

# **AN EXPLORATION OF THE INTERACTIONS BETWEEN DISABILITY AND EXERCISE**

**A thesis submitted in partial fulfilment of  
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## ABSTRACT

Regular exercise has been identified as being important to an individual's social, physical and psychological well being (Dishman, 1994). Yet very few people exercise to levels sufficient to accrue these benefits. Researchers have begun to develop an understanding of why some people exercise whilst others do not, but much of this research has focused upon non-disabled people, whilst very little is known about disabled people.

This research sought to investigate the 'Interactions between Disability and Exercise'. The main aims of this investigation were to first examine the exercise intentions of disabled individual's (wheelchair users) using the Social Model of Disability (Oliver, 1996), to act as a framework. Secondly, to determine the factors, which underpin intentions to exercise, attitude toward exercise, influence of significant others, choices and self-determination. Critical Social Research (Harvey, 1990), is the process which, is adopted throughout the research in order to examine underpinning factors, which could influence a disabled person's decision whether or not to participate in exercise.

The proposed methods of investigation of this study were as follows: First, a detailed review of literature on exercise adherence, disabled persons involvement in exercise with particular reference to intention to exercise, sociology of the body, therapy culture, body image, and the social model of disability. The outcome of this review was a framework of understanding, which could take account of both structural factors impacting on disabled peoples intentions to exercise and factors that influence actual choices made by individuals. Secondly, to examine disabled people's intention

to exercise, taking into account the social and physical factors and the psychological processes that impact upon the decision making of wheelchairs users.

Lastly, a survey devised to assess disabled peoples involvement in exercise, consisting of quantitative and qualitative data. The quantitative part of the research consisted of a questionnaire administered to wheelchair users either direct to them in person or through organisations ran for disabled people and/or by disabled people. The data collected from the questionnaires were analysed and used to develop the main themes for the study. The qualitative part of the research consisted of face-to-face semi-structured interviews and a 'user participation workshop'. This workshop was a very important part of the Critical Social Research (Harvey, 1990) process as it gave participants who had been interviewed a chance to receive feedback from the interview data and to take part in a participant led discussion. This maintained participant's involvement in the study at every stage of the research process.

In summary, the results of the data gathered from the questionnaires revealed that regardless of their age, participants felt that exercise was beneficial to people even if their circumstances prevented them from exercising themselves. The length of distance to travel to a leisure centre did not determine whether they attended that leisure centre or not as more people participated in exercise when they had further to travel.

The analysis of the interview and user participation workshop data revealed a significant finding that disabled people who receive social support and encouragement from friends, family or other people, are more likely to exercise than those who do

not receive any support. Disabled people have the same human and civil rights as non-disabled people, but they have additional needs. Suppliers of goods and service providers need to work closely with disabled people in order to adequately meet the needs of disabled people. Leisure centres need to be accessible to disabled and non-disabled exercisers with concessions for all disabled people to be made consistent across the nation. Vital information regarding financial help and resources, such as equipment for the home, wheelchairs and accessible motorcars, is not always readily available. Many disabled people are not aware of the help that they can receive with regards to benefits and equipment to help them with their mobility. Education authorities need to help with raising awareness in disability in schools for pupils from year 3. This needs to be an inclusive policy with both teachers and pupils. Raising awareness is vital if non-disabled people are ever going to recognise disabled people for the abilities and skills they can give to society, not for their disabilities.



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## **Declaration**

This thesis is the original work of the author, except where specifically referenced. No part of this thesis has been submitted previously, in any form, to this or any other Institution.

Janet Rice

Dedicated to

My late Father

Frank David Rice

And

Two dear Friends

Fred James Steele

Anthony Cardus

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## LIST OF ACTS

(CSADP)	Chronically Sick and Disabled Person's Act 1970
(DPA)	Disabled Person's Act 1981
(DDA)	Disability Discrimination Act 1995; 2005
(DRC)	Disability Rights Commission 2002
(EA)	Education Act 1981
(ERA)	Education Reform Act 1988

## **LIST OF ORGANISATIONS**

(AFAA)	American Fitness and Aerobics Association
(BSAD)	British Sports Association for the Disabled
(DA)	Disability Alliance
(DPI)	Disabled People's International 1986
(HMSO)	Her Majesty's Stationery Office 1989
(RADAR)	Royal Association for Disability and Rehabilitation 1996
(SSC)	Scottish Sports Council 1994
(WHO)	World Health Organisation 1980

## Chapter 1

### Introduction

Previous research (Rice, 1994) investigated the travel and tourism facilities that were available for disabled individuals (wheelchair users). Accessibility of transport and availability of accessible hotel and leisure facilities were investigated but there was very little information available on the use and accessibility of leisure facilities in order for wheelchair users to be able to participate in exercise and physical activity.

Previous research has identified that regular exercise is important to an individual's physical, social and psychological well being (Dishman, 1994). Paradoxically, few individuals exercise to levels sufficient to accrue these benefits (Dishman, 1994). I therefore felt that more research was needed which focused on understanding the processes and factors associated with adopting and maintaining regular exercise.

Researchers had begun to develop an understanding of the factors underpinning the adoption and maintenance of regular exercise (Dishman, 1994). However, much of this research had focused on non-disabled exercisers, and non-exercisers, but very little was known about disabled people.

Empirical (e.g., Monnazzi, 1982; Rimmer, 1999; Heller, 2002; Shaeffer & Proffer, 1989; Petruzello, 1991; Mullineaux, 2001; Mooney, 1998; and Wilson, 1992) and anecdotal evidence suggests that the benefits of exercise are just as pronounced for disabled people as they are for non-disabled people and in their research, Martin & Mushett (1996) have suggested that the social benefits are potentially greater for disabled people. The proposed research will build on existing research on exercise adoption for disabled people.

The proposed methods of investigation of this study are as follows: First, a detailed review of literature on exercise adherence, disabled persons involvement in exercise with particular reference to 'intention to exercise, disability issues (which include 'Sociology of the Body', and 'Therapy Culture'), with an introduction to the 'Biopsychosocial Model' and the 'Social Model of Disability'. The outcome of this review will be a framework of understanding, which could take account of both structural factors impacting on disabled people's intention's to exercise, and factors that influence actual choices made by individuals, exploring the potential for a synthesis of social and psychological models.

Secondly, to examine disabled people's intention's to exercise taking account of the physical and social factors and psychological processes that impact upon the decision making of wheelchair users.

Lastly, a survey devised to assess disabled peoples involvement in exercise, consisting of quantitative and qualitative data. The quantitative part of the research consisted of a questionnaire administered to wheelchair users; this was used to form the main themes for the study. The qualitative part of the research consisted of face-to-face semi-structured interviews and feedback from a 'user participation workshop'. This workshop gave participants who had been interviewed a chance to receive feedback from the interview data and to take part in a participant led discussion.

The Findings and Analysis (Chapter Four) is a thematically driven discussion of the findings from the questionnaire, face-to-face semi-structured interviews and the 'user participation workshop', which will cover the five themes derived from the

questionnaire. These themes are presented in the following order: Theme 1 'Cost of Disability', Theme 2 'Why do People Exercise?', Theme 3 'Access to Information', Theme 4 'The Politics of Disability', and Theme 5 'Inaccessible Society' (Barriers preventing Access).

This study is set within the framework of the 'Social Model of Disability' (UPIAS 1976; Oliver, 1996), and the context of 'Sociology of the Body' (Goto, 2004) and 'Therapy Culture' (Furedi, 2004).

Understanding the processes and determinants associated with the adoption and maintenance of regular exercise has been identified as an important area of research since regular exercise is known to have numerous health benefits (Dishman, 1994). Researchers (e.g., Dishman, 1994) have begun to identify the key determinants of the adoption and maintenance of regular exercise for non-disabled exercisers and non-exercisers and these include demographic (race, age, gender), psychological (self-efficacy, intention, control), social (social support, choices), environmental (access to facilities and transport), and economic (financial hardship) factors. Several theoretical models to describe, explain and predict adoption and maintenance have been proposed and tested, but they do not combine social and psychological factors. A model that does address social issues in disability was founded by the Union of the Physically Impaired against Segregation (1976) and developed by Oliver (1996) in the 'Social Model of Disability'. This model proposes that it is society that disables individuals, a consequence of social oppression, not their physical or psychological impairment. Researchers (e.g., Dishman, 1990) have found that intention to exercise is increased when individuals hold positive attitudes towards exercise, and when they

feel they have control over the ability to exercise. Research (Dishman, 1994) has yet to address this issue of the intention to exercise amongst disabled people.

Therefore the purpose of this study is to investigate the 'Interactions between Disability and Exercise'. The main aims of this investigation were to first, examine the exercise intentions of disabled individuals (wheelchair users) using Oliver's (1996) 'Social Model of Disability'. Secondly, to determine the factors underpinning intentions to exercise, attitude toward exercise, influence of significant others and self-determination.

There are issues (e.g., physical capabilities and social integration) that confront disabled people, which may challenge the findings and assumptions embedded in past research on non-disabled people. This work has the potential to identify factors that could be used to devise intervention strategies to promote greater exercise involvement and adherence for disabled individuals.

### **Discussion of Terminology**

I feel it is necessary to explain the meaning of the terminology used in this thesis. It is important to understand first what I mean by the term's 'impairment' and 'disability'. Following these definitions, I will discuss what I mean when I refer to the 'Medical', 'Biopsychosocial', and 'Social' Models of disability, and the debate, which is currently taking place with regards to the adequacy of the 'Social model of disability'. Finally, the various disability acts are listed earlier in this study, and this is followed by a separate list of organisations.

The definitions of impairment and disability used in this study were those of the Disabled Peoples International (1986). This is because in a society where the needs of disabled people may be affected by long established principles and practices, disability can be seen as more of a social model (Oliver, 1996) than a medical phenomenon. Its impact strongly depends on the context in which someone lives. This study is set within the framework of the 'Social Model of Disability', and therefore the following definitions are used:

### **Impairment (DPI)**

The functional limitation within the individual caused by physical, mental or sensory impairment.

### **Disability (DPI)**

The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers (Barnes, 1992).

### **Medical Model of Disability**

The medical model of disability saw the development of a perception of disability as a physical and mental deficiency brought about by the impairment. Those who were afflicted were very often disqualified from taking any important role in 'society'.

### **Biopsychosocial Model**

The Biopsychosocial model posits that biological, psychological and social factors all play a significant role in human functioning, including mental processes. This model depicts a health care concept that has evolved in close association with current 'pain' theory. It has sought co-existence with the determinant Biomedical model of healthcare, which describes 'disease' as a failure of or within the Soma (body), resulting from infection, injury or inheritance (Alonso, 2003).

### **Social Model of Disability**

The Social model (Oliver, 1996) identifies the much wider social cultural values and personal prejudices which combine to portray disabled people as peripheral to mainstream life and opportunities, and therefore of little social and economic value to society. Oliver is concerned, and expresses strongly the view that disabled people have been systematically excluded from British society. They have been denied inclusion into this society because of the existence of disabling barriers (p.106).

There is now however a debate going on in regards to whether or not the social model is as good as it was first thought to be, or whether there needs to be a new model developed (Shakespeare & Watson, 2001).

It becomes strongly apparent that whereas medical science is limited in its ability to cure some people's impairments, society can reduce the architectural (Imrie, 2000), and attitudinal barriers that restrict disabled people from getting on in life. However, even if society were designed in a way that removed all of its barriers, it would be unrealistic to believe that disabled people would enjoy the same opportunities and



choices as non-disabled people. This has led to a debate about the 'social' model, which some people feel has reached its 'sell by date' and asks should another model to cover the 'social and personal' be used in its place? This debate is discussed further in the literature review chapter of this thesis.

## Chapter 2

### Literature Review

#### Introduction

Previous research (Rice, 1994) investigated the travel and tourism facilities that were available for disabled individuals (wheelchair users). At the time this study began, there was very little information available on exercise facilities and an individual's 'intention to exercise' with regards to disabled people. I therefore felt that there was a need for further research to investigate and understand the factors, which determine why some disabled people (wheelchair users) participate in exercise involvement whilst others do not.

These factors as identified in my research are as follows:

- Social, physical and psychological benefits of exercise activity for disabled people;
- Factors determining intentions to participate by disabled people in social and physical activity;
- Recent developments in attitudes and provision for disabled people;
- Models of Disability;
- Definitions of disability

In this chapter these five areas are examined, in relation to 'Sociology of the Body' and 'Therapy Culture'.

At the time of this study there was no evidence of any research having been conducted which addressed the factors which influence a wheelchair users 'intentions to exercise' or not, in any form of physical activity. Yet there are numerous benefits to be accrued from regular involvement in exercise for wheelchair users as well as non-disabled people (Monnazzi, 1982, Martin & Mushett, 1996). For disabled people, regular exercise can improve functional status and independence in activities of daily living by increasing muscular strength and endurance, flexibility, balance, and cardiovascular and respiratory functioning (Rimmer, 1999). Exercise can also reduce the onset of acquired conditions for people ageing with a disability (Heller, 2002).

What research had been carried out in this area with regards to the benefits of exercise involvement had been conducted mainly on the involvement and maintenance of exercise for non-disabled people. There had not been any research conducted on disabled people, which addressed the issue of the 'interactions between disability and exercise. One study, which did address 'intentions to exercise', was Abraham and Sheeran (2004). Their study measured 'intentions to exercise' using the 'Theory of Planned Behaviour'. But this study was based upon a psychological perspective and it did not focus upon disabled people. My study examines the factors which determine whether or not a wheelchair user participates in exercise activity.

I start the literature review by first examining in (section 2.1), '**Sociology of the Body**' which studies how the social world affects our bodies. I then examine in (section 2.2) '**Therapy Culture**' (Furedi, 2004), and explore how it is similar to Oliver's '**dependency culture**' back in the 1980's. This will be followed by an

examination of exercise intentions amongst non-disabled and disabled people. The issues that came from this part of the literature review are presented as follows:

**Social, physical and psychological benefits of exercise activity for disabled people** are discussed in (section 2.3). **Factors, which determine intentions to participate in exercise and social activity by wheelchair users**, are investigated in (section 2.4). This discusses work carried out by Oliver, (1983; 1996); Heller (2002); Morris (2004); Haywood et al (1995) and Kew (2000). In his work Kew (2000) has recognised that to overcome inequitable access and opportunity, there are issues that need to be addressed. These areas are perceptual, attitudinal, physical and financial barriers, adapting and modifying sports and physical education at school. The issue of attitudinal barriers will be extended to include work by other authors on the history of disability which looks at attitudes towards disabled people going back as early as the writings of the bible. These issues will form the main themes to the literature review in order to investigate the key determining factors underpinning intention to exercise, attitudes toward exercise, influence of significant others, choices and self determination.

Then the debate will be broadened to include research on general issues of disability presented as follows:

**Recent developments in attitudes and provision for disabled people** are explored in (section 2.5). This focuses on organisations that have been formed and disability acts that have been brought into force to help disabled people; **Models of disability**

are discussed in (section 2.6); and finally **Definitions of disability** are explored in (section 2.7).

Sections 2.3 through to 2.7 will be examined by looking at them in relation to, and in the context of '**sociology of the body**', and '**therapy culture**'. I begin the literature review by first having a debate about 'sociology of the body', what it is, where it has come from and why it seems to be so important in recent years. Secondly, I discuss Furedi's work on Therapy Culture and examine Oliver's concept of Dependency Culture in his book 'Social Work with Disabled People' (Oliver, 1983), and explore the similarities between Furedi and Oliver. I discuss how Oliver argued back in the 1980's that it was very easy for disabled people to become dependent upon a professional person for help, and how this culture has developed further in the twenty first century under what is now termed 'therapy culture'.

## **2.1 Sociology of the Body**

Sociology of the body is an important new area of specialism within sociology (Jary, 1999), which has sought to repair a previous relative neglect of the body, and the implications of 'embodiment'. In recent years there has been an increase in popular as well as academic interest in the body 'social'. Academic interest is related to the growing influence of feminism; Foucauldian scholarship and post modernism schools of thought, which focus attention on the body as a social product as well as a physical entity (Jary, 1999).

Popular interest in the body is indicated by the multi-million dollar industries promoting exercise courses and weight reduction plans, the growth in popularity of self-help therapies and alternative medicine, and the emphasis on the body as an expression of individual identity. Further, the moral debates of the 1980's over contraception, abortion, pornography, embryo experimentation and homosexuality, the emergence of aids, and more recent controversy over drug use in sport or genetic engineering, have raised issues of interest to the population as a whole as well as to sociologists (Jary, 1999). The emerging sociology of the body has contributed to an understanding of the social regulation of bodies, particularly by legal and medical institutions (Foucault, 1973; Turner, 1984, 1987, 1992) and particularly of those bodies perceived as 'other' or as 'out of control'. The sociology of the body has also been concerned with issues of consumption (Featherstone, 1991) and has addressed the important issues of subjectivity, identity and the fashioning of the self (Giddens, 1991).

The social importance of the body has been a significant topic in both physical and social anthropology, but the sociology of the body has been, until recently, neglected (Abercrombie, 1994). The development of a sociological interest in the body is a consequence of feminism, the ageing of the population of advanced societies, the emergence of post modern social theory, changes in the nature of contemporary consumerism which emphasises the body, developments in medical technology and practice (such as organ transplants) which have made various aspects of the human body politically problematic, the growth of mass sport and leisure which have identified personal worth with the beauty of the body (Brumberg, 2006) (this could have an influence on an individual's intention to exercise), and the possibility of a radical enhancement of human functions by technology, namely the development of Cyborgs (cybernetic organisms). These cultural and technological changes have made the human body a topic of both political and theoretical debate (Abercrombie, 1994).

The rise of the sociology of the body has been associated with a critique of positivism and especially with a rejection of the legacy of R. Descartes (1596-1650), whose separation of the body and the mind resulted in a scientific approach (often referred to as Cartesian Dualism) in which all mental, spiritual or emotional events were treated as separate from, or simply manifestations of, biochemical changes of the body. This perspective had an important impact on the development of theories of knowledge, but in the twentieth century philosophers rejected dualism, emphasising instead the interaction of mental, physical and cultural phenomena. Human beings are not made up of two separate components (mind and body) rather they are embodied.

Sociologists and anthropologists have studied various aspects of the body in relation to fundamental aspects of culture and society: 1) the body has been important in the development of social metaphors of society in such notions as the head of church; 2) these metaphors are typically normative in that, for example, in many societies the left hand and left side are regarded as evil; 3) notions about body pollution are crucial in defining social normality – for example, dieting regulations form a significant part of religious beliefs and practices about the sacred, and deviations from these rules are regarded as dangerous for both individuals and the society as a whole (Abercrombie (1994).

A number of debates are important in the sociological analysis of the body. 1) There is the view that the human body is not simply a biologically given fact but a social construction, that is, the body is produced by discourses and social practices. 2) It is claimed, following the work of Foucault (1973), that the body has become in modern societies the target of endless, minute and detailed forms of surveillance, discipline and control. 3) Other theories, which have been influenced by Elias (1986), have examined long-term changes in body practices, which have been brought about by the civilizing process. 4) Feminist theories have been concerned to understand how patriarchy determines social attitudes towards women as frail, irrational and unpredictable; feminists deny that women are determined by their anatomy. 5) In general terms, sociologists are interested in how historically the regulation of the body (through diet, sport, dance, medical intervention, clothing and so forth) has been regarded as necessary for the regulation of society (Abercrombie, 1994). The body is an important feature of all social interaction, because our body-image (whether



disabled or non disabled) is regarded as an inevitable perspective of the presentation of the self.

Sociology of the body studies how the social world affects our bodies and is particularly concerned with processes of social change (Giddens, 2005, chapter 18). Oliver (1996) argues very strongly that it is the way that society is designed (environmental barriers and attitudes) which 'disables' a person, not the person's impairment. Oliver's (1996) 'Social Model of Disability', is the framework, which runs through this study and has very similar issues to that of 'sociology of the body'.

Modern social technologies have managed, for instance, to separate the body from nature, an example is the notion of dieting, which involves planned intervention in the functioning of our bodies in order to modify or regulate them in various ways. Food production in the modern world has been globalised: technologies of transportation and of storage (refrigeration) have meant that now everyone in the developed world is on a diet in some sense, having to decide what to eat each day (Giddens, 2005). Social relations influence such decisions.

Women especially are judged by physical appearance, but feelings of shame about the body can lead anyone to compulsive dieting, exercising or body building to make the body conform to social expectations. Disabled people are very aware of their body image, and many participants say that they like to exercise to keep fit and look good. This could be because society is pushing people for the body perfect (Brumberg, 2006), causing feelings of shame, which result to make disabled people either try harder, or give up. Or it could be personal feelings of satisfaction and achievement.

which influence their decision to exercise. Just how much control does society have over our bodies?

Sociologists are interested in the experience of illness – how being sick, chronically ill or disabled is experienced by the sick person and by those nearby. The idea of the sick role, developed by Talcott Parsons (1991,1951), suggests that a sick person adopts certain forms of behaviour in order to minimize the disruptive impact of illness. According to Giddens (2005) a sick individual is granted certain privileges, such as the right to withdraw from normal responsibilities, but in return must work actively to regain health by agreeing to follow medical advice.

Sociology of the body considers the relationship of the mind and the body from a variety of perspectives, examining the link between the body and personal identity, focusing on disability, race/ethnicity, and sex/gender, and considers how identity is enacted through bodily practices and manipulation (Giddens, 2005). It has been used as a tool to explore many different areas of life.

Howson (2001) traces out the intricate history of moves toward a 'Corporeal Sociology'. He identifies a central contradiction that affects all contemporary sociological practices, not just that dealing with the body, whilst Newton (2003), explores the relationship between sociology and biology through an examination of issues relating to the sociology of the body, emotion and health. Arguments for a 'biological' and yet social, body are considered before developing a critique of work on the sociology of the biological body.

Dance is another area, and ballet a type of dance, is for reasons that are unclear, a neglected topic in the sociology of the body. Wainwright (2006) works on three levels. First, as an account of ex-dancers 'lived experience' of embodiment; secondly, as an application of Bourdieu's theoretical schema; and thirdly, as a philosophically grounded critique of radical social constructionist views of the body. He describes Royal ballet dancers perception of their bodies, of ageing, of injury and of their careers. Dancers are extremely regulated, making their bodies perform to standards far beyond what most people would even think of being able to achieve.

Goto (2004) has written a paper on 'bridging the gap between sociology of the body and disability studies'. He explores the relevance of theoretical fusion of disability studies and sociology of the body. He discusses the 'social model of disability' as being the 'big idea' for many disabled people's movements. He then explores an issue which he feels is overlooked by the social model, which concerns the relationship between the status of the disabled body and the bio-politics of contemporary society. According to Goto this unnoticed yet earnest issue is informed by the perspective developed in sociology of the body. His paper examines the case of the disabled body in Japan, and he says it can be argued that a barrier free 'enabling' facility, which is endorsed by the social model, often cohabits with the bio-politics of 'regulating bodies'. Consequently, according to Goto, the disabled body seems to be one of the most regulated bodies in Japanese society.

In Japan, the government agreed to amend and/or create the laws for removing a social barrier. For the environmental barrier, the Government enacted and enforced a new 'Welfare City Planning Act' (1992), 'Hearty Building Law' (1994) and 'Barrier-

free Transportation Law' (2000). For the institutional barrier, the Government reconsidered the laws concerning the qualification for licences (driving licence, licence for practising medicine, licence for pharmacist, etc) that automatically disqualifies disabled people.

Goto argues therefore that there is a need to explore the theoretically and politically challenging topic of 'sociology of the disabled body', and that such exploration can be possible only by bridging the gap between disability studies and sociology of the body.

## **2.2 Therapy Culture**

Therapy culture is one of the greatest threats to public health according to Furedi (2004). Furedi has for some time been concerned about the rise of emotionalism in politics and culture. But the problem, he insists, is not only that today's society celebrates emotion above achievement and reason – it has also created a regime that 'praises some emotions and stigmatises others, creating an authoritarian and destructive dynamic'.

And therapy culture does not just focus simply on the charlatans and crackpot theories within the profession. Furedi says that 'every movement has its parasites', but the real problem with therapy is not its aberrances, but the way it 'most systematically expresses cultural norms'. That is, today's society has made therapy into a way of life, and that's what needs to be challenged. He goes on to say

'Every culture has a story about the human subject – the values it expects people to aspire to.'

Our culture's story is of a weak, feeble person, who is continually at risk, and for whom the chances of things going wrong are very great.

Therapy culture represents a shift from the view of the robust, independent person, capable of great individual and collective achievement, to the notion of the fragile, powerless victim in need of continual professional support. Furedi (2004) feels that 'far less is expected of humans in the twenty-first century than was expected in the

nineteenth'. Today's society operates around the belief that people can't cope on alone or face the challenges of life.

It is the society-wide belief that people cannot cope on their own that leads to the features of therapy culture that we are all too familiar with today; the burgeoning counselling industry, the relentless emphasis on boasting 'self-esteem', the expansion of categories such as 'trauma' to encompass more and more life events.

It can be argued that Furedi's Therapy Culture is very similar to Oliver's Dependency Culture as discussed in his book 'Social Work and Disabled People' (1983). Where policies have changed toward keeping people in the community, the ideology of personal tragedy theory (Oliver, 1990) has ensured that policies have been geared towards doing things to and on behalf of disabled people, rather than enabling them to do things for themselves (Oliver, 1990).

According to Gramsci (1971), 'ideas are material forces', and as these material forces change, so will ideology. Thus, as Oliver argues, capitalist economies have experienced a variety of fiscal crises, so the ideology underpinning welfare provision for disabled people has changed as well. No longer does it reflect tragedy and anxiety and the influence of benevolent humanitarianism. Rather, it reflects the burden that non-productive disabled people are assumed to be and the influence of monetarist realism. The ideological climate in which this finds expression focuses upon the notion of dependency.

John Moore, Minister for Health and Social Services in Britain (1988), provided a reinterpretation of the development of the welfare state:

For more than a quarter of a century after the last war public opinion in Britain, encouraged by politicians, travelled down the aberrant path toward ever more dependence on an ever more powerful state. Under the guise of compassion people were encouraged to see themselves as 'victims of circumstance', mere putty in the grip of giant forces beyond their control. Rather than being seen as individuals, people were categorised into groups and given labels that enshrined their dependent status: 'unemployed', 'single parent', 'handicapped'. Thus their confidence and will to help themselves was subtly undermined, and they were taught to think only Government action could affect their lives.

This kind of climate can in time corrupt the human spirit. Everyone knows the sullen apathy of dependence and can compare it with the sheer delight of personal achievement. To deliberately set up a system, which creates the former, instead of the latter is to act directly against the best interests and indeed the welfare of individuals and society (Moore, 1988).

This account argues that dependency is created through the application of particular social policies. Dependency is not constituted through changing ideas; it is created by a range of economic, political, social, technological and ideological forces (Oliver, 1990). Oliver felt that it was important at this point to distinguish between a social constructionist and a social creationist view of disability (1988). The social

constructionist view sees the problems as being located within the minds of able-bodied people, whether individually (prejudice) or collectively (through the manifestation of hostile social attitudes and the enactment of social policies based upon a tragic view of disability). The social creationist view, however, sees the problem as located with the institutionalised practices of society. The idea of institutionalised discrimination against disabled people has also been used in recent years (Oliver, 1985; 1988) to argue for anti-discrimination legislation in respect of disability, in order to change behaviour rather than attitudes.

Oliver defines the term 'dependency' in common sense usage as dependency implies the inability to do things for oneself and consequently the reliance upon others to carry out some or all of the tasks of everyday life. Conversely, independence suggests that the individual needs no assistance whatever from anyone else and this fits nicely with the current political rhetoric which stresses competitive individualism. But as Oliver says, in reality no one in a modern industrial society is completely independent; we live in a state of mutual interdependence. The dependence of disabled people therefore, is not a feature, which makes them out as different in kind from the rest of the population but different in degree.

Furedi (2004) asks 'what gave rise to this down beat view of human agency, this 'fatalistic epistemology' that recasts people as victims?' It is not that life in the twenty first century has suddenly become harder, or that people have become weaker for no reason at all. The decisive reason, Furedi says, is a broader political and cultural shift – in particular, the collapse of the left, and of any project for social change.



Oliver (1986) feels that dependency is reinforced from the patronising way politicians discuss disability in Parliament, through the failure of social policy analysts to examine critically the concept of disability, to the failure of policy makers to consult with disabled people. When the attention is turned to community care the discourse does not alter, for community care implies 'looking after people' (Audit Commission, 1986).

Furedi explains that 'the traditional conservative imagination has always presented a modest narrative about the human subject, in particular around the emphasis and deference, and people's inferiority to God'. The left historically had a more ambitious sense of human potential. What changed over recent decades was that the conservative imagination stayed the same – and the left's imagination adopted the mood of demoralisation, coming up with a version of the human potential that was even more powerless than that of the right. Having given up on the notion that human beings could change the world, the left focused instead on helping people to survive their circumstances.

Oliver (1984) points out that industrialisation had profound consequences for disabled people, both in that they were less able to participate in the work process and also because many previously acceptable social roles, such as begging or 'the village idiot' were disappearing. The new mechanism for controlling economically unproductive people was the workhouse or the asylum, and over the years a whole range of establishments were undoubtedly successful in controlling individuals who would not or could not work. It was soon recognised that these institutions not only created dependency in individuals but also created dependent groups. This led to fears about

the 'burdens of pauperism' in the early twentieth century and the establishment of the poor law.

Similar concerns are around now, although of course, the language is different, and current moves towards community care have a strong economic rationality underpinning them. Disabled people are likely to face exclusion from the workforce because of their perceived inabilities, and hence dependency is still being created (Oliver, 1990). Their condition or situation makes them economically unproductive and hence economically and socially dependent (Illsley, 1981).

The British Council of Disabled People (1987) criticised the nature of this discourse, thus:

The need to be 'looked after' may well adequately describe the way potentially physically disabled candidates for 'community care' are perceived by people who are not disabled. This viewpoint has a long history and a correspondingly successful application in practice – which has led to large numbers of us becoming passive recipients of a wide range of professional and other interventions. But, however good passivity and the creation of dependency may be for the careers of service providers; it is bad news for disabled people and the public purse (BCODP, 1987).

This political sphere lays the foundations for the ideological climate within which services are provided and professional practice carried out. There are a number of ways in which dependency is created through the delivery of professionalised services. The kinds of services that are available, notably residential and day care

facilities with their institutionalised regimes, their failure to involve disabled people meaningfully in the running of such facilities, the transportation of users in specialised transport and the rigidity of the routine activities taking place therein, all serve to institutionalise disabled people and create dependency.

Furedi explains that during the 1980's (the time of Oliver's Social Work with Disabled People) he was talking to people about employment schemes and how the government was introducing counselling for the unemployed, he was laughing about what a con it was. Yet 20 years later he says 'many of the same people with whom I laughed with then have become part of that industry'.

In a time when social change is off the agenda, therapy culture unites conservatism and radicalism under an umbrella of survivalism. When it is accepted that there is nothing that can be done about the circumstances that we live in, the big challenge of the new century becomes helping individuals merely to cope.

It is in a sense, that therapy culture promotes conformity; laying down a framework of acceptable emotions and behaviour that people transgress at their peril. Being in touch with one's emotions means that it is fine to cry in public or obsess on the 'trauma' of a bad experience – but those who get angry are sent on anger management courses to suppress their rage, and those who fall passionately in love are suspected of suffering the pathology of 'loving too much'.

Therapy culture to Furedi (2004) does not just mean public displays of emotion and rather too much counselling. It represents a process that is actively destructive of people's views of themselves, and their relationships with each other.

We have an obsession today with 'the fragility of internal life' – namely, the sense that people can no longer judge themselves on the basis of their achievements in society or their relationships with others. It all has to be down to how they feel themselves, emotionally, at any point in time. This represents the estrangement of people from one another – a process cultivated by therapy culture.

One of the justifications often put forward for why therapeutic intervention is needed by modern society is the fact that we live in an increasingly atomised world, in which the bonds between communities and families are weaker than before, leaving individuals isolated and lonely (Furedi, 2004)

Furedi argues that society is more atomised than 30 years ago – and for some years, he has been theorising about the causes and consequences of the process. But he says, 'It is not inevitable that social change breeds atomisation – change can bring with it feelings of solidarity'. Therapy doesn't necessarily provide the solution to atomisation; it only fuels this destructive trend pushing people further away from their nearest and dearest. By continually taking up the need for professional intervention to 'help' people with everything from the ins and outs of married life, stress at work and at school and unemployment, therapy culture weakens people's relationships of dependence upon each other, and encourages increasing dependence upon professionals. During the 1980's Oliver pointed out that whilst some attempts had

been made to address this problem of dependency creation in facilities such as residential, day care and specialised transport, it remains unfortunately true that power and control continue to remain with professional staff.

Many community services are delivered in similar ways and reinforce dependency; disabled people are often offered little choice about aids and equipment and times at which professionals can attend to help with matters like toileting, dressing or preparing a meal are restricted. Dependency represents a robust person who becomes a fragile person in need of support, losing power and control over their lives and depending upon professionals for help.

It is interesting that therapy culture today is not very different to Oliver's findings in 1984. We are now seeing a rise in therapy culture. Things are more out in the open today than they were 25 years ago. It is the developing culture now that people do have counselling and therapy for the slightest thing. People years ago never had counselling or therapy because there were no counsellors around, but what Oliver was saying very clearly then was that when professionals are involved with disabled people they seem to foster this dependency culture with them. The disabled person then becomes reliant upon the professional whether that is the social worker or health care professional. What is interesting now is that we are becoming much more dependent, as a society, upon professionals. With this growth of therapy culture, generally as a society we are becoming more reliant upon professionals for our well being. The next five sections of the literature review will therefore be examined in the context of: 'sociology of the body' which studies how the social world affects our bodies particularly with regards to disabled people and their 'Intentions to Exercise',

and 'therapy culture' which views people as fragile powerless victims in need of continual professional support.

### **2.3 Social, Physical and Psychological Benefits of Exercise Activity for Disabled People**

A number of researchers have identified the very positive outcome of involving disabled people in a variety of social and physical activities. Martin & Mushett (1996) propose that social interaction is very important to disabled individuals because many are often leading a sedentary lifestyle. Mullineaux, Barnes and Barnes (2001) in their study of non-disabled individuals found that the likelihood of being sedentary will increase with age, self-perception of lifestyle problems, lower scores on education, self perception of motivation to exercise, perception of their own participation in physical activity and recognition of exercising enough for health benefits. Lifestyle problems could be linked to the social context within which an individual lives.

The development of these ideas may lead one to conclude that the availability of exercise venues, the accessibility of transport in order to get to the chosen venue and the accessibility of the exercise facilities, once they actually arrive, are all determinants which could influence an individual as to whether to participate in exercise activity or not. Rice (1995) explored the opportunities available to wheelchair users seeking access to a variety of holiday destinations and leisure facilities and found that the needs of wheelchair users did not match the services and facilities that were claimed to be on offer to them.

Previous research highlights the many benefits that can accrue from disabled and non-disabled individuals participating in exercise activity. Monnazzi, (1982); Petruzello,

(1991); Mooney, (1998); Wilson, (1992); Schaeffer & Proffer, (1989); and Mullineaux, (2001) each claim that exercise involvement can have a variety of social, psychological and physiological benefits. Bouchard et al (1993) maintain that regular exercise is a cost effective alternative to the high cost of health care associated with treating ailments related to physical inactivity. In their study Bouchard et al, (1993) feel that some politicians might claim that having a healthy population could have a great economic benefit. Paradoxically, although it is assumed that exercise is good for all of us (disabled and non-disabled alike), very few people seem to exercise to sufficient levels to reap any benefits and sustain any level of exercise involvement (Dishman, 1994).

In an attempt to address these issues, Dishman (1994) focused on the factors that lead to initiation, maintenance and continuation of exercise behaviour. However, to date, this work has focused mainly upon the non-disabled population (Mullineaux, 2001) whilst relatively little is known about the extent to which disabled people exercise. The factors which determine whether an individual exercises or not, needs to be examined before a full understanding of disabled people and their exercise involvement can be gained. A key factor in determining whether such individuals do choose to engage in exercise is the perceived benefits that result from such a course of sustained physical activity.

The available evidence Monnazzi (1982) Mooney (1998) Wilson (1992) Schaeffer & Proffer (1989) suggests that exercise is of potential benefit to disabled individuals for the following reasons.



First, some disabled individuals could benefit from the increase in greater social integration and communication with other individuals, enabling them to build friendships with other people, along with the element of competition between individuals. Exercise can help disabled individuals to regain contact with the reality of the world they live in facilitating social reintegration. Gorden (1997) found that individuals with spinal cord injuries see a need for encouragement by family, friends and the wider community to pursue their dreams and goals. It also appears that social support is a very important part of the inclusion of disabled people into society. Heller et al (2002), found that when carers perceive greater benefits of exercise and when there are fewer access barriers, the adults with Downs Syndrome exercised more frequently.

Doyle (1994) found a different reaction when he conducted a study on the perspective of young adults from different ethnic backgrounds. He found that most of the individuals lived with informal carers, usually their mothers. Many had complex disabilities and were wheelchair users. Over 40% of these young people were living in a close family network, but these young people were less optimistic about their future prospects. Many had come to accept that poverty, disability and ethnic background would serve to isolate them from the wider community therefore reducing their chances of employment opportunities and social life. This study did not state whether or not these adults received any social support or encouragement from their family (i.e. their mothers) or friends.

Secondly, whilst I have considered a range of social benefits that may follow exercise activity, it is important to review possible psychological advantages. Regular exercise

can bring about beneficial psychological changes. It can improve a person's perception of their body image (Brumberg, 2006). These images of the body and the study on American adolescent girls in America relate to my participants and the issues they have about their body image. Exercise can also increase self-confidence (Schaeffer & Proffer, 1989), and is said to have a positive effect upon an individual's self-efficacy (Bandura, 1977). Exercise can also help to create a positive attitude (Mooney, 1998. and Wilson, 1992). Mooney (1998), in her research on paraplegic willpower, examined how a young man with a serious spinal injury defied doctors' predictions that he would never walk again. The 22-year-old had a positive attitude toward exercise and fitness and believed that it could help him back onto the road to a full recovery. Doctors remained sceptical throughout his treatment, doubting his ability, but within 3 weeks he was walking his first steps. He had to learn how to walk and control his arm movements during physiotherapy sessions. Later he started to go to the gym 3 times a week. A combination of medication and exercise helped to build up muscles to compensate for the ones he lost. After 6 months he was walking without a cane and his movements were getting stronger. He had a positive attitude toward weight training and believed this helped him to defy doctors' predictions..

Wilson (1992), who followed the study of a young female, Lynn Poole, who contracted a malignant tumour of the spinal cord during her infant years, backed up this case of a positive attitude. The only physical activity she was ever able to participate in was a walk and an occasional swim. Aged 22 she then had a fall and suffered spinal cord injury. Becoming paraplegic she lost her ability to walk and her general health declined. Some time later she started to use free weights, and as time went on she started to notice changes. Her upper body strength improved, stamina

and endurance increased and she quotes "my entire attitude began to take on a more positive dimension". With support from her trainer, Lynn started to attend a local aerobics class, with non-disabled people, and she learnt that she did not need to compare herself to other people in the class. Poole stated that:

"Fitness truly is more than physical - it is an integrated state of mind and body. It has evolved from an exercise program into a lifestyle that provides me with more energy, greater self-esteem and a more positive outlook on life"  
(Wilson, 1992).

Lynn Poole was one of the nation's first paraplegics to be AFAA (American Fitness and Aerobics Association) certified to become an aerobics instructor. She was then able to run an aerobics class and pass her motivation onto others.

Thirdly, people are generally aware of the physical health benefits to be gained from regular exercise involvement. Some individuals become involved in physical activity primarily for the development or enhancement of their physical prowess. Sociology of the body is clearly seen here and an example can be seen in ballet dancers who have to get their bodies into positions most people would not even dream of, and they become very regulated bodies (Wainwright, 2006). Other people become involved in exercise because of the feeling of well being that they achieve from regular exercise activity. For persons with a disability, regular exercise can improve functional status and independence in activities of daily living by increasing muscular strength and endurance, flexibility, balance, and cardiovascular and respiratory functioning (Rimmer, 1999). Also, exercise can reduce the onset of acquired conditions for

people ageing with a disability. This could be physically beneficial to those wheelchair users who may lead a sedentary lifestyle, because participation in exercise has been found to increase mobility for different groups of disabled individuals (Schaeffer & Proffer, 1989). In their study they found that participation in wheelchair athletic competitions increased mobility and improved self-image, again society is having a big effect upon the body and how it should look and perform (Jary, 1999). Exercise is known to improve blood circulation, and can strengthen the heart, lungs and muscles. But, on the negative side, there were common problems associated with participation at this level and they were soft tissue injuries, blisters, pressure sores and temperature regulation disorders.

Given the range of benefits, social, psychological and physiological that can be derived from regular exercise involvement it is increasingly important to understand what determines whether a disabled individual will participate in physical activity or not and how far does society go to have an influence in this decision? This issue is important to address because it has a social and economic benefit increasing the overall health of an individual and consequently relieving the amount of medical assistance and state aid. Because of the substantial number of sedentary adults in the population, it is essential to understand the determinants that lead to the adoption of physical activity (Dishman, 1994, p.3). We can then perhaps get a better understanding of the reasons why some individuals adopt and maintain exercise involvement, thus accruing some of the benefits to be gained, whilst others are prevented from, or decide not to participate, due to factors such as determinants or barriers.

## **2.4 Factors Determining Intentions to Participate by Disabled People in Social and Physical Activity**

Determinants are defined as all those factors, which exert a strong influence in the making of decisions to participate or not in a wide variety of physical and social activities. These might include: education at school and amongst service providers, employment, education and social opportunities (McNeill, 1993), home environment, environmental and structural barriers (Oliver, 1996), attitudes (Furedi, 2004), isolation, level of physical pain, personal factors, nursing care and previous experience of exercise. For those who have participated in the past it is likely that they have been able to pursue a range of physical activities and have benefited from a healthier lifestyle (Sherwood & Jeffrey, 2000).

Kew (2000) confirms the importance of the distinction between the terms 'impairment' (UPIAS, 1976), referring to the medical model, and 'disability' (Oliver, 1996), which identifies the social disadvantages experienced by a large group of people in sport and other areas of their lives. Kew uses the term 'disablism' therefore to suggest that medical divisions become crystallised into social divisions and consequently, inequalities in the ability of people to participate fully as members of the community.

Kew further agrees after describing the traditional medical model of disability and the more recent social perspective, that it is society which discriminates, handicaps and imposes barriers upon disabled people. Therefore he feels that "it is social organisations, developed with the needs and conveniences of non-disabled people in mind, which must change" (Kew, 2000, p109). He states that this same politicised

perspective needs to maximise the extent to which a historically dis-empowered group of people are able to realise their social and political rights to full citizenship.

In line with this second approach to disability, the Minister of Sports Review Group into sport for people with disabilities published "Building on Ability", (HMSO, 1989). This report contains a number of recommendations for sports organisations in the public and voluntary sectors centring on the need to "refocus sport for people with disabilities away from disability" (Marshall, 1991). This report is based upon a concern that stereotypes must be diminished by considering all people in terms of their abilities not their disabilities. This means that disabled people should not be segregated away from mainstream sports. Sports should be designed where anybody can join in.

Although "Building on Ability" only provides recommendations, rather than statutory requirements, these were taken up in 1993 by the Sports Council, which provided guidelines for sports governing bodies, and by the British Sports Association for the Disabled (BSAD). The formation of the Federation of Disability Sports Organisation in Yorkshire and Humberside provides an example of greater liaison between disability sports organisations, by incorporating British Blind Sports, Deaf Sports Council, and the UK Sports Association for people who are intellectually challenged. But the underlying problem of disablism remained, as Borrett et al (1995) state:

“Discourse..... still tends to be dominated by professional non-disabled people that perpetuates a world of sport based on non-disabled norms”.

What Oliver was saying two decades ago was that when professionals are involved with disabled people they seem to foster this dependency culture with them and become dependent upon professional people, i.e. social workers or health care professionals. In this present day society, in the type of society we live in now, Furedi (2004) feels that people from all walks of life are made to depend more heavily upon professionals for help.

