal outlook on life has changed markedly, to the extent that any such influences are now secondary to my lifestyle and attitudes. The fact that I am disabled and use a wheelchair is possibly one of the strongest influences upon my ontological perspective and it is this that had a major impact in determining the subject matter investigated during the course of this study. This issue is discussed in greater detail in the opening narrative of the introductory chapter. Taking a joint epistemological and ontological perspective I would describe myself as a socialist feminist who happens to be disabled.

## SECTION 2: PILOT STUDY, FIELDWORK & ANALYSIS

### 2.1 Methodological Approach

This study was conducted using an approach to disability based upon the approach outlined within the organising framework in section 4 of chapter 2. Thus the influence that socially and medically constructed factors played in shaping the volunteers' perceptions was considered throughout the study. Having developed a framework with which to conceptualise disability for the purposes of the study, the next stage of the research process was to develop a methodology appropriate to the identified research question.

It was decided that grounded theory methodology was the most appropriate approach for use within this study (Glaser & Strauss:1968). Glaser & Strauss (1968) argued that qualitative data is most appropriate for use with grounded theory methodology as it focuses upon the 'crucial elements of sociological theory such as data on structural conditions, deviances, norms, processes, patterns and systems' (p18). Thus it was decided to utilise semi-structured interviews based upon the themes identified during the course of the literature review: volunteering; disability and volunteering; and issues surrounding the management of disabled volunteers. A copy of the interview guide used during the fieldwork is given in Appendix 3 (page 314).

Previous literature suggests that the grounded theory approach provides a useful set of strategies with which to undertake social investigation into the experiences of disabled people (Chamaz: 1994). Moreover, this approach enables theory to be generated from a constant comparative analysis of the data generated during the research process. Generating theory from the data entails an inductive process in which the research questions may be worked out systematically in relation to the data during the course of the research (Glaser & Strauss:1968). Thus, the distinct nature of the volunteers' experiences was to be analysed and theory developed based upon evidence emerging out of the research data. It was anticipated that this theory would contribute to knowledge in both the disability and voluntary sector fields.

An alternative methodological approach given consideration prior to the study commencing was the participatory approach to disability research as proposed by Zarb (1992). This approach, which is based upon an emancipatory research paradigm, suggests that the research participants should be involved during all stages of the research process (Humphries 2000: Martin: 2000). In discussing participatory research Oliver (1992) argued that all research into disability should only be conducted by disabled people and should 'aim to challenge the routine oppression of daily life' (Oliver:1992: 159). Although elements of this approach appeared to be suitable for use within this study, a closer examination of disability participatory research led to the conclusion that it was unsuitable for a study of this nature as previous studies have shown that the act of volunteering can empower disabled people thereby enabling them to combat social exclusion (Bates & Davis: 2004, Davis Smith et al: 2004). Furthermore, whilst disabled people were consulted throughout the research process, the study focused upon their perceptions of volunteering and did not consider their experiences and perceptions of social oppression.

Another methodological approach considered for use in this study was that of symbolic interactionism (Mead:1934). Lenney & Sercombe (2002) argued that the symbolic meaning surrounding disability, particularly the use of a wheelchair, may prevent people from interacting with wheelchair-users depending upon how 'others have internalised the meaning of disability' (p9). Whilst this perspective appeared to be appropriate for use with this study, difficulties were anticipated regarding my own use of a wheelchair and the need to adopt and maintain an objective approach. Furthermore, as a wheelchair-user, the practicalities of using symbolic interactionism during the research process were deemed extremely problematic. It was thought that my own mobility problems may hinder the processes involved in observing and interpreting interactions between wheelchair-users and others.

In sum, it was decided that an approach based upon the principles of grounded theory was the most suitable for use within this study. Such an approach was adopted because it provided the tools with which theory could be generated from a process of constant comparative analysis.

## **2.2 The Research Design**

This section describes the research design as it was originally proposed for use within this study. Amendments made to this design following the pilot study are noted in the next section.

### **- Research Area**

This study focuses upon the experiences of physically disabled volunteers within Great Britain; it specifically deals with the experiences of wheelchair-users as an identifiable sub-set of that group. The reasons for this are two-fold: Firstly, having conducted the literature review it was evident that there is a large gap in knowledge about the experiences of disabled volunteers; moreover, there have been no previous social studies focusing upon the experiences of wheelchair-users as a specific group: Secondly, as a disabled volunteer myself I am particularly interested in this subject area and was keen to investigate the experiences of disabled volunteers in order to produce and disseminate useable knowledge which would promote volunteering amongst the disabled population. Whilst this study focuses upon the experiences of wheelchair-users many of the issues covered relate to disability in general and many of the study findings are applicable to disabled volunteers as a whole.

### **- Research Approach**

The main reason for choosing qualitative interview techniques was the expectation that such methods could provide the level of flexibility required to conduct research within the field of disability. King (1994) argued that qualitative interviews are what most research participants feel comfortable with; such techniques afford the researcher the opportunity to expand on certain points whilst giving the participant the freedom and opportunity to fully describe their experiences and feelings in depth. This perspective was also supported by Flick (1998) who argued that semi-structured interview techniques provide the interviewees with the opportunity to introduce new topics, whilst the researcher is able to ascertain that any pre-determined subject areas are covered. Thus it was believed that qualitative methods would give the research participants' the flexibility to discuss at length any issues they felt relevant to

the interview topic, whilst allowing myself as the interviewer to focus upon issues I deemed important. Furthermore, the semi-structured nature of the interviews meant that the questions could be tailored to the individual participants – thus enabling people with learning disabilities or communication difficulties to take part.

One of the main advantages of using semi-structured interview techniques is the potential to accumulate a richness of data. In discussing the use of qualitative methods in promoting evidence based practice in mental health nursing Dodd (2001) argued that ‘qualitative data can highlight some of the most thought-provoking experiences that can affect practice, but is often undervalued by practitioners’ (2001:13-14). Although Dodd was discussing people with mental health problems, such views are equally applicable when applied to research within the voluntary sector – particularly in relation to wheelchair-users. It is the particular and distinctive nature of the volunteers’ perceptions of their experiences that are important. Moreover, it was anticipated that semi-structured interview techniques would provide sufficiently detailed evidence-based data with which suggestions could be made regarding the management of disabled volunteers.

On the negative side, Critchen et al (1999) argued that qualitative interviews are often difficult to conduct and arrange. Furthermore, the content of qualitative interviews may be subject to distortion because of the reaction of the participant to the interviewer. Other disadvantages of qualitative interviewing techniques include the lack of standardisation and the problem of interviewer bias (Robson:1993). Thus the importance of objectivity was considered throughout the study and a research journal maintained in which my own thoughts and feelings recorded. An interview guide was developed (see Appendix 3, pp 314-315) in order to provide a level of continuity and all of the participants given the same opportunity to fully express their opinions.

The interview guide was based upon the themes discussed during the literature review and including matters relating to: the volunteers’ experiences of volunteering in general with questions focusing upon voluntary activities, motivations and experiences when first starting to volunteer; disability and volunteering in which questions were asked about how the volunteers’ disability impacted upon their experiences; and issues surrounding volunteer and organisational management,

including whether the volunteer had been given any training or was in possession of a task description.

In addition to semi-structured interviews, the original research design also included a proposal to undertake observations whilst in the field. Atkinson & Hammersley (1994) drew a distinction between participant and non-participant observation and argued that the former refers to observations carried out when the researcher plays an established role in the scene studied. They continued by arguing that this dichotomy has limited usefulness because it implies that non-participant observers play no recognised role whatsoever (Atkinson & Hammersley: 1994). Bryman (1989) however, adopted a different stance and drew attention to three different types of participant observation; 'covert, full and indirect' (pp160-161). Covert observations raised several ethical and practical questions and were thus deemed inappropriate for use within this study. Full observations which would have entailed my adopting a role within the organisations in which the volunteers were engaged (Waddington: 1994) were also thought inappropriate because of potential difficulties in recording observations and note taking. Indirect observations entail the researcher being constantly around an organisation whilst not taking any role or having any particular influence within that organisation (Bryman: 1989). This approach was identified as being the most suitable for the purposes of this study as it was anticipated that it would provide the opportunity for me to observe and record events whilst not personally influencing the research field. Thus it was decided to attend voluntary board and other committee meetings in order to observe the roles undertaken by wheelchair-users who volunteer upon such committees. An outline of the observation guide included in Appendix 4 (page 316).



## - Research Approaches Considered but Not Adopted

In the early stages of the research process the possibility that telephone surveys might provide a suitable approach with which to conduct this study was given serious consideration. One of the main advantages of conducting a telephone survey was highlighted by Frankfort-Nachmias and Nachmias (1996) who pointed to the convenience and cheapness of using this method. However, Miller (1991) noted the 'lack of rapport between respondent and interviewer' and suggested that high non-response rates are due to telephone interviews being a 'less rewarding experience and more of a chore than the personal interview' (p166). One of the main predicted difficulties with this methodology related to issues of reliability and validity. It is impossible to determine over the telephone whether a person is, or is not, a wheelchair-user. Moreover, the possibility that some of the participants may have been living with speech impairments was also considered. Thus it was decided that telephone interviews would not be appropriate for use within this study.

The possibility of using self-completing questionnaires by means of a mail survey was also considered during the early stages of the research process. One of the main advantages of this is the low cost involved (Bryman: 2001). Furthermore, errors due to interviewer bias are considerably lower in comparison with face-to-face interviews (Frankfort-Nachmias & Nachmias: 1996). However, when compared with personal interviews, which have a response rate of around 95%, poor response rates for surveys (between 20% and 40%) almost countermand the advantages of this method (Frankfort-Nachmias & Nachmias: 1996). When deciding upon an approach mail questionnaires were considered because they offer high levels of anonymity when researching highly sensitive issues. However, like telephone interviews, it is impossible to ascertain whether the interviewee is actually a wheelchair-user when using postal questionnaires. Moreover, the possibility that some participants may experience difficulties in writing because of their impairments also made this method unsuitable.

The third methodological approach considered but not adopted, was the use of structured interviews and standardized questionnaires. The aim of this research method is to give all interviewees the same context of questioning (Bryman: 2001).

Denzin & Lincoln (1994) identified four different types of structured interview; 'telephone interviews; face-to-face interviews; intercept interviews in public places; and survey research' (p364). This approach was considered to be unsuitable for use within this study because of the specialised, personal and highly specific nature of the research topic.

### **2.3. The Pilot Study**

The aim of the pilot study was to identify any 'problems of converting [the research] design into reality' (Robson: 1993: 301). Six wheelchair-users who volunteered were interviewed using semi-structured interview techniques. Details of the pilot study participants are given in Appendix 1, page 312. The interviews were tape-recorded, transcribed and analysed. Following the analysis it was decided that during the main-study interviews the participants would be asked to concentrate their answers in one area of voluntary activity only. The reason for this was that some participants volunteered in five or six different roles – making their replies to the interview questions somewhat confusing and the analysis problematic. No other changes were made to the interview guide.

In addition to semi-structured interviews non-participant observations were also undertaken during the pilot phase. On three occasions overt non-participant observations were carried out. The aim of these was to observe the role played by wheelchair-users during voluntary management board and other disability-related committee meetings. The use of this method during the pilot stage was to ascertain whether useful supplementary data could be acquired during the course of such observations (Robson:1993). An attempt was made to make contemporaneous notes during the course of the observations. However, the highly sensitive nature of the matters discussed during the meetings being observed resulted in ethical and practical problems. Not understanding the nature of social research, the participants frequently asked my opinion and advice regarding the issues being discussed. Because of the delicate nature of such issues and the complicated nature of the assistance required, it was decided that the needs of the participants and their organisations should come before the requirements of the research process. Moreover to ignore such requests for help would have been morally and ethically unacceptable. Thus the plan to conduct

observations was abandoned and it was decided that observational methodologies would be unsuitable for use during the main study fieldwork.

#### - **Participants Background Details**

The first stage of the interview process was to ascertain the participants' (interviewees) personal details. An outline of the questionnaire used in this process is given in Appendix 2, page 313. Other questions asked at this stage related to: the nature of the individual volunteer's impairment (diagnosis); the type of wheelchair used; whether the volunteer needed to utilise the assistance of a third party whilst volunteering; the nature of the voluntary work undertaken; and the type and name of the organisation in which the volunteer was engaged.

The aim of such precise background questions was in keeping with grounded theory methodology and aimed to provide suitable data from which a constant comparative analysis could be undertaken (Glaser & Strauss: 1968). Moreover, such detailed background questions were necessary to ensure that the criteria established within the sampling framework were adhered to (see figure 3.2, page 91). Thus a diverse research sample was identified resulting in a richness of data that reflected the varied and complex nature of the volunteers' experiences. The sampling and interview techniques and strategies adopted during the course of the study are discussed in the following section.

#### **2.4 The fieldwork**

In total 50 people were interviewed, 47 of whom were wheelchair-users who volunteered. Difficulties in locating and identifying suitable research participants are discussed later in this section. The decision to include 50 participants within the study was taken as it was anticipated that this number of interviews would afford a wide selection of different perspectives, thereby providing a depth and richness of data (Maxwell: 1996, Flick: 1998). In addition to this, time and monetary constraints were also considered when deciding upon the sample size (Bryman: 2001). A full breakdown of the participants' details and the characteristics of the organisations in which they were engaged are given in chapter 4.

The fieldwork began in April 2003 and continued through until November 2003. The following paragraphs draw attention to specific issues encountered during the fieldwork stage of the research process.

### - **Sampling Framework & Strategy**

In discussing the contribution made to society by volunteers Wilson & Musick (1997) identified three measures of human capital influencing an individual's volunteering experiences: education, income & health status. Other important influences identified by Wilson & Musick (1997) were age, ethnicity and gender. Thus it was decided that in addition to use of a wheelchair the above personal characteristics would be used in the selection of interviewees for the study. Figure 3.2 overleaf summarises these characteristics providing justification for their use and detailing the implications for the study.

There are over 8 million disabled people in the UK today, one million of whom are wheelchair-users (Chairpower: 2005). It is from this population that the research sample was taken. Because of the small size of the sample population it was determined that probability sampling techniques would be inappropriate. Thus non-probability sampling techniques were selected for use within this study (Maxwell: 1996). For the purposes of the pilot study convenience sampling techniques were utilised. Although convenience sampling techniques were appropriate for use during the pilot stage, issues of reliability and validity meant that such techniques were not suitable for use during the main part of the research study (Maxwell: 1996).

During the fieldwork stage of the research process, purposive sampling techniques were utilised (Patton: 1990). Such techniques enabled potential research participants to be selected on the basis of their impairment and volunteering activities. Prior to interview arrangements being made, it was first necessary to determine the following: whether the participant was a volunteer who was also a wheelchair-user; the nature of their impairment; and the nature of their volunteerism. Such questions were necessary in order to ascertain that the criteria depicted within the sampling framework would be achieved.

**Figure 3.2 Sampling Framework**

CHARACTERISTICS OF VOLUNTEERS	EVIDENCE FROM LITERATURE	IMPLICATIONS FOR STUDY
<b>GENDER OF PARTICIPANTS</b>	Evidence suggests that within the UK there are 3 million men and 3 million women of working age living with <u>long-term</u> disabilities, (ONS: 2000).	Equal numbers of male and female volunteers were interviewed during the course of this study: 25 MALES/ 25 FEMALES
<b>EDUCATION</b>	Research suggests that disabled people are twice as likely as non disabled people to have no formal educational or vocational qualifications, (ONS: 2002). A study conducted by Daone & Scott (2003) on behalf of SCOPE found that 2.2% of all disabled people have no formal or vocational qualifications whatsoever. There are between 1.1% and 4.6% of pupils per LEA with 'educational statements' (Don: 2003). At the other end of the scale 4.65% of university students have some form of disability, (Curtis: 2003).	It was decided to aim for a minimum of 10% of the participants in the study to have attended special school: [a minimum of 5 volunteers]  It was decided to aim for a minimum of 10% of the participants in the study to be educated to university level: [a minimum of 5 volunteers]
<b>INCOME</b>	Previous studies indicate that the vast majority of disabled people are living in a state of relative poverty, either on, or close to the 'breadline', (Coleridge: 1993, Stone: 1999, WHO: 2001).	It was decided that a minimum of 60% of the participants in the study would be either in receipt of Income Support, or will be solely dependent upon state benefits as their income: [a minimum of 30 of the participants will be solely dependent upon statements as their income]
<b>HEALTH STATUS – DISABILITY</b>	Research relating to the prevalence of disability amongst the adult population of the UK is somewhat dated, the only statistics available relating to the nature of disabled people's diagnosis suggests that out of 100 severely disabled adults, 44 had muscular skeletal impairments and 38 were living with neurological impairments. 11 of the people in the study had other impairments or were not diagnosed, (Martin et al: 1988).	It was decided that at least 40%, (20), of the participants will be living with muscular/skeletal impairments.  It was decided that at least 40%, (20), of the participants will be living with neurological impairments  IT IS ACKNOWLEDGED THAT SOME PARTICIPANTS WILL BE LIVING WITH BOTH
<b>TYPE OF WHEELCHAIR USED</b>	The categorisations of wheelchair usage outlined in Figure 2.1 of this chapter depicts 5 different types of wheelchair: <ul style="list-style-type: none"> <li>• Manual Self-Propelled</li> <li>• Manual Propelled by third party</li> <li>• Powered wheelchair – controlled by user</li> <li>• Powered wheelchair – controlled by third party</li> <li>• Mobility scooter</li> </ul>	At least 45 of the participants will need to utilise a wheelchair to facilitate their mobility whilst volunteering.
<b>AGE</b>	A report by the Audit Commission (2002) found that over 70% of the wheelchair-users in the UK today were aged over 60. However, it is likely that the vast majority of wheelchair-users over the age of 60 are severely disabled and consequently unable to volunteer.	The age of participants will be noted at the beginning of each interview as far as practicable the study will include equal numbers of people aged under 40, 40-50, 50-60 and 60+.
<b>ETHNICITY</b>	A report by the Volunteer Centre UK (1990) found that the number of people from black and ethnic minority groups who volunteered was low, averaging less than 3% of the total. At the time 5% of the UK population were believed to be from BME groups.	It was decided that if possible between 3% and 5% of the research sample would be from black and ethnic minority groups.

In addition to purposive sampling techniques, snowballing techniques were also used to identify potential participants (Robson: 1993). On the whole this technique was unsuccessful as very few of the volunteers were able to introduce other volunteers into the study. Moreover, the use of snowballing techniques was deliberately kept to a minimum in order to maintain diversity within the sample and thus avert potential difficulties with validity.