However, at the level of national mainstream and disability sports organisations there is a discernible shift towards a more inclusive range of activities and away from exclusive and segregated provision. Critical in this regard is the necessity for adequate resources; in terms of the training of sports teachers, coaches and organisers, and also specialist facility and equipment provision. But inclusive provision needs to be adapted to take account of an individual's day-to-day activities, as well as sport and exercise. Full participation in the community is ensured only when there is equitable access and opportunity. To overcome inequitable access and opportunity, the following issues need to be addressed. These areas are perceptual, attitudinal, physical and financial barriers, adapting and modifying sports and physical education at school (Kew, 2000).

a) Perceptual Barriers

Kew's (2000) definition of perceptual barriers refers to disabled people's awareness of the existence of facilities for sport, and of the organisations, which specifically cater for the needs of disabled people. It is important for children in both their early and later school days to be taught an understanding about their physical abilities and

limitations with regards to mobility and movement of limbs. Again a good example here of 'sociology of the body' is Wainwright (2006) in his study of ballet dancers, and how these dancers become very regulated bodies within society. This knowledge could give the growing child (young adult) a better understanding and awareness of their own bodies and what they can and cannot do. Disabled people also need to be made aware of the existence of facilities for sport and exercise, and of the organisations, which specifically cater for the needs of disabled people. Kew states that many disabled people have little contact with disability sports organisations, little or no knowledge of the opportunities so afforded, or that mainstream sports organisations are assuming an increased role in sports provision for disabled people, although there is still a need for greater awareness amongst service providers to gain a greater level of understanding regarding disabled people's needs. Many disabled people are still not aware of the information available to them regarding everyday living such as use of facilities, resources and the benefits available to them (Kew, 2000). Heller (2002) states that to increase accessibility, adults with disabilities need information on where fitness centres are and how to use the equipment. Choice and control cannot be achieved unless information relevant to the decision to be made is available in an accessible form. Advice and advocacy are also needed to assist people to make choices. Decision-making processes must involve the people who are affected, whether this is on an individual level (for example, assessments and care plans) or on a collective level (for example, commissioning and delivering services) (Morris, 2004).

Kew goes on to point out that many disabled people have had little previous opportunity, at critical learning periods in childhood, to develop the basic movement



abilities upon which more specific sports skills are based. Lack of previous experience in sport and exercise can often lead to a low assessment of one's own capabilities, and can consequently bring on avoidance of sport and exercise challenges through fear of failure or ridicule. Organisers of exercise facilities, coaches and sports providers having had little opportunity to work with disabled people are unlikely to have a full understanding of the specific challenges facing disabled people.

### b) Attitudinal Barriers

Disability awareness training is about changing attitudes and confronting myths and misconceptions about disability, which stem from a lack of understanding (Kew, 2000). The lack of understanding from some non-disabled people reflects their attitudes toward people who use a wheelchair for their means of mobility. In their study Furnham & Thompson (1994) stated that the sub-section of the disabled population who use a wheelchair has largely been neglected in the research concerned with attitudes towards people with a disability. Their study had two aims: first, to compare the attitudes towards wheelchair users of non-disabled people with people who actually use a wheelchair, and secondly, to examine the difference between how each group perceives the attitudes of the other towards this condition. The results of their study revealed a number of interesting differences between the expressed attitudes of the two groups, although their overall mean scores were comparable. The wheelchair user group were found to believe non-disabled people to hold more negative attitudes than they actually expressed. A few age and sex differences were found, as well as a number of differences depending on whether the respondents had congenital or acquired disabilities. Finally, the amount of contact with those using

wheelchairs was found to be associated with slightly more realistic attitudes among the non-disabled respondents. The results of their study are discussed in the light of previous research, and possible reasons for, and ways to counter, the lack of empathy between the two groups was considered. With regard to attitudes toward wheelchair users, there are prejudices which need to be broken down, and turned into acceptances by wheelchair users.

Maranda Wootton, editor of the Whizz Kids 'no limits' publication (2001) spoke to non-disabled teenagers and discussed their antipathy towards disabled people. The editor states: "There is little evidence to pinpoint exactly what the key to greater integration of non-disabled and disabled young people is. What research has been undertaken, however, has proved that for a non-disabled young person to have first hand interaction with a disabled young person, whether that be at school or in an extracurricular capacity, has a positive impact on the way they interact with other disabled young people."

The article goes on to say that the sheer presence of their powered wheelchairs also seems to play an important role in breaking down barriers. They can act as a talking point and arouse curiosity among their non-disabled contemporaries. After all it is an extension of their physicality.

This article, which is written for young disabled people, adds a positive attitude to the importance of confidence being a key issue. A positive self-image therefore seems to be imperative in promoting young disabled people as fully active members of teenage society. Equally, a wheelchair that the user is at ease with plays a crucial role, far

beyond functionality, that both encourages a more positive self-image and in turn changes the way that non-disabled teenagers perceive disabled young people.

Kew (2000) notes that stereotyping and labelling of groups (e.g., disabled, handicapped) creates crude distinctions which forefronts the medical condition, minimises individual difference and underplays abilities.

The Scottish Sports Council, in 1994, discussed attitudinal barriers thus:

In the case of a person who is disabled, the more visible and obvious the disability the more likely it is that the disability will become the main focus of attention. We will use this visual information to determine in our own minds, the capabilities of that person. Such assessments are rarely accurate and often result in the disabled person feeling patronised, inadequate and dependent. On the other hand, when we perceive and expect a person who is disabled to be resourceful, with a potential for a full and rewarding life, independence and life can be enhanced (Kew, 2000, p112).

As mentioned earlier in the literature review according to Furedi (2004) today's society has made therapy into a way of life. He feels that our culture's story is of a weak, feeble person, who is continually at risk, and for whom the chances of things going wrong are very great. Therapy culture represents a notion of the fragile, powerless victim in need of continual professional support.

This issue of attitudinal barriers is a really important factor and it is not something which has just suddenly happened. These attitudinal barriers are persistent and long lived problems for disabled people and not just to do with sport. A negative attitude towards disabled people can be observed as far back as the writings in the Bible. Throughout recorded history many societies, cultures and religions have sought, in their various ways, to come to terms with a wide spectrum of physical and mental impairments, handicaps, diseases and crippling injuries. Up to the present time the debates continue as to how such afflictions should be perceived, treated and prevented and equally crucially, what resources should be made available to alleviate them.

The literature from the world's main religions gives many insights into how those adherents and societies marginalised those of its members who were perceived to be abnormal because of their mental and physical disabilities.

The Torah (the first five books of Moses, a part of the Christian Bible) chronicles the elaborate procedures that those suffering from leprosy were required to go through with the priests playing a significant role in decisions that could lead to a sufferer being banished 'outside the camp' (Leviticus Ch. 14 v.3). Restrictive orders and 'removal' to care centres are still a part of modern responses to infectious diseases and mental illness where they are thought to pose a threat to society at large.

The Torah also suggests that notions of being punished by God and the affliction itself an opportunity of sacrifice to please the Lord, and expiation from past sins, may have been a part of the temple rituals and are described in Leviticus Ch. 14. Also the sick and infirm were barred from officiating in the temple because of their imperfection,

the belief that 'defective' people were not 'qualified' to offer prayers and sacrifices to the Lord (Leviticus Ch. 21 v.17).

The New Testament, particularly in the four gospels, abounds with instances of Christ healing the sick and afflicted, gives much emphasis to the need for caring and concern for those outcast and considered beyond charity and consideration by the society to his time (that viewed such unfortunate afflictions as forms of divine punishment).

This part of the Bible is interesting in that unlike the Torah and Quran it specifies a variety of physical and mental conditions that Jesus meets head on and effects what appear to be miraculous cures. However the notion still persists in these accounts that such afflictions are occasioned by 'devils' or 'sinfulness' and that when cured they should go and 'sin no more'.

Bringing this debate into a more modern frame emanating from developments in European thinking from the late nineteenth century - notably, liberal utilitarianism (Barnes, 2003) and social Darwinism (Pfeiffer, 1994; Suzuki, 2001; BCODP, 2003; DDA, 1997; Clapton & Fitzgerald 1997; and Wertz, 1999), the arguments have been put forward that in societies where economic survival is precarious, then any weak or dependent individuals should be 'removed' from that society. This could lead to children with impairments being 'exterminated' (Germany in the 1930's), adults with acquired handicaps and disabilities forced out of the community and elderly people left to die (Oliver & Barnes, 1998).

Fascist movements emerged after the first world war and two of them managed to turn a major country into a fascist state: Italy under Mussolini and Germany under Adolf

Hitler. The fascists promoted the league of health and beauty. They argued that, under the right leader, a nation can become perfect and therefore it is right to use any means to achieve this (Tames, 2000). Hitler stated that the blonde 'Aryan' race of Northern Europe creates the superior culture. Other races are valuable only to serve Aryans.

Fascism, Eugenism and Racial Superiority excluded black, disabled and gay people from society. When Jesse Owen the greatest black athlete of his time, won four gold medals at the 1936 summer Olympic games in Berlin, Germany, his performance was embarrassing to Adolf Hitler, the ruler of Germany. Hitler and his followers were happy that German athletes would prove that the Aryans - a term they used for Germans and certain other peoples of Northern Europe - were superior to all other peoples (World Book Encyclopaedia, 1986). Hitler wanted the Germans, the purest Aryans, to rule the world (Tames, 2003), and at that time there was no place for black or disabled people in any kind of sport.

Owens feat in Berlin had been an incalculable psychological boost to the pride of black Americans. But thirty years later when black American athletes were again in the ascendancy, those looking for a more tangible political response to their people's achievements were to remember that when Jesse Owens returned to his hero's welcome in America's southern states he still had to sit in the segregated seats on the bus.

Another approach leading to the exclusion of disabled people is described in the writings of Mary Douglas (1966) and Robert Murphy (1987). Responding to deep-

rooted psychological fears of the unknown, Douglas argues that 'primitive' cultures react to 'anomalies' such as an impairment, by reducing it, physically controlling it, avoiding it, labelling it dangerous or adopting it as a ritual (Douglas, 1966, pp.39-40). Such examples have already been highlighted above in the writings from the Torah and the New Testament.

While impairments of varying kinds, both congenital and acquired, have existed and been recognised throughout recorded history and in all known cultures and societies, social responses to impairments have varied considerably. Disability, or the social oppression of people with perceived impairments, on the other hand, is a social creation. Within Western culture to be a disabled person is to be viewed as, at best, somehow less than whole and, at worst, not quite human. As a consequence, disabled people have been and continue to be treated differently from non-disabled peers. Furthermore, from the beginnings of industrialisation through to the latter half of the twentieth century this has invariably resulted in their systematic exclusion from the mainstream of community life. Oliver's work in the 1980's points out that industrialisation had profound consequences for disabled people. Over the years a whole range of establishments were successful in controlling individuals who would not or could not work. These institutions not only created dependency in individuals but also created dependent groups. As Furedi (2004) argues, by continually taking up the need for professional intervention to 'help' people with everything in life, therapy culture weakens people's relationships of dependence upon each other, and encourages increasing dependence upon professionals.

Imrie (2000) states that writings about disabled people are usually a spatial or lack geographical frames of reference (Gleeson, 1999). Imrie feels that this is curious because geography is fundamental to an understanding of the social, economic, and political opportunities and/or constraints underpinning the lives of disabled people. A range of evidence demonstrates that disabled people's lives are conditioned, in part, by where they live. The spatialisation of social life can be illustrated in many ways. For instance, disabled people's identities, mobility and other social interactions, can be understood, in part, through the particular spatiality of disability (Imrie, 1996; Butler & Parr, 1999; Gleeson, 1999). One spatiality of disability relates to the production of segregated spaces, and the use of asylums and other institutions to discipline, protect and/or control disabled people, and their interactions with the rest of society. Howard's (1898) conception of the 'Garden City' is one such example, in which disabled people were provided with special places, day care centres and dial-a-ride bus services, all of which serve to demarcate and segregate disabled people into distinctive and discreet places, making them very regulated bodies within society (Goto, 2004). Such segregated spaces are, not surprisingly, infused with values, which identify disabled people as different and usually inferior to the rest of the society (Imrie, 2000).

Oliver & Barnes (1998) also make the argument that the classic welfare state built upon capitalism, industrialism and modernity seeks individual solutions to collective and structural problems - hence; it creates disability in the individual model.

However, post-modernist thinking tends to ignore history and, as such, fails to offer a way forward at this point in time, when globalisation and technological developments are bringing about fundamental changes to the nature of the welfare state. Their



analysis remains in the modernist paradigm and views the current historical phase as one of late capitalism in which welfare remains a contradiction:

Capitalism cannot exist with; neither can it exist without, the welfare state.

(Offe, cited in Oliver & Barnes, 1998, p.5.)

It was at the end of the Second World War when the new welfare policies were designed to treat all citizens as part of a more inclusive national order. In so doing it was to recognise the state as being responsible for caring for those who were in some way prevented from active economic participation (Giddens, 1994).

### c) Physical Barriers

It needs to be noted that many of the barriers are also determinants (e.g., accessibility to transport) which consequently influence individuals in their decision making process. The most obvious determinant, which may influence a disabled person's decision to participate in exercise or not is accessibility. As well as accessible transport (i.e., buses, trains and planes), that would include general facilities such as cinemas, shops, restaurants, leisure centres, and sport and exercise venues.

The physical barriers according to Kew (2000) are the most obvious connotations of 'accessibility'. The Disabled Persons Act 1981 (DPA) made it a statutory obligation for the design of local authorities' sports facilities to conform to minimum access requirements. But this was not retrospective and did not include buildings built before that date. Haywood et al (1995) list some of the extensive measures that need

to be considered to include toilet and changing facilities, ramps, lifts, wide car-parking bays, hand rails on stair flights, lever taps on wash basins, automatic doors and non-slip floors etc. There needs to be access on equal terms with able-bodied people and this is seldom achieved (Heller et al, 2002). In practice, the ideal of equal access is balanced with the realism of cost benefits (e.g., a lift to enable access to a water slide in a leisure complex (Haywood, 1995)). Sargent (1987) advocated that concerns about cost should be outweighed by concerns with equity, but public sector spending constraints are likely to ensure continued inequality of access (Kew, 2000).

A major geographical factor is likely to be the varying gradients of the local terrain and landscapes that wheelchair users encounter in their day to day mobility as they venture into their local communities, cities, towns or villages (Imrie, 2000). Urban and rural facilities vary for ease of movement, i.e., traffic flows, parking areas and well maintained roads and paths and can militate against the good intentions of wheelchair users to take advantage of leisure opportunities and outdoor exercise intentions. Local authorities are required, since October 2004, to ensure facilities and access to such areas are available and a discussion with the Disability Officer at Bedford Borough Council revealed that such measures, and their implementation, are being carried out.

An important part of disabled people's lives relates to their ability to gain access to particular places. Evidence suggests that the built environment is generally inaccessible to people with a range of physical and/or mental impairments, especially for those that are dependent on wheelchair use (Barnes, 1991; Gleeson, 1999; Imrie, 1996; Imrie, 2000). Local authorities have statutory responsibilities to regulate the

provision of accessible spaces in new build and/or refurbished public and/or commercial buildings by enforcing national accessibility standards. Such standards are itemised in Part M of the Building Regulations (for England and Wales), which requires developers to provide 'reasonable' access for wheelchair users and for people with vision impairments and loss of hearing (Imrie, 2000). However, Goto (2004) pointed out in his study on 'bridging the gap between sociology of the body and disability studies', that a barrier free 'enabling' facility, often cohabits with the bio politics of 'regulating bodies'. His paper examines the case of the disabled body in Japan. According to Goto, the disabled body seems to be one of the most regulated bodies in Japan.

The shortage and price of adequate housing and accommodation in recent years have put great pressures on disabled people generally in seeking living quarters that allow them a degree of equality and independent living. In 2002 the United Kingdom's Disability Rights Commission (DRC) adapted the aim of 'a basic enforceable right to independent living for all disabled people' (Disability Rights Commission, 2002). Although there are wider societal barriers to this aim, certain features of the community care legislative and administrative framework also create significant barriers.

According to Morris (2004) most definitions of independent living contain three elements. Firstly, an assertion that disabled people should have the same opportunities for choice and control as non-disabled people; secondly, a challenge to the usual interpretation of 'independent'; and finally, the aspiration that any assistance required should be controlled by disabled individuals themselves. As Simon

Brisenden, a pioneer of independent living wrote, 'independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it' (Brisenden, 1989, p.9).

Independent living is also, as Adolf Ratzka states, 'a philosophy and a movement of people.... who work for self-determination, equal opportunities and self-respect' (Ratzka, not dated). Independent living is essentially a challenge to the place of disabled people in society.

The goal of independent living is thus motivated by three fundamental ideas: First, disabled people should have access to the same human and civil rights as non-disabled people. Secondly, society's reaction to impairment and the failure to meet needs relating to impairment, has undermined disabled people's human and civil rights. Thirdly, this is not inevitable; impairment does not have to determine life chances. Our biology is not our destiny.

Independent living itself is a means to an end: it is a way of people accessing their human and civil rights. Disabled people have the same human and civil rights as non-disabled people but they are different from non-disabled people in that they have additional requirements, such as mobility needs, communication assistance, personal assistance and so on. A legislative framework that confers human and civil rights will not be effective for disabled people unless they also have entitlements to these additional requirements (Morris, 2004).

Additional requirements are usually called needs in the context of social care. They are related to both impairment and to disabling barriers. If needs are not met then this can result in a denial of human and civil rights (Morris, 2004). Independent living is also associated with the words 'choice' and 'control', and concerns both the environment in which someone lives and the assistance needed in order to go about daily life. The disability movement identified first seven (Davis, 1990) and then twelve 'basic needs', which are central to achieving independent living. These are:

- 1 Full access to our environment
- 2 A fully accessible transport system
- 3 Technical aids - equipment
- 4 Accessible adapted housing
- 5 Personal assistance
- 6 Inclusive education and training
- 7 An adequate income
- 8 Equal opportunities for employment
- 9 Appropriate and accessible information
- 10 Advocacy (towards self-advocacy)
- 11 Counselling
- 12 Appropriate and accessible health care provision

(Southampton Centre for Independent Living, not dated)

These are areas in which disabled people have requirements, over and above those of non-disabled people, which must be met if they are to experience equal access to

human and civil rights. However, the philosophy of independent living also emphasises that the way in which these additional requirements are met is crucial to whether this level playing field is achieved: the disabled person must have choice and control over how needs are met (Morris, 2004). When professionals are involved with disabled people, disabled people seem to foster this dependency culture with them and become in need of professional help in order to cope with daily life in their own homes (Oliver, 1984).

A good example of adapted housing and community facility was evidenced following a visit to Dunstable (Parksiders) earlier in this study, which also employs qualified staff and management to ensure disabled people and wheelchair users can participate more fully in the life of the community, whilst still keeping their independence and ability to live in their own homes.

#### d) Financial Barriers

Many of the areas in which disabled people have requirements, over and above those of non-disabled people, require extra income in order to fund them. One area in particular is that of technical aids - equipment, such as mobility needs (wheelchairs). There are many types and models of wheelchairs being loaned and sold across the country. Participants in this study showed concern that expensive electrically driven machines are very costly and the quality and reliability of those loaned and allocated by local Hospital Trusts vary considerably and will depend on the severity of the immobility. The most up-to-date lightweight machines, often provided for those who

drive specially adapted cars, require a recipient to be assessed and declared fully immobile.

To acquire better machines wheelchair users often must raise the necessary funds themselves. Those who are on state benefits often have to make do with whatever the local organisations can make available to them which may in some cases, be old and cumbersome machines, which have had little maintenance and do not match the type and level of disability and immobility being experienced. Being on benefits can also have an impact upon a disabled person's choice of leisure facilities.

In recent years the government, through a pilot scheme and backed up by funding, has allocated resources to 30 leisure centres and complexes, enabling them to adapt facilities and recruit trained staff to meet the special needs of those disabled users who are attracted to leisure and physical exercise e.g. Ripley. The Bunyan Centre at Bedford is of note where wheelchair users can now engage in the game of curling with special ramps and equipment at minimal cost to those on benefits.

Finding suitable, regular employment as a disabled person continues to be problematic. There is an economic gap between disabled people and their able-bodied peers, which means that disabled people do not have the same disposable income to spend on sport and other leisure activities. In 1988 figures showed that only 31% of disabled people of working age were in employment, and those in employment earned, on average, only 80% of the salaries of able-bodied peers. The weekly income of disabled people who are solely dependent on benefits is approximately £200.00 below the amount required for them to ensure an acceptable

and equitable quality of life (Rowntree, 2004). Three quarters of disabled adults had to rely on state benefits as their main source of income (Hunt, 1993), in 1994 this reached nearly 80 per cent of disabled people in the UK having to rely on state benefits for their basic income (Wood, 1994) and finally, the incomes of non-pensioner disabled families are only 72% of the national average (HMSO, 1989, Haywood, 1995). Labour Market Trends (2001) focused on the labour market experiences of disabled people as follows:

- \* According to autumn 2001 Labour Force Survey (Labour Market Trends, 2002), nearly one in five people of working age in private households had a long-term disability (3.7 million men and 3.4 million women).
- \* Fewer than 10 per cent of adults aged 16-19 years reported a disability in the autumn of 2001, but this proportion increased to around one third for adults in the 50 to retirement age category.
- \* Some 3.4 million disabled people were in employment in autumn 2001, an employment rate of 48 percent, compared with an employment rate of 81 per cent for non-disabled people. However, employment rates for disabled men and women have increased over a three-year period to autumn 2001 by 2.7 percentage points.
- \* The overall unemployment rate for disabled people was 8.3 per cent compared with 4.8 per cent for non-disabled people in autumn 2001.



- \* Approximately half of the disabled population in the UK are economically inactive (44 per cent men and 52 per cent women), compared with only 15 percent of the non-disabled population (9 per cent of men and 21 per cent of women).

Disability has a great impact on the combined economic activity status of households containing a disabled adult having a workless rate of 31.1 per cent compared with a rate of 9.7 per cent for those households where no disabled adult was present.

Most people spend a large proportion of their lives in the labour force and their interactions with the labour market have a large part to play in their broader social experience.

(Labour Market Trends, August 2002).

In his study 'Disablement in the informational age', Sapey (2000), mentions that the dominant messages to have appeared from the research on employment and disability in an industrial economy are that disabled people are far more likely to be unemployed than non-disabled people. If they are in employment they are likely to be in lower paid and less valued occupations (Drury, 1990; Barnes, 1991; LaPlant, Kennedy, Kaye and Wenger, 1997; McNeil, 1997; Meager et al., 1998; Roulstone, 1998; Stoddard et al., 1998).

It was interesting to note that Piggott (2005) carried out research on local government and disabled people's employment needs. She reported that all employment organisations she had contact with were working to an individual model of disability

and the need to change their orientation to that of a social model approach became the central recommendation of the first phase of her study. That was rejected by those funding the study because of their attachment to the individual model of disability. What was even more interesting was that at the end of the first year none of the organisations active in the area were able to identify a single disabled person who had returned to work as a result of their help. Piggott's research concluded that central government policies were doing little to change the perception of the employment needs of disabled people with local government.

#### e) Adapting and Modifying Sports

The level of physical pain that the individual suffers due to the impairment can also determine whether they exercise or not. Although involvement in exercise and sport can have numerous benefits they also provide gratuitously difficult challenges (Kew, 2000). For disabled people these challenges are even greater because of functional impairment. Koontz (2002), states that wheelchair propulsion has been implicated as a causative factor in developing shoulder pain and injury. An estimated 30 - 75 per cent of manual wheelchair users will develop shoulder pain during their lifetime. Functional rather than medical definitions of disability are more useful with respect to sports involvement. Brown (1987) identifies six problems, which might interfere with perceptual-motor performance in sports:

- lack of previous experience from being overprotected, sheltered and missing critical early learning
- hand and arm impairment (strength and control)

- ability to move with freedom (restriction of walking with assistive devices, wheelchairs)
- lack of voluntary control due to cerebral dysfunction
- sensory impairment (visual, auditory, kinaesthetic)
- psychological learning difficulties (visual-motor, visual-perceptual, spatial disorders).

Although there are some occasions when some disabled people can compete on equal terms with able-bodied peers (e.g. archery), in many cases the selection, modification and adaptation of sporting activities are necessary to make them accessible. Positive experiences and total involvement creates satisfaction, but this can only happen if the abilities and skills of the performer are commensurate with the modified or adapted challenge. Individual and team games for example might be adapted to make them accessible to disabled people (British Sports Association for the Disabled). All such modifications are based upon an assessment of the abilities of the performer, together with analysis of the psychomotor requirements of the sporting task. If there is congruence between the two elements, then accessibility is assured (Kew, 2000).

During a personal visit to Brunel University, Reading, earlier in the study, I was told how the University works towards this aim and specialises in adapted sports and exercise equipment to suit the needs of people with impairments.

#### f) School Physical Education

The issue of inclusion versus exclusion can be argued for all areas of life, from as early as education at school through to employment. Barnes et al (1999) discuss the

issue of the calls for inclusive (rather than integrated) education. The Education Act (1981) stipulates that many disabled young people should be integrated into mainstream schools. The subsequent development of a National Curriculum included a commitment that children with 'special educational needs' should have access to the same curriculum as other children and that curriculum delivery should change in order for this to happen. Arguably, according to Kew (2000) the successful integration of disabled children into most aspects of the curriculum has been achieved, but physical education and sport impose specific demands. The main benefits that inclusive education might bring include: fostering friendships between disabled and non-disabled children and thus 'removing ignorance and stereotypes'; allowing children with special educational needs to experience the benefits of a broader curriculum; promoting access to more teachers; offering opportunities to develop self-esteem and confidence; and acting as an alternative to the mystique and dependency of special schools (Barton, 1995: 31), which make it more difficult for disabled children to integrate into established leisure clubs and organisations having already been marginalised in educational and leisure facilities at a younger age.

Physical education provides a crucial opportunity for young people to develop a range of movement experiences in individual and team games, swimming, dance, gymnastics and outdoor pursuits (Kew, 2000).

Many disabled sports organisations have now been formed for the more elite sports athletes, but there are still many problems when it comes to accessibility of leisure facilities and public transport (Kew, 2000). Very often there is little information made available to disabled people with regards to exercise involvement for leisure and

enjoyment, with limited assistance at the leisure facility (Heller, 2002). I feel from literature that I have read, and data collected, that disabled people are often made to feel segregated from mainstream society, hence, having special days for different groups, rather than integration for all and not being accommodated for within established leisure clubs and organisations. As we are now living in a society which offers counselling and therapy for everything (Furedi, 2004), disabled people could easily fall into the trap of being offered therapy to help them merely cope with the hurdles of daily life rather than allowing them to live their own lives to the full with the same human and civil rights as non-disabled people.

The review of literature now broadens to include research on general issues of disability and I identify recent developments in attitudes and provision for disabled people. I focus on the different organisations that have been formed and the disability acts that have been brought into force. I lastly examine the different models and definitions of disability.

## **2.5 The recent Developments in Attitudes and Provision for Disabled People**

Wheelchair users form a significant group within the wider disabled population of Great Britain. In a survey conducted in 1996, through the auspices of the Royal Association for Disability and Rehabilitation (RADAR), it was estimated that there were approximately 700,000 wheelchair users whose lives, and well-being, are seriously being affected by the legal (different disability acts and laws), social (leisure and tourism) and environmental (accessibility to transport and public buildings) contexts which forever challenge the level and quality of life they seek to attain. Merry, A, & Edwards, D (2002), also confirm this as being the number of wheelchair users nationally.

It has been strongly asserted by Massie (1994) that disabled people experience more difficult and expensive lives than non-disabled people do. Reith (2001) concurs with this, in her article 'Disabled and Excluded', when she writes: "Disabled people face the combined effects of lower than average incomes and above average living costs." Morris (2004) confirms this when she states in her research that disabled people have additional requirements over those of non-disabled people. Reith (2001) goes on to say: "Extra expenditure can be considerable - special equipment and adaptation, help in the house, taxis, special diets, extra heating and hot water, prescriptions" - the list goes on. Lorna Reith has been Chief Executive of Disability Alliance since 1992, and is involved in many other roles regarding disability issues. She reaffirms that disabled people are subject to discrimination in both education and employment opportunities.

These factors combine to limit their life chances far beyond the restriction of disability itself.

In 1993, impetus from government and disabled agencies and associations such as RADAR (Royal Association of Disability and Rehabilitation), led to the setting up of the Commission on Social Justice. As referred to by Massie (1994) this commission identified the UK's map of injustice and outlined some of the ways in which society has failed to meet the basic needs of all its citizens, extend life opportunities and eliminate unjustified inequalities. It asserted that whether it is intended, or not, the unjust society is also the disabling society.

In his study, Bury (1996) states that national and local studies underlined, in particular, the economic dimensions of disability, and the hardship experienced by many, particularly in a period of growing recession. Though the Harris (1971) survey had been associated with the 1970 Chronically Sick and Disabled Persons Act, which for the first time obliged local authorities in Britain to estimate and meet the needs of disabled people, various research findings reinforced the view held by Mechanic and others in earlier U.S. work (Bury, 1996), that the consequences of disability were most obviously seen in financial hardship. In fact, a less well-publicised volume of the Harris study revealed the extent of financial hardship amongst the disabled (Harris et al., 1971b). Townsend's compendious work on poverty in the United Kingdom gave additional weight to the link between disability and inequality (Townsend, 1979).

The Chronically Sick and Disabled Person's Act (1970) focused on disabled persons who live in their own homes or in the community. The Act enabled Local Authorities to offer part practical, financial support for the purchase of special equipment, and help with adapting home circumstances to meet various needs within the home (e.g., telephones etc). The Government gave legal backing to disabled people in their own homes to enable them to keep a degree of independence. In order to do this some support was given to enable disabled people to access facilities in the community such as visits to health and community centres and swimming pools. Some assistance with transport and travel needs were given where it was economically viable and cost effective. The Act was viewed as demonstrating a more aware attitude to the needs of disabled people and a positive response to meeting some of their needs within a tight, controlled financial set of constraints under the monitorial control of the Local Authority.

Provision for the needs of disabled people received a further boost with the passing of the Disability Discrimination Act (1995). This attempted to deal with a wide range of issues concerning the way disabled people were treated and their statutory entitlements to many services and facilities, which were readily available to non disabled people but not to those who could not access them in view of their physical and mental capabilities.

This long, complex and technical legal framework requires much study and interpretation but may be summarised, for the purposes of this study, as attempting to alert agencies, organisations, national and local government and service providers to



the new statutory requirements when considering the setting up of new public and private services and facilities for disabled people.

For example, in Part III, of the DDA the section dealing with Goods and Services, it was to be made an offence to refuse "...to provide, or deliberately not providing, to the disabled person, any service, which he/she provides, or is prepared to provide, to members of the public." [Section (a)]. Although participants in this study felt that the situation had improved, as this study will show, there is still a long way to go before disabled people feel that their presence is both welcomed and encouraged. A range of evidence demonstrates that disabled people's lives are conditioned, in part, by where they live (Imrie, 2000). For instance, Barnes (1991, p. 139), in referring to the supply of special equipment by local authorities to disabled people, notes how services are characterised by a 'hotchpotch of provision delivered by a variety of sources' in which what you get depends, in part, on where you live.

Don Peet, Leisure Operations Manager at Bedford Borough Council's Commercial Services Department (February 2003), stated that many types of council across the United Kingdom have already implemented parts of the DDA with regard to improved access to buildings and leisure complexes through amendments to Building Regulations and the appointment of Disabled Monitoring Officers. He felt that it would ensure that more disabled people are accommodated in leisure complexes and owners of new buildings, as well as older ones, were likely to be advised of the change needed. He cited the Bunyan Leisure Centre in Bedford, with recent up-to-date access and facilities for sports participation by the disabled. He was aware of the mandatory changes to accessibility for wheelchair users, and other disabled groups

that would come into force by October 2004. Service and leisure providers will face much tighter monitoring by local authorities and the newly formed Disability Rights Commission are preparing for keener over viewing of levels of access provision across the UK from that date.

What remains contentious, however, is the regular use within the legal language used in the Act, of the term 'reasonable' [section 21], which has enabled some suppliers of public and private services to exploit this legal loophole on the grounds of cost, planning restriction and/or ignorance of the Act.

There remains also no enforcement to improve access to buildings constructed prior to 1981 (The Disabled Person's Act), which continues to be a barrier (as well as a determinant) to disabled people, particularly those with mobility difficulties. Sargent (1987), prior to the Act, had advocated that concerns about cost should be outweighed by concerns with equity, but public sector spending constraints are likely to ensure continued inequality of access (Kew, 1997).

An important part of disabled people's lives relates to their ability to gain access to particular places. Evidence suggests that the built environment is generally inaccessible to people with a range of physical and/or mental impairments, especially for those dependent on wheelchair use (Barnes, 1991; Gleeson, 1999; Imrie, 1996).

Local authorities have statutory responsibilities to regulate the provision of accessible spaces in new build and/or refurbished public and/or commercial buildings by enforcing national accessibility standards (Imrie, 2000). Such standards are itemised

in Part M of the Building Regulations (for England and Wales), which requires developers to provide 'reasonable' access for wheelchair users and for people with vision impairments and loss of hearing.

## 2.6 Models of Disability

In this section of the literature review I first discuss how the post war era, according to Massie (1994), saw the development of a perception of disability as a physical and mental (medical model) deficiency. Secondly, I speak generally of the significant change in attitude that has taken place toward disabled people in recent decades bringing with it the development of the 'social model' (Oliver, 1996). Thirdly, an in depth explanation of the 'social model' of disability is given followed lastly by a brief account of the 'biopsychosocial model'.

Massie (1994) draws attention to the significant change in attitude that has taken place toward disabled people, in general, in recent decades. The post war era according to Massie saw the development of a perception of disability as a physical and mental deficiency, brought about by the impairment that automatically disqualified those afflicted from taking any important role in society. Massie goes on to say, disability was considered tantamount to an 'illness' and given the term the '**medical**' model. His paper goes on to suggest that many of the disadvantages disabled people face arise from the way in which society is organised rather than anything intrinsic to disabilities. Social justice based on rights is needed for all citizens, not charity for disabled individuals. Many disabled people have little option but to stay at home because public transport is too poor to facilitate their mobility. This limits their geographical boundaries, so preventing access to a range of places and associated goods and services (Massey, 1996; Massey et al, 1999).

Disabled people were forced to live an intensely suppressed life throughout the modern industrial age, which prioritised productivity, efficiency and normalcy. They were commonly denied a citizenship and segregated from society. However, around the 1960's and 1970's, which many socialists observe as the beginning of a certain epochal shift, disabled people in all parts of the world began to mobilize and protest against their suppressed status in society (Driedger, 1989).

Arguably, one of the most successful ideas produced within this struggle of disabled people's movement, is the '**social model**' of disability (Oliver, 1996). The social model (according to Goto, 2004) can be summarised as consisting of three pillar concepts; protection of human rights; criticism of the medical model; and the removal of social barriers (Goto, 2004).

First, according to Goto, the social model claims that, almost universally, disabled people have been deprived of the fundamental human rights in modern society.

Disabled people were said to be 'socially dead' (Miller & Gwynne, 1972); it was widely accepted that they should stay quietly in the house, or should be confined to a residential institution. Furthermore, in the house and/or institution, they habitually suffered abusive treatment (violence, starvation, forced medical operation, deprivation of freedom of speech, etc). The social model exposes those facts and clarifies that those suppressions of disabled people are inexcusably human rights violation.

Secondly, according to Goto, the violative treatments of disabled people had been justified in the name of 'care' and 'supervision' by the medical discourse ('medical model') that considers disabled people as 'invalids' to be corrected or normalised.

Thirdly, according to Goto, in order to contest the medical model, Oliver (1996) argues that the cause of disabled peoples difficulties lies not in their physicality, but in a 'disabling' society. In other words, social barriers (institutional, attitudinal, and environmental) are the problem that 'disables' disabled people. Therefore, removal of the 'disabling' social barriers is the primary objective of the social model. It is considered as the best solution available for disabled people to transform society.

The American-born Independent Living Movement (ILM) has been internationally successful in promoting disabled people's autonomous life's, which is not limited to either living dependent on family or being confined in a residential institution (Barnes et al, 1999). Unlike the conventional definition of 'independent living' as physical and economical self-reliance (thus, closed to a majority of disabled people), ILM redefine 'independent living' as living with a command of their own life style by having proper support from society. The advocates of ILM stress that it is their right, and an obligation of society, to realize the 'independent living'.

Overall, the social model has empowered disabled people's movement significantly by providing a radical, but also rational and constructive explanation, which even the 'accused' (the non-disabled) can be readily convinced (Goto, 2004).

Oliver (1996) is a powerful advocate of the concept of the 'social' model which identifies the much wider social forces, cultural values and personal prejudices, which combine to portray disabled people as peripheral to mainstream life and opportunities, and therefore of little social and economic value to society. He is convinced, and expresses strongly the view that,

"...It is true that disabled people have been systematically excluded from British society: they have been denied inclusion into their society because of the existence of disabling barriers" (p106).

As already suggested earlier by Massie, society creates barriers for most people but disabled people are doubly disadvantaged. Furedi (2004) feels that instead of letting people realise their own achievements in life, within the era of 'therapy culture', they are just being encouraged and helped by professionals to merely cope with life. Their impairment may cause them pain, loss of function as well as the inability to do many of the things they would like to do. In addition to this, they face the attitudinal barriers, artificial environments and structural barriers created from the way in which society is organised.

Massie (1994, p6) had previously referred to Reith's comment about excluding disabled people when he writes ..."employers who refuse to recruit disabled people without considering the abilities and skills they could bring to the company are as much an unjust barrier as the flight of steps preventing a wheelchair user getting into a building".

The new deal for disabled people was accepted by local authorities as the mechanism for achieving employment targets for disabled people, and Jobcentre Plus and their contracted job broker organisations are formally required to address the needs of disabled people who are unemployed (Piggott, 2005). People are now being given therapy in order to cope with unemployment, stress in the work place and any

grievances or conflicts that may arise (Furedi, 2004). He says '20 years ago he laughed with people whom he then worked with when they were saying how his workmates felt that this therapy should be given, now it is the culture of our society for people to seek professional help in order to help them to cope'.

But as Oliver argues,

There is universal agreement that disabled people do not have the same access to jobs as the rest of the population. Estimates of the unemployment rates amongst disabled people suggest that this huge discrepancy cannot be accounted for solely on the grounds of impaired performance. However, government policies are, by and large, targeted at equipping impaired individuals for the unchanging world of work rather than changing the way work is carried out in order that more people might access it. Hence, much greater resources are currently spent on employment rehabilitation, training and so on (Individual model) rather than on removing the barriers to work or on attempting to prevent the labour market from operating in a non-discriminatory manner (Oliver, 2004, p. 21).

In England and Wales, government policies directly targeted at reducing unemployment of those who are disabled continues to be centred on incapacity benefits claimants. The New Deal for Disabled People and the Personal Advisor Scheme, launched in 1998, aimed to provide individually tailored packages of support to help people in work and at risk of losing their jobs through ill-health or impairment



to move towards and stay in work (Hills et al., 2001; Loumidis et al., 2001). This could, as Furedi (2004) suggests, be seen as a way for helping disabled people to merely cope with life and rely on professionals for help.

The Disability Discrimination Act (DDA) 1995 gives disabled people certain rights in the UK in respect of employment, in particular making it unlawful for an employer to discriminate against disabled people when they apply for a job, or when they are in employment, unless they can show that making necessary adjustments would be unreasonable. This statute is meant as a means of protecting disabled people from discrimination on the grounds of their disability, and is part of a new focus on helping unemployed disabled people into work whether they are claiming benefits or not.

There is a case to be made for the view that the overwhelming bulk of the policies introduced to address the problems encountered by disabled workers in the workplace have centred mainly on the supply side of labour (namely disabled workers), in the form of training schemes, subsidised wages and so on. All of which to varying degrees reinforce, rather than undermine, the assumption that disabled workers are somehow not equal to non-disabled peers.

Roulstone (1998) defines disability as the socially produced barriers that are the result of wider attitudes and structures that limit a person with a physical impairment where impairment is any limitation or difference resulting from a physical and/or sensory condition. Impairment is a precursor to the wider disabling processes that follow from such a physical deviation from the norm. For example, Roulstone (1998) maintains that exclusion from industrial society has profoundly influenced the way disabled people are viewed. Occupational segregation, workplaces designed for and

conceptualised by non-disabled people, and the attendant negative attitudes, cause disabled people to be either excluded from work altogether or to be undervalued as workers, depending once again upon professionals for help (Oliver, 1984). This social model of barriers to employment is still not fully understood by those who are making policy or those who are attempting to put it into practice (Piggott, 2005).

In her study 'Out of Touch', Piggott (2005), identified a number of key barriers to employment such as poor public transport infrastructure, employer attitudes, benefit disincentives and inadequate support both to re-enter employment and to remain in work. All of these were clearly illustrating the extent to which such barriers were social rather than individual, yet the response to this was to argue that these issues were already known or beyond their ability to affect, and what they wanted in order to take action was a better understanding of how particular impairments might limit individuals from working. This clearly reflects Oliver's (2004) point that while officially, many organisations may appear to agree that the problem is social, in the field of employment the solutions tend to focus on the individual.

Oliver (2004) suggests that in dealing with discrimination against disabled people, they should be recognised as citizens with full economic, political and moral rights. But what tended to happen, in Piggott's experience, is that unemployed disabled people were unlikely to be seen as contributing members of society, nor as a powerful interest group, nor as active citizens. They were more likely to be seen as simply deserving of help (Piggott, 2005; Oliver, 1984 Furedi, 2004).

The dominant messages to have appeared from the research on employment and disability in an industrial economy are that disabled people are far more likely to be unemployed than non-disabled people and that if they are in employment they are likely to be in lower paid and less valued occupations (Drury, 1990; Barnes, 1991; LaPlante et al., 1997; McNeil, 1997; Meager et al., 1998; Roulstone, 1998; Stoddard et al., 1998). This is despite evidence that disabled people are less likely to be absent from work due to illness (Kettle, 1970) and that they have been found by employers to be as productive, if not more so than non-disabled workers (Friedman, 1993; Gooding, 1993). Gooding suggests that employer attitudes towards the employment of disabled people are based on misconceptions about the type of work, which might be suitable for them and a concern that they would have to meet all the cost of adapting the workplace to be accessible. This directly results in the situation reported by Barnes (1991) in which, disabled people were six times more likely to receive a negative response to a job application than non-disabled people.

Despite the debates amongst proponents of the social model of disability about the validity or limits of the materialist analysis of industrialisation, there is considerable evidence that disabled people face disadvantage in employment and that this arises because of barriers that are both structural and attitudinal (Sapey, 2000).

Sapey (2000) talks of disablement in the informational age. He mentions that one result of this new area of economic activity is the extent to which global businesses are centered on North America, Europe and the Far East, and as a consequence some nations, and in the case of Africa most of an entire continent, can be socially excluded. Castells (1996) cites one study in Mexico for example, which described

some groups of people as being of such little value that they were not even worth exploiting, as a way of emphasising the nature of social exclusion in the global economy. Clearly, it is possible to begin to draw parallels between this level of social exclusion and the position of disabled people within industrial societies. The point is that the informational economy can be socially excluding and it follows that disabled people are likely to be vulnerable to this if they continue to be perceived as economically unproductive (Sapey, 2000).

Roulstone argues, that, if disabled people, the disability movement and disabled academics are to grasp the factors that shape employment and barriers in the twenty-first century we need to reflect on how the nature of employment is changing, to reflect on the global challenges for disabled workers, and to look again at the state project, trade unions and older collective struggles. Employment and disability policy research have to engage with the impact of globalisation on the nature and availability of work (Roulstone, 2002).

It becomes strongly apparent from writings of Massie, 1994; Reith, 2001; Roulstone, 2002; Sapey, 2000; & Piggott, 2005, that whereas medical science is limited in its ability to cure some people's impairments, society can reduce the architectural and attitudinal barriers that restrict disabled people from getting on in life. A social model of disability proposed by Oliver (1996) recognises that society imposes the greatest restrictions. If buildings and institutions were planned in a manner, which took account of the needs of every citizen, including those with impairments, the effects of disability would be significantly reduced. However, even if society were designed in a way that it removed these barriers, it would be unrealistic to believe that disabled

people would enjoy the same opportunities and choices as non-disabled people. Some individuals may choose not to find out for themselves whether these barriers, real or perceived, exist or not. Other people are prevented from doing so because they fall into the trap of becoming dependent upon professionals for help in order to cope (Oliver, 1984, Furedi, 2004).

Morris (1991) argues that although disability is undoubtedly a social phenomenon it is also a personal one. She writes:

'The domination of the disability movement by men has been associated with an avoidance of recognising our feelings about being disabled. A feminist perspective on disability must focus not just on the socio-economic and ideological dimensions of our oppression, but also on what it feels like to walk, to be in pain, to be incontinent, to have fits, to be able to converse, to be blind or deaf, or to have an intellectual ability which is much below average. There are positive and strong elements to these experiences but there are also negative and painful elements. The tendency of the disability movement to deny the difficult physical, emotional and intellectual experiences that are sometimes part of the experience of disability is a denial of 'weakness' of illness, of old age and death.'

If one has to live with both impairment and disability, then both contribute to the experience of disability at a personal level. Some feminists charged proponents of the social model with failing to take into consideration the whole realm of the

'personal and the experiential' (Thomas, 2001: 48), including what Jenny Morris (1991: 10) called 'the experience of our own bodies'.

The current state of the theoretical debate about impairment and the body among feminists involved in disability studies and the disabled peoples movement (who would not describe themselves as poststructuralist) is probably best illustrated by this passage from Carol Thomas's book 'Female Forms';

“I would argue that it is quite possible simultaneously to make a conceptual distinction between impairment and disability, reconceptualize the latter as a form of social oppression, understand that bodily variations classified as impairments are naturally shaped by all the interaction of social and biological factors and processes, and appreciate that impairment is a culturally constructed category which exists in particular times and places (1999: 41).”

It is important to note that the term disability only makes sense if it is understood to mean restriction of activity. The argument by Shakespeare and Watson (2001) is that such restrictions are obviously caused both by social barriers and by impairment per se.

Shakespeare and Watson see the social model's separation of impairment and disability as related to a problematic reduction of impairment to the biological (see also Hughes & Paterson, 1997; Hughes, 2002). Impairment, they argue, is not biological but profoundly social, not least because: 'the words we use and the discourses we deploy to represent impairments are socially and culturally determined'

(Shakespeare, T & Watson, 2001, p.18). In addition, and like other poststructuralist writers (Corker, 1998; Corker & Shakespeare, 2002), these authors take issue with the supposed modernist separation of 'impairment' and 'disability', something seen as representative of outdated dualistic, binary, thought;

Impairment and disability are not dichotomous, but describe different places on a continuum, or different aspects of a single experience. It is difficult to determine where impairment ends and disability starts, but such vagueness need not be debilitating, Disability is a complex dialectic of biological, psychological, cultural and social-political factors, which cannot be extricated except with imprecision. (Shakespeare, & Watson, 2001, p.22).

Thus disability - restricted activity - has to be understood as the product of multiple bio-psycho-social forces.

The **Biopsychosocial model** posits that biological, psychological and social factors all play a significant role in human functioning, including mental processes. Over the past two decades, researchers and clinicians have been developing and testing a model known as the biopsychosocial model. This model depicts a health care concept that has evolved in close association with current pain theory. It has sought co-existence with the determinant biomedical model of healthcare, which describes 'disease' as a failure of or within the soma (body), resulting from infection, injury or inheritance (Alonso, 2003).

The biomedical model has its roots in the Cartesian division between mind and body (Engel, 1977). In 1977, Engel described a crisis that modern medicine and psychiatry were facing. Disease, from a biomedical perspective was described in somatic parameters alone, there was little or no room for psychological, social and behavioural dimensions of illness within this model. This made adherence to this framework very difficult. There were somatic and mental disorders that simply did not fit the biomedical model, and hence it was no longer sufficient for the scientific and social responsibilities of either medicine or psychiatry (Engel, 1977: Campbell, L.C., Clauw, T.J., Keefe, D.J, 2003).

Engel set out to develop a new framework that could account for the biological, psychological and social dimensions of illness and disease. It was essential that this new model provide a basis for the understanding and treatment of disease, whilst taking into account the patient, his/her social context and the impact of illness on that individual from a societal perspective (Lutgendorf, S.K., Castano, E.S, 2003: Smith, G.C, & Strain, J.J, 2002). This represented the development of the biopsychosocial model (Engel, 1977). This model does not however look into the broader social factors, i.e., social barriers that can inhibit a disabled person's mobility.

This model states that ill health and disease are the result of an interaction between biological, psychological and social factors. It makes the distinction between pathophysiological processes that cause disease and the client's perception of their health and affects on it, called the illness (Hoffman, 1999). It seeks to build upon the biomedical model. Biological indices are still held in high regard; however, they



represent only one of the defining factors for the diagnosis and management of disease under a biopsychosocial framework (Engel, 1977).

These, bio-psycho-social forces, it is argued, is what must inform a more adequate theory of disability. To it must be added an understanding that everyone is impaired, in varying degrees (Shakespeare & Watson, 2001, p24). This perspective, they claim, offers an important insight into human experience, and can be used as a springboard for dismantling socially constructed divisions between 'the disabled' and the 'normal' (Thomas, 2004).

In a paper proposing that a critical realist theoretical perspective has much to offer medical sociology, Simon Williams (1999) illustrates his case with an examination of the disability debate. This allows him an opportunity to present his well-rehearsed argument that sociology must 'bring the body back in' (see Williams & Bendelow, 1998). On the other side of the debate, he claims, is the work of scholars in disability studies, proponents of the social model, who have attempted to:

... 'write the body out' completely from the biology/society equation... Writers such as Oliver (1990) reject the International Classification of Impairment, Disability and Handicap (ICIDH, 1980), in favour of an approach in which disability itself, far from being a result of limitations caused by impairment or physical trauma, is instead seen as a form of 'social oppression'. (Williams, 1999, p.803).

Williams shares Bury's view that such a position is untenable, but critiques it on the grounds that it entails a problematic denial of the social significance of 'the body', something that he thinks sociology guilty of more generally (see Williams & Bendelow, 1998).

Each disabled person will have their own individual approach to alleviating not only a degree of physical discomfort but also restrictive environmental barriers. A person with arthritis is likely to experience pain regardless of the social structure of society. But if they were able to gain easy access to public transport and buildings rather than struggling up difficult steps, the degree of pain may be reduced. Disabled people will react to their own disability in a variety of ways. Some will regret the limitations that disability imposes. Others will regard their disability as a positive aspect of their life, creating opportunities, which were not available previously. (Massie 1994). But if, as Furedi (2004) states 'by continually taking up the need for professional intervention to 'help' people with everything in life from the ins and outs of married life, stress at work, education and unemployment,' therapy culture weakens people's relationships of dependence upon each other, and encourages increasing dependence upon professionals', disabled people will never achieve the independence which they are entitled to as part of their civil and human rights.

## **2.7 Definitions of Disability**

One way of limiting opportunities for disabled people from accessing many mainstream facilities, pursuits and employment is to construct a variety of terms and definitions that control and limit many social, educational and economic access points. In order to understand the meaning and nuances of the definitions used in describing disability and how these may shape a disabled person's quality of life, it is useful here to consider different competing definitions of disability and disabled people.

The definitions of disability, which had the widest official usage, according to Massie (1994) were those of the World Health Organisation (WHO) (1980), which drew a distinction between impairment, disability and handicap, i.e.

### **i) Impairment: (WHO)**

Any loss or abnormality of psychological, physiological or anatomical structure or function.

### **ii) Disability: (WHO)**

Any restriction or lack of ability (resulting from an impairment) to perform an activity in a manner or within the range considered normal for a human being.

*iii) Handicap: (WHO)*

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 and social and cultural factors) for that individual (Wood, 1981).

These definitions were made operational by doctors in the medical profession and were consequently challenged by some disabled people who according to Massie saw their disability as resting in society rather than any factor inherent in disabled people (Massie, 1994, P5).

If disability is perceived simply in terms of functional limitation (i.e., inability to walk) there is a danger that the emphasis will be on disabled people adapting and conforming to the norms of the society in which they live, rather than putting the responsibility on the society to accommodate such groups so that it can meet the needs of disabled people.

In a society where the needs of disabled people may be affected by long established principles and practices, based on the belief that the care of disabled people was difficult to administer and resource, disability can be seen as more of a social model (Oliver, 1996) than a medical phenomenon. Its impact strongly depends on the context in which someone lives.

Regarding this shift to a social model the Disabled Peoples International (DPI) (1986) used the following definitions of impairment and disability:

*i) Impairment: (DPI)*

The functional limitation within the individual caused by physical, mental or sensory impairment.

*ii) Disability: (DPI)*

The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers (Barnes, 1992).

Massie (1994) affirmed that these definitions allowed for people to have an impairment without having a disability. If society were arranged in such a way that the functional loss had no impact there would be no restriction or disability.

It can be proposed that definitions can influence the way in which disabled people are viewed by society and by themselves. Such definitions also influence the type of provision made to meet the needs of disabled people. If disability is viewed only pathologically the 'solution' to disability is to cure disabled people and this task would almost certainly be given to the medical profession (Massie, 1994). The social context in which people, disabled and non-disabled, interact is excluded. If disability is perceived as a social phenomenon, legislators, architects and others who determine the shape of our built environment have a crucial role to play. Furthermore the value of including disabled people in the planning of suitable environments is most important; therefore attitudes towards disabled people must change.

## 2.6 Conclusion

As can be seen from the literature review, 'Sociology of the Body' is an important new area of specialism within society (Jary, 1999), which has sought to repair a previous relative neglect of the body, and the implications of 'embodiment'.

Popular interest in the body is indicated by the multi-million dollar industries promoting exercise courses and weight reduction plans, the growth in popularity of self-help therapies and alternative medicine, and the emphasis on the body as an expression of individual identity (Jary, 1999).

This has shown to be true with participants of this study who use a wheelchair for their main means of mobility. They all felt that exercise was beneficial to either themselves or other people socially, psychologically and physically.

Many of the participants in this study are very conscious of keeping fit in order to keep their weight down. This, they explained, is important in order to be able to transfer themselves manually from their wheelchair to car, wheelchair to bath/bed etc in order to keep their independence and to feel good about themselves.

Many disabled people use weights and weight training in order to develop an integrated state of mind and body (Wilson, 1992), whilst others have defied a doctor's diagnosis of never being able to walk again (Mooney, 1998) by having a positive attitude toward exercise and fitness and combining this with medication.

Some of the participants in this study were also very proud of their appearance and the way that they dressed. Most felt that exercise helped them as much psychologically as it did physically and socially. They explained that exercise would have a 'knock on effect'. They explained that when exercise helped them physically and socially it had a positive effect upon their outlook on life.

Symbolic interactivists have investigated how people cope with disease and chronic illness in their daily lives. According to Giddens (2005) the experience of illness can provoke changes in individual's self-identity and in their daily routines. Wheelchair users in this study have mainly coped very positively with their impairment but agreed with (Oliver, 1996) that it is society, which disables them not their impairment.

Impairment can often bring with it depression and feelings of helplessness. Some participants told me that after their impairment they felt useless and that they would never be able to enjoy life again, and this would have a big effect upon their spouse or family. But exercise, along with social support from friends and family has helped many of them through their depression, without the need for professional help or counselling. Just as important as social support they need an accessible environment to move around in. The 'social model of disability' is developed in order to help disabled people live their lives and move around freely. In the UK we can see that the 'social model' has helped disabled people, liberated them and given them empowerment to make their own decisions. Yet every culture is different. We have seen from the literature review that in Japan, a barrier free 'enabling' facility, which is endorsed by the social model, often cohabits with the bio-politics of 'regulating

bodies', where the disabled body seems to have become one of the most 'regulated bodies' in their society.

How people cope with disease and the experience of illness is a dimension of 'sociology of the body', which is becoming increasingly relevant for many societies. People are now living longer than ever before and tend to suffer from chronic debilitating conditions than from acute illness (Giddens, 2005). Sociology of the body therefore studies how society affects our bodies, particularly with the process of social change. Society affects the way we live (whether or not we have a disability), from what we eat, how we dress, how we perceive our bodies to look (Brumberg, 2006) and how we cope with illness and ageing. It is a factor that affects everybody in some way in every culture and every way of life, and it plays a very important part within this study, which investigates 'The interactions between disability and exercise'. It is particularly important with regards to how wheelchair users perceive their bodies to look as many have to wear body belts and other necessary appliances, which often make them feel self-conscious due to attitudes from non-disabled people staring at them. Society can also have a big effect upon how they cope with their impairment and the disabling barriers which society has confronted them with (Oliver, 1996). Oliver argues quite strongly that the cause of disabled people's difficulties lies not in their physicality, but in a 'disabling' society (Oliver, 1986).

The 'social model' is used in this study for the following reasons: First, it exposes the fact that when disabled people were kept at home or in a residential institution they habitually suffered abusive treatment (violence, starvation, forced medical operation, deprivation of freedom of speech etc). The social model clarifies that those



suppressions of disabled people are inexcusably human rights violations (Miller & Gwynne, 1972; Goto, 2004). Secondly, according to Goto, the violative treatment of disabled people had been justified in the name of 'care' and 'supervision' by the medical model discourse that considers disabled people as 'invalids' to be corrected or normalised (Goto, 2004). Thirdly, Oliver (1996) is a powerful advocate of the concept of the 'social model' which identifies the much wider social forces, cultural values and personal prejudices which combine to portray disabled people as peripheral to mainstream life and opportunities and therefore of little social and economic value.

Today's society operates around the belief that people cannot cope on their own or face the challenges of life (Furedi, 2004). Therapy culture represents a shift from the view of the robust, independent person, capable of great individual and collective achievement, to the notion of the fragile, powerless victim in need of continual professional support (Furedi, 2004).

Many of the participants in this study, have overcome many challenges and obstacles which society has thrown in their way and with the help of social support from friends and family have gone on to achieve gold medals in the paralympic games and self-satisfaction in some of the smaller tasks they have achieved in life, but not without tackling environmental and attitudinal barriers first. The 'social model' of disability has helped many disabled people face up to society and challenge the way it is structured. Organisations, which were put in place to help disabled people, were run by non-disabled people, now many are run by and for disabled people.

Yet this attitude towards disabled people is not something, which has only just happened. Two decades earlier, Oliver's (1983) 'Social Work with Disabled People' found that as a person became disabled their image would change from one of coping, having power and being in total control of their lives, to one of fragile, weak and dependent upon help from a professional.

Yet the encouragement to take beneficial, regular exercise has helped disabled people to keep their independence. It has assumed greater significance in the United Kingdom at the beginning of the new millennium. An ageing population, and the growing economic costs of health care and welfare, have added impetus to government legislation (e.g., Disability Discrimination Act, 1995) to direct certain groups in the population towards taking up those leisure interests and physical pursuits which help to develop and maintain more healthy lifestyles. In 2004 the DDA statutory regulations, quoted above, came into force and should be of benefit to a wide range of disabled people, particularly wheelchair users, who form 5% of an estimated six million people in Britain who have some form of impairment.

Sociology of the body is also apparent in this study in the way that disabled people feel segregated. Society has regulated disabled people in the way that they are often given certain times when they can participate in leisure activities like swimming at their leisure centre or swimming pool. Another way in which society has tried to regulate disabled people is the booking system, which is required in order to use the dial-and-ride bus system. Disabled people often have to give one day, if not several days notice of when they want to travel. This, as can be seen from this study, is not always suitable because whereas a disabled person may feel like going out today, they

may feel entirely different in two days time. They are also regulated to some extent when they want to travel by train. A wheelchair user has no way of getting onto a train unless there is a ramp available and again that has to be booked in advance and arranged at both ends of the journey. So it can be seen that although the social model has liberated disabled people and given them empowerment to live independently, it does slightly regulate their movement in some ways, but not as much as countries like Japan.

Kew (2000) recognises the need for a closer examination of how and why society at large 'discriminates, handicaps and imposes barriers on disabled people' (p.109). In his comprehensive review of the broader issues of the impediment facing disabled people (pp.108-123) he identifies 'integration' as an issue that greatly affects disabled people, in particular, those who are attempting to realise their social and political rights to full citizenship.

Whilst there has been a radical shift in recent years, towards providing more integrated accessible sporting and recreational facilities for disabled people, it is worth noting that some organisational structures may inadvertently encourage disabled groups to remain isolated from mainstream activity by providing separate facilities, on the basis of protecting them from the public's varied reactions to their disabilities and restricting access to them by non-disabled people who might wish to meet and talk with them. Some disabled people are actively isolated by the inflexibility of organisational structures, which are over protective, and monitor who will be given contact with their members. This can be seen as a form of regulation of disabled bodies. Society, as 'sociology of the body' implies is deciding what disabled

people need, even though the 'social model' has helped immensely to liberate disabled people and give them access to their human and civil rights.

Whilst it is not polite to name these organisations in this study because of confidentiality, it has to be said that it has been difficult to enlist help from such organisations in conducting research, possibly on the grounds of 'over exposure' or the amount of extra administrative work involved by staff. Parameters are set which mean less contact is possible with disabled people in the community and it requires much persistent effort to make the necessary contacts. This is almost like barriers within barriers, preventing different opinions being gathered from a wide array of those already 'overprotected' by a society that claims to be caring, but which very often is just enabling people to merely 'cope' and encouraging people to seek professional advice (Furedi, 2004; Oliver, 1983).

Various important themes and issues arose from this literature review that I have applied in my research. The literature review has been useful to help guide my thinking. It informed me as to the issues in the field, which needed addressing, such as, sociology of the body, discrimination, environmental barriers, integration and segregation, attitudinal, architectural and administrative barriers. It also helped to identify the issues of oppression and empowerment (Oliver, 1996). The Social Model of Disability played an important part in this research because it is the history of all 'the experiences of disabled people' that has led to the social model of disability. The other thing that guided my thinking for this research was the contact I had with the participants involved in this study.

## Chapter 3

### Methodology

#### Introduction

In this chapter I describe Critical Social Research (CSR) and explain how the approach works (Harvey, 1990). I then explain how the 'Social Model of Disability' (UPIAS, 1976), with the in-depth critical analysis provided by CSR constitutes an ideal methodological approach for this study. The rest of the methodology is divided into ten sections.

**In section one** I explore the design and choice of methods.

**Section two** is an introduction to methodological approach and techniques used to collect the data.

**In section three** I discuss the sampling strategy that was used to contact prospective subjects.

**In section four** I investigate the process and implementation of the questionnaires, interviews and the user participation workshop.

**In section five** I identify my subject population.

**In section six** I discuss questionnaire design and the advantages and disadvantages of using questionnaires. I explain the difficulty in actually getting to the subject population in the first place, in order for them to be able to complete a questionnaire.

Wording of questions was discussed. Open and closed questions were investigated and brief examples are given of each. Lastly the importance of the quantitative data was explained, and how it was used in this study.

**In section seven** I examine the interview strategy. I explain firstly, the interview schedule and piloting of interviews, and then I go on to discuss the interview techniques and lastly the advantages of using interviews.

**In section eight** I discuss the 'User Participation Workshop'. The 'user participation workshop' is a very powerful part of CSR because it makes sure that participants were able to take part in the research at every step of the research process. In this way they could maintain ownership of the project. As mentioned earlier in the study, this was a workshop set up in order to allow me, the researcher, to present the interview findings to participants who had formerly been interviewed. I take the reader through the stages of: booking it, contacting respondents, cancellation, arrival at the venue, the presenter and the presenting of the findings to the participants at the workshop.

**In section nine** on data analysis I describe the methods used to analyse the data that had been collected. This section is broken down into three areas. First, I examine the analysis of questionnaires. Secondly, the analysis of the interviews. In this area I also discuss discourse analysis and the transition process that I used to travel from Tesch's (1990) organising system (used to code and categorise the interview data) to Layders (1998) 'Adaptive Theory' which, was used to analyse the data. In the third area I also discuss this transition and examine the analysis of the user participation workshop

data, and the rationale for not running a user participation workshop again. **In the last section ten;** I discuss the limitations of the survey approach.

### **Critical Social Research**

Researching specific areas of social concern requires the establishment of a methodological process, or processes, that have links with particular paradigms or sets of established theoretical bases of enquiry.

Harvey (1990) cites, and describes in detail examples of particular approaches in social research that have been applied in the contexts of class (Vincent et al, 2008), gender and race, which he defines in the general terms of *Critical Social Research (CSR)*. He further advocates the feasibility of extending such approaches to more contemporary issues such as age, sex and disability.

One such area that I feel it can be used in is disability. The roots of the critique of social research on 'disability' can be traced back at least to the 1960's (Barnes & Mercer; 1997). Some of the participants in this study have said that many people with impairments are oppressed and feel that they lack the power to live a normal life because of social and attitudinal barriers. I therefore decided to use Harvey's (1990) Critical Social Research (CSR) as a methodological framework for my study.

CSR adopts an approach that incorporates three main elements, i.e. methodic practice, substantive theory and epistemological underpinnings in a critical-dialectical attempt to unearth the various layers that often lay buried deep below the surface presentation,

thus providing a more constructive understanding of contributory historically specific, oppressive social structures (Taylor, 1999). CSR does not take the apparent social structure, social processes or accepted history for granted. Instead, it tries to dig beneath the surface of appearances and asks how social systems really work and how ideology or history conceals the processes, which oppress and control people. CSR is intrinsically critical. It assumes that a critical process informs knowledge. In its engagement with oppressive structures it questions the nature of prevailing knowledge and directs attention to the processes and institutions which, legitimate knowledge. CSR thus aims at an analysis of social processes, delving beneath ostensive and dominant conceptual frames, in order to reveal the underlying practices, their historical specificity and structural manifestations. Christine Delphy's (1978) analysis of housework provides an illustrative example of this process of moving towards an understanding of a social process that is concealed in a taken-for-granted category.

Essentially, CSR allows the researcher to ask substantive questions about social processes. It is an evolving process and has to be located in its social milieu. It requires that empirical material be collected. It does not matter whether it is statistical material, anecdotes, directly observed behaviour, media content, interview responses, artwork, or anything else. But whatever it is, it must not be taken at face value. CSR aims to identify the hidden structures and dig deep beneath the surface of the issue to find the key cause of a problem. CSR looks at the wider social and historical context of the problem (Taylor, 1999). It is a way of approaching the social world, in which critique is central. It is the way the empirical evidence is approached and interpreted, the methodology not the method of data collection per se, which characterises critical social research. CSR is not bounded by a single (grand) theoretical perspective. Ann



Oakley's (1974a) 'The Sociology of Housework' is an early example of critical research which analyses gender oppression. She regards as axiomatic that women are discriminated against, that gender differences are cultural, and that it is desirable that changes in women's positions should be brought about (Oakley, 1974a, p.190). She takes up the issue of the invisibility of women and women's concerns in both society at large and the discipline of sociology in particular. The sexism of society, she maintains, is reflected in the sexism of sociology.

Oakley's study is indicative of the dynamic nature of critical social research. Feminist theory and analysis is now much more sophisticated than then, and Oakley's analysis of the sexist nature of sociology and its indifference to women's work is, as she admits, naïve by current standards (Oakley, 1974a, p.113).

The 'Sociology of Housework' none the less illustrates the critical process at work and provides a useful historically situated example of the development of gender based critical social research in a view attested to by the republication of the book in 1985 with a new preface.

Oakley's empirical analysis of housework differed from prior work in two respects. First, it treated housework as a job in its own right and not an extension of the woman's role as wife or mother. As such it disputes the biological determinist presupposition that women are reproducers and nurturers for whom housework is a rational extension of their maternal role. Second, it addressed housework from the point of view of those who did it, in this case housewives with young children. It thus offered a correction to the distorted male-orientated perspective. As such it opposed

the compliant approach of previous research by women on housework who while arguing that housework is work, also accepted that to analyse it as such would mean a fundamental critique of patriarchal ideology.

There is an apparent ambivalence in Oakley's approach to her research topic; she was restrained by the academic rigours of doctoral research in the early 1970's while also wanting to develop a feminist perspective on research (Harvey, 1990). The preponderant approach to social research in Britain at the time emphasised the 'scientific' collection of standardised, statistically analysable, objective data.

The sociology of housework represented the first approximation to a research style more fully discussed and developed by Oakley some years later. The approach, which was evident 'between the lines' (Oakley, 1985, p.xi), sets aside the prevailing objectivism of standard empirical enquiry. Oakley abandoned conventional interviewing ethics and did not treat the women interviewed simply as data providers. She adopted the view that the subjectivity of the subject is intrinsic to feminist analysis of social experience. Her approach gave more prominence to the subjective situation of women in both sociology and in society in general. Interviewing women was a strategy for documenting women's own accounts of their lives with the interviewer providing a vehicle for providing a sociology for women. Thus the interview is no longer a data-collecting instrument for researchers but has become a 'data-collecting instrument for those whose lives are being researched' (Oakley, 1981, p.49).

CSR and Oakley's (1981) approach will be used with Oliver's (1996) 'social model of disability' to dig deep beneath the surface of those factors underpinning the 'interactions between disability and exercise'. Using CSR as my methodological approach allowed me to keep participants (wheelchair users) involved in the research at every stage of the research process. Because of the complex nature of the research it was important that participants got something from the research, yet as Oakley (1981) explains, this is so rarely considered.

### **Social Model of Disability**

Oliver's (1996), 'Social Model of Disability' is the framework, which I use throughout this study. I felt that it was necessary for this model to be explained in some depth at this early stage of the research. In order to do this I have presented the reader with a historical background of the model, which follows.

As cited in Barnes & Mercer (2004), the late 1960's and 1970's was a period when economic and political upheavals produced an extraordinary level of political activism among disadvantaged groups around the world. In Britain, the politicisation of disabled people and their organisations moved into a new, more militant, phase (Campbell & Oliver, 1996; Barton, 2001). Disabled activists became increasingly discontented with 'pressure group' activity as a means of achieving social change. A further grievance was the 'colonisation' of disability organisations by non-disabled 'experts'. Such concerns encouraged moves towards a 'grassroots' politics, with organisations controlled by disabled people playing an increasingly central role, and a challenge to traditional assumptions that disability was a 'personal tragedy'.

Disabled activists began to explore an alternative 'social interpretation' of the 'disabling society', and the sources of widespread disadvantage and discrimination experienced by people with impairments (Hunt, 1966; UPIAS, 1976). These ideas provided the foundation for the 'social model of disability' (Oliver, 1981, 1990) that has exercised such a powerful influence on organisations of disabled people and disability politics and also underpinned the growth of academic teaching and research on disability in Britain.

The Disablement Income Group (DIG) was one of the key organisations instrumental in bringing disability on to the political agenda in 1965 (Barnes & Mercer, 2004). It opted to pursue traditional pressure group activity in order to advance the social and economic conditions of disabled people. However, some disability activists, disenchanted with the direction and speed of social change, began to explore innovative forms of disability politics.

One of the most influential of the new political groups set up and controlled by disabled people was the Union of the Physically Impaired against Segregation, (UPIAS). Its origin lay in a letter from Paul Hunt published in *The Guardian* on 20<sup>th</sup> September 1972 that called on disabled people to form their own organisation. UPIAS functioned mainly through confidential correspondence and circulars circulated amongst its members, many of whom were living in residential institutions (Campbell & Oliver, 1996). These exchanges led to the production of a policy statement and constitution in 1974. Two years later, it expanded on its thinking in the *Fundamental Principles of Disability* (UPIAS, 1976).

The orthodox view of disability, accepted by academic writers, policy makers and service providers, stressed the problems caused by an individual's flawed mind and body. In complete contrast, UPIAS focused on the ways in which the current organisation of society created and perpetuated diverse social barriers to the inclusion of disabled people with impairments:

It is society, which disables physically impaired people. Disability is something imposed on top of our impairments; by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS, 1976:3).

This recast disability as a historically contingent relationship in which people with impairments became a socially oppressed group (Barnes & Mercer, 2004).

A key architect of the UPIAS document was Vic Finkelstein, who had moved to Britain after being banished from South Africa, because of his involvement in the anti-apartheid protest movement. He drew strong parallels with the experiences of discrimination amongst disabled people. While biological inferiority was used routinely to justify discriminatory practices, the analytical spotlight was now re-directed towards a socio-political explanation.

As stated by Barnes & Mercer (2004), the ideas advanced by UPIAS were subsequently re-presented by Mike Oliver (1981-1990) as the 'social model of disability'. The emphasis on disabling social and environmental barriers was contrasted with the current orthodoxy that viewed disability as a 'personal tragedy' and

disabled people as in need of 'care'. Oliver drew on contemporary debates in the social sciences to explain this individualised approach to disability as a social creation of industrial capitalism (Barnes & Mercer, 2004).

The 'social model' approach pointed to areas where political action might bring about the social changes necessary to overturn the social exclusion of disabled people. However, both Finkelstein (2002) and Oliver (1996) insisted that UPIAS 'social interpretation' and the 'social model' were not equivalent to a theory of disability. Instead, they emphasised that the importance of the social model was primarily as a 'heuristic device' or an aid to understanding:

A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints (not available to us in reality) and it is this multi-dimensional replica of reality that can trigger insights which we might not otherwise develop (Finkelstein, 2002: 13).

Several of the most influential early attempts by British writers to theorise the disabling society were located within broadly Marxist perspectives (Barnes & Mercer, 2004).

The UPIAS re-definition of disability exerted a powerful impact on the wider disabled people's movement. The social model has been adopted by organisations controlled and run by disabled people across the UK (Barnes, Mercer and Morgan 2000). The social model was also adopted by the British Council of Organisations of Disabled

People (BCODP), now the British Council of Disabled People, which is the national umbrella for organisations controlled and run by disabled people.

In the process, the social model acquired an explicit 'rights now' focus. As Jenny Morris argued:

The social model of disability gives us the words to describe our inequality. It separates out (disabling barriers) from impairment (not being able to walk or see or having difficulty learning)... Because the social model separates out disabling barriers and impairments, it enables us to focus on exactly what it is which denies us our human and civil rights and what action needs to be taken (Morris, 2000: 1-3).

Whereas, the academic focus within the social sciences and humanities prior to the 1990's represented disability in terms of individual 'functional limitations' or 'flaws', caused by 'chronic illness' and or the complex interplay between the 'abnormal' body/mind, individual coping strategies and wider societal attitudes (Barnes & Mercer, 1996).

The social model of disability, which in a sense refocuses the past and present shortcomings of society's treatment of disabled persons, provides a fertile ground for examining how and why social structures and infra-structures do restrict disabled groups and individuals. This model, with the in-depth critical analysis provided by CSR, constitutes an ideal methodological approach, giving a cutting edge to an examination of intentions to participate, or not, in exercise behaviour.

### 3.1 Design and choice of methods

It has been necessary to identify the key determinants, which influence a disabled person's decision, whether or not to exercise. If disabled people (in this particular study, wheelchair users) do decide to engage in a form of physical exercise, it may be due to a number of factors and determinants. It would seem therefore a worthwhile proposition to seek opinions from this group as to what those factors and determinants might be. A sample of wheelchair users, living within a radius of 75 miles from Bedford, was initially approached and a system of questionnaire/interview/user participation workshop techniques introduced, which would enable me to analyse responses, employing both qualitative and quantitative procedures. Reasons for not exercising can thus be compared with those where participants did make a commitment to engage in exercise behaviour and provide useful information and data that could help in a better understanding of how and why such choices are made.

Cohen, Manion and Morrison (2000) describe the importance of choosing the most appropriate research method that includes asking questions, which will give depth and breadth, and by using triangulation to substantiate findings. The idea of combining qualitative and quantitative approaches in a single study owes much to past discussions about mixing methods, linking paradigms to methods, and combining research designs in all phases of a study (Cresswell, 1994, p.174). The term triangulation was borrowed from a navigation and military strategy, to argue for the combination of methodologies in the study of the same phenomenon (Denzin, 1978). The concept of triangulation was based on the assumption that any bias inherent in



particular data sources, investigators, and method would be neutralised when used in conjunction with other data sources, investigators and methods (Jick, 1979).

For this study a "between methods" approach was chosen, drawing on quantitative and qualitative data collection procedures (e.g. a questionnaire, face-to-face semi-structured interviews and user participation workshop). Credibility of the findings is enhanced by comparing data obtained from different sources from different investigators or different methods of collecting data (Breakwell, 2000). The methods Breakwell suggests to compare data, are either to carry out research over an extended period of time or to use a multi-centred study, e.g. matching case environments and treatment philosophies, and consistent styles amongst researchers. Breakwell goes on to say that if such comparisons show that the findings hold, then one can have more confidence in their interpretation. However, if the findings obtained by different methods of data collection differ, one must be careful before rejecting the usefulness of the findings. The difference may be the result of the methods used to obtain the data rather than the result of misinterpreting the data. The findings from the user participation workshop reinforced the questionnaire and interview findings. It also allowed the participants to go into greater depth than they could on a questionnaire.

Lewis and Munn (1987) support this view by stating, "there should be a logical connection between the research questions you are asking and the methods you use to provide the evidence to answer these questions" (p.19). My awareness and previous knowledge of the people I had decided to interview made it easier for me to ask the questions. Having an understanding of the kind of lives my prospective participants could be leading, allowed for empathy and a rapport to be built between us prior to the

interview taking place. This in turn helped to reduce any embarrassment, which could have developed due to the sensitivity of the questions being asked.

### **3.2 Methodological approach and techniques used to collect data**

After an analysis of the different research methods across the quantitative and qualitative domains, I decided upon, primarily, qualitative research methods with some data analysis from the quantitative base. This was because firstly, the questionnaire data would give general background information and would form the main themes of the study. The interview would provide information on the more sensitive questions such as body image. And secondly, it fitted within the CSR paradigm. I decided that the best approach for obtaining the data would be a questionnaire followed by face-to-face semi-structured interviews, with those individuals who returned the questionnaire and were willing to be interviewed. Participants were then invited to attend a user participation workshop at a later stage of the research. This user participation workshop was a chance for the findings of the interviews to be presented to the participants giving them the chance to interact and give their comments and opinions on the data that had been collected. It allowed participants to retain ownership of the research at every stage of the research process. I considered the benefits and limitations of these methods, their validity and reliability as well as the balance of quantitative and qualitative data that they provide. Robson (1993) acknowledges that "most real world study produces data which call for both quantitative and qualitative analysis" (p.307) a view shared by Allan (1991).

The questionnaire enabled me to gather basic general demographic information about each individual and formed the main themes for the study, whilst face-to-face semi-structured interviews and the 'user participation workshop' allowed for a richer data to be gathered. This highlighted key factors, which further helped to determine the underlying reasons for disabled peoples' choices of exercising or not.

Observation (Breakwell, 2000), case studies (Coolican, 1994) and diaries (Breakwell, 2000) were not felt to be suitable for this study in view of the reliability of interpretation. Although observation and case studies can provide very detailed information, their scope is limited and I felt they would not be appropriate for determining key factors (such as, variation of mood, physical limitations and accessibility of facilities and transport), that influence decision-making. Data from observation would only be possible with a small sample of people and it would be very time consuming (Breakwell, 2000). It would not allow me to draw out important beliefs such as the overall efficacy of regular exercise and the need for continuous commitment from individual respondents, although this method would give very direct and valid data (Robson, 1993). Case studies were considered, but rejected. The reasons given are as follows.

Case Studies in many ways are ideally suited to the needs and resources of the small-scale researcher. They endorse a focus on just one example, or perhaps two or three, giving a rich data. The disadvantage of case studies is that there is a high degree of unreliability involved, as no two cases are the same (Coolican, 1994). Many studies are quite unreplicable; indeed, their uniqueness is usually the reason for their being carried out in the first place. Their weakness is in lack of generalisability, the sample

does not represent as broad a range as would a sample from the general public (Coolican, 1999).

Diaries for individuals to complete (for them to record their thoughts and feelings about their individual decision making processes) were considered but rejected.

Diaries may be open to personal interpretation and less easy to compare across the sample because of the time it takes, the volume of data generated and the way in which the data is used. Diary studies also suffer significant problems with dropout: participants do not continue to provide information throughout the designated period (Breakwell et al, 2000, p.297).

### **3.3 Sampling**

This study uses a theoretical/purposive approach to sampling because the research lies within the interpretive/constructivist paradigm. It was necessary for me to begin with an identification of individuals where (and for whom) the processes being studied are most likely to occur (Denzin & Lincoln, 1994, p202).

Stratified purposeful sampling was the strategy, which I decided upon because it involved a combination of sampling strategies such that subgroups (i.e., wheelchair users), are chosen on specified criteria (i.e., age 18-64, disabled during adulthood) and the number of responses meeting those criteria were confirmed as my sample.

Various disability groups and organisations, which are managed by disabled people and groups run by non-disabled people for disabled people, were contacted in the first

instance by letter (appendix 1). The letter was typed on university headed paper. Mertens (1998) suggested that this 'appeal to authority' might produce a greater response. The purpose of the letter was to introduce myself and my research topic and to invite such groups, organisations and/or their members to participate in the research project by completing a questionnaire and a further choice of attending a follow up face-to-face semi-structured interview. Participants were invited to a user participation workshop at a later stage of the study. This letter was accompanied by an outline of my research (appendix 2). This outline explained what the study hoped to achieve and also expressed what the intended outcomes would be.

Responses were mixed and in some cases disappointing. One of the organisations contacted had taken 20 questionnaires to distribute to their members (1 was returned completed) whilst another took 50 to insert into their monthly newsletter of which they sent out 30 (8 were returned completed). Other organisations contacted were unable to take questionnaires, for various reasons (i.e. lack of resources or time), but offered to put an article into their quarterly newsletters. The article asked members to contact me direct by post or email, if they wished to participate in my research project. Some members contacted their organisation and asked for further information, others emailed me direct. Some of these participants referred me to others who they thought might like to participate. Despite my following up of the organisations that I had contacted, and my request to receive information about their work (e.g., a copy of their newsletter), only one actually replied with information. Other questionnaires were administered to members of smaller organisations and friends. Where possible, when an organisation offered to assist, an appointment was made to visit them and meet with the organiser. Where this was not possible I

arranged to converse with other members of staff and members of the organisation, if they were available. This gave me a chance to explain the research project in greater detail, the structure and layout of the questionnaire and the procedure for the semi-structured interviews.

A total of 150 questionnaires were finally sent out to individuals (many through organisations) who use a wheelchair for their main means of mobility, many of which had asked to participate in the research. 37 were returned to me completed. From the 37 participants who completed the questionnaires, 26 volunteered to be interviewed (80%). All 26 participants, who offered to be interviewed, were contacted. From those who were contacted 18 agreed to be interviewed. Face to face semi-structured interviews were chosen because my topic area was a very sensitive one, and I felt that it was easier to build a good rapport face to face than over the telephone. Each participant was interviewed once only, and the interviews were conducted over a six-month period due to the different geographical locations of each and the ability to make mutually convenient interview appointments. The participants were reminded of the aims of my research, and the purpose of the interview was explained. All participants gave permission for their interview to be recorded, transcribed and quoted from if appropriate, and they were assured of confidentiality. The interview schedule was followed in all cases.

Prior to receiving the completed questionnaires I had no pre-conceived idea of how many of the sample would be intended exercisers. Because my research question was to explore why some wheelchair users exercise, whilst others do not, it was important to focus on key elements of information on exercise. In order to keep focused I asked

them: what kind of exercise they participated in; where did they go; was there accessible transport available for them to use; what support system did individuals have and how confident were they about the exercise that they participated in? For the individuals who did not exercise I needed to find out the reasons why they did not. What restrictions did they face? What problems did they have physically, emotionally or medically? Did they receive negative or positive attitudes towards their decisions and what, if any, support or encouragement did they receive in making decisions?

These questions were felt to be most likely to produce the data required in analysing reasons given for exercising or not. This would better facilitate the coding of responses to the questionnaire so they could be analysed quantitatively using SPSS and qualitatively by analysing the interviews, using some elements of Discourse Analysis (Potter & Weatherall, 2002). At a later stage in the research participants were invited to attend a user participation workshop. As explained earlier, in section 2, page 7 of this study, this workshop was set up in order to feedback to participants the findings of the interview data. This is a very powerful part of CSR that makes sure that participants play an important part of the research all the way through allowing them to maintain ownership of the research.

### **3.4 Implementation**

The design and structure of the questionnaire was initially discussed with my supervisors who have knowledge of quantitative and qualitative research strategies. It was then further modified after conversation with a member of staff at the

Leicestershire Centre for Integrated Living who has special understanding in the area of disability awareness. Finally it was then piloted amongst a group of disabled people in my local area of Roxton, and amended accordingly.

Questionnaires (Appendix 3) were sent to participants, either through the organisations, or directly to individuals willing to participate in the research project. The questionnaire was accompanied by a covering letter (Appendix 4) on headed paper (Merten's, 1998, P127), which explained who I was and the purpose of the study. It explained to the participants which group of the population my research was focused upon and gave a definition of exercise as it was seen in the project.

The letter explained that data collected would be used in strictest confidence, and asked the participants if they would be prepared to take part in a follow up face to face semi-structured interview. Participants were able to omit their name and address from the questionnaire if they wanted to remain anonymous. This potentially increased the validity of the data by allowing them to give a more 'honest' response. The last question on the questionnaire, for both those who do, and those who do not exercise, asked them if they would be willing to be interviewed, in confidence, at a later date. Those who did agree to be interviewed had to have their name and address entered on the questionnaire in order for them to be contacted. A stamped-self addressed envelope was attached to make the return as easy as possible.

When, as on one occasion, questionnaires were left with the manager of an organisation (to distribute to willing members) a follow up phone call was made to the



organisation about two weeks later to enquire how the completion of the questionnaires was progressing and to see if any help was needed.

When the return of questionnaires started to diminish (or in some cases, failed to start) I telephoned the manager of the organisation to enquire as to the progress of completion and offered to collect any completed questionnaires. I felt that perhaps probing like this could prompt more returns but in this instance it did not. People are more likely to return a questionnaire, and promptly, if it comes to them on good quality stationery and carries a first class stamp on their reply envelope (Munn & Drever, 1990). There could be good reasons why some people had chosen not to reply (Munn & Drever, 1990). If individuals who personally requested a questionnaire did not respond within 3-4 weeks, I tried to make contact with them by letter and then by telephone to ask them if they needed a replacement questionnaire or any help with completion. However, when questionnaires were left with organisations, I did not know whom the questionnaires were going to be given to, so I had no control over getting in touch with them individually if they did not reply.

A card system was set up to record and monitor progress made with organisations, their members, or individual contacts. If organisations contacted by post did not reply within 4-5 weeks, it was entered onto their card as 'no response'. When organisations responded to me but said that they could not or would not help, but sent referrals of organisations who may assist, the referral and from whom it came, was entered on the card with the contact date. A new card was set up for the new referral. When emails arrived from willing individuals the contact name and address and date received was monitored, also on the card system. Participants, who did complete a questionnaire,

were sent a thank you letter. Those who had agreed to be interviewed were advised that they would be contacted at a later date, with regards to making arrangements for the face-to-face semi-structured interviews.

Out of 150 questionnaires administered, 37 were returned, giving a response rate of 25%, representing 7 out of 40 organisations contacted. (LCIL, Parksiders, Bedford Disability Information Centre, Luton and Dunstable Sports, Ataxia, Polio, Magic Carpet). Out of the 37 questionnaires completed and returned, 26 respondents agreed to be interviewed, that is 80%. When it was time to make contact with the participants to arrange interviews, 10 of them had not entered their phone number on the questionnaire. I wrote to these people asking for their telephone number or e-mail address, in order for me to arrange a convenient time to interview them, but only 2 of the 10 replied. Eighteen participants in total were interviewed. Following the interviews, participants were invited to attend a 'user participation workshop', where I presented the findings from the interview data collected. This was a chance for my participants to stay involved in the research at every stage of the research process and to also give their feedback. In this way I was giving them the power (Harvey, 1990) to express their feelings about the data, which had been collected

### **3.5 Subjects**

In my study the subject population are individuals who use a wheelchair for their main or only means of mobility, who have become disabled during their adult years, aged between 18-64 of either gender from a variety of social and cultural backgrounds. There are approximately 8.6 million disabled people in the UK (Reith,

2001), of which 700,000 are wheelchair users, making my sample size quite large. (Trying to identify local and regional figures of wheelchair users was impossible for the reasons discussed in the literature review). However, access to disabled individuals was very difficult. Because of the Data Protection Act (1998) some organisations were unable to give me names and addresses of their members who might have been willing to participate. Others lacked time or resources. This created a barrier between the disabled individual and myself; thus the completion rate of questionnaires was lower than I had expected. Because the response rate was low, reliability was lowered. Frey and Mertens (1995) explain that the sample size and response rate will affect the 'generalisability' of the findings. The number of participants who completed questionnaires and the number who agreed to be interviewed still make this study a viable and relevant enquiry. A very rich data was collected from the interviews and the user participation workshop.

### **3.6 Questionnaires**

#### *3.6.1) Advantages of the questionnaire approach*

Munn & Drever, (1999) describe the advantages of using questionnaires. They offer the possibility of a high return rate, anonymity for the respondent and efficient use of the researcher's time; although Cohen et al (2000) warn that a low response rate will affect the quality of the data. A questionnaire administered to disabled people either by post, or given personally, was thought appropriate to gain information from a

relatively large number of people, using a method, which would give a wide range of both quantitative and qualitative data.

A well-designed and easy to use survey contributes to the overall reliability and validity (Cohen et al, 2000). Reliability can be defined as a measure of consistency. Coolican (1994) describes reliability as being consistency within a test or between repeated uses of it in the same circumstances. Most questionnaires have a high reliability; for example, Cohen et al (2000) agrees that anonymity makes the data more reliable and honest. For this study the same standard questionnaire was sent to the entire sample, which had the option to remain anonymous if they so wanted (appendix 4). Even if questionnaires are standardised, they are still open to different interpretations. The information may describe rather than explain the phenomena, and can be superficial, even in open-ended questions (Munn & Drever, 1999).