- **Gaining Access to the Field: Identifying & Locating Suitable Participants**

Initially, access issues focused upon the research need to locate and identify suitable participants who would be willing to partake in social research. Although suitable participants were easily identified using convenience sampling techniques during the pilot stage of the research, such techniques were both impractical and inappropriate for use within the main study. Difficulties in identifying suitable participants willing to be interviewed quickly became an issue in the early stages of the research process. In order to overcome this problem over 80 organisations of and for disabled people were contacted by letter asking if any wheelchair-users who volunteered would like to take part in the study. Advertisements were also placed in the national disability press. The response was mixed. It soon became evident that one of the main problems in identifying suitable participants was that 'active' wheelchair-users whose impairment is caused by an injury tend to be healthy enough to undertake paid employment and have little time or energy for volunteering. Moreover, those wheelchair-users who do volunteer were often living with a multitude of different illnesses and impairments, and subsequently needed to 'balance' their time and lifestyle accordingly. A number of individual wheelchair-users did however respond to the request for study participants. Such people were scattered across the country making the practicalities of arranging the interviews very problematic. Difficulties in locating research participants when the researcher is not studying within one particular organisation or institute were highlighted by Flick (1998) who discussed the usefulness of snowballing techniques and other strategies such as local and national advertising. Throughout the fieldwork stage of the research process one particularly successful method of identifying research participants was through networking. I took the opportunity to get involved in numerous voluntary activities whereby I was likely to meet other wheelchair-users who volunteered. Furthermore, I also responded

positively to requests from voluntary sector agencies to assist with disability awareness training, funding applications and other episodic voluntary tasks; thus increasing the probability that I would encounter other wheelchair-users who volunteered.

In addition to the somewhat 'scattered' geographic location of potential participants, other problems in persuading people to take part in the study were caused by previous negative experiences of social research being undertaken by non-disabled researchers (Barnes & Mercer: 1997). Many wheelchair-users were very reluctant to take part in the study until I made face-to-face contact and they were sure that I could be trusted. The need for trust between researcher and participant was highlighted by Hammersley & Atkinson (1983) who argued that a persons knowledge of social research is often irrelevant and that participants 'are often more concerned with what kind of person the researcher is than with the research itself' (p78). They continued to argue that research participants will 'try to gauge how far [the researcher] can be trusted'(Hammersley & Atkinson: 1983: 78). The fact that I use a wheelchair was an obvious advantage once initial contact had been made with potential participants; it later proved to be invaluable in breaking down the unseen barriers that exist when two strangers meet formally the first time.

In order to overcome the difficulties encountered in locating suitable participants each reply to the advertisements was carefully vetted. Attempts were made to place participants into geographic clusters, potential gatekeepers were identified and contacted with a view to using snowballing sampling techniques. In three geographic areas this strategy proved reasonably successful; however it quickly became clear that snowballing techniques could not be relied upon, as early in the fieldwork, one particular 'gatekeeper', a manager employed in a regional organisation of disabled people who had initially promised three or four introductions failed to provide any. In total less than 10 participants were identified via snowballing techniques.

One notable weakness of the study is the failure to identify or include any participants from black or ethnic minority communities. This is despite the fact that in preparing for the fieldwork several organisations that reflect the multi-cultural nature of contemporary UK society were contacted with a view to identifying suitable

participants. Such difficulties in persuading people whose ethnicity differs from that of the researcher to take part in social research were described by Thomas (1999) who highlighted the problems she experienced in locating any black or ethnic minority participants for her own social research into the experiences of disabled women within British Society.

- **Gaining Access to the Field: Environmental & Impairment Related Issues**

A second more personal although not entirely unexpected access issue emerged whilst undertaking the fieldwork. As a wheelchair-user I frequently encountered environmental and attitudinal barriers to the research field. Issues of access were augmented by the fact that the majority of the people involved in the study, including myself, were living with a complex range of different illnesses and impairments; consequently issues relating to health frequently compounded physical, social and environmental access difficulties.

The fact that I am a wheelchair-user amplified the practical problems associated with access. On several occasions, poor architectural design meant that I was unable to enter a building via the front door. Instead I often found myself having to overcome a 'wheelchair assault course' simply to gain access to the research participant so that I could conduct an interview. As well as experiencing difficulties in physically entering buildings, other access difficulties encountered included: parking difficulties; excessively steep gradients of external, often purpose-built 'accessible' ramps to premises; poor sign-posting of disabled access; small and often clustered meeting places; and problems locating and then accessing 'disabled persons' toilets. Throughout the fieldwork, access problems of the same kind were encountered in most of the premises visited.

In addition to the difficulties relating to the physical environment, the symptoms associated with both my own, and the participants' impairments exacerbated issues of access. From a personal perspective, managing my own fatigue and pain proved very difficult and I had to employ a driver to help deal with this. On four occasions memory problems indicative of cognitive impairments resulted in participants simply



forgetting that they had a pre-arranged appointment with me, despite having been reminded by me in a telephone call the previous evening.

Such pre-interview telephone calls were one method I adopted in an attempt to overcome the many problems surrounding physical access. The aim of these telephone calls was primarily to ascertain that the participant was still available for interview. In addition to this, such calls provided an ideal opportunity to establish the overall accessibility of the premises and parking arrangements. Unfortunately this strategy was on the whole unsuccessful as many wheelchair-users become used to living within with their own day-to-day environment and simply learn to adapt to any access problems they might experience. Unless personal circumstances change or coping mechanisms fail, access issues within the 'home' and 'work' environment tend to become invisible. Consequently, throughout the fieldwork, I was not always made aware beforehand of the physical barriers that prevented ease of access to the research field. Problems associated with physical access remained a major issue for me throughout the research, often causing a good deal of unnecessary fatigue and frustration.

#### **- The Interviews**

102 people responded to the advertisements for research participants. Of these, almost a third (33) did not fit the sampling framework and were consequently unsuitable for use within the study. All of the remaining people were contacted and asked if they would be willing to participate. Provisional arrangements to interview potential participants were made at the point of initial contact and confirmed 3 to 4 weeks in advance in writing or by e.mail. Of the 69 people who originally agreed to take part in the study, 12 later withdrew. Of the remaining 57 potential participants, 4 were non-disabled managers of volunteers and the rest wheelchair-users who volunteered. Interview arrangements were made with all 57 people; however, 4 of these failed to turn up at the agreed interview location (although they had been contacted by telephone the day before) and 3 cancelled on the grounds of ill-health.

As previously stated, the interviews were semi-structured in nature and arranged at a time and place to suit the participants. The flexible nature of the interviews meant that

the volunteers were given the opportunity to discuss matters they felt important. As a consequence of this whilst the interview format remained consistent throughout the fieldwork, the depth, character and direction of the interviews varied greatly between individual participants. Prior to the interviews commencing the interviewees' background details were attained and recorded on a questionnaire, (see Appendix 2, page 313). With two exceptions, the interviews were tape-recorded and transcribed at a later date. Of the two interviews that were not tape-recorded, one was with a gentleman living with a profound speech impairments who could not speak at all. During this interview the gentleman concerned communicated by means of a pointer board [1] interpreted by his Personal Assistant. A contemporaneous record of this interview was recorded directly onto an electronic keyboard. Another of the volunteers who had mild speech impairments and learning disabilities was unwilling to be tape-recorded. This interview was also recorded verbatim directly onto an electronic keyboard[2].

All the interviews lasted between 30 and 90 minutes, with the average time being just under an hour. Problems associated with my own impairment meant that no more than 2 interviews could be undertaken in one day. Moreover, it was necessary for interview arrangements to be extremely flexible; with alternative arrangements being made in case of an individual participant's sudden inability to take part. Interviews were conducted at a time and place to suit the participants who were given as much, or as little, time as necessary to address the issues important to them, whilst not over-exerting themselves. The need for flexibility throughout the research process was discussed by Robson (1993) who described in some detail the unforeseen catastrophes that can interfere with a carefully pre-planned interview schedule. Such flexibility became one of the defining characteristics of the fieldwork. Interview times and locations were frequently changed or appointments cancelled and rearranged.

#### **- Reflection, Reflexivity and the Research Journal**

Research literature makes it clear that both the interviewer and the interviewee have an impact upon the interview situation (Alevesson & Skoldberg: 2000, Harris: 2001) From a personal perspective the fact that I am a woman in her early 40's, who is a

full-time wheelchair-user, of working class background, living with both muscular-skeletal and neurological conditions undoubtedly influenced each interview undertaken as part of the study; consequently issues of reflection and reflexivity were continuously raised during the fieldwork (Flick: 1998, Bryman: 2001). The need for reflexivity was particularly relevant when interviewing people living with similar impairments to my own, as I needed to be aware of the impact that my own thoughts, feelings and emotions could have on both the interview situation and on my 'self' as a person.

The keeping of a research journal in which I was able to record my own thoughts, feelings and state of health throughout the research process provided a useful tool with which I was able to tackle many of the complex methodological issues arising out of my own personal situation and 'closeness' to the research subject. There are many narrative examples of reflexivity and reflection being utilised within disability discourse to highlight how the writer's previous life-experiences of disability impact upon their current ontological perspective (Rabin, 1984, Gabel, 1999, Slack, 1999). One of the most positive aspects of keeping a research journal was that it provided an invaluable instrument into which I was able to vent my own feelings, and for the first time since becoming ill, acknowledge and record my own pain, discomfort and fatigue. In addition to this the journal proved to be invaluable when analysing data as it provided a detailed, almost contemporaneous record of my own thoughts and feelings during the interviews and also of the whole 'research experience'. The importance of such a journal to the research process is best illustrated by citing a passage from the journal itself;...

This afternoon I interviewed Simon... a gentleman who is totally unable to utter a word, yet he is the vice-chair of a local organisation of disabled people. Yesterday, [using a pointer-board], he gave a speech to a group of trainee social workers and O.T.'s about disability and user involvement. Simon was undoubtedly one of the most inspirational people I have met, unable to move – almost quadriplegic, unable to talk... yet his intellect and sense of humour shone through. He was a pleasure to interview.

I continued to note that meeting Simon...

... made me appreciate just how 'mobile' and 'physically able' I am...

Hammersley & Atkinson (1983) used the term 'reflexivity' to establish that the researcher is linked to the phenomena being studied. As a wheelchair-user who volunteers my own link to the phenomena being studied is evident. However, as a social researcher I remained very much aware of the need to sustain a professional persona throughout the fieldwork. I used reflection and reflexivity to maintain an awareness of the impact that my own thoughts, feelings and preconceptions could potentially have during the interview. The role of such reflection and reflexivity in promoting both professionalism and self-motivation within the research process is again best illustrated by the journal;...

... I wouldn't have thought **people like that** would be of much use to our organisation. I mean, what good would they be? Oh no, all of our members soldier on walking..... we don't have wheelchair-users at all in the group. They wouldn't be able to take part in our activities.

These were the words spoken during a telephone conversation between myself and the secretary of an organisation of disabled people operating within a local city. I had deliberately targeted this organisation because its membership consisted of people living with a degenerative muscular/skeletal condition. Such attitudes undoubtedly impacted upon my own sense of 'self' whilst strongly influencing my own motivation and perspectives. Later that evening when writing my journal I noted; ...

..... I am still a little taken aback by her disablist attitude. I explained to her that as a wheelchair-user I am a 'person like that'. Hopefully, I'm of use to someone, somewhere..... Conversations like this strengthen my resolve...

Such a negative response from another disabled person when discussing the abilities of wheelchair-users to contribute to their local organisation or community was quite rare. On the whole, other disabled people, whatever their own impairments, responded well to me as a wheelchair-user. Moreover, one of the most challenging aspects of the research was that many of the participants expected that I, as a fellow wheelchair-user, would feel ‘instant empathy’ with them. Most assumed that they and I shared many similar life experiences, thoughts and feelings. In all but one case, this was far from the truth. The ethnographic nature of the research meant that such assumptions had the potential to cause significant problems during the interview process, particularly when it was necessary for a certain amount of self-disclosure on my part to encourage the participants to express their own thoughts and feelings.

One method of addressing this problem was to give each participant the opportunity to freely discuss their general experiences as a disabled person prior to the interview commencing. During this time I was able to briefly disclose the nature of my own impairment whilst reinforcing the importance of each individual interviewee’s volunteering experiences. Although this strategy was on the whole successful, prolonging the time spent at each location often aggravated the symptoms of my own impairment, occasionally impacting upon my own concentration levels. This in itself increased the need for self-awareness, reflection and reflexivity.

In addition to keeping a research journal, I also made contemporaneous notes whilst conducting the interviews. Such notes, which were made on the reverse of a standard ‘background’ form, recorded the participant’s overall demeanour, manner and non-verbal communication during the interview. These notes acted as an aide-memoir when filling out my journal, and also provided a readily available record of my own impressions of both the interviewee and of the somewhat unique situation in which we found ourselves. The need for reflection and reflexivity was perhaps the most difficult methodological problem encountered during the fieldwork. However, once I had got into the ‘habit’ of keeping a research journal it became a natural part of the research process – providing a secure, retrospective basis for the analysis.

## - Representativeness

The small number of research participants means that the sample cannot be assumed to be representative of wheelchair-users who volunteer or of disabled volunteers in general.

### 2.5 Validity & Reliability

Bryman (1989) stated that 'reliability' refers to the consistency of a measure, and comprises of two elements, internal and external reliability. Internal reliability refers to the 'degree of internal consistency of a measure' whilst external reliability refers to the 'degree to which a measurement is consistent over time' (pp 270-271). In discussing the reliability of qualitative techniques Flick (1998) highlighted the need for the 'standardization' of notes. He also discussed the need for comparable interview guides and 'continual evaluation of procedure in observations' (Flick: 1998: 223-224). Throughout the research process issues of reliability were addressed by adherence to the interview guide. Thus all of the interviews followed a similar pattern, although the distinct nature of the issues raised meant that the exact content of the interviews differed between participants. All of the interviews were recorded contemporaneously and copies kept both of the interviews and the tape transcripts. Moreover, the research process was continually evaluated by means of the research journal and the PhD supervision process.

In defining validity as an 'estimate of the accuracy of an instrument or of the study results' Mellis et al (2002) differentiated between 'internal and external validity' (p105). They argued that 'external validity' refers to whether the results of a study can be 'applied to a wider population', whilst 'internal validity' refers to the 'accuracy of different methods and measurements' (Mellis et al: 2002: 108-109). The small size of the sample group, and the purposive sampling techniques utilised mean that the results of this study are not generalizable and cannot be scientifically applied to the general population; although it should be noted that many of the issues raised may be applicable to other wheelchair-users who volunteer. Moreover, because this study utilised qualitative methodologies, techniques such as control groups and randomised sampling of the research participants were not applicable. Maxwell (1996) described

the main threat to validity within qualitative research in terms of accurately 'describing what you saw and heard' (p89). This issue was dealt with by making a contemporaneous record of all of the interviews. Moreover, notes made during the interview regarding the participants' demeanour, body-language and overall appearance also addressed this issue. The second threat to validity identified by Maxwell (1996) related to the interpretation of the data . This matter was dealt with by meticulously transcribing the interview tapes. The transcripts were then used as the basis for the data analysis.

Issues surrounding theoretical validity were considered in detail whilst developing the organising framework outlined in chapter 2, section 4. This framework was also used to explain the volunteers' experiences and is further developed in chapter 6.

Throughout the research process careful attention was paid to identifying and dealing with the possibility of researcher bias (Miles & Huberman: 1994). The research journal went some-way to addressing this whilst all the data was analysed following similar patterns. Thus, whilst issues surrounding validity and reliability were not always easy to deal with, rigorous attention to detail and adherence to the research process minimised problems.

Moore et al (1998) questioned if issues of validity should be applicable to disability research and asked whether such 'sacrosanct criteria of, [ ] objectivity, validity, generalizability and accountability... invariably discount disabled people's own agendas and create disempowerment?' (p16). Although this perspective indicated that there may have been ethical questions associated with issues of validity, no such problems were encountered during the course of this study. Furthermore, issues of validity and reliability were considered to be an integral part of the research process.

## **2.7 Ethical Issues**

The fact that I am a wheelchair-user living with a neurological impairment had the potential to cause some ethical problems. Throughout the research process I was acutely aware that some of the participants had only agreed to take part in the study because they believed I could empathise with their situation. This issue was again

dealt with by maintaining high levels of self-awareness and reflection throughout the interview process.

One of the unexpected issues to arise during the research process was that six of the participants asked for my assistance in completing application forms for state welfare benefits. Although this was not difficult for me, the highly personalised nature of the information required to accurately complete such forms meant that matters of confidentiality and trust between the participants and myself were of paramount importance. Furthermore, in order to assure that the benefit application process would not interfere with the research process, such assistance was always given after the research interview had taken place – usually one or two days later. Helping with benefit applications enabled me to give something back to some of the interviewees.

The importance of maintaining confidentiality when researching disability issues was highlighted by Moore et al (1998). Issues surrounding confidentiality were particularly important during this study as some of the participants were concerned that if the Department for Works & Pensions (DWP) discovered that they were volunteering they would no longer be eligible for disability benefits. Whilst such concerns were unfounded (Murphy: 2001, do-it all: 2005, Volunteering England: 2005) they reflected deeply held feelings of mistrust and fear towards the DWP. Thus it was very important to guarantee confidentiality and anonymity to all of the participants.

## **2.8 Analysis Techniques**

The analysis of the research data proved to be a complicated task that was undertaken in various stages. Firstly, all of the interview tapes were carefully transcribed and filed under geographic location. The transcription of the tapes was a time consuming process made difficult by the fact that some of the participants were living with impairments that impacted upon the clarity of their speech. Such difficulties were augmented by regional accents. Thus, prior to commencing the analysis of data, just under 5 months were spent transcribing.



Having transcribed all of the tapes the next stage was to chunk-up the data into manageable segments. Each transcript was read and reread until emergent themes were identified and drawn out of the data. Each theme was coded and the data re-filed under thematic headings. In discussing the process of analysing data Strauss & Corbin (1998) argued that analysis techniques and procedures should only assist in the analysis of data and not be the driving force behind the analysis. It was decided not to use any of the available software analysis packages but to instead undertake the analysis using 'manual' constant comparative techniques. The main advantage of this was that by paying close attention to minute detail (Strauss & Corbin: 1998) a richness of data emerged. Thus, meticulous attention to detail was combined with a process of a constant comparison of the data to produce a rigorous analysis process. The results of this process was that the emergent themes were categorised into 5 different headings: volunteer characteristics; organisational issues; benefits of volunteering; barriers to volunteering; and general volunteering experiences.

Each segment of data was then carefully considered on a comparative basis with similar data. Such comparisons were made bearing in mind both context of the interview from which the data emerged and any similarities or differences with comparable data from different interviews. Having clearly established which elements of the data would be suitable for the purposes of the study the analysis chapters were written.

The results of this analysis are given in Chapters 4 and 5. Chapter 4 provides an analysis of the volunteers' characteristics and activities. It also gives a description of the organisations in which they were engaged. Chapter 5 builds on the themes given in chapter 4 and gives a detailed analysis of the volunteers' experiences; including the benefits of volunteering, the barriers to volunteering and an overview of the volunteers' daily experiences.

(NB: The six interviews conducted as part of the pilot study were analysed prior to the main fieldwork commencing. The results of the pilot study analysis are not included in the main analysis or discussed in the analysis chapters).

### **CONTRIBUTION TO KNOWLEDGE: CHAPTER 3**

This chapter commences by noting the lack of previous studies in this area. In providing a detailed account of the distinct methodological issues raised during the course of the study, this chapter contributes to academic knowledge. Most notably it provides:

- A synthesised conceptualisation of volunteering for the purposes of investigating the experiences of wheelchair-users who volunteer:
- A table categorising wheelchairs and wheelchair usage:
- An account of the distinct problems encountered during the course of the fieldwork that were directly related to disability:
- An outline of how reflexivity and reflection may be used as a successful research tool in the course of investigating the volunteering experiences of disabled people.

Thus this chapter contributes to the methodological literature as well as to the disability and volunteering literature.

### **CONCLUSION TO CHAPTER 3**

The lack of previous academic study in this area resulted in various distinctive methodological problems. Such problems, which were augmented by difficulties in identifying suitable research participants, included: a lack of previous literature pertaining to the volunteering experiences of disabled people making it difficult to develop pertinent and applicable research questions; difficulties in conceptualising the term 'wheelchair-user'; problems associated with the development of a sampling framework that reflected both the disabled population within Great Britain and the disabled people who undertake voluntary work within British society. Whilst such difficulties were irksome, overcoming them added to the richness of the research experience.

Having encountered (and overcome) various theoretical and methodological issues prior to entering the research-field, some difficulties were then experienced because

of the fact that I am a wheelchair-user. The research participants were located throughout Great Britain: as far South as Andover in Kent; as far North as Inverness; and as far West as Anglesey. However, whilst attitudinal barriers to the research process varied throughout the country, substantial access-related obstacles were evident in all areas. Such difficulties again added to the diversity of the research process whilst providing a frustrating insight into the similarities of disabled people's experiences throughout Great Britain.

The experiences gained as a social researcher who uses a wheelchair have led me to conclude that within British society the day-to-day experiences of the majority of wheelchair-users are shaped by problems related to environmental access. Moreover, during the course of the study such problems were augmented by more usual research access related problems such as identifying suitable participants. Thus, access became a double-edged problem that at times proved extremely difficult to deal with.

In sum, this chapter has outlined the methodological approach adopted throughout the course of this study. By utilising grounded theory methodology, high levels of flexibility were maintained throughout the fieldwork stages. Moreover, during the analysis process grounded theory methodology provided the appropriate research tools with which theory could be generated. Thus by closely adhering to the methodological approach laid down in this chapter, this study provides new insight into the experiences of wheelchair-users who volunteer.

The following chapters build upon the issues discussed thus far, providing a detailed analysis of the experiences of wheelchair-users who volunteer.

### **SUMMARY OF CHAPTER 3:**

This chapter commenced by drawing attention to the pre-fieldwork undertaken at the beginning of the research process. Attention was paid to the research questions and sub-research questions in addition to the conceptualisation of the term volunteering. Difficulties in defining the concept of a wheelchair-user were discussed and various categorisations of wheelchairs and wheelchair usage developed.

The second section of this chapter highlighted the role played by grounded theory throughout the research process. The research design was described in detail with particular attention being paid to the suitability of semi-structured interview techniques and overt non-participant observations. Prior to discussing issues encountered during the fieldwork, attention was paid to the lessons learnt during the pilot study.

Problems relating to access were raised followed by a discussion focusing upon reflection and reflexivity. Matters relating to validity and reliability were addressed prior to a look at the ethical issues encountered during the study. A brief overview of the analysis process was then given and attention paid as to how the chapter contributed to academic knowledge. The conclusion drew attention to the distinctive problems encountered during the course of the study.

### **ENDNOTES TO CHAPTER 3:**

**1. Communication by means of a 'pointer-board'.**

A pointer-board is a basic communication tool used by people with profound speech impairments who are either unable to afford an electronic device, or because of multiple impairments unable to use such a device. It comprises of a large 'black-board' upon which the letters of the alphabet are painted. In addition to this several basic words such as yes and no are also depicted on the board. The disabled person is then able to communicate by pointing to each letter or word.

**2. Recording of interview onto a keyboard.**

One of the participants, a woman living with mild learning disabilities, was unhappy about being tape-recorded whilst being interviewed. Thus instead of tape-recording her interview, contemporaneous notes were made onto a mobile keyboard used by myself as note-taker. After the interview the notes were read out to the interviewee and later transferred directly onto a computer.

## **CHAPTER 4: THE VOLUNTEERS AND THEIR ORGANISATIONS.**

Previous literature about volunteering has focused upon the voluntary experiences of non-disabled volunteers. Thus the volunteering experiences of disabled people remain largely undocumented. This chapter, which is the first of two in this thesis to present empirical data on this topic, provides information about the disabled volunteers involved within the study.

The chapter is divided into five main sections. The first of these sections provides an analysis of the various demographic, epidemiological and other characteristics of the volunteers studied. Much of the data presented in this section is displayed in tabular form.

The second section of this chapter analyses the volunteers' activities. This section commences with a table outlining the twelve different activities discussed by the volunteers during the course of the interviews. This is followed by an analysis of the amount of time the participants spent volunteering.

The third section of this chapter focuses on the volunteers' reasons for volunteering. It begins by discussing how the volunteers first got involved and suggests that, for the volunteer study participants, the most prevalent method of accessing volunteering was in response to a direct request for help. The volunteers' motivations for volunteering are then analysed. Such motivations include: altruism; the need to contradict perceived stereotypes about disability; reciprocity; personal fulfilment; personal belief in an organisation's philosophy; and the desire to make a contribution to society.

The fourth section of this chapter looks at the organisational context of the voluntary activities undertaken by the interviewees. It provides an outline of volunteer distribution within the various organisations in which they were engaged. A brief explanatory description of some of the organisations visited during the course of the study is then given. The final part of this section looks at governance issues within the organisations for which the interviewees volunteered.

The final section of the chapter takes the form of a discussion. This discussion begins by noting the lack of representativeness of the research sample. It then provides a critique of the various background characteristics and volunteering details analysed within the previous sections.

The contribution made to academic knowledge within this chapter is then discussed. More specifically, it is noted that this chapter adds to disability and health related knowledge by providing epidemiological and sociological data about the wheelchair-users interviewed. In addition, the chapter contributes to volunteering literature by analysing the various characteristics and other factors associated with the volunteering activities of the disabled volunteers interviewed as part of this study.

The concluding section commences by noting that one of findings was that relatively few of the volunteers studied were engaged within impairment-focused organisations. Attention is also drawn to the high levels of fiscal, managerial and social responsibilities accepted by many of the volunteers interviewed.

## SECTION 1: CHARACTERISTICS OF VOLUNTEERS INTERVIEWED.

This section begins by providing an overview of the study participants' demographic details with respect to age, gender and disability status. Other background details are then reviewed including a breakdown of welfare benefits and allowances received by the volunteers. The discussion then focuses on other factors including geographical location, educational background and impairment. The final part of this section draws attention to the need for some of the interviewees to utilise the assistance of a third party to facilitate their volunteering experiences.

### 1.1. The Research Participants: Demographic, Epidemiological and Other Characteristics.

This study involved interviews with fifty people, forty-seven of whom were wheelchair-users who volunteered. The remaining three participants were non-disabled paid managers of disabled volunteers. Figure 4.1 below gives a breakdown of the volunteers' ages and gender in relation to their use of a wheelchair; it also includes details of the non-disabled participants.

**Figure 4.1: Age and Gender of the Study Participants**

AGE (YRS)	N MALE WHEELCHAIR-USERS	N FEMALE WHEELCHAIR-USERS	N NON-DISABLED PARTICIPANTS		N TOTAL
			MALE	FEMALE	
20-30	1	1			2
31-40	2	3		1	6
41-50	3	2		1	6
51-60	10	11	1		22
61-70	6	5			11
70+	1	2			3
<b>TOTAL</b>	<b>23</b>	<b>24</b>	<b>1</b>	<b>2</b>	<b>50</b>

One of the most notable differences between the disabled and non-disabled participants was that the three non-disabled participants did not personally volunteer in any capacity; whereas all of the disabled participants undertook some voluntary work. The gender of the participants was equally divided. The youngest volunteers included within the study were a 24 year-old woman and a 27 year-old man. The oldest man and woman were both 74 years of age. The majority of the volunteers were aged between 51 and 60 years, with the average age of the female and male volunteers being 55 and 54 years respectively. Although the majority of the volunteers were of working age only three were in fulltime employment. This figure reflects the high rates of unemployment amongst the disabled population as discussed in the literature review.

## **1.2. Welfare Benefits, Allowances and Other Pensions.**

The heterogeneous nature of the volunteers' circumstances was reflected in the wide assortment of welfare benefits and allowances they received. A brief explanation of the relevant welfare benefits is given in the following tables. Figure 4.2 provides a key to Figure 4.3 which shows the distribution of benefits amongst the interviewees.

The complexities of the benefit system meant that whilst all of the volunteers were in receipt of the mobility component of Disability Living Allowance (DLA), their remaining income originated from various sources including an assortment of different benefits and allowances. The majority of the volunteers were in receipt of more than one benefit.



**Figure 4.2: Welfare Benefits & Pensions: Key & Explanation**



Paterson (2001)

**Figure 4.3: Welfare Benefits & Pensions Received by the Volunteers**

LOCATION AGE	NORTH ENGLAND	MIDLANDS	S. E. ENGLAND	WALES	SCOTLAND	TOTALS (BENEFITS)	TOTAL VOL'S: AGE
21-30			IS: 2			IS:2	2
31-40	IS: 2		IS: 1	IS: 1	IS: 1	IS: 5	5
41-50				IB: 1 IS: 1 ILF: 1	IB: 2 OP: 1 PP: 1	IB: 3 ILF: 1 IS: 1 OP:1 PP: 1	5
51-60	IB: 2 PP: 1	IB: 5 IS: 2 OP: 1 SP: 1 WP: 1	IB: 4 ILF: 1 IS: 1 PP: 1 SP: 1	IS: 1	IB: 3 IS: 1 OP: 2 PP: 2 SP: 1	IB: 14 ILF: 1 IS: 5 OP: 3 PP: 4 SP: 3 WP: 1	21
61-70	IB: 1 ILF: 1 PP: 1 SP: 2	SP: 1 WP: 1	SP: 2	ILF: 1 IS: 1 MIG: 1	IB: 1	IB: 2 ILF: 2 IS: 1 MIG: 1 PP: 1 SP: 5 WP: 1	11
71+				SP: 1 WP: 1	PP: 1 SP: 1	PP: 1 SP: 2 WP: 1	3
<b>TOTAL IN RECEIPT OF BENEFIT</b>	IB: 3 ILF: 1 IS: 2 MIG: 0 OP: 0 PP: 2 SP: 2 WP: 0	IB: 5 ILF: 0 IS: 2 MIG: 0 OP: 1 PP: 0 SP: 2 WP: 2	IB: 4 ILF: 1 IS: 4 MIG: 0 OP: 0 PP: 1 SP: 3 WP: 0	IB: 1 ILF: 2 IS: 4 MIG: 1 OP: 0 PP: 0 SP: 1 WP: 1	IB: 6 ILF: 0 IS: 2 MIG: 0 OP: 3 PP: 4 SP: 2 WP: 0	IB: 19 ILF: 4 IS: 14 MIG: 1 OP: 4 PP: 7 SP: 10 WP: 3	<b>47 VOLS IN RECEIPT OF 8 DIFFERENT BENEFITS AND PENSIONS</b>
<b>TOTAL VOLUNTEERS PER GEOGRAPHIC LOCATION</b>	<b>8</b>	<b>10</b>	<b>11</b>	<b>7</b>	<b>11</b>	<b>47 VOL'S IN 5 DIFFERENT AREAS OF BRITAIN</b>	

Table 4.3 shows that 14 of the volunteers were in receipt of Income Support. This is a means tested benefit given to people whose income is below a pre-determined subsistence level (Paterson: 2001). As such it is a good indicator of relative poverty. All of the volunteers under 40 years of age were in receipt of income support; whilst only one recipient of IS was over 60. The fact that 30% of the volunteers were in receipt of income support reflects the data in relation to poverty and disability discussed in the literature review.

Twenty-four of the participants were in receipt of some sort of pension. Ten of these volunteers were below the 'official' retirement age, (currently 60 years for women and 65 years for men). This suggests that at least ten of the volunteers had contributed to an occupational or private pension scheme whilst in paid employment. However, the level of such pensions varied greatly and did not necessarily indicate a better standard of living - three of the volunteers in receipt of a private or occupational pension were also on Income Support. Four of the volunteers requiring the assistance of a fulltime carer used the ILF to employ a Personal Assistant.

The influence that financial issues played in shaping the volunteers' experiences is also discussed in chapters 5 and 6.

### **1.3. Geographical Location of the Study Participants.**

One of the main factors which appeared to determine the volunteers' experiences was where they lived. Those volunteers living in isolated or rural areas often needed to travel large distances in order to access volunteering opportunities, whilst those residing within urban areas had a plethora of volunteering opportunities from which to choose. Other geographical factors influencing the volunteers' experiences related to the financing of their organisations. This was particular the case for those volunteers residing in North Wales whose organisations were eligible for European assistance. Figure 4.4 overleaf gives a breakdown of the place of residence of the volunteers and volunteer managers.

**Figure 4.4: Geographic Location of Study Participants**

<b>GEOGRAPHIC LOCATION</b>	<b><i>N</i> VOLUNTEERS PER LOCATION</b>	<b><i>N</i> VOLUNTEER MANAGERS PER LOCATION</b>	<b><i>N</i> TOTAL</b>
NORTHERN ENGLAND	8	2	10
MIDDLE ENGLAND (MIDLANDS)	10	1	11
SOUTH EAST ENGLAND	11	0	11
WALES	7	0	7
SCOTLAND	11	0	11
<b>TOTAL</b>	<b>47</b>	<b>3</b>	<b>50</b>

#### **1.4. The Volunteers' Educational Background.**

One of the elements of the sampling framework presented in Figure 3.2 in Chapter 3 relates to the education of volunteers. Figure 4.5 overleaf depicts the volunteers' education in relation to the type of organisation in which they were engaged.

**Figure 4.5: The Volunteers Education in Relation to (Primary) Organisation**

	SPECIAL SCHOOLS		SECONDARY		F.E.		H.E.		TOTALS		
	M	F	M	F	M	F	M	F	M	F	ALL
<b>VOLUNTARY SECTOR ORGANISATIONS</b>											
<b>DISABILITY ORGANISATIONS</b>											
ORGANISATION of DISABLED PEOPLE	2	2	10	4	1	2	1	1	14	9	23
ORGANISATION for DISABLED PEOPLE			1	2	1			1	2	3	5
<b>CHILDREN AND YOUNG PEOPLE</b>		1				1				2	2
<b>RELIGIOUS ORGANISATIONS</b>			1			1			1	1	2
<b>ADDICTION SUPPORT</b>			1						1		1
<b>NATIONAL ADVISORY ORGANISATIONS</b>				1			1		1	1	2
<b>PUBLIC SECTOR ORGANISATIONS</b>											
NHS		1	1	1					1	2	3
SOCIAL SERVICES		1		1						2	2
EDUCATION			1					1	1	1	2
LOCAL GOVERNMENT		2	2						2	2	4
GOVERNMENT QUANGO'S					1					1	1
<b>TOTAL</b>	<b>2</b>	<b>7</b>	<b>17</b>	<b>10</b>	<b>2</b>	<b>4</b>	<b>2</b>	<b>3</b>	<b>23</b>	<b>24</b>	<b>47</b>

Most of the volunteers left school at the age of 15 or 16 years with only a few continuing onto further education. There was no apparent correlation between the

highest level of education attained and the type of voluntary work or level of responsibilities undertaken. With one exception, all of those volunteers who were engaged within organisations of disabled people in the capacity of Chair Person had left school at the age of 16 and had not attended any further or higher educational institutions. Most of these volunteers had not necessarily acquired the relevant knowledge and management related skills through their paid-work experience. Details of those involved as voluntary board members in respect of positions held and responsibilities undertaken are shown in figure 4.13 (page 155) and discussed in detail in section 2 and 3 of this chapter. Only one volunteer stated that she used the knowledge and skills attained as part of a university degree course to benefit the organisations in which she was engaged.

### 1.5. The Volunteers' Impairments.

All of the volunteers included within the study were living with either muscular-skeletal or neurological impairments. Seventeen were living with two or more impairments. Literature pertaining to the impairments of wheelchair-users and their medical reasons for using a wheelchair is non-existent. It is therefore impossible to determine whether the study sample is representative of wheelchair-users living within the UK, although the small size of the sample would suggest that this is unlikely to be the case. A breakdown of impairment in relation to gender is given in Figure 4.6.

**Figure 4.6: Impairment in Relation to Gender**

IMPAIRMENT CATEGORY	N MALE	N FEMALE	N TOTAL: IMPAIRMENT
MUSCULAR-SKELETAL	14	14	28
NEUROLOGICAL	17	14	31
CARDIO-VASCULAR	2	1	3
SENSORY (VISUAL)	1		1
LEARNING DISABILITY		1	1
<b>TOTAL - VOLUNTEERS:</b>	<b>23</b>	<b>24</b>	<b>47 VOLUNTEERS IN TOTAL: 17 WITH MULTIPLE IMPAIRMENTS</b>

Of the forty-seven disabled people included in the study, eleven were either born disabled or became disabled during childhood. The influence that such childhood experiences had in shaping the volunteers approach to volunteering is discussed in the following chapter in sections 1.4 and 4.1.

The most frequently reported diagnostic classifications were: Arthritis (11); Poliomyelitis (10); Spinal Cord Injury (8); and Multiple Sclerosis (8). The influence that such medical labels had on the volunteers' activities varied greatly between individuals depending upon a variety of social and medical factors including the level of impairment and the volunteer's individual attitudes towards their own impairment. The complex nature of such influences meant that the medical, social and medical-social approach to disability depicted within the organising framework (page 72) worked particularly well with grounded theory methodology affording a high degree of flexibility thereby enabling the volunteers' to fully explore and articulate all the influences upon their experiences. Such an approach allowed the volunteers' to express how their experiences were influenced by socially constructed barriers such as negative attitudes towards disability, or environmental barriers in the form of steps into premises. It also gave them the freedom to talk about how the symptoms of their illness or impairment also impacted upon their experiences. The most frequently articulated health associated symptoms to influence the volunteers' experiences were pain and fatigue.

#### **1.6. Assistance Facilitating Volunteering.**

One of the unforeseen factors influencing the volunteers' experiences was the need for some to utilise the assistance of a helper or carer in order to facilitate volunteering. Twenty-three of the volunteers required such assistance which was obtained from a variety of sources including paid carers and family members. This proved to be a major factor influencing the experiences of individual volunteers and as such is discussed in detail in sections 2.2 and 3.5 of the following chapter.

Another important contributory factor shaping the volunteers' experiences was the type of wheelchair used whilst volunteering (see figure 4.7 overleaf).

**Figure 4.7: Type of Wheelchair Most Used Whilst Volunteering.**

TYPE OF WHEELCHAIR USED	N MALES	N FEMALES	TOTAL
MANUAL WHEELCHAIR	15	15	30
ELECTRICALLY POWERED WHEELCHAIR OR SCOOTER	9	8	17
<b>TOTAL</b>	<b>24</b>	<b>23</b>	<b>47</b>

Many of those who used a powered wheelchair whilst volunteering had purchased their own chair in order to promote their own independence. Without powered mobility equipment these volunteers would have needed the assistance of a third-party to facilitate their activities.

All of those who used a powered wheelchair or scooter whilst volunteering also occasionally needed to use a manual wheelchair. The reason for this was related to environmental access – most powered wheelchairs cannot be manoeuvred up steps or across rugged terrain whereas manual chairs can be ‘manhandled’ into buildings.