Robson (1993) acknowledges that the data may be affected by the characteristics of respondents and the accuracy with which they complete the questionnaires. He claims that ambiguities and misunderstanding of the questions may not be detected. To try to overcome these problems, I included my contact address on the covering letter, which accompanied the questionnaire, in case of queries. The follow up interviews with some of the sample provided an opportunity to discuss issues in greater depth. It was felt that the questionnaire was developed in a way that could be read as easily as possible and gave clear unambiguous instructions as to how many choices could be selected for each question.

Validity is a measure of how accurately the questions posed really do measure that which they are intended to measure (Cardwell, 1996). Robson (1993) describes internal validity as being dependent on the questions and the way they are asked and answered. Frey & Mertens (1995) state that validity will be compromised if participants do not answer correctly, omit questions or give answers that are socially acceptable rather than truthful ones.

### 3.6.2 Wording of the Questions

It is important to consider the wording of the questions to improve validity.

Breakwell et al (2000) stresses the needs for clear, unambiguous questions, which will be easier to answer and increase the likelihood of them being completed, a view supported by Cohen et al (2000). It was therefore decided to use a mixture of open and closed questions, always giving 'other, please state' as an option. The wording was made as simple as possible for ease of completion as some participants may need to ask somebody else to complete the questionnaire for them.

Cohen et al (2000) stress the importance of piloting the questionnaire to identify any ambiguous or leading questions, thus improving validity. The pilot should be carried out with a sample similar to that of the population to produce feedback on the type and order of questions, and whether the instructions are clear.

For this study the questionnaire was piloted with a small group of disabled contacts to get feedback on the appropriateness of specific questions. These included: any ambiguities in wording; any questions that were unclear how to answer; the order of

the questions and general layout as well as the time taken to complete the questions. The administration and completion of the questionnaires enabled me to consider which questions needed further clarification. Changes were made to the wording of some of the questions and their order was changed slightly. The questionnaire was designed in 3 sections. Section one was for all participants to complete. Section two for those who did exercise. Section 3 for those who did not exercise.

### 3.6.3) Questions

As stated earlier, the questionnaire covered enquiries in three main areas: basic information (i.e., age, gender), exercise involvement and access to facilities/travel. Section one asked the general questions, which covered demographics, i.e. age, gender, class and occupation etc. This section was for everyone to complete. Section two was to be completed by individuals who were physically participating in exercise activities. Participants were asked what kind of exercise they participated in, if there were facilities near to where they lived, how they travelled to their exercise venue, and how often they attended. They were also asked if they received any support or encouragement to exercise. Section three was to be completed by individuals who did not at that time participate in exercise. They were asked to state the reasons why they did not exercise and if they would consider taking up exercise in the future. Questionnaires were either administered and collected the same day, left with the head of the organisation for him/her to administer, posted direct to participants who made contact with me direct (through the disabled organisation) or they were inserted into a quarterly newsletter.

Four of the organisations which I had made contact with were unable to insert a copy of the questionnaire directly into their newsletters. The manager of each organisation asked me to send them an outline of my research study stating the selected criteria that I was exploring. In my letter to them, which accompanied the outline, I asked them if they would be able to send me a copy of the newsletter so I could see how the outline had been inserted. But they failed to do so. Because they did not send a copy to me, I had no way of monitoring whether such an inclusion was accurate. Furthermore this may have contributed to a relatively low response from possible interested subjects.

#### 3.6.4) Disadvantages of the questionnaire approach

It is important to consider whether all potential respondents would complete the questionnaire in the same way, or whether the original non-respondents would have completed it differently from those who did respond and affected their decisions not to return the questionnaire. It may be the case that those who do not respond may hold different views from those who do. Robson (1993) argues that if the characteristics of non-respondents are unknown it is impossible to know if the sample is representative. However, Mertens (1998) states that if it is possible to assume that respondents and non-respondents are similar (by following up non-respondents) a 50% response rate is acceptable. However, it was not possible to follow up non-respondents in this study because I had no way of knowing who the non-respondents were, because I was not in control of who the questionnaires were sent out to. Munn & Drever (1990), in their publication on using questionnaires in small-scale research state that the information collected by questionnaires tends to describe rather than explain why things are the way they are.

### 3.6.5 Open and closed questions

Where closed questions were used the option of "please comment" was available. Closed questions are relatively easy and quick to answer and usually provide a good response rate and have the advantage of not being open to interpretation by the researcher (McNiff et al, 1996). However, closed questions do not allow the respondent freedom to add or explain and therefore may lack authenticity and have the effect of 'leading' the answer, which will affect the validity of the data (Munn & Drever, 1999).

Open-ended questions give more scope for respondents to answer in their own way, increasing validity. An open-ended question can catch the authenticity, richness, depth of response, honesty, and candour, which are hallmarks of qualitative data (Cohen et al 2000, p.255). The disadvantage of open-ended questions is that they take longer to complete, reducing reliability and the responses are also harder to classify, but as Munn & Drever (1999) describe, categorising data from the responses reduced the effect of imposing your own interests on the data.

I decided to use a balance of open and closed questions to allow the respondents enough freedom to express their views, without making the questionnaire too difficult or time consuming. Closed questions included issues about the length of time participants had used a wheelchair, whether they participate in exercise or not, and whether they have leisure facilities near to them. Questions which asked 'How often do you use your leisure facilities?' and 'What activities would you like to be made



available to you?' were open ended to encourage a wide range of responses and provide qualitative data.

Questions were ordered to maximise potential, with easier, factual questions first, so the respondent is more likely to continue. Munn & Drever (1999) suggest that preliminary questions identify the range of respondents and levels of interest in the topic: open questions should come next; followed by closed questions. My questionnaire followed this structure at the beginning but then split into areas of exercise involvement and travel, with a separate section for individuals who do not exercise. Consideration was given to the issues of; time to complete the questions, the clarity of instructions, simplicity in wording and design, and the length of the questionnaire. This is important because some people may find difficulty in writing and transferring their thoughts onto paper.

It was not felt necessary with this questionnaire, and the type of questions asked, to use a rating scale. Although in describing the benefits of using rating scales, Cohen et al (2000) state that they "combine the opportunity for a flexible response with the ability to determine frequencies, correlations, and other forms of quantitative analysis". They afford the researcher the freedom to 'fuse measurement with opinion, quantity and quality' (p.253). It must be acknowledged that selection of a number is open to interpretation by the reader, making this method subjective (Cohen et al, 2000).

### 3.6.6 Analysis used

Data collected from the questionnaires was analysed using SPSS (Statistical Package for Social Sciences Version 10) to produce a quantitative analysis. Findings were presented in the form of graphs (i.e., histograms) and tables, which identified common and different elements within this small sample. Between-subjects design was used in order to see if there was a difference or a relationship between those participants who do participate and those who do not participate in exercise. Due to the study being a small-scale research, the potential for statistical analysis was limited slightly, but this did not affect the quality of the data collected.

The development and administration of the questionnaire gave me a framework on which to build my interview structure. Although I was not able to deduct vital in-depth information from this research method (such as levels of confidence), it helped me to decide what other information was needed, in order to answer my research question. This formed the basis of the interview structure (Appendix 5).

### 3.6.7 The benefit of quantitative data.

The purpose of this data from a sample of 37 participants assisted in describing, organising and summarising the responses from the questionnaires. From an examination and comparison of frequencies and cross tabulation it was possible to examine the relationships between the different variables, i.e., participation and gender, participation and availability of leisure facilities etc, in relation to the original aims of the research.

These aims were to firstly, examine the exercise intentions of disabled individuals (wheelchair users) using Oliver's (1996) Social Model of Disability. Secondly, to determine the factors underpinning intentions to exercise, attitudes towards exercise, influence of significant others, choices and self-determination. The quantitative survey helped to examine these determinants. The data collected from the questionnaires were analysed and used to develop the main themes for this study.

Oliver's (1996) model argues that it is society that disables and not the cause and effect of the impairment which is posited by the medical model. My initial aims enable me to look wider at the underpinning factors, which influence a disabled person's decision to exercise, or not, by using Harvey's (1990) critical social research.

The quantitative data collected from the questionnaires offered me a further dimension to the qualitative theoretical base, which explores and examines the evidence using forms of investigation and analysis preferred by Harvey (1990) in his text on Critical Social Research. It assists in questioning the social model of disability and determining the factors underpinning a person's decision to exercise or not, as mentioned above.

#### 3.6.8 Contributions offered to the rest of the study

Despite the effort to obtain a large sample of wheelchair users it has been apparent that the final sample of 37 fell far below what I had intended. But it did allow for a greater depth of analysis from the quantitative and qualitative data.

One area which was significant, was that from the youngest to the oldest, nearly all of the participants said that 'exercise is beneficial to their health', regardless of their age. This was in spite of the fact that some do not participate in exercise activity. Of course such a small sample cannot be expected to reach conclusions on key issues as the Social Model of Disability.

The quantitative data offered a different perspective on the original aims of the research highlighting some areas, which are very important. For example, it was found that frequency of use of exercise facilities correlated negatively with the distance from the leisure facility, showing no significance. Whereas with a much larger sample it could have revealed that in effect this was a significant factor.

The quantitative data also provided useful detail on the nature of the sample and highlighted the widely different lifestyle and resources available to the participants within the sample's geographical boundary.

The data derived from the questionnaire analysis formed the five main themes, which were portrayed in the interview and user participation workshop findings.

### 3.7 Interviews

Verma and Malik (1999) explain that interviews can collect supplementary data (covering the same ground as the questionnaire, but in more depth) or complementary data (on a different but related aspect of study). My interview structure had elements of both in that it looked at exercise involvement in greater depth and also addressed new issues. Participants were asked if they felt that exercise had increased their level of self-confidence. It asked them whether they lived alone or with somebody else and if they needed any help in the home. They were also asked the very sensitive question about body image. How did they perceive their body image to be when they were with other people? I felt these new issues would be better discussed face-to-face, once a rapport had been developed between the participant and myself, than on a questionnaire. I built up a rapport by just being friendly and taking the time to talk about something I thought the respondent was proud of. This could be their family, home, or some personal achievement or hobby. It proved quite difficult to design a question about 'body image', which was quite straightforward in these areas, as I did not want to offend the participant by coming over as rude or insensitive to their feelings. Sensitive topics such as 'body image' may take the form of psychic costs, such as guilt, shame, or embarrassment (Renzetti & Lee, 1993). As a result, the relationship between the researcher and the researched may become hedged with mistrust, concealment and dissimulation. This in turn raises a concomitant need for ethical awareness on the part of the research.

While quantitative data, gathered from the questionnaire, tends to have high reliability and repeatability, it can be less valued as there is no exploration of answers. Fraenkal

and Wallen (2000), explain that interviews are useful in that they can be used to clarify and develop answers and gain insight into data obtained by quantitative methods. McNiff et al (1996) agree that "interviews have advantage over questionnaires in that you can get a richer feedback as a result of being able to probe further". The more qualitative approach of the interview allows issues to be explored such as identifying and teasing out common problems that prevent exercise involvement.

Breakwell (2000) explains that semi-structured interviews allow the researcher to standardise the questions, while allowing some flexibility, depending on the answers given. They also allow the participant freedom to reply in their own way, facilitating participation and involvement, especially where open-ended questions were used. Semi-structured interviews were appropriate in this case as opposed to structured interviews, which would be rigid or open conversations without any control or specific purpose. This was because I needed to explore specific issues in more depth to identify key determinants, which influenced decisions to exercise.

Robson (1993) explains that open-ended questions can also offer unforeseen answers which may enlighten research, a view supported by Radnor (1994) who states that "because the interview is semi-structured, unexpected areas of interest might arise which leads to another question worth noting" (p.17). For my study the interview was structured in two parts, one for those who do exercise and the second for those who do not, as the questions were different for the two groups.

### 3.7.1 Interview schedule/Pilot interviews

At the early stages in the planning of the research the schedule started as a list of headings. This was elaborated on once feedback came from the questionnaires. I decided to conduct four pilot interviews, which would give me feedback on the clarity of the questions and the questioning technique. Banister (1998) explains that practice interviews can give frank feedback on the content and process of the interview. It helps to identify and iron out problems with the interview schedule, and with recording equipment (remembering to switch it on, to know where to position the microphone, not to have the machine on auto-reverse etc). I also found that I gained a lot of confidence from the experience. It also made me aware of the demands made upon me as interviewer.

These demands included the skill to be able to listen intently to what my participant was saying, reflecting on how this relates to my interests, preconceptions and schedule, and working out what to say and when to say it. It was important for me to be as open as possible about the aims of the interview. This was because most of the participants had been contacted through organisations run for or by disabled people, and we had never met before.

This openness included outlining the kinds of areas or questions that I wanted to discuss with them. I did this by giving them a list of subject areas that would be covered, and explained that if they did not feel happy about any of the subjects, we did not have to discuss it. This was done to allay participants' anxieties or reservations. I also explained at this stage what records I wanted to make of the

interview, seeking their permission to audiotape the interview. I then explained why this was useful and how I would transcribe the data.

The next stage of the schedule was to negotiate a research contract with each participant. This included; a guarantee of anonymity, a promise to terminate the interview at any point if the participant felt uncomfortable, the exclusion from the transcript or other record of anything the participant did not wish to be seen by others, and finally, I offered to keep them informed on the progress of the project if desired (Banister, 1998).

As with the questionnaires, care was taken over the wording and order of the questions. To increase reliability, prompts and probes were included in the planned interview schedule (Drever, 1995). These were unbiased and were used consistently (Robson, 1993). Prompts were used to jog memory of the participant, or encourage them to say more, while probes sought to clarify, develop or explain an idea (Drever, 1995). These were therefore written as part of the interview schedule to ensure consistency across the sample.

A detailed interview schedule, with questions addressing all the key issues would give the researcher reassurance, but it would need to be treated flexibly in the interview itself because too rigid adherence can intimidate the participant and can fail to follow the participant's train of associations and perspectives. I therefore decided to have a list of topics for myself; with the lists of issues I needed to cover, as short questions. They were arranged so that it was easy to check them out in the course of the interview. This made it easy for me to flow from one question to another.



The limitation of this approach as explained by Banister (1998), is that while responding to the particular context and moment to ask the question, I would betray too much of my own perspective in the formulation I use or, in the heat of the moment I could be lost for words. Because of this limitation I decided to pose topic headings in the form of questions. Then if the respondent started to answer a question I had not yet asked, it was easy to follow where we were in the interview structure.

Robson (1993) claims that data may be affected by characteristics and interactions of both the interviewer and interviewee, and that openness of the encounter may be affected by the fact that the interviewee cannot be anonymous. Participants who completed the questionnaire had the option to be interviewed, so there was no coercion, improving validity. But as the sample is self-selecting i.e., the choice of participating in the interviews was left to the individuals, there is inevitably bias as explained by Drever (1995). This may come about by the fact that those with a specific interest in exercise involvement may have volunteered. Cohen et al (2000) acknowledge that the relationship between interviewer and interviewee can have an effect. Lack of anonymity may cause participants to be less open, but self-selection may reduce this problem.

### 3.7.2 Interview techniques

When conducting my face-to-face semi-structured interviews, it was important, and also a good interview technique, to have the interviewer speaking for a minimum amount of time whilst the participant did the maximum amount of talking (Berg, 2004). As Berg mentions, when interviewing, the ideal is to have the subject speaking

80 to 90 per cent of the time. When interviewers take up too much of the conversation, little research information is gained (Berg, 2004). I consider that it is particularly important when interviewing wheelchair users to sit in a face-to-face position in order to have good eye contact and to limit the amount of movement the interviewee would have to make. Piloting the interview helped to develop these skills (Cohen et al, 2000). It was important that I created a relaxed and non-threatening environment, thus creating a good rapport between my participants and myself. This can be quite a difficult thing to do when conducting telephone interviews (Robson, 1993), as there are no visual clues, but they could be less time consuming and more convenient for the interviewee. I felt it would be difficult to build a good rapport over the telephone. So telephone interviews were not used in this study because of the sensitivity of some of the questions I needed to ask participants.

Because I was aware of the pitfalls and dangers of interviewing, and I knew how sensitive my research area could be, a supportive environment was valuable to my research. For this reason face-to-face semi-structured interviews were conducted for this research.

I had to be careful not to draw on my own knowledge and experiences of physical activity and sport, as well as my previous research of wheelchair accessibility and accessible facilities (Rice, 1994), whilst asking participants the topic questions, as this may bias the responses. This is emphasised by Drever (1995), when he discusses the importance of maintaining formality. I needed to be open and honest about the purpose of my research, and how it would be reported, and I needed to do this without colouring potential responses (Cohen et al, 2000). The purpose of my research and its

aims were addressed in the covering letter attached to the questionnaire and also the interview schedule.

Confidentiality and anonymity are important principles. Permission to tape the interviews was sought when the interview arrangements were made. As my research area can be a very sensitive one for some disabled individuals, I needed to know before the interview began that they were happy with the interview process, its aims and objectives. Active listening on my part was very important, and this was made easier by taping the conversations. This allowed me more time to consider the responses given, and to use my prompts and probes more effectively. Coolican (1994) argues that most people feel inhibited in the presence of a tape recorder, but it can also improve reliability by catching the exact terms and richness of the participants' experiences. The tape recorder had the advantage of leaving me free to converse naturally and encourage the greatest flow of information. At the end of the interview I asked the participant if he/she had anything else they wished to talk about. During the pilot studies, in the closing section of the interview, participants were asked if they found the questions easy to answer and if they felt any improvements could have been made.

Transcripts were made of the interviews and the information was collated and each set of answers was analysed. In all cases, care was taken to make sure that no organisation or individual could be identified. Letters of thanks were sent to all organisations and individuals who responded.

Ideally the transcripts could have been passed back to the participants for validation (Radnor, 1994). Cohen (2000) advised not to promise transcripts if you would not be able to deliver them. Participants had to know that they are involved in all stages of the research in order to maintain ownership of the research. I offered to give each of them a summary of the findings for them to comment upon. All participants interviewed accepted this offer. This was also in keeping with the methodological framework that Harvey adopts in Critical Social Research.

The forms of questioning employed during each interview enabled participants to evaluate, from their own perspective, the quality of service provision and access to community facilities that are available. Furthermore, the open endedness of the interviews sought to allow wheelchair users to explore the question of how far their choices to exercise compare with those of non-disabled people. It is important to investigate how far it is disabled people themselves, rather than an inequitable social system that results in non-participation to exercise.

### 3.7.3 Advantages of Interviews

The use of questionnaires, interviews and user participation workshop for data collection, making use of both quantitative and qualitative data, is defined by Cohen et al (2000) as 'triangulation'. It uses two or more methods of data collection and verification. The interviews gave me the opportunity to explain any of the questions, which I felt had been unclear in the questionnaire, and also allowed me to ask questions, which were too long or too complicated to be added to the questionnaire. It

showed whether or not the participants had understood the meaning of the questions on the questionnaire, and it gave me the chance to probe further into certain areas of the main themes derived from the questionnaire data. This enabled me to tease out more information that may lead to important key factors related to determinants and intention to exercise.

I was able to ask the more personal questions during the interview, that the participants may not have answered fully on a questionnaire. These questions covered issues concerning accessibility to transport and facilities, finance available to spend on leisure, confidence in the exercise that is being participated in and body image, i.e., the way the individual perceives their appearance.

It was initially important to build a good rapport with each participant. Potter (2002) suggests that it is very difficult to remain objective all of the time. Oakley (1979) emphasised that from a feminist perspective the interviewer is part of the event and in her study she was able to give more prominence to the subjective experience (p118).

As a researcher into disability it may well be that information can be shared between interviewer and participant. Oakley (1981, p.42) argued that there may be times when women ask you questions as a woman and the roles might well be reversed, hence the interviewer becomes the interviewee for a short time of the interview. Holman (1987), on his research on the poor, confirms this belief in two-way communication in his article on 'research from the underside', where questions are raised about who the research belongs to. Holman's point being, that valuable as it is, studies that have done something to improve services for the socially deprived, are largely research

about, on and for the poor, not by or with the poor. Holman states that although research may have done something for the poor, it also reflects their unequal position. Firstly, the decision to undertake studies is made not by the socially deprived but generally by statutory departments, research units and the general public. Secondly, the processes used to collect material also reinforce notions of superiority and inferiority.

The collection of questionnaire data and interview material sought not only to examine the factors that shape the intentions of wheelchair users to exercise or not, but rather examine in more detail the political situation regarding the treatment meted out to disabled persons at large, by society.

Being disabled in Britain today is, for some, often a struggle to survive, not only requiring 'liberation' from tiers and categories of bureaucratic labels, but the will to escape from the pervasive concepts of inadequacy that the so called 'able-bodied' governments, administrations and organisations consign them to. How we define disability is of central importance in relation to our expectation of, and interaction with, disabled people. A social political approach to disability emphasises the importance of difference, diversity and the heterogeneity of what it means to be human (Armstrong, 1999:212). Views of disability as a tragedy, a dependency creating condition or an individualised problem are all the subject of a powerful critique in which the struggle for rights, equity and participating citizenship is of fundamental significance.

A major issue is about control, and in a discussion about getting out of the 'charity trap' in which disabled people are encouraged to be grateful for the support they are given, Morris (1992:11) illustrates this perspective in the following questions: Who has got the right to say what we need? Who has the right to say how we should be presented to the public? In seeking to gain control over the power of naming, the interest is in positive self and collective images and identities. It is about being proud of who you are. The demands for equity and non-discrimination are derived from an informed understanding of the extent and stubbornness of the disabling barriers within society. It is these that need to be identified, challenged and reviewed. Nor is this merely an attitudinal problem, but one of institutionalised discrimination and oppression. This is most vividly recognised by Barnes (1991: 233), who maintains that:

The abolition of institutional discrimination against disabled people is not a marginal activity; it strikes at the heart of social organisations with both the public and private sectors. It would not be possible to confront this problem without becoming involved in political debate and taking up position on a wide range of issues.

A public affirmation is required that discrimination against disabled people is totally unacceptable. Supporting this stance is the struggle for anti-discrimination that the world is changeable and we need to find alternative ways of struggling to get things changed (Richardson, 1991).

Historically, the 'voices' of disabled people have been largely absent from discussion and decisions affecting the quality of their lives. Powerful professional bodies and organisations for disabled people have protected their vested interests, while articulating a language of facilitation and individual needs. Part of this experience has, for disabled people, been that of social exclusion and restraint (Armstrong, 1999: 212).

Oakley (1985) reflects in her study on housework on a comparatively similar form of 'structural oppression' endured by women in consigning them to a life of domesticity.

### **3.8 User Participation Workshop**

The user participation workshop was set up in order to present to participants the findings from the interview data. It gave them the chance to feedback, or add to, the interview findings. It allowed them to maintain ownership of the research at each stage of the research process, as this is a very powerful part of critical social research. In this section I take the reader through booking the room, contacting the participants, what I did when I received a last minute cancellation, what happened on arrival at the chosen venue, how I felt on the day of the workshop. Finally I examine the presentation of the findings.

The room was booked at Demontfort University, Polhill Campus, about 5 weeks before the date chosen. I was surprised that the room I was to have was on the first floor. I was assured that it was all right because they had a lift in the corridor. This lift was able to take people and their wheelchairs. I booked the room for a two-hour



slot because I felt that any longer may cause difficulties due to individual's coming with their carers, or the problem of heavy traffic if we left too late in the afternoon. I checked out the room and found it very spacious and containing about twenty-four chairs and six tables.

There was quite a lot involved in making arrangements for the meeting. First, I had to write to the participants and invite them to the workshop. When I had received their replies (seven of them never replied, so I contacted them by telephone), I then had to confirm the numbers to be attending with the estates manager in order to arrange for disabled parking. A parking attendant would be on the look out for the participants when they arrived in order to give them a parking permit. I then had to contact the catering manager to arrange refreshments on their arrival.

All 18 interviewees were invited to the user participation group workshop in order to participate in the presentation of the interview findings. Each respondent was sent a letter of invitation. This letter stated the date, time and venue of where it would be taking place. A map of location was included with the letter as well as instructions on how to find the room. I sent them a reply slip and a stamped self-addressed envelope to make it easy for people to return it to me. I asked them to return it as soon as possible in order for car parking arrangements to be made.

It was very difficult to get hold of people in order to get them altogether at one time. Of the 18 respondents that were invited, three of them attended two of these with carers. The responses from the other 15 varied. Two have not replied to date. Two were on holiday, one had moved further away, two were too ill to attend and the other

eight either did not have a vehicle of their own, or were dependent upon other people to drive them in their vehicle. These other people were previously engaged with other commitments. I felt it unfair to cancel it, as they would have already made arrangements with carers in order to attend. Those that did turn up had made a big effort in order to do so.

Thankfully, I arrived 45 minutes early and on arrival I found the lift 'out of order'. I reported it to reception who, then got in touch with the Estates Manager. She did not know how long the lift had been out of order or whether it was being repaired. I asked if there was an alternative route to get to the first floor, I was told 'no'. I asked about a room downstairs that I could use, they were all fully booked. I went up to check out the room. I arranged the room accordingly by pushing back the tables and arranging the chairs in a circle with room for wheelchairs in between. I then went back downstairs to see what the situation was with the lift.

By the time the Estates Manager had located the engineer for the lift repair, the first respondent had arrived in the corridor. The refreshments then arrived in the room, and the lift was miraculously repaired to take people up to the first floor.

I kept the presentation very informal. I started at 2pm by offering them refreshments, as two respondents had come quite a long way. After introducing each respondent to each other, I started the presentation at 2.15pm. Each respondent was given their own summary of the findings so they could follow where I was going. It took about 40 minutes to present the findings, and approximately half way through the presentation respondents started to intervene. I received a lot of feedback from the respondents. At

3pm I offered more tea and coffee. This was followed by 1 hour of feedback from respondents who felt that the discussion could easily have gone on another hour or two. All respondents were very responsive and they all listened to each other's points of view and said that they appreciated the opportunity to express themselves. I feel that this opportunity to meet gave participants control over the situation and empowered them. It was their research. Everybody who attended the workshop was very positive and they all said that they would like to meet up again as they enjoyed it so much. One respondent said she felt that I should contact an organisation in order to get all my work published so that it could be used to help other people.

### **3.9 Data Analysis**

Data collected by questionnaires were analysed using SPSS Version 10, to explore frequencies and descriptive statistics, whilst material from face-to-face semi-structured interviews and the user participation workshop was transcribed and analysed using some elements of discourse analysis. Tesch's (1990) organising system was used to help to organise the interview data into manageable chunks by way of coding and categorising the data. Layder's (1998) 'Adaptive Theory' was then used to analyse the data.

#### **3.9.1 Analysis of Questionnaires**

Thirty-seven questionnaires were completed and returned to me. The questions were open-ended with the option of (other please specify) for additional information. My sample was not representative of any gender, class or ethnic group. It was a sample of

people (wheelchair users) who responded to my invitation to fill in a questionnaire and be interviewed. The quantitative data was collected using questionnaires and analysed using descriptive statistics. From this analysis I was able to draw out the five main themes of my study. Whilst within a qualitative framework face-to-face semi-structured interviews were conducted and later on a user participation workshop. The user participation workshop enabled me to present to participants feedback from the interview data collected, giving them the chance to stay involved with the research at each stage of the research process, as this was an important part of the critical social research process.

Once the questionnaires were collected, the questions each had to be coded for data analysis. An example of the coding is 0 for yes and 1 for no. Alternatively each section of the question was coded i.e., 1=friends, 2=family, 3=peers, 4=other etc as on question 4. When data was missing the cell was left blank.

When working with smaller numbers, it is better to use descriptive statistics like frequencies to analyse the data. Because of this small sample I was more likely to get sampling bias than if the sample was larger.

#### 3.9.1.1 Frequencies

Large samples may also disguise weaknesses in the design experiment (Coolican, 1992). I decided to use frequencies to analyze my quantitative data. This was because they are obtained by counting the number of times a behaviour occurs during an observation period (Coolican, 2000). An example of this would be how many

times a week a respondent participates in exercise activity. This can then be expressed as a rate per day to allow for comparisons to be made between observation periods of different lengths (Breakwell, 2000), and different participants. Another example of frequencies would be to categorize the purpose of exercise activity into: 1) Leisure and Enjoyment, 2) Physiotherapy and 3) Sport. I used the figures 1, 2, 3 as labels only and not real numbers. The numbers within each category are known as frequencies. We can see by running frequencies on SPSS how often no's 1, 2, and 3 were selected and which category had been chosen the most.

Using descriptive statistics to analyse my data allowed me to find out frequencies. Examples of frequencies are the length of time individuals have used a wheelchair, the reasons why they do or do not exercise, and who gives the greatest level of social support. The use of frequency distribution allows me to see whether the observed values are spread out fairly evenly over the range or whether they tend to bunch together at any point (Rowntree, 1991). It shows up the frequency with which each value in the distribution is observed. An example of this is travel facilities. The number of times individuals travelled to the leisure centre in their own cars was recorded as?? occasions (frequency =?), whilst the number of times an individual traveled to the leisure centre by Dial-a-Ride was not recorded at all (frequency = 0).

I used frequency distribution to check whether any travel facilities were more frequently recorded than any other. The value in a distribution that has been observed with greatest frequency is called the mode of the distribution. It is the most 'fashionable' or 'popular' value. If there are two values showing the greatest popularity, then the distribution therefore has two modes. I used the mode because it

is often most useful as a description when the sample concerns categories rather than quantity-variables. It allowed me to find out whether most people exercised for leisure, physiotherapy or sport. The one that was selected the most would be the modal category.

I also decided to group the observations using group frequency distribution. This was useful for travel facilities as it brings out the overall pattern more clearly. But it loses information about the individual values observed. Detail is often sacrificed to clarify the overall pattern. The pattern in a grouped frequency distribution is made clearer with a histogram. This is a block diagram whose blocks are proportional in area to the frequency in each class or group. A histogram makes it easy to recognize which of the classes is the modal class. For this reason frequencies were graphically represented using histograms.

### **3.9.2 Analysis of Interviews**

Following analysis of the questionnaire data, the interview questions were written to provide an interview schedule, and prompts and probes were included to reduce bias and standardize the procedure. Again, piloting allowed feedback; the first stage was to discuss wording with my supervisor, and then a pilot run allowed the interview to be timed, and feedback was given on the clarity of the questions. This was taped and when I replayed it, it became apparent that one or two questions needed to be amended. My voice was sharp and clear on the tape, which meant that it was safe to assume that the interviewee had heard the questions, but had not necessarily

understood their meaning. After amendments were made, a further pilot was conducted with a different participant.

Once all of the interview material was gathered, the data were transcribed from tape to paper, word for word. It was now ready for analysis. Both Microanalysis (Corbin & Strauss, 1998; Denzin, 1978) and Discourse Analysis (Potter & Wetherall, 1987) were considered. Examining in detail the transcripts and subjecting them to forms of discourse raises the crucial issues of how the task needs to be structured and importantly how the information is codified and categorized. Terminologies, various words for describing what discourse analysis actually refers to, in the social science field particularly, are numerous (Potter & Wetherall, 2001) due to its application in a variety of natural and social science domains that includes psychology, sociology, linguistics and anthropology. The above authors highlight contemporary advances in the variety of ways different researchers have applied themselves to the task of analyzing discourses with reference to the work of continental approaches by such noted figures as Foucault (1972) and Levinson (1983) who used the term 'conservation analysis'.

The purpose of this study was to critically examine the factors that influence the interactions between disability and exercise, within a social psychological paradigm. The term 'discourse' will be used in the wider sense of accommodating all underlying themes and issues relating to the decision making process that could lead to intention, or lack of it, to exercise or not. In that sense it will attempt to go beyond the limits of discourse per se and not concern itself with forms of the microanalysis of language (Corbin & Strauss, 1998) forms and structures which are more the preserve of

linguists and those interests focus on the phonics and semantics of expression. A more qualitative interpretation of responses from wheelchair users would also better fit within the critical social research framework that I have chosen to pursue.

### 3.9.2.1 Discourse Analysis

Discourse analysis attempts to uncover evidence, listening to what people say and examines the reasons why they are saying it. I will be comparing how the different participants relate the same information. The comments that will be of major importance in my study relate to issues about the oppressive structures within society i.e., accessibility (framed with the Social Model of Disability, Oliver, 1996), and the individuals' level of confidence and their encouragement to exercise. CSR (Harvey, 1990) was at the forefront of my research, which aims to dig deep beneath the surface of those oppressive structures, so I feel it will be appropriate to use some elements of discourse analysis within my theoretical framework. The transcripts were coded using Tesch's (1990) organising system and were later analysed using Layder's (1998) adaptive theory.

The transcripts of my interviews were used as the texts in which discourses may be discerned. When interview material is used as a source of data for discourse analysis, there is no necessity to sample discourse from a large number of people (Breakwell, 2000).

The analysis stage of qualitative data was very time-consuming. But it was important for me to gather sufficient text to discern the variety of discursive forms that are



commonly used when speaking or writing about the research topic. Breakwell (2000) explains that this may be possible from an analysis of relatively few interview transcripts, especially where common discursive forms are under consideration.

There is no rigid set of formal procedures to guide discourse analysis (Breakwell, 2000). There are many levels of analysis within discourse analysis that could be attempted, but two that could fit are Deconstructionism and the usage of Interpretive Repertoires (Potter & Wetherall, 1987).

Deconstructionism implies examining the different levels of what is actually stated and any underlying assumptions and biases that need to be teased out from the responses recorded and transcribed; interpretive repertoires demonstrate the terms and styles of language that a person uses in the interview which would relate to whether the use of certain words and phrases convey responses that may hold two or more meanings and represent misunderstandings of the point or question. (Some people hear only what they want to hear or answer the questions or points in hand inconclusively). In view of the focus of my study resting within the CSR paradigm, I decided to adopt a Deconstructionist analytical format.

The first step of doing discourse analysis is to be the suspension of belief in what is normally taken for granted in language use (Potter & Wetherall, 1987). This involves seeing linguistic practices, not as simply reflecting underlying psychological and social realities, but as constructing and legitimating a version of events. The first stage of the analytic process begins with coding. This is the process of examining the text closely. During this examination instances of my research focus were identified.

I wanted to be as inclusive as possible so borderline instances of the research focus were noted, such as, type of exercise (TOE), benefits of exercise (BOE). Because the research focus had not been determined in advance, the coding process was more complex. Because of this it was necessary for me to read and reread the texts, looking for recurrent discursive patterns shared by the accounts under analysis.

The next stage of analysis involved reading the text mindful of what its functions might be. Any text has an action orientation and is designed to fulfil certain functions, so I had to ask 'what functions is this text fulfilling and how is it fulfilling them? The formulation of hypotheses about the purposes and consequences of language use is central to discourse analyses (Breakwell, 2000). But identifying the functions of language is often not a straightforward process because these functions may not be explicit.

As Parker and Burman (1993, p158) have noted, the analyst needs to be aware of broader contextual concerns such as cultural trends and political and social issues to which the text alludes. It was important that I knew what a text was referring to, in order for me to produce a form of analysis.

A person's account will vary according to its function. That is, it will vary according to the purpose of the talk (Potter & Wetherall, 2002, p33). For example, if we take two descriptions of a particular individual, we will expect them to vary in accordance with the feelings of the person doing the describing. As variability arises from the different functions that the discourse may be fulfilling, the nature of the variation can provide clues to what these functions are. Such analysis therefore involves the search

for both consistency (in the identification of discourses) and variability (in the analysis of discursive functions).

In order to be able to analysis my interview material it is necessary to adopt a coding procedure in order to reduce the interview transcripts into themes or categories. Tesch (1990) organising system has been chosen because it allows the data to be handled in manageable chunks and has an easy 'eight step' system to follow. These categories of information will have codes attached. These categories and codes form the basis for the emerging story to be told by the qualitative researcher. This process involves what has been called "Segmenting" the information (Tesch, 1990), developing "Coding Categories," (Bogden & Biklen, 1992), and "Generalizing Categories, Themes: or Patterns" (Marshall & Rossman, 1989).

In order to achieve this Tesch (1990) suggests reading through all of the transcriptions to get a sense of the whole, jotting down some ideas as they come to mind. Then to go through one of the documents asking yourself "what is it about" "what is its underlying meaning?" When this has been done for several transcripts, it is then an idea to make a list of all the topics. Similar topics get clustered together and these topics are formed into columns that may be arranged as major topics, unique topics, and left overs (Cresswell, 1994, p155).

The topics are now abbreviated as codes and these codes are written next to the appropriate segments of the text. The most descriptive wording is used for the topics and they are turned into categories. The list of categories needs to be reduced by grouping topics that relate to each other. A final decision must be made on the

abbreviation for each category and these codes are alphabetised. Finally, the data material belonging to each category is assembled in one place and a preliminary analysis is performed. It may be necessary for the existing data to be re-coded (Cresswell, 1994, p55). This whole performance becomes what is known as a systematic process of analysing textual data (Tesch, 1990).

### 3.9.2.2 Transition from Tesch (1990) to Layder's Adaptive Theory (1998)

I decided to use Tesch's (1990) organising system because I felt it was a very practical system that would give a structure to the way in which I organised my interview data once it had all been collected and transcribed. I found the eight steps of her organising system fairly easy and straightforward to follow, working through them one step at a time.

Reading through the interview transcripts as a whole first of all, really gave me an intimate relationship with my interviewee's responses to the questions I had asked them. Tesch's system organises data in a way that it becomes manageable, but she does not claim to be a Theory. Using Tesch's system helped me to understand Layders (1998) Adaptive Theory, which, would be used to analyse the interview and user participation workshop data.

Layder's Adaptive Theory was chosen because it fits in well with the way my data had been collected. It was used in order to overcome the problems of Grounded Theory (Glaser & Strauss, 1967). (For some more recent examples of Grounded Theory research, see Strauss & Corbin, 1997; Wilson & Hutchinson, 1996; Wright, 1997).

With Grounded Theory you leave behind the data that you have not used, this was too rigid and not as flexible as Layder's Adaptive Theory, which is a problem for the Critical Social Researcher. Critical Social Research demands reflexivity of the data, which means you always include all of the data whereas grounded theory does not. I already had some theoretical ideas and concepts prior to research, through previous knowledge and reading, whilst other theoretical ideas emerged from the data as it was analysed.

I initially found Layder's Adaptive Theory difficult to grasp and understand. Tesch helped me to understand Layder and lead into the way in which he analyses his research data. By the time I had worked through the first few steps of Tesch's organising system; I had already run parallel with Layder's Adaptive Theory.

By the time I had worked through the data interview transcripts, and marked each different area of the transcript as being an area of interest, I had already been led gently into Layder's approach. This step of marking data Layder calls Pre-coding/ Provisional-coding. The next step of Tesch's organising system, where I applied particular labels and names to 'classify' sections of my text, Layder calls Core and Satellite codes. This helps the researcher to become more familiar with what the findings include or contain.

This helps to answer questions such as 'what themes and patterns' give shape to this data. Examples of my Core and Satellite names are Attitudes, Participation in Exercise and Benefits. Layder says you need to be able to identify a segment of interview data as belonging to a certain category. This I have done.

Some of the Core and Satellite codes Layder was using emerged directly as a result of scrutiny of the interviews. Like Layder, I knew early on some of my code categories, and started to look for links between them and the interview data (this he calls Concept-Indicator Links). This helps the researcher with the help of theoretical memos, to build theory.

I already knew some of my core and satellite codes prior to transcribing mainly through prior reading and data collection through the questionnaire administration. A lot more emerged directly as a result of the interview transcripts.

Another parallel link between Tesch and Layder is the way that they both use memos. Tesch in step four talks of researcher's memos and Layder uses memos from which derive theoretical ideas.

Tesch (1990) allowed me to sort the raw data into manageable chunks and lead me gently into Layder's approach, which would then be used to analyse the data and develop theory. The findings of the interview data were then embedded within the five main themes derived from the questionnaire data.

### **3.9.3) Analysis of User Participation Workshop**

The data gathered from the user participant's workshop feedback was transcribed the same way as the data from the interview transcripts. It was then coded similarly to the interview data in order to find common themes and threads between the participants.

The findings were then again embedded into the five main themes derived from the questionnaire data.

The feedback from this workshop brought about the discussion of four social barriers; these were vehicle accessibility, wheelchair suitability, financial limitations and attitudes of the non-disabled general public and service providers. This backed up the data that had already been collected during the semi-structured interviews. But the focus was on two of these areas, which I had not previously considered in as much depth. The first related to the variety of financial support and constraints that individual wheelchair users have to contend with.

The second concerned the quality and variability of different wheelchair manufacturers, and how it was necessary for individual users to find vehicles that met their particular physical needs, i.e., comfort, size, ease of accessibility and adapting parts of the machine.

The user participation workshop was an excellent way of continuing the involvement of the respondents as well as collecting more data. It is part of my commitment to the respondents to make sure that they are involved at all stages of the process. This fell within the Critical Social Research paradigm. This workshop was a very valuable exercise to my research and added new emphasis to my findings.

### **3.9.4 Rationale for not running workshop again**

It would be very difficult, as witnessed from the first attempt, to arrange another meeting like this, with this particular group of respondents, when each have different barriers preventing them from attending. The main barriers were that they either did not own their own car or if they did, they were dependent upon somebody else (friend or family member), to drive for them. The problem was that these other people either had jobs to attend or children to fetch from school. This made it very difficult to bring respondents to such a workshop. Because of this in future research I will be exploring different ways of ensuring a higher response rate.

So if I were to run a user participation workshop again, I would address these barriers in two ways. The first way would be to arrange transport to pick up the respondents, take them to the workshop and take them home again afterwards. The second way to address these barriers may be to conduct a user participation workshop in a chat room on the Internet for those individuals who have access to a computer. That way they would not have to leave their homes.

The first strategy, arranging transport, is expensive. This would require a grant for funding. I would need a bus and special insurance on the vehicle in order to carry passengers. I would also need time available in order to make the arrangements. So although I feel this is a very good idea, I have learned from this experience that the next time I do something like this it would have to be built into the cost and the timetable.



The second way to address these barriers, designing an interactive user participation workshop in a chat room on the Internet, requires quite a lot of setting up. It requires the researcher to have some computer networking expertise. This would have to be built into the project as well, which may require extra funding and expertise designed into it.

### **3.10 Limitations of Survey Approach**

I tried to follow up organisations that had not responded but again did not get a positive response. Some of the organisations that could/would not help said it was due to them not being able to fulfil my sample category. The non-response rate of questionnaires sent to individuals who requested them was low. Although attempts were made to follow up non-respondents, time did not allow me to do this with everyone.

It is not easy to say how accurately a postal questionnaire is completed. Returns showed that questions were sometimes not completed. Questions not completed were on social class, age and facilities accessible. These only needed to be ticked. When they were not, it could be because respondents did not know which social class they belonged to, did not want to disclose this information or information about their age. Perhaps in some cases they did not understand the questions. For respondents who agreed to be interviewed, these questions could be clarified then, but for the respondents who wanted to remain anonymous and not be interviewed; the questions would remain blank when entered onto SPSS. This could affect the reliability of the

research. However, as 26 out of 37 people (80) % offered to be interviewed, this indicated a level of interest in the study.

Fraenkel and Wallen (2000) state, "when a conclusion is supported by data collected from a large number of different instruments, its validity is enhanced" (p.506). By using questionnaires to identify the main themes for the study, followed by face-to-face semi-structured interviews and a user participation workshop, it was hoped that more creditability would be given to the responses from the questionnaire, which could be supported and explained further at the interviews. This method of data collection also fits in well with the social model of disability, and personal beliefs as it offers participants the opportunity to reflect and comment on their reasons for choosing to exercise or not.

Given the above limitations it has been possible, however, to obtain 26/37 participants (80%) willing to be interviewed, 18 of which were actually interviewed, and thus providing a body of data for analysis into the question of 'why do some disabled people exercise, whilst others do not'? Whilst it may be argued such a survey response rate would have limited generalisability it will, nevertheless, provide some valuable insights into individual preference.

## Chapter 4

### Findings and Analysis

This chapter is a thematically driven discussion of the findings from the questionnaire, face-to-face semi-structured interviews and the user participation workshop, which will cover five themes. These themes are in the order as follows: Theme 1, 'Cost of Disability', Theme 2, 'Why do people exercise?', Theme 3, 'Access to Information', Theme 4, 'The Politics of Disability', and Theme 5, 'Inaccessible Society' (Barriers Preventing Access). Each of these themes will start with a quotation from an interviewee and this is followed by the findings of the research for each theme. A discussion on each theme will be integrated into the research findings.

## Theme 1

### Cost of Disability

“I receive a certain amount of financial support from the ‘Sailor’s Funds Society’, basically for the children’s clothes. Well it is not much but again the only financial support they could offer me was £10.00 per week because if you get any more than that then it is taken off from your benefits, so you don’t win. I don’t work.”