### **1.7. Time Spent Volunteering.**

Figure 4.8 overleaf shows that the average hours per week spent volunteering was 15.6 per week for women and 18.2 per week for men. The age groups that, on average, spent the most time volunteering were men aged over 71 and women aged 41-50. However, the unequal distribution of the volunteers across the different age categories distorts these figures. The median number of hours spent volunteering was 17 for women and 36 for men. The mode however was 14 hours for women and 16 for men. Whilst such figures suggest that the male volunteers may spend a little more time volunteering than their female counterparts, the reasons for this were unclear –



but possibly reflected the fact that many of the women also had domestic responsibilities.

**FIGURE 4.8: Average hours spent volunteering by age & gender**

AGE (YRS)	NUMBER OF WOMEN IN SAMPLE – PER AGE	TOTAL HOURS PER WEEK: WOMEN	AVERAGE HOURS PER WEEK: PER INDIVIDUAL: WOMEN	NUMBER OF MEN IN SAMPLE – PER AGE	TOTAL HOURS PER WEEK: MEN	AVERAGE HOURS PER WEEK: PER INDIVIDUAL: MEN
21-30	1	2	2	1	10	10
31-40	3	45	15	2	45	22.5
41-50	2	61	30.5	3	45	15
51-60	11	156	14.2	10	182	18.2
61-70	5	74	14.8	6	84	14
71+	2	22	11	1	70	70
<b>TOTAL</b>	<b>24</b>	<b>360</b>	<b>15.6 (AVERAGE ACROSS SAMPLE)</b>	<b>23</b>	<b>436</b>	<b>18.2 (AVERAGE ACROSS SAMPLE)</b>

## SECTION 2: THE VOLUNTEERS' ACTIVITIES

Previous literature focusing on the experiences of volunteers has drawn attention to the voluntary activities undertaken by non-disabled volunteers. Very little research has been undertaken examining and analysing the volunteering activities of disabled people. Moreover the voluntary activities of wheelchair-users have not been subjected to social research or analysis. Thus there exists a clear gap in academic knowledge. This section of the chapter addresses this gap in knowledge by using the volunteers' verbal accounts of their activities.

Because the majority of the volunteers were engaged by more than one organisation, in which most of them undertook two or three different activities, the interviews concentrated on those activities they considered to be the most important. Each volunteer was consequently asked to restrict descriptions of their volunteering experiences to one area of activity within a maximum of two organisations. Figure 4.9 overleaf depicts the various voluntary activities discussed by the volunteers during the interviews (it does not show the other voluntary activities the volunteers were involved with).

**Figure 4.9: The Volunteers' Activities and Sector**

ACTIVITY	ADMIN	ADULT TUTOR	CLASS-ROOM ASST	COMMITTEE MEMBER - NON BOARD LEVEL	COUNSELLOR	DISABILITY ADVICE & INFO	DISABILITY AWARENESS TRAINER	DISABILITY RIGHTS CAMPAIGN	FUND-RAISER	SHOP WORK	TRUSTEE - VOLUNTEER BOARD MEMBER	YOUTH WORK	TOTAL NUMBER ACTIVITIES
<b>SECTOR</b>													
VOLUNTARY	1	2	0	6	4	6	2	2	2	1	26	2	54
PUBLIC	1	0	2	6	0	2	2	0	0	0	0	1	14
<b>TOTAL</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>12</b>	<b>4</b>	<b>8</b>	<b>4</b>	<b>2</b>	<b>2</b>	<b>1</b>	<b>26</b>	<b>3</b>	<b>68</b>

Previous research suggests that the most frequently undertaken voluntary activities are fundraising, organising events, and committee membership (Atwood et al: 2003). The majority of the experiences discussed during the interviews related to committee work, either as organisational trustees or as members of other committees. Only two of the volunteers were directly involved in fundraising activities whilst none discussed organising events. The nature of the volunteers' impairments meant that most of the activities discussed during the interviews were undertaken sitting down.

The following paragraphs illustrate the diverse nature of the activities undertaken using the volunteer's individual accounts of their experiences.

#### - **Volunteer Board Members (Trustees)**

The most frequently undertaken voluntary role was that of volunteer board member with 26 of the volunteers holding the position of volunteer board member. Whilst the high number of study participants engaged as organisational trustees makes the sample unrepresentative of volunteers in general, it is possible that it may not be unrepresentative of wheelchair-users who volunteer. However, a lack of previous studies in this area make it difficult to assess the representativeness of the voluntary occupations held by the research sample.

Of the 26 people holding a position on a voluntary board, 20 were engaged by organisations of disabled people and 6 by organisations for disabled people. All voluntary board members were required to attend regular meetings:



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## **2.1 Concluding Remarks to Section**

This section has shown the wide-range of voluntary activities undertaken by the wheelchair-users included within this study. The nature of some of the activities, such as peer-counselling and disability benefits advisors, meant that being disabled was an advantage for the volunteers as they were able to empathise with their clients and were thus able to offer a highly personalised service. It was evident throughout the interviews that the majority of the volunteers were highly motivated and dedicated to their volunteering activities. This is fully illustrated in the following section which provides an analysis of the volunteers' motivations.

## SECTION 3: THE VOLUNTEERS' MOTIVATIONS

This section is divided into two parts. In considering the volunteers' initial motivations for volunteering it begins by highlighting how the interviewees first became involved in volunteering. The first, and most frequently expressed reason for getting involved in volunteering was in response to an individual request to get involved. The second way in which the volunteers first became involved was by personally approaching the organisations in which they wished to volunteer and offering to help.

After considering how the interviewees first became engaged in volunteering this section then considers why they volunteer. Five different motivating reasons for volunteering are noted including: altruism; a desire to combat perceived negative stereotypes about disability; reciprocity; personal fulfilment; and a belief in an organisation's philosophy.

### 3.1. How the volunteers first got involved in volunteering.

#### - They were asked

Research suggests that the most usual reason for volunteering is in response to a personal request (Liao-Troth & Dunn: 1999, Davis Smith: 1992). This was also the case for the majority of the volunteers interviewed as part of this study:



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Many of the volunteers described how they used previously acquired work-related to skills whilst volunteering. Such skills proved to be a valuable asset with which they were able to make a notable contribution to their particular organisations.

- **To Make a Contribution to Society**

Although the desire to make a contribution to wider society through volunteering is described in the literature as a commonly-held motivation (Volunteer Centre UK: 1990) this did not appear to be the case for the majority of the interviewees. Many of them volunteered in order to help a small section of the community – other disabled people. One volunteer did, however, state that she began volunteering because she wished to make a useful contribution to society:



**3.3 Concluding remarks to section**

It is evident that the volunteers' reasons were in many respects similar to those motivations previously illustrated within the academic literature about volunteering in general. The main exception to this was the desire to contradict perceived stereotypes about disability. That none of the volunteers were motivated by a desire to help others living with a similar impairment, but were motivated to help other disabled people in general, was one of the surprising issues to emerge from the interviews – although this is supported by the fact that only a small minority of the volunteers were engaged by impairment focused disability organisations.

## SECTION 4: THE VOLUNTEERS' ORGANISATIONS

This section provides an analysis of the organisations in which the volunteers were engaged. A further analysis of the influence that the organisational setting of the voluntary work had on the volunteers' experiences is included in chapter 6.

The forty-seven volunteers interviewed during the study discussed their experiences in 40 different organisations, with many of them highlighting experiences within two different organisations or agencies. Figures 4.10 and 4.11 provide a breakdown of the different types of organisational setting in which the voluntary work took place. A complete list of the organisations included within the study is given in Appendix 5.

**Figure 4.10: Volunteer Distribution in Voluntary Organisations**

TYPE OF ORGANISATION	<i>N</i> VOLUNTEERS	<i>N</i> ORGANISATIONS (DISCUSSED IN INTERVIEWS)
<b>DISABILITY ORGANISATIONS</b>		
- ORGANISATION OF DISABLED PEOPLE	33	16
- ORGANISATION FOR DISABLED PEOPLE	12	5
<b>CHILDREN AND YOUNG PEOPLE</b>	2	1
<b>RELIGIOUS ORGANISATIONS</b>	3	3
<b>ADDICTION SUPPORT</b>	1	1
<b>NATIONAL ADVISORY AGENCIES</b>	3	3
<b>HOUSING ASSOCIATION</b>	1	1
<b>SENIOR CITIZENS' ORGANISATIONS</b>	1	1
<b>TOTAL</b>	<b>45 OF THE VOLUNTEERS INVOLVED WITH 1 OR MORE VOLUNTARY SECTOR ORGANISATION</b>	<b>EXPERIENCES IN 31 DIFFERENT VOLUNTARY SECTOR ORGANISATIONS DISCUSSED IN INTERVIEWS</b>

**Figure 4.11: Volunteer Distribution in Public Sector Organisations**

<b>TYPE OF ORGANISATION</b>	<b>N VOLUNTEERS</b>	<b>N ORGANISATIONS – (DISCUSSED IN INTERVIEWS)</b>
<b>SOCIAL SERVICES</b>	1	1
<b>HEALTH SERVICES</b>	4	3
<b>EDUCATION</b>	2	2
<b>LOCAL GOVERNMENT</b>	3	2
<b>GOVERNMENT QUANGO</b>	1	1
<b>TOTAL</b>	<b>11 VOLUNTEERS INVOLVED IN PUBLIC SECTOR ORGANISATIONS</b>	<b>EXPERIENCES IN 9 DIFFERENT PUBLIC SECTOR ORGANISATIONS DISCUSSED DURING INTERVIEWS.</b>

The above tables reveal that most of the volunteers were engaged in some capacity within the voluntary sector; the majority were involved with disability organisations. Eleven of the interviewees volunteered in the public sector; of these only two did not also volunteer within voluntary sector organisations. Although some of the volunteers undertook voluntary work within three or four different organisations, the interviews were focused on their experiences within the one or two organisations that they themselves identified as being those to which they were most committed. The maximum number of participants interviewed from one single organisation was ten; although of the eight volunteers interviewed from this organisation, five were also volunteering elsewhere. It should be noted that for much of the time the volunteers were engaged within organisations where they were the only wheelchair-user (although not necessarily the only disabled person).

Just over half of those interviewed as part of this study were volunteering within a local CIL (Centre for Integrated or Independent Living). These CILs, which are generic organisations of disabled people, were located throughout Great Britain and varied greatly in size and in the services they provided. The largest CIL in which the volunteers who took part in this study were located had an annual turnover of over £1million and employed 5 full time paid staff and over 100 volunteers. It also employed several out-reach workers and numerous care staff on a sub-contract basis. This particular CIL, located in the North of England, provided an array of different services to disabled people within its geographic locality including: a benefits advice service; a telephone help-line; peer counselling; disability awareness training; support with managing the Independent Living Fund; and management of some community care workers. The organisation was also involved in a limited amount of disability rights campaigning; although at the time of the interviews this was restricted to postal and other secondary campaigning methods as opposed to direct action. Whilst all of the volunteers and board members of this organisation were disabled, the Chief Executive, and three most senior managers were not.

Another one of the larger CILs visited during the study was located in North Wales. This organisation provided a variety of services to the disabled population living within its catchment area. It was originally founded by a local social-entrepreneur working on a voluntary basis and had grown in size to provide an array of different services; including numerous volunteering and leisure opportunities for local disabled people. In addition to this the organisation also provided various volunteering and leisure opportunities for local unemployed people regardless of disability status, many of whom were living on income support. Unlike the previously mentioned CIL, all of this organisation's employees were disabled, as were all of its board members.

The smallest CIL referred to by the volunteers was located within a Social Services Department Elderly Day Care Centre. This small agency was managed on a day-to-day basis by a handful of disabled volunteers. Despite having very little funding this particular CIL provided a benefits advisory service and a general telephone help-line for disabled people and their families. It had no paid employees and for its funding relied totally on financial assistance from the statutory services and on donations from members of the public.

Four of the five organisations for disabled people were impairment-focused organisations whose role was to offer support for people living with a particular medical condition or illness. These large organisations, which have charitable status, have branches and centres located throughout the UK. Two of the three volunteers within such organisations volunteered at a local branch or centre. Only one person included within the main study sat on the management board of an organisation whose primary function was to support people with the specific medical condition that he himself had been diagnosed with.

Other organisations of disabled people in which the volunteers were involved included those that focused on one single political or social issue. One such organisation campaigned vigorously for basic human rights for disabled people using direct action as a method of protest. Three of the organisations provided various leisure activities for disabled people including access to the open countryside and disability sport. Two of the Scottish organisations of disabled people provided disability awareness training to various businesses within their localities.

The management structure and funding mechanisms of the five large charities for disabled people differed greatly from that of the smaller organisations of disabled people. The charities were managed by non-disabled executives and governed by voluntary management boards primarily consisting of non-disabled professionals; whereas the majority of the smaller grassroots organisations were managed and governed by disabled people. The two largest CILs in which the volunteers were engaged were managed by non-disabled people, but governed by disabled people.

For many volunteers one of the major influences on their choice of voluntary organisation was the fact that they were themselves disabled and wished to help others in a similar position. Another important factor shaping their choice of voluntary organisation was environmental access. Figure 4.12 overleaf outlines the distribution of volunteers throughout the different organisations with regard to their primary impairments. As many of the volunteers were living with multiple impairments and were volunteering in more than organisation these figures do not correspond with those given in Figure 4.6 .

**Figure 4.12: Field of Voluntary Activity by (Primary) Impairment**

	N VOLUNTEERS LIVING WITH MUSCULAR – SKELETAL IMPAIRMENTS	N VOLUNTEERS LIVING WITH NEUROLOGICAL IMPAIRMENTS
<b>DISABILITY ORGANISATIONS</b>		
ORGANISATIONS of DISABLED PEOPLE	13	17
ORGANISATIONS for DISABLED PEOPLE	1	8
<b>CHILDREN AND YOUNG PEOPLE</b>	1	1
<b>RELIGIOUS ORGANISATIONS</b>	1	1
<b>ADDICTION SUPPORT</b>		1
<b>ADVISORY ORGANISATIONS</b>	1	2
<b>HOUSING ASSOCIATION</b>	1	1
<b>SENIOR CITIZENS' ORGANISATIONS</b>		1
<b>PUBLIC SECTOR ORGANISATIONS</b>		
- SOCIAL SERVICES		1
- HEALTH	4	
- EDUCATION	1	1
- LOCAL GOVERNMENT	1	2
- GOVERNMENT QUANGO		1
<b>TOTAL</b>	<b>24</b>	<b>37</b>

The influence that impairment had on the volunteer's choice of voluntary field is difficult to determine, however the above table reveals that two thirds of those volunteering within disability organisations were living with neurological impairments; whilst less than half of those within such organisations had muscular-skeletal impairments. This may reflect an increased requirement for good environmental accessibility by those volunteers living with neurological impairments, some of whom were paralysed and thus unable to walk at all.

Impairment did not appear to be a significant influence upon those volunteering within other voluntary fields; however the complex and individual nature of impairment meant that it was difficult to establish to what degree the volunteers' choice of voluntary field was influenced by the effect of impairment or disability.

#### 4.1. Volunteers and Governance

Just over half of the volunteers (twenty-six) held positions as volunteer board members within their organisations; twenty-five of them were located within organisations of disabled people. Figure 4.13 provides a breakdown of the positions held by the members of voluntary boards.

**Figure 4.13: Board Members & Position by Gender**

	CHAIRPERSON	VICE-CHAIR	TREASURER	OTHER TRUSTEES	TOTAL
MALES	7	2		4	13
FEMALES	5		2	6	13
TOTAL	12	2	2	10	26

Of those twenty-six sitting on voluntary boards, eleven took an active part in the day-to-day management of their organisations with four being solely responsible for the day-to-day routine management of their organisations. In addition to accepting responsibility for the administration of their organisation, these volunteers also managed personnel issues; taking responsibility for staff-pay and setting the shift patterns for both volunteers and employees. Throughout the interviews issues relating to the training of board members were raised. Such issues are discussed in chapters 5 and 6.

During the course of the interviews it quickly became evident that the majority of the volunteers were unwilling, or unable, to discuss management or governance issues in any great detail. This included those sitting on voluntary boards, many of whom were also reluctant to discuss their feelings regarding the manner in which their organisations were managed. Thus, this study can only provide a limited account of the volunteers' perception of management. Moreover, many of the volunteers were unaware of how their organisation was managed on a day-to-day basis. Despite this, all of the volunteers were encouraged to discuss managerial issues and were asked questions regarding administration.

All of the volunteers were asked whether they had signed any formal documentation outlining their voluntary responsibilities and duties; or whether they had a written task description. Of the forty-seven volunteers, six stated they had signed a formal volunteer contract and five recalled being given a written task description. Most of the volunteers were however, unsure whether they would have benefited from any formal documentation including a written outline of their voluntary duties.

Twenty of the volunteers felt they were clear about to whom they were accountable whilst volunteering. Eight of these stated they were accountable to their line manager, whilst ten believed that, as part of a disability organisation, they were accountable to the disabled people their organisation was established to serve. Two of the volunteers felt that they had a level of responsibility to the funders of their organisations.

The issue of equal opportunities was also discussed during the interviews. Eight of the volunteers engaged within the voluntary sector were aware of the existence of an equal opportunity policy, although none felt able to comment on its effectiveness. Conversely, of those engaged within the public sector, only two were aware of the existence of an equal opportunities policy. Both of these volunteers however, commented on what they perceived to be the ineffectiveness of such a policy.



One of the major organisational issues raised during the interviews was that of finance and volunteer expenses. Only five of the volunteers claimed expenses from the organisations in which they volunteered.

#### **4.2 Concluding Remarks to Section**

This section has drawn attention to the organisational context of the volunteers' experiences including the type of organisation in which they were engaged. That the majority of the volunteers were very reluctant to discuss managerial issues reflects the qualitative nature of the interviews; most preferred to focus on the issues they believed to be important, from their perspective as disabled volunteers.

## **SECTION 5: DISCUSSION AND CONCLUSION TO CHAPTER**

The lack of previous academic knowledge pertaining to wheelchair-users in general and disabled volunteers in particular, is noted throughout this study. The lack of previous social investigation has resulted in a notable dearth of empirical data about wheelchair-users and disabled volunteers within contemporary society. Thus, by providing a critical analysis of the empirical data that has emerged from this study, this chapter contributes to academic knowledge pertaining to wheelchair-users and disabled volunteers.

### **- Wheelchair Use and Impairment**

A prolonged and in-depth literature search failed to identify any previous academic studies describing the epidemiological, demographic, or other statistical characteristics of wheelchair-users. The impairments or diagnoses of wheelchair-users within the UK are not recorded within the academic literature. This study is therefore unique in that it highlights the medical reasons why a group of 47 volunteers needed to use a wheelchair whilst volunteering. That there are no comparative studies with which to contrast and evaluate the figures given in this chapter reinforces the uniqueness of the study. Moreover, by outlining the volunteers' medical reasons for using a wheelchair this study contributes to both disability and health related discourse.

### **- Wheelchair Type**

The lack of knowledge about wheelchair usage may reflect the fact that many wheelchair-users purchase their own equipment and do not rely on NHS wheelchair services. Figure 4.7 shows the different types of wheelchair used by the interviewees whilst volunteering. That 60% of the volunteers used a manual wheelchair and 40% a powered wheelchair may reflect price differences between the two. However, it may also reflect variations within the NHS eligibility criteria for the issuing of wheelchairs. Provision of powered wheelchairs varies greatly across the country. In South Staffordshire for example, having been assessed as eligible for a powered wheelchair a disabled person will then be placed on a list for approximately 3 years

before receiving a chair; whereas a few miles away in North Warwickshire the waiting time is half of this (BLT Wheelchair-User Group: 2005).

### **- Facilitated Volunteering**

The high number of manual wheelchair-users was a major factor in determining how many of the volunteers needed the assistance of a third-party whilst volunteering. Many such volunteers simply needed assistance mobilising their wheelchairs. But the lack of such assistance for some wheelchair-users constituted a considerable barrier to volunteering.

Twenty-three of the interviewees required assistance to facilitate their volunteering activities. The role played by facilitators in assisting disabled people to volunteer is discussed in greater detail in chapters 5 and 6. By drawing attention to the high numbers of interviewees requiring assistance whilst volunteering, this chapter contributes to current practitioner debates regarding shortages of volunteer labour. It seems that if voluntary and public sector organisations wish to attract more disabled volunteers some provision will have to be made to accommodate paid carers and family members who assist such volunteers.

Previous studies into volunteering have not considered the need of some disabled people to utilise the assistance of a third party in order to facilitate volunteering. Thus in drawing attention to the phenomena of facilitated volunteering this chapter makes a distinct contribution to academic knowledge about the experiences of disabled volunteers.

### **- Income, Poverty & Age**

The analysis of the volunteers' characteristics in section 1 of this chapter reveals the heterogeneous nature of the research sample. All the same, the manner in which disability is perceived and dealt with within contemporary society means that some similarities in the volunteers' social and economic backgrounds were inevitable. For example, all of the volunteers under 40 years of age were in receipt of income support (IS) and not in receipt of incapacity benefit (IB). The contributive nature of incapacity

benefit suggests that such volunteers had not previously earned sufficient wages, or paid sufficient National Insurance, to be eligible for IB. That three of the volunteers within this age category had never been able to secure full-time paid employment supports this contention. Income support is a subsistence benefit that is considerably less in monetary terms than incapacity benefit. This suggests that the younger study participants were more likely to experience high levels of poverty than their older counterparts.

By drawing attention to the unemployment experienced by the younger interviewees, this study supports previous academic work pertaining to disability and employment.

#### **- Activities**

Figure 4.8 reveals that the majority of the volunteers in this study were members of either voluntary management boards or other committees. These figures support previous research into volunteering indicating that committee membership is one of the most popular volunteering activities (Davis Smith: 1992). However, that only two of the volunteers were engaged in fundraising activities contradicts previous studies and suggests that unlike their non-disabled counterparts, physically disabled volunteers prefer not to get involved in fundraising. This may reflect the physically demanding nature of fundraising.

The volunteers' educational background in respect of voluntary field is given in Figure 4.5. This study found that the volunteers' highest level of educational attainment did not necessarily reflect the high level of fiscal, managerial or social responsibility accepted whilst volunteering.

#### **- Motivations**

The third section of this chapter focused upon the volunteers' motivations. It reveals that many of the interviewees began volunteering after being personally approached and asked to get involved. This well-recognised route into volunteering (NCVO: 1990) was not taken by all of the volunteers – some chose to directly contact a specific organisation and personally offer their services.

Having established how the interviewees accessed volunteering, section 3 of this chapter then considers the volunteers' reasons for volunteering. The most frequently expressed motivations, which reflect previous studies into volunteering, related to altruism, reciprocity and personal fulfilment (NCVO: 1990). Another (disability related) motivating factor for the volunteers' actions was the need to challenge negative stereotypes about disability. This previously undocumented motivation for volunteering relates directly to the volunteers' impairments. In drawing attention to the motivations of disabled volunteers this chapter makes a distinct addition to both voluntary sector and disability knowledge.

#### - **Organisational Issues**

In total the volunteers were engaged within a total of thirty-one voluntary sector and nine public sector organisations and agencies. The majority were engaged in more than one organisational setting, with over half volunteering within disability organisations. The high numbers of volunteers engaged within disability organisations reflects the practical requirement of a wheelchair-accessible environment – as most disability organisations were reasonably accessible.

One of the unexpected issues to emerge out of the research was the apparent lack of correlation between the volunteers' impairments and their choice of voluntary organisation. Only a small minority volunteered within impairment related organisations. By highlighting the apparent precedence given by the volunteers to physical accessibility over impairment when selecting an organisation in which to volunteer, this study contributes to voluntary sector discourse; furthermore it implies that in order to attract more disabled volunteers, volunteer managers should concentrate on issues related to access rather than impairment.

Organisations for disabled people are mostly managed and governed by non-disabled professionals. Subsequently they are not always totally accessible to wheelchair-users.

## CONCLUSION TO CHAPTER 4

One of the most unexpected findings was the small number of participants who volunteered within impairment related organisations or charities. Furthermore, only a small minority of the volunteers were members of such organisations. The reasons for this are difficult to determine but may be linked to a number of different factors:

1. During the early stages of the research process over 80 different disability-related organisations and agencies were contacted with a view to identifying suitable research participants. This included a large number of impairment related organisations. Although Multiple Sclerosis is the main cause of disability in young adults (Robinson et al: 2000), my own 'closeness' to this particular impairment group meant that for methodological and ethical reasons the principal organisation within England for people living with MS was not contacted. (However, other groups and organisations for people living with MS were contacted and members of such organisations included within this study).
2. All of the disabled participants interviewed as part of the study appeared to have 'come to terms' with their disability – and thus may have not needed the type of peer support offered by the larger organisations and charities for disabled people.
3. Over half of the volunteers were engaged within generic organisations of disabled people. Such organisations tend to actively encourage participation from all sections of the disabled community, and as such are usually highly accessible and representative of the disabled population as a whole.

In conclusion, this chapter draws attention to the wide-variety of tasks undertaken by the wheelchair-users interviewed as part of this study. The diverse nature of such activities reflected the different levels of expertise brought to the various organisations by the volunteers. Such expertise ranged from vocationally acquired skills associated with management and administration to personal life and communication skills gained through living with a disability. By utilising such skills to

the advantage of their organisations many of the volunteers took on high levels of fiscal, managerial and social responsibility; in doing so they made a considerable contribution both to the organisations in which they were deployed and to society as a whole.

#### **SUMMARY OF CHAPTER 4**

This chapter commenced by providing an analysis of the various demographic, epidemiological and other characteristics of the volunteer study participants. The second section of the chapter drew attention to the various activities undertaken by the volunteers included in this study. This section also provided an analysis of the amount of time spent volunteering.

The third section of this chapter focused on the volunteers' reasons for volunteering. It began by discussing how the volunteers first got involved and suggested that most got involved in response to a direct request for help. From this the volunteers' motivations for volunteering were analysed and included: altruism; the wish to contradict stereotypes; reciprocity; personal fulfilment; personal belief in an organisation's philosophy; and the desire to make a contribution to society.

The fourth section discussed matters relating to the organisations in which the volunteers were engaged and included where the volunteers were engaged; the distribution of the volunteers within voluntary and public sectors; the relationship between impairment and voluntary field; and issues surrounding governance.

The final sections of the chapter comprised of a discussion and conclusion. The discussion drew attention to the key points of the chapter and noted how the chapter contributed to current literature. The conclusion drew attention to the wide-range of activities undertaken by the volunteer study participants. It concluded by noting the sizeable contribution made by the volunteers to both to the organisations in which they were deployed and to society as a whole.

## ENDNOTES TO CHAPTER 4:

### [1] **Disabled Peoples' Rights and Freedoms Bill**

- This document is currently being written by the British Council of Disabled people (BCODP) and Disability Action Now (DAN). Its primary function is to secure the full and equal human and civil rights of disabled people living in the UK. The proposed Bill covers issues such as direct and indirect discrimination. Amongst other issues it also covers; the right to life,(anti-abortion on the grounds of disability); the right to have a family; the right to work; the right to secure independent advocacy; the right to work; the right to live independently; and the right for disabled people to receive sufficient welfare benefits to cover the unseen costs of disability. The Bill should be enforceable by law and be given precedence over all previous legislation.
- The Bill has not been adopted by any of the major UK parties (BCODP: 2004).

### [2] **DDA October 2004**

- This quote relates to one aspect of the Disability Discrimination Act (1995). With affect from 1<sup>st</sup> October 2004 all businesses and other service providers offering a service to the public are obliged by law to make that service accessible to disabled people. There are various exceptions to this law including: transport; education (covered by different legislation); and businesses housed in buildings with 'listed status'. Thus all businesses are required by law to make 'reasonable adjustments' to accommodate all disabled people, regardless of impairment. This includes mobility and sensory impaired people as well as those living with learning disabilities.
- With effect from 1/10/04, the DDA also covers employment. It is now illegal for any employer to discriminate against an individual on the grounds of disability. This includes disabled people going through the recruitment process, as well as those employees who become disabled whilst employed. (DRC: 2005).



## CHAPTER 5: THE VOLUNTEERS' EXPERIENCES

The aim of this chapter is to provide an analysis of the volunteers' perceptions of their voluntary experiences. In order to achieve this aim the chapter is divided into four sections each of which focuses on a different aspect of the volunteers' experiences. The perspectives and experiences of the three volunteer managers are also included when appropriate and attributed accordingly.

The semi-structured nature of the interviews meant that the volunteers were given the opportunity to discuss matters they felt to be important. As a consequence of this whilst the interview format remained consistent throughout the study, the character, depth and direction of the interviews varied greatly between individual volunteers. Thus the interviews reflected the diverse nature of volunteers' experiences.

The literature analysed in chapter 2 indicates that there is a wide gap in knowledge pertaining to the volunteering experiences of physically disabled people. Disabled people are generally perceived to be the recipients or beneficiaries of voluntarism rather than being the providers or instigators of any voluntary services. The volunteering experiences of the wheelchair-users interviewed as part of this study contradict this widely-held perception – particularly as many of the volunteers were living with severe physical impairments. Thus, by drawing attention to the many different aspects of the volunteers' perceived experiences, and by providing a critical discussion of such experiences, this chapter contributes to academic knowledge in both the disability and voluntary sector studies.

Page removed for restrictions.

### **SECTION 3: PERCEPTIONS OF PRACTICE: GENERAL EXPERIENCES OF VOLUNTEERING.**

There is a substantial body of academic literature about volunteering and voluntarism. However, much of this literature concentrates on conceptualising the term volunteer or volunteerism (Van Til: 1988, Cnaan et al: 1996, Davis Smith: 1998, Brudney: 2001); or on providing a statistical analysis of volunteer activities and motivation (Volunteer Centre UK: 1990, Lynn & Davis Smith: 1991, Liao-Troth & Dunn: 1999, Attwood et al: 2003). Thus, there remains a large gap in literature describing and analysing volunteers' own perceptions of their experiences. This gap is particularly noticeable when considering the experiences of disabled volunteers. This section aims to address this matter by drawing attention to volunteers' perceptions of their voluntary activities. It also draws attention to some of the associated issues that the volunteers identified as being integral to their experiences and perceptions of volunteering.

By drawing attention to different aspects of the volunteers' experiences, this section aims to contextualise those experiences which cannot be considered to be either positive or negative. Such experiences were concerned with: dealing with the general public; issues around governance and management; office relationships; impairment related issues; familial support when volunteering; and other influences on volunteering.

The following paragraphs use the volunteers' own accounts of their experiences to highlight different aspects of their perceptions of volunteering.

#### **3.1. Dealing with the general public**

##### **- Interacting with clients.**

All of the volunteers believed that it was important to undertake their voluntary work in a professional and knowledgeable manner. Such professionalism was particularly important given the often-sensitive nature of the client group:

## SECTION 4: DISCUSSION & CONCLUSION TO CHAPTER 5

### 4.1. Discussion of Findings

The aim of this section is to provide a critical discussion of the data presented in the previous three sections of this chapter. It considers the impact that various identified factors had on the volunteers' experiences including:

- Impairment and Disability:
  - Age:
  - Gender:
  - Organisational Matters:
  - Volunteering Matters:
  - Politics:
  - Location.
- 
- **Impairment & Disability**

For many of the volunteers, the manner in which disability impacted upon their volunteering experiences reflected the way in which they perceived their own impairment. Moreover, it seemed that perceptions of volunteering were often influenced by symptoms of individual impairments and illnesses. Thus, for most of the interviewees, the relationship between volunteering experiences and impairment reflected a complex mixture of biological, sociological, and organisational influences.

One of the most important influences upon the volunteers' experiences appeared to be whether they had been disabled during childhood. Of the forty-seven volunteers interviewed within this study, eighteen had been disabled children (eight were born disabled, nine contracted poliomyelitis during childhood and one became disabled as a baby as a result of a 'medical accident'). Such volunteers tended to view disability differently from those who became disabled during adulthood – and thus experienced volunteering in a different manner. This was most notable when interviewees were discussing issues surrounding disability discrimination. Many of the volunteers who had been disabled children did not view environmental barriers as being discriminatory; whilst some did not think that they had ever been discriminated

against on the grounds of disability. At the same time volunteers disabled during childhood tended to be more politically aware than those disabled as adults. This was reflected in comments made regarding government recognition for voluntary activities, the lack of statutory rights for volunteers, and the existence of a 'benefits trap' preventing some of the disabled interviewees accessing paid employment.

In addition to influencing perceptions of discrimination, childhood experiences were also relevant to those engaged as peer counsellors who generally believed that their lifelong experiences of disability enabled them to offer a more empathetic service to their clients, which then benefited other disabled people, parents of disabled children and the organisations in which they were involved.

Although, in the study, peer-counselling activities were only undertaken by those who had been disabled children, impairment appeared to have little effect on the whole upon the type of activities undertaken. It did however appear to be a factor shaping how many hours the volunteers contributed. Those volunteers who had become disabled early in life after contracting polio undertook the highest number of voluntary hours per week; whilst those living with MS, all but one of whom had become disabled as adults, undertook the least. Those living with degenerative conditions such as MS were more likely to identify issues associated with health as being a barrier to volunteering. Many of these volunteers frequently required the (voluntary) assistance of family members to facilitate their voluntary activities. Those living with spinal cord injuries required the most practical and personal assistance to access volunteering – but were also the most likely to receive such assistance from the government in the form of the ILF.

One of the most notable ways in which the disabled study participants' experiences differed from those of non-disabled volunteers was that almost half needed some sort of assistance whilst volunteering (see Chapter 4 section 1.6). For some, a lack of such assistance constituted a major barrier to participation. For others it provided the opportunity to involve family members in volunteering. Thus there was a high degree of familial volunteering within the study sample.

Although the nature of individual volunteers' impairments appeared to influence tangible aspects of their experiences, such as number of the number of hours spent volunteering or the amount of assistance required, it did not appear to impact upon on their perceptions of those experiences. Moreover, for some of the volunteers the most influential disability related factor impacting upon their experiences appeared to be the fact that they were wheelchair-users – the nature of their individual impairments was often a secondary consideration. Experiences of feeling different and of being patronised often seemed to be associated with the use of a wheelchair. The nature of the study sample means that is difficult to assess whether volunteers living with other impairments share such experiences, although the literature would suggest that the majority of disabled people feel alienated and stigmatised within contemporary society (Bates & Davis: 2004, Bradley et al: 2004, Locke et al: 2005, Zitzelberger: 2005).

- **Age**

The most significant age related factor influencing the volunteers' experiences was their perception of volunteering and employment. Those younger volunteers who had never held a paid position tended to perceive volunteering as a substitute for paid employment; whereas many of the older volunteers perceived it in terms of being a replacement for previous employment. Thus, for the younger volunteers, volunteering provided the opportunity to gain work related skills, whilst for the older volunteers it provided the opportunity to use previously acquired work related skills.

Such differences in perceptions reflect broader social issues about unemployment and disability. That three of the younger volunteers had never been able to secure paid employment reflects the experiences of many disabled young people who are denied the opportunity to earn a wage because of their disability (McClean: 2003, Smith-Randolph & Andresen: 2004). The perspectives of the older volunteers about volunteering being a replacement for previous employment suggests that one of the motivational factors shaping their experiences may be the wish to keep occupied.

## - Gender

As this study concentrated on the experiences of volunteers in relation to their disability, it does not provide a detailed analysis of the influence that gender plays in shaping volunteering experiences. However, during the data analysis it became apparent that some of the volunteers' experiences may have been influenced not only by their disability and age but also by their gender.

Twenty-six volunteers interviewed were involved as voluntary board members – of which half were male and half female. However, the majority of male board members held the position of chair or vice-chair, whilst women tended to hold more general positions. Gender related differences in voluntary board member positions may reflect variations in the volunteers' perceptions of the skills brought to volunteering. Whilst both genders perceived personal communication skills to be important factors shaping their activities; male voluntary board members were more likely to believe that previous experience of organisational management was one of the most important factors determining how they experienced volunteering; whilst many of the female board members believed life experiences of disability were the more important influence.

For the volunteers involved in non-governance related activities gender related differences in perceptions and influences were more difficult to identify. The exception to this was one of the female volunteers who believed that she was discriminated against on grounds of age and gender, and not because she was disabled.

## - Organisational Matters

This study has drawn attention to the perceived experiences of volunteers involved in a diverse assortment of voluntary activities within a relatively limited spectrum of voluntary fields (see Chapter 4: Figure 4.9). The influence that organisational factors played in shaping volunteers' experiences was linked to: the type and size of organisation; the economic sector in which it was located; and the manner in which the organisation was managed and funded.

In some voluntary sector disability organisations the volunteers perceived their activities as a type of mutual-aid – they wanted to help others in a similar position by providing advisory, welfare or counselling services. The high numbers of volunteers involved within such service providing organisations reflects recent changes in public policy regarding the provision of welfare services and the widening role of the voluntary sector (Forester Jones et al: 2002, Priestley & Rabiee: 2002, Claire & Cox: 2003). Within the study it may also indicate broadening perceptions of mutual-aid, which for many of the volunteers seemed not only to refer to the actions of small groups of people brought together for mutual support and empathy – but to also reflect the activities of those volunteers engaged in larger, service providing organisations (such as community transport or national advisory services).

Those volunteers involved in advocacy related activities were all engaged within public sector organisations. That the experiences of service-users are being utilised to benefit others by means of advocacy, suggests that the personal experiences (gained in the role of patient, client or service-user) is a valuable commodity for both public sector service providing organisations and the users of those organisations.

Perceived barriers to volunteering were described by volunteers involved within a wide range of different organisations. Environmental barriers were described by the majority of the volunteers; but particularly by those engaged within public sector organisations. The continued exclusion of disabled people from both public sector organisations and from public transport suggests that changes in the law regarding access are failing to make an impact (Napolitano: 1996, Barnes et al: 1999, Barnes: 2000, DRC: 2005). Moreover, the experiences of the disabled interviewees suggest that environmental barriers to volunteering are often underpinned by attitudinal barriers. Such barriers were reflected in negative attitudes towards disability held by some managers and other professionals in both public sector and voluntary sector organisations – including organisations of disabled people. In addition to this the volunteers' experiences suggest that some organisational cultures were based upon a philanthropic ethos that reinforced stereotypical images of dependency and helplessness.



Another important influence on the volunteers' experiences was a lack of formal training. Although difficulties caused by this issue appeared to be most acutely experienced by those engaged as voluntary board members, volunteers across a wide range of organisations identified inadequacies.