(Micky)

In this section of the chapter (‘Cost of Disability’), I first explore the **financial limitations** experienced by disabled people, Then, I examine the **cost of exercise and transport** and this is followed by an investigation into the **additional requirements** that disabled people need, e.g., assistance using leisure facilities, the cost of equipment to help with their mobility, and their living arrangements. This will be underpinned by literature on poverty, disability and employment, as discussed in the literature review. Finally, participants discuss another area of the cost of disability, which is not directly financial. This is **segregation**, how disabled people can often find themselves segregated from participating in leisure and exercise activities with non-disabled people.

#### **Financial Limitations**

Eleven of the 18 participants who were interviewed for this study said they received financial support of some kind toward their living expenses and mobility. Only one

participant was in full time employment, two had a spouse still working, one was in receipt of a pension, one was living off of compensation and two never mentioned finance or support at all.

Micky was a merchant seaman when he had his accident on board ship and became disabled. He has had his house modified so that he has full accessibility around his home. This was paid for by council grants.

In my study the most commonly received disability benefits were 'Disability Living Allowance' and 'Mobility Allowance'. Disabled people are able to receive these benefits at top level and still receive a company pension or employer's wage because these benefits are not means tested.

One participant said she was receiving a company pension after working for the one company for 37 years, and she also received:

"Disability Living Allowance and Mobility Allowance at top level. I get that and that is tax free."

(Val)

She told me that when she was working she was driving a three wheel 'invalid car', and when she gave that up she became entitled to Disability Living Allowance and Mobility Allowance. She went on to say:

“My car is a standard car with hand controls. That basically keeps it on the road, keeps it maintained, serviced and insured. So out of my other money I use money to put petrol into it. Because I get these I don't get any other financial support. I think my income will be higher than the basis for income support or housing benefit. We do get a reduction for council tax as a disabled person. If you have modifications done to your house then your rating band is reduced by one. My rating band is only 'A'. I also get my 25% single person's discount. I can also get VAT reduction on the tyres of my wheelchair.”

(Val)

One of the participants who received benefits was only working part-time when she was required to do so. She still received her benefits because they were not means tested:

“I am not fully self-sufficient. I only work when there are cases to work on, so it is not a full-time job. I get Disability Living Allowance and Mobility Allowance.”

(Jean)

Another participant told me that she teaches the piano part-time. She also gets her home help come in for one hour a day to do the meals:

“That is funded by Social Services. I have Independent Living Fund who give me so much a week, and with that I have people like Jenny and Anne come in

for a couple of hours a day, and that helps, and my Disability Living Allowance so that goes towards help as well. Yeah, I'm ok. I am quite comfortable. I am not well off; I do have to watch what I buy."

(Jenny)

Being able to receive Disability Living Allowance and Mobility Allowance whilst they were in receipt of an employment pension or working part-time gave them some freedom and helped to top up their income.

However, only one participant from my sample of 18 who were interviewed was in full-time employment. Finding suitable employment as a disabled person continues to be problematic. Labour Market Trends, (2002) show that there is an economic gap between disabled people and their non-disabled peers, which means that disabled people do not have the same disposable income to spend on sport and other leisure activities. In 1988 figures showed that only 31% of disabled people of working age were in employment, and those in employment earned on average only 80% of the salaries of non-disabled peers. In autumn 2001 some 3.4 million disabled people were in employment, an employment rate of 48%, compared with an employment rate of 81 per cent for those not disabled. Employment rates for disabled people have increased over a three-year period to autumn 2001 by 2.7 percentage points (Labour Market Trends, 2002).

Three quarters of disabled adults have to rely on state benefits as their main source of income (Hunt, 1993). In 1994 this reached nearly 80% of disabled people in the UK having to rely on state benefits for their basic income (Wood. R, 1994). The weekly

income of disabled people who are solely dependent on benefits is approximately £200.00 below the amount required for them to ensure an acceptable and equitable quality of life (Rowntree. 2004). Finally, the incomes of non-pensioner disabled families are only 72% of the national average for other families (HMSO, 1989, Haywood. L, 1995).

In his study 'Disablement in the Informational Age', (Sapey, 2000), mentions that the dominant messages to have appeared from the research on employment and disability in an industrial economy are that disabled people are far more likely to be unemployed than non-disabled people. If they are in employment they are likely to be in lower paid and less valued occupations (Drury, 1990; Barnes, 1991; LaPlant et al., 1997; McNeil, 1997; Meager et al., 1998; Stoddard et al., 1988).

It was interesting to note that Piggott (2005) carried out research on local government and disabled people's employment needs. She reported that all employment organisations she had contact with were working to an individual model of disability and the need to change their orientation to that of a 'social model' approach became the central recommendation of the first phase of her study. That was rejected by those funding the study because of their attachment to the 'individual model' of disability.

What was even more interesting was that at the end of the first year none of the organisations active in the area were able to identify a single disabled person who had returned to work as a result of their help. Piggott's research concluded that central government policies were doing little to change the perception of the employment needs of disabled people with local government.



One participant of this study told me in her interview that she teaches the piano part-time. She was disabled during a road traffic accident, and had trained as a counsellor after recovering from the accident. She was keen to work in order to help other people recover from their traumas and saw a job advertised that suited all her qualifications. She applied for the job and the employer was so thrilled when she told him about her qualifications, that he asked her along for an interview straight away. She told me:

“I asked him which floor of the building would the interview take place and he told me ‘the second’. I asked him if there was a lift to the second floor as I am a wheelchair user and the employer told me that there wasn’t a lift anywhere in the building. He never even tried to make the interview possible. I never made it to the interview and it has cast a shadow in my mind that my wheelchair is disabling me.”

(Jenny)

Jenny felt that the wheelchair was a barrier to her accessibility rather than a means to her freedom.

Massie (1994, p6) wrote: “...employers who refuse to recruit disabled people without considering the abilities and skills they could bring to the company are as much an unjust barrier as the flight of steps preventing a wheelchair user getting into a building”.

The New Deal for disabled people was accepted by local authorities as the mechanism for achieving employment targets for disabled people, and Job Centre Plus and their contracted job broker organisations are formally required to address the needs of disabled people who are employed (Piggott, 2005).

But as Oliver argues,

There is universal agreement that disabled people do not have the same access to jobs as the rest of the population. Estimates of the employment rates amongst disabled people suggest that this huge discrepancy cannot be accounted for solely on the grounds of impaired performance. However, government policies are, by and large, targeted at equipping impaired individuals for the unchanging world of work rather than changing the way work is carried out in order that more people might access it. Hence, much greater resources are currently spent on employment rehabilitation, training and so on (Individual model), rather than on removing the barriers to work or on attempting to prevent the labour market from operating in a discriminatory manner (Social model) (Oliver, 2004, p.21).

Piggott (2005) identified a number of key barriers to employment such as poor transport infrastructure, employer attitudes, benefit disincentives and inadequate support both to re-enter employment and to remain in work. These all clearly illustrate the extent to which such barriers were social rather than individual, yet organisations would argue that what they wanted in order to take action was a better understanding of how particular impairments might limit individuals from working.

This clearly reflects Oliver's (2004) point that while many organisations may appear to agree that the problem is social; in the field of employment the solutions tend to focus on the individual.

Roulstone (1998) maintains that exclusion from industrial society has influenced the way disabled people are viewed. Occupational segregation, workplaces designed for and conceptualised by non-disabled people, and negative attitudes, he feels, cause disabled people to be either excluded from work altogether or to be undervalued as workers. Oliver (2004) suggests that in dealing with discrimination against disabled people, they should be recognised as citizens with full economic, political and moral rights. But what tended to happen, in Piggott's experience, is that unemployed disabled people were unlikely to be seen as contributing members of society, nor as a powerful interest group, nor as active citizens. They were more likely to be seen as simply deserving of help (Piggott, 2005; Furedi, 2004; Oliver, 1983).

Yet many disabled people are not aware of the help and benefits that they are entitled to:

“A good friend of mine [Lyn] worked on an access panel. She told people about their entitlements etc. Well I had breast cancer four years ago and it made my arms weaker. I wanted a lightweight wheelchair. Well my friend said ‘what about the voucher system’? Well, I had never heard of the voucher system.”

(Val)

Val continued to tell the group at the user participation workshop that she went to her hospital and told them and they said they had never done a voucher system before, but they did it for her. When Gregg, Dora's Husband and carer asked what it was, Paula explained:

“Well you can get quite a lot of money off your wheelchair. I wanted a lightweight one and because I had got some compensation from my accident, I did not know if I could get some help, and I was told there was a voucher system and I could get help. What they do is they take the value of the normal chair off of the one you are buying that is cheaper.”

(Paula)

Val said she got half paid for her. But Paula continued to tell us that she in fact did not get any help with the payment of her chair that time because the vouchers were not available. When Gregg had to first buy a wheelchair for Dora, about 10 years ago, he went to a wheelchair centre and was told that they buy the standard chairs in for £150.00 each and sell them to the customer for £250.00 and higher. This vast mark up on the cost of wheelchairs was confirmed by Paula:

“My £4000.00 electric wheelchair they are getting for £350.00. I don't know how they are allowed to do it. I have still got my voucher and I shall hang on to it until my old chair wears out. I will still be able to get about £1300.00 off of it.”

(Paula)

As mentioned earlier, The Chronically Sick and Disabled Person's Act (1970) enabled local authorities to offer part practical, financial support for the purchase of special equipment and help with adapting home circumstances to meet various needs within the home. As discussed during the user participation workshop one of the benefits that are available to help disabled people is the 'voucher system'. Another benefit that was mentioned which two members of the group had not heard of was 'VAT exemption'.

One of the participants at the user participation workshop told me that disabled people could get VAT exemption when buying a new car providing it has not been pre-registered. A person can get VAT exemption providing it is not driven before the modifications are made to the car. This can be very difficult if the person buying the car can only drive it using hand controls, as is the case with Val. She had to have the car sent from the Honda showroom to a garage in Milton Keynes. Then to the hand control centre and they sent it back to her signed, sealed and delivered. Disabled people can also get VAT exemption off the cost of tyres for wheelchairs and a lot of equipment for the home. They do not, however, get VAT exemption off the cost of tyres for a motorcar.

With regards to the cost of exercise, one participant made the point that all disabled people pay the same price to get into a leisure centre regardless how much money they have coming in each week through either benefits or wages. He felt that it would be a good idea to:

“... get introduced some sort of sliding scale policy, so that people that are on the lowest form of income, which is income support, could possibly use the leisure facilities for nothing. When you think of group membership for leisure centres for say £42.00 per month, if a disabled person is on income support that is a lot of money. But a doctor’s referral system does not apply to disabled people because you have a permanent disability, so you have not got a chance.”

(Micky)

This participant felt that this was unfair. He had discussed the idea about a ‘sliding scale policy’ with his local council. He went on to mention that people with mental health problems such as depression could actually be referred by their doctor in order to be able to use the leisure centre, which is great. He said:

“Before, people with mental health problems were not using the leisure centre at all. Since they had that referral system there has been about 100% take up of the facility, which is absolutely wonderful.”

(Micky)

### **Additional Requirements**

“I would like an electric bike chair. But they are so expensive. I have not seen one for years, but when you do they are outrageous prices and I could not afford anything like that.”

(Pete)

The cost of specialist equipment for the home, wheelchairs and motor vehicles is extremely expensive. Many people on benefits cannot afford the prices charged for things that would help them with their everyday mobility, so they have to go without, as 'Pete' just explained. An electric bike chair would give him the freedom to be able to go out on his own when he wanted to, but he was unable to afford the prices that were being asked.

It became clear from discussions with participants during the interviews and in the user participation workshop that any kind of equipment to help aid with mobility for disabled people is very expensive. Disabled people have the same human and civil rights as non-disabled people but they are different from non-disabled people in that they have additional requirements, such as mobility needs, communication assistance, personal assistance and so on. Additional requirements are usually called 'needs' in the context of social care. They are related to both impairment and disabling barriers. If needs are not met then this can result in a denial of human and civil rights (Morris, 2004).

It has been strongly asserted by Massie (1994) that disabled people experience more difficult and expensive lives than non-disabled people. Reith (2001) concurs with this in her article 'Disabled and excluded', when she writes, "Disabled people face the combined effects of lower than average incomes and above average living costs". Morris (2004) confirms this when she states in her research that disabled people have additional requirements over those of non-disabled people.

Many of the areas in which disabled people have requirements over and above those of non-disabled people, require extra income in order to fund them. Reith (2001) goes on to say, "Extra expenditure can be considerable – special equipment and adaptation, help in the home, taxis, special diets, extra heating and hot water, prescriptions", - the list goes on. One area in particular, which was discussed in the user participation workshop, was that of technical aids – equipment, such as mobility needs (wheelchairs). There are many types and models of wheelchairs being loaned and sold across the country.

Electric wheelchairs can be very expensive. One participant paid £12,000 for her latest electric wheelchair, which was supposed to be able to help her stand in the standing frame. A new battery for the chair cost her £400.00. She was having problems with the chair falling over or the wheels falling off. She went on to tell me of her previous chair:

"I had another one before this one. I had a £8,000 one. I paid a deposit and the wheel fell off that after only 3 days of having it. I could tell you so many stories."

(Paula)

When repairs need to be done to a wheelchair there is often a 2-3 day wait before somebody can come out and repair it for you. Participants in this study showed concern that electrically-driven wheelchairs are very costly, and the quality and reliability of those loaned and allocated by local hospital trusts varies considerably and will depend on the severity of the immobility. The group explained how the most



up to date lightweight machines often provided for those who drive adapted cars, require a recipient to be assessed and declared fully immobile. To acquire better machines wheelchair users must often raise the necessary funds themselves, but as mentioned earlier finding suitable, regular employment for disabled people continues to be problematic. This means that disabled people do not have the same disposable income as non-disabled people to spend on resources and facilities. This leads to many disabled people becoming dependent upon professionals for help (Oliver, 1983), with many disabled people becoming 'regulated bodies' within a society, which is supposed to be caring.

The cost of disability does not stop at low paid jobs, cost of entrance fees into leisure centres and the price of wheelchairs. The cost of purchasing a specially adapted car and rear access vehicle can also be very expensive:

"Dora never could get into our standard car."

(Gregg)

To be eligible for a car from Motability, you must be receiving the higher rate mobility component of Disability Living Allowance (DLA), or War Pensioners Mobility Supplement (WPMS) for 2 years or more from the date the car is delivered. Contract Hire facilities are provided by Motorbility Finance Ltd (MFL) and MFL can only supply the models approved by the manufacturers.

Rental charges on most cars require the total amount of Government allowance to be paid over to MFL. The rental covers all routine maintenance and servicing costs. A

maximum of four tyres will be replaced free of charge, subject to fair wear and tear.

The customer will always be responsible for replacement/repair costs of damaged and punctured tyres.

Val went on to explain the complexity of mileage allowance and the cost of upgrading equipment in a car with its consequences when the car needed replacing:

“I was doing too much mileage; it’s gone up to 45,000 now. You were only allowed to do so many miles per year otherwise you had to pay a penalty. It is steep, so much per mile. You are not supposed to scratch your car. You have to return the vehicle in the manner in which it came to you.”

(Val)

Charges are made to mileage in excess of 12,000 miles per year. These charges vary from 5p per mile plus V.A.T for 12,000 – 15,000 miles to 10p per mile plus V.A.T for over 20,000 miles. For a person leasing a Motability vehicle those charges have changed from 2005. A user is allowed to travel 45,000 miles within their three-year contract. Each mile they travel over that 45,000 is charged at 5p per mile extra.

This rule can be very restricting if people have to travel frequently to hospital appointments, employment or leisure facilities. Having adjustments made to the vehicle in order to gain access can be very expensive as this participant explained:

“Had I paid Motability and had a new car, I would have to pay for all the adaptations and I wanted to have a button that you could press so the door

would move backwards and forwards, so I could get into the car easier. That was going to cost about £700.00, and I was paying for all the adaptation as well on top of that.”

(Paula)

As Gregg, the carer pointed out:

“If you get a standard car from Motability that does not need adaptations, then you are ok, otherwise it gets expensive.”

If adaptations are required, they will be at an additional cost as will their removal at the end of the hire contract. Adaptations for disabled people should be provided V.A.T free. Rental covers AA membership, including, home Start, Relay and Relay Plus for all cars.

Paula discussed the foot pedal adjustments she has on her car:

“It is a plate that fits in front of the pedal. It screws on, and if my carer wants to drive the car she just takes it off.”

Val explained how her foot pedals are on a spring, so you just push them down when you need somebody else to drive the car.

The cost of adjustments and maintaining the motor vehicle can be very high indeed as

Val continued to tell the group:

“My adjustments cost me £800.00 extra but this time I had a brand new car and I did get V.A.T exemption on the car which I had never done before. If the car is pre-registered you cannot claim for exemption. But this car was brand new.”

Paula found maintaining her vehicle in good condition:

“Exacting and sometimes expensive. They came out and valued the car. Because I have kept it in such good condition, I had to pay more for it because the car was worth more. You cannot win can you?”

Mobility allowance does at least pay for the running of a car from Motorbility, but often, if it is a rear access vehicle then a large deposit has to be paid in advance:

“Rental charges on most cars require the total amount of Government allowance to be paid over to Motability Finance Ltd (MFL), and MFL can only supply the models approved by the manufacturers.”

(Val)

As explained by Paula:

“This can make it very difficult to find a vehicle, which is accessible for a person using a wheelchair. The seat has to be the correct height and the door

the correct width in order for a person to be able to transfer from their wheelchair to the car seat.”

When talking to participants about their motor vehicles this participant told me how she had had a standard car on lease for three years. It was renewed for a further three years, but during that time she was:

“unable to gain access into the vehicle.”

(Dora)

It was a requirement that she had to carry out her three-year lease agreement on her standard car before she could apply for a converted vehicle with rear access, which could take her in her wheelchair. Unlike the standard vehicle, which had a nil deposit, these vehicles required a:

“high advance payment of between £3000 and £10,000 deposit. I had to apply for grant assistance towards this rear access vehicle and I was told that there was an 18 month waiting list.”

(Dora)

She actually waited 12 months before funding was granted, and she got her rear access vehicle on a 5-year lease. When I asked her how she felt the first time she was able to go out in it she said:

“It was lovely. I could do my shopping and that to me was marvellous. I haven't got to do shopping lists for Gregg to do. I can go out and have a look now.”

(Dora)

Whether it is the cost of a bike chair, wheelchair, motorcar, or equipment to help with their mobility in the home, the cost is extremely high. As Reith (2001) mentioned earlier in this chapter, 'extra expenditure can be considerable'. She reaffirms that disabled people are subject to discrimination in both education and employment opportunities, and these factors combine to limit chances far beyond the restriction of disability itself. It is these factors that are the disabling factors, not the impairment (Oliver, 1996).

As we have seen with the situation of the participant earlier, and her experience with electric wheelchairs, high price does not guarantee high quality. When problems do occur as they did with Paula, it can be very costly and alarming. So can finding a deposit for accessible vehicles when disabled people do not have available funds and have to rely on benefits.

Eleven participants in this study live either with their spouse, parents or friends, whilst seven lived alone. From the eleven who live with somebody else, three did not participate in exercise activity. Whilst of the seven that lived alone, only one was not involved in exercise.

When participants were asked if they had a preference as to whether they lived alone or with other people most of the participants who lived alone said they preferred to be alone. They enjoyed the independence of living alone rather than having to go into any form of institution.

“I prefer to be on my own in my own house rather than in any form of institution.”

(Pete)

Another one replied:

“I live alone but I have a lot of people coming and going so I am hardly ever alone if you know what I mean.”

(Jenny)

One participant said he preferred it on his own. Since he has been divorced he has lived on his own. Some participants had been so used to living on their own that they really did not seem worried about it. This participant who had MS and was also blind told me:

“I don't mind, I am used to being on my own. I have lived in [The Ferns] on my own. I lived in London on my own. I have occasionally fallen and a carer comes and gets me up.”

(Pete)

If disabled people can choose when they want help and what type of help they need, that can help them to keep their independence. Having help at the press of a button is a lifeline for some people. Sometimes it can be quite serious, as this next participant who lived alone pointed out. She told me how she was in her new expensive wheelchair and it toppled over whilst she was cooking the dinner. She was holding a frying pan at the time:

“My only way to get help was to press the community alarm button. I could not get to the phone. The lifeline people could not hear me, so they then phoned to get an ambulance. If that frying pan had caught fire nobody would have got into me.”

(Paula)

According to Morris (2004) most definitions of independent living contain three elements. First, an assertion that disabled people should have the same opportunities for choice and control as non-disabled people; secondly, a challenge to the unusual interpretation of 'independent'; and finally, the aspiration that any assistance required should be controlled by disabled people themselves.

I asked participants if they needed any help in their home. Most of those who live with somebody said 'no', but those living alone needed help with housework, washing, ironing, shopping and cooking:



“I have carers come in the morning and night. They do anything that needs doing.”

(Jenny)

As participants explained, there was a lack of consistency between departments of social services when it came to the type of care package received. Some social services would allow their carers to do certain things for their clients like housework, and others strictly forbade it, giving only personal care, i.e., getting them in and out of bed, bathing and dressing them. One participant said how his care agency used to do his housework for him but now he is receiving carers provided by Social Services, they should not be doing housework. Their carers (people employed by Social Services Department to attend to the patient's personal care) are not allowed to do the housework. The job of the Social Services carer is to bath, wash and dress the patient and to get them in or out of bed and assist them to the toilet. Sometimes they are allowed to prepare food for the patients and help to feed them. This makes it difficult for some disabled people who are on benefits as they may not be able to pay for private help.

Yet this participant has a carer come in each day to get his meals ready and also:

“She does my ironing once a week on a Friday and she does my shopping on a Thursday. They put on the care sheets that they do meals, household chores, which is doing your washing and stuff, cleaning and shopping. Obviously Social Services have to pay for it.”

(Pete)

Through the Chronically Sick and Disabled Persons Act (1970), the government gave local backing to disabled people in their own homes to enable them to keep a degree of independence. This was sometimes difficult to maintain when service providers appear to change the rules between departments. The DDA (1995) attempted to deal with a wide range of issues concerning the way disabled people were treated and their statutory entitlements to many services and facilities. There needs to be a clear understanding of what a care package entails, and it should be fair to everybody who needs it, in order for care in the community to work and be fair to all its citizens. In order to keep their degree of independence in their home, the CSDPA (1970) enabled local authorities to offer practical, financial support for the purchase of special equipment, and help with adapting home circumstances to meet various needs within the home (e.g., telephones etc). One participant had received grants to have his house fully adapted for his needs when he became a wheelchair user. The Act was viewed as demonstrating a more aware attitude to the needs of disabled people and a positive response to meeting some of their needs within a tight, controlled financial set of constraints under the monitorial control of the local authority.

But as Simon Brisenden, a pioneer of independent living wrote, 'Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it' (Brisenden, 1989, p9).

Independent living itself is a means to an end. It is a way of assessing disabled people's human and civil rights, but they are different from non-disabled people in that they have additional requirements, such as mobility needs, communication

assistance, and personal assistance and so on. A legislative framework that confers human and civil rights will not be effective for disabled people unless they also have entitlements to these additional requirements (Morris, 2004). Morris (2004), goes on to say that additional requirements are usually called needs in the context of social care. They are related to both impairment and disabling barriers. If the needs are not met then this can result in a denial of human and civil rights. She says that independent living is also associated with the words 'choice' and 'control', and concerns both the environment in which someone lives and the assistance needed in order to go about daily life. As seen earlier in the literature review, the Disability Movement identified first seven (Davis, 1990) and then twelve 'basic needs', which are central to achieving independent living. These range from having full access to our environment, a fully accessible transport system, equipment, accessible housing, personal assistance, equal opportunities for employment and appropriate and accessible information. (Southampton Centre for Independent Living, not dated).

These are some of the areas in which disabled people have requirements, over and above those of non-disabled people, which must be met if they are to experience equal access to human and civil rights. However, the philosophy of independent living also emphasises that the way in which these additional requirements are met is crucial to whether this level playing field is achieved: the disabled person must have choice and control over how needs are met (Morris, 2004), and this should include, where possible, the choice of carer:

“I was fortunate in finding a suitable person.”

(Paula)

During the user participation workshop the issue of the assignment of carers, both public and private was considered. The group agreed that the organising of carers was fraught with problems. Gregg [Dora's carer] told the group how Dora had experienced some disappointing incidents with carers regarding quality, timing and scheduling. He said:

“There have been some occasions when the carer has not turned up to wash Dora and get her into bed. This meant many hours of waiting and often resulted in me having to cope on my own, otherwise she would have been left for many hours in the chair.”

He was told the next day that the care manager had not been notified of the situation and that was why a replacement carer from Social Services had not attended. The physical lifting of the client can be very difficult at times, and should not be attempted by one person alone. Paula had advertised for private care and told the group that she was very fortunate in finding the right person.

The group also agreed that costs, funding and allowances required advanced skills in negotiating and understanding, and the quality varied widely. Where wheelchair users like Paula employed carers privately there was a need for legal cover and certain employee rights. Paula goes on to explain this:

“Yes, I pay insurance for public liability.”

When somebody lives in rented accommodation, as in Dora's case they are only insured for contents of their home. This concerned Gregg, Dora's carer, who was unclear who was responsible if any accidents happened whilst the carers were in her home. He explained how he had contacted the care agency and arranged a meeting with the social worker and a middle manager from the care agency to find out where he stood. He was told:

“The agency told me that their insurance covers for liability of their staff when they are in a rented accommodation of a client.”

The group at the user participation workshop also discussed the issue of how much the carer should actually do for their client? Sheila (another carer) told the group how important it is for

“The carer to acknowledge the independence of their client when they were quite capable of carrying out many functions and activities for themselves.”

(Sheila)

As Oliver (1983) pointed out, when a professional becomes involved with a disabled person it is very easy for that person to become dependent upon the health care professional or carer. Sheila went on to explain that she is allocated 50 hours carer time per week, which has to be well managed and organised to suit the client's needs. Her main activities were to assist with bathing, dressing, helping with the transference from wheelchair to car, or driving Paula around if she felt unable to drive herself.

But independent is also, as Adolf Ratzka (not dated) states, 'a philosophy and a movement of people who work for self-determination, equal opportunities and self-respect. Independent living is essentially a challenge to the place of disabled people in society. Often an enabling society (Oliver, 1996) free of environmental barriers can become a society in which disabled people become 'regulated bodies' (Goto, 2004), forced into a situation in which they become dependent upon professional help in order for them to just merely cope (Furedi, 2004; Oliver, 1983).

### **Segregation**

"I don't want to be segregated away from non-disabled people; I want to swim in with them."

(Annie)

Participants who exercised for the purpose of leisure did not mind whether they exercised alone or with other people, although some did not like to be segregated from non-disabled people. At the level of national mainstream and disability sports organisations there is a discernible shift towards a more inclusive range of activities and away from exclusive and segregated provision (Kew, 2000).

The issue of inclusion versus exclusion can be argued for all areas of life, from as early as education at school through to employment. Barnes et al (1999), discuss the issue of the calls for inclusive (rather than integrated) education. The Education Act (1981) stipulates that many disabled young people should be integrated into mainstream schools. The subsequent development of a National Curriculum included a commitment that children with 'special educational needs' should have access to the

same curriculum as other children and that curriculum delivery should change in order for this to happen.

Arguably, according to Kew (2000) the successful integration of disabled children into most aspects of the curriculum has been achieved, but physical education and sport impose specific demands. One of the benefits that inclusive education could bring is fostering friendships between disabled and non-disabled children and thus 'removing ignorance and stereotypes'.

I feel that from the literature I have read and what the participants of this study have told me, some disabled people are often made to feel segregated from mainstream society. They are not always accommodated for within established leisure clubs and organisations and when they are, participants have told me that they often have special days for different groups, rather than integration for all.

Imrie (2000) argues that geographical and/or spatial terms of reference are important in understanding disabled peoples lives. Disabled peoples identities, mobility and other social interactions, can be understood in part through the particular spatiality's of disability (Imrie, 2000; Butler & Parr, 1999; Gleeson, 1999). For disabled people, institutionalisation is spatialised in other ways too, from special schools to day care centres and dial-a-ride, all of which serve to demarcate and segregate disabled people into distinctive and discreet places. Such segregated spaces are, not surprisingly, infused with values, which identify disabled people as different, and usually inferior to the rest of society.

But it is interesting to note that the analysis of the interview data also revealed that for some participants, who have physiotherapy, having a safe environment away from the general public was very important. Hospitals have supervised sessions and knowledgeable staff, which makes participants, feel safe and secure. It can also be a very solitary means of exercise but at the same time beneficial for motivation, as one participant pointed out to me during an interview.



## Theme 2

### Why do People Exercise?

“Everything, in every way. Absolutely yes. It’s an absolute must.”

(Jenny)

In this section of the chapter, I investigate the **physical, psychological and social benefits** that can be gained from regular exercise involvement, and I examine the literature that supports these benefits. I then explore ‘**Attitudes toward Exercise**’ and participants ‘**Intentions to Exercise**’. Intentions to exercise will take into account any health problems, which they may encounter and the problems faced with choice of wheelchair due to these problems. Participants discuss the **type of exercise** that they participate in, **self-determination** and **past exercise involvement**. Finally, I will discuss the **social support** received by participants and the previous research that has been conducted on the importance of social support for disabled people.

#### **Benefits of Exercise**

From the 18 participants who were interviewed 13 participated in some form of exercise and five did not. It was of significance to find that of the five who do not participate in exercise, three felt that there were definite benefits to be gained from participation. These three had only stopped exercising due to the pain that they were in. Whilst the other two said they felt that it may be beneficial to other people in some way depending upon the individual.

Previous research highlighted the many benefits that can be accrued from disabled (Monnazzi, 1982), and non-disabled (Dishman, 1994) people participating in exercise activity. Schaeffer & Proffer, (1989); Petruzello, (1991); Mullineaux, (2001); Mooney (1998) and Wilson (1992) each claim that exercise involvement can have a variety of physiological, psychological and social benefits. Participants in this study felt that it was important to exercise to prevent further health problems arising. They exercised to improve their physical well being (Wilson, 1992). This enabled them to stay fit and propel themselves in their manual wheelchairs:

“Keeps your muscles flexed and healthy and circulation of blood.

Psychologically, it makes you feel more confident in yourself.”

(Lewis)

“To keep me going, because when I get stiff I can’t move.”

(Sheena)

Another participant felt that it was important to exercise in order to keep herself going and to stop getting too much muscle wastage. Lack of exercise can also cause stiffness of the muscles and can cause painful spasms:

“Basically, I get spasms because I don’t do enough exercise. The more I go in and out of the car, the more I go out wheeling, the easier it would be and better for me. Yes, mentally it is better too.”

(Paula)

Exercise is also known to improve blood circulation, and can strengthen the heart, lungs and muscles (Schaeffer & proffer, 1989). This could be physically beneficial to those wheelchair users who lead a sedentary lifestyle, because participation in exercise has been found to increase mobility for different groups of disabled people. For disabled people, regular exercise can improve functional status and independence in activities of daily living by increasing muscular strength and endurance, flexibility, balance and cardiovascular and respiratory functioning (Rimmer, 1999). Exercise can also reduce the onset of acquired conditions for people ageing with a disability (Schaeffer & Proffer, 1989). This can be seen as a physical benefit to be gained from exercising if people can exercise regularly enough.

Whilst some participants exercise to prevent pain, others were prevented from participating in exercise due to the pain they suffered. The level of physical pain that an individual suffers due to the impairment or a health problem can also determine whether they exercise or not. Although involvement in exercise and sport can have numerous benefits they also provide gratuitously difficult challenges (Kew, 2000). For disabled people these challenges are even greater because of functional impairment:

“I am prevented from exercising at the moment due to shoulder cuff damage.

I cannot push as hard or as far as I used to.”

(Joe)

Constant propelling of a manual wheelchair has caused this participant ‘shoulder cuff damage’ (Rotary Cuff). Koontz (2002), states that wheelchair propulsion has been

implicated as a causative factor in developing shoulder pain and injury. An estimated 30-75 per cent of normal wheelchair users will develop shoulder pain during their lifetime. As the study by Koontz was conducted after the participants of this study were interviewed, there was not the opportunity to inform them that the constant vigorous propelling of a manual wheelchair could cause wear and tear and damage to the shoulders, and that perhaps a gentler approach may be more beneficial to health. Schaeffer & Proffer (1989) found that although participants in wheelchair athletic competitions increased their mobility and improved self-image, there was a negative side to it as well. This will be discussed in the issue of 'health problems' later in this section.

Whilst others felt that it also made them feel good physically and psychologically:

"I don't know about socially, because I don't exercise in a group, but it keeps you going and stops you getting too much muscle wastage. I do so much intensive voluntary work, which involves me with housing & local government. You have to have a break from all those sorts of things. So you just go and empty your mind. It just helps, empties your mind completely and you can enjoy what is there to be seen. It is quite relaxing really."

(Annie)

Annie went fishing to relax and found that it kept her arm muscles strong, whilst some exercised to improve their perception of their body image (Bamburg, 2006) and to increase their self-confidence (Goldberg & Shepherd, 1982; Schaffer & Proffer, 1989). Bandura (1977), found it to have a positive effect upon an individual's self-

efficacy, whilst Mooney (1998) in her study of paraplegic willpower found that exercise participation could also help to create a positive attitude. Whilst others enjoyed having other people around them when they exercised, some participants did a lot of voluntary work, which can be rather sedentary, so they felt that exercise was important to give themselves a break and empty their minds and just relax.

Many enjoyed the social interaction, which was gained from exercise participation.

Martin & Mushett, (1996) propose that social interaction is very important to disabled people because many are often leading a sedentary lifestyle:

“Physically definitely, socially probably, particularly if you are exercising with other people and psychologically, that’s bound to knock on isn’t it?”

(Cole)

“Physically, yes I do. Socially, yes I do yes; I have other people with me when I have physiotherapy. Psychologically yes, stronger up here, stronger in my head.”

(Lena)

“I think it is necessary to exercise to keep myself going. Socially, yes, in a way, because we all go to the centre. Psychologically it is difficult to say. I feel I get some value from the fact that I am exercising. If you don’t use it, you lose it.”

(Pete)

“Psychologically, I think and physically. It’s socially in terms of Jane has become a friend now as well as my physiotherapist.”

(Micky)

Some disabled people benefit from the increase in greater social interaction and communication with other individuals because of the chance to build friendships with other people (Monnazzi, 1982; Goldberg & Shepherd, 1982). As mentioned earlier one participant in my study said that his physiotherapist had become his friend as well as a professional, so he benefits from the additional friendship as well as the physiotherapy.

According to Bouchard et al (1993) regular exercise is a cost effective alternative to the high cost of health care associated with treating ailments related to physical inactivity. One participant (who was on the committee at his local leisure centre) explained to me during his interview, that when swimming was made available to mentally challenged young people, it gave them an interest and stimulated them mentally and physically. This changed their behaviour and they became more relaxed and less anxious. He observed from this that the chance to exercise did help them with their behaviour problems. He told me that it cost the government less money to set up the opportunity for these people to swim, than it would have done to correct the problems caused by their challenging behaviour. He went on to say however, that the service was withdrawn from the leisure centre and he saw the behaviour problems of these young people return.

In his research, Dishman (1994) found that although exercise is said to be good for us (disabled and non-disabled alike); very few people seem to exercise to sufficient levels to reap any benefits and sustain a level of exercise involvement. Yet in this study, from the data collected from the questionnaires, interviews and workshop, just over three quarters of my sample participate in exercise and all of them, regardless of their age and whether they exercise or not, felt that exercise is beneficial in some way.

### **Attitudes towards Exercise**

“I exercise because the condition I have can cause osteoporosis and muscle wasting, so it is really important to exercise.”

(Carrie)

The reasons for participating in exercise activities are diverse. For example, these summaries came from participants' accounts:

“I do my own exercises at home with weights to strengthen my shoulders and triceps. You see it is very important, the arm strength, because I could have easily had an electric wheelchair but I didn't want one because I wanted to keep my arms strong and fit. I love swimming and I enjoy sport and I just wanted to keep really fit.”

(Jenny)

“I do it because I think it is necessary to exercise to keep myself going.”

(Pete)

"I get spasms because I don't do enough exercise. If I don't exercise I will start to seize up."

(Paula)

It is apparent from these quotations that there are many reasons for exercising. It is interesting to note that the reasons here are because of the benefits, which the individual gets from participation.

What follows is an account of the reasons why five of the participants in this study did not participate in exercise activities, two of which state they cannot exercise due to the pain they suffer:

"I do not participate in any form of exercise because I cannot stand up because I have no use in my legs."

(Dora)

Whilst another felt that she had a full day already:

"I don't have to exercise, I work hard enough."

(Jean)

Three of the participants were very keen exercisers in the past but now cannot due to the pain they suffer. Two of these participants explain why:



“The reason I am not exercising at the moment is because of damage to my shoulder cuffs [Rotary Cuff injury] (Koontz, 2002). This prevents me from exercising because of the pain.”

(Joe)

“I am physically unable to do so. I have not got sufficient strength, and suffering from arthritis as well as spinal trouble (broken back); of course it is just too painful.”

(Cole)

Although empirical evidence (Monnazzi, 1982) suggests that the benefits of exercise are just as pronounced for disabled people as they are for non-disabled, it is interesting that many individuals in this study exercise to prevent pain, whilst others cannot exercise due to the pain, which they suffer.

Participants were asked how they felt about engaging in sport and exercise activities. The group said they felt that this was valuable and beneficial in many ways, but sometimes difficulties could arise, as this one participant explained during the ‘user participation workshop’. She told the group of her experience when she went sailing:

“I was sailing on my own and it all went wrong. I had to sit on the floor on the cushion from my chair and I could not see very much because I am so low in the boat. But I was steering, I enjoyed that, being able to steer.”

(Paula)

Paula went on to say that she felt that a lot of people, the young ones especially, are actually happier in a wheelchair than they would have been normally, because it has allowed them to do what they wanted to do. The group went on to discuss how during the paralympics (2004), one young man they knew who was training at the time said he would never have been given this marvellous opportunity if he had not become a wheelchair user. [By this he explained that sport had never really interested him that much until he became disabled, and then he became determined that he wanted to train for the paralympics, and he did].

Also during the 'user participation workshop', Val told us how she and her husband formed their own sports club when she was in her late thirties. She said the upshot of that was:

"You can't do it [form a sports club] and not join in."

From that time she became a regular swimmer and later was participating in Archery at the Paralympic games. Her husband encouraged her to learn to drive and later on in life, when he had his stroke, she was glad she had made the effort. She was then able to drive him around and had her independence to live a full life.

The user participation workshop group briefly discussed the different leisure opportunities that were available for people with impairments, such as swimming, archery and sailing. They said that these vary from region to region. Although 'action committees' were set up in various areas in order to help get people involved, the

group felt that they had little or no influence. One participant let the group know how she felt when she said they could be:

“just ‘talking shops’ with no resources available. People in wheelchairs don’t seem to want to join in, do they?”

(Paula)

Participants who did participate in exercise did so quite frequently except for Paula who, after arriving at her leisure centre on one occasion, found out that the electric hoist had not been charged up the night before so she was unable to use the swimming pool. This incident influenced her decision not to go swimming as frequently in the future as she had in the past.

Many interesting comments came out in the responses to a question asking participants who did participate in exercise, whether they had a preference to exercising alone or with other people. Those who exercised for leisure liked both. They enjoyed exercising with other people in order to be able to socialise, or were quite happy to be alone or accompanied:

“No I like both. I mean I am a very disciplined person. I discipline myself because I want the best out of life and I want to lead a full life so I discipline myself to do my own exercises, but I also enjoy swimming with other people as well.”

(Jenny)

“It makes the evening, because when you have been in the water you go upstairs to the cafeteria when it is open, and you have some refreshments and you have a chat up there and something to eat.”

(Joy)

“If I am doing archery I am always with somebody, but if I am doing basic exercise then I do it here on my own.”

(Val)

“It didn’t make any difference. When I went swimming I used to do 20 lengths and I used to have somebody swim at the side or walk at the side of me and count the lengths. But I am not talking to anyone really apart from the person who is going up and down the pool with me; they used to hold a conversation.”

(Paula)

“Sometimes my friend has gone fishing with me, but we have usually ended up in different parts. It’s relaxing.”

(Annie)

The participants in this study did not seem to have a preference whether they exercised alone or with other people. It would just depend upon whether they were participating in a solitary sport or team activity. But when interviewing the five participants who have physiotherapy, having a safe environment was very important for one participant:

“With the physiotherapy and hydrotherapy, it’s the hospital gym or the hospital hydrotherapy pool, there are other people there and there are always supervised sessions there anyway. Everybody has a different reason for being there, so you tend to have your own programme that you can follow, and the important thing is that it is a safe environment.”

(Carrie)

Two participants reported it to be a very solitary means of exercise:

“I do my neck exercises at home alone everyday.”

(Mike)

“I think it is better for me to be alone. Because you are easily distracted if you do it with other people and you don’t work so hard.”

(Pete)

Physiotherapy for the other two participants meant a combined effort of movement because they both told me that they have help from the physiotherapist. They cannot move their own legs so the physiotherapist has to move their legs for them. All five participants who have physiotherapy were keen to get the best out of their sessions in order to keep their bodies mobile and fit.

When I asked participants how long they had been involved in exercise, whether currently exercising or not, all participants answered the question. As one would

expect the responses varied. One participant said she had never been involved in exercise, two participants were involved for a long time in the past but not any more, five had been involved since childhood, one said she had been involved ever since her disability had worsened, and one since before she was disabled although not as much, two said they had always exercised, one of these no longer participates in exercise due to a broken neck. One had been having physiotherapy for 20 years, another for 9 years. One had been involved most of her life, another for 12 years, one just said 'yes' and one never directly answered the question.

Two participants exercise more now than they did before they became disabled. The reason for this is because it is so important in order to prevent the condition getting any worse. They told me 'now there is a purpose':

"I do swim more lengths now being disabled than I did before. There is a purpose now because if I do not keep fit then I am a cabbage."

(Paula)

"I have actually done more exercise since I have become more seriously disabled than I ever did when I was able bodied. This is partly because I have had to for my condition."

(Carrie)

Five participants chose not to exercise or were prevented from exercising due to the severity of the disability. Five participants had regular physiotherapy. The frequency of the physiotherapy varied:

“More or less for 20 years, since I have been using the wheelchair.”

(Mike)

Another participant said she had been having physiotherapy since a road traffic accident 9 years ago. One goes to the MS centre every Wednesday and another had physiotherapy at a centre four days a week and one has it when she feel she needs it.

### **Intentions to Exercise**

“After three days of using an electric wheelchair, I find I am very sluggish when I go back to the manual wheelchair, my strength has gone. If I am in the manual wheelchair every day then I am much better, but then I have got my independence to go out on my own.”

(Paula)

Health problems, some associated with age, can have a possible effect upon disabled people. This study identified how exercise intention can be affected by these health problems. For some people problems such as cancer, weak muscles and shoulder damage (Koontz, 2002) can be very painful and can affect their capability of manoeuvring a manual wheelchair. This can affect a person's level of independence (Morris, 2004), changing their lifestyle in many ways. Wheelchair users are dependent upon their arms and it is vital that they are able to keep these muscles strong. During the interviews and 'user participation workshop' participants gave their accounts of the problems they faced with regards to health problems. The benefits of having a knowledgeable doctor, a good physiotherapist and 'pain clinics'

were also examined. Lastly, some members of the group discussed the pain and discomfort brought on by spasms.

Paula explained how difficult it is to return to a manual control wheelchair after using an electric wheelchair. She told the group that it is very hard to control 'bulky unwieldy' chairs and it is often difficult to add fixtures which are needed for night mobility.

Age came across as being an important factor when deciding which vehicle or wheelchair to choose as the wheelchair user may develop a deterioration of strength, fitness and overall well being later in life.

Paula told the group that she was:

“..doing more at the beginning. When individuals are 19 and they have a Road Traffic Accident, they always get on very well. All the young people I know in their teens and twenties have coped with it very well strength wise. I was 53 when it happened to me and now I am 62 and age is definitely coming into it.”

Another participant told me that she could have lost the muscle strength had the hospital staff failed to listen to what she was saying:

“Two and a half years ago, I was diagnosed with breast cancer and I was more worried at not being able to push myself.. It was not the pain so much as the



fact that when they do a breast operation they start with the lymph nodes and I was worried that I would lose the strength or ability to control the arm. So I gave the consultant a bashing because I am 120% dependent on my arms so don't mess me up and all the rest of it. So I was back in the wheelchair the next day."