#### **- Volunteering Issues**

Some of the issues raised by the volunteers reflected previous literature about volunteering. Such issues were associated with: negative attitudes of paid staff and managers towards volunteers (Taylor: 1997, Pearce: 2001, Davis Smith et al: 2004); the value placed on volunteers and volunteering by paid staff and management (Rochester: 1992, Mc Curley & Lynch : 1998, Davis Smith et al: 2004); collegial relationships between volunteers (MacDonald: 1994, Mason: 1996, Davis Smith et al: 2004); and the need to balance volunteering and family life (Loeser: 1974, Obaze: 1992, Raynolds: 1999). It is evident therefore, that some of the volunteers' experiences were not associated with their disability but instead reflected issues relating to volunteering and volunteer management.

#### **- Politics**

A small number of the volunteers commented about the lack of recognition by government given both to disabled people as a whole and to the work undertaken by disabled volunteers. The literature records disabled people's feelings of disenfranchisement and overall dissatisfaction with the manner in which their concerns are dealt with by politicians (Oliver & Barnes: 1993, Walmsley: 1993, Oliver: 1996, Charlton: 2000). This suggests that some of the volunteers' feelings about the way in which their volunteering and campaigning efforts were overlooked by politicians is indicative of political and social attitudes towards disability.

#### **- Location**

The volunteers' place of residence was an important factor in determining the type of voluntary work available and how they were able to access volunteering. Those volunteers residing within rurally isolated areas had fewer volunteering opportunities

from which to choose. For many such volunteers problems identifying suitable voluntary activities were augmented by transport difficulties.

## **CONTRIBUTION TO KNOWLEDGE: CHAPTER 5**

This chapter commenced by noting the gap in academic knowledge about the volunteering experiences of physically disabled people. By drawing attention to the disabled research participants' perceptions of their volunteering experiences, this chapter addresses that gap. In particular it draws attention to the perceived benefits of, and barriers to, volunteering for physically disabled people. In providing an in-depth analysis of different aspects of the volunteers' daily experiences, this chapter also highlights some of the distinct issues faced by disabled people whilst volunteering.

## **CONCLUSION TO CHAPTER 5**

The issues raised in this chapter relate to the volunteers' perceptions of their volunteering experiences. It was noteworthy that many of the research participants experienced volunteering in a deeply personal way – particularly in relation to the influence that disability had upon their activities. What some volunteers perceived to be a barrier, others viewed either nonchalantly or as a challenge to be overcome. Furthermore, whilst many of the benefits to volunteering were individually perceived they were often collectively experienced. This suggests that for the volunteers interviewed for this study, perceptions of volunteering were the result of a complex mixture of personal, organisational and societal influences.

## SUMMARY OF CHAPTER 5

The first section of this chapter focused on the perceived benefits of volunteering. The interviews revealed that from the volunteers' perspectives the benefits of their voluntary activities were five-fold. Their activities benefited the volunteers' themselves; other disabled people; the general public; the organisations in which they were engaged; and external organisations and agencies. Whilst enjoyment of volunteering was identified as being one of the key personal advantages of volunteering for many of the volunteers, for others the main perceived benefit was a marked improvement in their mental health. The majority of the volunteers believed that by volunteering they were able to utilise various skills acquired during previous paid employment to benefit the organisations in which they were placed. In addition to this the majority of the volunteers felt that their voluntary activities provided them with the opportunity to use their interpersonal and other life skills in a manner that directly helped other disabled people.

The second section of the chapter then highlighted the barriers to volunteering as seen by the volunteers: environmental barriers; personal barriers; attitudinal barriers; and organisational barriers. Environmental barriers were experienced in three different ways: external physical barriers in the built environment such as steps and narrow doorways; internal physical barriers within organisational buildings such as insufficient hand-rails and inaccessible toilets; and transport related barriers caused by inaccessible public transport. Personal barriers related to individual health and personal finance, whilst attitudinal barriers related to negative social attitudes towards disability. The final perceived barriers to volunteering identified in this chapter related to organisational policies and procedures.

Other matters raised in this chapter included: dealing with the general public; issues around governance and management; office relationships; impairment related issues; familial support when volunteering; and other issues including the perceived relationship between paid work and volunteering. The final section of this chapter contextualised the volunteers' experiences by providing a critical discussion of the volunteers' experiences including: impairment and disability; age; gender; organisational matters; volunteering issues; politics; and geographic location.

## NOTES TO CHAPTER 5:

### 1. **Inaccessible public transport:**

Of the 18 towns and cities visited during the course of the study none provided a public transport system that I as a wheelchair-user was able to access. Thus it would have been impossible to undertake this study using public transport! However, four of the locations did provide a separate 'ring and ride' system which specifically catered for elderly and disabled people living within a specific area. Two of these 'ring and ride' services were funded and managed by the voluntary sector. At present the Disability Discrimination Act (1995) does not adequately cover public transport. Whilst all trains have to be accessible, railway stations do not. Bus and Coach Operators have until 2025 to make their transport fully accessible to disabled passengers (DRC: 2005)

### 2. **Resignation of volunteer from post because of barriers to volunteering:**

Six months after being interviewed I was contacted by Julie who stated that she had been forced to stop volunteering as Treasurer of her local CIL for a number of reasons. Whilst her health had deteriorated this was not the primary reason for her decision. She explained that the (non-disabled) Chief Executive in charge of her organisation had refused to acknowledge that she had disability related needs; furthermore she felt under pressure to contribute as many hours as paid employees, which in itself added to her discomfort. For Julie the act of volunteering in the position of treasurer at this particular organisation was causing her to feel disabled. Consequently she resigned from the CIL to become an 'episodic' volunteer at a local Health Care Trust (MacDuff: 2005)

### 3. **Position of counselling supervisor**

In his role as a counselling supervisor Harry was required to 'supervise' the case-load of the other counsellors employed by his organisation. This involved offering support and (when appropriate) counselling, to his voluntary colleagues.

#### **4. The benefit system as a barrier to work.**

All of the volunteers were in receipt of DLA (see chapter 4, Section 1.2).

Those volunteers who were also in receipt of income support felt unable to accept paid work as this would mean losing both income support, incapacity benefit/SDA and housing benefit (Paterson: 2001). Thus, because they were not physically able to work full time, they felt trapped by what they perceived to be an inflexible welfare system.

## **CHAPTER 6: DISCUSSION: EXPLAINING THE FINDINGS AND REFLECTING ON THE RESEARCH**

There is little literature which attempts to explain the experiences of volunteers generally and disabled volunteers in particular. Thus, the aim of this chapter is to provide explanations for the experiences of the volunteers studied, building theory grounded in the empirical data. The chapter begins with a resume of the starting research questions and organising framework.

The first section of this chapter utilises the organising framework to explain the volunteers' experiences from a medical, social and medical-social perspective. Section 2 then provides a summary of those experiences which are not explained by the organising framework (either partially or fully). A summary, which is given in tabular form, highlights theoretical explanations for the volunteers' experiences and suggests that in addition to medical, social and medical-social factors, there are various other important influences upon the volunteers' experiences.

The final section adopts a reflexive approach to contextualise the research process from my own perspective as a disabled researcher conducting research into the lived experiences of other disabled people. The thesis concludes by drawing attention to the implications of the study for future research.

## **SECTION 1: EXPLAINING THE VOLUNTEERS' EXPERIENCES USING THE ORIGINAL ORGANISING FRAMEWORK**

This section commences by re-capping the research questions set out in the methodology chapter (section 1.1). A diagram of the original organising framework is given together with an account of how this framework may be used to explain the volunteers' experiences as found in the empirical study and set out in Chapters 4 and 5.

### **1.1. Contextualising the Problem: The Research Questions.**

The literature review in chapter 2 (section 3.2) drew attention to the lack of knowledge about the experiences of disabled volunteers. The research questions that emerged out of the literature review are outlined in Chapter 3 (section 1.1) thus:

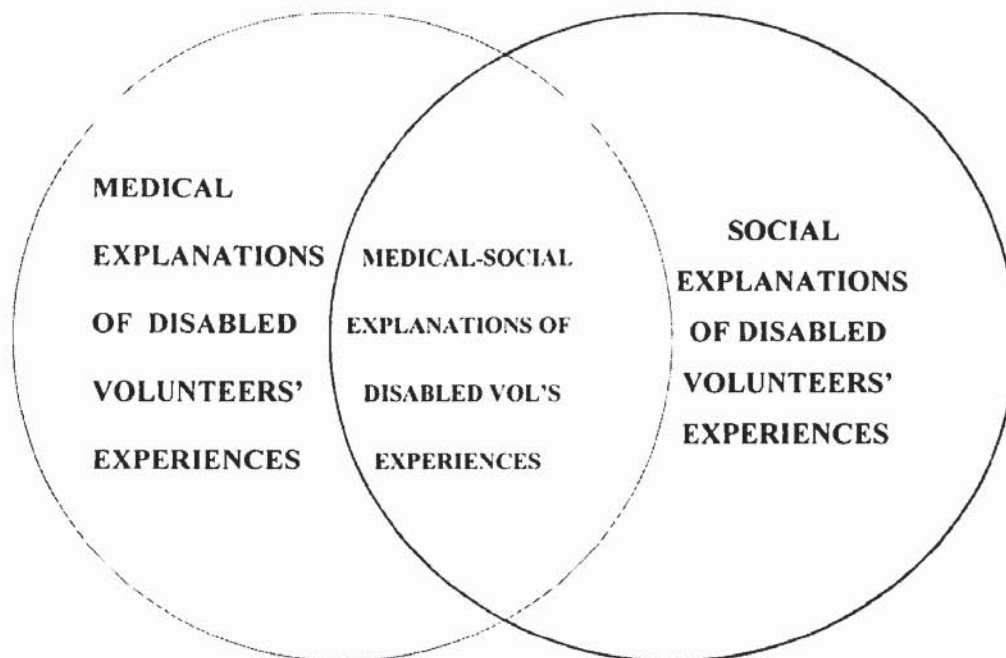
- What are the experiences of those disabled volunteers who need to use a wheelchair whilst volunteering?

The sub-research questions take a wider perspective and build upon the theories used in the formulation of the organising framework:

- How are the volunteers' experiences shaped by medical influences?
- How are the volunteers' experiences shaped by social influences?
- How are the volunteers' experiences shaped by a combination of medical and social influences?
- What other issues impact upon the experiences of wheelchair-users who volunteer?

The following paragraphs consider how the original organising framework may be used to explain different aspects of the volunteers' described experiences. Figure 6.1 overleaf illustrates how the framework may be used as an explanatory tool.

**Figure 6.1: The Original Organising Framework as an Explanatory Tool**



As discussed in Chapter 2 (section 3) previous voluntary sector literature linking health related matters, social participation and volunteering has tended to draw attention to the experiences of non-disabled and older volunteers, (Dorfman: 1995, Schervish & Havens: 2002, Hadden: 2004). Moreover, contemporary disability discourse generally focuses upon social model approaches whilst ignoring the impact that medically grounded influences and experiences can have on disabled people's experiences (Oliver: 1996, Barnes: 1998). Figure 6.1 shows how both of these perspectives are relevant to the experiences of physically disabled volunteers. It suggests that some of the volunteers' experiences are explained by social factors, some by medical factors and some by a combination of the two.



Using the organising framework as an analytical tool, the following paragraphs attempt to explain the volunteers' accounts of their experiences using a medical, social and medical-social approach. This approach involves bringing together two seemingly opposed perspectives by considering all of the medical and social determinants of disability. In addition to this the approach detailed within the original organising framework accounts for the heterogeneous nature of the disabled population in relation to impairment and illness whilst accepting the homogeneous nature of experiences reflecting socially constructed barriers. Basically, it acknowledges that whilst many socially constructed barriers to society may result in shared experiences of disability discrimination or negative social attitudes towards disability, health related barriers such as illness, fatigue and pain are always individually experienced and perceived.

The following paragraphs follow a similar format to chapter 5. This section therefore begins by applying the original organising framework to explain, as far as possible, the perceived benefits of volunteering. Five different beneficiaries of the volunteers activities were identified during the study: the volunteers themselves; other disabled people; the organisations by which the volunteers were engaged; the general public; and other organisations and agencies.

## **1.2. Explaining the Perceived Benefits of Volunteering**

For many of the volunteers one of the main personal advantages of volunteering was that it provided a substitute or replacement for paid employment. Although the majority of the volunteers were of working age, only three were in fulltime employment. Such high levels of unemployment reflect the disabled population as a whole (Hahn: 1997, Charlton: 2000, Oliver: 2003). Using the organising framework it seems that a combination of medical and social factors interacted with each other to reinforce the barriers to employment faced by the disabled volunteers (Vickers: 2001, Hubbard: 2002). For example, the three younger volunteers for whom volunteering was perceived to be a substitute for paid work, described both socially constructed and medically derived barriers to employment. Health related issues such as pain and fatigue meant that they were unable to work fulltime. Each was willing to work part-

time but prevented from doing so because of the manner in which the state welfare benefit system is constructed.

For the majority of the disabled study participants, volunteering provided the means by which they were able to fill a personal void caused by forced unemployment and prolonged economic activity. For such individuals volunteering was perceived as a replacement for previous paid employment. It provided them with the opportunity to combat socially derived barriers such as negative attitudes towards disability and state regulations about disability benefits whilst enabling them to promote their own health and overall well-being. It also provided the means by which they were able to maintain links with the world of work whilst utilising previously gained employment related skills to combat negative stereotypes about disability. In sum, for the majority of the volunteers, the physical symptoms of illness and impairment were aggravated by socially constructed barriers to work such as the benefits trap and prejudicial attitudes towards disability. Volunteering afforded the flexibility for them to make a positive contribution to society whilst balancing personal health needs with the requirements of their voluntary organisations.

In addition to the perceived individual benefits of volunteering many of the volunteers also believed that their voluntary work benefited other disabled people. That so many of the volunteers were engaged by organisations that provided services to disabled people is indicative of recent shifts in welfare provision from the public to the third sector under the guise of New Public Management, (Billis: 1993b, Deakin: 2003). The experiences of those volunteers involved in service provision to other disabled people may partially be explained using the organising framework. For example, for those volunteers involved in counselling, the services offered to the public were influenced by a number of different factors including: their own particular health circumstances; life experiences; personal interests, attitudes and abilities. Likewise, in addition to being influenced by their own health and well-being, the experiences of those volunteers involved in welfare benefit advice were also influenced by the complicated design of disability benefit claim forms (Johnson: 2001, Paterson: 2001), negative social attitudes towards disability and feelings of stigma associated with the claiming of social benefit (Alland: 2002, Beresford et al: 2002). Such a complex accumulation of medical and social factors shaped each aspect of the voluntary experience –

including the volunteers' interactions with their organisations' clients and service users.

The majority of the volunteers were engaged within the disability field. Many had themselves successfully made the transition from being fully employed reasonably able-bodied and healthy individuals to being unemployed and disabled. In many instances such circumstances forced the volunteers to live on a restricted income. From the perspectives of the disabled volunteers interviewed as part of this study, many of whom were reluctantly forced into unemployment, the physical, emotional and social aspects of disability contributed to an invisible stigma, (Goffman: 1963, Abberley: 1993). Such stigmatising factors made the volunteers' previous employers reluctant to support disabled employees (Vickers: 2001). Thus, for those volunteers reluctantly forced into unemployment, volunteering provided the ideal situation with which they were able to put previously acquired work related skills to good use. The previous employer's loss became the volunteers' organisations gain. The volunteers, who were driven by both medical and social factors, were able to offer a rich assortment of managerial, technological, accounting and other work-related skills – all of which were 'freely' acquired by the organisations in which they were deployed.

Employment related skills were not the only benefit the volunteers believed they were able to offer their organisations. For many, the most useful resource they felt able to offer their organisations reflected interpersonal skills acquired whilst living life as a disabled person; such skills were put to use when dealing with health care and other professionals on behalf of their organisations' clients. When considering the influence that life-related skills played in shaping the experiences of the volunteers it is reasonable to assume that such skills reflected the multifaceted nature of their lives. With one exception, all of the volunteers described the impact that living with a chronic health condition had on their personal outlook on life. Likewise, many described how they had personally experienced socially constructed barriers and negative social attitudes towards disability. The intertwined nature of the medical and social influences on the volunteers' experiences is particularly relevant when considering how their personal attitudes and opinions impacted upon volunteering experiences. By using all of their life skills and experiences the volunteers were able

to offer their organisations a distinct perspective and insight – and were subsequently able to offer their organisations’ clients a sensitive yet diverse service.

### **1.3. Explaining the Perceived Barriers to Volunteering.**

Life-experience also played an important role in shaping the volunteers’ attitudes towards barriers to volunteering encountered during the course of their voluntary activities. Chapter 5 discusses how such barriers can be classified into four different areas: environmental barriers; personal barriers; attitudinal barriers and organisational barriers. Environmental barriers were then further divided into three different categories: external barriers; internal barriers and transport related barriers. Each of these is now explained using the original organising framework.

The marginalisation of disabled people indicative of a lack of access to the built environment is well documented (Oliver: 1990, Napolitano: 1996, Barnes: 2000). Moreover, social alienation resulting from inaccessible public transport is also frequently portrayed within disability literature (Hasler: 1993, Barnes et al: 1999, Gleeson: 1999). For the wheelchair-users, access related problems were an everyday occurrence, experienced both in and out of the volunteering environment. Although contemporary disability literature tends to conceptualise and explain access related problems in terms of the social construction of disability (Oliver: 1990, Napolitano: 1996) for the majority of the volunteers it was not that simple. Many described how access related problems were not only caused by an inaccessible physical environment but were also related to their own personal health. The ability to access a particular building and take part in volunteering depended not only on the nature of the built environment but also on personal health circumstances on any given day. In such cases access problems reflected continually changing interactions between socially constructed and medically derived barriers.

Using the approach depicted in the original organising framework health related factors such as fatigue and pain need to be considered alongside socially constructed barriers when explaining the volunteers’ experiences. For the majority of the volunteers, access-related issues reflected a combination of medical and social factors; dependent not only on socially constructed barriers but also on their

individual state of health and overall well-being. Thus access-related issues were perceived differently by individual volunteers, dependant upon their impairment and ability to stand and walk, and on their general health and well-being. Most could, with the assistance of a walking aide climb up one or two steps, and so were able to gain entrance to some premises that were not totally 'barrier free'; however those volunteers unable to weight-bear [1] (just under a third of the total) were always excluded from any premises with 'stepped' rather than level entrances. Such differences in perceptions and experiences of access-related issues reflected the heterogeneous nature of the research sample. The approach depicted within the organising framework can be utilised as an explanatory tool to account for access related issues as it is flexible enough to account for different experiences and perceptions of socially constructed and health related barriers to volunteering.

Personal matters relating to finance and health constituted the second barrier to volunteering described by the volunteers, the majority of whom were living on means-tested state benefits and were thus subsisting on a low income (see Chapter 4, Figure 4.3). The correlation between social and economic deprivation and the need to rely on means-tested benefits is reflected in the academic literature (Titmuss: 1968, Barnes: 2000, Lister: 2003). For the volunteers such financial difficulties reflected an accumulation of various medical and social factors. The majority of volunteers had previously held paid positions; however, the sudden onset of (or deterioration in) physical impairment or disability resulted in health related difficulties that meant they were no longer able to undertake paid employment and were thus reliant on state welfare benefits for most or all of their income. Inadequacies in the social benefits system meant that many of the practical costs of disability were not adequately accounted for; this in itself intensified difficulties associated with living with a physical impairment or illness.

Like financially related matters, perceived barriers to volunteering linked to health can be partly explained using the original organising framework. Issues relating to health and illness are usually conceptualised within the medical model of disability (Moon & Gillespie: 1995, Purdy & Banks: 2001, Nettleton & Gustafsson: 2002). However, for many of the volunteers, health related barriers to volunteering were augmented and reinforced by socially constructed factors such as limitations in the

provision of NHS wheelchairs (empower: 2005) and negative social attitudes towards disability (Oliver: 1990, 1996, Borsay: 2005).

Such negative social attitudes towards disability formed the third perceived barrier to volunteering. On the surface this barrier appeared only to reflect the ethos of the social model of disability. However, the disability literature suggests that negative social attitudes reflect the medicalisation of disability and are thus rooted in medically derived opinion and stereotypes (Oliver: 1990: 1996, Barnes et al: 1999, Leach Scully: 2002). From the volunteers' perspectives the consequences of such medical hegemony within society was manifested in experiences of being patronised or ignored which were then compounded by feelings of stigma and exclusion. It is therefore evident that a combination of medical and social factors interacted to create and augment social barriers.

Negative attitudes towards disability were also evident in the fourth perceived barrier to volunteering, organisational barriers. Such barriers reflected a complicated mixture of medical, social and organisational factors and as such can be partly explained by the organising framework. However, in taking a medical-social approach it is possible to postulate that organisational factors may have acted to exacerbate any health related or social barriers encountered by the volunteers.

#### **1.4. Explaining the Volunteers' General Perceptions of Volunteering**

The third section of chapter 5 considers the volunteers' perceptions of their general experiences of volunteering. The first such experience which may be explained using the organising framework relates to the perceived 'benefits trap' described by three of the younger volunteers, all of whom were discouraged from working because they feared they would suffer financially. The previous paragraphs suggest that for these three, volunteering was perceived to be a replacement for paid work. Such perceptions reflected the multifarious nature of their personal lives and volunteering experiences and as such were influenced by both medical and social factors. The nature of their impairments meant that they were physically unable to work fulltime; whilst the socially constructed benefits system failed to take account of the fact that, like many disabled people, they were only fit enough to work a few hours a week. Thus these

three volunteers felt 'trapped' – unable to accept part-time employment because of penalties within the benefits system, yet unable to work fulltime because of health restrictions.

Earlier paragraphs considered how perceived negative social attitudes and discriminatory behaviour towards disabled people, and the resultant barriers to volunteering may be explained by the original organising framework. Three of the volunteers viewed episodes of discrimination or negative behaviour towards them as disabled people to be non-problematic. Rather than perceiving discriminatory behaviour as a barrier to volunteering, each of these volunteers viewed it in a down-to-earth almost blasé manner refusing to allow themselves to feel discriminated against. Two volunteers also described feeling that their disability was an advantage whilst volunteering. The organising framework partly explains such perceptions because they reflect an elaborate mixture of medical and social influences. These volunteers appeared to accept the physical limitations associated with their medical condition whilst viewing socially constructed 'barriers' as non-problematic. In addition to medical and social factors such perceptions may also have been influenced by other factors such as individually held attitudes towards disability and health.

Another experience which can only be partly explained by the organising framework was the need for some volunteers to rely on assistance from another person to facilitate their activities. The importance of such help in promoting independence is well documented (Martin et al: 1988, Morris: 1993, Vasey: 1996, Charlton: 2000) although there have been no previous academic studies examining disabled volunteers' experiences of 'facilitated' volunteering. From the approach outlined in the organising framework, facilitated volunteering reflects how medically related needs and socially derived barriers may be simultaneously overcome by the employment of another person (irrespective of whether that person is a paid employee or a volunteer).

The final experiences which may to a certain extent be explained by the organising framework again related to social attitudes towards disability. Two of the volunteers described how, in the course of their activities, they encountered people living with painful medical conditions. Medically associated symptoms of pain and fatigue can

often be compounded by feelings of frustration towards socially derived barriers. As wheelchair-users themselves, the volunteers were able to empathise with such feelings and experiences. Another attitudinal matter dealt with by the volunteers in the course of their activities was the perceived need to promote a positive image of disability amongst NHS staff. Historically, when referring to disabled people, medical professionals have promoted images of dependence and vulnerability, (Morris: 1996, Barnes et al: 1999). In order to rebut such attitudes the volunteers involved in NHS staff training felt the need to show disability in a positive light.

### **1.5. Concluding Remarks to Section**

This section has used the original organising framework to provide an explanation of some of the volunteers' experiences from a medical, social and medical-social perspective. Some of the experiences described within this section, such as the influence of pain and fatigue, were mostly health related and thus explained by a medical approach to disability. Others, such as the benefits trap, were totally socially constructed and thus explained by a social approach. However, most of the experiences were explained by a combination of medical and social influences (ie. a medical-social approach).

The following section continues by identifying and explaining those experiences that are not explained by the original organising framework (either fully or partially). It commences by summarising, in tabular form, both medical and social explanations for the volunteers' experiences and suggests possible alternative (or additional) theoretical explanations for such experiences.



## SECTION 2: THE RESEARCH JOURNEY

The aim of this final section is to discuss different aspects of my own 'research journey' thereby contextualising the matters discussed and analysed thus far from my own perspective as a disabled researcher undertaking social investigation into the lived experiences of other disabled people. In order to achieve this aim three separate vignettes are given. A reflexive approach is utilised to contextualise the interviews and fieldwork processes by considering how my own personal background, experiences and assumptions contributed to the construction of the research situation and thus impacted upon the research interviews (Giddens: 1991, Alvesson & Skoldberg: 2000, Doane: 2003, Finlay & Gough: 2003).

The usefulness of the vignette as a methodological tool for discussing sensitive or delicate issues is reflected in the academic literature. This suggests that during the writing-up stage of the research process, a reflexive researcher can utilise vignettes to comment on how personal issues (or any other exogenous or unpredicted circumstances) may have impacted upon the research interview - thereby affecting the researcher's conduct or the tone of the interview (Hughes: 1998, Brewer: 2000, 2004, Bryman: 2001). Excerpts from the research journal and brief contemporaneous notes made during the course of the interviews are therefore used to enrich the data already reported. This narrative is also intended to provide further contextualisation – particularly relating to the immediate and wider circumstances in which the research was pursued. Excerpts from the journal are shown within the vignettes by the use of an italic font.

This highly sensitive and often personal discussion contributes to the uniqueness of the thesis whilst also informing disability discourse and qualitative methodology literature. The need to maintain an ethical approach at all times means that confidentiality is particularly important when reflecting upon one's research. Therefore, in order to guarantee total anonymity all pseudonyms used in this part of chapter 6 differ from those used in the main research project.

## 2.1 Managing Disability & Fieldwork: A Personal Insight.

In addition to dealing with all the usual, yet unpredictable, occurrences that can disrupt the smooth running of the fieldwork (such as participants arriving late for an interview or not keeping pre-arranged appointments) the need to manage the ever-changing and occasionally severe symptoms of my own impairment became a defining feature of my experiences in the field. The following vignette reflects on such experiences highlighting some of the health-related difficulties and triumphs of my own 'research-journey'.

### **Managing MS & Research: A Personal Perspective**

Undertaking social research whilst living with Multiple Sclerosis was not easy. Constant fatigue and pain, together with intermittent episodes of paralysis, double vision and other more personal symptoms had the potential to overwhelm the research processes:

*21/4/03: Woke up today totally and utterly exhausted. Not sure how I found the energy to get out of bed – but did..... Thanks to a bit of help got to interview on time and managed OK...*

*17/7/03: The travelling is taking its toll. Am totally exhausted today... The pain is getting too much...*

*6/9/03: My pain levels are exceptionally high today, in fact my whole body feels as if I've been invaded by 'hot irons' causing deep burning sensations which appear randomly and are made worse by the pain in my spine which has twisted rendering me almost paralysed..... Today's interview was a bit hard but I managed to concentrate and see it through to the end in fact it was a good interview...*

The need to manage the pain became a major consideration, shaping how and when the interviews were arranged. Careful pre-planning of each day meant that rest and recuperation were balanced with interviews and travel. The almost impossible task of managing the fatigue was achieved by keeping the amount of travel, in any one day, to a minimum. This meant that in addition to organising the interviews into geographic clusters, I arrived at the interview destination the day before the appointments were arranged.

**Continued...**

The interview schedule was carefully planned; interviews were limited to a maximum of two per day and every third day kept free. In short, 'self-management' of my symptoms became a central feature of the fieldwork facilitated by the employment of a driver/helper and driven by my intense determination to succeed. From a personal perspective, the need for me to present a professional and objective face for each of the participants was of paramount importance to both myself and to the research process:

*1/7/03: ... despite the pain I feel the interview went well. I soon forgot my own discomfort and became engrossed in what I was doing...*

*14/7/03: Have upgraded my painkillers over the past two days to deal with the pain. Although I don't like taking dihydrocodeine it does allow me to function and carry on... today's interview went well.. feeling quite good...*

*30/8/03: Interviewed two people today... I feel as if I deserve a medal. I kept smiling, ignored my own discomfort and focused on the task in hand - the interviews. In fact I found that my refusal to let my disability affect the quality of my work meant that by the time I had finished the first interview I had totally forgotten that I feel horrendous and was completely immersed in what I was doing and what the participant had said. Good stuff. However, am totally fatigued and falling asleep now...*

MS is an ever-present part of my life, the symptoms of which vary from day-to-day, week-to-week and occasionally hour-to-hour. Thus, the need to maintain a flexible, yet focussed, approach is necessary in all aspects of my life. Moreover, the unpredictable nature of MS meant that the strategies adopted in relation to the fieldwork needed to be applied throughout each stage of the research process.

The tone of the above citations reflects the content of the journal as a whole, which was generally used to record my personal thoughts and perceptions about what it felt like to undertake social research whilst living with Multiple Sclerosis. In this respect, the journal provided a valuable tool which enabled me, for the first time since becoming disabled, to reflect on how everyday activities impact upon my physical and psychological well-being. By adopting a professional persona I was able to ignore my own discomfort and pain and concentrate on the task in hand – the research interviews. Moreover, the importance of reflexivity in enabling me to portray such an

image throughout the fieldwork cannot be understated – particularly in relation to how I perceived and dealt with the participants, many of whom were living with what were, on the surface, extremely disabling conditions.

## **2.2 Dealing With Others' Disabilities Whilst Undertaking Fieldwork: A Personal Perspective.**

The literature discusses the importance of adopting a reflexive approach in order to contextualise social research situations (Giddens: 1991, Steier: 1991, Alvesson & Skoldberg: 2000, Doane: 2003, Finlay & Gough: 2003) This research indicates that reflexivity involves developing an insight into how a given situation is influenced by personal experiences, assumptions, contextual events and occurrences. Thus, from a personal perspective, the manner in which I approached the fieldwork was influenced by my current situation and also by my previous life experiences (see section 1.2, chapter 1). The following vignette shows how such past life experiences impacted on how I perceived the unique situation in which I found myself and how I dealt with meeting and interviewing the participants. Some of the interviewees were living in what I perceived to be vulnerable, isolated and socially 'neglected' circumstances. In order to maintain anonymity and confidentiality, no dates or locations are given and pseudonyms are used.

### **Reflexivity, Interviewing and Objectivity.**

As a social scientist conducting research into the lived experiences of disabled volunteers I was acutely aware that some of the participants were living with severe disabilities and that the disabling symptoms of their impairments could potentially impact upon their ability to fully take part in the research. Each participant was living in unique circumstances. Thus, while everyone was asked similar questions, it was necessary for me to take an individualised approach to each interview. The skills, knowledge and insight that I had acquired during the course of my own volunteering activities with disabled people proved invaluable and shaped my ability to view each participant and their circumstances as distinctive. Such insight enabled me to adopt a flexible and individualised approach to each person interviewed:

**Continued...**

*Lavender explained she had learning disabilities and said she felt uncomfortable about being tape-recorded. I slightly adapted the questions to make them easier for her to understand and also turned off the tape, typing her answers directly onto my keyboard... It was a good interview. She is a remarkable lady.*

*Ash explained he was in a lot of pain. He was also obviously fatigued. I offered to cancel the interview but he refused saying he'd been looking forward to it. I suggested we stop for a break halfway through and I also cut some of the questions short. This seemed to work and he made it to the end of the interview – after which I made us both a drink!*

*I looked at Holly and could see she was in agony. She explained that her spinal injury meant she could only sit still for a few minutes. She held the tape-recorder on her lap and I put the 'mike' on her jacket. She was able to answer my questions whilst moving herself around. Although this was disconcerting at first I soon got used to it - the interview went well..*

During the course of the fieldwork my personal belief that everyone in society has a basic human right to be treated with respect and dignity grew as I became aware of the desperate and isolated situations in which some of the participants were forced to live – particularly those forced to rely on paid 'carers':

*Amber was the first person I had ever met who also had primary MS. She had been ill for over 30 years and I arrived at her home to find her sitting, unable to move, in total agony waiting for a carer to take her to the toilet. I felt helpless. Unable to assist her, at first I wanted to run away. This woman had the same impairment as me. Fleetinglly, it occurred to me that I could be looking at my future; then I reminded myself of what an unpredictable and individual illness MS is. I put my fears and feelings aside and asked what I could do to help. There was nothing. She was at the mercy of the 'caring agency'. What a state for someone to be in...*

*Violet relied on carers to facilitate all her activities of daily living – including volunteering. When I arrived at her home the paid carer was just leaving – Violet was upset and explained that her 'carer' had refused to return later to take her to a meeting..... she's too afraid to complain to her 'care manager' fearing that things will just get worse. I found myself feeling angry and helpless, but mostly angry at my inability to offer any worthwhile advice or solutions.*

**Continued...**

*Red relied totally on a paid 'live-in' carer. He seemed to get on well with the young man (who was from Eastern Europe) but explained that language problems often caused difficulties and occasionally he was left in a 'mess'. I wondered momentarily what it would be like to have a stranger living in your home, someone who you have to rely on for every little thing...*

Interviewing people living in what I perceived to be socially isolated and unacceptable circumstances was at times difficult. However, my previous work experience as a police officer and psychiatric nurse (when I was often required to deal with people living through the worst times of their lives) taught me how to appear detached and act in a professional manner whilst appearing to put my own thoughts, feelings and fears aside. Such detached professionalism is a valuable skill that I continue to use as a social-researcher. Whilst I often felt desperately sorry for the participants, by adopting a reflexive approach I was able to conduct the interviews with as much objectivity as possible.

During the course of the fieldwork I came across some remarkable people, many of whom were living in very difficult conditions. Indeed, the need for me to set aside my own thoughts and feelings became a central part of how I coped with the realities of what life can be like for some disabled people. Many of the participants assumed that I would be able to fully empathise with their situation. In reality this was not the case. Moreover, the heterogeneous nature of disability meant that each interviewee experienced, and dealt with, the difficulties of living with their own physical impairment in a unique and individual manner.

### **2.3 Accessing the Research Field**

The uniqueness of individual circumstances was highlighted in how the volunteers had adapted to their own external environment. Although all of the participants were wheelchair-users, most had developed individual coping strategies to overcome local environmental barriers. Thus, I was not always made aware in advance of the very real and socially constructed barriers blocking my own access to the field.

This final vignette looks at issues of access. It describes how socially constructed environmental barriers had the potential to impede my own progression whilst

negative social attitudes towards disability proved to be a persistent and unremitting irritant.

### **Access all Areas? Steps, Stereotypes and Social-Research**

Difficulties in accessing public transport meant that it would have been physically impossible to conduct the fieldwork using public transport. However, travelling to interviews in my own vehicle was not without problems:

JULY 2003: CENTRAL ENGLAND: *Arrived at [the organisation] to find it located on top of a very steep hill with no parking outside. I parked at the bottom of the hill and slowly wheeled myself up what felt like a mountain. It took me over half an hour to get to the top. By the time I arrived I was totally exhausted and needed to rest and regain some energy before going in...*

JULY 2003: LONDON: *Drove around central London looking for [organisation] for over half an hour. Finally found it and drove into an underground car-park. The car-park only had a stepped pedestrian exit so I had to wheel myself up the 'road' ramp, dodging the traffic whilst trying not to get too dirty...*

AUGUST 2003: NORTHERN ENGLAND: *Parked outside [organisation] in a disabled parking space. Whilst I was inside interviewing, someone (without a disabled badge) parked behind me and blocked me in. They didn't return for over two hours by which time I was angry but too exhausted to argue. I collapsed later...*

Whilst parking-related problems were a constant annoyance, the more practical task of actually getting into the various buildings in order to conduct the interviews proved to be even more challenging:

AUGUST 2003: NORTHERN ENGLAND... *Hyacinth lived on a farm. I parked in the lane and had to go through 3 gates and over a cattle-grid in my wheelchair to get to where she was – what a nightmare. My wheels got stuck in the grating and I ended up getting out, crawling on the road and dragging the chair behind me... Once inside the house however, it was fully accessible... Hyacinth said she presumed I would be using a powered wheelchair (with wide wheels) she explained that she actually has a large mobility scooter to manoeuvre around the farm and from the 'garage' to the house...*

**Continued...**

AUGUST 2003: NORTH WALES... *For an organisation of disabled people [the building] was a disgrace. Big heavy doors, a service-counter that seemed 12 foot high and a toilet without a lock...*

OCTOBER 2003: CENTRAL ENGLAND: *Like most local authority buildings [it] was not fully accessible. The ramp was uneven, dangerous even. The automatic door had broken and the bell to call for assistance out of arms-reach...*

Environmental barriers, whilst annoying are, from a personal perspective, very much a fact of life and in many respects were relatively easy to overcome with a little determination and ingenuity. Such barriers were, however, frequently augmented by negative social attitudes and stereotypes towards myself as a disabled person:

JULY 2003: SE ENGLAND: *I arrived at [location] which was situated in a local social services day centre. The staff-member who greeted me immediately assumed I was the new 'work-experience girl' and carefully pointed out the toilet, bathroom and kitchen. She even told me that hot water burns!... Eventually she showed me to [the participant's] office but then stood, with the other staff members, staring and whispering trying to work out who I was and why I was there... I heard them eventually conclude that I was obviously a new client... Her attitude towards me as a disabled person was exceptionally patronising, I dread to think how she deals with the disabled service-users of the day-centre...*

AUGUST 2003: SCOTLAND: *Once inside the building it seemed I turned invisible. The receptionist totally ignored me and spoke to the person pushing my chair... even when I spoke to her directly she ignored me and addressed the person I was with – who was actually stood behind me...*

OCTOBER 2003: CENTRAL ENGLAND: *... I just don't believe what happened today... When he was showing me to [the participant's] office the security officer patted me on the head... He was so patronising... Lucky for him I didn't have the energy to run over his feet or elbow him somewhere painful ...*

The experiences described above, both in respect of environmental and social access, are not exceptional and reflect the barriers and attitudes I encounter with mundane frequency almost every single day of my life. In addition to impacting upon the fieldwork and research processes, negative social attitudes towards disability, which are often augmented by widely-held misconceptions about the nature of MS, continue to impede my access to society as a whole.