(Val)

At the 'user participation workshop' Val gave another example of the difficulties involved in needing surgery on her hands for Carpel Tunnel Syndrome and the implications for her of this operation:

"Well my body is wearing out. I have just been warned that I have Carpal Tunnel Syndrome. One of the hospital consultants said 'if we fit you up with a chair with two wheels on one side and then we swap it over, could you manage, could you transfer'? And I said 'no'. I need both arms to do everything that I do. 'Well 'he said' in that case if you go down that path you will have to have them both done together and be fed, watered and toileted for the time it takes you to recover', and that fills me with total dread. So I am doing everything I can to prevent major surgery."

When I asked her if she would still be able to move her elbows, she said she would but she would not be able to transfer from her wheelchair to her armchair or bed. She was also concerned that she would not be able to participate in archery. Val realised that the options for her continued help and independence could be strongly threatened

if the operation was not successful or if it took her a long time to recover from the operation she may lose the strength in her muscles.

It is not just exercise that individuals find they are not able to participate in anymore; it is being able to use the wheelchair. The length of time a person uses a manual wheelchair, and the exercise they participate in to strengthen the top half of their body, can also cause health problems. This participant explained to me that due to the constant pushing of the manual wheelchair and the exercise he has done, he now has difficulty propelling the wheelchair because he has:

“damage to my shoulder cuffs [Rotary Cuff injury]. I get very tired now. It hurts to wheel my wheelchair. I cannot push as far, and I cannot push as hard as I used to.”

(Joe)

As mentioned earlier, literature shows that constant propelling of a manual wheelchair will lead very often to shoulder injury later in life (Koontz, 2002).

On the other hand one participant who had become diabetic since using a wheelchair was very positive when he told me during his interview:

“Diabetes has not done me any harm. In fact, it has done me a lot of good, because I think it was caught very early. It lets me eat proper things and not eat fast food.”

(Lian)

Of the 18 participants who were interviewed, nine participants had health problems during the time they had been using a wheelchair.

The 'user participation group' discussed the importance of having a knowledgeable doctor that is supportive of the individual's needs, and also the benefit that physiotherapy can bring to some individuals. Physiotherapy can help to prevent spasms, mainly in the legs, even if the physiotherapist is moving the legs for the individual. But as this participant pointed out to the group:

"They won't do it, I have tried. My physiotherapist gave me 3-4 weeks of therapy and then told me what I am supposed to do and that is it. I can't move my legs on my own, so in the morning when I come out of the shower my carers dry me off, and they exercise my legs by lifting them up and down and they turn the ankle round. This is just five minutes in the morning; I could do with it in the evening as well. It helps with the circulation."

(Paula)

Sometimes just being left with exercises to do is just not enough. Often individuals need extra encouragement to keep going. Many times the individual does not have full control over movement of his/her legs and needs help from the physiotherapist. Having physiotherapy can be classed as an 'additional requirement'. As mentioned by Morris (2004), the philosophy of independent living emphasises that the way in which additional requirements are met is crucial to whether this level playing field is achieved. The disabled person must have choice and control over how their needs are met.

The group said that dealing with constant pain needed an awareness of what medications were available to alleviate some of the pain intensities. The value of 'pain clinics' was discussed and it was very useful for one of the participants who had never heard of them. Those participants suffering from spasms described the discomfort they brought and discussed how they could be dealt with. When this participant was asked if she was taking medication to help with the spasms in her legs she replied:

"I have just changed over. I am with the 'pain clinic' at Northampton. They are changing all my medication. It was my doctor that suggested it when I was talking to him about medication, not knowing whether to go onto it or not, he said 'either do that or go to the pain clinic'. So I said I would go to the pain clinic and I was so pleased, he is a lovely doctor. It is just getting the appointment, it is a long wait, but it has gone very quickly."

(Paula)

I asked Paula whether it was just the drugs or pain management as well: She answered:

"Medication mainly. Just trying different drugs and giving them time to work. You think it is going to act straightaway but it doesn't. You need weeks and weeks before it works. I do think it has helped me with my spasms and the neurological pain that I get. I don't know whether it has done any good, probably a little bit. I am still always in pain, all over, all the paralysed bits,

that is always there. It is just like being bound up with a tight bandage and I get a burning feeling. The doctor does not know if he can help with that at all. The nerves are trapped I suppose in the spinal cord.”

During the user participation workshop, one of the other participants and her carer told me that the doctor will come out and see them, but they had never heard of ‘pain clinics’. The group agreed that pain clinics were a good idea and although they felt that exercise was beneficial they found that health problems could often make it difficult to participate. They all felt that physiotherapy helped with regards to improvement of the circulation and the ease of spasms.

When participants were asked what type of exercise they participated in and whether it was for leisure, sport or physiotherapy, their responses varied:

“I have been involved in paralympics and all sorts since I have been in a wheelchair. I have got all my medals on show up there. I hold five British swimming medals, one medal for athletics and four medals for air rifle shooting. I also have a silver medal in bowls. But I hold five British swimming records.”

(Jenny)

Jenny had been very involved in paralympic level sport, and was so proud of what she had achieved since being injured in a road traffic accident at the age of nineteen. In contrast this participant told me:

“... swimming and exercises at home. I lift my legs up and down whilst sitting in my chair, but it makes you puff a bit. I also lift my sticks as high as I can.”

(Joy)

Both of these participants go swimming, but one participated at Paralympic level whilst the other liked to go to the swimming pool to do her exercises in water because she finds it easier that way. But exercise to this participant was equally as important to her as it was to the one involved at paralympic level.

Another participant I interviewed had been involved in sailing and told me:

“When I first became disabled I did not want to know anything about sport or exercise, a cripple ‘sailing’. But my friend persuaded me to have a go and it was wonderful. I was involved in ‘Rutland Sailability’. I am currently involved with several things, one being the ‘Harborough Hackers’ disabled cycling club. Also I am involved with disabled archery.”

(Micky)

Five participants were involved in physiotherapy; two of these now do their exercises at home. But whether they were involved in paralympic level sport, exercise at home or physiotherapy this study showed that each participant was extremely proud of their involvement in exercise.

The availability of exercise venues, accessibility of transport in order to get to the chosen venue and the accessibility of the exercise facilities, are all determinants which could influence an individual's decision to participate in exercise or not and decide upon which type of exercise to do.

The type of exercise, which an individual participates in, is often decided for them by the physical barriers, which disabled people may face. The Disabled Persons Act, 1981 (DPA) made it a statutory obligation for the design of local authorities sports facilities to conform to minimum access requirements. There are extensive measures, which need to be considered to include suitable toilet and changing facilities, handrails, and automatic doors (Haywood et al, 1995). There needs to be access on equal terms with non-disabled people and this is seldom achieved (Heller et al, 2002). If it was achieved, disabled people may have a greater say over the type of exercise that they can participate in and thus reap some of the benefits to be gained from regular exercise involvement. Exercise has also been found to have psychological advantages, one of which is increasing a person's self-confidence:

“Oh, definitely, yes. I wasn't a confident person, but I am now.”

(Jenny)

When the 13 participants who exercise were asked if they felt that exercise had increased their level of self-confidence, not just within exercise participation but in every day things, seven said it had increased their confidence. One participant told me how he had had a go at sailing and found it was great:

"It increased my level of confidence."

(Micky)

Other examples were:

"Yes indeed it has, because I would not be where I am now if it wasn't for that."

(Lena)

"Well what I used to like as well, is that the past 25 years I worked on a production floor and that was predominantly men. Well, I am not interested in what you did with your girlfriend the night before or what you had for dinner. But I can sit and talk about rugby or golf. So we would discuss, you know, I did well with my bow and arrow and he did well with his golf. So we had an interest in common although it was not the same sport."

(Val)

By contrast three said they were already confident before they started to participate in exercise. Two of these examples are:

"I think I was anyway. Since I've been in the wheelchair I'm just, even in everyday life you just have to be quite bolshy if you are going to go around on your own."

(Carrie)



“No, I am a confident person anyway.”

(Annie)

Two participants did not feel that exercise had increased their level of confidence.

One participant told me that he had been very nervous of meeting me:

“It may be because you are unknown to me.”

(Mike)

But when I asked him if he was still nervous, he said ‘no’. The five participants who do not participate in exercise were not asked this question.

Seven of the 13 participants who participate in exercise said that they found exercise had increased their level of confidence in exercise and everyday things, but two did not.

Past literature shows that regular exercise can bring about beneficial psychological changes. It can improve a person’s perception of their body image and self-confidence (Schaeffer & Proffer, 1989), and is said to have a positive effect upon an individual’s self-efficacy (Bandura, 1977). Exercise can also help to create a positive attitude (Mooney, 1998).

What literature has shown is that it does seem of vital importance that disabled people and non-disabled people integrate at as young an age as possible in order to create a positive impact. When Maranda Wootton, editor of the Whiz Kids ‘No Limits’

publication (2001) spoke to non-disabled teenagers and discussed their antipathy towards disabled people, she states that "there is little evidence to pinpoint exactly what the key to greater integration of non-disabled and disabled young people is". But what research had been undertaken, however, has proved that for a non-disabled young person to have first hand interaction with a disabled young person, whether that is at school or in an extracurricular capacity, has a positive impact on the way they interact with other disabled young people.

This article, which is written for young disabled people, adds a positive key to the importance of 'confidence' being a key issue. A positive self-image therefore seems to be imperative in promoting young disabled people as fully active members of teenage society. Exercise can help to promote this positive self-image as can be seen earlier. Equally, a wheelchair that the user is at ease with plays a crucial role, far beyond functionality, that both encourages a more positive self-image and in turn changes the way that non-disabled teenagers perceive disabled young people. The type of wheelchair that the participants in this study use and the problems they face with barriers preventing access into buildings will be discussed later in this chapter in 'theme five'.

When participants were asked if there were any other exercise activities that they would like to participate in but felt that they could not, most of them had a goal to achieve. For some this was no trivial pursuit. One participant who already goes sailing said:

“I think I do enough as it is. No, I think the only thing is I would like to be more competitive from a sailing angle.”

(Micky)

Whilst another who had been competitive for twenty years, sailing in the paralympics, had a desire to take to the air or travel at great speed on four wheels:

“Well the thing I haven't done is gliding. Oh yes, I was going to do it last year but I got distracted and didn't, but yes there is a gliding club near where I can go gliding. I would have liked to have done more motor racing.”

(Lian)

In contrast to Lian one participant said she had no desire to take on anything else:

“No I am quite happy with the way I am.”

(Annie)

To be able to use their legs again was a goal for the following two participants:

“Oh yes, I would like to be able to jog or something like that, but of course I cannot.”

(Lewis)

“I would like to be able to run like I used to. I used to be a long distance runner. I would like to be able to achieve that again.”

(Lena)

Both of these participants wanted to do something that they used to be able to do in the past, but which was now impossible. Another was prevented from participating in riding an electric bike, because the cost was far too expensive and outside of his reach. One participant answered this question by saying,

“I would like to go to work.”

(Sheena)

She felt that being able to go out to work and earn a living was in her eyes a form of exercise. Three participants were prevented from exercising again in any physical activity due to the severity of the pain, which they had to endure. When I asked one of these if she would like to participate in exercise again in the future, she replied:

“Knowing what has happened to me in the past, no.”

(Pat)

Pat had found that when she exercised the pain worsened. And, the fact that having no feeling, movement or balance prevented this participant from doing anything:

“Where the spinal column was actually severed. I have no feeling, no movement and no balance at all there, which means I always have to be

leaning on something or holding onto something just to start riding a wheelchair. This precludes you from playing basketball or volleyball or anything like that.”

(Cole)

The third participant who was prevented from exercising due to the pain said he wanted to get his shoulder cuff problems corrected so he could exercise again.

Some participants in this study had set themselves quite high goals to achieve. Some felt that they could not do anything whilst others wanted to do what they used to be capable of doing before they became disabled.

Many of the participants in this study told me that they have been involved in exercise for a long time. Nine had been involved since childhood and seven since they became disabled. One had not been involved in exercise at all, and one participant was overlooked and not asked the question. Some exercised more now than they did before they became disabled. One participant felt that:

“If I did not exercise and keep fit then I would become a cabbage.”

(Paula)

She felt that it was very important in order to prevent the condition getting any worse and that she now has a purpose. The responses from the seven participants who spoke of their past exercise involvement since they have become disabled varied:

“I set up a wheelchair basketball team and bought all the wheelchairs through funding. It is still going to this day, I think.”

(Jean)

“I have always gone fishing.”

(Annie)

Four participants had become involved in paralympic level sports since becoming a wheelchair user, and they held many medals for sailing, swimming, shooting and archery.

For disabled people, regular exercise can improve functional status and independence in activities of daily living by increasing muscular strength and endurance, flexibility, balance, and cardiovascular and respiratory functioning (Rimmer, 1999). For some participants who had been exercising for a long time it was because it was so important in order to prevent their condition getting worse. Exercise can also relieve the onset of acquired conditions for disabled people, as they grow older (Heller, 2002).

For the five participants who received physiotherapy each had been receiving treatment either since the accident or since they had started to use their wheelchair:

“Physiotherapy, I now have to do the exercises at home.”

(Joy)

Whilst nine participants referred back to before they became disabled and the responses showed that each participant was really enthusiastic about what they had done, eight of these commented as follows:

“Hockey up to the age of 16. I was in the Merchant Navy prior to my disability and I used to do a lot of fell walking.”

(Micky)

“I played Rugby.”

(Mike)

“Long distance swimming, cycling and bench pressing. I have always swum since the age of 7. I used to swim with friends and we would do it to raise money for charity. We would swim the channel.”

(Joe)

“I was well into horses and kept my own horse. I also used to, strangely enough; teach disabled riders who were too good for the normal riding class for the disabled. I was first put up on a horse when I was three years old. I was hounding after the poor old mare, so to enable her to move around in safety, I was plonked on her back.”

(Cole)

“I was ever so good at swimming when I was able bodied.”

(Lena)

“When I was working at the solicitors I used to play football. I was also involved in running.”

(Pete)

“I liked badminton. I used to play at a club for badminton a long while ago. I was energetic and I was quite a powerful swimmer but I didn't go to the swimming baths very often, just when I was on holiday.”

(Paula)

Another participant told me how his grandfather had hoped that he would one day go to sea and how he encouraged him from a young boy to take an interest in sailing:

“I had my first boat when I was 1 year old. Then when I was five years old my grandfather gave me a sailing canoe and I was sailing internationally when I was 8 years old.”

(Lian)

Six of the nine participants who participated in exercise before they became disabled, still exercise now they have become disabled. According to McNeill (1993), there are factors, which exert a strong influence in the making of decisions to participate, or not, in a wide variety of physical and social activities. These might include: education at school and amongst service providers, employment education and social opportunities, home improvements and structural barriers, attitudes, isolation, level of physical pain, personal factors, nursing care and previous experience of exercise. For those who have participated in the past it is likely that they have been able to pursue a



range of physical activities and have benefited from a healthier lifestyle (Sherwood & Jeffrey, 2002). Kew (2000) points out that many disabled people have had little previous opportunity, at critical learning periods in childhood to develop the basic movement abilities upon which more specific sports skills are based. Lack of previous experience in sport and exercise can often lead to a low assessment of one's own capabilities, and can consequently bring on avoidance of sport and exercise challenges through fear of failure or ridicule.

### **Social Support**

This study has shown that participants who receive encouragement and social support from friends, family or significant others, are more likely to exercise than those who do not. Social support can play a very important part in an individual's decision whether to exercise or not. Participants in this study were asked whether or not they received encouragement and support to participate in exercise by friends, family or significant others. For this study 'significant others' means people like a doctor or physiotherapist, whose opinion participants may trust.

Nine participants reported that they received support from family, friends and/or others. Two of these said they were also self-motivated. Eight received no support at all. One was totally self-motivated:

"It comes from within yeah? But it also comes from meeting all the different people I have met in my life that cannot do as much as they want to. And I

think I am not going to be like that. I am going to do as much as I want to. It makes me more determined to have a good life.”

(Jenny)

One participant explained that as well as receiving support from his friends, wife and family; he also gets support from the press and photographers. He is involved with members of the local council and says:

“Well obviously the friends I have got are from the disabled sporting side of things so most of my friends are athletes anyway. I am fairly well known with the local councillors. I am usually in the press once a week at least.”

(Micky)

Jenny also said she received support from her friends and family especially at times like sponsorship, but she said:

“I also receive support from my physiotherapist who visits me at home a couple of times a week. I can talk to her about any pain that I may have.”

(Jenny)

This next participant explained how she received encouragement from her partner and her family but also from the medical profession:

“The unit I go to at Addenbrookes Hospital are very good plus I see a Rheumatologist and an Orthopaedic surgeon so between them I really sort of

trust them. Also the physiotherapist locally that I see we really got a kind of long term relationship now.”

(Carrie)

However, she reported that she was not so encouraged by the lack of consistency regarding accessibility to facilities and transport. The next participant also had trust in his doctor and physiotherapist:

“I mean I go to my doctor and say ‘look I am fed up with this it hurts and I have come for my injection’, he will say ‘ok, let’s change the drugs’ I have great faith in the paralympic physiotherapist, she is gorgeous and lovely.”

(Lian)

Whilst some participants appear to get encouragement from all around, others did not seem to be so fortunate. When asked if her family gave her encouragement to exercise this participant replied:

“No I don’t think they do.”

(Dora)

Dora did not participate in any form of exercise and had not been interested in participating in the past, not even before she became disabled. Mick did not receive any encouragement from family as he did not see any members of his family, but did

receive encouragement from his physiotherapist to carry out his exercises at home.

Mick was also impressed by other people's attitudes. He said:

"I admire their self-determination and how they will not allow themselves to give up."

The next participant said it was her family and her diary that encouraged and motivated her to exercise. She tried to keep to a rigid exercise programme. She did not receive any encouragement to exercise from friends or from her doctor:

"My friends seem to have forgotten me now I am disabled and they just get on with their own lives. My doctor does not want to bother with me."

(Lena)

This next participant did not receive any encouragement to exercise from family and had no friends. He had lived in his present location for 12 years and attended the MS centre each week to exercise. He said:

"Mainly the friends I have are the people I meet in the MS centre. I only see them while I am at the MS centre."

(Pete)

The only other people he saw were his carers.

Participants were asked what motivated or encouraged them to participate in exercise activity. The responses were the physical feeling of well being that they received from exercise participation:

“You’ve got a feeling of well being, the adrenaline that flows from that gives you a better feeling. Everything that comes from exercise is better as well.”

(Micky)

Keeping weight off (which was important in order to stay fit enough to manoeuvre a manual wheelchair):

“... even though I don’t weigh very much, it helps to keep my weight down. I exercise just to keep going, I suppose.”

(Pete)

“... because when you sit in a wheelchair you put weight on in certain areas. I am a fairly young woman and it is important that I feel fit.”

(Carrie)

Motivation received from other people:

“I am motivated by all the people I meet who cannot do as much as I can.”

(Jenny)

And the fear of losing their independence:

“If I didn’t do it I would not be able to go to college.”

(Sheena)

“Fear of not being able to participate.”

(Val)

Val was afraid of not being able to participate in exercise and daily activities, and afraid of losing her independence and fearful that she would have to go into a home to be looked after. That gave her the determination to carry on. The Chronically Sick and Disabled Person’s Act (1970) and the Government focused on helping disabled people to live in their own homes or in the community in order for them to keep their degree of independence. In order to do this some support was given to enable disabled people to access facilities in the community such as visits to health and community centres and swimming pools.

One participant, who received support from his family and fellow exercise colleagues, gave quite a full account of the lack of motivation shown, and excuses used by other disabled people when they were asked to participate in physical activity. He told me that if he wanted to go cycling, he would get onto the bike even if he had to crawl there in order to get to it. He complained about the negative attitude of one of his members (also a participant in this study) who used the excuse for not exercising as not being able to transfer from chair to bike. He gave a full account of how he felt about other disabled people when they use excuses for not exercising:

“ No, I mean one of the interesting things when I was with the 2.4 fleet which was athletes at the top end of the paralympics type stuff, there was never any talk of disablement or any talk of benefits or any, it was just purely sport, sport and sailing, that’s all we talked about. When you come down to the national class, challenger class, and other sports then you start, ‘well, you know, I would have liked to come out last week but you know I couldn’t because of my Multiple Sclerosis’ or ‘my leg was falling off’, or whatever. People’s minds are set. As you come down, I mean I’ve got a lady from [Dutton], ‘oh I would like to do it but I can’t transfer off my wheelchair’. But even if I have got to crawl into that bike I’m going to crawl into it. Because I want to go and take part, I want to do the sport. I’ll do it because that is what I want to do, is to enjoy it. But she comes from a very negative ‘but I would like to do it but I can’t because I haven’t got a hoist’. But I have got a dozen paraplegic athletes here that say never mind about that, they are not bothered about that, we want to go biking and we want to go sailing and we will do so no matter what even if we have to crawl. We will do it because we want to do it. Different attitudes. And that is what I tend to find with local people.”

(Micky)

A positive attitude toward exercise can help in the aid to recovery from injury.

Mooney (1998), in her literature on paraplegic willpower, examined how a young man with a serious spinal injury defied doctor’s predictions that he would never walk again. The young man involved in the diving accident had a positive attitude toward exercise and fitness and believed that it could help him back onto the road to a full

recovery and in Mooney's study, it did. Wilson (1992) followed the progress of a young female, which contracted a malignant tumour of the spinal cord during her infant years (this case showed how a positive attitude and strong determination to succeed can help a person achieve their goals). The only physical activity this young lady was ever able to participate in was a walk and an occasional swim. When she was aged 22, she had a fall and suffered a spinal cord injury. She lost her ability to walk and her health declined. Yet, with support from her trainer, she started to exercise using weights and her upper body strength improved. Her stamina and endurance increased and this young lady quotes: "My entire attitude began to take on a more positive dimension". She became one of the nations first paraplegics to become AFAA (American Fitness and Aerobics Association) certified to become an aerobics instructor. She further states: "...fitness truly is more than physical – it is an integrated state of mind and body..." (Wilson, 1992).

Participants who received a high level of social support appeared to be more actively involved in exercise participation of different kinds than those who did not receive support. Gordon (1997) found that individuals with spinal cord injuries see a need for encouragement by family, friends and the wider community to pursue their dreams and goals. It also appears that social support is a very important part of the inclusion of disabled people into society. Martin & Mushett (1996) propose that social interaction is very important to disabled individuals because many are often leading a sedentary lifestyle. They feel that some individuals could benefit from the increase in social integration and communication with other individuals. Exercise can help disabled individuals to regain contact with the reality of the world they live in facilitating social integration.



This is interesting because Doyle (1994) found a different reaction when he conducted a study on the perspective of young adults from different ethnic backgrounds. He found that most of the individuals lived with informal carers, usually their mothers. Many had complex disabilities and were wheelchair users. Over 40% of these young people were living in a close family network, but these young people were less optimistic about their future prospects. Many had come to accept that poverty, disability and ethnic background would serve to isolate them from the wider community. It would appear that just because a person has a strong family network, they do not necessarily receive the support and encouragement that they need in order for them to decide to participate in exercise activity.

Heller (2002) also felt that social support is a very important part of the inclusion of disabled people into society. She found that when carers perceive greater benefits of exercise and when there are fewer access barriers, adults with Downs Syndrome exercised more frequently.

A very significant finding of this study was that participants who receive social support, whether it comes from friends, family or others, are more encouraged and therefore participate in exercise more than those who do not receive social support or encouragement from other people.

**Theme 3****'Access to Information'**

"I went to Stoke Manderville hospital, I went to the physiotherapist at the general hospital and I could not find anybody that could help me."

(Paula)

In this section of the chapter I explore the difficulty in which disabled people gain access to vital information regarding: benefits, leisure facilities, and the purchasing of resources and receiving advice. Participants were asked how they, as individuals, gained the information they needed regarding these issues. This will be supported by literature written by Kew (2000) and other research.

As well as receiving social support from other people to encourage them to exercise, equally as important is the way in which disabled people have access to vital information. Many participants did not know what was available and on offer to them with regards to benefits and resources,

During the interviews participants discussed the difficulty of finding specialist equipment for the first time. Whereas some participants who were interviewed appeared to be quite knowledgeable as to what help was available to them with regards to their equipment, Paula found it more difficult and very difficult to get advice about acquiring the correct type of equipment for her needs.

She continued to tell me that she:

“I went to the wheelchair lady and a disabled exhibition and I have now discovered that what you have to do is to go to your GP and ask for a referral note to go to these people and then you get things done. I have been paying for boards. When I knew about this board I wanted, I went to the senior occupational therapist at the wheelchair services. She said ‘you have to go to your doctor and get a referral’ and that is how I found out about it. I had to wait a few weeks and then the occupational therapist came out and she was offering me all sorts of things to get my legs on the bed, amazing.”

She also discovered too late that her care manager could have helped her with the purchase of a new bed and mattress, which she need not have paid for. But she had not been given adequate information about this at the time.

Buying a new wheelchair to suit her needs and a car that was accessible was also difficult. She told me:

“From the day I had the chair I found it was impossible to get into anybody else’s car. The car I had ordered, the Vauxhall, the seal was so wide I could not even get across it. I went to every garage to find a car that I could get into and out of and a Nissan is the only one.”

Participants in this study reported that to try and cope with their impairments and adjust to life is difficult. They also said that on top of this, they find themselves in a

very difficult situation not knowing where to go for help and information about the benefits and resources that are available to them:

“Nobody tells you these things. I belong to the Disabled Drivers Association, but it is all ‘word of mouth’. I did work for the Citizens Advice Bureau (CAB) for 5 years, but now I have become disenchanted with the CAB and I work for ‘Age Concern’ and I do insurance advice.”

(Val)

During the ‘user participation workshop’ it was agreed amongst the group that there seemed to be a wide level of interpretation regarding who received what and the conditions, sometimes quite stringent, which were attached.

I asked the group if they felt that this was mainly where disabled people got their information from: just ‘word of mouth’, talking to other people. Val went on to say:

“A good friend of mine worked on an access panel. She told people about their entitlements etc. Well I had breast cancer four years ago and it made my arms weaker. Well my friend said ‘what about the voucher system?’ Well I had never heard of the voucher system.”

But as the group had discussed earlier, many disabled people are still not aware of the information available to them regarding everyday living such as use of facilities, resources and benefits (Kew, 2000). Some disabled people only find out about the

benefits that they are entitled to through 'word of mouth' and often only when it is too late. There needs to be a better means of communication between the wheelchair user and the service provider in order to convey important information to those who need it the most. Those who are on state benefits often have to make do with whatever the local organisation can make available to them which may, in some cases, be old and cumbersome machines, which have had little maintenance or do not match the types and level of disability and immobility being experienced. As Massie (1994) argued, society creates barriers for most people, but disabled people are doubly disadvantaged. They are sometimes being deprived of the vital information that is needed for them to live normal, active lives (Massie, 1994).

Participants discussed the difficulty of finding specialist equipment for the first time. Some participants interviewed appeared to be quite knowledgeable as to what help was available to them. But many people are still not aware of the information available to them regarding everyday living such as facilities, resources, vouchers and the benefits available to them as disabled people.

Very often there is little information made available to disabled people with regards to exercise involvement for leisure and enjoyment, with limited assistance at the leisure centre (Heller, 2002). Despite the fact that the 'social model' of disability has liberated disabled people, and the DDA (1995, 2005) have made it a requirement for 'any goods or service which is made available to the general public must be accessible and available to disabled people', we can see from the data collected in this study and the literature review, that needs are still not being fully met.

Disabled people need to be made aware of the existence of facilities for sport and exercise, and of the organisations which, specifically cater for the needs of disabled people. Kew (2000) states that many disabled people have little contact with disability sports organisations, little or no knowledge of the opportunities so afforded, or that main stream sports organisations are assuring an increased role in sports provision for disabled people, although there is still a need for greater awareness amongst service providers to gain a greater level of understanding regarding disabled peoples needs. Heller (2002) states that to increase accessibility, adults with disabilities need information on where fitness centres are and how to use the equipment. But the equipment needs to be made readily available and set up for use. Choice and control cannot be achieved unless information relevant to the decision to be made is available in an accessible form. Advice and advocacy are also needed to assist people to make choices. Decision-making processes must involve the people who are affected, whether this is on an individual level (for example, assessments and care plans) or on a collective level (for example, commissioning and delivering of services) (Morris, 2004).

## **Theme 4**

### **Politics of Disablement**

“... a total lack of control during this manoeuvre.”

(Dora)

In this section of the chapter (Politics of Disablement), I first, discuss the issue of disempowerment. This will explore participant's feelings of lack of control over the use of equipment, transport, finance and the inequality when it comes to employment. This will be supported by literature in this field. Then Therapy Culture (Furedi, 2004), and Dependency Culture (Oliver, 1983) will be explored to investigate how we have become a society of people in need of help and therapy.

Secondly, I discuss literature that has been written on the 'Sociology of the Body', and examine how these new ways of thinking may shape the attitudes of disabled people regarding their perception of their body image and their attitudes toward exercise involvement.

#### **Disempowerment**

Referring back to the quote from 'Dora', at the 'user participation workshop', this was the response I received when I asked her how she felt when she was being manoeuvred from her armchair in the lounge into her bed in her bedroom, and back again, by means of a hoist. She told the group she was very nervous each time this manoeuvre happened, in case she swung out too far in the hoist and hurt herself, as

she had no control over how she was being handled. She had also been let down by social services on numerous occasions when the carer did not turn up at all. She had no control over whether or not the carers would come.

As Morris (2004) wrote:

‘Our body is not our destiny.’

The goal of independent living is thus motivated by three fundamental ideas. First, disabled people should have access to the same human and civil rights as non-disabled people. Secondly, society’s reaction to impairment and the failure to meet needs relating to impairment, has undermined disabled peoples human and civil rights. Thirdly, and this is not inevitable; impairment does not have to determine life chances. Independent living is also associated with the words ‘choice’ and ‘control’, and concerns both the environment in which someone lives and the assistance needed in order to go about daily life (Morris, 2004).

According to Goto (2004), the social model argues, that the cause of disabled peoples difficulties lies not in their physicality, but in a ‘disabling society’. In other words, social barriers (institutional, attitudinal, and environmental) are the problems that ‘disable’ disabled people:

“One morning, after taking three hours to get up and washed ready to go out, with the help of my carers, I drove to the leisure centre to go for a swim. On my arrival there I got changed ready to swim only to find that the hoist had not



been electrically charged the night before. So I was unable to get into the swimming pool. I was so disappointed at what had happened; I decided not to go to the leisure centre so often after that experience.”

(Paula)

This is an example of ‘regulated disabled bodies’ (Goto, 2004). The leisure centre had the equipment there in order to make the facilities accessible to disabled people, yet for reasons unknown to Paula, they decided when it suited them not to charge the hoist. This disempowers disabled people, limiting their choice.

As mentioned earlier, the social model of disability provides the view that it is society, which disables people not the individual impairment. Kew (2000) argues that organisers of exercise facilities, coaches and sports providers having had little opportunity to work with disabled people are unlikely to have a full understanding of the specific challenges that disabled people face. As this study was conducted within the Critical Social Research framework, we need to question why this incident with the hoist and incidents like this one are allowed to happen, and ask ‘how did it happen?’ The charging of the hoist could have been overlooked by members of staff, who perhaps felt it was not very important at the time to go to all this trouble just for one individual, who may or may not, attend the leisure centre regularly? This is an example of an ‘enabling’ society that regulates disabled bodies (Goto, 2004).

It was very important for Paula to be able to gain access to the swimming pool, as she was fully aware of the benefits to be accrued by regular exercise involvement (Dishman, 1994).

As Barret et al (1995) state:

“Discourse still tends to be dominated by professional non-disabled people that perpetrate a world of sport based upon non-disabled norms.”

The most obvious determinant, which may influence a disabled person's decision to participate in exercise or not, is accessibility. As well as accessible general facilities such as leisure centres, cinemas, shops, restaurants and sports venues, that would also include access onto public transport (e.g., buses, trains, planes etc). According to Kew (2000) the physical barriers are the most obvious connotations of 'accessibility':

“I would not dare. I mean, it is just too scary.”

(Carrie)

This was the reply from one participant during her interview when I asked her if she travelled on public transport, for example on a bus or a train. She went on to discuss with me how:

“The dropped curbs are often not at the same place as the bus stops, and not all buses are accessible.”

(Carrie)

She also described her experience travelling by train, and how frustrating it can be:

“...having to book the ramp two days in advance. Also, once on the train, there is often somebody sitting in the disabled spot, so you have to ask them to move. Also this spot is not by the window so I could not see if the guard was at the other end of my journey with the ramp to help me get off the train. This is very worrying.”

(Carrie)

Many disabled people have little option but to stay at home because public transport is too poor and unaccommodating to facilitate their mobility. This limits their geographical boundaries, so preventing access to a range of places and associated goods and services (Massey, 1996; Massey et al, 1999).

Another form of disempowerment is the lack of control many disabled people have over their financial situation, either with regards to the level of financial support they receive or the amount of financial help the leisure centres receive. One participant told me:

“I waited six years in order for a simple shower chair to be purchased at the leisure centre where I go to exercise.”

(Micky)

Micky continued to tell me how the leisure centre had been built with a spa bath, which had been positioned up a set of steps:

“...there was absolutely no way a disabled person could get to it, no lift, no ramp, no way at all to use this bath. I asked the manager at the leisure centre why this bath was not accessible for wheelchair users? His reply was ‘well what do you need it for? It is only like taking a hot bath in a wet suit’. But that is not the point. The point here is that if it is made available to the general public, it should be available to disabled people.”

If providers of goods and service providers do not make available and accessible to disabled people that which is on offer to the general public, then it is a criminal offence according to the Disability Discrimination Act (DDA, 1995, 2005).

Disabled people were forced to live an immensely suppressed life throughout the modern industrial age, which prioritised productivity, efficiency, and normalcy. They were commonly ‘denied’ a citizenship and segregated from society. However, around the 1960’s and 1970’s, which many socialists observe as the beginning of a certain epochal shift, disabled people in all parts of the world began to mobilize and protest against their suppressed status in society (Driedger, 1989).

According to Goto (2000), the 'Social Model' (Oliver, 1996), claims that, disabled people have been deprived of their fundamental human rights in modern society. Disabled people were said to be 'socially dead' (Miller & Gwynne, 1972). It was widely accepted that they should stay quietly in the house or should be confined to a residential institution. This participant told me:

"I would rather live on my own here in my flat, than in a residential home."

(Pete)

By this Pete meant that he would not want to live in a nursing home. Overall the social model has empowered disabled people's movement significantly by providing a radical, but also a rational and constructive explanation, when even the 'accused' (the non-disabled) can be readily convinced (Goto, 2000).

Disabled people are also disempowered when it comes to employment. They find themselves excluded from employment as this participant explains:

"I applied for a job as a counsellor. I had all the correct qualifications and was invited along for an interview. I was told that the interview would take place on the second floor of the building. So I asked the employer if there was a lift, as I am a wheelchair user, and he said no. There was no way to get up to where the interview was taking place."

(Jenny)

Jenny went on to tell me that she felt very upset by this and felt that her wheelchair was becoming a barrier preventing her from gaining access into buildings. The employer did nothing at all to try to make the building accessible for her, so the interview did not take place.

As Massie, (1994, p.6), writes:

“Employers who refuse to recruit disabled people without considering the abilities and skills they could bring to the company are as much an unjust barrier as the flight of steps preventing a wheelchair user getting into a building.”

The New Deal for disabled people was accepted by local authorities as the mechanism for achieving employment targets for disabled people, and Job Centre Plus and their contracted job broker organisations are formally required to address the needs of disabled people who are unemployed (Piggott, et al 2005).

But as Oliver argues:

“There is a universal agreement that disabled people do not have the same access to jobs as the rest of the population. Government policies are, by and large, targeted at equipping impaired individuals for the unchanging world of work rather than changing the way work is carried out in order that more people might access it. Hence, much greater resources are currently spent on employment rehabilitation, training and so on (individual model), rather than

on removing the barriers to work or on attempting to prevent the labour market from operating in a discriminatory manner” (social model) (Oliver, 2004, p.21).

Oliver (2004) suggests that in dealing with discrimination against disabled people, they should be recognised as citizens with full economic, political and moral rights. But what tended to happen, in Piggott’s experience, is that unemployed disabled people were unlikely to be seen as contributing members of society, nor as a powerful interest group, nor as active citizens. They were more likely to be seen as simply deserving of help (Piggott, 2005; Oliver, 1984; Furedi, 2004).

As mentioned earlier, in the literature review, the Disability Discrimination Act (1995), gives disabled people certain rights in the UK in respect of employment, in particular making it unlawful for an employer to discriminate against disabled people when they apply for a job, or when they are in employment, unless they can show that making necessary adjustments would be unreasonable (This did not happen in Jenny’s case, as the employer did not try to make other arrangements to interview her). This statute is meant as a means of protecting disabled people from discrimination on the grounds of their disability, and is part of a new focus on helping unemployed disabled people into work whether they are claiming benefits or not. There is a case to be made for the view that the overwhelming bulk of the policies introduced to address the problems encountered by disabled workers in the workplace have centred mainly on the supply side of labour (namely disabled workers), in the form of training schemes, subsidised wages and so on. All of which to varying degrees reinforce,

rather than undermine the assumption that disabled workers are somehow not equal to non-disabled peers.

If disability is perceived simply in terms of functional limitation there is a danger that the emphasis will be on disabled people adapting and concurring to the norms of society in which they live, rather than putting the responsibility on to society to accommodate such groups so that it can meet the needs of disabled people.

Roulstone (1998) defines disability as the socially produced barriers that are the result of wider attitudes and structures that limit a person with a physical impairment where impairment is any limitation or difference resulting from a physical and/or sensory condition. Impairment is a precursor to the wider disabling processes that follow from such a physical deviation from the norm. For example, Roulstone (1998) maintains that exclusion from industrial society has profoundly influenced the way disabled people are viewed. Occupational segregation, workplaces designed for and conceptualised by non-disabled people, and the attendant negative attitudes, cause disabled people to be either excluded from work altogether or to be undervalued as workers. This could make them dependent upon professionals for help (Oliver, 1984). This social model of barriers to employment is still not fully understood by those who are making policy or those who are attempting to put it into practice (Piggott, 2005).

In her study 'Out of Touch' Piggott (2005), identified a number of key barriers to employment such as poor public transport infrastructure, employer attitudes, benefit disincentives and inadequate support both to re-enter employment and to remain in



work. If disabled people continue to be perceived as economically unproductive, then as the informational economy can be socially excluding then they are likely to be vulnerable to this (Sapey, 2000).

Roulstone argues that, if disabled people, the disability movement and disabled academics are to grasp the factors that shape employment and barriers in the twenty first century, they/we need to reflect on the global challenges for disabled workers, and to look again at the state project, trade unions and older collective struggles. Employment and disability policy research have to engage with the impact of globalisation on the nature and availability of work (Roulstone, 2002).

Furedi (2004) sees our culture as being of a society of people that is in need of help. People cannot cope alone anymore. More and more people have begun to depend upon professionals to help them get through all the problems of life. But this dependency goes back earlier than this; it goes right back to Oliver's (1983) 'Social Work with Disabled People'. Oliver found that when disabled people get involved with professional people like a carer, or social worker, they often become dependent upon their help, and are more likely to be seen as simply 'deserving of help' (Piggott, 2005).

This attitude can undermine disabled persons self-confidence and lower their self-esteem, hence having a negative effect upon his/her perception of their body image.

Popular interest in the body is indicated by the multi-million dollar industries promoting exercise courses and weight reduction plans, the growth in popularity of

self-help therapies, and alternative medicine, and the emphasis on the body as an expression of individual identity. The emerging 'sociology of the body' has contributed to an understanding of the social regulation of bodies, particularly by legal and medical institutions (Foucault, 1973; Turner, 1984; 1987; 1992), and particularly of those bodies perceived as 'other' or as 'out of control'.

The development of a sociological interest in the body is a consequence of amongst other things, the growth of mass sport and leisure which have identified personal worth with the beauty of the body (Brumberg, 2006). This participant felt:

"I am dressed as smart as anyone else; in fact I am dressed smarter than some people on feet. I think my image is quite good."

(Jean)

That was the response I received when asking this participant if she had any issues about body image. She was very confident when she told me that using a wheelchair was just an extension of her and she felt very positive about her body image.

But in contrast this participant felt:

"Conscious, I am very self-conscious. One of the things that I am conscious of is my body in a sense that I've been, I am not the most body beautiful, you know I have got various bits of equipment here, there and everywhere. When I go swimming and stuff like that I am very self-conscious. I have got to peel

my clothes off. I get very conscious of people staring at me in the swimming baths. I feel like people are looking, you know, an invalid, I say it as I feel, you know that is how I feel at times. It is not very nice if a disabled person has a catheter and a body belt. Non-disabled people look at you and it isn't nice."

(Micky)

A number of debates are important in the sociological analysis of the body. One of these is how, in general terms; sociologists are interested in how historically the regulation of the body (through diet, sport, dance, medical intervention, clothing and so forth) has been regarded as necessary for the regulation of society (Abercrombie, 1994). The body is an important feature of all social interaction, because our body image (whether disabled or non-disabled) is regarded as an inevitable perspective of the presentation of the self.

Participants in this study felt that they were often stared at because of their disability, feeling that they are judged by their physical appearance:

"I am still a fairly young woman, so I like to keep fit and look good."

(Carrie)

Sociology of the body studies how the social world affects our bodies and is particularly concerned with processes of social change (Giddens, 2005).

Feelings of shame about the body can lead to compulsive dieting (Brumberg, 2006), exercising or bodybuilding to make the body conform to social expectations. Disabled people are very aware of their body image, and many participants in this study said they liked to exercise to keep fit and look good. This could be because society is pushing people for the body perfect, causing feelings of shame, which results in making disabled people either try harder, or give up. Or it could be personal feelings of satisfaction and achievement, which influence their decision to exercise.

Sociology of the body considers the relationship of the mind and the body from a variety of perspectives, examining the link between the body and personal identity, focusing on disability, race/ethnicity, and sex/gender, and considers how identity is enacted through bodily practices and manipulation. It has been used as a tool to explore many different areas of life. Ballet dancers for instance are extremely regulated, making the body do what most people could not even dream of doing.

Disabled people are very regulated in some countries. Goto (2000) examines the case of the disabled body in Japan, and says it can be argued that a barrier free 'enabling' facility, which is endorsed by the 'social model', often cohabits with the bio-politics of 'regulatory bodies'. Consequently, according to Goto, the disabled body seems to be one of the most regulated bodies in their society.

Examples of regulated disabled bodies in this study were the transport system as mentioned earlier in the section on 'lack of control'. Disabled people are 'regulated' as to when and how they travel. They have to phone two days in advance of travelling to arrange for a porter to be available with the ramp in order for them to be able to board the train. Disabled people also have to give 2-3 days notice when

booking a seat on a community transport system like 'dial-a-ride. Very often these systems are only operable within the county, and would not be able to cross the border if a person happened to live near the dividing line.

"I simply cannot afford the price of the taxi fare, it is so expensive."

(Jean)

Taxi's that are wheelchair accessible are so expensive and many disabled people cannot afford the cost of the fares, especially if they are in receipt of benefits.

Another example is that disabled people are regulated to a degree when it comes to using leisure centres, swimming pools and shops. The management of leisure centres often arrange allotted times for disabled people to swim thus segregating them away from the non-disabled general public. Data gathered from this study show that when it suits them management of leisure centres decide whether or not to make facilities available to disabled people.

They are also 'regulated' when it comes to financial benefits and employment, and what equipment and resources are available to them. Participants in this study told me how difficult it is to gain 'vital information' that disabled people need in order to fulfil their needs. This inaccessible society that 'regulates' disabled bodies can cause lack of choice and disempowerment for disabled people.

**Theme 5****Inaccessible Society****(Barriers preventing Access)**

“There is plenty of choice, the problem is accessibility.”

(Micky)

In this section of the chapter participants in this study discuss the different barriers, which make society inaccessible for disabled people. The barriers addressed are: structural, attitudinal and physical. Participants start by discussing the structural barriers, which restrict access into buildings and the use of facilities inside (i.e., leisure centres, swimming pools), reducing a disabled person's choice and often causing them to be segregated from non-disabled people. This will be underpinned by legislation of the Disability Discrimination Act, DDA (1995, 2005). Participants also discuss the problems they encounter when trying to use public transport, acquiring an accessible motorcar and finding a suitable wheelchair. They also examine the skills needed for new wheelchair users.

Next, attitudinal barriers are explored and participants reveal how the negative attitudes of other people toward disabled people can have a negative impact upon the perceived perception of a disabled person's body image.

Lastly, physical barriers are investigated and participants discuss how health problems and 'pain' can prevent participation in exercise activities.

## Structural Barriers

Picking up from Micky's quotation at the beginning of this theme, many participants in this study felt that there was not very much choice regarding exercise facilities when it came to accessibility. Although most of them had exercise facilities within a reasonable distance from their homes they were not necessarily accessible.