## 2.4 Reflexivity & Research: A Personal Perspective

As the fieldwork progressed I became increasingly aware that some of the experiences of the disabled volunteers described during the course of the interviews were similar to my own experiences as a disabled researcher. The homogenous manner of disabled peoples' experiences in respect of being excluded from society by socially constructed environmental and attitudinal barriers is recorded in the literature (Vickers: 2001, Blackman et al: 2003, Darcy: 2003, Trembley et al: 2005). However, whilst socially constructed barriers are homogeneously experienced, the individual manner in which illness is both perceived and experienced reflects the heterogeneous nature of the disabled population (Kelly & Field: 1998, Hubbard: 2002, Law et al: 2005). Thus, from a personal perspective, although some of the experiences described by the volunteers were similar to my own whilst conducting research, the manner in which I perceived and dealt with the various socially constructed barriers I encountered was undoubtedly influenced by my own previous life experiences, current situation and own personality. Although environmental and attitudinal barriers may, on occasion, restrict my activities such restrictions have become part of life - I have adapted and moved on. Moreover, I frequently forget that I am living with a disability or mobility impairment, to the extent that I tend to view my wheelchair as an extension of my self. It reflects my character and enables me to live an 'ordinary' life.

Whilst socially constructed barriers may be relatively easy to ignore or overcome, medically-related barriers and problems are more difficult to deal with. The negative impact that living with a painful life-limiting or degenerative illness can have on an individual's lifestyle and perceptions is discussed in the literature (Hunt: 1966, Wendall: 1996, Alland: 2002, Twigg: 2002, Tremblay et al: 2005). However, from a personal perspective, the greatest hindrance to my progression in the field was fatigue. Such fatigue is, in many respects, unpredictable and therefore difficult to manage. However, since developing MS, the experiences gained whilst studying, volunteering and studying have enabled me to develop several 'coping strategies' which were used both during the course of the fieldwork and throughout the research process. Such strategies included careful pre-planning of all my activities and restricting the amount of hours spent working in any one day. They did not always work or were not always

suitable. Therefore, in addition to attempting to predict how certain situations could potentially impact upon my health, I also used reflexivity to mentally 'balance' how I dealt with the symptoms of MS whilst undertaking the fieldwork.

Whilst reflexivity provided the means by which I was able to monitor how my impairment and disability may have impacted upon the research interviews, all attempts to use such practices to predict how the research process could affect my health, on a day-to-day basis, failed. I was often too fatigued to realistically estimate how much a given activity might augment my symptoms. However, by adopting a reflexive approach, I found that I was able to deal psychologically with the physically and mentally demanding task of undertaking interviews. In addition to this, there is little doubt that the manner in which I perceived each of the research participants and acted in each interview was influenced both by my current situation and previous work and life experiences.

I approached the fieldwork in a similar way to a military operation and continued determinedly and stubbornly until it was finished. Interview skills learned during my time in the Police Force whilst working with sexually abused women and children were utilised to make the participants feel at ease. Counselling skills gained whilst working and volunteering with mentally ill people were used to make sure that I approached each participant in a non-judgemental and open-minded manner. Thus in many respects, reflexivity constituted an important part of how I both managed my self, my impairment and my feelings towards the participants and the situations in which they were living.

## **CONTRIBUTION TO KNOWLEDGE: CHAPTER 6**

This contribution made to academic knowledge by this chapter is two-fold. First, it utilises the organising framework set out in chapter 2 to show how the experiences of disabled volunteers may be explained by medical, social and medical-social factors. In applying this framework in the specific context of volunteering, the chapter makes a unique contribution to both disability and volunteering literature. Second, the reflexive approach adopted in the second half of the chapter adds to both

methodological and disability literature by contextualising the interviews and wider research processes from my own perspective as a disabled researcher.

## **CONCLUSION TO CHAPTER 6**

By contextualising the research process from my own perspective as a disabled researcher this chapter shows how, in many respects, the volunteers' experiences described throughout this thesis were similar to my own experiences in the field. This was particularly the case in respect of the socially constructed barriers to participation identified by the volunteers. Throughout the fieldwork, my progression was frequently impeded by socially constructed barriers that reflected poor environmental access and negative social attitudes towards disability. However, the evidence offered in chapter five, which highlights the individual manner in which disability is experienced and perceived, suggests that any similarities are superficial. Moreover, there is little doubt that each of the volunteers experienced volunteering in a distinct manner and that as a disabled researcher my experiences were unique to the somewhat inimitable situation in which I found myself. This chapter suggests that the heterogeneity of disabled peoples' experiences reflects the complex nature of the various social, medical and medical-social influences upon those experiences.

In conclusion, the use of reflexivity within the second half of this chapter has contextualised the research process whilst prompting a detailed evaluation of how my previous life experiences and current situation may have impacted upon my perceptions of the participants and their volunteering experiences. Moreover, as a result of my experiences in the field, I have become increasingly aware of the integral role that reflexivity plays in my everyday academic and personal life. I have developed an awareness of how I deal with contemporary events and occurrences by contextualising them in terms of my own lived experiences. In addition to this, it appears that the use of reflexive practices throughout the fieldwork enabled me to adopt and maintain a professional persona, putting my own thoughts and feeling aside. This enabled the participants' voices to be heard. In this respect, the research journal has provided an invaluable analytical 'tool'; it has enabled me to contextualise the interviews whilst providing a rich source of reflexive data. This resulted in the

high quality of data depicted and analysed in this thesis, which reveals the valuable roles played within society by wheelchair-users who volunteer.

## **CONCLUSION TO THESIS: IMPLICATION FOR FUTURE RESEARCH**

The implications of this thesis for future research lie in two different areas of academic study, disability and volunteering. Each of these areas is now briefly critiqued in view of the findings of this study and suggestions made as to where future research projects could focus.

### **Implications of the Study for Disability Research**

Chapter 2 provides a detailed critical analysis of the social and medical models of disability prior to positioning the two approaches together in an organising framework (page 72). This framework postulates that disabled peoples' experiences are influenced by both medically and socially constructed factors as well as by a combination of these two factors acting together. Whilst the medical model is empirically grounded in scientific and academic research (Moon & Gillespie: 1995, Field & Taylor: 1998) the social model is criticised because it tends to reflect the circumstances of those who are living with non- degenerative impairments caused by injuries (for example, amputees, and people living with spinal cord injury) rather than those diagnosed with a degenerative or genetic disorder (Crow: 1996, Swain & French: 2000). Much criticism of this model relates to the fact that it fails to encapsulate illness and thereby excludes the lived experiences of the majority of disabled people (Morris: 1991, Crow: 1996, Corker: 1998). When asked to articulate the nature of their disability all of the disabled participants interviewed as part of this study described their medical symptoms using medical terminology. None used the language of the social model of disability. This would suggest that there is a need for research to be conducted into how disabled people actually perceive and experience disability. Such research could be used to develop an alternative conceptualisation of disability which takes account of the impact that illness, injury, genetics and any socially constructed barriers may have on an individual's ability to live a fulfilling and self-actualising life.

Many of the socially constructed barriers to volunteering identified by the volunteers related to inadequate environmental access. This study was conducted prior to the introduction of Part III of the Discrimination Disability Act (DDA: 1995) which came into effect on October 1<sup>st</sup> 2004 and which relates to environmental access. All service providing organisations are now required to make 'reasonable adjustments' in order to assure equity of access (DRC: 2005). Access difficulties were identified by the majority of the participants, irrespective of geographic location or type of organisation in which they were engaged. Furthermore, my own access to the research field was frequently impeded by environmental barriers. Contemporary disability and other media reports suggest that little has changed since the introduction of Part III of the DDA and that disabled people continue to be excluded from mainstream society (Choppin: 2005, Yourable: 2005, BBC 8/11/05 ). This would indicate that there is a need for further social investigation in this area. Such research could evaluate the effectiveness of the DDA in terms of environmental and social access. In addition to this, this study suggests that there is a need for social research to gauge whether recent changes in legislation have improved disabled people's experiences in terms of service provision across all sectors of the economy.

### **Implications of the Study for Research into Volunteering**

One of the frequently depicted problems identified within the study related to a lack of appropriate training for those volunteers engaged as voluntary board members. In this respect, the study supported the findings of previous research which identifies inadequate training of board members as a generic voluntary sector problem (Harris: 1993, 2001, Scott & Russell: 2001). Thus it would seem that there is a need for further social investigation in this area. Such investigation could focus on the competencies, abilities and knowledge of current board members whilst examining the value and the relevance of the training given to new board members. This research would be particularly useful in the governance and management of the voluntary sector as it could identify weaknesses in current training provision and possibly make suggestions as to how such weaknesses might be addressed.

There exists a large gap in academic knowledge about volunteering by disabled people. By providing an empirical analysis of the experiences of wheelchair-users

who volunteer, this study goes some way to addressing that gap. However, the focus of the study means that whilst many of the study findings may be relevant to volunteers living with other disabilities (or to non-disabled volunteers) the study mainly relates to the experiences of mobility impaired physically disabled volunteers. Thus, there is a need for further empirically grounded investigation in order to determine to what extent the findings are applicable to wider groups. Such research could be used to identify the benefits of, and barriers to, volunteering for people living with other physical, psychological or learning disabilities and would be of use to volunteers and volunteer managers alike.

- *And a Few Final Thoughts.....*

As this research journey draws to an end I find myself reflecting on how far I have progressed both academically and personally over the past four years. I am surprised not only at how much I have learned, but also at how much my perception of my own situation in terms of my disability has changed. When I was first diagnosed several years ago, I believed that MS had taken my future away. Now I have it back again and so another journey begins...

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## **APPENDIX 1: ORGANISATIONS VISITED AND INDIVIDUALS CONSULTED DURING PRE-PILOT AND PILOT STAGES OF RESEARCH PROCESS**

### **A. ORGANISATIONS VISITED DURING PRE-PILOT STAGE OF RESEARCH PROCESS**

The following organisations were visited during the pre-pilot and pilot stages of the research process. Such visits took place between November 2001 and September 2002:

1. The MS Society: 5 different branches – all located within the Midlands area.
2. The MS Society: Head Office, London.
3. The Spinal Injury Association, Milton Keynes (meeting at Space Centre, Leicester).
4. The Princes Youth Trust: 3 different branches – all located with the Midlands area.
5. Tamworth Volunteer Bureau
6. Burton-Upon-Trent Volunteer Bureau
7. Royal Air Force Association: three branches located within the Midlands
8. Tamworth SPIN (Special People in Need – organisation supporting disabled children and families)
9. Tamworth TIGERS (Disabled peoples sports club)
10. Staffordshire based branch of Arthritis Care
11. Tamworth disabled swimming club
12. 3 different CIL's – Derbyshire, Shropshire & West Midlands
13. Mental Health Care Trust: Wolverhampton
14. Disability Rehabilitation Team: BLT NHS Trust (Burntwood, Lichfield, Tamworth).

Such visits provided the opportunity to network and to determine what areas of volunteering were important to disabled people.

### **B. INDIVIDUAL'S INTERVIEWED DURING PILOT STUDY**



## **APPENDIX 2: BACKGROUND QUESTIONNAIRE**

1. DATE OF INTERVIEW:
2. PLACE OF INTERVIEW:
3. NAME:
4. AGE (D.O.B.)
5. GENDER
6. MARITAL STATUS
7. HOME ADDRESS
8. VOLUNTARY ORGANISATION
  - HOURS SPENT VOLUNTEERING (PER WEEK/MONTH ETC)
9. VOLUNTARY POSITIONS
  - VOLUNTARY POSITION DISCUSSED IN INTERVIEW
10. REASON FOR USING WHEELCHAIR
11. TYPE OF WHEELCHAIR USED
12. HOW LONG HAVE YOU BEEN A WHEELCHAIR-USER?
13. PREVIOUS OR CURRENT PAID OCCUPATION
14. HIGHEST LEVEL OF EDUCATION/ AGE OF LEAVING SCHOOL – type of school attended
15. WHAT STATE BENEFITS ARE YOU IN RECEIPT OF?
16. DO YOU RECEIVE ANY OTHER PENSIONS OR ALLOWANCES?
17. DO YOU NEED THE ASSISTANCE OF ANOTHER PERSON TO ASSIST YOU WHILST VOLUNTEERING?

**ALL ANSWERS IN TOTAL CONFIDENCE**

**Jane Andrews: Aston Business School: Aston University**

**DISCUSSION AREAS**

These questions are intended for use as an interview guideline. All of the subject areas will be covered within the interviews. The interviewees are to be given the flexibility to address issues deemed important to them.

**1. VOLUNTEERING**

**SUB-THEMES:**

- **VOLUNTEERING ACTIVITIES**
- Describe to me what you do in a single voluntary session
  - What special skills do you have to enable you to do this
  - How do those around you respond to you whilst you are volunteering
    - Staff – paid/unpaid
    - Members of public
- Can you remember what it felt like on your first day
  - Who helped you out
- **MOTIVATION**
- Tell me what motivates you to do this sort of voluntary work
  - Why volunteer in this organisation
  - Why did you start volunteering in the first place
  - Why continue to volunteer
  - What do your friends and family think about you volunteering
- How do you get on with your fellow volunteers
- How do you get on with the paid staff/professionals in the organisation
- How do you feel members of the public respond to you whilst you are volunteering

**2. DISABILITY AND VOLUNTEERING**

- What would you say are the main challenges in your role as a volunteer in (this organisation).
  - How did you overcome such challenges
  - Have you experienced any discrimination
  - Access problems
  - How did you feel when such problems arose
  - How did you overcome such problems
- Do you feel as if your disability places any restrictions on your volunteering activities
  - How do such restrictions make you feel
  - How do you cope with these restrictions
- Describe to me impact volunteering has on your health
  - Physical health
  - Mental/psychological health
    - Positive effects
    - Negative effects
- What sort of relationship do you have with your fellow volunteers?
- Are there any paid staff?
  - What sort of relationship do you have with the paid staff?

**3. ORGANISATION AND MANAGEMENT**

- What sort of activities does the organisation get involved with
- Describe to me the day to day (week to week – or month to month) running of the organisation
  - Practical Help – advice etc
  - Social activities
- Is there anything the organisation doesn't do that you feel it should be doing
- Can you describe to me the main benefits to you personally of being involved with this group
- What do you feel the other group members get out of belonging to the group
- If you had to choose just one thing, what would you say is the main advantage of being a member of the group
- If you could change just one thing about the organisation what would it be
- Has the group ever encountered any hostility from members of the public whilst out socialising?
  - How did that make you feel?
- **ORGANISATIONAL MANAGEMENT**
  - How do you feel about the way this organisation is managed
    - Formal contracts
    - Job description
    - Accountability
    - Funding
    - Equal opportunities
    - Use of disabled volunteers
- **VOLUNTEER TRAINING**
  - Did you receive any training for this position
    - **YES** : Can you describe the sort of training you have undertaken
      - How did you feel once you had completed the training (course etc)
    - How do you feel you benefited from this training
    - **NO** : How do you feel you could benefit from training
- **VOLUNTEER 'RIGHTS'**
  - Treatment of volunteers by organisations / government
  - How do you feel about the lack of statutory rights for volunteers
  - Do you feel as if the amount of voluntary work undertaken by disabled people in the UK is adequately recognised by the public

**IS THERE ANYTHING I HAVEN'T COVERED THAT YOU WOULD LIKE TO ADD?**

**FOOTNOTE TO APPENDIX:** This interview schedule was used during both the pilot study and during the course of the main research. The only difference in the approach taken was that during the main interviews the research participants were asked to limit their answers to a maximum of two organisations.

DATE:

TIME:

LOCATION OF MEETING:

PURPOSE OF MEETING:

INDIVIDUALS PRESENT:

ADMINISTRATIONAL SUPPORT: (Minutes of previous meeting etc)

MATTERS DISCUSSED:

PREDETERMINED THEMES OF MEETING ADHERED TO?

QUESTIONS RAISED?

BY WHOM?

ISSUES ADDRESSED?

ISSUES RAISED NOT PART OF PRE-MEETING SCHEDULE:

OBJECTIVES OF MEETING CLEAR?

OBJECTIVES ACHIEVED?

ROLE OF CHAIR – RESPECTED/IGNORED/ADHERED TO?

NATURE OF INTERACTIONS BETWEEN DISABLED/NON-DISABLED  
INDIVIDUAL'S DURING MEETING

DYNAMICS OF MEETING?

DISAGREEMENTS?

ROLE OF PROFESSIONALS WITHIN MEETING?

OTHER POINTS NOTED:

**APPENDIX 5: LIST OF ORGANISATIONS IN WHICH VOLUNTEERS WERE ENGAGED**

**A: VOLUNTARY SECTOR ORGANISATIONS**

1. DCIL DERBYSHIRE (Derbyshire Centre for Integrated Living)
2. BCODEP DERBYSHIRE (British Coalition of Disabled People)
3. DIAL TELFORD (Disability Information & Advice Line)
4. SHREWSBURY WHEELCHAIR-USERS GROUP
5. SHREWSBURY ACCESS GROUP
6. DISABILITY ACTION NOW (London)
7. DABB (Disability Action in the Borough of Brent)
8. ESSEX CIL (Centre for Independent Living)
9. BUTE AND ARGYLL CIL (Centre for Independent Living)
10. SCOTTISH DISABILITY AND EQUALITY FORUM (Based Edinburgh)
11. AWARE ABERDEEN (Disability Advisory Agency)
12. ABERDEEN ACTION ON DISABILITY
13. SCOTTISH DISABLED RAMBLERS (Based Dundee area).
14. DENBIGH FORUM OF DISABLED PEOPLE (Rhyl)
15. TARAN ANGELSEY (Centre for Integrated Living)
16. ARTHRITIS CARE
17. CANINE PARTNERS (Provides assistance dogs for disabled people – based in Sheffield)
18. POLIO FELLOWSHIP
19. CAPABILITY SCOTLAND (Training agency)
20. PARKINSON'S ASSOCIATION
21. MS SOCIETY
22. GIRL GUIDES ASSOCIATION
23. SAMARITANS
24. ANGLICAN CHURCH, WORCESTERSHIRE



**APPENDIX 5: LIST OF ORGANISATIONS IN WHICH VOLUNTEERS WERE ENGAGED**

25. CATHOLIC CHURCH, DERBYSHIRE
26. CAB FIFE
27. CAB KENT
28. CAB DERBYSHIRE
29. WATERLOO HOUSING ASSOCIATION (MIDLANDS)
30. AGE CONCERN, CHESTERFIELD

**B: PUBLIC SECTOR ORGANISATIONS**

1. SOCIAL SERVICES AND NHS EQUIPMENT LOAN, LLANDUDNO (User group funded by social services)
2. SHREWSBURY NHS TRUST USER GROUP FORUM
3. SHROPSHIRE NHS FORUM OF SERVICE USERS
4. NHS WHEELCHAIR SERVICES, DERBYSHIRE
5. LEA KENT (Primary school in Ashford)
6. LEA WEST MIDLANDS (Volunteer visited various schools in region)
7. CHILDREN AND YOUTH SERVICES, BRENT.
8. STAFFORDSHIRE COUNTY COUNCIL
9. DISABILITY ADVISORY COMMITTEE FOR SCOTTISH PARLIAMENT, EDINBURGH

**APPENDIX 6: TABLE OUTLINING PARTICIPANTS BACKGROUND DETAILS: FEMALE VOLUNTEERS [1]**



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