A problem affecting accessibility, which was highlighted during the interviews, was a lack of funding for some leisure centres. Lack of funding can result in leisure centres having inadequate resources lacking sometimes very simple things that will make a difference. Micky explained how he had waited six years for a simple shower chair to be put into the changing room of the leisure centre, just in order to be able to shower off after swimming. He went on to explain:

"I mean the staff are great, but we find getting the money down to do the improvements is very difficult."

(Micky)

It is not just having access into the leisure centre itself that was an issue here, but being able to use the full range of facilities once inside as Micky continued to tell me:

"I mean we've got the hydrotherapy pool that is placed four feet above the level, so you have to walk up a set of steps. There is no way you can actually get there. We have looked at hoists and so forth, no way you can get up to it.

We have spoken to the leisure manager, spoken to the sports development

manager, we've spoken to environmental officers and the answer comes back 'well what do you want it for? It is only like taking a bath in a hot suit'. But that is not the point. The point is if it is available to them, then why can it not be available to others?"

(Micky)

As mentioned earlier, it is not just accessibility into the leisure centre; it is being able to use the full range of facilities once the people are inside that is equally important. This participant actually had some input into the requirements for wheelchair users because he is on various committees, but it did not matter who he spoke to, whether it was management at the leisure centre or environmental officers, the answer came back the same 'what do you need it for?' The point here is that if it is on offer to the general public, it should be available and accessible to everyone (DDA, 1995, Part III, Goods and Services). It is an offence since October 2005 to refuse to provide or deliberately not providing, to a disabled person, any goods or service which the service provider provides or is prepared to provide to members of the general public. What remains contentious, however, is the regular use in the legal language used in the Act, of the term 'reasonable' [Section 21], which has enabled some suppliers of public and private services to exploit this legal loophole on the grounds of cost, planning restrictions and/or ignorance of the Act (1995, 2005).

Sargent (1987), prior to the DDA Act, had advocated that concerns about cost should be outweighed by concerns of equality, but public sector spending constraints are likely to ensure continued inequality of access (Kew, 1997).



The user participation workshop group discussed leisure facilities and said that the different leisure opportunities that were available varied from region to region. Some leisure centres have quite good facilities whilst others suffered from too small changing rooms with lack of privacy when changing. Sometimes the disabled person has their carer with them in the changing room for assistance, so they need a fair amount of space.

Provision of the needs of disabled people received a boost with the passing of the Disability Discrimination Act (1995). This Act attempted to deal with a wide range of issues concerning the way disabled people were treated and their statutory entitlements to many services and facilities, which were readily available to non-disabled people but not to those who could not access them, in view of their physical and mental capabilities.

This may be summarised as attempting to alert agencies, organisations, national and local government and service providers to new requirements when considering the setting up of new public and private services and facilities for the disabled. But there remains no enforcement to improve access to buildings constructed prior to 1981.

This continues to be a barrier (as well as a determinant) to disabled people, especially those with mobility difficulties.

In contrast to those who felt that leisure facilities were inadequate, one participant seemed quite happy with what was on offer, although he doesn't actually use a leisure centre. He felt that he was very:

“...fortunate because it is all very flat around here. It is a lovely area with lakes and woodlands and I get on my bike. The more organised physical activities I have not gone to because, one of the reasons is that my doctor say's 'don't be daft, you have done enough already.'”

(Lian)

By this he meant that he had been sailing in paralympic championships for twenty years, and felt that he had done enough with that. But this participant was not actually referring to the accessibility of buildings but access to open spaces in which to ride his bike. He did not have a problem with segregation because he was free to cycle with whom he wanted.

But when it came to using exercise facilities at a gym or a public swimming pool, things can be very different. Often disabled people have to attend slots made available by the service manager, and this segregated them from the general public. This participant was not at all happy about being segregated away from the general public and given allotted times to swim:

“I wouldn't want to be separated from the general public, I want to swim in with them, not have a slot for disabled people.”

(Annie)

Sometimes these allotted slots were not on a day that suited the participants even if they did not mind being excluded from the general public:

“They have got a school centre at Parkside, but their sessions for disabled people to swim are on a Sunday, and that is not convenient.”

(Joy)

Disabled people are often still being segregated by having to join in sessions for disabled people arranged by service providers. In doing this they are regulating disabled bodies to conform to what service providers and society want to offer:

“We have a swimming pool in Newport Pagnall, they hold two disabled swimming sessions a week. A lot of disabled people want to be integrated with able-bodied individuals.”

(Val)

But for some individuals it is important to exercise in a ‘safe environment’. During ‘Carries’ interview she told me how it is important for her to exercise in a safe environment. Although she believes that integration is better than segregation, she does actually feel:

“...better in a safe environment of the hospital gym or swimming pool. I have people around me who understand my condition and are not likely to expect me to get out of the way quickly. But I still like to exercise with other people.”

(Carrie)

“There is plenty of choice when it comes to leisure facilities, the problem is accessibility.”

(Micky)

These were the words spoken earlier in this chapter by one of the participants in this study. The choice of leisure facilities for the general public is there, but the choice is taken away from disabled people when it comes to the issue of accessibility.

An important part of disabled people’s lives relates to the ability to gain access to particular places. Evidence suggests that the built environment is generally inaccessible to people with a range of physical and/or mental impairments, especially for people dependent on wheelchairs (Barnes, 1991; Imrie, 1996).

Local authorities have statutory responsibilities to regulate the provision of accessible spaces in new build and/or refurbished public and/or commercial buildings by enforcing national accessibility standards. Such standards are itemised in Part M of the Building Regulation (for England and Wales), which requires developers to provide “reasonable access for wheelchair users and for people with vision impairments and loss of hearing”.

Accessibility is the most obvious determinant, which may influence a disabled person’s decision to participate in exercise. The Disabled Person’s Act 1981 (DPA) made it a statutory obligation for the design of local authorities sports facilities to conform to minimum access requirements. There are some extensive measures (as listed by Haywood et al, 1995) that need to be considered. Any service, which a

service provider has provided or is prepared to provide to members of the general public, must be available to disabled people (DDA, 1995, 2005). If it is not it becomes an offence. But at the time of the interviews and 'user participation workshop' although participants told me that they felt the situation of accessibility was improving, there was still a problem for wheelchair users with access into shops and leisure facilities, restaurants and theatres. Oliver's (1996) social model of disability supports this when he states, "it is society which disables not the impairment". So if it is now an offence to refuse to provide any service, which is offered to members of the general public, why do wheelchair users still find accessibility a problem?

There needs to be access on equal terms with non-disabled people and this is seldom achieved (Heller et al, 2000). In practice, the idea of equal access is balanced with the realism of cost benefits (e.g., a lift to enable access to a water slide in a leisure complex) (Haywood. L, 1995).

Geographical and/or spatial terms of reference are important in understanding disabled people's lives. Imrie (2000) seeks to describe and account for geographical variations in local authority policies and practices in addressing disabled people's access needs in the built environment (Imrie, 2000). Although there are occasions when some disabled people can compete on equal terms with non-disabled peers (e.g., archery), in many cases the selection, modification and adaptation of sporting activities is necessary to make them accessible. Positive experiences and total involvement creates satisfaction, but this can only happen if the abilities and skills of the performer are commensurate with the modified or adapted challenge. All such

modifications are based upon an assessment of the abilities of the performer, together with the analysis of the psychomotor requirements of the sporting task. If there is congruence between the two elements, than accessibility is assured (Kew, 2000).

As well as public buildings being inaccessible for disabled people, participants found the experience of travelling by public transport often stressful and very frustrating:

“I wouldn’t even dare in a wheelchair; I mean it is just too scary.”

(Carrie)

This was the reply of one participant when I asked her if she had tried to gain access onto a bus:

“I am not sure of where the dropped curbs are, they are certainly not right in front of the bus stop. That might mean a five or ten minute detour to get to a dropped curb. You could get half way through your journey and find your next bus is not accessible.”

(Carrie)

Carrie continued to tell me of her experience when travelling one time by train to Leicester:

“Using a train can be quite frustrating because you have to book your journey two days in advance, if you need to get wheelchair ramps. Sometimes you’re

kind of stressed because you cannot see the porter, and you think 'how am I going to get off the train'? Quite often there is someone sitting in the accessible space, which is meant for a wheelchair. So you have to move people along, you cannot see the window from where you are sitting in the wheelchair spot so you do not know if the man is coming with the ramps so you don't necessarily know that they are going to look out for you when you get off the train or not? Oh, it's traumatic."

(Carrie)

Only being able to get onto those buses which are accessible, and having to book wheelchair ramps at railway stations two days in advance does not make an accessible society, but would appear to be a form of regulating disabled bodies (Goto, 2004).

Six participants told me that they used the community transport system 'Dial a Ride' which is accessible to them. For some disabled people that is their only means of transport if they live in a village in the countryside:

"That is our only method of transport because we don't drive. There are some taxis in Bedford but who can afford them, there are some black cabs that you can get that are wheelchair accessible, but you are sitting sideways in them and a lot of people feel nauseated when they have to sit sideways. And also we have tried but we can't afford the taxi fare."

(Annie)

One of the problems with a community transport system like 'Dial a Ride' is, as this participant put it:

“Dial a Ride can take me in my chair to wherever I want to go in Bedfordshire, but you have to ring up a week in advance and I cannot always do that. So I have never used them.”

(Lena)

As well as public transport, acquiring a motorcar that is accessible and suitable for the needs of a disabled person can be problematic as very often the seats are too high or too wide as this participant explained:

“I am limited to what car I can get into because I am only short. The seat is usually too high and I have to pull myself up.”

(Joy)

Another participant said that transferring from her wheelchair into a car could be difficult unless the doors are big enough. It was very difficult finding a car that she could get into:

“I cannot actually get into the car on my own, I am a lot better now but it has taken a long, long while to get there. A friend came up to see me and I could not get over how easily she got into her car and out of it. I discovered that a lot of it was to do with the sliding board she used. The sliding board I had was plastic and it did not help me slide very much. I looked at her light wooden boomerang board and it was so much lighter. I was able to get in and out of other peoples cars then as long as the doors were big enough.”

(Paula)



Twelve participants said they had a specially adapted car as transport was not really accessible and taxi services were double the price when they are wheelchair accessible. But sometimes having their own car did not always give them the freedom to travel when they wanted to if they had to rely upon somebody else to drive them, if they were unable to drive themselves:

“I have a vehicle that has been adapted but my mum has to drive it and that annoys me immensely.”

(Lena)

It can be frustrating to have to depend upon family or friends or other people to drive the car if disabled people are unable to drive it themselves. Participants also expressed the importance of having the correct design of car in order for it to be accessible for the individual wheelchair user.

Participants felt that car manufacturers could design a better car that has better access for wheelchair users. Sometimes the seat can be either too high or too low and the wheelchair user cannot slide from their wheelchair onto the seat inside the car. One carer at the ‘user participation workshop’ spoke of his wife when he said:

“She never did get into our standard car.”

(Gregg)

This was because being totally dependent upon her wheelchair it was not possible to transfer from her wheelchair onto the car seat by means of a hoist. This participant found that after going from one manufacturer to another:

“Nissan seem to be ahead in this department. It is the only one I can get into. I have foot pedal adjustments on my car; it is a plate that fits in front of the pedal. It screws on, and if my carer wants to drive the car she just takes it off. It has got a lip on the front window and across the top and I can actually, I get this leg in first and I pull myself in. I use this hand to hold me up to lift me over the wheel to get in.”

(Paula)

This seemed quite a performance in order to get into the car but she felt that it worked well for her. When Paula asked one of the other participants, who did not have a carer with her, how she got into the car, she replied:

“I don’t lift my chair I roll it. I gain access to my car using a hook and pulley system. I have a three door automatic car with full hand controls. As I am not aware of what my feet are doing, my foot pedals are on a spring, so when you need somebody else to drive for you they just push them down, so they can drive the car. But to get in I drop my chair onto the board and bolt the chair up. I have a block of wood behind the driver’s seat. So I have wheels on that and I just pull it in. I have a top box fitted on the car.”

(Val)

“and so you put it up on the roof?”

(Gregg)

“Well you sit in the seat and just fold the chair up and put it onto the hook and it takes it up.”

(Val)

This interested Paula:

“But you have got to have that type of chair that clamps flat to go up on the roof. But if you have one like mine they haven't got the facilities to put it on the roof. Because you can do it with a pulley can't you?”

(Paula)

Val answered by agreeing that you could do it using a pulley system. This seemed a much easier and straightforward way of handling the wheelchair.

The last part of this section on structural barriers explores the use of a wheelchair and acquiring one that is suitable, the type of wheelchair that participants used, having power-assisted wheels and the skills needed to be acquired for new users of wheelchairs.

One participant told me during his interview that he had an electric wheelchair onto which had been fitted a little control box. This control box operated all the doors in the house which each had a motor on the bottom of them. By having the house electrically wired up it gave him the ability to move around his home in his chair,

between visits from his carers, and this gave him independence. The attitude received from some non-disabled people can be upsetting for wheelchair users. Another participant has had her chair built for her because it has to be high to support her neck. She has found that some bus drivers have been known to get awkward when transporting her in her chair onto the bus:

One driver said it is an awkward wheelchair because it has been built for me.”

(Sheena)

Electric wheelchairs can be very expensive to buy but they are supposed to be able to do many wonderful things. This participant explained how her wheelchair was supposed to help her to stand in the standing frame. It was excellent at first for going to the dentist and doctors:

“I had my chair serviced every year and it was very highly insured. I have already had two new wheels, now another wheel has fallen off, and it has taken away all of my confidence. I was down at Budgens, I had a harness holding me in, and luckily my brace holding my legs in you see, and the wheel fell off and the chair fell over with me in it. It is so heavy. But it is going now. It has been going wrong every year.”

(Paula)

From the 18-wheelchair user participants interviewed, only three used an electric wheelchair, whilst the other 15 used a manual one. The reasons given for using a

manual wheelchair were mainly to stay fit. It enabled participants to keep the upper part of their bodies strong and healthy:

“You see I could have had, you see it’s very important the arm strength because I could have easily have had an electric wheelchair but I didn’t want one. I wanted to keep my arms strong and because I love swimming and I enjoy sport and I just wanted to keep really fit. I have these tiny side guards just to keep my hips in place. It is easier to slide too.”

(Jenny)

But now with damaged shoulder cuffs [Rotary Cuff Injury] this participant was finding it very difficult to get around using a manual wheelchair and he felt that he has decreased in his mobility since he has had to give up exercising:

“I cannot push as far, and I cannot push as hard as I used to in a manual wheelchair. But I will not use an electric wheelchair.”

(Joe)

But he cannot exercise now due to the pain that he is in, and when I asked him if using a manual wheelchair affected his shoulder cuffs, he replied:

“Oh yes it does very much so, it hurts. But it is something that, I wont give in to. I want to get my shoulder cuffs done.”

(Joe)

Power assisted wheels on wheelchairs can be of great use if individuals are unable to propel themselves. Participants in this study told me that the reasons why they may not be able to propel themselves could be that the chair is too heavy for them or it could be due to a weakness of their muscles or perhaps due to a hand or shoulder injury as a result of many years vigorously propelling a wheelchair (Koontz, 2002). Also it can be due to health problems requiring an operation, which during that time of recovering from the operation the muscles can weaken, making it difficult to propel:

“I have a standard chair and I have ordered powered wheels to go on it. They weigh 20lb in weight. You have a battery on the back, they are heavy and if I am going out with someone who can't lift my chair into the car, then I put the ordinary wheels back on.”

(Val)

Paula thought:

“It gives you a bit of a zip.”

(Paula)

Paula told us at the 'user participation workshop' about her lovely wheelchair, which had just one problem:

“I bought a lovely little electric wheelchair it does not stand me up or bend me back, it is just for indoor and outdoor use but it doesn't go up a very steep curb. It has got lights on it as well. But it is bulky. My bungalow is big but there isn't anywhere really to house it. Why can't they make equipment that is not bulky?”

(Paula)

The problem with wheelchairs is getting one to suit the individual's needs. They can be lightweight, heavy, bulky, too high, too low, electric or manual with power-assisted wheels, or without. It is finding one that is suitable and this can take quite a long time. Often there is help available towards the cost of purchase, but the general public are not always aware of what benefits and resources are available to them. Once a suitable wheelchair has been obtained the individual then has to start negotiating obstacles and learn how to overcome them.

It was suggested during the 'user participation workshop' session that new skills were needed when wheelchairs were allocated to new users. For example negotiating slopes could pose major difficulties until the technique has been mastered. Another skill that has to be mastered is how to get through many of the doors in our present day society.

As Paula pointed out:

“Curbs and shops and doors that are too heavy. We have a modern leisure centre where I live, yet the doors are not automatic, and they are very heavy doors, and so difficult to push.”

During the interview with Annie, the problem of accessibility into shops was being discussed and she told me the problem she experienced trying to get her manual wheelchair between the rows of clothing that had been rammed into the shop so tightly. When I mentioned if she would have to take a detour, if any other customers had stopped to look at anything, she responded:

“No I just go straight through and if the rack comes with me then that is the shops fault for putting it there. It is not usually in the same place when I visit the same shop next time.”

(Annie)

Participants reported that there are many problems for first time wheelchair user's, these include heavy doors that need to be pulled open, handles that are too high, and the spring on the door too strong making it very difficult to hold.

### **Attitudinal Barriers**

“People that know us do not patronise, people that don't know us, do.”

(Jean)

Most participants felt that they were admired and respected by their friends and family with regards to their decisions to exercise. But they found that the attitudes of service providers and members of the general public to be very negative at times and sometimes patronising. This can cause disabled people to feel self-conscious.



When I asked Jean what kind of things people said about her and whether she gets that attitude more from service providers and shop assistants rather than the general public she replied:

“Well I have had people pat me on the head and ask me if I am alright, or ask my daughter ‘is she alright today’? and I am sat there you know. I get that sort of thing... I mean I went into a shop in Milton Keynes and I bought a pair of shoes and the girl in there asked my daughter if I wanted polish for them? I was paying for them.”

When discussing during the interview whether or not she felt that other people accepted her, this participant felt quite strongly about how service providers and members of the general public are very naïve in respect to knowing how to best offer help to a disabled person:

“At the hospital yes, you know I feel accepted there, that’s fine. At leisure centres and things, it’s different. If I go out somewhere and somebody is naïve or they don’t quite do it right I’d rather try and be polite and explain to them how it’s easier for me, or what I need or what my needs are than to kind of be sulky or snappy about it. The way I see it is if you can change someone’s mind and get them to see how best to assist a disabled person, how best to ask, then hopefully the next person who comes along they are going to

do it right for them and so really sort of out in general public I'm kind of on my guard so I feel confident that I can deal with a situation if it comes up."

(Carrie)

The attitude of service providers can be very negative toward wheelchair users. This can cause the individual to feel self-conscious. Service providers can also be patronising as Carrier went on to explain:

It's the staff really, you know if someone is not comfortable when dealing with someone in a wheelchair or sometimes people are really helpful but they are really patronising."

(Carrie)

Kew (2000) acknowledges that there is still far greater awareness needed amongst service providers to gain a greater level of understanding regarding disabled peoples needs. He goes on to say that organisers of exercise facilities, coaches and sports providers having had little opportunity to work with disabled people, are unlikely to have a full understanding of the specific challenges facing disabled people. The general public come across as being very naïve in respect to knowing how to best offer help to a disabled person.

In their study, Furnham & Thompson (1994) compared the attitudes towards wheelchair users of non-disabled people with people who actually use a wheelchair. They also examined the difference between how each group perceived the attitude of

the other towards this condition. The results of the study revealed that the wheelchair user group was found to believe non-disabled people to hold a more negative attitude than they actually expressed. A few age and sex differences were found, as well as a number of differences depending on whether the respondents had congenital or acquired disabilities. The amount of contact with those using wheelchairs was found to be associated with slightly more realistic attitudes among the non-disabled respondents. It was found in their study that with regard to wheelchair users, there are prejudices, which need to be broken down, and turned into acceptances to wheelchair users.

Disability awareness and acceptance needs to start at a young age, and can, as was told in an article in "The Whizz Kids" publication (2001). The editor of the article talked to non-disabled teenagers about their antipathy towards disabled people. The editor states that what research had been undertaken, however, has proved that for a non-disabled young person to have first hand interaction with a disabled young person, whether that be at school or in an extra curricular capacity, has a positive impact on the way they interact with other disabled young people. Sometimes the presence of their powered wheelchair can play an important role in breaking down barriers and this can act as a talking point.

It was mentioned by many participants in my study that young children are often curious about a disabled person's wheelchair, but the parents of these children often pull them away telling the child not to trouble them. The lack of understanding from some non-disabled people reflects their attitudes towards people who use a wheelchair for their main means of mobility.

This is highlighted in my study when disabled people are being avoided and the person who is with them is asked a question, which, the disabled person is fully capable of answering him or herself:

“It’s just getting peoples attitudes to change.”

(Annie)

Disability awareness training is a way of changing attitudes and confronting myths and misconceptions about disability, which stem from a lack of understanding (Kew, 2000).

“I don’t know why it is, a lot of people cannot look you in the eye when you have got a disability. I don’t think it is because of being rude, I think it is just they are embarrassed most of the time.”

(Jean)

Some participants said that there was often a lack of eye contact. They said non-disabled people seem to find it difficult to look a disabled person in the eye. They felt that the reasons for this were due to embarrassment and sometimes not knowing how best to help a disabled person. Responding to deep-rooted psychological fears of the unknown, Douglas (1966) argues that ‘primitive’ cultures react to ‘anomalies’ such as impairments, by reducing it, physically controlling it or avoiding it.

During the 'user participation workshop' participants talked about attitudes and acceptance toward them by non-disabled general public. It was commented upon about the fact that non-disabled people will just stop dead in front of a person in a wheelchair, whether it is a manual or electric chair, they just stop dead. As one participant said:

"They don't see you until they are on you."

(Paula)

Another participant and her carer had problems on one occasion when shopping in a busy store. Her carer told the group:

"I have been pushing Dora in Bedford and you have got like a crowd in the shop and they will just stand and watch you struggle."

(Gregg)

The other carer in the group, who was privately paid, told the group that she was very aware how individuals and the general public perceived wheelchair users, often avoiding eye contact and she said:

"There is still also this 'Does he take sugar', attitude. When non-disabled people will not ask the disabled person the question but will ask instead the carer (mother, father, husband, wife) who is with them. I feel it is not just

with wheelchair users though, whether I have my elderly father with me or my teenage daughter, I can be asked a question about them when they are right next to me.”

(Sue)

But maybe the problem of not making eye contact or asking the person direct is not just with the non-disabled general public. This participant told the group how she was not always able to make eye contact with people:

“I look at the person and I go blank. If I am talking about something that I am not sure of and I have to think about it, I look at the floor when I am talking to somebody. I cannot actually look at the person. I go blank. If I was having to think and talk, I would have to look away.”

(Paula)

As Kew (2000) points out, when he quotes from the Scottish Sports Council (1994);

In the case of a person who is disabled, the more visible and obvious the disability, the more likely it is that the disability will become the main focus of attention of that person. Such assessments are rarely accurate, and often result in the disabled person feeling patronised, inadequate and dependent. On the other hand, when we perceive and expect a person who is disabled to be resourceful, with a potential for a full and rewarding life, independence and life can be enhanced (Kew, 2000, p112).

This negative attitude towards disabled people is a long-lived problem and goes back in history as far back as the bible. It can affect a disabled person's daily life in many ways, not just exercise participation. A negative attitude from employers can affect a disabled person's employment needs as well as affordable living accommodation.

This in turn could have a negative impact upon the whole of their lives.

The attitude of other people was noticed by nearly all of the participants. Many of them commented that although children are willing and wanting to learn from wheelchair users, their parents are preventing them from doing so by pulling them away as this participant goes on to say:

“Well my buggy is bigger than their buggy. The parents are very embarrassed when the child asks me ‘why are you in a buggy like me’? ‘You should not ask these questions’. Well why shouldn't they? You know they are not going to learn otherwise.”

(Annie)

There is still the attitude ‘does he take sugar’? People will ask the person who is with the wheelchair user the question, as though the disabled individual is not there. They see the chair and very often not the person who is sitting in the wheelchair. Also people will stop, and stare. This can make disabled people feel very self-conscious about their bodies:

"Puts a curb on it."

(Carrie)

Carrie went on to say that when she was swimming with non-disabled people, this is how she felt, as she is aware of people looking at her and this makes her feel self-conscious, although exercise itself made her feel pleased with her body. Like Blumberg's (2006) study of 'The Body Project' which studied a group of adolescent girls in America and how their eating, sexual habits and menstruation had a vast effect on their body image, disabled people are often affected by being stared at and the negative attitude toward them by non-disabled people. It can make them self-conscious and lower their self-esteem, which in turn affects their perception of their 'body image'.

When this participant was asked during her interview if she had any issues about body image she was very confident when she told me that using a wheelchair was just an extension of herself and that she had a very positive image about herself:

"I am dressed as smart as anyone else in fact I am dressed smarter than some people on feet. I think my image is quite good."

(Jean)

In contrast, one participant, who is normally a very confident individual and accepted by others, told me that when he goes swimming he is very self-conscious:



“Conscious, I am very conscious. One of the things that I am conscious of is my body in a sense that I’ve been, I’m not the most body beautiful, you know I’ve got various bits of equipment here, there and everywhere. When I go swimming and stuff like that I am very self-conscious I have got to peel off my cloths and go in and obviously it comes then to the issue of, I have got to get into the swimming pool and just quietly slip into the pool without anyone knowing. It is such a palaver because then you have got to get out of the ‘flaming’ swimming pool. I cannot just ‘get out’. I have to have someone there to hold the wheelchair or whatever. I get very conscious too of people starring at me in the swimming baths. I feel that people are looking, you know, an invalid. I say it as I feel; you know that’s how I feel at times.”

(Micky)

He went on to tell me that he was fine when he was fully clothed, it was the fact of having to get undressed in changing rooms that had no privacy because you get non-disabled people walking in and out, and he said he felt that it:

“Was not very nice if a disabled person has a catheter bag and a body belt. Non-disabled people look at you and it isn’t nice.”

(Micky)

He felt that some sort of private changing area was needed to help overcome this situation.

We have seen from this section that attitudes of non-disabled people against disabled people can have a very negative impact upon a disabled person's self-confidence and self-esteem creating barriers which prevent disabled people from having an accessible society in which to live. Participants in the 'user participation workshop' went on to speak about how disabled people are badly portrayed on the television:

"Television soaps rarely give a true picture of life in the wheelchair."

(Val/Paula)

Participants in the 'user participation workshop' felt that public attitudes could be improved by a better representation of wheelchair users in the media. They felt that wheelchair user action groups or wheelchair actors could be used. This carer was quite impressed with a new comedy show:

"It is on a Friday night with Jasper Carrot. It starred a young male wheelchair user who had a voice box fitted."

(Gregg)

This carer was impressed with this show because it portrayed true life of a person in a wheelchair. The group suggested that the attitudes towards disabled people could be helped if disabled people were able to take a more active role in the media. For instance starring in television programmes or speaking on the radio.

## Physical Barriers

In the last part of this section participants discussed the physical barriers preventing access. These barriers are health problems and the level of pain which some disabled people suffer:

“I can't push as far, and I can't push as hard as I used to in my manual wheelchair. I won't use an electric wheelchair.”

(Joe)

Having major surgery can be a problem for a manual wheelchair user's continued independence. If the operation is not successful or if it takes a long time to recover from the operation a wheelchair user may lose the strength in their arm and shoulder muscles. It is not just exercise that some individuals found themselves unable to participate in anymore, it is being able to use the wheelchair as they used to. Often years of constant propelling of a manual wheelchair can cause shoulder pain and damage. Koontz (2002), state that wheelchair propulsion has been implicated as a causative factor in developing shoulder pain and injury. An estimated 30-75 per cent of manual wheelchair users will develop shoulder pain during their lifetime.

One participant in the user participation workshop told the group that dealing with constant pain needed an awareness of what medications were available to alleviate some of the pain intensities. She told the group that she used a 'pain clinic'. A pain clinic is for the management of pain by use of drugs and giving them time to work.

Pain management over time can help with spasms and neurological pain but it cannot help with all pain. The group felt that exercise was beneficial to themselves and other people but as they got older, health problems could often make it difficult to participate in exercise. Physiotherapy was found to help with regards to circulation and the ease of spasms.

The social model of disability claims that it is 'society' which disables a person, not the impairment. But pain can sometimes be very difficult to cope with. An important part of disabled people's lives relates to their ability to gain access to particular places. Evidence suggests that the built environment is generally inaccessible to people with a range of physical and/or mental impairments, especially for those dependent on wheelchair use (Barnes, 1991; Gleeson, 1999; Imrie, 1996). Oliver (1996) expresses strongly that:

“they have been denied inclusion into the society because of the existence of disabling barriers.”

(Oliver. 1996; p106).

It becomes strongly apparent from writings of Massie, (1994, 2001); Roulstone, (2002); Sapey, (2000); and Piggott, (2005), that whereas medical science is limited in its ability to cure some people's impairments, society can reduce the architectural and attitudinal barriers that restrict disabled people from getting on in life and hence ease the amount of physical pain a disabled person may suffer. If buildings and institutions were planned in a manner, which took account of the needs of every

citizen, including those with impairments, the effects of disability would be significantly reduced (Oliver, 1996).

Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers (Barnes, 1993). But if society were arranged in such a way that the functional loss had no impact, there would be no restriction or disability (Massie, 1994).

## **Conclusion**

In conclusion, the quantitative and qualitative data revealed some very important factors that influence a disabled person's decision whether, or not, to participate in exercise activities.

Disabled people incur financial limitations due to being in receipt of benefits or in low paid employment. The cost of exercise can far exceed the disposable income which, disabled people have to spend on leisure and exercise. Disabled people have to pay the same entrance fee to use leisure facilities whether they are in receipt of benefits or in paid employment. Once inside the leisure centre the facilities are not always available to disabled people often due to the lack of finance or low resources.

Participants in this study found that often facilities (e.g., a hoist), are not electrically charged ready for them to use at their leisure centre, this can be seen as a way of 'regulating' disabled bodies. This creates a lack of choice and participants often found themselves segregated from joining in with non-disabled exercisers.

Travelling on public transport is very expensive and the inconsistency across the nation of concessions on fares to travel again 'regulates' disabled bodies.

Disabled people need additional requirements. These additional requirements include the cost of equipment to help with mobility in the home, wheelchairs, adapted motor vehicles and expensive medication. These can often exceed the disposable income, which disabled people have to spend.

At the time of this study, employers still had a very negative attitude toward disabled people, looking at their disabilities rather than the abilities and skills, which they can offer the company.

Participants in this study felt that exercise was beneficial to themselves or other people, socially, psychologically and physically regardless of their age. This study showed that participants who received social support and encouragement to exercise from friends, family and/or other people such as a doctor or physiotherapist, are much more likely to participate in exercise activity than those who do not receive any support.

There is still a lack of important information regarding financial benefits, leisure facilities and the purchasing of resources and receiving of advice for disabled people. Often the only means of access to information is by 'word of mouth'.

Participants in this study said they felt a lack of control over the use of equipment, and whether or not vital equipment in leisure centres is ready for use. They also felt a

lack of control over the purchase and positioning of equipment at a leisure centre. This inaccessible society causes a lack of choice and disempowerment for disabled people, and can be seen as a way of 'regulating' disabled bodies.

Often disabled people are looked upon as not being able to contribute fully to society, leaving them to feel that they are of little worth and merely deserving of help.

Another example of 'regulating' disabled bodies can be seen from this study when participants explained how they feel they have lack of control over when they can exercise. Management of leisure centres arrange allotted times, off peak, when disabled people can use the leisure centre and this often segregates them from participating in exercise with non-disabled people.

The 'social model of disability' has liberated disabled people and the provision of needs of disabled people received a boost with the passing of the Disability Discrimination Act (1995), which attempts to deal with a wide range of issues concerning the way disabled people are treated and their statutory entitlements to many services and facilities made available to non-disabled people. But participants in this study still found there was a negative attitude toward disability from the general public and service providers, and this can harm their self-esteem and confidence and affect their social inclusion.

## **Chapter 5**

### **Conclusions**

In chapter four (findings and analysis) the findings of this study were presented under five themes: “Cost of Disability”, “Why do people Exercise?”, “Access to Information”, “Politics of Disablement” and “Inaccessible Society”. These themes were set within the context of ‘Sociology of the Body’, and ‘Therapy Culture’, and the framework of the ‘Social Model of Disability’.

In conclusion, data collected from questionnaires, face-to-face semi-structured interviews and the user participation workshop revealed some very important factors that influence a disabled person’s decision whether, or not, to participate in exercise activities.

Because I have used the ‘social model’ of disability all the way through my research, I will now be drawing conclusions from the analysis of my research and presenting these factors using the main fundamental features of the ‘social model’ of disability which concern: economics, social support, information, equality, physical structures and attitudinal barriers.



**Economics**

The social model of disability proposes that barriers and prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society.

The social model also proposes that people can be disabled by a lack of resources to meet their needs. It addresses issues such as the under-estimation of the potential of disabled people to contribute to society and add economic value to society, if given equal rights and equally suitable facilities and opportunities as others.

This study showed that disabled people were still being discriminated against when it came to employment opportunities, with no provision being made to make it possible to access a building in order to attend a job interview.

In the United Kingdom, the Disability Discrimination Act defines disability using the medical model – disabled people are defined as people with certain conditions, or certain limitations on their ability to carry out 'normal day-to-day activities'. But the requirement of employers and service providers to make 'reasonable adjustments' to their policies and practices, or physical aspects of their premises, follows the social model. By making adjustments employers and service providers are removing the barriers that disable – according to the social model; they are effectively removing the person's disability.

Disabled people incur financial limitations (a cost of disability) due to being in receipt of benefits or in low paid employment. The cost of exercise can far exceed the disposable income which, disabled people have to spend on leisure and exercise. It was pointed out by one participant in this study that disabled people have to pay the same entrance fee to use the leisure centre facilities whether they are in receipt of benefits or in employment. When participants could afford to use their leisure facilities, they often found that the range of facilities on offer to them were not accessible to them once they were inside, and this created another 'cost of disability'.

As mentioned earlier the social model of disability proposes that barriers and prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognises that while some people have physical, intellectual, or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal'.

Disabled people have the same human and civil rights as non-disabled people but they have additional requirements. These additional requirements can be very expensive and can include the cost of equipment, wheelchairs, adapted motor vehicles, and medication. The additional requirements a wheelchair user would need in order to participate in swimming for example, include an electric hoist in order for them to gain access into the swimming pool, a shower chair in order for them to use the shower room, and a larger changing cubicle, as often disabled people have a carer with them to help them dress and undress. But as shown in this study, very often the

hoist may not have been electrically charged, or a shower chair not available, or the changing cubicle is too small, and can lack the privacy disabled people are entitled to. Disabled people may also need assistance in the leisure centre to help them with their mobility. But leisure centres very often do not have the finance to purchase extra equipment or the resources available in order to meet disabled peoples needs once inside the leisure centre. Participants felt that they had lack of control over how money that was allocated to leisure centres was spent. It is often used to purchase new resources and facilities, which are not accessible to disabled people. But disabled people are entitled by law to have full use of the facilities, which are on offer to the general public.

In 2006, amendments to the Disability Discrimination Act called for local authorities and others to actively promote disability equality. The DDA (2005) made it a legal requirement that any provider of goods and service providers who offer a service to the general public must make it accessible to disabled people.

When the social model proposes that people can be disabled by a lack of resources to meet their needs it does not just refer to employment, or exercise equipment at leisure centres, but can also be applied to the cost of travelling on public transport. Many disabled people find that having to arrange to travel by train or community bus service in advance 'regulated' when disabled people travelled. This creates a lack of choice as to whether or not disabled people participate in exercise activities, as many do not have their own motor vehicle. When access onto public transport is possible, many disabled people cannot afford the cost of the fares, especially when they are on benefits.

Additional requirements far exceed access into leisure facilities or transport, also the cost of equipment to help with mobility in the home, wheelchairs, and expensive medication often far exceed the disposable income which disabled people have to spend. As disabled people are still at a disadvantage when it comes to employment, this makes it very difficult for them to have the same spending power as non-disabled people, as they often earn less than non-disabled people and the percentage of disabled people who are not in employment is higher than that for non-disabled people. They can find themselves earning £200.00 less per week than the amount they require in order for their needs to be covered.

According to the social model, disability is shown as being caused by 'barriers' or elements of social organisations, which take no or little account of people who have impairments. This was certainly the situation presented during this study.

### **Social Support**

The social model of disability often focuses on changes required in society. One of these is social support. Data collected from this study has shown that participants who received social support and encouragement to exercise from friends, family, and/or other people such as a doctor or physiotherapist are much more likely to participate in exercise activity than those who do not receive any support.

Support is not just from friends. The social model of disability suggests changes required in society can include help dealing with barriers, resources, aids and positive discrimination to overcome them. Disabled people often feel at a loss for all the

things they would like to do but cannot; a loss of goals and dreams that seem unobtainable. Some of these goals involve exercise. Previous research and data collected from this study has shown that there are social, psychological and physiological benefits to be gained from regular involvement in exercise.

Data collected from the questionnaire, showed that participants in this study, regardless of their age, felt that exercise was beneficial to themselves or other people, even if they did not participate in exercise themselves. Participants who received physiotherapy felt that it was necessary for the physiotherapist to be involved with their exercise programme at all times as many had been left with exercises to do on their own and after a short time participants either lost the motivation to continue or they did not have the ability to lift their legs on their own and so were unable to continue with the exercise programme. The social model suggests disabled people need help dealing with circumstances such as these.

But despite the different barriers that society erects, and lack of help with dealing with resources, aids or positive discrimination to overcome them, this study showed that there were many reasons why participants in this study liked to exercise. They exercised in order to keep the upper part of their bodies strong, so they were able to continue using a manual wheelchair, and keep their independence.

Disabled people often feel they are a burden on family and friends, and a problem for doctors who cannot cure them. But participants in this study were more likely to participate in exercise activities when they received social support and encouragement from family and friends. Many participants in this study exercised to prevent health

problems from worsening and to help relieve the problem of 'spasms', whilst others exercised to keep their bodies fit and strong, as 'body image' was so important to them. Some of the participants often felt that non-disabled people were staring at them, or they themselves felt embarrassed when in a swimming pool or leisure centre because of the various pieces of equipment they had to use. The social model of disability focuses on changes such as anti-discrimination and positive attitudes to overcome problems such as these negative responses to disability.

But disabled people can also feel patronised by attitudes of non-disabled people who do not always know the best way to help them with regards to their needs. The traditional view of disability is the 'Medical Model of Disability', because it sees people as medical problems. As a result disabled people are expected to see their impairment as their problem, something they will have to make the best of and accept that there are many things they cannot do.

The 'social model' of disability enables disabled people to look at themselves in a more positive way, which increases their self-esteem and independence. In this study participants who participated in exercise prior to becoming disabled were more likely to become involved in exercise again once they became disabled. The reasons for this were that they understood their physical limitations and abilities and understood the benefits to be gained from regular exercise activity.

Exercise can increase a disabled person's level of self-confidence both in exercise involvement itself and also with daily living. Many exercise to help prevent the onset of age related problems that can occur, whilst others found that as they got older they

acquire health related problems with their shoulders or wrists, which have resulted from many years of vigorous hard propelling of a manual wheelchair.

Society is shown to disable people who have impairments because the way it has been set up prevents disabled people from taking part in everyday life. It follows that if disabled people are likely to be able to join in mainstream society, the way society is organised must be changed. Removing barriers, which exclude (disable) people who have impairments, can bring about this change.

### **Information**

The issue of information is another area, which needs to change according to the social model of disability. The social model focuses on changing the way information is conveyed to disabled people, for example using suitable formats (e.g., Braille), or levels (e.g., simplicity of language), or coverage (e.g., explaining issues others may take for granted).

Data collected from this study showed that there was still a lack of information regarding financial benefits, leisure facilities, and the purchasing of resources and receiving of advice made available to disabled people. Many of the participants in this study did not know what financial benefits they were entitled to; in this instance there was not enough coverage of this vital information. Many disabled people do not know how to go about getting specialist equipment and resources that are vital to aid their mobility. Participants in this study had found it very difficult to get advice about acquiring the correct type of equipment for their needs.

The internet is now host to much information regarding benefits: access to public transport, concessions on fares when travelling, and the employment regulations for disabled people and much more, but many disabled people do not have access to a computer, so the problem of access to information still exists for some disabled people, because of a lack of communication between the provider of goods and services and disabled people. Very often the only means of access to information is by 'word of mouth'. Participants in this study felt that 'nobody tells you these things'. Even when participants had worked for some of the organisations run for disabled people, it was often only 'word of mouth', and sometimes information was received far too late.

Very often there is little information made available with regards to exercise involvement for leisure and enjoyment, with limited assistance at the leisure centre. The 'social model' has liberated disabled people and the DDA (1995, 2005), have made it a requirement for 'any goods or services which are made available to the general public must be available and accessible to disabled people'. Although in 2006, amendments to the DDA called for local authorities and others to actively promote disability equality, we are yet to see if this means the social model of disability will be more regularly observed.



## **Equality**

The social model of disability implies that attempts to change 'fix' or 'cure' individuals, especially when against the wishes of the patient, can be discriminatory and prejudiced. It is often contended that this attitude, often seen as stemming from a medical model and a subjective value system, can harm the self-esteem and social inclusion of those constantly subjected to it (e.g., being told they are not as good or valuable, in some overall and core sense, as others).

This study found that disabled people are often looked upon as not being able to contribute fully to society leaving them feeling that they are of little worth and merely deserving of help. Participants in this study felt disempowered when it came to employment. As mentioned earlier, the employment rate is higher for disabled people than it is for their non-disabled peers, and when they are in employment they are in lower paid jobs than non-disabled people giving them lower spending power.

Employers often look at a disabled person's disability. The social model looked toward a solution of educating employers to look at the abilities and skills that disabled people can give to the company, not their disabilities. Now that we have the 'Access to Work' scheme disabled people cannot by law be discriminated against regarding employment opportunities.

Participants in this study also said they felt a lack of control over the use of equipment, when somebody else was in control of that manoeuvre. This could be either in their own home when they have to be moved by use of a hoist, or at a leisure centre when they want to go swimming and find that the hoist that lowers them into

the swimming pool has not been electrically charged. Although the management of the leisure centre has not verbally told the disabled person they are not as good or valuable as non-disabled people, it is indirectly being implied. That would appear to be the case when no explanation or apology is given as to why the hoist has not been charged. This harms disabled peoples self-esteem and social inclusion with other people who are swimming. When management of leisure centres choose whether or not to make facilities available to those people who need it the most, this can be seen as a way of 'regulating' disabled bodies. This creates a lack of choice and disabled people often find themselves segregated from participating in leisure and exercise activities with non-disabled people, so they feel excluded by society as the social model proposes. This is also a sign of 'regulating' disabled bodies.

Participants also felt that they were segregated from participating in exercise activities with non-disabled people when they are given allotted 'slots' as to when they can swim or participate in other activities. This also socially excludes disabled people and can harm their self-esteem. They are being made to feel that they can only participate in exercise when management allow them to (i.e., off peak time).

There was also a feeling of lack of control over where certain facilities were positioned at leisure centres (e.g., a spa bath up a flight of stairs with no lift to enable wheelchair users to use it). An inaccessible society causes a lack of choice and disempowerment for disabled people. As Massie (1994) states;

“If disability is perceived as a social phenomenon, legislation, architects, and others who determine the shape of our built environment have a crucial role to play”.

Participants in this study also felt a lack of control over how leisure centres spent the money, which had been allocated to them in order to improve facilities and make them accessible for disabled people. A small thing like purchasing a ‘shower chair’ can make such a huge difference as to whether disabled people participate in exercise activities or not.

A fundamental aspect of the ‘social model’ concerns equality. The struggle for equality is often compared to the struggle of other socially marginalized groups. Equal rights are said to give empowerment and the ‘ability’ to make decisions and the opportunity to live life to the fullest. Participants in this study felt that they were often stared at because of their disability, feeling that they are judged by their physical appearance. Feelings of shame about the body can lead to compulsive dieting, exercising or bodybuilding to make the body conform to social expectations to improve the perception of their body image. Participants in this study were very aware of their body image, and many liked to exercise to keep fit and look good, whilst others were very self-conscious of their appearance. The social model of disability enables disabled people to look at themselves in a more positive way, which increases their self-esteem and independence.

Yet, as mentioned earlier, this study found that disabled people are often looked upon as not being able to contribute fully to society leaving them to feel that they are of

little worth and merely deserving of help. Previous literature and data collected from this study shows that today's society has made therapy into a way of life. Our culture conveys a story of a weak, feeble person, who is continually at risk, and for whom the chance of things going wrong are very great. It is easy for disabled people to become institutionalised and dependent upon professional care, when it would often be better to enable them to have control over the care they need and when they need it.

The 'social model' of disability has liberated disabled people, but in some countries an 'enabling' barrier free environment has often meant very 'regulated disabled bodies'. Examples of 'regulation' that can be seen in this study are: the structure of the public transport system, inconsistency of concessions on fares when travelling, access into leisure centres and the use of facilities once inside, and concessions for disabled people to use those facilities, sometimes only being available during off peak times of the day, and inconsistent across the nation. This inconsistency can lead to exclusion by society for some disabled people. A related phrase often used by disability rights campaigners, as with other social activists is 'nothing about us without us'.

### **Physical Structures**

Another change required in society as seen by the social model' is the physical structures. At the time of this study, it could be seen that society was still creating barriers onto public transport and into some buildings. In 2005 the DDA made it a legal requirement that any provider of goods and service providers who offer a service to the general public must make it accessible to disabled people. Participants in this

study found that once inside buildings (e.g., leisure centres) the facilities were often not accessible or available to disabled people. Management of these centres can decide when disabled people can use the facilities allotting them times when they can swim and this segregated disabled people away from the non-disabled general public.

But, barriers preventing access are not just structural as in buildings; there was also a problem when it came to the design of motorcars and wheelchairs. Participants in this study found it difficult to transfer from their wheelchair into a motorcar due to the doors of the car not being wide enough, or the seats being too low or too high. The 'social model' sees the term 'disabling' to refer to the restrictions caused by society when it does not give equivalent attention and accommodation to the needs of individuals with impairments.

### **Attitudes**

Another change required in society as seen by the social model, is attitudes. For example, a more positive attitude toward extra mental traits and behaviours, or not underestimating impairments.

Participants in this study found there was still the attitude of 'does he take sugar'? Participants often felt patronised by non-disabled service providers and shop keepers. Many non-disabled people still have a negative attitude toward disabled people and are unable to make eye contact with them. This can affect a disabled person's perception of their body image, causing them lack of self-confidence and low self-esteem. Participants in this study felt that the media (e.g., television soaps), do not

always portray a true picture of disabled people's lives and this can give the impression of disabled people being 'deserving of help'.

Disabled people have the same human and civil rights as non-disabled people, but it can be seen from previous literature and data gathered from this study that there is still a negative attitude towards disabled people, and as Oliver (1983) found in his 'Social Work and Disabled People', it would be so easy for disabled people to become dependent upon a professional for help, in today's society of therapy culture, as it was 25 years ago. The 'social model' of disability is helping disabled people to become liberated and receive equal opportunities to live life to the full, the same as non-disabled people.

## Chapter 6

### Recommendations

#### **Private Finance Initiative**

Organisers of exercise facilities, coaches and sports providers need to work closely with disabled people in order to gain a fuller understanding of the specific challenges that disabled people face in order to adequately meet their needs, to ensure that disabled people have equal opportunities to accessing sports and leisure facilities. But to be able to do this leisure centres and sports facilities need financial help, in order to purchase extra equipment and the resources necessary to cater for disabled people's 'additional needs'.

One way for leisure facilities to receive the financial help they need would be for borough councils to enter for 'private finance agreement initiative' (PFI) agreement credits from central government. This gives leisure centres the money to transform the councils leisure centres. A (PFI) initiative involves a public sector organisation entering into a partnership with a private sector organisation to deliver a service to higher standards and with greater investment than either could deliver individually. These partnerships are made possible through financial support from central government. Whoever decides to become the private financier needs to work closely with access groups and sports clubs for disabled people. This needs to happen consistently across the nation before all disabled people have equal opportunities in sport and leisure, thus enabling disabled people to accrue the benefits that regular exercise involvement has to offer.

### **Sliding Scale Pricing Policy**

Participants in this study reported that disabled people often have to pay the same entrance fee into a leisure centre regardless of whether they are in receipt of benefit or within paid employment. Therefore it was suggested that a 'sliding scale pricing policy' needs to be put in place to enable those on the lowest incomes to get into leisure centres for 'free'. Many councils do now have discount cards/schemes that are available for disabled residents. Some offer between 30%-40% discount, whilst others offer free admittance at certain times. But these discount schemes are inconsistent across the nation. Therefore councils and local government need to work together to arrive at a consistent 'sliding scale' policy, which will enable all disabled people on the lowest incomes to attend facilities free of charge.

### **Concessions on Public Transport**

In order for more disabled people to be able to participate in leisure and exercise involvement there needs to be consistent concessionary fares for disabled people across the nation, and a better accessible transport system.

From April 2006 disabled people were entitled to at least free 'off peak' local bus travel. From 1st April 2008 free bus travel has been extended to allow bus travel in every area of the country. So whether using the bus locally, or when visiting other parts of the country, disabled people will be able to travel free on the bus. But not all buses are wheelchair accessible and disabled travellers are advised to contact



'Transport for London Access and Mobility' when travelling in London, or purchase a guide published for disabled travellers, when travelling outside London.

Some districts have a scheme called the 'taxicard'. This subsidises the cost of taxi's for people with serious mobility problems who cannot use public transport. But there is also inconsistency across the nation regarding concessions for Taxi users, and this needs to be tightened up in order for all disabled people to be able to afford the fare. More schemes like the 'taxi card' need to be put into place across the nation or disabled peoples allowances need to be increased in order for them to be able to afford the high fares. Funding for this would need to come from central Government.

Half price coach fares are offered to disabled people through 'Department for Transport', but when a disabled person plans to travel by coach they need to contact the operator to see if the facilities exist to meet disabled people's needs.

When travelling by train a disabled person can purchase a 'disabled persons railcard', which will allow them to buy discounted rail tickets. The railcard costs £14.00 per year and the user gets one third off the price of a rail ticket.

Since 1998 all trains operated by Northern Ireland Railways are accessible to disabled people, but on the British mainland if you are a wheelchair user and need help to get 'on' and 'off' the train, you need to contact the train operator and give at least 48 hours notice of when you intend to travel in order to arrange for a porter to be at the station with the ramp in order to board the train.

Whether a disabled person travels by bus, taxi, coach or train, the concessions vary and so does the accessibility. This needs to be tightened up by 'ministry of transport' & 'Transport for London access and mobility', in order for disabled people to have the freedom to travel wherever they live and the empowerment they are entitled to.

### **Raising awareness in Disability**

Raising awareness in disability could help in dealing with the negative attitudes towards disabled people which have been around since the time of the Bible. 'Special Stories for Disability Awareness' published by Kingsley Publishers, provides stories that fire the imagination and promote disability awareness and discussions among children aged four to eleven. These stories are about universal issues such as fear, loss, feeling 'different', bullying, exclusion, success, friendship and emotional growth. The stories provide a safe environment for young children to discuss painful emotions as well as a tool for teachers, parents and professionals to understand the experiences of disabled children.

This could be a way forward to raising awareness in disability. For education authorities to financially back up schools who could use a book like this one to begin raising awareness in children from year three upwards as part of an inclusive policy at school for disabled children and staff. Education on disability awareness needs to start at a very young age in order for disabled people to be understood and valued as human beings who have the same human and civil rights as non-disabled people and have a lot of abilities and skills to offer society. Creating a positive attitude toward disabled people is crucial because the 'body' is an important feature of all social

interaction, and the growth of mass sport and leisure has identified personal worth with the 'beauty of the body'.

### **Cost of Equipment**

The cost of motorcars, wheelchairs and equipment to help disabled people with their mobility in the home is very expensive. The cost of this equipment needs to be closely monitored by local health authorities and central government to make sure that disabled people are not being over charged for equipment that is so vital to aid their mobility.

### **Social Support Networks**

When disabled people receive social support or encouragement by friends, family and significant others, they are more likely to participate in exercise activities than those who do not receive any support. Therefore, the NHS and local health authorities need to make sure that 'social support networks' are made available when a disabled person attends a rehabilitation programme, hospital or doctors surgery. This vital information could also be passed onto the disabled person by Social Services, Primary Care Trusts or carers when visiting disabled people in their own home. This could be a cost effective way of dealing with health problems associated with people who lead a sedentary lifestyle.

### **Vital Information**

Vital information about leisure facilities, resources, financial benefits, employment, DDA, concessions when travelling on public transport and entrance fees into leisure facilities etc, needs to be easily accessible for disabled people. The internet now hosts masses of information regarding these important issues, but not all disabled people have access to a computer or the internet. Therefore, local health authorities and local government need to make sure that disabled people are adequately informed about where to go and whom to contact, regarding these issues. This would help to give them a better form of communication between the wheelchair user and the provider of goods and services.

### **Physiotherapy**

Physiotherapists have specialist skills in the physical treatment and rehabilitation of people and offer a range of therapies including exercise, electrotherapy and manual therapy. The role of the physiotherapist is to improve a person's mobility and independence, yet it has been shown from this study that sometimes disabled people are left to do their own exercises at home after a few perfunctory physiotherapy sessions. Many are not able to move their legs without assistance and this could mean that they miss out on the benefits that physiotherapy can offer in regard to controlling pain and helping with mobilisation.

Therefore the National Health Service, Primary Care Trusts, and specialist centres that supply the physiotherapists need to ensure that disabled people are getting the full complement of physiotherapy that they need.

In identifying the factors that determine whether, or not, a disabled person participates in exercise, I was keen to explore how participants in this study felt about the benefits to be gained from regular exercise involvement, their body image, and who or what encouraged or motivated them to participate in exercise activity. I am aware that participants felt very strongly about the issue of their perceived body image, but an issue came out of this study which I was not aware of and that is the impact that society has upon our bodies. Therefore, it would be of interest to explore the impact society has upon a disabled person's body image. Is it the same factors with disabled people (i.e., power or/and attractiveness) as it is with non-disabled people? Do wheelchair users in general exercise because of the benefits to be gained from regular exercise involvement or is it pressure from society that makes them participate? The growth of mass sport and leisure has identified personal worth with the 'beauty of the body', and the 'body' is an important feature of all social interaction. Are disabled people becoming 'regulated disabled bodies'?

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## **APPENDICES**

## **Appendix 1: Letter to organisations**

20<sup>th</sup> September 2000

The Manager  
The National Centre for Independent Living (NCIL)  
250 Kennington Lane  
London SE11 5RD

Dear Sir/Madam

May I thank you first of all for taking the time to read this letter.

I am currently reading for my PhD in Sociology at DeMontfort University, School of Social and Community Studies, Scaptoft Campus, Leicester. My supervisors for my research are Mr George Taylor and Mr Dave Rowley.

The proposed title of my project is 'The Intentions to Exercise amongst Disabled Individuals'. This work will be conducted from a sociological perspective, whilst having integrated into it psychological inputs thought to be relevant for this research.

I am writing to invite you and members of your organisation to participate in this project in order for it to remain inclusive of the researcher and the individuals helping with the project. By so doing it is hoped that it will not become exclusive of the people who actually make the project possible. Please find attached an outline of my project for your information.

Thank you for your time and co-operation. I would be very happy to come and discuss the project with you in more detail at a time convenient with you. Please feel free to contact me at the above address or you can e-mail me on [j.r.rice@talk21.com](mailto:j.r.rice@talk21.com) I look forward to hearing from you soon.

Yours Sincerely

Janet Rice

## **Appendix 2: Outline of the study**

## **Outline of Project**

The main aim of the project is to examine 'The Intentions to Exercise amongst Disabled Individuals'. This investigation will use Olivers (1996) Social Model of Disability, to act as a framework for determining the factors which underpin intentions to exercise, attitude toward exercise, influence of significant others, choices and self-determination. For the purpose of this project, Exercise is defined as any *physical leisure activity that stimulates the mind and body. I am primarily focusing upon adults between the age of 18 - 65 years, of either gender, from various backgrounds, who have become disabled during their adult years, who use a wheelchair for their main means of mobility. The study will cover a 60-mile radius of Bedford, Bedfordshire.*

The project will consist of the gathering of information through using questionnaires and individual and group interviews. I want to gather information in order to find out why some people participate in exercise and leisure activities whilst others do not.

Regular exercise has been identified as being important to an individual's social, psychological and physical well being, yet very few individuals exercise to levels sufficient to accrue these benefits. Researchers have begun to develop an understanding of why some people exercise whilst others do not, but much of this research has focused upon non-disabled people whilst very little is known about disabled people.

The purpose of this project is to try to understand why some disabled people decide to exercise whilst others do not. It is hoped that the project will identify the factors (Social, Psychological and Physical in nature, or a combination of all three areas) for these decisions. It is intended that the research will be carried out in a way that includes disabled participants at all stages of the research. That way the community can share the outcomes of the finished project. I would be more than happy to supply you with a copy of the finished project, should you require one.



## **Appendix 3: Questionnaire**

Exercise for wheelchair users

**QUESTIONNAIRE**

**EXERCISE FOR WHEELCHAIR USERS**

**SECTION ONE**

**Name**

**Address**

*(You do not need to fill in your name and address unless you would like to participate in a follow up interview)*

**Age**

**Sex**

Male ( )      Female ( )

**How would you describe your social class?**

**How would you best describe your occupation?**

Employed ( )

Seeking work ( )

Voluntary work ( )

Retired ( )

## Exercise for wheelchair users

### Ethnic Origin (Optional)

I would describe my cultural and ethnic origin as:

White	( )	Black African	( )	Black Caribbean	( )
Black Other	( )	Indian	( )	Pakistani	( )
Bangladeshi	( )	Chinese	( )	Other Asian	( )

Other, please specify.

**1) What was the cause of your impairment? Please state:**

**2) How long have you been a wheelchair user? (Please state)**

**3) Do you think there are any benefits (physical, psychological and social) to be gained by regular exercise involvement?**

Physical	Yes ( )	No ( )
Psychological	Yes ( )	No ( )
Social	Yes ( )	No ( )

**Exercise for wheelchair users**

**SECTION TWO**

**EXERCISE INVOLVEMENT**

**4) Do you participate in exercise activities?**

Yes ( )      No ( )

*(For people who do not exercise please answer the questions 21-25 in section 3 of this questionnaire)*

**5) If you answered yes to the above question, then is it for the purpose of:**  
*Please tick as many of the following as apply*

Leisure and enjoyment ( )

Physiotherapy ( )

Sport ( )

Other categories, please indicate below.

**6) How is information made available to you about the leisure facilities for disabled people?**

**Is it?**

By Post ( )

In the library ( )

G.P's Surgery ( )

Church ( )

Local newspaper ( )

Lamp posts ( )

Other please state....

**7) Do you have leisure facilities near to you?**

Yes ( )      No ( )

**Exercise for wheelchair users**

**8) How far away is your nearest leisure facility?**  
Please state.

**9) How often do you use your leisure facilities?**  
(Please state)

**10) Do you find the following areas suitable to you and your access needs?**

	Yes	No
Entrance	( )	( )
Reception	( )	( )
Gym	( )	( )
Pool	( )	( )
Changing rooms	( )	( )
Showers	( )	( )
Car parking	( )	( )
Other, please state.		

**11) Given the range of activities available at the exercise venue:**

**a) What is accessible to you**

**b) What is not accessible to you**

**12) Do you feel that this range of activities is sufficient for you?**

Yes ( )      No ( )

Please comment

**Exercise for wheelchair users**

**13) What activities would you like to be made available to you?**

Please comment

**14) Is there assistance available if you need it at your exercise venue?**

Yes ( )      No ( )

**15) How satisfied are you with the exercise you do?**

Dissatisfied ( )

Satisfied ( )

Extremely satisfied ( )

Other please comment:

**16) Are you encouraged to participate in exercise by:**

Friends ( )

Family ( )

Peers ( )

Other, please state:

**17) Would you say that the cost of the activities are:**

Very reasonable ( )

Reasonable ( )

Over priced ( )

Free ( )

**Exercise for wheelchair users**

***TRAVEL***

**18) How do you travel to the leisure facilities?**

a) Bus ( )

b) Train ( )

c) Coach ( )

d) Taxi ( )

e) Private hire car ( )

f) Private owned car ( )

Other please state.

**19) Do you consider the travel facilities adequate?**

Yes ( ) No ( )

**If no, how do you feel they could be improved?  
Please state.**

**20) *Would you be prepared to be interviewed, in confidence, at a later date?***

***Yes ( ) No ( )***

***Thank you for your co-operation.***

**Exercise for wheelchair users**

**SECTION 3**

**(Those who do not exercise please continue here)**

**21) Why do you not exercise?**

a) I choose not to do so ( )

b) I am prevented from doing so ( )

Please comment.

**22) Are you considering taking up exercise in the future?**

Yes ( ) No ( )

**23) What would help you take up exercise activities in the future?**

Please comment

**24) Are you encouraged to participate in exercise by:**

Friends ( )

Family ( )

Peers ( )

Other, please state:

**25) Would you be prepared to be interviewed in confidence at a later date?**

Yes ( ) No ( )

***Thank you for your co-operation***



## **Appendix 4: Covering Letter**



**DE MONTFORT  
UNIVERSITY  
LEICESTER**

Faculty of Health and  
Community Studies  
Department of Social and  
Community Studies

Professor David Ward LLB MA  
Head of Department

Dear Participant

My name is Janet Rice and I am currently reading for my Ph.D., in Sociology at DeMontfort University, School of Social and Community Studies, Scraptoft Campus, Leicester.

The purpose of this project is to gather information using questionnaires and individual and group interviews to try and understand why some disabled people decide to exercise whilst others do not. I am primarily focusing upon adults between the age of 18 - 65 years, of either gender, who have become disabled during their adults years. For the purpose of this research, exercise is defined as any physical activity that stimulates the mind and body.

It is intended that the research will be carried out in a way that includes disabled participants at all stages of the research. That way the community can share the outcomes of the finished project.

This questionnaire is for people who use a wheelchair for their main or only means of mobility. The data collected will be used in the strictest confidence. If you would be prepared to take part in a follow up interview, please tick the relevant box, and you will be contacted at a later date.

Thank you for your co-operation.

Janet Rice

## **Appendix 5a: Structure of interview for those who do exercise**

**INTERVIEW STRUCTURE 3**  
*For people who do exercise Feb 02*

NAME

ADDRESS

AGE

STATUS

ETHNICITY

HOW LONG WHEELCHAIR USER

DO YOU HAVE ANY HOBBIES, THINGS YOU LIKE TO DO?

**1 - EXERCISE INVOLVEMENT**

Q) What kind of exercise activity do you participate in?

*Prompt* What kind of exercise do you do?

*Prompt* To what extent are you involved?

*Prompt* How often do you go?

*Prompt* Do you exercise alone ?

*Prompt* Do you exercise with others?

*Prompt* Do you have a preference?

**PREVIOUS EXPERIENCE**

Q) Have you been involved in exercise for a long time?

*Prompt* How long?

Q) Do you feel that exercise has increased your level of confidence?

*Prompt* Do you feel that you are confident in doing every day things?

**2 - ATTITUDES**

Do you feel that exercise is beneficial to you?

Socially (yes) (no)

Psychologically (yes) (no)

Physically (yes) (no) /

Q) In what way do you feel that it helps you?

Q) What does encourage you to exercise? /

### 3 - Perceived Behavioural Control / ABILITY

- Q) Are there exercise activities you would like to do, but cannot?
- Q) What prevents you from doing these things?

### 4 - LEISURE FACILITIES AND TRANSPORT

- Q) Do you feel you have adequate choice of exercise facilities near to where you live?  
*PROMPT Can you tell me about the exercise facilities near you?*
- Q) Do you have a public transport system which is accessible to you?  
*PROMPT Whats the transport like?*
- Q) What other forms of transport are available to you?

### 5 -SUPPORT FROM FAMILY AND FRIENDS

- Q) Do you receive encouragement to exercise from your family?  
*PROMPT What kind of things do they say to you?*
- Q) Do you receive encouragement to exercise from your friends?  
*PROMPT What kind of things do they say to you*

### 6 -SUPPORT FROM PEOPLE WHO ARE NOT FAMILY AND FRIENDS

- Q) Are there people that are not family or friends whose opinion you trust?
- Q) Who are they?  
GP      Footballer      Occupational Therapist      Priest
- Q) Do they encourage you?

### 7 - ATTITUDES TOWARDS YOU

- Q) What do you think your friends feel about you doing this exercise?
- Q) What do you think your family feel about you doing this exercise?

### 8 -Attitudes and acceptance

- Q) When you exercise how do you feel you are treated?
- Q) Do you feel that you are accepted by others?
- Q) Are there any issues about body image?
- Q) Do you feel good about your body image when you exercise with other people?

**9 - Living arrangements**

Q) Do you live alone or with others?

Q) Do you have a preference?

Q) Do you need any help in your home?

Q) Do you receive support from other people?

Q) What kind of things do you have in your home to help with your mobility?

Is there anything else you want to tell me?

*Finish off routine*

Thank you for your help and cooperation  
I would like to tell you what will happen next

**What will happen next**

All the interview material will be transcribed into notes, and analysed to look for themes and similarities. Names will not be quoted, all information will be kept strictly confidential.

**Keep them informed**

## **Appendix 5b: Structure of interview for those who do not exercise**





## **2-ATTITUDES TOWARD EXERCISE**

**Q) Do you feel that exercise is beneficial?**

**Socially (yes) (no)**

**Psychologically (yes) (no)**

**Physically (yes) (no)**

## **3- Leisure Facilities and Transport**

**Q) If you did decide to exercise, do you have adequate choice of exercise facilities and accessible transport?**

**Prompt** Can you tell me about the exercise facilities near you?

Are they adequate?

Is there a choice?

What is the transport like?

## **4- Support from family and friends**

**Q) Do you receive encouragement to exercise from your family?**

**Q) Do you receive encouragement to exercise from your friends?**

**Q) What do they say to you?**

**Q) How do you think your friends feel about your decision not to exercise?**

## **5-Support from people who are not family or friends**

**Q) Are there people outside of your family and friends whose opinion you trust?**

**Q) Who are they?**

**Prompt. GP**

**Footballer**

**Occupational Therapist**

**Priest**

**Q) Do they try to encourage you to exercise?**

## **6- Living arrangements**

**Q) Do you live alone or with others?**

**Q) Do you have a preference?**

**Q) Do you need any help in your home?**

**Q) What kind of things do you have in your home to help you with your mobility?**

## **7- Financial Support**

**Q) Do you receive any financial help towards everyday living expenses?**

**8) Attitudes and Acceptance**

**How do you feel you are treated by other people?**

**Do you receive a positive attitude from them?**

**Are you accepted?**

**Are there any issues about body image?**

**Is there anything else you want to tell me?**

***Finish off routine***

**Thank you for your time and co-operation**

**Keep them informed with what will happen next**

**Appendix 6: Table 1**

**Percentage of males and females who participate in exercise**

**Crosstabs**

**Case Processing Summary**

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
gender * participation	37	100.0%	0	.0%	37	100.0%

**gender \* participation Crosstabulation**

Count

		participation		Total
		yes	no	
gender	male	11	3	14
	female	18	5	23
Total		29	8	37

**Appendix 7: Table 2**  
**Gender and impairment**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
gender * impair	29	78.4%	8	21.6%	37	100.0%

### gender \* impair Crosstabulation

Count

		impair						
		accident	ms	polio	arthrit	other	RTA	ataxia
gender	male	1	2	3	1	3		1
	female		5	1	2	5	3	1
Total		1	7	4	3	8	3	2

### gender \* impair Crosstabulation

Count

		impair	Total
		illness	
gender	male		11
	female	1	18
Total		1	29

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
gender * impair	29	78.4%	8	21.6%	37	100.0%

### gender \* impair Crosstabulation

Count

		impair						
		accident	ms	polio	arthrit	other	RTA	ataxia
gender	male	1	2	3	1	3		1
	female		5	1	2	5	3	1
Total		1	7	4	3	8	3	2

**Appendix 8: Table 3**  
**Frequency and impairment**

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
frequency * impair	21	56.8%	16	43.2%	37	100.0%

frequency \* impair Crosstabulation

Count

		impair					
		accident	ms	polio	arthrit	other	RTA
frequency	never		1	1	1	1	1
	2-3 per week			2			
	occassionally		1			1	
	weekly		1		1	4	2
	fortnightly	1					
Total		1	3	3	2	6	3

frequency \* impair Crosstabulation

Count

		impair		Total
		ataxia	illness	
frequency	never		1	6
	2-3 per week	1		3
	occassionally			2
	weekly	1		9
	fortnightly			1
Total		2	1	21



**Appendix 9: Table 4**  
**Gender and participation**

## Crosstabs

### Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
gender * participation	37	100.0%	0	.0%	37	100.0%

### gender \* participation Crosstabulation

Count

		participation		Total
		yes	no	
gender	male	11	3	14
	female	18	5	23
Total		29	8	37

### Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.000 <sup>b</sup>	1	.982		
Continuity Correction <sup>a</sup>	.000	1	1.000		
Likelihood Ratio	.000	1	.982		
Fisher's Exact Test				1.000	.657
Linear-by-Linear Association	.000	1	.982		
N of Valid Cases	37				

a. Computed only for a 2x2 table

b. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 3.03.

mpc

**Appendix 10: Table 5**  
**Age and participation in exercise**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
years * participation	34	91.9%	3	8.1%	37	100.0%

### years \* participation Crosstabulation

Count

		participation		Total
		yes	no	
years	28	2		2
	29	1		1
	31	1		1
	32	1		1
	33	1		1
	35	2		2
	37	1		1
	38	1		1
	40	1		1
	47	1	1	2
	48	3		3
	49	1		1
	51	1		1
	53	1		1
	54		1	1
	59		2	2
	60	2		2
	61	1	1	2
	62	1	1	2
	64	1		1
	65	3		3
	68	1		1
	73	1		1
Total		28	6	34

**Appendix 11: Table 6**  
**Frequency of participation in exercise and gender**

## Crosstabs

### Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
gender * frequency	29	78.4%	8	21.6%	37	100.0%

### gender \* frequency Crosstabulation

Count

		frequency					Total
		never	2-3 per week	occassionally	weekly	fortnightly	
gender	male	3	3		4	1	11
	female	5	1	3	8	1	18
Total		8	4	3	12	2	29

**Appendix 12: Table 7**  
**Gender and satisfaction**

## Crosstabs

### Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
gender * satisfaction	24	64.9%	13	35.1%	37	100.0%

### gender \* satisfaction Crosstabulation

Count

		satisfaction			Total
		dissatis	satis	exsatis	
gender	male	1	8	2	11
	female	5	6	2	13
Total		6	14	4	24

### Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	2.805 <sup>a</sup>	2	.246
Likelihood Ratio	3.031	2	.220
Linear-by-Linear Association	1.442	1	.230
N of Valid Cases	24		

a. 4 cells (66.7%) have expected count less than 5. The minimum expected count is 1.83.



**Appendix 13: Table 8**  
**Gender and encouragement**

## Crosstabs

### Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
gender * encouragment	24	64.9%	13	35.1%	37	100.0%

### gender \* encouragment Crosstabulation

Count

		encouragment						Total	
		.00	friends	family	other	ALL	friends & family		self-motivated
gender	male		4			1	2	2	9
	female	1	3	1	3	4	2	1	15
Total		1	7	1	3	5	4	3	24

### Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	6.161 <sup>a</sup>	6	.405
Likelihood Ratio	7.826	6	.251
Linear-by-Linear Association	.157	1	.692
N of Valid Cases	24		

a. 14 cells (100.0%) have expected count less than 5. The minimum expected count is .38.

**Appendix 14: Table 9  
Gender and occupation**

## Crosstabs

### Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
gender * occupation	36	97.3%	1	2.7%	37	100.0%

### gender \* occupation Crosstabulation

Count

		occupation						Total
		employed	volunwk	retired	student	retired/vol	unable to work	
gender	male	2	4	8				14
	female	5	2	11	1	1	2	22
Total		7	6	19	1	1	2	36

### Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	4.890 <sup>a</sup>	5	.429
Likelihood Ratio	6.236	5	.284
Linear-by-Linear Association	.782	1	.377
N of Valid Cases	36		

a. 10 cells (83.3%) have expected count less than 5. The minimum expected count is .39.

**Appendix 15: Table 10**  
**Age and Type of impairment**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
years * impair	26	70.3%	11	29.7%	37	100.0%

## years \* impair Crosstabulation

Count

	impair								Total
	accident	ms	polio	arthrit	other	RTA	ataxia	illness	
years 28						1			1
32		1							1
33					1				1
37					1				1
38					1				1
40								1	1
47	1	1							2
48		1	1						2
49					1				1
51						1			1
54			1						1
59		1			1				2
60		1				1			2
61		1			1				2
62				1	1				2
64				1					1
65			2						2
68							1		1
73							1		1
Total	1	6	4	2	7	3	2	1	26

### Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	138.512 <sup>a</sup>	126	.210
Likelihood Ratio	80.814	126	.999
Linear-by-Linear Association	.000	1	.986
N of Valid Cases	26		

a. 152 cells (100.0%) have expected count less than 5. The minimum expected count is .04.

**Appendix 16: Table 11**  
**Physical benefits of exercise**



# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
ofexercise * participation	34	91.9%	3	8.1%	37	100.0%

## ofexercise \* participation Crosstabulation

Count

		participation		Total
		yes	no	
ofexercise	yes	24	6	30
	no	3	1	4
Total		27	7	34

**Appendix 17: Table 12**  
**Psychological benefits of exercise**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
ofexercise * participation	32	86.5%	5	13.5%	37	100.0%

### ofexercise \* participation Crosstabulation

Count

		participation		Total
		yes	no	
ofexercise	yes	23	6	29
	no	2	1	3
Total		25	7	32

**Appendix 18: Table 13**  
**Social benefits of exercise**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
ofexercise * participation	32	86.5%	5	13.5%	37	100.0%

### ofexercise \* participation Crosstabulation

Count

		participation		Total
		yes	no	
ofexercise	yes	23	7	30
	no	2		2
Total		25	7	32

**Appendix 19: Table 14**  
**Age and physical benefits**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
years * ofexercise	31	83.8%	6	16.2%	37	100.0%

### years \* ofexercise Crosstabulation

Count

		ofexercise		Total
		yes	no	
years 28	1		1	
29	1		1	
31	1		1	
32	1		1	
33		1	1	
35	2		2	
37	1		1	
38	1		1	
47	2		2	
48	2	1	3	
49	1		1	
51	1		1	
53	1		1	
54	1		1	
59	1		1	
60	1	1	2	
61	2		2	
62	2		2	
64	1		1	
65	3		3	
68	1		1	
73	1		1	
Total	28	3	31	

**Appendix 20: Table 15**  
**Age and social benefits**



# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
years * ofexercise	29	78.4%	8	21.6%	37	100.0%

### years \* ofexercise Crosstabulation

Count

		ofexercise		Total
		yes	no	
years	28	1		1
	29	1		1
	32	1		1
	33	1		1
	35	2		2
	37	1		1
	38	1		1
	40		1	1
	47	2		2
	48	2		2
	49	1		1
	51	1		1
	54	1		1
	59	1		1
	60	1	1	2
	61	2		2
	62	2		2
	64	1		1
	65	3		3
	68	1		1
	73	1		1
Total		27	2	29

010 ✓

**Appendix 21: Table 16**  
**Age and psychological benefits**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
years * ofexercise	29	78.4%	8	21.6%	37	100.0%

### years \* ofexercise Crosstabulation

Count

		ofexercise		Total
		yes	no	
years 28		1		1
29		1		1
31		1		1
32			1	1
33		1		1
35		2		2
37		1		1
40			1	1
47		2		2
48		2		2
49		1		1
51		1		1
54		1		1
59		1		1
60		2		2
61		2		2
62		2		2
64		1		1
65		3		3
68		1		1
73		1		1
Total		27	2	29

**Appendix 22: Table 17**  
**Reasons for involvement in exercise**

# Frequencies

## Statistics

		of exercise	PURPHYS	PURSPOR	PUROTHE
N	Valid	28	28	28	18
	Missing	9	9	9	19

## Frequency Table

### of exercise

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	20	54.1	71.4	71.4
	no	8	21.6	28.6	100.0
	Total	28	75.7	100.0	
Missing	System	9	24.3		
Total		37	100.0		

### PURPHYS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	15	40.5	53.6	53.6
	no	13	35.1	46.4	100.0
	Total	28	75.7	100.0	
Missing	System	9	24.3		
Total		37	100.0		

### PURSPOR

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	13	35.1	46.4	46.4
	no	15	40.5	53.6	100.0
	Total	28	75.7	100.0	
Missing	System	9	24.3		
Total		37	100.0		

### PUROTHE

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	7	18.9	38.9	38.9
	no	11	29.7	61.1	100.0
	Total	18	48.6	100.0	
Missing	System	19	51.4		
Total		37	100.0		

**Appendix 23: Table 18**  
**How is information received**

# Frequencies

## Statistics

		information	INFOLIB	INFOGP	INFOCHUR	INFONEWS	INFOLAMP	INFOOTHR
N	Valid	24	24	24	24	24	24	27
	Missing	13	13	13	13	13	13	10

## Frequency Table

information ?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	6	16.2	25.0	25.0
	no	18	48.6	75.0	100.0
	Total	24	64.9	100.0	
Missing	System	13	35.1		
Total		37	100.0		

INFOLIB S

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	5	13.5	20.8	20.8
	no	19	51.4	79.2	100.0
	Total	24	64.9	100.0	
Missing	System	13	35.1		
Total		37	100.0		

F.  
Low frequency.  
Shows in ability to access information

INFOGP 3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	3	8.1	12.5	12.5
	no	21	56.8	87.5	100.0
	Total	24	64.9	100.0	
Missing	System	13	35.1		
Total		37	100.0		

INFOCHUR 0

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	no	24	64.9	100.0	100.0
Missing	System	13	35.1		
Total		37	100.0		

INFONEWS 7

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	7	18.9	29.2	29.2
	no	17	45.9	70.8	100.0
	Total	24	64.9	100.0	
Missing	System	13	35.1		
Total		37	100.0		

INFOLAMP 0

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	no	24	64.9	100.0	100.0
Missing	System	13	35.1		
Total		37	100.0		

Yes?

Table 8

Discussion of wheelchair users in homes & communities  
 Isolation of wheelchair users in homes & communities  
 may result in not being able to access information facilities



INFOOTHR 23

14

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
yes	23	62.2	85.2	85.2
no	4	10.8	14.8	100.0
Total	27	73.0	100.0	
Missing				
System	10	27.0		
Total	37	100.0		

Table 8 ✓  
✓

**Appendix 24: Table 19**  
**Participation and distance of leisure centre**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
frequency * miles	26	70.3%	11	29.7%	37	100.0%

### frequency \* miles Crosstabulation

Count

		miles					
		1	2	2	3	4	5
frequency	never	1		1		1	1
	2-3 per week	1			1	1	
	occassionally			1	1		
	weekly	3	1	1		1	1
	fortnightly	1				1	
Total		6	1	3	2	4	2

### frequency \* miles Crosstabulation

Count

		miles			Total
		6	7	8	
frequency	never			2	6
	2-3 per week		1		4
	occassionally		1		3
	weekly	1	2	1	11
	fortnightly				2
Total		1	4	3	26

### Symmetric Measures

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Interval by Interval	Pearson's R	-.186	.176	-.927	.363 <sup>c</sup>
Ordinal by Ordinal	Spearman Correlation	-.179	.197	-.892	.381 <sup>c</sup>
N of Valid Cases		26			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

c. Based on normal approximation.

frequency \* miles Crosstabulation

Count

		miles			Total
		6	7	8	
frequency	never			2	6
	2-3 per week		1		4
	occasionally		1		3
	weekly	1	2	1	11
	fortnightly				2
Total		1	4	3	26

Symmetric Measures

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Interval by Interval	Pearson's R	-.186	.176	-.927	.363 <sup>c</sup>
Ordinal by Ordinal	Spearman Correlation	-.179	.197	-.892	.381 <sup>c</sup>
N of Valid Cases		26			

- a. Not assuming the null hypothesis.
- b. Using the asymptotic standard error assuming the null hypothesis.
- c. Based on normal approximation.

**Appendix 25: Table 20**  
**Frequency of use and distance in miles**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
frequency * miles	26	70.3%	11	29.7%	37	100.0%

### frequency \* miles Crosstabulation.

Count

		miles					
		1	2	2 ??	3	4	5
frequency	never 5	1		1		1	1
	2-3 per week 1	1			1	1	
	occasionally 4			1	1		
	weekly 2	3	1	1		1	1
	fortnightly 3	1				1	
Total		6	1	3	2	4	2

Table 2

### frequency \* miles Crosstabulation

Count

		miles			Total
		6	7	8	
frequency	never			2	6
	2-3 per week		1		4
	occasionally		1		3
	weekly	1	2	1	11
	for.ightly				2
Total		1	4	3	26

### Symmetric Measures

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Interval by Interval	Pearson's R	-.186	.176	-.927	.363 <sup>c</sup>
Ordinal by Ordinal	Spearman Correlation	-.179	.197	-.892	.381 <sup>c</sup>
N of Valid Cases		26			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

c. Based on normal approximation.

calculate the means.

**Appendix 26: Table 21**  
**Suitability of areas within leisure centre**

suitability of food

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	13	35.1	76.5	76.5
	no	4	10.8	23.5	100.0
	Total	17	45.9	100.0	
Missing	System	20	54.1		
Total		37	100.0		

suitability of charging room

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	12	32.4	66.7	66.7
	no	6	16.2	33.3	100.0
	Total	18	48.6	100.0	
Missing	System	19	51.4		
Total		37	100.0		

suitability of shower

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	10	27.0	62.5	62.5
	no	6	16.2	37.5	100.0
	Total	16	43.2	100.0	
Missing	System	21	56.8		
Total		37	100.0		

suitability of car park

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	13	35.1	72.2	72.2
	no	5	13.5	27.8	100.0
	Total	18	48.6	100.0	
Missing	System	19	51.4		
Total		37	100.0		

suitability other

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	2	5.4	33.3	33.3
	no	4	10.8	66.7	100.0
	Total	6	16.2	100.0	
Missing	System	31	83.8		
Total		37	100.0		



# Frequencies

## Statistics

		suitability	suitability	suitability	suitability	suitability	suitability
N	Valid	19	17	14	17	18	16
	Missing	18	20	23	20	19	21

## Statistics

		suitability	suitability
N	Valid	18	6
	Missing	19	31

# Frequency Table

*suitability of entrance*

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	16	43.2	84.2	84.2
	no	3	8.1	15.8	100.0
	Total	19	51.4	100.0	
Missing	System	18	48.6		
Total		37	100.0		

*suitability of reception*

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	13	35.1	76.5	76.5
	no	4	10.8	23.5	100.0
	Total	17	45.9	100.0	
Missing	System	20	54.1		
Total		37	100.0		

*suitability of gym*

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	10	27.0	71.4	71.4
	no	4	10.8	28.6	100.0
	Total	14	37.8	100.0	
Missing	System	23	62.2		
Total		37	100.0		

**Appendix 27: Table 22**  
**Sufficiency of exercise facilities**

# Frequencies

## Statistics

sufficiency

N	Valid	20
	Missing	17

sufficiency

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	12	32.4	60.0	60.0
	no	8	21.6	40.0	100.0
	Total	20	54.1	100.0	
Missing	System	17	45.9		
Total		37	100.0		

**Appendix 28: Table 23**  
**Assistance available at leisure centre and frequency of use**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
assistance * frequency	22	59.5%	15	40.5%	37	100.0%

### assistance \* frequency Crosstabulation

Count

		frequency					Total
		never	2-3 per week	occasionally	weekly	fortnightly	
assistance	yes	2	3	1	8	2	16
	no	1	1	2	2		6
Total		3	4	3	10	2	22

### Symmetric Measures

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Interval by Interval	Pearson's R	-.202	.160	-.922	.368 <sup>c</sup>
Ordinal by Ordinal	Spearman Correlation	-.212	.190	-.972	.343 <sup>c</sup>
N of Valid Cases		22			

- a. Not assuming the null hypothesis.
- b. Using the asymptotic standard error assuming the null hypothesis.
- c. Based on normal approximation.

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
frequency * miles	26	70.3%	11	29.7%	37	100.0%

### frequency \* miles Crosstabulation

Count

		miles					Total
		1	2	2	3	4	
frequency	never	1		1		1	1
	2-3 per week	1			1	1	
	occasionally			1	1		
	weekly	3	1	1		1	1
	fortnightly	1				1	
Total		6	1	3	2	4	2

**Appendix 29: Table 24**  
**Level of satisfaction from exercise and whether encouragement received**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
satisfaction * encouragement	20	54.1%	17	45.9%	37	100.0%

## satisfaction \* encouragement Crosstabulation

Count

		encouragement				
		friends	family	other	ALL	friends & family
satisfaction	dissatis	1	1	1	1	
	satis	3		1	3	3
	exsatis	2			1	
Total		6	1	2	5	3

## satisfaction \* encouragement Crosstabulation

Count

		encouragement	Total
		self-motivated	
satisfaction	dissatis	1	5
	satis	1	11
	exsatis	1	4
Total		3	20

## Symmetric Measures

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Interval by Interval	Pearson's R	-.019	.252	-.082	.936 <sup>c</sup>
Ordinal by Ordinal	Spearman Correlation	-.017	.241	-.073	.943 <sup>c</sup>
N of Valid Cases		20			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

c. Based on normal approximation.

**Appendix 30: Table 25**  
**Cost of activity and satisfaction with exercise**



# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
cost of activity * satisfaction	22	59.5%	15	40.5%	37	100.0%

## cost of activity \* satisfaction Crosstabulation

Count

		satisfaction			Total
		dissatis	satis	exsatis	
cost of activity	veryreas	1	2	3	6
	reas	2	7	1	10
	overpric	2	1		3
	free	1	2		3
Total		6	12	4	22

## Symmetric Measures

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Interval by Interval	Pearson's R	-.403	.175	-1.968	.063 <sup>c</sup>
Ordinal by Ordinal	Spearman Correlation	-.430	.191	-2.130	.046 <sup>c</sup>
N of Valid Cases		22			

- a. Not assuming the null hypothesis.
- b. Using the asymptotic standard error assuming the null hypothesis.
- c. Based on normal approximation.

**Appendix 31: Table 26**  
**Satisfaction of exercise and frequency of use**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
satisfaction * frequency	24	64.9%	13	35.1%	37	100.0%

## satisfaction \* frequency Crosstabulation

Count

		frequency					Total
		never	2-3 per week	occassionally	weekly	fortnightly	
satisfaction	dissatis	2			3	1	6
	satis	4	3		6	1	14
	exsatis		1	1	2		4
Total		6	4	1	11	2	24

## Symmetric Measures

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Interval by Interval	Pearson's R	-.047	.190	-.220	.828 <sup>c</sup>
Ordinal by Ordinal	Spearman Correlation	-.035	.203	-.164	.871 <sup>c</sup>
N of Valid Cases		24			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

c. Based on normal approximation.

**Appendix 32: Table 27**  
**Satisfaction of exercise participation and travel facilities**

# Crosstabs

## Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
satisfaction * travel facilites	20	54.1%	17	45.9%	37	100.0%

## satisfaction \* travel facilites Crosstabulation

Count

		travel facilites		Total
		yes	no	
satisfaction	dissatis	1	4	5
	satis	9	2	11
	exsatis	3	1	4
Total		13	7	20

## Symmetric Measures

		Value	Asymp. Std. Error <sup>a</sup>	Approx. T <sup>b</sup>	Approx. Sig.
Interval by Interval	Pearson's R	-.415	.213	-1.937	.069 <sup>c</sup>
Ordinal by Ordinal	Spearman Correlation	-.424	.222	-1.984	.063 <sup>c</sup>
N of Valid Cases		20			

- a. Not assuming the null hypothesis.
- b. Using the asymptotic standard error assuming the null hypothesis.
- c. Based on normal approximation.

**Appendix 33: Table 28**  
**Participants who do not exercise**

# Frequencies

## Statistics

34

count.  
city do not exercise

reason

N	Valid	8
	Missing	29

reason

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	choice	2	5.4	25.0	25.0
	prevention	6	16.2	75.0	100.0
	Total	8	21.6	100.0	
Missing	System	29	78.4		
Total		37	100.0		

Table 28

only 8/37 (22%) who do not exercise

of the 8 75% (6) are prevented  
from exercising and only 2 (25%)  
do not exercise

✓

**Appendix 34: Table 29**  
**Means of travel**



means of travel

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	taxi	3	8.1	12.5	12.5
	privhic	8	21.6	33.3	45.8
	privocar	10	27.0	41.7	87.5
	other	1	2.7	4.2	91.7
	bus/taxi	1	2.7	4.2	95.8
	door to door	1	2.7	4.2	100.0
	Total	24	64.9	100.0	
Missing	System	13	35.1		
Total		37	100.0		

*new table  
299*